

Not for service

Experiences of injustice and despair in mental health care in Australia

"they're in the community living like ghosts – they are dying alone"



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Experiences of Injustice and Despair in Mental Health Care in Australia

A report of the consultations by the Mental Health Council of Australia and the Brain and Mind Research Institute in association with the Human Rights and Equal Opportunity Commission

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Special thanks to Cristina Ricci and the staff of HREOC Public Affairs for their expertise and patience in producing this report.

Note: All written submissions are directly quoted in this report.

Cover quotes:
"Recently when I phoned the triage service for help I was told that I had been categorised by the Mental Health Team as 'Not for Service'." (Consumer, Victoria, Morwell Forum #17)

"I think for those who are severely ill and are isolated in the community due to their illness they often have no form of support even from family or friends. For people like that they are in the community living like ghosts – they are dying alone." (Consumer, Male, Victoria, Footscray Forum #11).

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FOREWORD

Dr Sev Ozdowski OAM
Human Rights Commissioner and Acting Disability Discrimination Commissioner
Human Rights and Equal Opportunity Commission

> *The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.*
>
> International Covenant on Economic Social and Cultural Rights, Article 12

Australia has made a commitment under international human rights law to provide the 'highest attainable standard' of mental health care. As one of the wealthiest nations in the world, this commitment means that Australia should be setting the example for others to follow. This report demonstrates that while Australia has made many advances, there is still a long way to go.

Since starting my term as Federal Human Rights Commissioner in 2000, I have met hundreds of people all over Australia from all walks of life. During the many conversations I had over the first few years, I was struck by the large number of people who came to me saying that their friend, neighbour or relative had a mental illness and that I simply wouldn't believe the trouble that they had in getting adequate care. I was therefore delighted to work with the Mental Health Council of Australia (MHCA) and the Brain and Mind Research Institute (BMRI) last year on community consultations regarding the human rights of the mentally ill.

Of course, the Human Rights and Equal Opportunity Commission (HREOC) has substantial background in this area. More than 10 years ago the Commission published the ground-breaking *'Burdekin Report'* on Human Rights and Mental Illness. And just last year the Commission published a report on children in immigration detention – *A last resort?* One of the primary findings of that report was that children in long-term immigration detention were at high risk of mental illness and did not enjoy their human right to the highest attainable standard of mental health care.

This report is slightly different to the Commission's two other reports because its primary purpose has been to capture the personal stories of those people who interact with Australia's mental health care system on a daily basis. It was our view that governments needed to hear how Australia's mental health consumers and professionals felt about the system that they were dealing with.

Some of the stories we heard demonstrated the incredible strength of the human spirit and perseverance of mental health professionals doing the best they possibly could in the circumstances. However, it must be said that the vast majority of stories described a crumbling mental health care system that brought about anguish and desperation.

There have been positive changes since the 1993 *Burdekin Report* was published. One has been a trend towards the de-institutionalisation of Australia's mentally ill. Another has been the development of a National Mental Health Strategy that contains some positive policy initiatives which reflect Australia's human rights obligations towards the mentally ill.

However, the stories we heard during these consultations suggest that the process of de-institutionalisation has not been accompanied by corresponding supports for mentally ill people to live in the community. This has left many people with serious illnesses without the help that they need and deserve. Further, Australia has some way to go before the ideas in the National Mental Health Strategy translate into a mental health care system that delivers 'the highest attainable standard' of health care.

While HREOC has been glad to lend its expertise to the consultation process, this report has been drafted by the MHCA and BMRI. I am extremely grateful for their enormous efforts and I feel privileged to have been involved in this project. I would particularly like to thank Keith Wilson, Dr Grace Groom, Professor Ian Hickie and John Mendoza for giving me the opportunity to learn from them. I also want to thank the various State, Territory and Commonwealth Government Ministers and officials who opened their doors to us and listened to what we had to say throughout this process. I hope that this report serves as a wake-up call and prompts our politicians into bringing about real change.

However, I am most grateful to the mental health consumers and their carers, the mental health practitioners and the community groups who so generously shared their very personal stories with us. They took the time to write submissions and to come to the community consultations. I thank them for their efforts and hope that this report does justice to their stories.

FOREWORD

Keith Wilson
Chair, Mental Health Council of Australia

In a very real sense any attempt to provide a foreword to this report is unnecessary - it speaks eloquently for itself as a chronicle of the recorded voices speaking directly to all who read it. These voices speak of the ongoing pain, hopelessness and grief for the loss of life opportunities taken for granted by government and the majority of those whose families have never been impacted by mental illness and don't wish to broach the issue.

Many of those whose stories are recorded here were told with tears because their stories were recalling the experience of loved ones whose deaths were in many cases preventable but for which no one seemed accountable. These hundreds of stories speak of the daily lived experiences of Australian citizens, citizens of a wealthy nation, denied their basic right of access to appropriate and sustained quality health care.

I applaud the deep interest and readiness of the Human Rights and Equal Opportunity Commissioner, Dr Sev Ozdowski to partner the Mental Health Council of Australia in the public forums held in every state and territory and in numerous other meetings as well as in the huge task involved in writing a report that would respect the authenticity of its sources. There is no doubt that the direct participation of the Commissioner added enormous credibility to the hearings and the willingness of hundreds of others to lodge written submissions. His direct involvement brought a sharper focus to the seriously neglected human rights issues implicit in many of the submissions and presentations made during the community forums.

I also applaud the invaluable commitment and expertise contributed by Professor Ian Hickie of the Brain and Mind Research Institute in the University of Sydney. Professor Hickie collaborated closely with our former CEO, Dr Grace Groom, in devising the research framework and setting up the basis for the public forums at most of which he was present as a panelist. He was of course central to the difficult task of writing up such a large report.

An additional feature of this report has been the specific focus on the community's response on the current status of mental health reform in each state and territory. Those of us who attended the nationwide forums were struck by the similarity of the stories of systemic failure, neglect, the lack of accountability and the continued neglect of workforce issues in all parts of Australia.

Regrettably, we have seen from a number of jurisdictions a level of defensiveness and a rejection of the findings from this community assessment. The responses from a number of governments pointed to a 'lack of rigor' or 'poor research method' and 'the need for strategic analysis'. In some cases there was a concerning tendency to 'blame the victim'. These claims ignore the fact that our governments have not implemented basic and routine needs assessments nor regular and system-wide evaluations. Such responses also ignore the

growing body of support for the findings from this review – reviews by Parliamentary committees, Auditors Generals, Public Advocates and others empowered to undertake ad hoc reviews of public services.

While such a response is indeed regrettable, it is not unexpected. An all too frequent response from some governments since the signing of the Second National Mental Health Plan in 1998 has been in the oft quoted mantra that “we must expect that progress on mental health reform will be slow". Unfortunately while this slow pace is comfortable for some, if change is not forthcoming, an increasing number of mentally ill Australians will find themselves "*not for service*".

If on the other hand senior members of government at state and federal levels are prepared to reflect on the forlorn truth of the accounts voiced in this report, to accept their validity and in response show real leadership, then all Australians will have their rightful access to quality mental health care.

I have reserved my concluding remarks to recognise the distinguished contribution made by Dr Grace Groom, our former CEO, in bringing this report to fruition. The huge effort required to develop the groundwork for the public forums in all states and territories, to correlate the resultant data and begin the analysis on a shoestring budget is a tribute to the enthusiastic and strong leadership, and passionate commitment to mental health reform that marked the whole of her two short years as an outstanding CEO of the Mental Health Council of Australia.

FOREWORD

Ian Hickie
Professor of Psychiatry and Executive Director
Brain & Mind Research Institute, University of Sydney

In the early 1990s, as a result of a decade of clinical innovations in community-based mental health care, Australia occupied a unique position internationally. Community, political and professional enthusiasm for a major overhaul of mental health was evident. National leadership was clear and major policies and plans were set in place. Innovation was supported directly by national funding and key movements to promote better community understanding were born. It can be argued that a great deal was achieved between 1993 and 1998. Services were largely moved out of asylums and the needs and rights of those with mental illness and their families were formally recognised. The development of a broad population-based agenda for both prevention and treatment of common mental disorders was supported. National standards for specialist services were constructed. The national mental health survey detailed the extent of mental disorders in the community. The patterns of health care usage described provided the evidence-base for other major reforms in community education, preventative psychiatry and general practice reform.

Since the late 1990s, however, there have been persistent and disturbing reports of fundamental service failures. These reflect disorganised and dislocated health and welfare systems and a lack of commitment to the provision of quality mental health care, particularly in the public sector. Community-based care depends not only on organised health services but coordination of welfare, housing, police, justice and emergency care services. Multiple state-based inquiries have been conducted by health departments, coroners, auditor-generals, parliamentary committees and non-government organisations. The Brain and Mind Research Institute has now worked with the Mental Health Council of Australia on two national reports. *'Out of Hospital, Out of Mind'* was published in 2003 and now '*Not for Service'* in 2005. Both have been based on a combination of qualitative and quantitative methods. Fundamentally, they rest on extensive consultations with persons with mental illness, their families and carers. Additionally, they include the perspectives of those health care professionals who provide services at local level. Tragically, the themes from all these investigations converge. When any of us seeks mental health care we run the serious risk that our basic needs will be ignored, trivialised or neglected.

In our view, such *ad hoc* reports of system failures should be unnecessary. We should have in place government-supported but independently conducted systematic reviews of access to care, experiences of care and human rights. Contrary to the view put by most State and Territory governments, and consistent with data collected in 2003/04 in Victoria, we suspect that the adverse experiences we reported in 2003 and again now in 2005 are not isolated or unusual incidents. Instead they appear to be the tip of an iceberg of poor quality and disrupted experiences of mental health care. In the Victorian survey of persons utilising adult mental health services, negative experiences (related to access to care, information, protection of rights and meeting of individual needs) were reported by 28-42% of consumers and 42-55% of carers. It should be clearly

unacceptable within our health systems for somewhere between a third and a half of persons to report such negative experiences.

We urgently need all Australian governments to commit to a process of genuine and well-resourced reform. *What we do not need* is continued blaming of those who use the services, those professionals who provide the services or those independent bodies who report on them. Continuation of this culture of blame will only worsen the workforce crisis in public sector mental health services. Consistent with this approach, we were advised by Health Departments that this report represented a further threat to the viability of the mental health care system. We were implored to write a 'balanced' rather than 'accurate' report. It was clearly assumed by most States and Territories that they provide high quality care on a day to day basis, despite the lack of any substantive data to support that claim.

For genuine and rapid progress we now need more than committed individuals. Most of our current leaders have recently expressed some support for national reform. However, we need major actions, support for innovation in mental health care and enhanced whole-of-government approaches (e.g. to solve accommodation or employment issues). Independent and genuine scrutiny of progress is essential. Given the likelihood that every family in Australia will be affected by mental health problems at some stage, it can no longer remain an isolated and marginal concern.

While many 'blueprint' documents for mental health reform have been produced by governments, what has been unclear is whether any government is prepared to accept responsibility for implementing real actions. As demonstrated by our organisations over recent years, together with our community and legal partners, we will continue to monitor closely the adverse impacts of systematic neglect on the lives of those who experience mental illness.

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EXECUTIVE SUMMARY

The drive for national mental health reform in Australia in the early 1990s had its origins in the convergent desires of consumers, families, carers and mental health professionals to see a high quality, comprehensive and responsive mental health care system. It coincided with the adoption by the United Nations of the *Principles for the Protection of People with Mental Illness and the Improvement of Mental Health Care* (UN General Assembly Resolution 46/119, 17 December 1991; United Nations, 1991), which emphasised community-based care options and respect for the basic rights of persons with mental illness.

In Australia, the 1993 *Report of the National Inquiry into the Human Rights of People with Mental Illness* (Burdekin Report; Human Rights and Equal Opportunity Commission) brought many issues to wider public attention. It focused on violations of the human rights of people with mental illness, particularly within boarding houses and other sub-optimal forms of community care. Since that time the Human Rights and Equal Opportunity Commission (HREOC) has maintained an active interest in the experiences of persons with mental illness. In 2004, HREOC launched its report on the adverse consequences of prolonged incarceration of children in immigration detention centres (*A last resort?*; Human Rights and Equal Opportunity Commission, 2004).

In response to ongoing community criticism of experiences of care, in 2004, the Mental Health Council of Australia (MHCA) and the Brain and Mind Research Institute (BMRI, University of Sydney), in association with HREOC initiated a new national review – the subject of this report. The goal of this review was to capture the current critical themes in mental health care from the perspective of those who use and deliver its services on a daily basis.

Not for Service is based on national data collected from 2003 to 2005 and utilises a combination of qualitative and quantitative methods. Our goal was to determine the key concerns of those who have recently sought primary care or specialist mental health services. Additional information was provided by health professionals, non-government organisations and other private health care providers. The nature of the partnership between the MHCA, BMRI and HREOC meant that a particular emphasis was placed on collection of data relevant to the human rights of those with mental health problems. The primary mechanisms used to collect data for this review included:

- open community forums in each state and territory;
- individual meetings with specific community, professional and non-government groups;
- a call for written submissions; and
- two community surveys conducted by the MHCA and BMRI.

Due to the broad nature of the consultation process, submissions were received from many individuals and organisations covering a wide range of issues. It was agreed by the MHCA, BMRI and HREOC that the most useful framework for organising the vast amount of written and verbal data collected through the consultation process was the *National Standards for Mental Health Services* (the Standards). The Standards were agreed to by all governments in 1996-97.

Following the systematic collation of the primary data, each government in Australia was given the opportunity to comment on a draft report. Almost all governments responded by highlighting recent initiatives that suggest active responses to some of the concerns raised in the report.

Despite the fact that evidence was not specifically sought in order to prove or disprove the successful implementation of the Standards, the volume and consistency of the information demonstrates the gaps and the difficulties governments have had in meeting these Standards. This report is careful to present the data as a cumulation of personal experiences rather than definitive proof of neglect of the Standards.

The great majority of written and verbal submissions focused on deficits in key aspects of mental health care services. While a wider range of community and other welfare, housing and custodial services were the subject of individual or group submissions, the fundamental issue of inadequate access to quality health services for persons with mental illness dominated the discourse. The contrast between experiences of care when presenting with a physical illness as compared to presenting with a mental illness was profound. A lack of respect for persons with mental illness or their families was commonly reported. The combination of this lack of respect, poor resources and inadequate facilities appeared to underpin the numerous reports of reduced safety within mental health care services. Pleas for the provision of basic care with dignity were almost universal.

Consumers and their family and carers prioritised a number of aspects of health care and related services – and these are generally consistent with other independent notions of delivering quality health care services. These included:

i) access to professional care, particularly in emergency and other acute care settings;
ii) treatment with dignity and concern for the individual irrespective of location of care;
iii) prioritisation of safe and high quality services;
iv) an emphasis on clinical care, rather than 'containment' of those with mental disorders;
v) earliest possible access to professional care in acute and non-acute circumstances;
vi) response to individual needs, including recognition of the complexity of comorbid substance abuse, personality dysfunction or socio-economic deprivation;
vii) coordination of health, welfare and related community support services;
viii) access to programs and support to live independently and work;
ix) respect for the legitimate interests of family and carers in accessing care and participating in ongoing treatment decisions;
x) support for those who provide direct clinical services;
xi) provision of appropriate community housing options; and,
xii) access to appropriate medical as well as psychological services.

What this cumulative data shows is that after 12 years of mental health reform in Australia, any person seeking mental health care runs the serious risk that his or her basic needs will be ignored, trivialised or neglected. The adverse health, social and economic effects of Australia's mental health care system falls largely on those with recurrent or chronic disorders and their families and carers. These are some of the most vulnerable people in our community.

In the short-term, the system as it currently operates may result in a failure to provide basic medical and psychological health care, inappropriate use of short term seclusion, confinement or over-reliance on sedating medications. Longer-term, the impact may include deteriorating mental health and wellbeing, suicide, higher rates of homelessness, prolonged unemployment, incarceration or increased financial burden and poverty. Failure to attend to the urgent needs of those with severe mental disorders on a systemic basis may also lead to

infringements of the wider rights of the community to reside in a safe and secure environment. For many people, ongoing financial and personal support from family and friends is the only real safeguard against these outcomes.

A number of individual participants in the consultations for this report expressed distress at repeating their own or their family's tragic experiences. Some said that they had sought resolution with a wide range of authorities such as health services, complaints commissions or other state authorities but had failed to achieve any specific outcome. The general tendency of these authorities was to portray an adverse experience as an isolated occurrence within an otherwise well-functioning mental health system. However the consistency of these types of stories proved to be powerful indicators of systemic weaknesses.

In short, the available evidence suggests that persons with mental illness still struggle on a daily basis to access appropriate health care or be treated with respect or dignity when they do enter our health care systems. These same human rights concerns were raised in the Burdekin Report, 12 years ago.

Despite the slow pace of real progress since the Burdekin Report, there have been notable examples of political leadership and commitment. Successive Federal governments have continued to support a national approach to reform and Commonwealth investments have increased by 128% in the last nine years. New national organisations such as the Mental Health Council of Australia and *beyondblue: the national depression initiative* represent strong steps forward in terms of destigmatising mental health. There have also been significant reforms of the primary care sector through the *Better Outcomes in Mental Health* initiative. These are positive initiatives, but they are insufficient to address the problems identified in this report.

Given the likelihood that every family in Australia will be affected by mental health problems at some stage, it can no longer remain an isolated and marginal concern of the health care system.

There have been many 'blueprint' documents to guide mental health reform produced by governments over the past 12 years and most share common themes. This report and the stories it contains point to the substantial gaps between the aspirations expressed in these documents and the reality of Australia's mental health care system.

The findings of this report are supported by a substantial body of evidence contained in reports from parliamentary inquiries, ministerial reports, and independent assessments which point to the systemic problems with mental health care services in Australia. In our view, ad hoc reports such as *Not for Service* should be superseded by systematic annual reviews of experiences in the mental health care system. We suspect that the adverse experiences presented to us represent the tip of an iceberg of poor quality and disrupted mental health care.

It is now urgent for all governments, state, territory and national to work together and commit to a process of genuine and adequately resourced reform. In simple terms this will involve:

- a recognition by all Australian governments that mental health reform is a national priority;
- real leadership at the most senior political and bureaucratic levels to drive change through a whole-of-government response;
- real and sustained increases in the overall funding for mental health care services over the next five years to align mental health and disability burden with funding;
- an emphasis on accountability at all levels on a nationally consistent basis to ensure funding is delivered and the impacts and outcomes of the investment are available to the Australian community on a timely basis; and
- urgent and resolute action to address the looming crisis in the mental health care workforce.

RECOMMENDATIONS

The Mental Health Council of Australia and Brain and Mind Research Institute recommend:

1. Leadership and governance

a. a whole of government service model must be developed and agreed to by the Heads of Australian Governments (through the Council of Australian Governments – COAG) based on collaboration, integration, community need, accountability, flexibility and innovation;
b. that leadership for mental health reform be primarily vested in the Federal Cabinet Minister for Health;
c. that new governance arrangements be developed to ensure true collaboration between government, non-government and private sectors and the participation of consumers and carers; and
d. inter-government service agreements (such as those recently developed under COAG leadership for delivering real outcomes in Indigenous communities) should be developed to provide an improved basis for whole-of-government responses to address the issues raised in this report.

2. Policy framework

a) that a fundamental shift occur from a preoccupation with process and statutory relationships to providing services under a re-invigorated National Mental Health Strategy (NMHS);
b) that national prevalence studies to determine and monitor the extent of mental health problems and mental illness within the Australian community must be undertaken on a tri-annual basis thus enabling informed, on-going policy decision-making;
c) that national strategies and policies relating to alcohol and other drugs be reviewed and aligned to ensure they are effectively integrated with the NMHS and National Mental Health Plans (NMHP); and
d) that the NMHS and associated policy documents be reviewed and simplified to address the recommendations of this report.

3. Funding

a) that all Australian governments increase expenditure on mental health care services by 1% per annum for each of the next five years such that by 2010 expenditure will be equivalent to 12% of total health care funding in real terms;
b) that funding to NGO service providers be significantly increased from the current national average level of less than 6% to around 15% of mental health funding;
c) that a greater proportion of new funds for mental health care be allocated to special needs populations (youth, Culturally and Linguistically Diverse, rural and remote, Indigenous), early intervention and other forms of community-based assessment and care;
d) that funding to support integrated drug and alcohol and mental health services become a high priority;

e) that funding be increased for community education to raise the level of mental health literacy and overcome continuing widespread stigma;
f) that new funding be allocated to enhance the role of consumers and carers in the development and implementation of the NMHS;
g) that research funding be increased from the current level of less than 4% of health research funding to around 10% to ensure that more effective diagnostic and treatment options are available to the Australian community; and
h) that specific funds be allocated through a non-medical organisation to conduct research into effective care and improving outcomes for people with a mental illness.

4. Legal and Human Rights

a) that all governments work to achieve the highest attainable standard of mental health care as required by the International Covenant on Economic, Social and Cultural Rights and the Convention on the Rights of the Child and apply the UN 'Principles for the protection of persons with mental illness and the improvement of mental health care';
b) that as a matter of urgency all jurisdictions develop nationally consistent guidelines on the assessment, sentencing and provision of specialised mental health care (according to the NMHS) for mentally ill people in contact with the justice and/or detention systems; and
c) that all Australian jurisdictions provide specialised legal services, diversionary and reintegration programs for people with a mental illness in contact with in the justice and/or detention systems.

5. Workforce

a) that all governments recognise the need for urgent and resolute action to address the declining morale and chronic skills shortages now evident in the mental health care workforce;
b) that programs and additional resources to attract and retain staff in mental health care services are implemented in all jurisdictions in the forthcoming year;
c) that there be better use of and access to the psychology workforce, which is available and skilled, and can reduce pressure on other areas of the workforce;
d) that training programs to integrate the drug and alcohol and mental healthcare workforces be undertaken in all states/territories; and
e) that consumers become part of the mental health care workforce.

6. Accountability

a) that the Commonwealth Government establish an annual formal reporting mechanism (The National Mental Health Report Card) to the Prime Minister and Heads of all Australian Governments on specific key indicators;
b) that the National Mental Health Report Card include real 10-year targets for mental health outcomes as well as more intermediate outcomes and impact measures based on consumer, carer and service provider needs;
c) that responsibility for The National Mental Health Report Card be vested in an independent national office with direct access to the Prime Minister;
d) that independent monitoring of the experiences of care and the experiences of treatment should be undertaken by the Mental Health Council of Australia on an annual basis; and
e) that funding agreements at national, state, territory and area service levels be based on the principles of other successful pay-for-performance models.

STORIES OF INJUSTICE AND DESPAIR

The following are just a small sample of the stories and themes of injustice and despair that were revealed during the community consultations and in written submissions. Further stories can be found throughout this report.

Preventable deaths?

[O]ne night [my son] started hallucinating. He was on a trip with a friend in NSW…The hospital called me to let me know what had happened and I was assured he would be OK...The hospital needed to get his patient history from our normal hospital in Echuca [Victoria] but there was a delay in getting this information…The Psychiatric Consultant who examined [my son] phoned me and told me he was going to be discharged as he was only homesick. I pleaded with him not to discharge him as he was really sick and needed help…[My son] was discharged the next morning and on the drive on the way home with his friend he killed his friend because he was still sick and hallucinating. He was sent to jail and had his glasses and hearing aid removed and not returned. He was supposed to be sent to a hospital with a psychiatric ward but instead he was sent to Silver Water jail…That is where he stayed for 2 months…[He was then] moved to Long Bay Jail where he was supposed to undergo a psychiatric assessment prior to his court hearing. On the day of the assessment the doctor never turned up …and neither did the solicitor who was acting on his behalf. As such the hearing never took place and as a result he became very suicidal...I informed and pleaded with the authorities to make them aware he was sick and suicidal. They informed me he would be put in a cell with another inmate who could watch him but in fact he was placed in a single cell on Friday…and hung himself on the Friday night. I would like to know why he was failed by three government departments? How did this happen? [October 2004]

(Carer, Mother, Victoria, Footscray Forum #8)

His suicide was tragic, made all the more so because it was preventable, we believe, but for the inadequacy of the public mental health system. [X] died just two weeks after his first suicide attempt, eight days after his discharge from the Canberra Hospital psychiatric unit, two days after being refused admission to the psychiatric [unit] following a second suicide attempt, and within hours of contact with the mental health crisis team. On the day of his death, [X] had contact with the mental health system no less than three times. [Suicide occurred early in 2004]

(Anonymous, Australian Capital Territory, Submission #288)

I was amazed on one of my visits to see my mother so distressed that after two days they were sending her home to us the family to give the care she had not received in the Hospital. May I add also that this particular incident occurred after her third attempt on life. She was so frightened because she knew she was not any better…it was having a huge affect on the whole family. The answer to my question to the doctor about how many attempts would be enough. Apparently the answer to that question as found out was five. Because on the fifth occasion, at approximately 1:30pm on the 15th October 2003, my mum decided to douse herself in petrol and set herself alight.

(Carer, Son, Queensland, Submission #184)

When is a crisis a crisis?

In the past I have been told by CAT [Crisis Assessment and Treatment] team members whilst in crisis "You know more about your diagnosis than we do, Call us back if you can't get it under control". In those days control usually meant I would SM [self mutilate] so badly I would have to sew or patch myself up. How far does a person have to go to say I need help and I need it now?

(Consumer, Victoria, Submission #112)

My sister had suffered with bi polar disorder for 30 years…Sadly she took her life on 18th June 2004. On that day I was going to take her shopping but she didn't feel well. She said to me what about Psychiatric Services. But she always presented so well when they interviewed her that I knew they wouldn't take her in, so I took her home. She said she felt better just talking to me on the way over to our place. And many times over the years I would bring her home for a few days or a week to help her get over her depression. The next day I was going to be home at 2:00pm from work. That morning she took her life. What a waste of life. If only the system had a more open door policy. I wouldn't feel so guilty for leaving her that day.

(Carer, Sister, Victoria, Submission #286)

A failing community care system?

The dream of closing psychiatric institutions and moving towards community based care has turned into a nightmare. Community care is under resourced and integrated services are lacking. Too many people are denied treatment and slip through the gaps.

(ARAFMI Tasmania, Tasmania, Submission #245)

The system is chronically under-funded and under-resourced. There is a chronic shortage of psychiatric beds. Community Clinics are overworked and under-resourced. Supported accommodation options for mental health clients are severely lacking. The Psychiatric Emergency Service is viewed as a joke by clinicians and clients alike and functions as little more than a telephone advisory service.

(Clinician, Western Australia, Submission #4)

Early intervention – reality versus rhetoric?

Regarding 'involuntary intervention'; although the Mental Health System espouses 'early intervention' and carers are encouraged to practice this, the constraints surrounding 'involuntary intervention' can make 'early intervention' impossible. From personal experience, it means that intervention will not be carried out without the consumer's consent until that person is acutely unwell and a 'crisis situation' arises. Although it will then, still be without the consumer's consent, probably even more so, and will probably mean a more forceful intervention, somehow this policy is considered more humane...As ridiculous as it sounds, it means that the behaviour of the unwell person has to disturb, alarm or frighten a member of the public enough to bring it to the attention of the police or the Mental Health Service - a carer's word that the person is at risk is not enough...and we talk about reducing the stigma of mental illness.

(Carer, Mother, Victoria, Submission #178)

Where is the follow-up care?

After exhibiting psychotic behaviour my son spent 21 days (detained) in Glenside Hospital in March 2002. He was counselled and medicated then turned out into the community with some medication but no follow up care. Shortly afterwards he stopped his medication, reverted to his anti-social, aggressive and irrational behaviour, a state he has been in unchecked for two years.

(Carer, Mother, South Australia, Submission #11)

Families and carers taking the brunt?

Major service gaps are on the rise, with plans, strategies, and government promises failing to meet the needs of this vulnerable community group. This results in carers, families and the community sector, being forced to take the brunt. As a result, the community sector feels under constant pressure to respond to hopelessness, helplessness, and the despair felt among consumers / carers as they attempt to do the impossible - fill the gaps, but at what cost?

(Mental Health Foundation ACT, Australian Capital Territory, Submission #256)

I am an NGO service provider – our surplus of funding from last year was taken from us by the Government without notice. The Government just doesn't think about the implications of taking away funding from NGOs. We already have long waiting lists and taking away funding makes them even longer. One of the young consumers who was on one of our waiting lists for four months was also caring for her mum – she killed herself because she felt she couldn't cope looking after her mum anymore without some support. Waiting lists for support from us have gone up from three weeks to four months.

(NGO Service Provider, Western Australia, West Perth Forum #29)

Police - the de facto mental health service?

When I turn up there and they are in crisis, I call the Crisis Assessment Team and they tell me to call the police! I want to know why I'm standing there alone and nobody is coming to help me.

(Carer, Mother, Victoria, Footscray Forum #1)

Even though they claim to be available 24 hrs a day/7 days a week through a 1800 telephone number, they are not providing a true 24/7 service…Currently, police are finding themselves being called prematurely and often unnecessarily to assist in the management of patients who have been released into the community or who are allegedly being treated while living in the community. They are also often being asked to retrieve AWL [Absent Without Leave] patients from the community without any attempt of the mental health teams to bring the patients back to hospital using their own resources.

(Police Association of New South Wales, New South Wales, Submission #59)

Where do people live if they can't get supported accommodation?

On the 6/8/04 my son rang distressed saying he had to have somewhere permanent to live if he had a CTO [Community Treatment Order]. Apparently it was suggested to him an alternative possibility would be a backpackers hostel. He asked to live with us again…Again whilst discussing suitable accommodation my son suggested he sleep at a friend's on a couch. I told the nurse this was not an option. My son then suggested sleeping in his car, something he did for periods prior to his hospitalisation. Again I expressed the belief that this is not conducive to his mental and medical rehabilitation. I was taken aback at her suggestion that living in the car is an option, it is an alternative lifestyle that some people like. This I believe is not an option for a vulnerable person in Australia in 2004. We have seen no evidence of my son being able to function alone.

(Carer, Mother, South Australia, Submission #11)

Prisons – the new institutions for people with mental illness?

The prison system is not the place to provide care for those with a mental illness. My work and the work of others has shown that many people who end up in jail do so as a result of not being able to access a mental health service. In many cases you will find it is deemed to always be the fault of the individual if something happens. We need to know why the services are never ever held accountable for failing to provide care?

(Consumer Advocate, Victoria, Footscray Forum #9).

What progress since Burdekin?

After 30 years of social work practice I've entered many SRFs [Supported Residential Facilities] - starting in 1970s. I can confidently say that the Burdekin Report made absolutely no difference to the lives of these men & women, most of whom experience mental illness. Their level of physical & mental health is at the same disastrous level as homeless & Aboriginal people…Going into some of the Facilities today, I feel like they are in worse shape than in the 1970s when many were established at the encouragement of the government to "empty out" the back wards of the psychiatric hospitals. And talking with the managers, it's clear that they do not feel that they and their residents are receiving anywhere near an adequate service from the mental health services.

(Family Member and Service Provider, South Australia, Submission #34)

PART ONE: METHODOLOGY

It's the patients who can best tell it "as it really is" and professionals need to develop the mechanisms and the skills to listen to patients with "authentic curiosity".

(Nicolls et al 2000; Quote appears in the *Office of the Chief Psychiatrist's Clinical Review Framework* Information Card, Office of the Chief Psychiatrist (WA), November 2003)

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1.1 OVERVIEW

1.1.1 Background

The drive for national mental health reform in Australia in the early 1990s had its origins in the convergent desire of consumers, families, carers and mental health professionals to see a high quality, comprehensive and responsive mental health service system. It coincided with the adoption by the United Nations of the *Principles for the Protection of People with Mental Illness and the Improvement of Mental Health Care* (UN General Assembly Resolution 46/119, 17 December 1991; United Nations, 1991), which emphasised community-based care options and respect for the basic rights of persons with mental illness.

In Australia, the *1993 Report of the National Inquiry into the Human Rights of People with Mental Illness* (Burdekin Report; Human Rights and Equal Opportunity Commission) brought many of these issues to wider public attention. It focused on violations of the human rights of people with mental illness, particularly within boarding houses and other sub-optimal forms of community care. Since that time the Human Rights and Equal Opportunity Commission (HREOC) has maintained an active interest in the experiences of persons with mental illness, with a recent focus on those who are treated within restrictive environments such as immigration detention centres. In 2004, HREOC launched its report on the adverse consequences of prolonged incarceration of children in immigration detention centres (*A last resort?*; Human Rights and Equal Opportunity Commission).

Following the release in 2003 of *'Out of Hospital, Out of Mind'* (Groom et al, 2003), the MHCA and HREOC have continued to note community concerns that basic mental health and related community services are inadequate. For example, the 3rd National Mental Health Plan (2003-08), has been criticised for failing to attend to the major community priorities that were articulated in *'Out of Hospital, Out of Mind'* (including: early intervention, management of comorbid substance abuse, increased access to a wider spectrum of acute care settings, enhancement of services in rural, regional and poorly resourced areas, genuine implementation and adherence to the national mental health standards for specialist services). In response to ongoing community criticism of experiences of care, in 2004, the MHCA and the Brain and Mind Research Institute (BMRI, University of Sydney), in association with HREOC initiated a new national review. The goal of this review was to capture the current critical themes in mental health care from the perspective of those who use or deliver its services on a daily basis.

1.1.2 Overview of methods

The primary mechanisms used to collect data for this review included:

- the convening of open community forums in each state and territory from 05 July – 14 October 2004 (see Appendix 8.1);
- individual consultation with specific community, professional and non-government groups (see Appendix 8.1);
- a call for written submissions on 05 July 2004 with a deadline of 30 September 2004 (late submissions were accepted until January 2005) (see Appendix 8.2 and 8.3); and
- two community surveys conducted by the MHCA and BMRI over 2003-2004.

In early November 2004, the Human Rights Commissioner wrote to all State and Territory governments seeking more detailed information about the levels of community need and the effectiveness of mental health services.

A first draft of the report was provided to each State and Territory government on 24 March 2005 and to the Commonwealth government on 5 April 2005. As at 27 May 2005, all but the Northern Territory and Western Australia provided comments for inclusion in this final report.

The report is based on national data collected from 2003 to 2005 and utilises a combination of qualitative and quantitative methods. Our goal was to determine the key concerns of those who have recently used primary care or specialist mental health services. Additional information was provided by health professionals, non-government organisations and other private health care providers. The nature of the partnership between the MHCA, BMRI and HREOC meant that a particular emphasis was placed on collection of data relevant to the human rights of those with mental health problems.

1.2 COMMUNITY CONSULTATIONS

The MHCA, BMRI and HREOC convened community forums open to all members of the public. Advertisements for the community forums indicated that the aims were to "investigate claims that the system has turned its back on those in need of mental health care" or that the forums were "being held as part of national research into the human rights of people affected by mental illness". Advertisements also indicated that "the results of this research will allow HREOC and the MHCA to review progress made since the 'Burdekin Report' in 1993".

Two-hour forums were scheduled over a four month period in metropolitan and regional areas across Australia (see Appendix 8.1 for a list of consultations). Special care was taken to capture the diversity of experiences and concerns of all people trying to either access or deliver services. Participants were asked to consider sharing both positive and negative experiences in all contexts, not just the health care system. However, no specific questions were set during the consultations so as to avoid pre-empting or constraining the responses and attendees were free to raise any concerns or describe their personal experiences.

The consultations were co-chaired by the Human Rights Commissioner (Dr Sev Ozdowski), HREOC and the Chairperson (Mr Keith Wilson) or CEO (Dr Grace Groom) of the MHCA. Most forums were also attended by Professor Ian Hickie from the BMRI and other representatives from MHCA member organisations. A local consumer and a carer representative were invited to participate in the leadership of the meetings. Participants were encouraged to identify themselves and the nature of their role in using or providing health or other services. At times, participants were asked to clarify or elaborate their comments by the chairperson.

The forums were attended by a broad spectrum of people including: consumers, carers, general members of the community, clinicians, advocates, service providers (e.g. mental health, general health, accommodation providers), emergency personnel (e.g. police), academics and administrators. While participants were asked to identify the perspective from which they were speaking, no names or other identifying features were recorded during the meetings. Nineteen forums were held across Australia and an approximate total number of participants at all forums was 1180 (See Appendix 8.1 for a list of forums held by State / Territory)

Additionally, individual consultations were also held with certain community, professional and non-government groups (see Appendix 8.1 for a list of meetings) to cover specific issues.

1.3 CALL FOR SUBMISSIONS

Advertisements to the forums, and information on the MHCA website, indicated that written submissions could be lodged in electronic or hardcopy format with either the MHCA or HREOC. In order to encourage people to share their personal stories, it was emphasised that anonymous submissions would also be accepted. Similar announcements were also made at the beginning and conclusion of all community forums. A total of 351 submissions were received, 109 of which were confidential (see Appendix 8.3).

1.4 ANALYSIS OF SUBMISSIONS AND INFORMATION PRESENTED AT FORUMS

Due to the broad nature of the national consultation process, submissions were received from many individuals and organisations. They covered a wide range of issues.

It was agreed by the MHCA, BMRI and HREOC, that the most useful framework for organising the vast amount of written and verbal data collected through the consultation process, was the *National Standards for Mental Health Services* (The Standards; Commonwealth Department of Health and Family Services, 1996). The Standards were agreed to by all governments in 1996-97. The Standards are a useful measure by which to gauge the extent to which governments are protecting the rights of people with mental illness according to the level agreed to by all governments.

Despite the fact that evidence was not specifically sought in order to prove or disprove the successful implementation of the Standards, the volume and consistency of the information demonstrates the gaps and the difficulties governments have had in meeting these Standards. This report is careful to present the data as a cumulation of personal experiences rather than definitive proof of neglect of the Standards.

The analyses of the submissions and forums are presented in three forms. First, from a national perspective, we highlight those common themes encountered across most States and Territories (Parts 2.2, and Parts 4 and 5). Second, we emphasise the key regional and State differences. There are important differences in State organisation of services, responsiveness to community experiences, workforce attitudes, clinical leadership and service innovation and resource investment. Third, we provide data on the key issues raised within each State or Territory (Part 6).

Due to the personal nature of many submissions, all identifying information has been removed from the text of the report and organisational names have appeared in the text only if permission was granted. With regards to the submission list in the Appendix, unless anonymity was specifically requested, the Mental Health Council of Australia sought permission to disclose identifying information from all those who made submissions and provided contact details. If confirmation was not received, identifying information has not been disclosed and "Anonymous" has been substituted for their name(s) in the Appendix.

Some organisations chose to submit material that had been prepared recently for other national or state reviews. Several described a sense of "submission fatigue", in that they were tired of responding to inquiries without evidence that such processes actually bring about systemic change.

A number of individual participants expressed distress at repeating their own or their family's tragic experiences. Some said that they had sought resolution with a wide range of authorities such as health services complaints commissions, the coroner or other state authorities but had failed to achieve any specific outcome. The general tendency was to portray their adverse experiences as isolated occurrences within an otherwise well-functioning mental health system. However the consistency of these types of stories proved to be powerful indicators of systemic weaknesses.

Some representatives of key provider and non-government organisations were also distressed by having to repeat their assertions about system failures. They expressed concern about possible retribution against individuals, particularly when those individuals were employed by State Health services. Additionally, non-government organisations were concerned that States might withdraw their ongoing financial support for speaking out. Service providers often felt blamed by both consumers of services and by the administrators of services for failing to protect the service from complaints. Consumers, carers and service providers who brought matters of concern to public attention all felt that they were in danger of being further marginalised by their local health services. It was their view that the system as a whole lacked perspective about the potential benefits that may flow from a more open critique of the gaps and failings of the current systems.

Some individuals and organisations expressed concern about the broader impact of conducting yet another national review. They were worried that a report may attract further public attention to current service inadequacies and that this, in turn, might lead to further demoralisation of existing workforces. However, the overwhelming majority welcomed the opportunity to continue to express their concerns to independent organisations like the MHCA, BMRI and HREOC.

Another criticism of this process expressed by a small minority of persons, and most State and Territory governments, was that a process focussing on the voice of mental health consumers and carers may not adequately detect or report significant improvements in care. By contrast, many others felt that it was necessary to continue to highlight discrepancies between government descriptions of an improved health care system and everyday experiences of that same system, particularly where such groups affected have little community recognition or an active voice.

1.5 SURVEYS

In April 2003, the Mental Health Council of Australia launched its national review of mental health services in Australia '*Out of Hospital, Out of Mind!'* (Groom et al, 2003). The report highlighted deficiencies in care and developed community priorities for further action. As these priorities were not formally recognised by governments, and as little work had been presented by the National Mental Health Strategy that focused on actual experiences of service development or direct care, two specific survey mechanisms were designed.

The first survey evaluated the extent to which the national and community priorities identified within '*Out of Hospital, Out of Mind!'* (Groom et al, 2003; Table 2, p.38), have been implemented at either the local or state level. The survey was designed to be completed by both providers and users of our mental health services. The earlier stages of the survey which dealt directly with the community's perception of the key aspects of the National Mental Health Strategy were reported back to the Commonwealth Department of Health and Ageing in 2003. Key aspects of the community's disappointment with the lack of genuine progress against set policy goals were noted in the formal evaluation by the Commonwealth of the Second National Mental Health Plan.

The second survey, which was distributed through the MHCA to appropriate consumers and carers, was commenced in 2004. It assesses direct experiences of care, using internationally-developed benchmarks for quality health care (Picker Institute Europe; http://www.pickereurope.org). This approach assumes that the widespread collection of actual experiences of care can provide an ongoing overview of key changes within health care systems (Picker Institute Europe; http://www.pickereurope.org). While many health care systems utilise critical-incident reporting mechanisms for the same purpose (or analyses of collected critical-incidents such as the 2004 NSW Health *Tracking Tragedy* Report), such limited and ad hoc review mechanisms may be quite unrepresentative of more general experiences of care. Additionally, they may completely omit more common but less disastrous instances of poor quality care or variations in care.

The first survey provides a snapshot of the views of mental health stakeholders in 2003-04 as to the degree of progress that had been achieved after a decade of national mental health reform. The second survey is ongoing and will expand to become a continuing mechanism for active review of patterns of current service delivery. This approach has been widely utilised in other areas of quality improvement in health care services (Picker Institute Europe; http://www.pickereurope.org) and has recently been extended to the mental health field.

We believe that both of these survey mechanisms have provided a unique opportunity for genuine input by the broader mental health sector. To date, such mechanisms have not been actively promoted by government. In particular, the second survey mechanism could be easily taken up by regional, state or national health authorities.

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2.1 MENTAL HEALTH AND HUMAN RIGHTS IN AUSTRALIA

2.1.1 INTERNATIONAL HUMAN RIGHTS AND THE RIGHT TO MENTAL HEALTH CARE IN AUSTRALIA

> *Perhaps it is time to frame the concerns of persons with mental disability not simply as a social problem, but as a human rights imperative.*
>
> (Gostin, 2004, p. 11)

It is commonly assumed that the only relevant human rights issues for people with mental illness in Australia relate to the protection from arbitrary detention and the right to humane and dignified care when treated in institutions. However, people with mental illness have exactly the same fundamental human rights as every other person, whether they are being treated in a hospital, or in the community. For example, everyone has the right to the highest attainable standard of health and the right to an adequate standard of living. The current international and national trend towards deinstitutionalisation and community-based care brings all those other rights into sharper focus.

> *Today, it is clear that, at least in relation to mental health problems, equality before the law should be complemented by equity in resource distribution, fraternity needs to be understood as solidarity with people who need help, and liberty should be interpreted in the light of duties and responsibilities that all of us should accept as members of societies that strive to be civic.*
>
> (Sartorius, 2002, p. 13)

The movement to consider the experiences of people with a mental illness within a human rights framework has gained momentum internationally. All countries struggle with the stigma and discrimination associated with mental illness and the negative personal, social and economic outcomes that arise due to inadequate health and social services. There is acknowledgement that human rights violations against the mentally ill are widespread, occurring both within and outside the delivery of health care (World Health Organization Europe, 2004). While many countries have attempted to tackle such violations by enacting legislation to protect such rights, some have argued that these measures have often failed to protect the rights of people with mental illness due to popular or political pressure (Gostin & Gable, 2004).

> *The shameful history of benign and sometimes malignant neglect of persons with mental disabilities is well understood: the deep stigma and unredressed discrimination, the deplorable living conditions, and the physical and social barriers preventing their integration and full participation in society. Countless promises have been made to right the wrongs, but new forms of neglect have always emerged. The mentally disabled have ended up in prison, in equally deplorable adult homes, or on the streets, homeless and destitute, while the wider society has averted its eyes.*
>
> (Gostin, 2004, p. 11)

Human rights jurisprudence involving involuntary detention, conditions of confinement, civil rights and access to mental health services has been growing in Europe and the Americas (Gostin & Gable, 2004). With regards to improving access to quality mental health care, WHO Europe suggests that legislation "can make a difference in ensuring parity with other health services and ensuring that what is provided is appropriate to people's needs" (WHO Europe 2004, p. 2). However, legislation is not of itself a guarantee against human rights violations (WHO Europe, 2004).

2.1.1.1 International Instruments

> *Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.*
>
> (Universal Declaration of Human Rights, Article 25(1))

Providing the best possible health care is not just a desirable social goal, it is a fundamental human right and it applies to all people no matter who they are or what their illness. Associated with the concept of a 'right to health' is a growing body of international law of a 'right to health services' requiring 'nation states to take affirmative steps to assure that residents of the country have access to population-based health protection measures and also affordable health care in the context of the nation's economic resources and cultural mores' (Kinney, 2001, p. 1458). The international human right to health is established both via international treaties and a growing body of international customary law (Kinney, 2001). There is growing recognition that international human rights law is a powerful means by which to advance the rights and interests of people with mental illness (Gostin & Gable, 2004; Quinn & Degener, 2002; Kinney, 2001).

> *The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.*
>
> (International Covenant on Economic Social and Cultural Rights, Article 12)

Australia is a party to the International Covenant on Economic, Social and Cultural Rights (ICESCR; United Nations 1966a), the International Covenant on Civil and Political Rights (ICCPR; United Nations 1966), and the Convention on the Rights of the Child (CRC; United Nations 1989). Australia is therefore bound under international law to ensure that all people in Australia enjoy the following rights, amongst others:

- The right to the highest attainable standard of physical and mental health (Article 12 ICESCR; Article 24 CRC)
- The right to an adequate standard of living including food, clothing and housing (Article 11 ICESCR; Article 27 CRC)
- The right of children to an environment that fosters the health, self-respect and dignity of a children where they are in need of psychological recovery from neglect, exploitation, torture or trauma (Article 39 CRC)
- Where children have been placed under mental health programs they have the right to periodic review (Article 25 CRC)
- The right of children with disabilities to access appropriate health and rehabilitation services (Article 23 CRC)
- The right to life (Article 6 ICCPR; Article 6 CRC)
- The right to freedom from cruel, inhuman or degrading treatment (Article 7 ICCPR; Article 37 CRC)
- The right to liberty and security of person (Article 9 ICCPR; Article 37 CRC)
- The right to be treated with respect for dignity and with humanity when deprived of liberty (Article 10 ICCPR; Article 37 CRC)
- The right to freedom of movement and choice of residence (Article 12 ICCPR)
- The right to freedom of interference with privacy or family life (Article 17 ICCPR; Articles 9 and 16 CRC)

In addition to the fundamental human rights enshrined in the International Covenants, there are specific UN Principles that deal with some of the particular issues facing people with mental illness.

The *UN Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care* (the UN Mental Health Principles; United Nations General Assembly, 1991) were adopted by the United Nations in 1991. While it is not a binding instrument in itself, the Commonwealth, State and Territory governments have recognised the value of incorporating those principles into policy, and attempted to do so in the First National Mental Health Strategy.

The UN Mental Health Principles reinforce the rights enshrined in the International Covenants and provide valuable guidance as to how those rights ought to apply to people with mental illness. For example Principle 8(1) makes clear that people with mental illness have the right to the same standard of health care as other ill persons and Principle 14 states that mental health facilities should have the same level of resources as any other health facility. Additionally, Principle 7 emphasises the right to be treated and cared for as far as possible in the community and Principle 9 emphasises the importance of 'the least restrictive' alternative in relation to treatment. The Burdekin Report treated the UN Mental Health Principles as a benchmark in determining whether or not the rights of people with mental illness were being protected (Burdekin Report; Human Rights and Equal Opportunity Commission, 1993, p31).

2.1.1.2 Recent international developments

The Council of Europe, comprising 45 member states, recently drafted a comprehensive set of recommendations to protect the rights of people with mental illness and to promote higher standards of care (Kingdon et al. 2004). The recommendations cover a wide range of areas including:

- the right to non-discrimination and mental health promotion;
- the right to be accommodated in appropriate environmental and living conditions while receiving treatment and support;
- the right to live and work in the community;
- limitations on the use of seclusion and restraint options of people needing treatment;
- criteria and procedures for involuntary placement and treatment;
- the right to individualised treatment;
- the right to treatment in the least restrictive environment;
- guidelines for the involvement of police (who should also receive appropriate training to respond appropriately), the courts and the prison system in the context of mentally ill persons; and
- guidelines for the treatment of 'minors'.

In reforming systems to protect the rights of the mentally ill, the Council for Europe also emphasises the fundamental need for monitoring quality standards in the provision of mental health services (Kingdon et al. 2004).

In the context of the general trend towards deinstitutionalisation and the growing rate of homelessness, incarceration of people with mental illness and community fears of danger, recommendations from the Council of Europe also emphasise the need for vigilance to ensure that involuntary orders are made 'for therapeutic purposes' and not solely for the purposes of removing the person from the community:

> *Involuntary placement should include therapeutic purpose. The mental health system therefore should not be used for custodial reasons alone, even when there is significant risk of serious harm to others. Where such potential for harm exists but no therapeutic intervention is indicated, this is a matter for the criminal justice system.*
>
> (Kingdon, Jones & Lönnqvist, 2004, p. 277)

The World Health Organisation (WHO) (Project on Mental Health and Human Rights; WHO 2005a) is also currently preparing a mental health legislation manual to assist countries to develop a legal framework to protect the rights of people with mental illness both within the health delivery context and in the broader community. Specifically, within health service delivery environments, WHO "frames the right to mental health in terms of population-based services and would require that countries offer screening for mental illnesses, mental health education, and psychiatric services" (Gostin, 2004). On a broader level, WHO argues that while mental health legislation is not sufficient to address the rights of the mentally ill, it is an essential complement to mental health policy and provides the legal framework with which to meet its aims and that it is an evolving process:

> *Mental health legislation can provide a legal framework for addressing critical issues such as the community integration of persons with mental disorders, the provision of care of high quality, the improvement of access to care, the protection of civil rights and the protection and promotion of rights in other critical areas such as housing, education and employment. Legislation can also play an important role in promoting mental health and preventing mental disorders. Mental health legislation is thus more than care and treatment legislation that is narrowly limited to the provision of treatment in institution-based health services.*
>
> (World Health Organisation, 2003, p. 2)

In 2002, the United Nations Human Rights Commission appointed a Special Rapporteur on the Right to Health. The Special Rapporteur has the mandate to collect information on the realisation of the right to the highest attainable standard of physical and mental health and make recommendations on how to ensure compliance with that right (http://www.ohchr.org/english/issues/health/right/index.htm).

2.1.2 A SUMMARY OF CHANGES IN AUSTRALIAN POLICY AND PRACTICE SINCE THE BURDEKIN REPORT

> *Little since the Burdekin Report has changed save that the process of deinstitutionalisation has hastened. While patients who are involuntarily detained now possess a number of enshrined rights that regulate the circumstances of their detention, increasing numbers of still psychotic patients are discharged under pressure for hospital beds. Problems continue to exist with the coverage of disability discrimination legislation. No appreciable increases in resources has been allocated for the escalating numbers of significantly symptomatic patients cared for within the community. In such circumstances, there is a real limit upon the extent to which it can be said that those with mental illness have rights to treatment and, in particular, to adequate treatment. A real issue within mental health law, as increasingly it is in within the wider area of law, is how patients can insist, with the assistance of the law, upon being provided with the treatment that they need for the alleviation of their pain and suffering.*
>
> (Freckelton & Loff, 1998, 267 at p. 285)

> *While the aims of the Second [National Mental Health] Plan have been an appropriate guide to change, what has been lacking is effective implementation. The failures have not been due to lack of clear and appropriate directions, but rather to failures in investment and commitment.*
>
> (Steering Committee for the Evaluation of the Second National Mental Health Plan 1998-2003, 2003, p. 3)

The neglect of mental health services in our society has a long and well-documented history. The personal and family consequences of decades of neglect were highlighted for the whole nation by the widespread publicity given to the 1993 National Inquiry into the Human Rights of People with Mental Illness (The Burdekin Report; Human Rights and Equal Opportunity Commission, 1993). In response to growing criticism regarding the quality of mental health services in the early 1990s, state, territory and federal governments attempted to enshrine human rights protection into mental health care policies.

The first of these attempts was in 1992, when all Australian State and Territory governments, as well as the Commonwealth Government, agreed to develop a common National Mental Health Policy and Strategy. This gave birth to the first National Mental Health Plan which covered the five-year period from 1993 to 1998. The Plan demonstrated a commitment to a human rights based approach to the reform of mental health care in Australia. Specifically, in 1992 all State and Territory governments agreed to develop legislation by 1998 that was consistent with the UN Mental Health Principles (Rees 2003, p. 33).

In 1996 the Attorney-General's Department developed a 'Rights Analysis Instrument' to measure compliance of State and Territory legislation with the UN Mental Health Principles (Watchirs & Heesom 1996). A review of mental health policies against that instrument found that the legislation did comply or that the Governments were in the process of appropriately amending their mental health legislation (Watchirs 2000).

Despite these advances, by 1998, when the Second National Mental Health Plan was developed, all reference to human rights had disappeared (Rees 2003, p. 34).

There has been some criticism of the effectiveness of the Rights Analysis Instrument as a measuring tool (Rees, 2003; Carney, 2003; Freckleton & Loff 1998). On the basis of the results of the Rights Analysis Instrument review, some commentators suggest that mental health legislation in all Australian States and Territories is now consistent with the UN Mental Health Principles (Whiteford & Buckingham, 2005; Whiteford et al. 2000; see also Rees, 2003). However, the stories related by consumers and practitioners during these consultations suggest that either the legislation is not yet consistent with the UN Mental Health Principles or that the legislation has not been effective in protecting consumers and carers against abuses.

In a recent critique of the capacity of mental health law and policy to respond to current and future challenges of community based care, Carney (2003) argues that while Australian legislation and policies may pass human rights scrutiny in principle, there is insufficient focus on the monitoring processes to ensure implementation and adherence to those measures (Carney, 2003, p. 12).

Since the Burdekin Report, there has been a more rapid move towards deinstitutionalisation and concurrently the rights of those who are still institutionalised seem to be better protected. However, the recent community consultations, and writings of academics, clearly suggest that it would be incorrect to assume that those advances have solved the multiple rights issues facing the mentally ill. While there is a lot to be said for preferring community treatment over institutional treatment, we cannot assume that community treatment is actually being effectively delivered. Just releasing mentally ill men, women and children into the community without appropriate supports is not an adequate reaction to the problems arising from institutionalisation.

In addition to the problems associated with institutionalisation in the early 1990's, the Burdekin Report dealt with some of the deficiencies in community care. The stories heard during these consultations suggest that little has changed since then, other than the fact that there are increasing numbers of persons relying on that community care.

> *[A]nyone working within the public system today in any part of Australia or New Zealand (as well as in most Western countries) will be acutely aware of a range of problems in the post-deinstitutionalisation environment. Particular difficulties include the challenge of accessing inpatient care even in crisis situations; the heavy emphasis on pharmacological management of serious mental illnesses, generic case management leading to professional de-skilling, extensive use (over-use?) of compulsory treatment orders in the community; and inadequate resources allocation and staffing of mental health services. The result is arguably a sub-standard system of semi-institutionalisation within the community that lacks many of the best features of the old system. There cannot be said to be a true asylum for those with mental illnesses that need one. There is limited availability of effective multidisciplinary approaches to treatment, especially for those with comorbidities. It is dubious whether there can accurately be said to be appropriate protection from harm to self and others for people suffering acute effects of their mental illness. Stigma and lack of community understanding and support leave many suffers of mental health problems with poor quality of life, inadequate community supports, and reduced functionality and capacity to contribute to and enjoy life and work.*
>
> (Freckelton & Lesser, 2003, p. v)

Further, ten years after the first National Mental Health Plan, the key reviews of the outcomes (as opposed to the written policies) by government, independent authorities and non-government bodies suggest ongoing problems in accessing appropriate care.

> *…the clear message from the community is that people continue to experience problems in accessing services during crises and finding services that are responsive to their individual needs.*
>
> (Christopher Pyne, Parliamentary Secretary to the Minster for Health and Ageing, Foreword, National Mental Health Report 2004; Commonwealth Department of Health and Ageing, 2005)

The stories told during these consultations and surveys by mentally ill persons and their families suggest a pattern of continuing neglect. It seems that, even where there has been good policy or law, the policy has not been translated into reliable, high quality health care. Genuine empowerment of persons with illness and their families does not seem to have occurred at a local, regional or state level. The quality of life of those living with enduring illnesses in the community appears to be continually compromised by discontinuities of care, stigmatising community attitudes and overt and covert discriminatory practices in employment, education and social welfare.

State and territory governments have once again declared their commitment to continued reform. In the last 18 months most Health Ministers have recognised the long-standing neglect. However, while stand-out programs can be identified, there is no clear evidence of a systemic commitment to improved access to quality care. In fact, these consultations and other reviews of the mental health system suggest that we now have reached a point of serious and systemic neglect. Some governments have argued that they cannot keep up with increased demand and high expectations of good quality services.

> *Many of the major structural reforms proposed at the outset of the Strategy ten years ago have been followed through by all jurisdictions, and are near completion in some cases. The mental health service system is now faced with a different set of challenges, arising from both the new demands of community service delivery and growing awareness of the need for mental health care.*
>
> (National Mental Health Report 2004; Commonwealth Department of Health and Ageing, 2005, p. 30)

However, governments have been fully aware of the major gaps in services since at least the early 1990s. They agreed collectively in 1993, 1998 and 2003 (when each five-year mental health plan came into being) to correct basic system failures. Ignorance of the nature and the extent of the problem can no longer be used as an explanation.

It is apparent that the priority placed on resources for mental health has been decreasing, rather than increasing. Total health expenditure has increased rapidly over the last decade with Australian national health spending reaching 9.5% of GDP in 2003 ($72.2 billion, up from 8.4% in 1995-96). However, as a proportion of this expenditure, total mental health spending (excluding aged care), has remained static at less than 7% of recurrent funding (National Mental health Report 2004; Commonwealth Department of Health and Ageing, 2005).

> *...current funding levels in all states and territories may not be enough to meet priority community needs.*
> (National Mental Health Report 2004; Commonwealth Department of Health and Ageing, 2005, p. 18)

There is a fundamental inequity in health care expenditure allocation in Australia (Hickie et al. 2004). Generally speaking, expenditure on chronic or recurring illnesses like respiratory, nervous system and musculoskeletal diseases is greater than expenditure on health issues that create shorter term crises like cancer, cardiovascular episodes or accidents. The exception in this trend is expenditure on mental health. In other words, unlike the situation of those with physical illnesses, expenditure on our mental health care services does not meet the needs of the recurrent or chronically-disabling disorders that most people with a mental illness suffer. Rather the services cater to short-term and limited care.

> *The question of whether the existing service configuration is appropriate to meet the demand for services, or whether a different service configuration is required, remains fundamental.*
> (National Mental Health Report 2004; Commonwealth Department of Health and Ageing, 2005, p. 31)

These inequities in resource allocation and the failure to develop innovative and comprehensive services have major health and social consequences for those with mental illness and the wider community. For example, when persons who are ill cannot access appropriate health care they are more likely to become unemployed, homeless or enter into the criminal justice system.

Multiple and disjointed short-term solutions have been attempted over the last decade. Currently, the states and territories focus largely on improvements in the acute care and forensic areas with specific responses. However, without recognition that systemic inequities in resource allocation and service development exist, Australia is unlikely to develop the more comprehensive system of community-based care that offers the best chance of a high quality of life and protection of the basic rights for those persons whose lives are disrupted by mental illness.

2.1.3 HUMAN RIGHTS AND THE NATIONAL STANDARDS FOR MENTAL HEALTH SERVICES

Throughout this report, we have attempted to align the key themes expressed in the public meetings, individual consultations and written submissions with the National Standards for Mental Health Services that were agreed by all governments in the mid 1990s (Commonwealth Department of Health and Family Services, 1996).

While these standards are not a direct replica of the UN Mental Health Principles, they do reflect a basic commitment to provide services that respect individual human rights and equitable access to high quality mental health services.

The National Standards for Mental Health Services underpin a nationwide movement to implement appropriate community-based services and reflect our national commitment to provide 'the highest attainable standard' of mental health care as required by ICESCR and the Convention on the Rights of the Child. As such, any genuine improvement in the provision of mental health services can be measured against these standards, and current failures in provision of services or respect for individual human rights amongst persons with mental illness are best understood against this background.

2.2 KEY THEMES FROM NATIONAL CONSULTATIONS AND WRITTEN SUBMISSIONS

The great majority of written and verbal submissions focused on deficits in key aspects of mental health care services. While a wider range of community and other welfare, housing and custodial services were the subject of individual or group submissions, the fundamental lack of access and failings in the access to quality health services available to persons with mental illness dominated the discourse. The contrast between experiences of care when presenting with a physical illness as compared to presenting with a mental illness was profound. A lack of respect for persons with mental illness or their families was commonly reported. The combination of a lack of respect, poor resources and inadequate facilities appeared to underpin the numerous reports of reduced safety within mental health care services. Pleas for the provision of basic care with dignity were almost universal.

A fundamental difference in perspective was evident between those who used services at a local or district level and those who administered services. Those who use services have grown tired and frustrated by presenting their individual stories to a long line of independent national or state-based reviews and inquiries. They feel exploited by the process and repeatedly traumatised. Many are frankly cynical about the process and do not feel that reporting their experiences now is likely to result in genuine government or professional responses. Nevertheless they did share their experiences with us.

Consumers and their family and carers prioritised a number of fundamental aspects of health care and related services – and these were generally consistent with other independent notions of quality of health care services (see Picker Institute Europe [http://www.pickereurope.org]). These included:

i) access to professional care, particularly in emergency and other acute care settings;
ii) treatment with dignity and concern for the individual irrespective of location of care;
iii) prioritisation of safe and high quality services;
iv) an emphasis on clinical care, rather than 'containment' of those with mental disorders;
v) earliest possible access to professional care in non-acute circumstances;
vi) response to individual needs, including recognition of the complexity of comorbid substance abuse, personality dysfunction or socio-economic deprivation;
vii) coordination of health, welfare and related community support services;
viii) access to programs and support to live independently and work;
ix) respect for the legitimate interests of family and carers in accessing care and participating in ongoing treatment decisions;
x) support for those who provide direct clinical services;
xi) provision of appropriate community housing options; and
xii) access to appropriate medical as well as psychological services.

After 4 January 2002 when our daughter had been transferred from the MHU [Mental Health Unit] into medical ward 2East, she was immediately treated by the staff as a whole person with dignity, respect, compassion and empathy. We observed that the medical ward staff was a professional caring team at all times, even when our daughter was a handful. They accepted the challenge with care, diligence, resourcefulness and a great team effort which achieved a great result in a short time in comparison with the five weeks that our daughter was in the MHU where she deteriorated badly. As parents, we are grateful for the clear concise and accurate information the medical ward team offered us, keeping us informed and assured that our daughter's medical treatment was on-track.

(Carers, Parents, New South Wales, Submission #106)

I have to wonder if it were a serious physical illness or aliment if medical personnel would allow an individual to go unmediated for such a long period of time.

(Anonymous, Queensland, Submission #82)

People with mental illness are not receiving the same care as those with physical illnesses. There is inequity in funding for mental health projects.

(St Bartholomew's House Inc, Western Australia, Submission #37)

In Esperance we have had no psychiatrist for 5 months. If consumers need acute care they have to be taken to a GP and then tranquilised and strapped to stretcher to be transported to Perth. I was told when I was suicidal, to drive myself to the city.

(Consumer, Western Australia, Perth Forum #45)

Why on earth are consumers who are exhibiting signs of a relapse not taken seriously? Why is it that the consumer needs to be either psychotic, suicidal, or in some other emergency before they are seen and treated?

(Carer, Husband, Western Australia, Submission #146)

We need a clinic we can walk into just like a 24 hr clinic you would attend for the flu. Why can't we have it? Why do I need to self harm myself to receive relief? Why do I need to overdose to receive attention? Do I and many, many more need to die before we attend to what we preach that mental illness is like a physical illness?

(Consumer, Victoria, Submission #202)

Although St Bartholomew's House continues to try and provide a quality service in supported accommodation (SAAP), the lack of resources, a staff ratio of 1:54, poor education of staff and the numbers of people requiring care limits the capacity to delivering safe quality care.

(St Bartholomew's House, Western Australia, Submission #37)

Our son had done no wrong and as a mentally ill person deserved to be treated with dignity, care and understanding not to be confronted by police.

(Carer, Father, Western Australia, Submission #175)

I had an incident a while ago when I went to hospital in Bunbury, I was put aside (waited) a couple of hours – I wanted to go home but the hospital wouldn't let me go. I finally went home and a few hours later the police came to take me back to the hospital. I went willingly and saw the doctor who said I needed an injection. I was threatened that the police would hold me down while I had the injection so I agreed to have it. After they injected me I was taken to Graylands Hospital in Perth but nobody informed my family of my admission to Graylands.

(Consumer, Western Australia, Bunbury Forum #1)

For me this is not strong language, during the ten years I have been a carer of a severely physically disabled mentally ill person, I feel I have been treated less then human, and the person I care for, as well as others with disabilities, looked upon as worthless citizens who the governments wished didn't exist. Our loved ones are offered inferior care, if care is what it can be called.

(Carer, Husband, Northern Territory, Submission #68)

When a patient needs assistance, the Ambulance usually will not transport and the caller is directed to phone the police. Police will transport the client to the hospital in the back of a police wagon. This is a very degrading experience!

(Supported Accommodation Service Provider, Northern Territory, Submission #217)

Because intervention comes so late, consumers and families report that once the police are involved and no matter how the police are, there is still a sense of not being treated with dignity. One consumer explained the situation: "I know when I get sick that I quickly lose insight and will resist treatment but I am sick and there I am being handcuffed by police. No other groups of people with an illness are treated like this. Why are we? Surely there can be a better way. I think it starts with me being able to say, I'm becoming unwell and clinicians taking me seriously."

(Mental Health Community Coalition Consumer and Carer Caucus,
Australian Capital Territory, Submission #342)

By contrast, those who planned or administered services were perceived by consumers, carers and clinicians (evidenced by presentations at forums and in written submissions) to be preoccupied by:

i) the location of care services rather than the actual provision of care;
ii) the cost-efficiency of different models of care;
iii) managing down rather than responding to the increased demand for better quality services;
iv) avoiding direct accountability for specific service failures and failures to invest in new services;
v) planning without consultation with staff, services, consumers and carers;
vi) negating an emphasis on enhanced community care in favour of acute and custodial care; and
vii) rejecting legitimate critiques of the current systems of acute and community care.

Staff confidence in senior management involved in the redevelopment is at an all time low due to their refusal to listen to grass roots workers, consumers and carers. Front line continue to be pressured to provide more with less, services are fragmented, Staff are burning out, and positions are vacant for long periods due to the appalling pressure and conditions.

(Anonymous, Tasmania, Submission #254)

Despite the successes in making the changes outlined in the chapter on 'Changes Made' there are still unacceptable practices to be addressed. The outcomes though commendable do not represent 'best practice' or indeed in many cases even 'good practice'.

(Eamon Shanley, Professor of Mental Health Nursing, Western Australia, Submission #33)

Those who are conscious of the practical and economic problems in providing care to over half the population at some point and up to a quarter within a 12 month period, have argued that a diagnosis should be associated with substantial functional disability before treatment should be funded and accessed (Regier et al 1998, Spitzer et al 1998). This is superficially attractive, however it means that people are required to become functionally disabled by their symptoms before they can be offered help. Such disability is usually hard to reverse even when treatment is effective…Restricting access in this way is antithetical to preventive and early intervention approaches, would be completely unacceptable in general medical care where people with mild disorders, such as a viral illness, can gain ready access, and may prevent the most cost-effective phase of serious illness from being treated. Mild disorders should be able to access treatment of some kind for all these reasons (Kessler 2003).

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

Deinstitutionalisation has not failed. What has failed is the political will to fund essential support services in the community. The existing services are overwhelmed by the heavy demand they currently face and they are not able to provide the level of care and support required to assist recovery. This lack of support options dramatically increases the hardships faced by people who have a mental illness and their families, in terms of their health and their budgets. Ultimately, it is a failure of systems which is making people sick and forcing them into the costly acute care sector.

(Anglicare Tasmania, 'Thin Ice: Living with Serious Mental Illness and Poverty in Tasmania', Tasmania Submission #144)

There is an increasing number of people accessing mental health services which dilutes the quality of existing services – so with the quality of existing services being poor already you can see we are heading for a disaster.

(Clinician, Victoria, Morwell Forum #4)

The ability of Mental Health Services to deliver quality care has been severely restricted by continual budget cuts and the lack of funding to community services.

(Anonymous, Tasmania, Submission #254)

I would like to know why mental health funding is dominated by the medical model when funding could be better used to develop mechanisms to provide assistance for when people are well. We need to give people an opportunity of a life worth living. In the ACT less than 5% of the funding for health goes into social programs to help people do what they want to do with their lives. People's expectations are so low…The medical model is about risk management. We neglect people when we leave them out to rot – in front of a TV all day! I lost all my social skills – I see so many of my fellow consumers who can't do this because they have been dominated by the medical model. People go into self-medication with pills and drugs – we are now the dominant group in the criminal justice system. We need case workers who have no more than 8-10 clients and who can give due attention to people's long-term needs.

(Consumer and Consumer Activist, Victoria, Footscray Forum #3)

I feel the inpatient unit in Bunbury provides a second-rate service to the mentally ill in the region as it does not provide a multi-disciplinary team. The Therapy Department went from 4 Full Time Employees, providing a day-service to clients for six-weeks intensive therapy to prevent hospital admissions, to now only 1.5 FTE, providing only an abbreviated day program to the current inpatients. The therapy department is now housed in the nursing station of the High Dependency Unit, due to the Community Staff moving into their space when they lost their premises. The patients have lost their group room, which now houses community staff, desks and computers. The whole APU is an overcrowded situation with the community staff moving into the small premises.

(Clinician, Western Australia, Submission #55)

We found that the therapeutic situation in the MHU [Mental Health Unit] is unacceptable in its overall treatment of people with mental illness…We found that the management of the MHU raises issues of delinquency or malpractice, whether by inadvertence, incompetence or deliberation. We observed the MHU staff working under considerable pressure, their services being under-resourced and their numbers inadequate for their patients' safety. We are hesitant to single out particular staff, but we believe that individually it is their responsibility to practice appropriate duty of care and nursing similar to that demanded in hospital medical wards.

(Carers, Parents, New South Wales, Submission #106)

On a personal level, working in the APU [Acute Psychiatric Unit] provides a lot of anxiety for me at times. I feel there is no commitment by the hospital to provide a high standard of care for the mentally ill, funding is lacking, and the issue of safety, being an expensive one, does not hold high priority for the hospital or the current government.

(Clinician, Western Australia, Submission #55)

A constant catch-cry in feedback is the lack of community services. Failure to provide adequate community services perpetuates a revolving door outcome for the acute sector. There are numerous studies which demonstrate that well-structured community and support services are cost-saving to the health system in the long term.

(Mental Illness Fellowship of Australia, National, Submission #331)

What is needed are PROPERLY RESOURCED community based services which provide social and emotional supports, peer support and advocacy - which return to people their humanity, their dignity, their self-respect. (author's emphasis)

(Consumer Advocate, NSW Submission #153)

Only a fraction even of the most seriously mentally ill can gain secure tenure in this system. So even with a system heavily targeted to chronic schizophrenia, only a minority even of these cases gain appropriate coverage. The rest are referred back to unsupported GP's after the latest patch-up job otherwise called "episode of care".

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

Just because it is becoming more common to relocate such community-based services in Emergency Departments and elsewhere on acute hospital sites, doesn't imply that this is the most effective deployment at all. This retreat to a "fortress" hospital mentality is ostensibly due to administrative staff OH&S concerns. However it is really due to Health Executives' "land hunger", plus the perceived need to make shortsighted attempts to assuage general hospital clinical pressures, eclipsing the real need for community based services which prioritise the best possible outcomes for service users and their families.

(Clinician, New South Wales, Submission #351)

There is a good reason for us to have a better community focus. Services at the moment are focused internally which is located in the hospital. To the Broken Hill people it may seem like just another hospital service.

(Clinician, New South Wales, Broken Hill Forum #9)

2.2.1 THEMES RELATING TO THE NATIONAL GOVERNMENT, NATIONAL MENTAL HEALTH STRATEGY AND NATIONAL RECOMMENDATIONS

The National Mental Health Strategy was developed over a decade ago to respond to obvious service failures and human rights concerns. An analysis of the current manifestations of that Strategy, namely the 2004 National Mental Health Report and the 2003-2008 Third National Mental Health Plan, suggest that we do not yet have a national process for translating the policy rhetoric into real increases in resources, enhanced service access, accepted service standards or service accountability.

As detailed in Parts Four and Five of this report, submissions and presentations at forums make it clear that neither those who use nor those who provide services have any faith in the continuation of the current national processes. The submissions suggest that key issues such as: national implementation of early intervention strategies; coordination of national alcohol, drug, mental health and suicide prevention strategies; implementation and ongoing review of national mental health standards; enhanced access to public and private sector mental health services (particularly for those who live in rural and regional areas); introduction of national measures of quality and safety; improved clinical care for the aged; support for innovation, research and sustainable new systems; and prioritisation of supported employment and rehabilitation services will not be realised by the current governments employing conventional bureaucratic processes.

Submissions and presentations at forums highlighted issues which need specific attention at the national level. These included:

i) poor access to psychiatrists, particularly outside major metropolitan centres;
ii) poor access to psychologists, due to general lack of government or private insurance rebates;
iii) lack of appropriate workplace-based rehabilitation and recovery programs;
iv) declines in bulk-billing among general practitioners and psychiatrists over the past decade resulting in greater out-of-pocket expenses;
v) difficulties in accessing private health insurance cover;
vi) limited access to new medications in outpatient settings, especially restrictions on the provision of PBS scripts;
vii) major difficulties in personal dealings with Centrelink and other Federal welfare and support agencies; and
viii) major difficulties with restricted access to the Disability Support Pension (DSP), Carer Allowance or other related welfare and health benefits.

The Burdekin report stated that "restriction to access to psychologists results in important treatment options being denied to many individuals affected by mental illness and that the lack of access is incompatible with human rights and is economically unsound". It seems immoral that in 2004 clinical psychologists are not routinely available to people suffering mental disorders.

(ARAFMI Tasmania, Tasmania, Submission #245)

There's only a visiting psychiatrist for this area. They come one day a week. We need more access than that. But then the problem in Adelaide if you can get up there is that there's very little bulk billing psychiatrists in Adelaide. Earlier in the year I was told that I needed a psychiatrist but I couldn't find one that was bulk billing that was taking new patients. There's not even a social worker here now, no OT now, no psychologists after several years. It's all left to the mental health nurses who are expected to carry the load.

(Consumer, South Australia, Murray Bridge Forum #2)

There are no services available for the 25 to 55-year age range beyond employment programs, whose existence and quality are inconsistent across the region.

(Anonymous, Northern Territory, Submission #271)

Consumers in the community are left dry. They are put out into their flat and that's the end of it. The services we have are good but they lack staff resources and skill development. Some consumers are never given the opportunity to have rehabilitation.

(Carer, Mother, Northern Territory, Alice Springs Forum #13)

There is no supported employment program that meets the criteria of best overseas practice. My son would dearly love to work part-time, but in a field in which he has experience.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

Australia is poorly served with employment programs for people with a mental illness and associated psychiatric disability. Traditional vocational rehabilitation services are far less effective than supported employment. As an example successful employment programs Trieste in northern Italy report an employment rate of 60% of people with schizophrenia whereas in Australia over 75% of people with schizophrenia are not working and on a disability pension.

(Mental Illness Fellowship of Australia, National, Submission #331)

People experiencing mental illness as well as their families frequently experience financial problems. For the people with the illness themselves, the longer they are sick or the more episodes they experience the more likely it is that their only income is Centrelink payments. It is very difficult to subsist on Centrelink payments. A Centrelink payment barely covers board or rent and people are often left with little for food, transport, clothing and other necessities. People with mental illness frequently have difficulty in affording health care and medications as well.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

The following issues are of grave concern to us…A significant number of same-day hospital based psychiatry services require a co-payment to be met by the consumer, as the full cover of the services are not met by certain levels of cover offered by private health insurance funds. This effectively limits access to those services. If these co-payments increase, then some consumers will have to consider the option of dropping their private health insurance cover thus placing more strain on the public system.

(The National Network for Private Psychiatric Sector Consumers and Carers, National, Submission #225)

The following issues are of grave concern to us…The new atypical anti-psychotic medications should be available to consumers who suffer a mental illness, apart from schizophrenia. There is strong evidence that these medications can be used in low doses to very usefully to treat other disorders, particularly mood disorders. Currently, psychiatrists working in the public hospital system are able to prescribe these medications for disorders other than schizophrenia. However, psychiatrists in private practice are not, which effectively prohibits them from providing evidence-based best practice for many of their patients.

(The National Network for Private Psychiatric Sector Consumers and Carers, National, Submission #225)

2.2.2 KEY NATIONAL THEMES THAT EMERGE FROM REVIEW OF THE SERVICE ENVIRONMENTS WITHIN EACH OF THE STATES AND TERRITORIES

Review of the services within each state and territory highlighted many common themes that fall within the responsibility of state and territory governments. These included:

i) the scramble for acute care beds within each State;
ii) restriction of access to acute care by exclusion on the basis of diagnosis (e.g. personality disorder, drug-related mental health problem) rather than clinical need;
iii) premature discharge of unwell persons who remain at risk from inpatient and other acute care facilities;
iv) difficulties accessing professional care during onset and to prevent deterioration of illness;
v) lack of access to medium or long-term care facilities, institutionally or community-based;
vi) lack of coordinated and genuine youth-based or early intervention services;
vii) lack of rehabilitation or recovery services;
viii) poor state of forensic mental health services;
ix) poor and dangerous processes for transfer of mental health patients to clinical facilities;
x) inappropriate use of 'privacy' and 'confidentiality' considerations to exclude families and carers from treatment planning;
xi) lack of support for local clinical governance models, service innovation and local community partnerships;
xii) over-reliance on crude service access or risk checklists, service protocols and other arbitrary non-clinical tools to regulate local service characteristics; and
xiii) lack of genuine and transparent data mechanisms pertaining to assessment of ongoing safety and quality of services.

I work with young people aged 13-18 years, but this is getting pushed out to work with people as old as 25. I provided 24 hour support to a 21 year old recently who couldn't get care anywhere.

(Service Provider, Australian Capital Territory, Canberra Forum #20)

Parents have difficulty accessing limited child psychiatrists and psychologists for their disturbed youngsters. Adult facilities are inappropriate, overburdened and inaccessible. Early intervention and accurate diagnosis, stressed as priorities in the National Mental Health Plan 2003 – 2008, remain as rhetoric instead of reality.

(ARAFMI Tasmania, Tasmania, Submission #245)

The psychiatrist that was here before was great with feedback to other services and families – now the situation is hopeless. There are two of us (school counsellors) covering 8,000 people in this area. There is no child psychiatrist in the area and the service knew for about 12 months that he was leaving. Nothing has been done that I can see to replace him.

(Clinician, Western Australia, Bunbury Forum #8)

Young people's mental health services are the most difficult to access. Often they are told they are not sick enough and then told they can't get care because they have a comorbid drug and alcohol problem.

(Clinician, Queensland, Brisbane Forum #7)

No access to a spectrum of intervention, including whole of life span target groups. Anangu living on the NPY Lands have access only to a small range of acute mental health services whose responses are crisis driven and in circumstances where their involvement is most likely to be involuntary.

(Anonymous, Northern Territory, Submission #271)

People with personality disorders and those who self harm are treated with contempt and a lack of understanding particularly by unit staff. There is little or no expertise in working with people with this disorder.

(Anonymous, Queensland, Submission #113)

But there's nowhere to go when you get out of Flynn. There's no step-up or step-down care.

(Consumer and Consumer Consultant, Victoria, Morwell Forum #5)

*It seems to me clear that staff were over anxious to discharge [X] due to the perennial shortage of beds at Mandala and that this is one of many cases which highlight Government neglect in the area of mental health facilities. Many promises are made but many do not eventuate or are delayed excessively. This is causing needless deaths in the community. The mental health beds at Wyong hospital have been promised for some time but are still not available. The public are entitled to expect that the mentally ill will be properly cared for by government funded services…The standard of care provided for [X] left much to be desired. After considerable questioning, this was reluctantly conceded by some of the doctors who gave evidence at this inquest…[X] was discharged with a minimum of formality and no guidance or assistance… (excerpt from t*he coroner's report) *[Suicide occurred in December 2002, 10 hours after being discharged from the Mandala Psychiatric Unit on the Central Coast. He made 2 suicide attempts prior to admission. [X] was released from the unit after 36 hours in the hospital.]*

(Carers, Parents, New South Wales, Submission #137)

What is acceptable about refusing to carry out early intervention until the person is 'acutely' unwell, which leads to a very distressing forceful intervention, then having to administer extremely strong dosages of medication which induce obvious physical side effects which take months to subside?…What is acceptable about not keeping people with a mental illness as well as they can possibly be, thus reaching and maintaining their full potential within the illness?

(Carer, Mother, Victoria, Submission #178)

Andrews has attempted to calculate how much of the burden associated with psychiatric disorders is avertable with modern evidence-based treatments (Andrews 2000). While it seems clear he has underestimated this for schizophrenia (Goldberg 2003, Warner 2003), his general conclusions seem to be that much of this burden, up to 40% on average across a range of disorders is potentially avertable. If evidence based treatment were made available and coverage were increased we could avert nearly 30% of the burden in contrast to the present 13%.

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

2.3 NATIONAL SURVEY OF MENTAL HEALTH PRIORITIES IMPLEMENTATION

This national survey conducted by the Mental Health Council of Australia, with support from the Brain and Mind Research Institute, University of Sydney, (as of 2 November 2004) resulted in 714 completed responses. The majority of respondents described their role within the mental health sector as public providers of specialist treatment (n=246, 34%). This was followed by consumers and carers (n=162, 22%) and then non-government community service providers (n=74, 10%).

For the top five community priorities for national mental health reform (that were identified earlier by community surveying during the development of '*Out of Hospital, Out of Mind!*' [2003]), evidence of implementation at a local service level was extremely low. National rates for high level or full implementation of each of the priorities were:

- 17% for implementation of early intervention services;
- 11% for development of innovative services for those with comorbid substance abuse;
- 12% for development of a wider spectrum of acute and community-based care systems;
- 15% for implementation of the national standards for mental health services; and
- 9% for programs that promote attitudinal changes among health workers.

Importantly, these top priorities are not new, some were agreed targets of the previous national mental heath plan (1998-2003) – such as implementation of the National Standards for Mental Health Services, and all should be at the forefront of national and state/territory expenditure lists. They relate to the fundamental aspects of delivery of specialised mental health services in this country.

When respondents were then asked to rate other priorities that required implementation at a broader state/territory level, the low levels of national endorsement of high level or full support for implementation were equally disappointing. Worth highlighting were the low rates of:

- 13% for development of specific intergovernmental service agreements;
- 10% for innovation, research and service evaluation;
- 10% for introduction of specific schemes to enhance access to specialists;
- 11% for support of non-government agencies; and
- 11% for mechanisms for clear accountability of mental health strategy funds.

Finally, respondents living or working in rural, regional, remote or poorly resourced areas were asked about the extent to which service development was being supported in these areas. The national endorsement rates for high level or full support were so low (7% for rural and regional areas, 2% for poorly resourced areas) as to suggest a lack of basic interest or commitment by all governments to the development of new services in this high need areas.

2.4 NATIONAL SURVEY OF CONSUMER AND CARER EXPERIENCES OF CARE

Much of the work of the national mental health reform process in Australia has focused on moving the locus of care from institutions to the community-settings. By contrast, little work has actually focused on whether the experiences of care by those who use services have been enhanced by this process. What work has been done has tended to draw mostly from critical incident reviews rather than everyday experiences of care.

This novel survey mechanism introduced through the Mental Health Council in 2004 seeks to record ongoing experiences of care by those who actually use mental health services. It extends a framework initially developed in other areas of heath care to measure the quality of services provided (Hickie et al 2003 Australasian Psychiatry). It is in marked contrast to the mechanisms currently used or even proposed by the responsible governments. It relies on actual experiences of care and is not simply limited to critical incident reporting or *ad hoc* surveys of consumer participation or satisfaction with services.

As of 2 November 2004, 228 complete surveys had been received, including 127 (56%) from consumers, 58 from carers (25%) and 43 (19%) from family members or close friends. All respondents had experience (either direct or indirect) with mental health services during the previous twelve months. Forty-one percent (n=94) had contact with public health services, 30% (n=69) with private health services, and the remaining 29% (n=65) a mixture of the two.

With regard to key results from the survey, only 57% of respondents said that they were treated with respect and dignity always or nearly always, 69% felt that they did not have adequate access to services and 20% said that they were not able to find a health professional to talk to about their concerns. Two out of five (41%) participants felt they were given insufficient or no information about the condition or treatment. Of those respondents who wanted information given to family and friends, nearly 60% felt that not enough information was given. In situations where medication was prescribed for the mental health problem, only 24% responded that the purpose, benefits and side-effects were fully explained. Over one third (39%) did not feel they had enough say in decisions about care and treatment, and 19% had not had the diagnosis discussed with them (17% of consumers, 10% of carers and 37% of family members or close friends). Only five consumers (6%) had received a care plan, which is a document that outlines mental health needs and who will provide services. About one third (33%) of consumers rated the healthcare received in the last 12 months as poor to very poor, 30% as fair to good, and 37% as very good to excellent.

The Mental Health Council is committed to continuing this process of active review of individual experiences of care. It is not yet clear whether the responsible governments in Australia, or any of those other bodies who share responsibility for the provision of services, are also committed to this goal. However, current proposed Key Performance Indicators for Public Mental Health Services (National Mental Health Strategy 2003-08) do not include regular measures of consumer or carer outcome, or safety, nor do they propose such innovative measures of experiences of care.

2.5 SUMMARY OF NATIONAL MENTAL HEALTH REPORT 2004

The biennial National Mental Health Report has been the principal mechanism by which governments participating in the National Mental Health Strategy report their progress. It is based on primary data submitted by the States and Territories and the Commonwealth, which is then independently analysed. The focus of the report is largely on inputs and process variables, rather than actual services delivered or the quality or safety of those services. As the most recent report was released in November 2004 (detailing changes in expenditures up to mid 2002), it provides the most comprehensive national picture of the current state of mental health expenditures and service organisation.

The National Report (2004) indicates that the growth in government mental health spending (64.9%) has only just outpaced the growth in overall health expenditure (61.1%), indicating no real change in the overall pattern of health expenditure. National spending on specialised mental health services still only accounts for 6.4% of total gross recurrent expenditure on health care, even though mental illness accounts for over 13% of total health burden, or over 15% if the additional burden due to suicide and self-inflicted injury are included. While Commonwealth Government spending increased 128% during this period, two-thirds of that growth was due to new pharmaceuticals. State government spending increased only 40% or 26.2% in per capita terms. There continued to be wide variations between the States in terms of expenditure, service mix and implementation of quality and safety procedures.

> *The significant disparity that existed between jurisdictions at the commencement of the strategy largely remained nine years later… Differences in spending between the states and territories point to wide variation in the level of mental health services available to their populations.*
>
> (National Mental Health Report 2004; Commonwealth Department of Health and Ageing, p. 3)

The National Report highlights the change in allocation of spending from hospital-based to community-based services since 1992-93, with the latter now accounting for 51% of funds (up from 29%) and accompanied by a 109% increase in the number of clinical staff providing ambulatory mental health care. The support for non-government service providers has grown from 2% to 5.5% of expenditure, though varying from 1.9% in South Australia to 9.3% in Victoria. However, as the report highlights, much of the change is accounted for largely by radical changes within one State, namely Victoria. NSW had already instituted such changes largely before the Strategy commenced and some other States such as South Australia have still not moved away from their reliance largely on institutional services.

The number of beds in stand alone psychiatric hospitals has fallen by 60%, largely due to reduction in the non-acute service sector with these beds having been reduced by 53%. The number of beds located in general hospitals increased by 65% with the overall number of acute beds in the system therefore remaining largely static (approx. 3,700 beds, unchanged since 1993) and despite the increased growth in the population and demand for services since that time. Actual total public sector inpatient beds per 100,000 fell from 45.5 to 30.4 from June 1993 to June 2002, a staggering 33% decrease during a period of increased demand for services. For all inpatient services, there was a 26% reduction in total beds and a 11% reduction in clinical staff.

> *All states and territories have experienced increased demand for mental health care right across the health sector, and in particular for inpatient care.*
>
> (National Mental Health Report 2004; Commonwealth Department of Health and Ageing, p. 7)

Over the same period, changes in use of outpatient medical services funded by the Commonwealth peaked in the mid to late 1990s and have been declining since. Although there are more registered providers of these services, they are increasingly working part-time. The disparity between rural and regional services provided and urban areas is great (Burgess Report).

> *Major disparities continue to exist between the states and territories in the level and mix of psychiatric beds provided to their populations…The number of beds required to treat and care for people affected by mental illness is also a function of whether alternative community based services are available.*
>
> (National Mental Health Report 2004; Commonwealth Department of Health and Ageing, p. 7)

The move away from institutional services was designed both to improve the spectrum of care services available as well as provide a more cost-efficient model. However, it seems that the movement away from a hospital base has meant that hospital-based services are now in short supply. Further, community-services and related workforces have not expanded sufficiently to meet the increased demand and the relative needs for increased expenditure on mental health seem to have lost out to the other traditional hospital-based and procedural areas of medicine (Hickie et al. submitted).

> *…these indicators (comparative per capita staff employed in ambulatory care) provide a simplified view of the relative progress by states and territories…they do not tell us about the ambulatory care workforce required to meet priority community needs nor the amount of care actually provided.*
>
> (National Mental Health Report 2004; Commonwealth Department of Health and Ageing, p. 21)

While the participation by mental health consumers in formal representation within mental health organisations has grown from 33% to 77% since 1992-93, actual participation rates in key processes (e.g. complaints review, 57%) are substantially lower. For carer participation, the rates are even lower (e.g. 48% for complaints review). From a quality and safety perspective, only 49% of public mental health systems had completed reviews under the National Standards by the previously agreed finishing date of June 2003.

> *Concerns about poor service quality were a major factor leading to the development of the National Mental Health Policy in 1992… Much of the previous and current criticism of mental health services concerns its alleged failures in these areas.*
>
> (National Mental Health Report 2004; Commonwealth Department of Health and Ageing, p. 32)

2.6 SUMMARY OF AUSTRALIAN PROGRESS AGAINST WORLD HEALTH ORGANISATIONS (WHO) RECOMMENDATIONS (2001) FOR MENTAL HEALTH REFORM IN BETTER RESOURCED COUNTRIES

TABLE 2.6.1: Progress on actions required for the improvement of mental healthcare in developed countries with a high level of resources (e.g. Australia) based on overall recommendations made by WHO (World Health Organization, 2001, Table 5.1, p. 114).

RECOMMENDATION	ACTION	NOTES ON PROGRESS IN AUSTRALIA
1. Mental health treatment to be provided in primary care	Effective management of mental disorders in primary care to be improved	Although significant primary care developments are now supported by the Australian Government, major barriers still exist with regards to access to appropriate non-pharmacological therapies. This is particularly the case for those treated in primary care environments. Consequently, there is over reliance on medications and under utilisation of effective psychological strategies (Hickie et al. 2001).
	Patterns of referral to be improved	Access to mental health specialists is inequitable in Australia and is contributed to largely by lower socio-economic status and significant distances between major population centres (Burgess et al. 2002).
2. Psychotropic drugs to be made available	Easier access to be provided to newer psychotropic drugs (under public or private treatment plans)	While Australia's PBS system does offer equitable access to most medicines at low cost to the consumer, differences do arise between availability of new compounds for inpatients versus outpatients. Specifically, over the last five years, submissions indicated that access to some of the newer antipsychotic agents has been effectively limited to those receiving care or through the public hospital sector.
3. Care to be given in the community	Remaining custodial mental hospitals to be closed down	Considerable progress has been made with regard to closure of stand alone or custodial hospitals (National Mental Health Report 2004). However, some very large institutions remain, most notably Glenside Hospital in South Australia.
	Alternative residential facilities to be developed	Submissions indicated that development of alternative residential or community-based long-stay facilities has not been prioritised and remains a major gap in the services structure.
	Community care facilities to be provided (100% coverage)	Submissions noted that while community-based treatment services are universal in their coverage, access to emergency care or effective ongoing care through such facilities is limited.

RECOMMENDATION	ACTION	NOTES ON PROGRESS IN AUSTRALIA
3. Care to be given in the community (cont.)	Individualised care to be given in the community to people with serious mental disorders	Case-management systems have been the standard mode of care, emphasising individual treatment plans. However, submissions challenged whether the quality and effectiveness of such plans is ever audited.
4. The public needs to be educated	Public campaigns to be launched for the recognition and treatment of common mental disorders	The Australian Government in association with lead states such as Victoria established *beyondblue: the national depression initiative.* Some major states, notably NSW and WA, declined participation in the national program with adverse effects for their constituents (Jorm et al. 2005). Other schools-based programs such as *MindMatters* make a significant contribution (Waring 2000).
5. Communities, families and consumers to be involved	Advocacy initiatives to be fostered	The Mental Health Council of Australia was established and supported by the Australian Government to represent views to the Minister. It incorporates the views of consumers and families, and includes provider and other non-government organisations. Australian Government also provides support to other national consumer networks. Support for other specific consumer, carer or community advocacy agencies, particularly at a state and local level has been more episodic (National Mental Health Report 2004).
6. National policies, programmes and legislation need to be established	Fairness in healthcare financing (including insurance) to be ensured	Medicare related systems have underpinned equity in individual health care access for those with mental disorders. However, submissions indicate that more recent developments in private health insurance now pose a serious threat to these principles. At a population level, mental health is not resourced appropriately relative to its disease burden or the availability of effective treatments (Hickie et al. 2004).
7. Human resources need to be developed	Specialists to be trained in advanced treatment skills	Currently, services provided by psychiatrists in the private sector are in decline (National Mental Health Report 2004). In some States difficulties now exist with regard to recruitment to specialist psychiatrist training (e.g. NSW in 2005). Psychiatrists working in the public sector report increased dissatisfaction with their roles (Rey et al. 2004) Submissions indicated that there is a major workforce shortage in mental health nursing and that specialist psychologists are relatively

underutilised in the Australian health care system.

RECOMMENDATION	ACTION	NOTES ON PROGRESS IN AUSTRALIA
8. Other sectors need to be linked	Special facilities to be provided in schools and the workplace for people with mental disorders	While increased mental health literacy programs are now promoted to some schools and in some workplaces, actual access to care is not mandatory.
	Evidence-based mental health promotion programmes to be initiated in collaboration with other sectors	Mental health promotion has been supported in Australia, but the reach and intensity of programs is limited in reach and duration.
9. Community mental health needs to be monitored	Advanced mental health monitoring systems to be developed	Mental Health Information systems, particularly with regard to tracking experiences of care in individual persons, are in their infancy in Australia. Submissions highlighted that basic issues of service and the maintenance of quality and safety have received inadequate attention.
	Preventive programmes to be monitored for effectiveness	Where new preventative programs have been established, evaluation has been accepted as an intrinsic component (Hickie 2002, 2004).
10. More research needs to be supported	Research on the causes of mental disorders to be extended	National expenditure on basic and clinical research is low by developed world standards (Hickie et al. 2004).
	Research on service delivery to be carried out	Health services research is poorly supported by current mechanisms (Jorm et al. 2002).
	Evidence on the prevention of mental disorders to be investigated	Significant preventative trials have been supported directly and indirectly by the Australian Government and NMHRC. (Hickie 2002)

Note: "Actions" accompanying each recommendation for countries with low and medium levels of resources for mental healthcare are described in the original report.

2.7 STATE / TERRITORY BASED SUMMARIES

While many common issues were presented across the country, there were also significant differences in various states and territories.

The following text attempts to summarise some of those differences and their implications as derived from data obtained from the consultations and submissions, the MHCA surveys and the 2004 National Mental Health Report. However for a fuller consideration of the mental health care system in each state and territory please refer to the main body of this report (see especially Part 3 and Part 6) and the full National Mental Health 2004 Report (see Part 7 for reference).

a) From the National Mental Health Report 2004

The National Mental Health Report shows that state/territory differences have decreased marginally between 1993 and 2002 but this has been insufficient to lift services to a comparable level across jurisdictions.

Comparisons between the jurisdictions has therefore failed to lift spending in most states that were lowest on the table in 1993. A more effective response would be to assess the level of funding required to meet community needs. While measurement of jurisdictional funding levels should be secondary to measurement of consumer service levels, in the absence of such data, we are restricted to comparing expenditure levels, staff numbers and bed numbers.

The better performers:

- *Western Australia* leads per capita spending - $110.82 (national average of $92.03) and has improved from fourth position in 1992-93.
- *Western Australia* reports the highest number of clinical staff working in ambulatory mental health services (42.9/100,000).
- *Victoria* reports the highest percentage of expenditure to non-government organisations (9.3%) and has the best developed psychiatric rehabilitation services.
- *Tasmania* reports the highest number of total inpatient and 24 hour staffed residential beds (51.0/100,000) and the highest number of clinical service delivery staff (104.0/100,000).
- *Victoria* reports the most dramatic growth in expenditure on community and general hospital services ($291.2 million) and the most dramatic reduction on spending in stand alone facilities ($180.5 million).

The poorer performers:

- Of the bottom four states and territories (NSW, NT, ACT and QLD) in 1992-93, *New South Wales* had the lowest per capita percentage growth over the next decade (23.0% in NSW compared with 36.9%, 38.3% and 41.8% in the others respectively).
- *Queensland* reports the lowest number of clinical staff working in ambulatory mental health services (29.8/100,000).
- *South Australia* reports the lowest percentage of expenditure to non-government organisations (1.9%).
- The *Northern Territory* reports the lowest number of total inpatient and 24 hour staffed residential beds (16.2/100,000), while of the states, *New South Wales* reports the lowest at 34.0/100,000. Similarly, the NT has the lowest number of clinical staff (78.1/100,000) while NSW is almost as bad (81.2/100,000).
- *South Australia* reports no reduction in expenditure on stand alone psychiatric facilities and only a modest growth in expenditure on community and general hospital facilities ($37.8 million). South Australia has the highest proportion of psychiatric beds still in stand alone facilities (73%).

b) From the MHCA Surveys

The MHCA surveys discussed in Part 3 of the main report suggest the following:

The better performers:

- Perceived implementation of national mental health priorities is somewhat better in *Victoria* and the *Australian Capital Territory*.
- *Victoria* demonstrates the greatest commitment to mental health promotion, destigmatisation and illness prevention.
- *Victoria* houses the most innovative service development systems in youth and early intervention services.

The poorer performers:

- Perceived implementation of the national priorities in mental health is poor in *South Australia* and *New South Wales.*

c) From the Public Consultations and Written Submissions received

The written and oral submissions made by consumers, advocates, mental health professionals and others suggest the following:

The better performers:

- *Victoria* is perceived to be the national home for service development for *early intervention* for persons in the initial stages of psychosis or other severe mental disorders.
- *Victoria* is perceived to be at the forefront of community-based initiatives to improve understanding of depression, anxiety and other common mental disorders.
- *Victoria* has implemented a new service specifically for persons with severe personality disorders.
- *Victoria* has the standout forensic mental health institutions.
- *South Australia* has an impressive magistrates court diversion program.
- *Tasmania* is perceived to be in the process of significant increases in resource allocation.

The poorer performers:

- *New South Wales* has the highest degree of demoralisation and dissatisfaction among mental health clinicians, consumers and carers.
- *New South Wales* and *Queensland* are perceived to have a high emphasis on a 'law and order' rather than enhanced clinical care approach.
- *New South Wales* is perceived to be backing an institutional and emergency care focus at the expense of community service development.
- *South Australia* is perceived to have made little genuine commitment to support persons with mental illness to live effectively in the community.
- *Western Australia* is perceived to have made few efforts to deal with the problems faced by regional and remote communities.

d) State and territory perspectives

As Part 1 of this report sets out, each state and territory was provided a draft of this report for comment. The full text of those responses can be found at Appendix 8.2.

2.7.1 NEW SOUTH WALES

2.7.1.1 Overview

The deficiencies in mental health services in NSW continue to attract widespread media and community attention (see Appendix 8.7). In December 2002, after a comprehensive analysis of the current state of delivery of mental health services, the Hon Dr Brian Pezzutti, the Chair of the Legislative Council Select Committee on Mental Health stated:

> *The objectives of the Richmond Report and the deinstitutionalisation process have been undermined by practical problems arising during implementation. Consequently, NSW has a community mental health sector with a large responsibility for mental health care, but not the necessary resources. The weight of evidence presented to the Committee highlights that mental health services in NSW need revolutionary improvement. Deinstitutionalisation, without adequate community care, has resulted in a new form of institutionalisation: homelessness and imprisonment. (p. xv)*

The Select Committee not only highlighted inadequacy of funding but also raised concerns about the model of resource allocation and the accountability of funds once disbursed. Implementation of State policy at an Area Health Service level was cited as a serious problem. Additionally, with regard to the Burdekin Report, the Select Committee stated:

> *The Burdekin Report identified not only inefficient planning and organisational arrangements to integrate services within hospitals, but also a lack of procedures to involve families in the community treatment process. It was considered that these issues had not been adequately addressed. Evidence received by this Select Committee indicates that in NSW these issues still require further attention. (p. 13)*

The Pezzutti inquiry led to a number of specific State Government responses. In December 2003 the NSW Mental Health Sentinel Events Review Committee reported on its systematic review of suicides and homicides amongst mental health patients. It stated:

> *Such events are an unmitigated tragedy for the victims, their families and their friends, and also result in great distress to the staff of mental health services and to other patients. The fear and concern they raise in the community is significant, and is largely responsible for the continuing and unjustified stigmatisation of the vast majority of people suffering from mental illness who pose no risk except to themselves. (p. v)*
>
> (NSW Mental Health Sentinel Events Review Committee (2003). Tracking tragedy: A systemic look at suicides and homicides amongst mental health inpatients. First report of the Committee, December 2003)

More specifically, the report acknowledged that many people with mental illness are not able to access care in times of crisis:

> *Admission to mental health beds is widely seen as the most effective short-term risk mitigation strategy in high risk cases. However, anecdotal evidence strongly suggests that on occasions patients are not being admitted, or are being discharged early or without comprehensive follow up, due to an inability to access an available inpatient bed. (p. vi)*
>
> *The report also highlighted concerns with regard to assessment procedures, communication and documentation practices, lack of family involvement, staffing issues and non-uniform implementation of NSW Health policies and guidelines which may "act to impede the efficient provision of a standardised approach to care delivery" (p. ix).*
>
> (NSW Mental Health Sentinel Events Review Committee (2003). Tracking Tragedy: A systemic look at suicides and homicides amongst mental health inpatients. First report of the Committee, December 2003)

The release of *Tracking Tragedy* attracted community criticism as some of its recommendations emphasised increased security and further restriction of patient's rights within acute hospital settings rather than enhanced clinical care (Sydney Morning Herald, Jan 2004). A major alliance of non-government organisations and professional groups wrote to the Premier in early 2004 to express their lack of confidence in the provision of mental health services in NSW. Ongoing media criticism was high and coronial reports continued to highlight major service deficiencies, particularly for young people with severe disorders.

The NSW Health Minister responded positively and met with community stakeholders and professional groups. In mid 2004 the State Government announced that an additional $241 million would be spent on mental health over the next four years. Further, it prioritised the development of new forensic mental health services, announcing its intention to build a new forensic hospital on the existing Long Bay Gaol site.

The subsequent release of the National Mental Health Report (NMHR, November 2004), indicated, however, that there had been little improvement in NSW's comparative position over the last decade (the NMHR 2004 is based on 2001-2 data). Key indicators included low overall expenditure (now ranked sixth out of eight states and territories), low bed availability or limited employment of new community-based staff. NSW now faces serious manpower shortages across all clinical disciplines.

Issues raised by the formal submissions and the community forums included the Government's failure to respond positively to workforce demoralisation, its dismissal of clinicians' objections to the introduction and utility of the new clinical outcomes documentation and that its failure to integrate clinical and academic leadership with local service innovation or clinical service development. The fierce criticisms by professional groups of the central administration of public mental health services were consistent with an independent survey of practicing psychiatrists reported in 2004 (Rey et al., 2004).

The future capacity of NSW to attract high quality staff to meet basic service requirements may well be compromised by a lack of attention to basic clinical leadership, clinical governance and clinical career development issues. It appears that central and local bureaucracies demand greater reporting by clinical staff without providing the support or space for local clinical innovation, clinical leadership or resources for significant local service initiatives. In 2005, NSW instigated an urgent review of the training of psychiatrists in the state (Medical Training and Education Council of NSW {MTEC}, 2005).

While NSW has supported the development of a specialist mood disorders research Institute (Black Dog Institute. Available at: http://www.blackdoginstitute.org.au.), it remains the only state not participating in the national depression initiative: *beyondblue*. Additionally it has been under-represented in the early take-up of new general practice-based and federally-funded access to allied mental health practitioner programs (Hickie et al, 2004). The building of a new forensic hospital on an existing corrective services site does not suggest that expansion of clinical care and reduction of the stigma associated with severe mental illness is a high government priority.

While substantial new financial commitments have been made for the period 2005-09, the accumulated deficit in recurrent funding is large and there seems to be a preference towards funding acute hospital and forensic services. The emphasis on building new Psychiatric Emergency Care Centres (PECC) in Emergency Departments may lead to a re-segregation of persons with mental disorders from persons with other physical health emergencies. One major driver to this process is the poor quality of acute care provided to persons with mental illness. However, it is possible that the belief of at least some emergency room clinicians that persons with mental illness are "interfering with" or "detracting from" the acute care of other patients may also be influencing this new trend.

The relationship between poor ongoing community care and increasing demand for acute care services and the relative failure to partner effectively with consumers and carers, general practice and other non-government service providers does not appear to have yet received serious attention. Data from NSW indicates a continuing rise in the number of acute admissions to psychiatric facilities and an increasing proportion of admissions occurring on an involuntary basis.

Even though there were positive accounts of the success of court diversion programs in NSW, there were many more stories that spoke scathingly about the increased focus on security in NSW. The perception remains that the State's main agenda for people with a mental illness is overly focused on incarceration or detention rather than expansion of non-custodial clinical care. There is no doubt that the increasing presence of security staff, rather than health professionals such as nurses and psychologists, within acute care facilities reinforces this perception.

The introduction of a transparent and efficient system for monitoring and reporting not just the quantity but the quality of services provided, with a specific emphasis on deaths and critical incidents among those seeking or receiving mental health care, remains a priority. Consumers and carers remain unconvinced that there is serious interest in monitoring either routine experiences of care or implementing changes evident from these critical incident reviews.

The release of *Tracking Tragedy 2004* (the second report of the NSW Mental Health Sentinel Events Review Committee) in March 2005 also highlights areas of concern regarding access to services. This Report was a systematic review of homicide by mental health patients and suicide death of patients recently discharged from mental health inpatient units over a five-year period (1999-2003). The Committee concluded:

> *Overall the group data provided some evidence for a link between reduced access to inpatient care and higher rates of post-discharge suicide death. Area Health Services with lower numbers of mental health beds relative to their estimated population-based bed requirements had higher rates of post-discharge suicide death. People dying by suicide within one month of discharge had a shorter length of stay than the overall population of people being discharged from mental health services, and in particular, a higher number of short (2-3 day) admissions. In Individual cases inappropriately short length of stay may have contributed to the poor outcome.*
>
> (NSW Mental Health Sentinel Events Review Committee, 2005, p. viii)

On 11 March 2005, the Government released another new blueprint for mental health services in NSW (The NSW Government's Plan for Mental Health Services) and re-announced the its $241 million commitment to increased funding over a four year period. The new Plan commits the Government to opening 240 new mental health beds in the next three years, expansion of the PECCs from two to five hospitals, introduction of new electronic medical record systems, and expansion of the Housing Support Accommodation Initiative (HASI) to a further 460 people in public and community housing. The documentation claims that the increased expenditure will lift NSW's per capita spending by $14.30.

In May 2005, the NSW Auditor-General released a report on the performance of Emergency Mental Health Services (Auditor-General's Report, Performance Audit, Emergency Mental Health Services, May 2005). The report states the following view:

> *The increase in demand for emergency mental health services has offset many (and perhaps all) of the gains from funding increases. The system is under considerable pressure, and patients can face lengthy delays before being admitted to a bed.*

There is a continuing cycle over the past few years of adverse reports, followed by announcements by the government to address the mental health care system, followed by further reports indicating little change. This is cause for a fundamentally different approach, consistent with the recommendations in this report, to tackling the systemic issues evident in the NSW mental health services.

2.7.1.2 Key issues raised by consultations and submissions

The major issues highlighted by the consultations and formal submissions in NSW were:

i) the apparent emphasis on a 'law and order' agenda rather than enhanced clinical care;
ii) the emphasis on enhanced security measures within acute care settings, with increased use of security rather than clinical care staff;
iii) continued and widespread difficulties in accessing acute care services, particularly outside business hours and through emergency departments of general hospitals;
iv) a critical lack of mental health beds including not only acute care beds but also medium term services;
v) lack of support for community-based acute and ongoing clinical care;
vi) lack of support for non-government service providers, particularly in employment support and rehabilitation services;
vii) lack of support for genuine consumer and carer participation in planning, review and distribution of services;
viii) workforce shortages across all disciplines leading to further demoralisation of the existing workforce;
ix) inadequate and inappropriate forensic mental health services;
x) lack of accountability for mental health spending, service deficits and critical incidents in the mental health sector;
xi) resentment at the manner of introduction of new outcome-based clinical measurement systems at the expense of enhancement of actual clinical services; and
xii) poor coordination of inter-departmental responsibilities and most notably those that involved service provision and protection of children.

2.7.1.3 Positive developments

While the general level of distress expressed by NSW consumers, carers, non-government and professional bodies was among the highest nationwide, our attention was also drawn to a number of positive state-wide developments or local initiatives. These included:

i) statewide development of a forensic mental health service to be managed by Justice Health rather than the Department of Corrective Services;
ii) the development of a statewide Court Liaison service in 2003/04 program for persons with mental disorders presenting to magistrate and district courts;
iii) recent NSW commitments to support a new mind and neuroscience research strategy as well as a Professor of Schizophrenia-related research in association with NISAD;
iv) very positive attitudes to mental health being expressed by police and emergency services, reflecting a major change in attitudes over the last decade;
v) development of a joint initiative between NSW Health, the NSW Department of Housing and other non-government organisations (HASI) to improve the community and housing supports for those with very high levels of disability; and
vi) increased commitment by NSW Health to monitor systematically experiences of care by consumers and carers within its services and report publicly.

New South Wales: Court Diversion Programs

The diversion of individuals with mental health issues and/or intellectual disability is exemplified by recent changes to Section 32 of the Mental Health (Criminal Procedure) Act 1990. Courts are now able to divert individuals to treatment and able to enforce such orders by virtue to the individual being returned to court following notification by COS [Community Offender Services] of failure to comply with Section 32 treatment orders. These changes in legislation are a result of negotiation and agreement between COS, the Attorney General's Department, NSW Health and the Department of Disability, Home Care and Ageing.

COS provide sentencers with a range of community-based sentencing options including Community Service Orders and the Intensive Supervision Program as alternatives to incarceration. However, both the Community Service Orders and the Intensive Supervision program require a degree of stability, including stable accommodation and appropriate intervention resources.

In order to meet the conditions of the order and the offending needs of the individual, COS both develops and delivers core programs and brokers a range of services from government and non-government agencies that are funded to provide services within the community. Major partners in the provision of services and programs to offenders with complex needs are the Department of Housing, NSW Health (Community Mental Health and Community Health), the Department of Ageing, Disability and Home Care, the Department of Education, Employment and Training and Centrelink.

(Community Offender Services, Probation and Parole Service, Department of Corrective Services, New South Wales, Submission #317)

Housing and Support Initiative

The Housing and Supported Accommodation Initiative (HASI) aims to strengthen the partnership with Housing and NGO's in delivering accommodation support to people with mental illness to live successfully in the community. The initiative is underpinned by policy, by statewide tender programs to ensure standard levels of care and by evaluation and review mechanisms. The development of the HASI program for NSW will be a staged process:

- *Stage One – 118 Medium to High Support places in the community*
  NSW Health is funding $5m/year recurrently to mental health non-government organisations (NGOs) for high-level accommodation support.
  The DOH has provided housing stock of approximately $7.8m.
  Preliminary outcomes in the South Eastern Sydney trial over a twelve month period show that inpatient beds days for enrolled patients decreased from 197 days to 32 days.
- *Stage Two - 460 Low outreach support places to people in public and community housing*
  NSW Health is funding $15m over 4 years to mental health NGO's for low-level disability outreach support for people with mental illness and disability associated with that illness already living in community and public housing.
- *Stage Three - 126 places in medium to high support*
  The 2005/2006 mental health budget announced on 24 May 2005 has allocated an additional $8 million for NGOs to provide moderate to high-level accommodation support. Housing will fund stock component. These places will be allocated across all Area Health Services. This program is due to go to Statewide tender processes within the next two months for the NGO support component.

…(after 3 years) the Government will be providing support to an additional 700 people with a mental illness to live a quality life in the community, not hospital.

(Media Release 24 May 2005 and supporting information from the office of the NSW Minister for Health, Hon. Morris Iemma.)

2.7.1.4 National Mental Health Report (NMHR) 2004 (analysis of expenditure and services)

According to the NMHR 2004, NSW finishes sixth out of the eight states and territories in terms of per capita expenditure ($85.13), and remains well below the national average ($92.03). It was ranked fifth in 1992-93 at the start of the national strategy. Over the last decade, mental health spending has increased 23% in per capita terms with the national state average being 26.2%. Only Victoria reporting a lower per capita increase (14.2%). In NSW, there has been a considerable growth in community and general hospital services ($170.9m, compared with the highest, Victoria, at $291.2m), but only a modest reduction in spending on stand alone institutions (a $35m reduction compared with Victoria's reduction of $180.5m).

In terms of clinical staff employed in ambulatory care settings it ranks sixth (35.2/100,000 population compared with national average of 35.9 and a high of 42.9 in Western Australia). With regard to clinical care staff, NSW ranks seventh (81.2/100,000) only outperforming the Northern Territory (78.1) and below the national average of 90.0 and the high of 104.0 in Tasmania. NSW ranks seventh in terms of funding to non-government organisations (2.4% of mental health funding compared with national average of 5.5% and the highest being in Victoria at 9.3%). NSW ranks sixth in terms of total inpatient and 24 hour staffed residential beds per 100,000 population (34.0 compared with the highest nationally of 51.0 in Tasmania). Total public sector inpatient beds in NSW ranked fifth in the Commonwealth (30.3/100,000).

2.7.1.5 Mental Health Council Survey Reports

As expected, the largest number of responses to the survey were from NSW organisations and individuals (n=239). There remains a low level of perceived support for or actual implementation of the community's top five priorities for mental health reform at a local level (namely early intervention [15%], innovative services for comorbid substance abuse [10%], wider spectrum of acute and community care [11%], implementation of the national mental health standards [14%], programs to support attitudinal change [8%]). With regard to state-wide initiatives, again there was a very low level of perceived support for or implementation of key initiatives (namely, specific inter-governmental service agreements [13%], support for innovation [8%], enhanced access [12%], clear accountability for funds [12%]).

2.7.1.6 Conclusions

NSW is faced with the dual difficulties of a combination of an extended period of low per capita expenditure on mental health and low confidence among clinicians about its capacity to bring about rapid improvements. Additionally, there appears to be a focus on expansion of old models of acute and hospital-based services rather than genuine service innovation or new partnerships with non-government or primary care service providers.

2.7.2 VICTORIA

2.7.2.1 Overview

The deficiencies in the provision of mental health services in Victoria have continued to attract widespread media and community attention, with a particular focus on deficits in acute and emergency care. Deficiencies in acute care services were highlighted by a report of the Victorian Auditor-General (2002) "*Mental Health Services for People in Crisis".*

> *This audit identifies a range of concerns about the timeliness of service provision, the completion of key service delivery processes in compliance with relevant standards and guidelines, and the burdens placed upon carers and families. In making these findings, I do not wish to impugn the many dedicated professionals providing mental health services. It is clear that the service system is under significant stress, due to demand pressure, work force shortages and the increasing complexity of mental disorder in our society.*
>
> J. W. Cameron, Auditor-General (14, pg. vii)

The negative impact of poor mental health on consumers, their families and the wider community was also cited in the Victorian Auditor-General's Report (2002) as was the higher rate of unemployment, substance abuse, physical illness and social dislocation amongst people with mental disorder. These problems have been also been identified in each of the three National Mental Health Plans. The audit sought to examine mental health services for people in crisis and found:

> *Increasing service demand and associated levels of unmet demand are resulting in service access difficulties for many consumers, early discharge from hospital, and increased burden on family and carers. These outcomes increase the likelihood of future unplanned re-admissions.*
>
> (Victorian Auditor-General's Report, 2002; 6)

Many recommendations were made regarding assessment procedures, documentation, timeliness and appropriateness of service responses to crises, discharge practices, integrated care, involvement of carers and families, rights of involuntary patients and evaluation of the effectiveness of mental health services. The Auditor-General noted that many of the recommendations arising from this audit were promptly recognised and incorporated in the new five-year plan for the delivery of public mental health services *New Directions for Victoria's Mental Health Services: The Next Five Years* (2002).

The stated underlying guide of the *New Directions for Victoria's Mental Health Services: The Next Five Years* (2002) is Victoria's whole-of-government social policy framework *Growing Victoria Together*. This places this plan in an ideal position to deal with the associated health, social and economic ramifications experienced by many people with mental illness and their families and carers. The *New Directions* five-year plan identified the following key areas as the focus of reform over this period:

1. *manage the growing demand for mental health services;*
2. *respond to increasingly complex consumer needs — particularly the needs associated with increasing drug use amongst young people with mental illness;*
3. *develop improved responses to consumer and carer needs, including developing new models of care - particularly for people with high needs;*
4. *establish and maintain an appropriate balance between inpatient and community-based services;*
5. *address workforce challenges, including education, training, recruitment and retention; and*
6. *ensure the future sustainability of services.*

(New Directions for Victoria's Mental Health Services: The Next Five Years 2002, p.5.)

Resource distribution, both between inpatient and community based care and allocation to rural and regional areas, and the benefits of focussing on early intervention to reduce demand on acute care and negative impacts on consumers were also addressed. Many short- and long-term initiatives were outlined in this plan to redress gaps in service provision.

Two recent reports also outline initiatives to redress gaps in the provision of mental health services and protection of the rights of people with mental illness: *Victoria's Implementation of the National Standards for Mental Heath Services: Progress Report (September 2004)* and the *Annual Report 2003 Office of the Chief Psychiatrist (November 2004)*. However, both documents failed to self-identify areas of concern and

disappointingly, no attempt was made to benchmark progress against the implementation of the National Standards for Mental Health Services (NSMHS). However, under each of the eleven NSMHS, lists were presented (not against specific criteria) describing some current and possible future initiatives. The list for Standard 11 (Delivery of Care), the most detailed of all the Standards, was minimal.

Victoria has seen considerable mental health promotion and prevention development under the independent auspices of VIC HEALTH and the recent commitment to establish a research centre devoted to this task. It has also led the development of the national depression initiative: *beyondblue* (which is now supported by the Australian Government for a further four years to June 2009) and has been one of the active participants in the new general practice-based and federally-funded access to allied mental health practitioner programs.

It has been at the forefront of Australian developments in institutional forensic mental health services through the establishment of Forensicare at the Thomas Embling Hospital. Academic clinical service and basic neuroscience research developments, particularly related to psychosis, have been of international standing. The establishment of Orygen Youth Health through community and service partnerships has been a major development. However, the internationally-leading work of Professor McGorry and colleagues with regard to early intervention in young persons with psychosis (recognised by an NHMRC Program Grant 2005-2009) has not yet been implemented substantially throughout the state.

> *In Australia the requirement for entrenched disability or life-threatening risk operates at a high threshold at the entry points to specialist care. Primary care access is theoretically better, however practically still a problem. Generally, treatment for milder disorders and earlier phases of disorder is provided through little better than a lottery system in which affluence and local factors are key influences. Such people are often derided as the "worried well" even within psychiatry. They may not need years of treatment but they do have a right of access to appropriate treatment. Why not acknowledge that ready access to mental health care of some kind, much of it relatively simple, even informal and self-care, is as necessary as access to general medical care? This should not be controversial.*
>
> (Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

Since the commencement of the National Mental Health Strategy in 1993, Victoria is the state that has undertaken the most systematic reforms consistent with the spirit of that strategy. That is, it has drastically reduced its reliance on beds in stand alone psychiatry hospitals with a significant move to new beds in general hospitals, other community-based beds and support for longer-term services provided by non-government organisations (Vic Auditor-General's Report 2002; New Directions Report 2002). It has also fared well in amending legislation to protect many rights of people with mental illness (Watchirs 2000, Carney 2003).

At a macro-level, therefore, it is easy to comprehend the direction of service reform. However, it is also clear that expenditure growth has not backed this process of systematic reform and that there is considerable variation in quality of services provided across the state. Gaps in service provision are common. Medical staff shortages in rural and regional areas are being filled largely with overseas trained doctors. Access to private sector services is strongly tied to inner and eastern Melbourne. The main focus of care in Victoria still appears to be on acute care and the protection of rights of involuntary patients rather than early intervention and protection of the broader rights to social, economic and political participation of people with mental illness and mental health problems. The impact of inadequate mental health services in emergency departments has been particularly emphasised by both health professionals and users of the services.

The recent announcement of the *Victorian Strategy for safety and quality in public mental health services 2004-2008* by the Victorian Department of Human Services heralds a major breakthrough for the improvement of safety and quality of practice in the delivery of mental health services. To date, the inclusion of mental health within broader health, safety and quality assurance programs has failed at both state and national levels. This new initiative should assist with the identification of systemic problems and issues of accountability. Victoria's commitment to the rights of people with mental illness is also evidenced by the recent release of *Patient Rights Booklets* in twelve languages in December 2004.

Just prior to the release of this report, Victoria announced a new mental health package value at approximately $180 million over four years, with approximately $55 million devoted to capital works and $125 million in recurrent spending over four years. Just over $30 million per year is an approximate increase of 5% in recurrent spending. Increases in funding were announced to acute community-based assessment teams, support for assessments in emergency departments and for facilities that can function as alternatives to acute hospitalisation.

2.7.2.2 Key issues raised by consultations and submissions

The major issues highlighted by the consultations and formal submissions in Victoria were:

i) continued and widespread difficulties in accessing acute care services, particularly through emergency departments of general hospitals;
ii) a critical lack of mental health beds, including not only acute care beds but also medium term services;
iii) lack of support for community-based acute and ongoing clinical care;
iv) inadequate rural and regional services, with a strong emphasis on providing minimal intervention services; and
v) lack of accountability for mental health spending, service deficits and critical incidents in the mental health sector.

Although the mental health system in Victoria is more appealing at a macro level than many of the other state-based services, the general level of distress expressed by Victorian consumers, carers, and non-government and professional bodies was still very high. Critical incidents and day-to-day service failures were not perceived to be given sufficient priority by government and professional bodies.

2.7.2.3 Positive developments

Our attention was drawn to a number of positive state-wide developments or local initiatives. These included:

i) the Orygen Youth mental health services providing early interventions for young people with psychosis;
ii) institutional forensic mental health services, and in particular the Thomas Embling Hospital services which are of a high international standard;
iii) Victorian support for a wide range of mental health promotion (VIC HEALTH), illness awareness and destigmatistion campaigns (*beyondblue*: the national depression initiative) and mental health and neurosciences research (Neurosciences Victoria, Mental Health Research Institute); and
iv) development of a wider spectrum of step-up and step-down acute care facilities.

In the process of consultation with the Victorian Department of Human Services, we were provided with the outcome of 2003-04 survey of consumer and carer experience of Victorian Public Adult Mental health services. Throughout our national consultations, this was the only substantive piece of work provided to us by any government department that had actually recorded systematically experiences of care. The associated documentation described a process dating back to 2001/02 conducted of the process by an externally-commissioned agency. Consumers between 18 and 64 years of age who had used an adult mental health services (AMHS) during 2003 were surveyed. Although the target population had been 300 consumers and 200 carers in each of 21 AMHS, there were only 1,586 respondents (908 consumers, 678 carers) giving an overall response rate of 15.1%. While the report focused on the net 'positive' response rates (% rating an aspect of care as good, very good or excellent) we found the high rate of net 'negative' responses to be consistent with the pattern of our own consultations in Victoria.

While we commend the Victorian Department for commencing such a process, we question why the survey has not been repeated. For the key indicators chosen (see table) negative response rates by consumers ranged from 28-42% and, importantly, for carers from 42-55%. These high levels of negative responses are not consistent with the expressed view of the Government (see Appendix 8.4.2) 'that service quality in Victoria is generally of a high standard'.

	Negative responses	
	Consumers	**Carers**
Provision of Information about rights and responsibilities when needed	33%	44%
Understandable information about rights and responsibilities	33%	45%
Enabling access to help	28%	43%
Getting help when needed	29%	42%
Provision of treatment information when needed	42%	53%
Understandable treatment information	43%	55%
Meeting Individual Needs	37%	51%

Victoria: ORYGEN Youth Health – Expanding Access and Care for Young Persons

At Orygen youth health, we do have the capacity to treat around 600 new 15 –25 year olds with non-psychotic disorder each year, however we still have to refer out large numbers of patients (1400 referrals p.a.) who really need a specialist approach (as one index of this, 25% of those we are unable to accept have attempted suicide recently and are clearly significantly impaired). Moreover, we have no consultation-liaison team to work with GP's or counsellors to manage these and other cases.

(Patrick McGorry, Clinician and Academic, Victoria, Submission #180)

ORYGEN is a unique organisation made up of a specialist youth mental health service, a research centre and a range of education, advocacy and health promotion activities. The overall goal of ORYGEN is to integrate knowledge gained from clinical practice and research activities to implement, and advocate for, high quality mental health services for young people.…The Clinical Program at ORYGEN Youth Health is part of Victoria's public mental health system and provides mental health assessment and treatment to young people aged 15 to 24 years who live in the western and northwestern areas of Melbourne. Traditionally, the Victorian public mental health system is divided into Child and Adolescent Mental Health Services (1-18) and Adult Mental Health Services (16-65). In 2002 however, ORYGEN Youth Health decided it was time for a new approach. ORYGEN Youth Health began offering services to young people aged 15 to 24 years, the first youth-specific

mental health service ever developed in Victoria. This decision highlighted the fact that mental health issues are the most common health concern for young people and that the development of specialised services minimises the impact of mental illness on a young person's learning and development.

(Information obtained from ORYGEN website. Accessed 18 May 2005. http://www.orygen.org.au/contentPage.asp?pageCode=ABOUT)

Victoria: Spectrum – The personality disorder service for Victoria

I have also been reading about Spectrum in Melbourne which is the State-wide Borderline Personality Disorder Service. It is so good that, at last, people are starting to put just a little money into people with Borderline.

(Consumer, Female, Victoria, Submission #203)

Victoria has a statewide personality disorder service. This has come after a realisation that the State had to do something! It is very useful but it is insufficient. They cannot possibly cover all the need across the State. It would be like having one State-wide Schizophrenia service.

(Consumer, Advocate, Victoria, Submission #166)

Spectrum is an Australian state-funded service providing consultation, training, treatment and research in relation to people with severe and borderline personality disorder who are at risk from serious self harm.

Since the early 1990s there has been a growing body of research and clinical wisdom about effective treatment strategies for this client group. In 1993 the Second National Mental Health Strategy clearly endorsed the right of these clients to access state mental health services.

Spectrum was established in late 1998 with two aims:

- *provision of support to state mental health services in the process of change towards new treatment strategies*
- *provision of specialised intensive assessment and treatment services for clients with particularly complex needs.*

We are located in East Ringwood but we provide services to the whole of Victoria.

Spectrum provides four types of services.

- *consultation to staff within the state mental health services to support their work with clients who meet the criteria for a diagnosis of Borderline Personality Disorder*
- *training to staff from state mental health services*
- *residential assessment and treatment*
- *research*

(Information obtained from the Spectrum website: http://www.spectrum-bpd.com/front.htm. Accessed 22 March 2005)

2.7.2.4 NMHR 2004 (analysis of expenditure and services)

According to the NMHR 2004, Victoria finishes second out of the eight states and territories in terms of per capita expenditure ($98.81), above the national average ($92.03). However, it was ranked first in 1992-93 at the start of the national strategy. Over the last decade, mental health spending has increased only 14.2% in per capita terms, well below the national state average of 26.2% and the lowest in the Commonwealth (the highest nationally being Western Australia at 52.4%). In distinct contrast to all other states and territories, there has been a marked increase in growth in community and general hospital services spending (now at $291.2m) and a correspondingly marked drop in spending on stand alone institutions (-$180.5m).

In terms of clinical staff employed in ambulatory care settings it ranks fifth (37.3/100,000 population compared with national average of 35.9 and the highest of 42.9 in Western Australia). With regard to clinical care staff, Victoria ranks fourth (93.7/100,000) and is above the national average of 90.0 but well below the highest nationally (104.0 in Tasmania). Victoria is the leading state in terms of funding to non-government organisations (9.3% of mental health funding compared with national average of 5.5%). Victoria ranks third in terms of total inpatient and 24 hour staffed residential beds per 100,000 population (41.6 compared with the highest of 51.0 in Tasmania). Surprisingly, total public sector inpatient beds in Victoria ranked a poor sixth in the Commonwealth (23.3/100,000), only outperforming the NT and the ACT.

2.7.2.5 Mental Health Council Survey Reports

A total of 134 responses to the survey were received from Victorian organisations or individuals (see Part 3). Although there was a low level of perceived support for actual implementation of the community's top five priorities for mental health reform at a local level (namely early intervention [21%], innovative services for comorbid substance abuse [11%], wider spectrum of acute and community care [16%], implementation of the national mental health standards [17%], programs to support attitudinal change [9%]), the results for early intervention and a wider spectrum of services were better than in other states and territories. However, with regard to state-wide initiatives, there was a very low level of perceived support for, or implementation of key initiatives (namely, specific inter-governmental service agreements [12%], enhanced access [6%], and clear accountability for funds [10%]), though recognition of support for innovation [16%] was somewhat higher than elsewhere.

2.7.2.6 Conclusions

Against most of the agreed indicators, Victoria may be seen as the leading state in mental health services delivery. It has supported both community-based innovations as well as systematic reorganisation of its service structures. The reality for consumers of the services, however, is that insufficient attention has been placed on increasing real investments and recurrent expenditures and supporting key innovations such as the early psychosis and forensic movements. Additionally, insufficient attention has been directed to responding constructively to consumers' and carers' experiences of care.

2.7.3 QUEENSLAND

2.7.3.1 Overview

Issues relating to security and the perceived threat to the community posed by persons with mental disorders have received excessive and unbalanced media attention in Queensland. Government responses have emphasised a strong 'law and order' rather than expanded clinical care approach. While mental health spending has increased in Queensland in recent years, it comes after many years of low funding and given the difficulties in servicing such a geographically-spread and diverse population, it is unsurprising that there are many reports of poor access to basic services throughout the state. The government faces a very large resource and workforce challenge if it is to provide acceptable community-based mental health care in the major regional and larger rural centres.

In 2002, *Smart State 2020: A Vision for the Future,* was released by the Queensland Government. In both the Summary Discussion Paper and Directions Statement, while mental health is briefly acknowledged as contributing to increasing disease burden, changes to mental health service delivery or the overall prioritisation of such activities are not evident. For example, in the futuristic description of the health system in *2020*, one of

the 12 descriptors refers to "mental health and aged care services delivered in community or home environments as opposed to institutional settings" (page 13). Again, while depression and suicide were nominated as two of the six target areas for major health gains, the strategies identified failed to address the current critical barrier of access - the very limited, if any, services for people with mental illness or mental problems. The strategies identified were:

> *Actions to reduce the incidence and impact of depression include:*
> - *proactive mental health promotion programs including intersectoral action to create supportive environments*
> - *promoting resilience strategies in children and youth*
> - *assisting people to recognise depression early when it does occur encouraging those affected to seek help and facilitating access to appropriate services*
> - *provision of effective treatment and management strategies*
> - *reducing the stigma and discrimination experienced by people with mental health problems.*
>
> (Smart State 2020: A Vision for the Future – Directions Statement, 2002, pages 21-22)

The *Smart State 2020* report was used to develop the 2004 Queensland Health Strategic Plan. Consequently, there was very little mention in the Strategic Plan of specific reform to the delivery of mental health services, although integrated mental health services were listed as an 'output' in the diagram of the strategic planning framework (page 10). The 2004 Health Determinants Report highlighted mental health issues for children, but only fleetingly mentioned it as a factor for the whole population. The 2004 Strategic Plan does not mention mental health as a health risk factor.

In budget announcements for 2004-2005 on 11 November 2004 the Queensland Government only allocated $13 million for improved mental health services out of a total announced package excluding capital works and partnerships of $135.2 million. Mental health was not mentioned when the Government announced a new team to lead Queensland Health, and the major issues of concern were described as follows:

> *From next year, for the first time anywhere in Australia, we will be looking to train doctors in the private sector, develop more community health care campuses, introduce new programs to deliver more elective surgery and more dental treatments, and take on the difficult decision-making around Australia's current shortage of specialist medical staff.*
>
> (Queensland Minister for Health, Media Release, 27 December 2004)

This trend of discussing mental health reform but not translating talk into concrete actions and observable differences in the lives of people with mental illness has also been highlighted recently by the Office of the Public Advocate in Queensland.

> *The national mental health reform process marches on with the most recent third National Mental Health Strategy – yet, for many people with a psychiatric disability, this policy process is yet to be fully realised in their daily life. The ideals that drive the language of our policy makers – the promise of recovery, genuine and available alternatives to acute admission, whole of government responsibility for mental health, seamless service delivery from clinic to community, access to timely and effective services for all – are yet to be shaped into the fully resourced organisational arrangements that can make a significant difference to this marginalised group of Queensland citizens.…*

Nowhere is the stigma and discrimination of which the Public Advocate spoke before more evident than in such an inequitable resource allocation. It is hard to imagine a significant improvement in the quality of mental health care without a sizeable increase in funds. … I should note that our critical concern around many of these issues is directed less to mental health services staff, than to the underlying systemic cause of much of this – the stigma and discrimination practised by many ordinary citizens, the consequent low priority given to mental health issues in the political domain, and the consequent under-resourcing of the area regardless of what the facts tell us about the national burden of disease.

(Lindsay Irons, Office of the Public Advocate, 'Mental Health in Queensland Today', Speech delivered at the Public Advocate's Mental Health Forum, Brisbane 01 June 2004, page 1)

It is now well acknowledged that the predictive factors of emotional and social well-being are diverse indeed. It has been said many times before that, while there is considerable focus on inpatient hospital care, it is not the health system which largely determines the community's health – contrary to what most medical clinicians might believe. Nowhere is this more apparent than in mental health. In fact, many risk and protective factors for mental illness lie beyond not only the field of psychiatry, but also beyond the health system itself. These factors are complex, and obtain from the circumstances of our everyday lives – material well being, education, community inclusion and acceptance, employment opportunities, social cohesion and, perhaps most importantly, housing and accommodation.

(Lindsay Irons, Office of the Public Advocate, 'Mental Health in Queensland Today', Speech delivered at the Public Advocate's Mental Health Forum, Brisbane 01 June 2004, page 3)

2.7.3.2 Key issues raised by consultations and submissions

The key issues identified in Queensland were:

i) limited access to key services, particularly in larger regional and rural centres;
ii) poor resource distribution across the state;
iii) stigma and stereotypes being apparent in the community and perpetuated by the media;
iv) very poor treatment of Indigenous persons with mental disorders;
v) lack of rehabilitation and supported employment programs;
vi) lack of adequate consultation measures with consumers, families and carers;
vii) unresponsive complaints processes; and
viii) lack of support by a wide variety of government departments (health, housing, employment, justice) to enable persons with illness to reside in the community.

2.7.3.3 Positive developments

Attention was drawn to a number of positive state-wide developments or local initiatives. These included:

i) use of e-health and telepsychiatry mechanisms to attempt to overcome some of the geographical challenges;
ii) better coordination of GP-based mental health developments; and
iii) Queensland's Mental Health Court.

Queensland: Queensland's Mental Health Court

At this time [28 February 2002] The Mental Health Court was established to make determinations in relation to persons with a mental illness or intellectual disability who are charged with a criminal offence. It also hears appeals against decisions of the Mental Health Review Tribunal and is empowered to conduct enquiries of the detention of patients in authorised Mental Health Services…

The Mental Health Court is constituted by a Supreme Court Judge. The Judge is assisted by 2 Assisting Psychiatrists…The functions of the Court are: to decide references of the mental conditions of persons; to hear appeals from the Mental Health Review Tribunal; and to investigate the detention of patients in Authorised Mental Health Services…The matter of a person's mental condition relating to an indictable offence may be referred to the Court if there is reasonable cause to believe that: the person is mentally ill or was mentally ill when the alleged offence was committed…

Once a reference is made, criminal proceedings are suspended until the Court has made its decision on the reference. …

Where a person is found not of unsound mind and fit for trial the Court orders the proceedings continue according to Law and, depending on the person's mental health and the circumstances of the case, it may order that he/she remain in hospital, be remanded in custody or be granted bail. Where the Court finds that the patient was of unsound mind at the time of the offence or that he/she is unfit for trial it may make a Forensic Order. The person then becomes an involuntary patient at an Authorised Mental Heath Service. The Court may order that he/she be placed in a Secure Unit or other Service for inpatient treatment and care and may approve limited Community Treatment. A person found to be unfit for trial but not permanently so will be subject to regular reviews by the Mental Health Review Tribunal. …

It is the view of the Court that it must take into consideration not only the patient's treatment needs but the protection of the community and always in the context of the seriousness of the crime.

The Mental Health Court works well, as did its predecessor, the Mental Health Tribunal. It is unique and innovative. Its values have been under recognised in the fields of Law and Mental Health and its forensic interface. Public confidence in the system is warranted. … mentally ill offenders are identified early, treatment provided and ensured where necessary in a way which will protect the public. …. Expansion of rights and responsibilities, accountability and best practice in law and medicine does not come cheaply. There must be no deterioration through attrition.

(Lawrence JM, (2004) Queensland's Mental Health Court: The first twelve months)

2.7.3.4 National Mental Health Report 2004 (analysis of expenditure and services)

Although Queensland still finished *last* in per capita spending on specialised mental health services when compared with all other jurisdictions ($84.83, national average of $92.03), mental health spending had increased 41.8% in per capita terms over the last decade (with the national state average being 26.2%). In Queensland, there has been a considerable growth in community and general hospital services ($151m, compared with the national high of $291.2m in Victoria), and a modest reduction in spending on stand alone institutions (-$27.9m compared with Victoria's national high of –$180.5m).

In terms of clinical staff employed in ambulatory care settings Queensland finished last again (29.8/100,000 population compared with national average of 35.9). With regard to clinical care staff, Queensland ranks fifth (89.7/100,000), just below the national average of 90.0. However, Queensland finished second highest in terms of funding to non-government organisations (7.0% of mental health funding compared with national average of 5.5% and a national high of 9.3% in Victoria). Queensland ranks fourth in terms of total inpatient and 24 hour staffed residential beds per 100,000 population (37.3 compared with a national high of 51.0 in Tasmania). Total public sector inpatient beds in Queensland ranked second in the Commonwealth (35.1/100,000).

2.7.3.5 Mental Health Council Survey Reports

A total of 95 responses to the survey were received from Queensland organisations or individuals (see Part 3). As Queensland has been consistently one of the lowest of all jurisdictions with regard to expenditure, and given the specific geographical and population challenges it faces, it is unsurprising that it mirrors the national trends for low implementation of key priorities (namely early intervention [16%], innovative services for comorbid substance abuse [10%], wider spectrum of acute and community care [7%], implementation of the national mental health standards [19%], programs to support attitudinal change [9%]). The Queensland system appears to rely particularly heavily on hospital bed-based notions of acute care. Similarly for state-wide initiatives, there was a low level of perceived support for or implementation of key initiatives (namely, specific inter-governmental service agreements [11%], enhanced access [11%], clear accountability for funds [11%]), or recognition of support for innovation [12%]).

2.7.3.6 Conclusions

> *Over the past year, the Office has endeavoured to gain a better understanding of the experience of Queensland citizens who have a mental illness or psychiatric disability. In doing so, the Office has witnessed divergent, almost irreconcilable, views of policy-makers and patient advocates across the state…Policy-makers highlight the achievements already made in mental health…However there is a widespread view on the part of the patient advocates across Australia that the mental health system is in crisis…..*
>
> *The Office acknowledges the progress achieved by the Queensland mental health system over the past decade, and the ongoing reform process that is underway. However, these should not blind us to the systemic problems identified within the service system, nor to the level of scrutiny and resolve that will be needed to address them*
>
> Annual Report 2003/4, Office of the Public Advocate, Queensland

The conclusions reached by the Queensland Office of Public Advocate are consistent with the submissions and presentation made to the MHCA. As in many jurisdictions, the Office has pointed to the gap between the views of policy makers and those responsible for administering care, and those who use the services and the clinicians employed.

The challenges facing mental health development in Queensland are large. There have been decades of neglect and low expenditure and there are cultural, demographic and geographical hurdles to face. There needs to be changes in resource investment, accountability mechanisms and workforce development to improve experiences of care within mental health services. While there have been important developments in Queensland child and family mental health, Indigenous health, population mental health and significant new commitments in basic neurosciences, there is no clear commitment to a radical enhancement of services, particularly within the larger regional centres and rural communities. Political, professional and community leadership is urgently required. Additionally, an emphasis on blaming the existing workforces for failures in service delivery needs to be rejected. The current inquiries into Queensland Health established in May 2005 offer an opportunity for fundamental reform of the entire health care system.

2.7.4 SOUTH AUSTRALIA

2.7.4.1 Overview

Crises in mental health services are rarely out of the news in South Australia. The services have undergone multiple reviews over the last decade. There have been now been three directors of the state mental health service since late 2001 (although one of these changes was brought about by the tragic murder of Dr Margaret Tobin).

However, as reported in the National Mental Health Report (2002), the task of substantive reform and a move way from an institutionally-base service system has only made limited progress. Since the election of the Rann Government, there has been little perceived progress in terms of resolution of the long-standing service organisation and delivery problems. The recently formed Mental Health Coalition has produced a blueprint of major items requiring urgent attention.

Over the years, South Australia has repeatedly acknowledged that it has neglected mental health and failed to implement reforms within adequate time frames. For example, in 2002 SA stated:

> *In the National Mental Health Report 2000, South Australia acknowledged inadequate demonstration of progress and lack of coordinated focus towards achieving the nationally agreed objectives. This year we are able to report significant progress toward these objectives. South Australia continues to strive toward implementing the Second National Mental Health Plan, while acknowledging that we are still actively pursuing completion on some components of the First National Mental Health Plan.*
>
> (National Mental Health Report 2002, p. 92)

More recently, in June 2003, after the release of the Final Report of the Generational Health Review (2003), the SA Government again acknowledged it had neglected mental health reform:

> *Mental Health has been neglected in this State for almost 10 years. Independent audits have proven our state is far behind national standards. This must change. On coming to government we immediately committed an extra $34 million over four years for mental health reform, to build much needed services in the community. This is just the beginning. We will continue to implement mental health reforms and build the necessary supports our community deserves.*
>
> *(*First Steps Forward – South Australia Health Reform, June 2003, Hon. Mike Rann, Premier, and Hon. Lea Stevens, Minister for Health)

Specifically, the Final Report of the Generational Health Review (2003) identified that in SA there were significant health inequalities for some population groups and that these groups had very poor health or limited access to health services. Included in these groups were: people with mental illness, Aboriginal people and young children. It was acknowledged in this report that the health system alone could not address these inequalities and a whole-of-government approach was required (Recommendation 6.1). With regards to people with mental illness, the report made the following specific recommendation:

> *Recommendation 6.15 The State Government as a priority, fund DHS to implement the ongoing mental health reform agenda, including provision of parallel capacity, a capital and service development plan, legislation, workforce, improved service system coordination, community mental health reform, and community consultation and communication.*

The mental health reform agenda referred to is *The Action Plan from Reform of Mental Health Services 2001-2005* (Mental Health Services, Department of Human Services, 2001). Despite these acknowledgements and pledges of funding and implementation of reform, to date, little has changed with regards to mental health service delivery. As stated earlier in this Report, South Australia still has a major focus on the provision of acute inpatient care and has failed to divert resources to the expansion of community based services.

Unlike many other states, the SA Government has acknowledged that poor health and limited access to services for people with mental illness is a human rights issue, and that in SA certain groups are discriminated against and inequity has resulted.

> *Enjoyment of the highest attainable standard of health is a fundamental right of everyone.…Health as a human right means universal access to adequate health care, but also access to education and information, and the right to food in sufficient quantity and quality, to decent housing and to live and work in an environment where known health risks are controlled…Nonetheless Australia, like all other countries, does have human rights blemishes and ongoing work is required to guard against human rights abuses. The purpose of this section is to specify several population groups that require specific effort.* ***The right to health is not equitably distributed****. GHR [Generational Health Review] has identified the following population groups for priority attention:…People with mental health issues...All need to be considered within a whole-of-government approach. (author's emphasis)*
>
> (Final Report of the Generational Health Review (2003), pages 153-154)

The continued and increasing presentation of people with mental illness before the criminal justice system is reaching a crisis point, especially with the piloting of a new police prosecution policy in 2004. The increasing number was linked both with the policy, but more importantly, with the failure of mental health services to provide adequate treatment and support resulting in police and the criminal justice system becoming the de facto mental health service:

> *That the police are the only agency that will take the calls of members of the community upon whom the actions of the mentally ill may be impacting does not mean courts are then required to engage in long and expensive criminal justice processes resulting in people with mental illnesses being rebadged as criminals and institutionalised in jails instead of in hospitals…There comes a point at which it is necessary to say 'enough', and this court has reached that point.*
>
> (Quote by Magistrate Rosanne McInnes in artyIce by Rebecca DiGirolamo "
> "Law row over man who thinks he's god", The Australian, 30 July 2004)

Perhaps the best indication of the ongoing crisis in mental health services in SA was the resignation of the Director of Services, and past President of the RANZCP, Dr Johnathon Phillips in May 2005. He was reported by *The Advertiser* as saying he had "left a system that had hit the wall". The Government, has attempted to respond to these challenges but the experiences of care reported by those who use services remain poor.

2.7.4.2 Key issues

The key issues raised in the public consultations and formal submissions in South Australia were:

i) there is an urgent need for new models of care to be adopted. The strong and ongoing reliance on institutional and inpatient models has limited the development of community-based care;
ii) there is a major lack of basic services in most smaller communities outside of Adelaide;
iii) there is a general lack of community based health and accommodation services;
iv) lack of meaningful consultation with consumer and carer representatives;

v) lack of attention to the needs of Indigenous people;
vi) lack of services for children and adolescents; and
vii) high levels of stigma and discrimination in the community, with particular emphasis on potential for violence.

2.7.4.3 Positive developments

Against this backdrop of considerable community frustration, some model programs have been developed and implemented. For example: the Magistrates Court Diversion Program; The Medical Specialist Outreach Assistance Programme in South Australia; the uptake of new General Practice Initiatives and the development of a Mental Health Coalition of Providers to advocate for immediate reforms.

South Australia: The Magistrates Court Diversion Program – Diverting people with mental illness out of the criminal justice system

The pilot Magistrates Court Diversion Program (MCDP), which…commenced operation in the Adelaide Magistrates Court in August 1999…was the first 'problem solving' court in Australia designed to deal with offenders with mental impairment…The impetus for this court came, in part, from South Australia's then Chief Magistrate who recognised that courts needed to improve their ability to identify and respond to people who had a mental impairment. He noted that people "who did not belong in the criminal justice system" were continually appearing before Magistrates and were "being punished for things which were nothing but a manifestation of their problems" (Alan Moss, 1999).

Aims and Objectives of The Magistrates Court Diversion Program…The MCDP was designed to 'better ensure that people with a mental impairment who come before the court have access to appropriate interventions that will assist in addressing their offending behaviour' (Justice Strategy Unit, 2000). Overall then, in line with other courts predicated on a therapeutic jurisprudence model…the aim was to use the defendant's contact with the criminal justice system as a vehicle for providing a treatment and support program designed to effect behavioural change.

Description of The Program Persons suspected of a mental impairment and who are charged with a summary or minor indictable offence are referred to the program, generally at the time the charges are laid. Upon referral, the individual is assessed to determine his/her suitability for the program. At that time, the defendant's willingness to participate is also ascertained. Those who do not want to participate are referred back to the normal court process...If a defendant is accepted onto the program, his/her case is then adjourned and an individualised intervention plan is developed which outlines appropriate intervention strategies designed to address the individual's mental impairment issues, any associated factors such as homelessness, and drug and alcohol addiction. For many clients who are already in treatment, the program aims to reinforce and support their continued engagement with their treatment or service provider. For others, it may involve referral to new treatment agencies and services. It should be noted that the court itself does not provide treatment. Instead, the client is referred to existing treatment and service providers…At the end of the program (which generally extends for between 4 to 6 months), the charges against some defendants are withdrawn by prosecution. In the majority of cases, though, the defendant is sentenced, with his/her progress while on the program taken into account at that point. The majority of defendants are given a good behaviour bond.

Evaluating The Program…Overall, the results showed a reduction in both the number of participants who were apprehended for offending post-program compared with pre-program, as well as a reduction in the actual number of incidents charged against this group. In particular: There was a significant reduction in the number of participants who offended as well as in the number of incidents detected post-program. Two thirds (66.2%) of program participants did not offend during their post-program year 1. At an individual level, just over three quarters (76.4%) of the participants either became non-offenders or were charged with a smaller number of incidents post-program…Although these findings must be treated with caution, they suggest that the program may be having a greater impact on the more serious pre-program offenders…These findings…auger well for its future.

(Office of Crime Statistics and Research, Attorney-General's Department, Government of South Australia, South Australia Submission #278)

The Medical Specialist Outreach Assistance Programme in South Australia – Improving services to rural and regional areas

November 2003 marks the second anniversary of the expansion of visiting psychiatric services to rural South Australia under the Medical Specialist Outreach Assistance Programme (MSOAP)…The MSOAP-funded psychiatrists now visit 20 towns and communities in rural and remote South Australia. They provide consultation/liaison services that emphasize the upskilling of local general practitioners (GPs) and other health-care workers. Although most of the visiting psychiatrists provide adult services, child psychiatrists now visit four regional centres. The child psychiatry services have been an important development for MSOAP because this is an area of special need and clinician numbers are quite limited. Local child mental health services are highly desired. The disruption to family life is substantial when a child is ill and treatment always involves the inclusion of one or both parents and often other family members. If treatment occurs in the capital city, there is inevitably a major disruption to the family routine, with substantial stress arising from the added costs and social dislocation. Furthermore, the provision of child psychiatric services in the local community facilitates the mobilization of the community resources for the immediate treatment and ongoing management of the child's condition. The new MSOAP services are likely to improve continuity of care and will help prevent future complications and trauma, both for the patient concerned and the local community. Indigenous South Australians are also beginning to benefit from MSOAP initiatives.

(Nigel Cord-Udy, Psychiatrist, South Australia Submission #274)

2.7.4.4 NMHR 2004 (analysis of expenditure and services)

According to the NMHR 2004, South Australia finishes third out of the eight states and territories in terms of per capita expenditure ($96.19), just above the national average ($92.03). It was ranked second in 1992-93 at the start of the national strategy. Over the last decade, mental health spending has increased 25.5% in per capita terms, close to the national state average of 26.2% but well below the national high in Western Australia [52.4%]). In distinct contrast to all other states and territories, there has been very modest growth in community and general hospital services spending ($37.8 m, compared with Victoria's $291.2m) and a zero reduction in spending on stand alone institutions (compared with the highest reduction Victoria of –$180.5m).

In terms of clinical staff employed in ambulatory care settings South Australia ranks fourth (39.0/100,000 population compared with national average of 35.9 and the highest of 42.9 in Western Australia). With regard to clinical care staff, SA ranks second (102.2/100,000) and is above the national average of 90.0. SA is the lowest state in terms of funding to non-government organisations (1.9% of mental health funding compared with national average of 5.5%). SA ranks second in terms of total inpatient and 24 hour staffed residential beds per 100,000 population (45.0 compared with the highest of 51.0 in Tasmania), but is quite different from other states in that nearly all such beds are within hospitals and that 73% of such beds are within stand alone psychiatric hospitals (compares to the national average of 39% and the lowest in Tasmania at 6% and Victoria

at 11%.). Total public sector inpatient beds in South Australia are the highest in the Commonwealth (43.7/100,000).

2.7.4.5 Mental Health Council Survey Reports

A total of 69 responses to the survey were received from South Australian organisations or individuals (see Part 3). As expected, given the very high reliance on traditional institutional approaches to mental health care in SA, there was a very low level of perceived support for actual implementation of the community's key priorities for mental health reform at a local level (namely early intervention [7%], innovative services for comorbid substance abuse [9%], wider spectrum of acute and community care [12%], implementation of the national mental health standards [7%], programs to support attitudinal change [6%]). The results largely reflect those same characteristics of lack of real action that were reported by the state Mental Health Unit in 2002. Similarly for state-wide initiatives, there was a very low level of perceived support for or implementation of key initiatives (namely, specific inter-governmental service agreements [6%], enhanced access [9%], clear accountability for funds [7%]), or recognition of support for innovation [6%]).

2.7.4.6 Conclusion

Despite repeated inquiries and multiple ministerial and government commitments, there has been little evidence of substantial mental health reform in South Australia. It remains the State with the greatest emphasis on institutional forms of care. While a great deal of community, media and professional criticism has been expressed about proposed changes to the mix of hospital and community care, there is also a clear desire for real reform. Reform will need to be backed by genuine resource investment as well as real leadership.

2.7.5 WESTERN AUSTRALIA

2.7.5.1 Overview

Whilst the West Australian Government has signed each of the National Mental Health Plans over the last decade, and significantly increased its per capita expenditure relative to other states, its actions have not yet led to implementation of an effective mental health system. Current mechanisms for leadership, reform implementation and accountability in mental health have failed to bring about the necessary changes. Although very recently new funding commitments have been made, other aspects of current planning suggest that the size and scope of the problem is not apparent to those who drive health reform in WA.

Evidence of the current dissatisfaction with both the availability and quality of mental health services was recently reported by the Standing Committee on Environment and Public Affairs in its inquiry into the provision of Mental Health Services in Western Australia. The Interim Report released in November 2004 stated:

> *The majority of the submissions expressed serious concerns that the mental health services in Western Australia are inadequate and consumers cannot get access to services when needed. Also expressed was a frustration at the lack of funding going into the mental health system, which has resulted in poor conditions and an increased level of need.*
>
> (Standing Committee on Environment and Public Affairs, Report 12, November 2004, 7)

Furthermore, the recent Report of the Health Reform Committee *A Health Future for West Australians* fails to recommend significant changes to redress inequities of access and improved service delivery for people with mental illness. In the 86 recommendations made by the Committee only three recommendations were made directly pertaining to mental health. These recommendations were broad, and hence inadequate for facilitating genuine reform:

> *Recommendation 12: Recognising the importance of mental health and the projected growth in mental illness, a whole of government approach to mental health and mental illness is needed to provide a framework for action by government departments, the non-government sector and the community.*
> *Recommendation 13: A major focus in the treatment of mental health should be in prevention and early intervention programs and services.*
> *Recommendation 14: Initiatives aimed at improving community-based mental health care and the integration of these services with the hospital, mental health hostel and supported accommodation sector should be pursued.*
>
> (Health Reform Committee*, A Health Future for West Australians, March 2004)*

Other recommendations spoke of the reconfiguring of hospitals to provide mental health services (viz Recommendations 26 and 28) indicating a failure to commit to the improvement of community-based services but instead returning to hospital-based forms of care. This is supported by the Committee's analysis of expected growth in demand for hospital bed days in psychiatry and failure to realise that if community-based treatment and support services were improved, potential crises resulting in the requirement for hospitalisation could be averted.

> *The expected dramatic growth...in psychiatry where the additional demand will take up 315 beds by 2013/14.*
> (Health Reform Committee, *A Health Future for West Australians*, March 2004, p. 13)

Importantly, in the section devoted to 'Equity in Health and Health Care' people with mental health problems are identified as one of three major groups where there are 'significant disparities and gaps in health status and access to health care' (the other two groups being Indigenous people and people of lower socio-economic status). Apart from being a listed group requiring focus in 'Reducing Inequities' very little substantive information was provided to address this. Even Recommendation 72, which advocated a funding model that quarantined funding for mental health services and programs, lacks the clarity need for decisive implementation action.

2.7.5.2 Key issues

The community consultation process and formal submissions in WA highlighted many of the issues associated with providing accessible and reasonable quality services across a vast geographical area and within the context of historically-low levels of investment. The key issues raised were:

i) very poor access to basic levels of services, particularly in any of the major centres outside of Perth;
ii) tendency to replace real clinical services with telephone triage services;
iii) inadequate community-based health and housing services;
iv) excessive use of physical restraint and sedation for the purposes of transfer for psychiatric assessment;
v) lack of consultation with consumers, families and carers;
vi) lack of services for children and adolescents; and
vii) increasing reliance on security guards and services rather than expansion of clinical services.

2.7.5.3 Positive developments

Western Australia has been recognised previously for significant developments in general practice-based mental health partnerships and Indigenous mental health service developments. The uptake of the Federally-funded *Better Outcomes in Mental Health* program in Perth, Fremantle and surrounds is particularly notable (Hickie et al. 2004). This has increased access to clinical psychologists and associated non-pharmacological treatment options.

The development of a state-wide service quality review program through the Office of the Chief Psychiatrist is seen as a key quality and safety initiative. The Office of the Chief Psychiatrist has conducted 11 reviews with three of these being the pilots for the development of a clinical governance framework (visit *http://www.chiefpsychiatrist.health.wa.gov.au)*. The new framework includes consumers and carers in the review process. Training is provided to them to enable more effective participation alongside clinicians. Most importantly, the framework adopted by the Chief Psychiatrist's Office recognises the consumer's experience of care "as paramount".

> *The Chief Psychiatrist's Clinical Governance Review Program commenced in November 2003 with the introduction of the Chief Psychiatrist's Clinical Governance Review Framework and the development of methodology designed to assess levels of clinical governance implementation. As part of the program development the Chief Psychiatrist has completed three pilot reviews...*
>
> *These three sites provided the Chief Psychiatrist with the opportunity to test the review methodology in three different settings including metropolitan, rural and in a statewide forensic environment. Each of the reviews provided challenges in relation to the methods used to assess clinical governance implementation and in particular the recruitment of consumers and carers to participate in the review process. As a result of the three pilots the Chief Psychiatrist has expanded the review methodology to enable consumers and carers to provide feedback in a variety of ways. A Clinical Governance Review Guide for Mental Health Services is currently being developed and will be available from the Office of the Chief Psychiatrist (OCP) website in March 2005.*
>
> *In addition to refining the methodology the pilots also provided the Chief Psychiatrist with the opportunity to further develop the Clinical Governance Reviewer Training Program. The program offers a one-day training session for clinical governance reviewers and includes consumer and carer reviewers. Reviewers are provided with a background in clinical governance, an in-depth review of the methodology to be employed during the site visit and are also given an opportunity to practice the types of skills that will be required of them during the review period. A Clinical Governance Reviewer Training Manual has been developed as part of the program.*
>
> (Office of the Chief Psychiatrist, WA, Inform Newsletter, Summer 2005, p 4)

The potential for this process to impact on local services is significant. It is hoped that data from this exercise will be publicly released on an ongoing basis.

2.7.5.4 NMHR 2004 (analysis of expenditure and services)

Western Australia led the way in per capita spending ($110.82, national average of $92.03), having substantially improved its position from fourth in 1992-93. Over the last decade, mental health spending has increased 52.4% in per capita terms with the national state average being 26.2%. In WA, there has been a considerable growth in community and general hospital services ($107m compared with the national high of $291.2 m in Victoria, but only a modest reduction in spending on stand alone institutions (-$13.8 m compared with the national high in Victoria of –$180.5m).

In terms of clinical staff employed in ambulatory care settings WA also ranks first (42.9/100,000 population compared with national average of 35.9). With regard to clinical care staff, WA ranks third (101.5/100,000) well above the national average of 90.0. WA ranks third in terms of funding to non-government organisations (5.7% of mental health funding compared with the national average of 5.5%). However, WA ranks fifth in terms of total inpatient and 24 hour staffed residential beds per 100,000 population (34.4 compared with the highest nationally of 51.0 in Tasmania). Total public sector inpatient beds in WA ranked third in the Commonwealth (33.2/100,000).

2.7.5.5 Mental Health Council Survey Reports

A total of 99 responses to the survey were received from West Australian organisations or individuals (see Part 3). As Western Australia has been at the higher levels of expenditure when compared with other jurisdictions, one would anticipate more evidence of implementation of key community priorities (namely early intervention [26%], innovative services for comorbid substance abuse [15%], wider spectrum of acute and community care [13%], implementation of the national mental health standards [17%], programs to support attitudinal change [12%]). The result for implementation of early intervention strategies was one of the better results nationally. For state-wide initiatives, the reporting of implementation was comparable with other states and territories (namely, specific inter-governmental service agreements [16%], enhanced access [11%], clear accountability for funds [8%]), or recognition of support for innovation [11%]).

2.7.5.6 Conclusions

While WA has increased its spending in mental health and made major commitments to primary mental health care (in association with Federal funding enhancements) it faces considerable cultural, geographic and professional challenges. There is a real need to articulate an agenda for the development of community-based care and quality primary and secondary mental heath services in the larger regional and more remote rural centres.

2.7.6 AUSTRALIAN CAPITAL TERRITORY

2.7.6.1 Overview

Over the past three years the ACT Government has committed substantial energy to devising a new framework within which to improve the mental health and well-being for those living in the Australian Capital Territory. In November 2002, ACT Health released *Health Action Plan 2002* which set the direction for public health services in the ACT for the subsequent three to five years. Importantly, the Health Action Plan prioritised mental health as a strategic area of focus and recognised the health inequalities (both in terms of health status and access to services) experienced by people with mental illness.

The Health Action Plan also acknowledged that the ACT was ranked last in comparison with other states and the Northern Territory in 1999-2000 with regard to expenditure on mental health and that increasing the resources allocated to mental health was a key priority for the future. The Government indicated that these additional resources would not be dependant on additional resources being committed to the health budget; instead "the Government will place a high priority on increasing the funding for key priorities in the annual budget processes" (Health Action Plan 2002, page 5).

The identification of mental health as a key priority area resulted in the Department of Health and Community Care conducting a wide consultation process to develop the *ACT Mental Health Strategy and Action Plan 2003-2008.* The Mental Health Strategy and Action Plan continues the emphasis on equity for all people with mental illness and the community as articulated in the Health Action Plan:

> *The principles that underpin the Plan reflect a* ***framework of human rights*** *and promote a fresh and innovative approach to managing mental health issues…It is important to note that the vision for mental health in the ACT focuses on maintaining good mental health. The Plan acknowledges that mental health is the responsibility of the whole community* ***and it aims to facilitate a shift in emphasis away from treatment towards a well-being model****. This shift will require clinical and welfare services, accommodation services and other social and economic services in the community committing to this cultural change…The Plan is aligned with the broader policy framework of the Canberra Plan and, in particular the Social Plan, together with the ACT Health Action Plan and a range of other strategies being developed in the ACT and nationally" (emphasis added)*
>
> (ACT Mental Health Strategy and Action Plan 2003-2008, p. 4)

Key features of the strategy include: emphasis on mental health promotion; expanded support for prevention and early intervention initiatives; emphasis on access and integrated service delivery especially for high prevalence disorders; a focus on recovery and improved links with supported accommodation, vocational training and rehabilitation services; and systems which enhance accountability and the planning, implementation and evaluation of service delivery.

> *Both consumers and carers reported that in the ACT it is almost impossible to get intervention or be listened to at an early stage when warning signs are initially beginning to appear.*
>
> (ACT Mental Health Consumer and Carer Caucus, ACT Submission # 342)

As a consequence of the Strategy, the *ACT Mental Health Promotion Prevention and Early Intervention (PPEI) Plan 2004-2008* was released in December 2004. The PPEI Plan uses a whole of community model for mental health and lists actions to promote mental health, prevent illness and enable the consumer and the mental health system to respond to early warning signs for established illness to reduce the impact of illness. The PPEI Plan identifies specific strategies and actions for priority groups which address critical gaps in mental health service delivery, whole of government approaches and stigma reduction and community acceptance campaigns. The plan however, fails to address the key problem of shortage of services (mental health, accommodation etc) and clinicians to support the responses required.

2.7.6.2 Key issues

The key issues identified in public consultations and formal submissions in the ACT were:

i) great deal of difficulty accessing services, even in a crisis;
ii) totally inadequate approach to management of forensic mental health issues;
iii) lack of basic hospital and rehabilitation services;
iv) little attention to issues of early intervention;
v) major staff shortages impacting on quality of services delivered;
vi) large role played by police and emergency service in acute mental health care;
vii) lack of community-based health and housing services; and
viii) inadequate responses to serious incidents.

2.7.6.3 Positive developments

The most positive development in the ACT is the willingness of the Government to recognise the inadequacies of the current system. Generally, the Government has been non-defensive and willing to work with other national developments. The government has undertaken a number of reviews of the mental health services – in 2002/03 the "*Investigation into Risk of Harm to Clients of Mental Health Services" (Patterson report) and in 2003 "The review of the design and operation of the Psychiatry Services Unit (PSU), Canberra Hospital*" (Mann/LaRoche Report). The Government has acted quickly to implement all 58 recommendations of the Patterson report and commit to capital works to address the problems at the PSU.

Another notable development of the ACT Government has been the enactment of Australia's first Bill of Rights under the ACT Human Rights Act in 2004. The Government has engaged Monash University to audit the ACT Mental Health Act 1994 against the Human Rights Act. The results of the audit will be of interest to all those involved in mental health care in Australia.

2.7.6.4 NMHR 2004 (analysis of expenditure and services)

According to the NMHR 2004, the ACT finishes seventh out of the eight states and territories in terms of per capita expenditure ($84.86), well below the national average ($92.03) and unchanged from its ranking in 1992-93. Over the last decade, mental health spending has increased 38.3% in per capita terms, above the national state average of 26.2% but well below the nation's highest increase in Western Australia [52.4%]). In terms of clinical staff employed in ambulatory care settings the ACT ranks second (42.6/100,000 population compared with national average of 35.9). With regard to clinical care staff, the ACT ranks sixth (82.6/100,000) - well below the national average of 90.0. The ACT is mid-ranking in terms of funding to non-government organisations (5.5% of mental health funding compared with national average of 5.5%). The ACT ranks seventh in terms of total inpatient and 24 hour staffed residential beds per 100,000 population (21.9 compared with 51.0 in Tasmania). Total public sector inpatient beds in the ACT ranked last in the Commonwealth (14.7/100,000).

2.7.6.5 Mental Health Council Survey Reports

Given the population of the ACT, there was a larger than expected number of responses to the survey from ACT-based organisations and individuals (n=43) (see Part 3). The level of perceived support for actual implementation at a local level of the community's top five priorities for mental health reform was better than in most other states (namely early intervention [21%], innovative services for comorbid substance abuse [16%], wider spectrum of acute and community care [21%], implementation of the national mental health standards [23%], programs to support attitudinal change [23%]). With regard to territory-wide initiatives, there was generally a low level of perceived support for, or implementation of key initiatives (namely, specific inter-governmental service agreements [26%], support for innovation [12%], enhanced access [5%], and clear accountability for funds [16%]).

2.7.6.6 Conclusions

The most important aspect of recent developments in the ACT has been the clear commitment of the Government to rapid improvement in mental health services. There appears to be both community and political awareness of the parlous state of services. The range of infrastructure, attitudinal and workforce challenges, however, are considerable.

2.7.7 NORTHERN TERRITORY

2.7.7.1 Overview

Mental health services have a long history of neglect in the Northern Territory, particularly in the rural and remote regions and specifically for Indigenous persons. The socio-demographic, health and population profile of persons living in the NT, however, indicates that from a mental health perspective it is one of the most at-risk groups in the nation. However, there has recently been a state-wide review of mental health services and a commitment to improve services outside Darwin.

While the Government has committed an additional $12.7 million extra funding into mental health services the recent *Building Healthier Communities: A Framework for Health and Community Services 2004-2009* mentions gaps in the delivery of services as though they were minor irregularities amidst a "high quality health and community services system" (page 18). It states that "most Territorians enjoy services as good as – or better than – those in other parts of regional Australia" (page 3). These remarks neglect the reality of poor service access and health outcomes for Aboriginal Territorians and people living outside Darwin or Alice Springs in remote communities. Very little specific detail was provided with respect to programs or areas targeted for development.

The *Building Healthier Communities* framework was developed after the review of the Department of Health and Community Services by a team led by Alan Bansemer. The Bansemer Report specifically noted that there were significant problems with the health and community services budget and 'inadequate management in key areas, lack of transparency in resource allocation, poor budget control, and service "creep"' (page 13). With regard to mental health services, the report identified that given the poor level of coverage of services across the Territory, there was need for mental health services to be brought 'to a parity level with other Australian jurisdictions' (Recommendation 082). Furthermore, given the magnitude of the problem of substance abuse and its relationship with mental health in the Territory, the Bansemer Report recommended that 'A Mental Health and Alcohol and Drug Services Division should be established and should be charged with responsibility for ensuring the provision of a full range of mental health services across the NT' (Recommendation 081). This recommendation was not adopted.

In August 2002 the NT Department of Health and Community Services engaged Healthcare Management Advisors (HMA) 'to assess and make recommendations on the core elements of a Mental Health Service System Development Strategy'. The final report was released on February 2003. In its review of mental health services during 2002, HMA noted the relatively limited emphasis on mental health promotion, the limited emphasis on the development and implementation of mental health prevention strategies and early intervention, and that these were poorly addressed within the system. This was attributed to the relative scarcity of resources and a focus on the treatment of acute mental illness (HMA Final Report, 2003).

The following characteristics were also noted as significant considerations for the planning of mental health services: the NT is characterised by two populations (those residing in metropolitan Darwin and those in smaller remote communities across the Territory); the large Indigenous population and the social, economic and cultural strains placed on Indigenous communities in remotes areas distinguishes the NT from other States and Territories regarding planning and resource distribution; the need for a whole of government approach is particularly important given the diverse social and economic factors which impact on mental health in the NT. The HMA recommended that due to the magnitude of the problems to be addressed and population distribution, that "consideration be given to allocating a minimum of 1.5 times the national average per capita funding for the population living outside the Darwin and Alice Springs metropolitan areas" (recommendation 3). Due to the lack of detail in the *Building Healthier Communities* report, it was difficult to determine the level of adoption of the recommendations made in this report.

2.7.7.2 Key issues

The key issues identified in the public consultations in the Northern Territory were:

i) lack of access to basic assessment and treatment services, even during periods of crisis;
ii) tendency to rely heavily on police and other emergency and custodial services rather than providing mental health care;
iii) lack of services for persons with comorbid mental health and alcohol or other substance abuse disorders;
iv) lack of focus on any prevention or early intervention programs;
v) lack of appropriate medical, nursing and other staff to support service developments in services outside of Darwin;
vi) lack of sufficient development of culturally appropriate treatment services for Indigenous persons, particularly within remote communities;
vii) lack of attention to the close relationships between poor physical health and mental health problems, particularly in Indigenous persons;
viii) lack of support for non-government organisations and for provision of housing and accommodation services;
ix) lack of sufficient consultation with relevant consumer, carer, family and cultural groups; and
x) less access to accepted forms of effective treatment.

2.7.7.3 Positive developments

Some of the positive developments in the Northern Territory include:

i) some development of innovative primary care and other Indigenous programs to service remote communities; and
ii) enhanced support by the Government and the responsible Minister.

Culturally Appropriate Services

> *One initiative to provide culturally appropriate mental health services is the employment of Aboriginal Mental Health Workers (AMHW). AMHWs play an instrumental role in overcoming challenges at the individual and community level by contributing to the delivery of well-informed information and interventions to Aboriginal people. They work hand in hand with the mainstream mental health professionals to provide services and act as brokers and mediators, as well as providing mental health assessments, management and education at an individual, family and community level.*
>
> (NT Department of Health and Community Services, Submission #259, Nov 2004)

2.7.7.4 NMHR 2004 (analysis of expenditure and services)

According to the NMHR 2004, the NT finishes fifth in terms of per capita expenditure ($85.56) and well below the national average ($92.03). Over the last decade, mental health spending has increased 36.9% in per capita terms, above the national state average of 26.2%. In terms of clinical staff employed in ambulatory care settings the NT ranks third (40.3/100,000 population compared with national average of 35.9). With regard to clinical care staff, the NT has the lowest number (78.1/100,000) and is well below the national average of 90.0. The NT ranks fifth in terms of funding to non-government organisations (5.4% of mental health funding, consistent with the national average of 5.5%). The NT ranks last in terms of total inpatient and 24 hour staffed residential beds per 100,000 population (16.2 compared with the highest nationally of 51.0 in Tasmania). Total public sector inpatient beds in the Northern Territory are also low (16.2/100,000), only outperforming the ACT (14.7).

2.7.7.5 Mental Health Council Survey Reports

Given the population of the NT, there were only a small number of responses to the survey (n=9). Although it is difficult to draw conclusions from this limited database, it was suggestive that major service developments are limited in the Territory.

2.7.7.6 Conclusions

In the past, mental health services have been seriously neglected in the Territory, particularly outside Darwin and specifically for the needs of younger persons and Indigenous people. In recent years the NT Government seems to have brought a stronger commitment to improving mental health; however the results are not yet clear. As in Queensland and WA however, the challenges of culture, workforce, demographics and geography are large. A great deal of coordination of national and state-based enhancements is urgently required.

2.7.8 TASMANIA

2.7.8.1 Overview

Tasmania faces a range of medical workforce, infrastructure and community development challenges but has achieved some major reforms during the decade of the mental health strategy. The recent release of the *Bridging the Gap: Review of Mental Health Services* report in October 2004 and accompanying the $47 million four-year funding increase (announced 09 November, 2004) to implement some of the major recommendations of the report, heralds a significant opportunity for improving the delivery of services to people with mental illness in Tasmania.

Prior to this review, the Department of Health and Human Services in Tasmania had acknowledged that critical gaps existed in the delivery of services to people with mental illness as a result of the move from institutional to community-based care and incomplete implementation of three National Mental Health Plans (1993, 1998, 2003). *Bridging the Gap* addressed these and other pressing issues in the reform of service delivery and the announced funding package indicates the magnitude and breadth of problems faced by people with mental illness and/or mental health problems in Tasmania.

> *This package will fund an historic expansion of community mental health services to provide earlier access to more effective treatment. There will be a significant statewide increase in supported accommodation, and a new network of regional recovery programs.*
>
> (Media release, David Llewellyn, Deputy Premier, $47 million to Bridge Gaps in Mental Health, 09 November 2004)

The comprehensiveness of this review, the areas targeted for reform and level of detail in the recommendations was made possible due to the composition of the Review Team and Reference Group and willingness to incorporate findings from a number of other recent reviews. In particular, findings from the *Supported Accommodation for People with Mental Health Problems Strategic Framework* (Department of Health and Human Services, final report released 24 November 2004) and *Thin Ice: Living with Serious Mental Illness and Poverty in Tasmania* (Anglicare Tasmania, May 2004) were used:

> *The overwhelming conclusion from this research is the urgent need for an increased range and supply of support services to assist people with serious mental illness and their families to live successfully in the community. Deinstitutionalisation has not failed. What has failed is the political will to fund essential support services in the community. The existing services are overwhelmed by the heavy demand they currently face and they are not able to provide the level of care and support required to assist recovery. This lack of support options dramatically increases the hardships faced by people who have a mental illness and their families, in terms of their health and their budgets. Ultimately, it is a failure of systems which is making people sick and forcing them into the costly acute care sector.*
>
> (Anglicare Tasmania, "Thin Ice: Living with Serious Mental Illness and Poverty in Tasmania", Tasmania Submission #144, p2).

The report made recommendations in seven areas: quality and safety; specialist resource levels; community-based care (including supported accommodation); comprehensive care for all consumers; workforce development; strategic planning; and legislation and patient rights. Importantly the recommendations bring to life some of the theoretical underpinnings of the National Mental Health Plans that have previously prevented the realisation of community based care: lack of staff and resources in the community to provide early intervention and prevention services and supported accommodation options for people to live in their community. *Bridging the Gap* appears to lay the foundations for increasing community-based services across Tasmania. Increased funding to non-government organisations was also provided for, as was the distribution of resources to rural and regional areas, the growth of child and adolescent mental health services and immediate targeted expansion of the clinical workforce.

> *Anglicare CEO, the Rev'd Chris Jones, praised the fact that the $47 million investment would go to the areas those people had identified as vital to their ongoing survival within the communit. 'This money is going, as they said it needed to, into a range of supported accommodation models, increased resources for community mental health teams, and the establishment of a range of services in the community to assist them with their recovery and with everyday activities," he said. "However, it is imperative that their needs be recognised as a priority by State Governments beyond the life of this four-year package."…The Rev'd Jones said that people affected by serious mental illness and workers in the field had been struggling with a lack of support and resources for years. "It is gratifying that their voices have finally been heard and responded to," he said.*
>
> (Anglicare Tasmania website www.anglicare-tas.org.au 23 December 2004)

Another positive development to protect the rights of people with mental illness has been the Mental Health Tribunal Representation Scheme. This Scheme is described below.

2.7.8.2 Key issues

The key issues identified through the public consultations and submissions inevitably draw attention to the deficiencies in the service system that have also been identified and recognised by the Tasmanian Government. These include:

i) lack of access to basic services, particularly for those who did not fit a narrow band of diagnostically-driven group of persons to be assisted;
ii) lack of community-based health and housing services;
iii) lack of attention to prevention, early intervention or recovery meant that most effort was reactive and acute care-based;
iv) lack of service provision outside Hobart, with particular emphasis on workforce and resource shortages in the Northern parts of the States;
v) lack of concern for persons with comorbid mental health and alcohol or other substance abuse problems; and
vi) lack of consultation with consumers, staff and NGO service providers in the planning and delivery of services.

2.7.8.3 Positive developments

The Government's commitment to major new investments is the most positive development in Tasmania. Other examples, however, included:

i) Tasmania's Mental Health Tribunal Representation Scheme.

Tasmania: Tasmania's Mental Health Tribunal Representation Scheme - Steps to protect the rights of people with mental illness

[T]he Tasmanian Mental Health Act 1996, s57, grants representation for people appearing before the Mental Health Tribunal in keeping with the United Nations Principles for the Protection of Persons with Mental Illness…Until the Representation Project was commenced this had not happened, despite the fact that Tasmanians can be, and are, deprived of their liberty in psychiatric hospitals across the state for 6 months, and beyond…This lack of representation was brought to Advocacy Tasmania Inc's attention in 2000 by Ms Debra Rigby, President of the Mental Health Tribunal…Ms Rigby expressed concern that people appearing before the Tribunal were unrepresented. She believed it was a denial of their rights and potentially disadvantageous for them. Of 102 hearings held in 1999/2000 only 2 clients were represented. Ms Rigby enquired as to whether the state mental health advocate's role included representing those mentally ill people appearing before the Mental Health Tribunal…

The mental health advocate, Ms Valerie Williams, did not, and could not provide the necessary representation as time and resources did not allow for the sole mental health advocate to provide a service for so many clients. However, Ms Williams…made the commitment that achieving representation for this group of mental health clients would be the mental health program's priority systemic issue and began working to achieve this goal.

In accordance with this commitment, Ms Williams, with the support of Advocacy Tasmania, the Mental Health Tribunal, the University of Tasmania, and a small grant from the Department of Health and Human Services (Mental Health Services), developed the Mental Health Representation Project. University of Tasmania Law Students offered their free time to undertake extensive training prior to providing voluntary representation for, arguably, Tasmania's most vulnerable citizens.

The project commenced in a limited way, offering representation before the Tribunal to patients in the Psychiatric Intensive Care Unit (PICU) and the Department of Psychological Medicine (DPM) at the Royal Hobart Hospital. Since commencement in early December 2003, at least 86 people have been offered free representation…The project has received positive support from patients, volunteers, the Mental Health Tribunal, Mental Health Services, clinicians, the Law Society as well as the University of Tasmania Law School and the Legal Practice Course. The Law School is planning to integrate the training of students into their mainstream program as an elective Mental Health Advocacy unit in 2005.

While the scheme has only operated in 2 of its 7 sites where Mental Health Tribunal hearings are held, it is aimed to expand the project to cover all of Tasmania within the coming months…The Pilot Project demonstrated that it is an effective model for providing representation to patients appearing before the Mental Health Tribunal. Prior to the commencement of this project the only means was for the patient or their family to employ a lawyer to provide the representation, which few are able to afford.

A long term expected outcome will be an improved quality of legal representations to people with a mental health disorder in the wider community because of the training and experience of lawyers when they were students. A long term unexpected outcome has been the response from other Australian states, with states such as Victoria, SA, WA and NSW expressing interest in the Scheme, and WA requesting Ms Williams to undertake specific training for a group of university students in Perth, where an elective in Mental Awareness is already established.

(Advocacy Tasmania Inc - Mental Health Tribunal Representation Scheme, Tasmania Submission #189)

2.7.8.4 NMHR 2004 (analysis of expenditure and services)

According to the NMHR 2004, Tasmania finishes fourth in terms of per capita expenditure ($93.86) just above the national average ($92.03). Over the last decade, Tasmanian mental health spending has increased 25.7% in per capita terms, consistent with the national state average of 26.2%. Additionally, there has been a substantial reduction in expenditure on stand alone psychiatric hospitals (-$16.1m) and a growth in community and general hospital services ($26.2m). In terms of clinical staff employed in ambulatory care settings Tasmania ranks seventh (31.9/100,000 population, below the national average of 35.9). With regard to clinical care staff, however, Tasmania ranks first (104.0/100,000) well above the national average of 90.0. Tasmania ranks sixth in terms of funding to non-government organisations (3.3%, well below the national average of 5.5%). Tasmania ranks first in terms of total inpatient and 24 hour staffed residential beds per 100,000 population (51.0). Total public sector inpatient beds in Tasmania are mid-range at 30.9/100,000.

2.7.8.5 Mental Health Council Survey Reports

Given the size of Tasmania, it was not surprising that there was only a limited number of responses from local organisations and individuals (n=26) (see Part 3). Although this is a limited data set there was little indication that the community's key priorities for mental health reform have been implemented (namely early intervention [8%], innovative services for comorbid substance abuse [4%], wider spectrum of acute and community care [0%], implementation of the national mental health standards [15%], programs to support attitudinal change [4%]). With regard to state-wide initiatives, there was generally a low level of perceived support for or implementation of key initiatives (namely, specific inter-governmental service agreements [8%], support for innovation [4%], enhanced access [12%], and clear accountability for funds [12%]).

2.7.8.6 Conclusions

Tasmania has recently made some significant new investments in mental health reform. However, it faces many significant workforce and service development challenges. Previously, political and community awareness of these challenges did not translate into improved experiences of care for those who use services. More innovative approaches will be required to achieve both population coverage and improved quality of service delivery.

PART THREE: RESULTS OF SURVEYS

3.1 Survey One: A review of implementation of community priorities in mental health 93

3.2 Survey Two: Consumer and carer experiences of care 114

After the Mental Health Council of Australia (MHCA) launched its national review of mental health services in Australia in 2003 ("Out of Hospital, Out of Mind!"), it set about gathering more specific data from government agencies about the status of mental health services at local, regional and state/ territory levels. Together with the Brain and Mind Research Institute (BMRI), the MHCA developed two surveys as tools to collect the relevant information. This process was completed prior to the commencement of community consultations with the Human Rights and Equal Opportunity Commission.

The following data summarises the results of those surveys.

3.1 SURVEY ONE: A REVIEW OF IMPLEMENTATION OF COMMUNITY PRIORITIES IN MENTAL HEALTH

The first survey, conducted over 2004-04, sought the views of mental health stakeholders about the progress in the implementation of community priorities in mental health. The survey was divided into three sections:

- The first asked some demographic information about the respondent and their service.
- The second asked the respondent to rate how the priorities have been implemented or supported within their LOCAL area.
- The third asked respondents to rate how the priorities have been implemented or supported at a STATE level.

3.1.1 SURVEY ONE - NATIONAL DATA SET

As of 2 November 2004, 714 complete surveys had been received. The majority of respondents described their role within the mental health sector as public providers of specialist treatment (n=246, 34%). This is followed by consumers and carers (n=162, 22%) and then non-government community service providers (n=74, 10%). Across Australia, most respondents were located in New South Wales (NSW; Table 3.1.1.1).

Table 3.1.1.1: Total number of respondents by state; N=714.

STATE	TOTAL NUMBER (%) OF RESPONDENTS
New South Wales	239 (33%)
Victoria	134 (19%)
Western Australia	99 (14%)
Queensland	95 (13%)
South Australia	69 (10%)
Australian Capital Territory	43 (6%)
Tasmania	26 (4%)
Northern Territory	9 (1%)

With regards to the national priorities as identified in "Out of Hospital, Out of Mind!", respondents rated the extent to which they have been implemented or supported in their LOCAL areas (Table 3.1.1.2).

Table 3.1.1.2: Implementation or support for priorities at a LOCAL level; N=714.

		No action taken or no support N (%)*	Discussion and planning or low level support PLUS implementation begun or moderate support N (%)*	Nearly complete or high level support PLUS fully implemented or full support N (%)*
1.	Implementation of early intervention services	171 (24%)	414 (58%)	121 (17%)
2.	Development of innovative services for people with mental health and alcohol or substance abuse disorders	244 (34%)	379 (53%)	77 (11%)
3.	Development of a wider spectrum of acute and community-based care settings	213 (30%)	406 (57%)	85 (12%)
4.	Implementation of the national standards for mental health services	158 (22%)	421 (59%)	110 (15%)
5.	Programs that promote attitudinal change among mental health workers	225 (32%)	399 (56%)	67 (9%)
6.	Increased support for stigma reduction campaigns	265 (37%)	352 (49%)	73 (10%)
7.	Development of specific inter-governmental service agreements (e.g. Between health, education, housing, employment, and social security)	173 (24%)	414 (58%)	99 (14%)
8.	More genuine consumer participation	172 (24%)	413 (58%)	114 (16%)
9.	Direct support for 'innovation', 'research' and 'service evaluation' in mental health	260 (36%)	358 (50%)	81 (11%)
10.	Introduction of specific schemes to enhance access to mental health specialists	235 (33%)	379 (53%)	83 (12%)
11.	More genuine carer participation	176 (25%)	400 (56%)	121 (17%)
12.	Support for enhanced role of non-government organisations in all aspects of care	184 (26%)	440 (62%)	70 (10%)
13.	Clear accountability for expenditure of mental health strategy funds	235 (33%)	361 (51%)	76 (11%)
14.	Specification of clear primary care and specialist workforce roles	223 (31%)	378 (53%)	90 (13%)

*Where numbers do not tally to 714 (100%), respondents have either responded "Don't know" or left the question blank.

Next, respondents rated the extent to which priorities have been implemented or supported within their STATE (Table 3.1.1.3).

Table 3.1.1.3: Implementation or support of priorities at a STATE level; N=714.

		No action taken or no support N (%)*	Discussion and planning or low level support PLUS implementation begun or moderate support N (%)*	Nearly complete or high level support PLUS fully implemented or full support N (%)*
1.	Development of specific inter-governmental service agreements (e.g. between health, education, housing, employment, and social security)	184 (26%)	410 (58%)	89 (13%)
2.	Direct support for 'innovation', 'research' and 'service evaluation' in mental health	190 (27%)	438 (61%)	73 (10%)
3.	Introduction to specific schemes to enhance access to mental health specialists	195 (27%)	433 (61%)	68 (10%)
4.	Support for specific disease prevention initiatives (e.g. In anxiety, depression, alcohol or substance abuse)	178 (25%)	445 (62%)	79 (11%)
5	Support for general mental health promotion	185 (26%)	437 (61%)	81 (11%)
6.	Support for enhanced role of non-government organisations in all aspects of care	191 (27%)	421 (59%)	81 (11%)
7.	Clear accountability for expenditure of mental health strategy funds	221 (31%)	380 (53%)	75 (11%)
8.	Ongoing support for suicide prevention campaigns	175 (25%)	424 (60%)	97 (14%)
9.	Development of datasets for monitoring the quality of local services	173 (24%)	421 (59%)	98 (14%)
10.	Service development for those in forensic (i.e. prison-based) services	201 (28%)	395 (56%)	81 (11%)
11.	Specification of clear primary care and specialist workforces	210 (30%)	406 (57%)	68 (10%)
12.	Service enhancement for persons from culturally – and linguistically-diverse backgrounds	173 (24%)	440 (62%)	85 (12%)
13.	Support for community leadership in mental health	172 (24%)	447 (63%)	67 (9%)
14.	Support for professional leadership in mental health	196 (28%)	435 (61%)	64 (9%)
15.	Development of specific procedures for reporting Human Rights abuses or neglect	211 (30%)	397 (56%)	73 (10%)
16.	Increased support for stigma reduction campaigns	151 (21%)	463 (65%)	77 (11%)

*Where numbers do not tally to 714 (100%), respondents have either responded "Don't know" or left the question blank.

Finally, respondents living and/or working in regional or rural and poorly resourced areas were asked to rate the extent to which such factors have been implemented or supported within their STATE (Table 3.1.1.4).

Table 3.1.1.4: Implementation or support for regional or rural and poorly resourced areas.

		Nearly complete or high level support PLUS fully implemented or full support
1.	IN YOUR STATE, what is the level of support for service development in rural and regional areas? (n=366)**	25 (7%)
2.	IN YOUR STATE, what is the level of support for service development in poorly resourced areas? (n=369)**	7 (2%)

** The total number of respondents answering this question reduced from 714 depending on whether the respondent identified as living in either a rural or regional area (n=366) or a poorly resourced area (n=369).

Table 3.1.1.5: Implementation or support of TOP TEN national priorities at a LOCAL level; N=714.

		No action taken or no support N (%)*	Discussion and planning or low level support PLUS implementation begun or moderate support N (%)*	Nearly complete or high level support PLUS fully implemented or full support N (%)*
1.	Implementation of early intervention services	171 (24%)	414 (58%)	121 (17%)
2.	Development of innovative services for people with mental health and alcohol or substance abuse disorders	244 (34%)	379 (53%)	77 (11%)
3.	Development of a wider spectrum of acute and community-based care settings	213 (30%)	406 (57%)	85 (12%)
4.	Support for service development in rural and regional areas (n=372)**	94 (26%)**	243 (66%)**	25 (7%)**
5.	Implementation of the national standards for mental health services	158 (22%)	421 (59%)	110 (15%)
6.	Support for service development in poorly resourced areas (n=373)**	133 (36%)**	227 (62%)**	7 (2%)**
7.	Support for programs that promote attitudinal change among mental health workers	225 (32%)	399 (56%)	67 (9%)
8.	Increased support for stigma reduction campaigns	265 (37%)	352 (49%)	73 (10%)
9.	Development of specific inter-governmental service agreements (e.g. Between health, education, housing, employment, and social security)	173 (24%)	414 (58%)	99 (14%)
10.	More genuine consumer participation	172 (24%)	413 (58%)	114 (16%)

*Where numbers do not tally to 714 (100%), respondents have either responded "Don't know" or left the question blank.

** The total number of respondents answering this question reduced from 714 depending on whether the respondent identified as living in either a rural or regional area (n=366) or a poorly resourced area (n=369).

Conclusions

The responses of local providers of services, and many consumers, carers and non-government organisations, indicate clearly that the key community priorities for national mental health reform have not been implemented. The results are an indicator of the performance of government in turning mental health policy into real local action in Australia. Very basic structural issues of implementation of the National Mental Health Standards, accountability for funds, involvement of consumers and carers and engagement and support of the non-government sector have not been attained. Real program development such as implementation of early intervention strategies, management of concurrent alcohol and drug problems and development of a greater range of acute care settings remain largely on the drawing board. Rural and regional areas and areas within states with low levels of other resources still appear to be neglected. The perceptions of the providers and users of services continue to reinforce the data originally described in "Out of Hospital, Out of Mind!".

As there are likely to be significant variations by both region and state in the degree of mental health reform, this same data is presented on a state-by-state basis.

3.1.2 SURVEY ONE - NEW SOUTH WALES

Table 3.2.1.1: Implementation or support for priorities at a LOCAL level in NSW; N=239.

		No action taken or no support N (%)*	Discussion and planning or low level support PLUS implementation begun or moderate support N (%)*	Nearly complete or high level support PLUS fully implemented or full support N (%)*
1.	Implementation of early intervention services	58 (24%)	143 (60%)	36 (15%)
2.	Development of innovative services for people with mental health and alcohol or substance abuse disorders	90 (38%)	121 (51%)	23 (10%)
3.	Development of a wider spectrum of acute and community-based care settings	71 (30%)	140 (59%)	26 (11%)
4.	Implementation of the national standards for mental health services	50 (21%)	147 (62%)	33 (14%)
5.	Programs that promote attitudinal change among mental health workers	80 (34%)	131 (55%)	19 (8%)
6.	Increased support for stigma reduction campaigns	92 (39%)	111 (47%)	27 (11%)
7.	Development of specific inter-governmental service agreements (e.g. Between health, education, housing, employment, and social security)	54 (23%)	144 (60%)	32 (13%)
8.	More genuine consumer participation	57 (24%)	137 (58%)	40 (17%)
9.	Direct support for 'innovation', 'research' and 'service evaluation' in mental health	94 (39%)	115 (48%)	24 (10%)
10.	Introduction of specific schemes to enhance access to mental health specialists	82 (34%)	126 (53%)	26 (11%)
11.	More genuine carer participation	49 (21%)	141 (59%)	43 (18%)
12.	Support for enhanced role of non-government organisations in all aspects of care	52 (22%)	154 (64%)	26 (11%)
13.	Clear accountability for expenditure of mental health strategy funds	71 (30%)	126 (53%)	27 (11%)
14.	Specification of clear primary care and specialist workforce roles	77 (32%)	119 (50%)	35 (15%)

*Where numbers do not tally to 239 (100%), respondents have either responded "Don't know" or left the question blank.

Next, respondents rated the extent to which priorities have been implemented or supported within their STATE (Table 3.2.1.2).

Table 3.2.1.2: Implementation or support of priorities at a STATE level in NSW; N=239.

		No action taken or no support N (%)*	Discussion and planning or low level support PLUS implementation begun or moderate support N (%)*	Nearly complete or high level support PLUS fully implemented or full support N (%)*
1.	Development of specific inter-governmental service agreements (e.g. between health, education, housing, employment, and social security)	58 (24%)	145 (61%)	30 (13%)
2.	Direct support for 'innovation', 'research' and 'service evaluation' in mental health	66 (28%)	150 (63%)	19 (8%)
3.	Introduction to specific schemes to enhance access to mental health specialists	61 (26%)	145 (61%)	28 (12%)
4.	Support for specific disease prevention initiatives (e.g. In anxiety, depression, alcohol or substance abuse)	56 (24%)	153 (64%)	28 (12%)
5	Support for general mental health promotion	67 (28%)	146 (61%)	25 (11%)
6.	Support for enhanced role of non-government organisations in all aspects of care	69 (29%)	137 (57%)	25 (11%)
7.	Clear accountability for expenditure of mental health strategy funds	70 (29%)	128 (54%)	28 (12%)
8.	Ongoing support for suicide prevention campaigns	57 (24%)	142 (59%)	39 (16%)
9.	Development of datasets for monitoring the quality of local services	55 (23%)	144 (60%)	32 (13%)
10.	Service development for those in forensic (i.e. prison-based) services	75 (32%)	131 (55%)	23 (10%)
11.	Specification of clear primary care and specialist workforces	72 (30%)	136 (57%)	20 (8%)
12.	Service enhancement for persons from culturally – and linguistically-diverse backgrounds	55 (23%)	157 (66%)	25 (11%)
13.	Support for community leadership in mental health	54 (23%)	154 (64%)	21 (9%)
14.	Support for professional leadership in mental health	60 (25%)	154 (64%)	16 (7%)
15.	Development of specific procedures for reporting Human Rights abuses or neglect	81 (34%)	126 (53%)	22 (9%)
16.	Increased support for stigma reduction campaigns	47 (20%)	152 (64%)	33 (14%)

*Where numbers do not tally to 239 (100%), respondents have either responded "Don't know" or left the question blank.

3.1.3 SURVEY ONE - VICTORIA

Table 3.1.3.1: Implementation or support for priorities at a LOCAL level in VIC; N=134.

		No action taken or no support N (%)*	Discussion and planning or low level support PLUS implementation begun or moderate support N (%)*	Nearly complete or high level support PLUS fully implemented or full support N (%)*
1.	Implementation of early intervention services	32 (24%)	71 (53%)	28 (21%)
2.	Development of innovative services for people with mental health and alcohol or substance abuse disorders	39 (30%)	74 (56%)	15 (11%)
3.	Development of a wider spectrum of acute and community-based care settings	39 (29%)	70 (52%)	21 (16%)
4.	Implementation of the national standards for mental health services	35 (26%)	67 (50%)	23 (17%)
5.	Programs that promote attitudinal change among mental health workers	45 (34%)	70 (53%)	12 (9%)
6.	Increased support for stigma reduction campaigns	53 (40%)	59 (44%)	12 (9%)
7.	Development of specific inter-governmental service agreements (e.g. Between health, education, housing, employment, and social security)	37 (28%)	72 (54%)	15 (11%)
8.	More genuine consumer participation	32 (24%)	80 (60%)	19 (14%)
9.	Direct support for 'innovation', 'research' and 'service evaluation' in mental health	43 (32%)	69 (52%)	19 (14%)
10.	Introduction of specific schemes to enhance access to mental health specialists	37 (28%)	74 (56%)	17 (13%)
11.	More genuine carer participation	37 (28%)	76 (57%)	16 (12%)
12.	Support for enhanced role of non-government organisations in all aspects of care	40 (30%)	76 (57%)	12 (9%)
13.	Clear accountability for expenditure of mental health strategy funds	49 (37%)	62 (46%)	9 (7%)
14.	Specification of clear primary care and specialist workforce roles	44 (33%)	69 (52%)	13 (10%)

*Where numbers do not tally to 134 (100%), respondents have either responded "Don't know" or left the question blank.

Next, respondents rated the extent to which priorities have been implemented or supported within their STATE (Table 3.1.3.2).

Table 3.1.3.2: Implementation or support of priorities at a STATE level in VIC; N=134.

		No action taken or no support N (%)*	Discussion and planning or low level support PLUS implementation begun or moderate support N (%)*	Nearly complete or high level support PLUS fully implemented or full support N (%)*
1.	Development of specific inter-governmental service agreements (e.g. between health, education, housing, employment, and social security)	42 (31%)	63 (47%)	16 (12%)
2.	Direct support for 'innovation', 'research' and 'service evaluation' in mental health	33 (25%)	76 (57%)	22 (16%)
3.	Introduction to specific schemes to enhance access to mental health specialists	36 (27%)	84 (63%)	8 (6%)
4.	Support for specific disease prevention initiatives (e.g. In anxiety, depression, alcohol or substance abuse)	35 (26%)	84 (63%)	12 (9%)
5	Support for general mental health promotion	35 (26%)	79 (59%)	16 (12%)
6.	Support for enhanced role of non-government organisations in all aspects of care	37 (28%)	74 (55%)	17 (13%)
7.	Clear accountability for expenditure of mental health strategy funds	45 (34%)	59 (44%)	14 (10%)
8.	Ongoing support for suicide prevention campaigns	35 (26%)	70 (53%)	21 (16%)
9.	Development of datasets for monitoring the quality of local services	40 (30%)	67 (50%)	17 (13%)
10.	Service development for those in forensic (i.e. prison-based) services	41 (31%)	53 (40%)	26 (19%)
11.	Specification of clear primary care and specialist workforces	35 (26%)	71 (53%)	18 (14%)
12.	Service enhancement for persons from culturally – and linguistically-diverse backgrounds	32 (24%)	76 (57%)	21 (16%)
13.	Support for community leadership in mental health	34 (26%)	76 (57%)	16 (12%)
14.	Support for professional leadership in mental health	38 (28%)	77 (58%)	14 (10%)
15.	Development of specific procedures for reporting Human Rights abuses or neglect	39 (29%)	65 (49%)	16 (12%)
16.	Increased support for stigma reduction campaigns	33 (25%)	80 (60%)	13 (10%)

*Where numbers do not tally to 134 (100%), respondents have either responded "Don't know" or left the question blank.

3.1.4 SURVEY ONE - QUEENSLAND

Table 3.1.4.1: Implementation or support for priorities at a LOCAL level in QLD; N=95.

		No action taken or no support N (%)*	Discussion and planning or low level support PLUS implementation begun or moderate support N (%)*	Nearly complete or high level support PLUS fully implemented or full support N (%)*
1.	Implementation of early intervention services	29 (31%)	49 (52%)	15 (16%)
2.	Development of innovative services for people with mental health and alcohol or substance abuse disorders	37 (39%)	47 (50%)	9 (10%)
3.	Development of a wider spectrum of acute and community-based care settings	32 (34%)	53 (56%)	7 (7%)
4.	Implementation of the national standards for mental health services	22 (23%)	51 (54%)	18 (19%)
5.	Programs that promote attitudinal change among mental health workers	33 (35%)	48 (51%)	8 (9%)
6.	Increased support for stigma reduction campaigns	33 (35%)	46 (48%)	13 (14%)
7.	Development of specific inter-governmental service agreements (e.g. Between health, education, housing, employment, and social security)	25 (26%)	54 (57%)	11 (12%)
8.	More genuine consumer participation	33 (35%)	46 (48%)	12 (13%)
9.	Direct support for 'innovation', 'research' and 'service evaluation' in mental health	38 (40%)	40 (42%)	13 (14%)
10.	Introduction of specific schemes to enhance access to mental health specialists	35 (37%)	45 (47%)	11 (12%)
11.	More genuine carer participation	32 (34%)	41 (43%)	18 (19%)
12.	Support for enhanced role of non-government organisations in all aspects of care	34 (36%)	48 (51%)	8 (8%)
13.	Clear accountability for expenditure of mental health strategy funds	36 (38%)	38 (40%)	12 (13%)
14.	Specification of clear primary care and specialist workforce roles	34 (36%)	46 (48%)	10 (11%)

*Where numbers do not tally to 95 (100%), respondents have either responded "Don't know" or left the question blank.

Next, respondents rated the extent to which priorities have been implemented or supported within their STATE (Table 3.1.4.2).

Table 3.1.4.2: Implementation or support of priorities at a STATE level in QLD; N=95.

		No action taken or no support N (%)*	Discussion and planning or low level support PLUS implementation begun or moderate support N (%)*	Nearly complete or high level support PLUS fully implemented or full support N (%)*
1.	Development of specific inter-governmental service agreements (e.g. between health, education, housing, employment, and social security)	25 (27%)	54 (57%)	10 (11%)
2.	Direct support for 'innovation', 'research' and 'service evaluation' in mental health	22 (23%)	58 (61%)	11 (12%)
3.	Introduction to specific schemes to enhance access to mental health specialists	23 (25%)	57 (61%)	10 (11%)
4.	Support for specific disease prevention initiatives (e.g. In anxiety, depression, alcohol or substance abuse)	26 (27%)	49 (52%)	15 (16%)
5	Support for general mental health promotion	19 (20%)	54 (57%)	18 (19%)
6.	Support for enhanced role of non-government organisations in all aspects of care	20 (21%)	55 (58%)	14 (15%)
7.	Clear accountability for expenditure of mental health strategy funds	26 (27%)	52 (55%)	10 (11%)
8.	Ongoing support for suicide prevention campaigns	19 (20%)	55 (58%)	14 (15%)
9.	Development of datasets for monitoring the quality of local services	19 (20%)	57 (60%)	15 (16%)
10.	Service development for those in forensic (i.e. prison-based) services	23 (25%)	47 (50%)	16 (17%)
11.	Specification of clear primary care and specialist workforces	28 (30%)	48 (51%)	13 (14%)
12.	Service enhancement for persons from culturally – and linguistically-diverse backgrounds	23 (25%)	49 (52%)	17 (18%)
13.	Support for community leadership in mental health	24 (25%)	57 (60%)	7 (7%)
14.	Support for professional leadership in mental health	29 (31%)	51 (54%)	11 (12%)
15.	Development of specific procedures for reporting Human Rights abuses or neglect	21 (22%)	56 (59%)	11 (12%)
16.	Increased support for stigma reduction campaigns	20 (21%)	62 (65%)	7 (7%)

*Where numbers do not tally to 95 (100%), respondents have either responded "Don't know" or left the question blank.

3.1.5 SURVEY ONE – SOUTH AUSTRALIA

Table 3.1.5.1: Implementation or support for priorities at a LOCAL level in SA; N=69.

		No action taken or no support N (%)*	Discussion and planning or low level support PLUS implementation begun or moderate support N (%)*	Nearly complete or high level support PLUS fully implemented or full support N (%)*
1.	Implementation of early intervention services	15 (22%)	49 (71%)	5 (7%)
2.	Development of innovative services for people with mental health and alcohol or substance abuse disorders	27 (39%)	36 (52%)	6 (9%)
3.	Development of a wider spectrum of acute and community-based care settings	21 (30%)	40 (58%)	8 (12%)
4.	Implementation of the national standards for mental health services	20 (29%)	44 (64%)	5 (7%)
5.	Programs that promote attitudinal change among mental health workers	20 (29%)	45 (65%)	4 (6%)
6.	Increased support for stigma reduction campaigns	31 (45%)	34 (49%)	4 (6%)
7.	Development of specific inter-governmental service agreements (e.g. Between health, education, housing, employment, and social security)	20 (29%)	40 (58%)	9 (13%)
8.	More genuine consumer participation	15 (22%)	43 (62%)	11 (16%)
9.	Direct support for 'innovation', 'research' and 'service evaluation' in mental health	27 (39%)	38 (55%)	4 (6%)
10.	Introduction of specific schemes to enhance access to mental health specialists	24 (35%)	39 (57%)	6 (9%)
11.	More genuine carer participation	21 (30%)	38 (55%)	10 (15%)
12.	Support for enhanced role of non-government organisations in all aspects of care	14 (20%)	49 (71%)	6 (9%)
13.	Clear accountability for expenditure of mental health strategy funds	30 (44%)	34 (49%)	5 (7%)
14.	Specification of clear primary care and specialist workforce roles	20 (29%)	41 (59%)	8 (12%)

*Where numbers do not tally to 69 (100%), respondents have either responded "Don't know" or left the question blank.

Next, respondents rated the extent to which priorities have been implemented or supported within their STATE (Table 3.1.5.2).

Table 3.1.5.2: Implementation or support of priorities at a STATE level in SA; N=69.

		No action taken or no support N (%)*	Discussion and planning or low level support PLUS implementation begun or moderate support N (%)*	Nearly complete or high level support PLUS fully implemented or full support N (%)*
1.	Development of specific inter-governmental service agreements (e.g. between health, education, housing, employment, and social security)	21 (30%)	43 (62%)	4 (6%)
2.	Direct support for 'innovation', 'research' and 'service evaluation' in mental health	22 (32%)	43 (62%)	4 (6%)
3.	Introduction to specific schemes to enhance access to mental health specialists	22 (32%)	40 (59%)	6 (9%)
4.	Support for specific disease prevention initiatives (e.g. In anxiety, depression, alcohol or substance abuse)	19 (28%)	48 (70%)	2 (3%)
5	Support for general mental health promotion	20 (29%)	45 (65%)	4 (6%)
6.	Support for enhanced role of non-government organisations in all aspects of care	24 (35%)	41 (59%)	4 (6%)
7.	Clear accountability for expenditure of mental health strategy funds	27 (39%)	37 (54%)	5 (7%)
8.	Ongoing support for suicide prevention campaigns	22 (32%)	41 (59%)	6 (9%)
9.	Development of datasets for monitoring the quality of local services	26 (38%)	38 (55%)	5 (7%)
10.	Service development for those in forensic (i.e. prison-based) services	24 (35%)	41 (59%)	2 (3%)
11.	Specification of clear primary care and specialist workforces	27 (39%)	39 (57%)	3 (4%)
12.	Service enhancement for persons from culturally – and linguistically-diverse backgrounds	23 (33%)	42 (61%)	4 (6%)
13.	Support for community leadership in mental health	27 (39%)	39 (57%)	3 (4%)
14.	Support for professional leadership in mental health	26 (38%)	40 (58%)	3 (4%)
15.	Development of specific procedures for reporting Human Rights abuses or neglect	25 (36%)	38 (55%)	6 (9%)
16.	Increased support for stigma reduction campaigns	16 (23%)	47 (68%)	6 (9%)

*Where numbers do not tally to 69 (100%), respondents have either responded "Don't know" or left the question blank.

3.1.6 SURVEY ONE – WESTERN AUSTRALIA

Table 3.1.6.1: Implementation or support for priorities at a LOCAL level in WA; N=99.

		No action taken or no support N (%)*	Discussion and planning or low level support PLUS implementation begun or moderate support N (%)*	Nearly complete or high level support PLUS fully implemented or full support N (%)*
1.	Implementation of early intervention services	26 (26%)	47 (48%)	26 (26%)
2.	Development of innovative services for people with mental health and alcohol or substance abuse disorders	30 (30%)	54 (55%)	15 (15%)
3.	Development of a wider spectrum of acute and community-based care settings	35 (35%)	50 (51%)	13 (13%)
4.	Implementation of the national standards for mental health services	18 (18%)	62 (63%)	17 (17%)
5.	Programs that promote attitudinal change among mental health workers	30 (30%)	57 (58%)	12 (12%)
6.	Increased support for stigma reduction campaigns	31 (31%)	56 (57%)	11 (11%)
7.	Development of specific inter-governmental service agreements (e.g. Between health, education, housing, employment, and social security)	25 (25%)	54 (55%)	18 (18%)
8.	More genuine consumer participation	22 (22%)	61 (62%)	15 (15%)
9.	Direct support for 'innovation', 'research' and 'service evaluation' in mental health	36 (36%)	50 (51%)	12 (12%)
10.	Introduction of specific schemes to enhance access to mental health specialists	34 (34%)	47 (48%)	17 (17%)
11.	More genuine carer participation	23 (23%)	60 (61%)	15 (15%)
12.	Support for enhanced role of non-government organisations in all aspects of care	31 (31%)	57 (58%)	10 (10%)
13.	Clear accountability for expenditure of mental health strategy funds	32 (32%)	53 (54%)	12 (12%)
14.	Specification of clear primary care and specialist workforce roles	31 (31%)	54 (55%)	13 (13%)

*Where numbers do not tally to 99 (100%), respondents have either responded "Don't know" or left the question blank.

Next, respondents rated the extent to which priorities have been implemented or supported within their STATE (Table 3.1.6.2).

Table 3.1.6.2: Implementation or support of priorities at a STATE level in WA; N=99.

		No action taken or no support N (%)*	Discussion and planning or low level support PLUS implementation begun or moderate support N (%)*	Nearly complete or high level support PLUS fully implemented or full support N (%)*
1.	Development of specific inter-governmental service agreements (e.g. between health, education, housing, employment, and social security)	25 (25%)	56 (57%)	16 (%)
2.	Direct support for 'innovation', 'research' and 'service evaluation' in mental health	29 (29%)	58 (59%)	11 (11%)
3.	Introduction to specific schemes to enhance access to mental health specialists	28 (28%)	60 (61%)	11 (11%)
4.	Support for specific disease prevention initiatives (e.g. In anxiety, depression, alcohol or substance abuse)	22 (22%)	63 (64%)	14 (14%)
5	Support for general mental health promotion	26 (26%)	64 (65%)	9 (9%)
6.	Support for enhanced role of non-government organisations in all aspects of care	29 (29%)	58 (59%)	12 (12%)
7.	Clear accountability for expenditure of mental health strategy funds	32 (32%)	58 (59%)	8 (8%)
8.	Ongoing support for suicide prevention campaigns	23 (23%)	67 (68%)	9 (9%)
9.	Development of datasets for monitoring the quality of local services	22 (22%)	62 (63%)	15 (15%)
10.	Service development for those in forensic (i.e. prison-based) services	22 (22%)	69 (70%)	7 (7%)
11.	Specification of clear primary care and specialist workforces	31 (31%)	59 (60%)	8 (8%)
12.	Service enhancement for persons from culturally – and linguistically-diverse backgrounds	21 (21%)	68 (69%)	9 (9%)
13.	Support for community leadership in mental health	13 (13%)	76 (77%)	9 (9%)
14.	Support for professional leadership in mental health	23 (23%)	63 (64%)	12 (12%)
15.	Development of specific procedures for reporting Human Rights abuses or neglect	29 (29%)	60 (61%)	9 (9%)
16.	Increased support for stigma reduction campaigns	18 (18%)	72 (73%)	8 (8%)

*Where numbers do not tally to 99 (100%), respondents have either responded "Don't know" or left the question blank.

3.1.7 SURVEY ONE – AUSTRALIAN CAPITAL TERRITORY

Table 3.1.7.1: Implementation or support for priorities at a LOCAL level in the ACT; N=43.

		No action taken or no support N (%)*	Discussion and planning or low level support PLUS implementation begun or moderate support N (%)*	Nearly complete or high level support PLUS fully implemented or full support N (%)*
1.	Implementation of early intervention services	4 (9%)	30 (70%)	9 (21%)
2.	Development of innovative services for people with mental health and alcohol or substance abuse disorders	7 (16%)	29 (67%)	7 (16%)
3.	Development of a wider spectrum of acute and community-based care settings	5 (12%)	29 (67%)	9 (21%)
4.	Implementation of the national standards for mental health services	7 (16%)	26 (61%)	10 (23%)
5.	Programs that promote attitudinal change among mental health workers	6 (14%)	27 (63%)	10 (23%)
6.	Increased support for stigma reduction campaigns	12 (28%)	27 (63%)	4 (9%)
7.	Development of specific inter-governmental service agreements (e.g. Between health, education, housing, employment, and social security)	3 (7%)	27 (63%)	12 (28%)
8.	More genuine consumer participation	6 (14%)	24 (56%)	13 (30%)
9.	Direct support for 'innovation', 'research' and 'service evaluation' in mental health	6 (14%)	27 (63%)	9 (21%)
10.	Introduction of specific schemes to enhance access to mental health specialists	10 (23%)	27 (63%)	5 (12%)
11.	More genuine carer participation	9 (21%)	18 (42%)	16 (37%)
12.	Support for enhanced role of non-government organisations in all aspects of care	6 (14%)	32 (74%)	5 (12%)
13.	Clear accountability for expenditure of mental health strategy funds	5 (12%)	30 (70%)	7 (16%)
14.	Specification of clear primary care and specialist workforce roles	7 (16%)	27 (63%)	8 (19%)

*Where numbers do not tally to 43 (100%), respondents have either responded "Don't know" or left the question blank.

Next, respondents rated the extent to which priorities have been implemented or supported within their STATE (Table 3.1.7.2).

Table 3.1.7.2: Implementation or support of priorities at a STATE level in the ACT; N=43.

		No action taken or no support N (%)*	Discussion and planning or low level support PLUS implementation begun or moderate support N (%)*	Nearly complete or high level support PLUS fully implemented or full support N (%)*
1.	Development of specific inter-governmental service agreements (e.g. between health, education, housing, employment, and social security)	7 (16%)	24 (56%)	11 (26%)
2.	Direct support for 'innovation', 'research' and 'service evaluation' in mental health	11 (26%)	26 (61%)	5 (12%)
3.	Introduction to specific schemes to enhance access to mental health specialists	10 (23%)	30 (70%)	2 (5%)
4.	Support for specific disease prevention initiatives (e.g. In anxiety, depression, alcohol or substance abuse)	8 (19%)	29 (67%)	5 (12%)
5	Support for general mental health promotion	8 (19%)	26 (61%)	8 (19%)
6.	Support for enhanced role of non-government organisations in all aspects of care	4 (9%)	31 (72%)	8 (19%)
7.	Clear accountability for expenditure of mental health strategy funds	8 (19%)	28 (65%)	7 (16%)
8.	Ongoing support for suicide prevention campaigns	10 (23%)	28 (65%)	4 (9%)
9.	Development of datasets for monitoring the quality of local services	5 (12%)	27 (63%)	11 (26%)
10.	Service development for those in forensic (i.e. prison-based) services	7 (16%)	31 (72%)	5 (12%)
11.	Specification of clear primary care and specialist workforces	8 (19%)	28 (65%)	6 (14%)
12.	Service enhancement for persons from culturally – and linguistically-diverse backgrounds	7 (16%)	29 (67%)	7 (16%)
13.	Support for community leadership in mental health	9 (21%)	24 (56%)	9 (21%)
14.	Support for professional leadership in mental health	10 (23%)	28 (65%)	5 (12%)
15.	Development of specific procedures for reporting Human Rights abuses or neglect	7 (16%)	28 (65%)	8 (19%)
16.	Increased support for stigma reduction campaigns	9 (21%)	28 (65%)	6 (14%)

*Where numbers do not tally to 43 (100%), respondents have either responded "Don't know" or left the question blank.

3.1.8 SURVEY ONE – NORTHERN TERRITORY

Table 3.1.8.1: Implementation or support for priorities at a LOCAL level in the NT; N=9.

		No action taken or no support N (%)*	Discussion and planning or low level support PLUS implementation begun or moderate support N (%)*	Nearly complete or high level support PLUS fully implemented or full support N (%)*
1.	Implementation of early intervention services	2 (22%)	6 (67%)	0 (0%)
2.	Development of innovative services for people with mental health and alcohol or substance abuse disorders	2 (22%)	5 (56%)	1 (11%)
3.	Development of a wider spectrum of acute and community-based care settings	4 (44%)	4 (44%)	1 (11%)
4.	Implementation of the national standards for mental health services	2 (22%)	6 (67%)	0 (0%)
5.	Programs that promote attitudinal change among mental health workers	2 (22%)	5 (56%)	1 (11%)
6.	Increased support for stigma reduction campaigns	4 (44%)	4 (44%)	0 (0%)
7.	Development of specific inter-governmental service agreements (e.g. Between health, education, housing, employment, and social security)	4 (44%)	3 (33%)	1 (11%)
8.	More genuine consumer participation	1 (11%)	7 (78%)	0 (0%)
9.	Direct support for 'innovation', 'research' and 'service evaluation' in mental health	5 (56%)	4 (44%)	0 (0%)
10.	Introduction of specific schemes to enhance access to mental health specialists	3 (33%)	6 (67%)	0 (0%)
11.	More genuine carer participation	2 (22%)	6 (67%)	0 (0%)
12.	Support for enhanced role of non-government organisations in all aspects of care	2 (22%)	5 (56%)	1 (11%)
13.	Clear accountability for expenditure of mental health strategy funds	5 (56%)	3 (33%)	0 (0%)
14.	Specification of clear primary care and specialist workforce roles	3 (33%)	6 (67%)	0 (0%)

*Where numbers do not tally to 9 (100%), respondents have either responded "Don't know" or left the question blank.

Next, respondents rated the extent to which priorities have been implemented or supported within their STATE (Table 3.1.8.2).

Table 3.1.8.2: Implementation or support of priorities at a STATE level in the NT; N=9.

		No action taken or no support N (%)*	Discussion and planning or low level support PLUS implementation begun or moderate support N (%)*	Nearly complete or high level support PLUS fully implemented or full support N (%)*
1.	Development of specific inter-governmental service agreements (e.g. between health, education, housing, employment, and social security)	4 (44%)	4 (44%)	0 (0%)
2.	Direct support for 'innovation', 'research' and 'service evaluation' in mental health	2 (22%)	7 (78%)	0 (0%)
3.	Introduction to specific schemes to enhance access to mental health specialists	5 (56%)	4 (44%)	0 (0%)
4.	Support for specific disease prevention initiatives (e.g. In anxiety, depression, alcohol or substance abuse)	3 (33%)	5 (56%)	0 (0%)
5	Support for general mental health promotion	3 (33%)	5 (56%)	0 (0%)
6.	Support for enhanced role of non-government organisations in all aspects of care	4 (44%)	4 (44%)	0 (0%)
7.	Clear accountability for expenditure of mental health strategy funds	5 (56%)	3 (33%)	0 (0%)
8.	Ongoing support for suicide prevention campaigns	5 (56%)	2 (22%)	1 (11%)
9.	Development of datasets for monitoring the quality of local services	3 (33%)	5 (56%)	1 (11%)
10.	Service development for those in forensic (i.e. prison-based) services	3 (33%)	5 (56%)	0 (0%)
11.	Specification of clear primary care and specialist workforces	5 (56%)	4 (44%)	0 (0%)
12.	Service enhancement for persons from culturally – and linguistically-diverse backgrounds	5 (56%)	2 (22%)	1 (11%)
13.	Support for community leadership in mental health	3 (33%)	5 (56%)	0 (0%)
14.	Support for professional leadership in mental health	4 (44%)	5 (56%)	0 (0%)
15.	Development of specific procedures for reporting Human Rights abuses or neglect	3 (33%)	5 (56%)	0 (0%)
16.	Increased support for stigma reduction campaigns	3 (33%)	4 (44%)	1 (11%)

*Where numbers do not tally to 9 (100%), respondents have either responded "Don't know" or left the question blank.

3.1.9 SURVEY ONE - TASMANIA

Table 3.1.9.1: Implementation or support for priorities at a LOCAL level in TAS; N=26.

		No action taken or no support N (%)*	Discussion and planning or low level support PLUS implementation begun or moderate support N (%)*	Nearly complete or high level support PLUS fully implemented or full support N (%)*
1.	Implementation of early intervention services	5 (19%)	19 (73%)	2 (8%)
2.	Development of innovative services for people with mental health and alcohol or substance abuse disorders	12 (46%)	13 (50%)	1 (4%)
3.	Development of a wider spectrum of acute and community-based care settings	6 (23%)	20 (77%)	0 (0%)
4.	Implementation of the national standards for mental health services	4 (15%)	18 (69%)	4 (15%)
5.	Programs that promote attitudinal change among mental health workers	9 (35%)	16 (62%)	1 (4%)
6.	Increased support for stigma reduction campaigns	9 (35%)	15 (58%)	2 (8%)
7.	Development of specific inter-governmental service agreements (e.g. Between health, education, housing, employment, and social security)	5 (19%)	20 (77%)	1 (4%)
8.	More genuine consumer participation	6 (23%)	15 (58%)	4 (15%)
9.	Direct support for 'innovation', 'research' and 'service evaluation' in mental health	11 (42%)	15 (58%)	0 (0%)
10.	Introduction of specific schemes to enhance access to mental health specialists	10 (39%)	15 (58%)	1 (4%)
11.	More genuine carer participation	3 (12%)	20 (77%)	3 (12%)
12.	Support for enhanced role of non-government organisations in all aspects of care	5 (19%)	19 (73%)	2 (8%)
13.	Clear accountability for expenditure of mental health strategy funds	7 (27%)	15 (58%)	4 (15%)
14.	Specification of clear primary care and specialist workforce roles	7 (27%)	16 (62%)	3 (12%)

*Where numbers do not tally to 26 (100%), respondents have either responded "Don't know" or left the question blank.

Next, respondents rated the extent to which priorities have been implemented or supported within their STATE (Table 3.1.9.2).

Table 3.1.9.2: Implementation or support of priorities at a STATE level in TAS; N=26.

		No action taken or no support N (%)*	Discussion and planning or low level support PLUS implementation begun or moderate support N (%)*	Nearly complete or high level support PLUS fully implemented or full support N (%)*
1.	Development of specific inter-governmental service agreements (e.g. between health, education, housing, employment, and social security)	2 (8%)	21 (81%)	2 (8%)
2.	Direct support for 'innovation', 'research' and 'service evaluation' in mental health	5 (19%)	20 (77%)	1 (4%)
3.	Introduction to specific schemes to enhance access to mental health specialists	10 (39%)	13 (50%)	3 (12%)
4.	Support for specific disease prevention initiatives (e.g. In anxiety, depression, alcohol or substance abuse)	9 (35%)	14 (54%)	3 (12%)
5	Support for general mental health promotion	7 (27%)	18 (69%)	1 (4%)
6.	Support for enhanced role of non-government organisations in all aspects of care	4 (15%)	21 (81%)	1 (4%)
7.	Clear accountability for expenditure of mental health strategy funds	8 (31%)	15 (58%)	3 (12%)
8.	Ongoing support for suicide prevention campaigns	4 (15%)	19 (73%)	3 (12%)
9.	Development of datasets for monitoring the quality of local services	3 (12%)	21 (81%)	2 (8%)
10.	Service development for those in forensic (i.e. prison-based) services	6 (23%)	18 (69%)	2 (8%)
11.	Specification of clear primary care and specialist workforces	4 (15%)	21 (81%)	0 (0%)
12.	Service enhancement for persons from culturally – and linguistically-diverse backgrounds	7 (27%)	17 (65%)	1 (4%)
13.	Support for community leadership in mental health	8 (31%)	16 (62%)	2 (8%)
14.	Support for professional leadership in mental health	6 (23%)	17 (65%)	3 (12%)
15.	Development of specific procedures for reporting Human Rights abuses or neglect	6 (23%)	19 (73%)	1 (4%)
16.	Increased support for stigma reduction campaigns	5 (19%)	18 (69%)	3 (12%)

*Where numbers do not tally to 26 (100%), respondents have either responded "Don't know" or left the question blank.

3.2 SURVEY TWO: CONSUMER AND CARER EXPERIENCES OF CARE

This survey mechanism introduced through the Mental Health Council in 2004, seeks to record ongoing experiences of care by those who actually use mental health services. It extends a framework initially developed in other areas of heath care to measure the quality of services provided (Hickie et al 2003). It is in marked contrast to the mechanisms currently used or even proposed by the responsible governments. It relies on actual experiences of care and is not simply limited to critical incident reporting or ad hoc surveys of consumer participation or satisfaction with services.

As of 2 November 2004, 228 complete surveys have been received, including 127 (56%) from consumers, 58 from carers (25%) and 43 (19%) from family members or close friends. All respondents had experience (either direct or indirect) with mental health services during the previous twelve months. Forty-one percent (n=94) had contact with public health services, 30% (n=69) with private health services, and the remaining 29% (n=65) a mixture of the two.

Eighty percent (n=182) of the sample was female with an average age of 41 years. The majority of respondents (67%) resided in major urban areas, with only 13% of the sample from rural areas with populations less than 10,000. Across Australia, most respondents were located in Victoria (31%) and New South Wales (31%; Table 3.2.1).

Table 3.2.1: Total number of respondents by state; N=228.

STATE	TOTAL NUMBER (%) OF RESPONDENTS
New South Wales	71 (31%)
Western Australia	20 (9%)
Victoria	71 (31%)
South Australia	14 (6%)
Queensland	30 (13%)
Australian Capital Territory	14 (6%)
Tasmania	6 (3%)
Northern Territory	2 (1%)

Only 57% of respondents (mostly consumers and carers) said they were treated with respect and dignity nearly always or always (Table 3.2.2).

Table 3.2.2: The extent to which health professionals treated the consumer or someone close to them with respect and dignity.

	CONSUMER	CARER	FAMILY MEMBER OR CLOSE FRIEND
N	127	58	43
Always	32%	26%	16%
Nearly always	34%	29%	19%
Sometimes	20%	33%	42%
Not often	10%	12%	21%
Never	4%	0%	2%

The majority (69%) felt they did not have adequate access to services (Table 3.2.3), with 20% not being able to find a health professional to talk to about their concerns.

Table 3.2.3: The extent to which access to adequate services for mental health problems was achieved.

	CONSUMER	CARER	FAMILY MEMBER OR CLOSE FRIEND
N	127	58	43
Always	14%	10%	0%
Nearly always	26%	15%	9%
Sometimes	25%	40%	26%
Not often	25%	26%	58%
Never	10%	9%	7%

Over one third (41%) of participants felt they were given insufficient or no information about the condition or treatment. Of those respondents who wanted information given to family and friends, more than half (99/165) felt that not enough information was given. In situations were medication was prescribed for the mental health problem, only 24% responded that the purpose, benefits and side-effects were fully explained (Table 3.2.4).

Table 3.2.4: The extent to which medications prescribed for a mental health problem was explained in terms of purpose, benefits and/or side effects; N = 215.

	CONSUMER	CARER	FAMILY MEMBER OR CLOSE FRIEND
N	119	57	39
Yes, definitely	31%	19%	8%
Yes, to some extent	23%	23%	15%
Yes, a little	25%	26%	33%
No	21%	32%	44%

Approximately one third of the sample (35%) said that the health professionals involved agreed always or nearly always with one another. Over one third (39%) did not feel they had enough say in decisions about care and treatment (Table 3.2.5), and 19% had not had the diagnosis discussed with them (17% of consumers, 10% of carers and 37% of family members or close friends).

Table 3.2.5: Whether the consumer, carer or family member/close friend felt they had enough say in decisions about care and treatment.

	CONSUMER	CARER	FAMILY MEMBER OR CLOSE FRIEND
N	127	58	43
Yes, definitely	38%	19%	0%
Yes, to some extent	36%	33%	37%
No	26%	48%	63%

Eighty-seven consumers answered more detailed questions regarding their care and treatment. The majority (86%) had seen a psychiatrist in the previous 12 months (see Table 3.2.6 for ratings), only 26% a community psychiatric nurse and 70% had seen some other mental health professional. All but six consumers had taken medications for mental health problems in the last 12 months and 66% had received a talking therapy. Half the consumers (50%) had an after hours contact in a mental health service, and of these people 60% had used this form of crisis care in the previous 12 months.

Table 3.2.6: Consumer ratings of psychiatrists they had seen in the last 12 months; (n=72).

	Psychiatrist listened carefully to you	You have trust and confidence in the psychiatrist	Psychiatrist treated you with respect and dignity	Given enough time to discuss condition and treatment
Yes, definitely	54%	40%	54%	29%
Yes, to some extent	28%	29%	35%	33%
No	18%	31%	11%	38%

Only five consumers (6%) had received a care plan, which is a document that outlines mental health needs and who will provide services. About one third (33%) of consumers rated the healthcare received in the last 12 months as poor to very poor, 30% as fair to good, and 37% as very good to excellent.

PART FOUR:
ANALYSIS OF ALL SUBMISSIONS AGAINST THE TOP TEN NATIONAL COMMUNITY PRIORITIES IN MENTAL HEALTH

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In April 2003, the Mental Health Council of Australia released its national review of mental health services in Australia '*Out of Hospital, Out of Mind!'* (Groom et al, 2003). This report highlighted deficiencies in care and developed a set of community priorities for further action.

The community priorities were derived through a national consultation process with individuals and organisations including consumers, carers, clinicians, service providers and administrators (for a description of this process see Hickie & Groom, 2004). The consultation process identified 26 potential areas for further action. A survey was developed and individuals and organisations were then asked to rank their top ten preferences 'for focussing activity over the next five years in mental health planning'.

The top ten priorities that emerged through this process were:

1. Implementation of early intervention services nationally;
2. Development of innovative services for persons with mental heath and alcohol or substance abuse disorders;
3. Development of a wider-spectrum of acute and community-based care settings;
4. Support for service development in rural and regional areas;
5. Implementation of national standards for mental health services;
6. Support for service development in poorly resourced areas;
7. Support for programs that promote attitudinal change among mental health workers;
8. Increased support for stigma reduction campaigns;
9. Development of specific inter-governmental service agreements (e.g. between health, education, housing, employment and social security); and
10. More genuine consumer participation at regional and local service levels.

The extent to which these priorities have been met provides a useful indication of the real impact of national mental health reform on the lives of those people who seek mental health care.

The surveys described in Part 3 suggest that people were generally of the view that the priorities were not being implemented.

The following extracts from the submissions and community consultations measure the experiences of those who use or provide care against these priorities.

> *I'm sick to death of inquiries, committees and the like who simply write and report, have a bit of fan fare and absolutely nothing changes. Oh let's write another policy. We don't need more policies. We need the one's we've got actually taken seriously and implanted and consequences for MHS and Staff and Directors who actually don't implant them.*
>
> (Consumer and Consumer Advocate, New South Wales, Submission #8)

4.1 PRIORITY 1: IMPLEMENTATION OF EARLY INTERVENTION STRATEGIES NATIONALLY

The submissions and presentations suggest that access to early intervention services is limited and that the community clearly recognises the need to extend access to these services. The comments relate to: (a) some of the highly regarded services specialising in the early stages of psychotic disorders and (b) the wider spectrum of services catering to depression, anxiety and substance-abuse related problems.

Mental health consumers and their families have commented on the contrast between mental health care, with its relative lack of provision of early intervention services, and the physical health care system. Providers of mental health care expressed frustration at the lack of administrative and financial support to develop early intervention services.

From the perspective of many of those who made submissions, the mental health care system seems to provide a palliative care rather than early intervention model of service. They suggest that only those who have reached the most severe or the most chronic forms of illness are prioritised for specialised or ongoing care.

> *What is acceptable about refusing to carry out early intervention until the person is 'acutely' unwell, which leads to a very distressing forceful intervention, then having to administer extremely strong dosages of medication which induce obvious physical side effects which take months to subside? …What is acceptable about not keeping people with a mental illness as well as they can possibly be, thus reaching and maintaining their full potential within the illness?*
>
> (Carer, Mother, Victoria, Submission #178)

> *Early intervention should focus on maintaining life skills and personality – trying to keep family supportive and involved – explaining to the patient exactly what their condition is, what treatments are to be tried and what side effects / benefits can be expected.*
>
> (Anonymous, Queensland, Submission #49)

> *Both consumers and carers reported that in the ACT it is almost impossible to get intervention or be listened to at an early stage when warning signs are initially beginning to appear.*
>
> (Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

> *Youth mental health services are disconnected and often staffed by people with limited or no experience in working with these client groups. At the moment there's no access to services at all – previously there was a 6-months waiting list – so the notion of early intervention or prevention doesn't exist for this community. We can't get staff with the right skills to this area. The situation is very poor and we rarely receive information about what's happening with services.*
>
> (Anonymous, Western Australia, Bunbury Forum #8)

> *All we are talking about now is more beds. We don't want more beds – we want a system of community based care. We want early intervention in the community. We have to move from talking to doing.*
>
> (Consumer Consultant, New South Wales, Parramatta Forum #9)

> *In our region people have the choice of living in the community and only have access to public hospitals when they become critically unwell. This leads to increased strain on family members who are coping with little support. Critical incidents can follow which feeds into community perceptions of people with a mental illness and setbacks the person with a mental illness. The alternative of earlier and timely interventions are desirable but seemingly not possible under the current funding and care model.*
>
> (Service Provider, Victoria, Submission #266)

> *We support a population health model, with its emphasis on promotion, prevention and early intervention in mental health. Many of our organisations believe that the Eastern Suburbs Mental Health Program is falling far short of achieving systematic and strategic approaches to early intervention, often failing to respond effectively or provide any service at all, on many occasions when consumers in our services are in need of proper assessment and timely intervention… We request the implementation of National Standards as they relate to early intervention and continuity of care.*
>
> (Eastern Area Interagency NSW, New South Wales, Submission #100)

There is a lack of resources to ensure good quality mental health care in NSW. Our son was unable to access early intervention and rehabilitation. Instead his condition was left to deteriorate, resulting in gross violations of his human rights on his imprisonment at Long Bay Hospital. His future prognosis has been compromised by the years of neglect by the system and his level of disability is worse that it would have been, had he received the treatment he required.

(Carers, Parents, New South Wales, Submission #75)

Depending on the nature, severity and urgency of the problem, other barriers may then come into play, such as "closed books", waiting lists, reluctance of specialist services to get involved (a mix of work practice and funding barriers) or the frightening and uninviting nature of such environments. This means that people typically present late in their illness course, and may be much less personally accessible and responsive to treatment. Treatment often gets off on the wrong foot and there is much collateral damage to repair.

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

A new model of integrated care linking adolescent and young adult psychiatry resources with substance abuse services and primary care for young people should be engineered and mainstreamed with educational, vocational, sports and leisure programs in key locations across all capital cities and regional centres.

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

National Mental Health Plan 2003-2008… Page 20 – "Outcome 9: Improved access to early intervention services." As discussed above, the reality is 'the system' does nothing unless the consumer is either psychotic, suicidal, or in some other emergency.

(Carer Advocate, Western Australia, Submission #339)

"To invest in the effective treatment of young people where mental health issues are a concern is of paramount importance. It can and does change the entire trajectory of an illness over a lifetime as so many studies have indicated. I'm sure this needs no debate." (Consumer contribution to Mental Health Coalition Council On-line forum).

(Consumer Advocate, Western Australia, Submission #338)

With regard to remote communities in Central and North West Queensland, further inadequacies become evident with the local mental health system insisting that an individual must present with a clinical diagnosis in order to receive any type of service intervention. This policy flies in the face of research and the National Mental Health Strategy which emphasis the need to provide interventions early and to prevent the actual incidence of mental illness. I have personally found it very difficult to make referrals to Queensland Mental Health service due to barriers within the system. Employees within state mental health cite lack of resources and difficulties attracting staff to remote areas for their inability to accept referrals.

(Clinician, Queensland, Submission #285)

During this time of trying to obtain help for my son, I received a phone call from someone from the clinic informing me that my son was discharged from the service. When I asked how this could be when it was on record that my son was most unwell and that I had been reporting this for some time, his answer was "That's how it is, there is nothing that you can do about it, but of course we will do something if and when he comes to our attention". In other words my bringing it to their attention was worthless, once again it would require my son behaving in such a way that would bring him to the attention of the police or perhaps something far worse happening.

(Carer, Mother, Victoria, Submission #178)

4.2 PRIORITY 2: DEVELOPMENT OF INNOVATIVE SERVICES FOR PERSONS WITH MENTAL HEALTH AND ALCOHOL OR SUBSTANCE ABUSE DISORDERS

In the submissions and consultations, the community clearly recognised that many people with mental health problems are at great risk of developing alcohol or other substance abuse disorders. The extent to which mental health services refuse to deal effectively with these common presentations of illness is seen as nonsensical and anachronistic. The impact of this system seems to fall disproportionately on young people.

Reports indicate that persons with comorbid mental health and substance abuse problems are commonly picked up by the criminal justice rather than the mental health system. Many feel that the chances of achieving reasonable personal, social or economic outcomes once young people have entered the criminal justice systems become markedly decreased.

Despite ongoing recommendations about co-management of these problems by both mental health and alcohol and drug services, there do not seem to be sufficient or effective service structures. Not only are inadequate resources devoted to the task but the negative attitudes of health care providers to such persons seems to have created further problems.

> *As the incidence of substance misuse is so high it is essential that mental health issues are addressed within this context. According to NT / SA Remote Mental Health team in 2002 half of their referrals also involved substance misuse.*
>
> (Anonymous, Northern Territory, Submission #271)

> *The key issues as I see them are the lack of support services available to young people with comorbid mental health and drug and alcohol problems … There is a lot of buck passing that goes on between mental health, justice and welfare departments. Ultimately these young people are primarily dealt with by the justice system. The other departments have failed them and they end up in trouble.*
>
> (Youth Advocacy worker, Queensland, Brisbane Forum #6)

> *I've been banging on doors and writing letters. My son became ill at 15, he's now 18 and in the justice system. They're not about rehabilitation, just containment. There are no facilities for people with mental health and drug and alcohol problems….you get worn out. You get fobbed off. There's like a blanket discrimination.*
>
> (Carer, Father, Northern Territory, Darwin Forum #3)

> *Where are the services for people suffering form a dual diagnosis (mental patients who use drugs / alcohol)? The drug services want mental health to assist these people. Mental health want the courts and prison system to deal with these people. And the Courts consider the issue to rest with Mental Health. Inevitably these people end up in prison, which seems to be the dumping ground for anyone with mental health issues and obviously this is not an appropriate place for them. There are not enough beds for mental health patients which means that the few beds available go to the "deserving few" – whatever that means, presumably it means those people who do not have a drug / alcohol problem.*
>
> (Anonymous, Western Australia, Submission #145)

> *Due to a lack of appropriate facilities for persons with mental health issues and substance abuse issues, many emergency accommodation hostels find themselves in the position of having to accommodate people with disabilities they are not resourced to care for appropriately. A large percentage of homeless persons have nowhere to go if not accommodated by hostels such as St. Bartholomew's.* (excerpt from Coroners Report, 2004)
>
> (St Bartholomew's House Inc, Western Australia, Submission #37)

We're also really concerned for those young people with comorbid mental health and drug and alcohol problems. Who picks them up? Nobody really, they get shifted back and forth because nobody wants to deal with them.

(Accommodation Service Provider, South Australia, Adelaide Forum #4)

When these individuals are refused to be scheduled on the basis of being affected by drugs or alcohol or if they are deemed to have behavioural disorders, they are being let down by the health system. Police then have only one avenue available to them in their duty of care, and that is to proceed by charge when inappropriate… In order to provide protection to the mentally ill person and the community, for example to stop further criminal acts, breaches of the peace and self-harming, police feel they have no alternative but to go around the mental health system who are currently not doing their job.

(Police Association of New South Wales, New South Wales, Submission #59)

My son [X] committed suicide 2 years ago – he was 26. He was extremely intelligent, creative and a good athlete. His story started when he was 17 and started smoking marijuana and became quite depressed. My husband and I encouraged him to go to the local mental health service - where he saw [Y] and was encouraged by [Y] not to "prostitute" his ideals or lifestyle choices. I also went to see [Y] separately (as did my husband) who more or less said it was none of my business - he's 17… Anyway – [my son] started drinking and smoking at the age of 21 (before that he didn't like alcohol) then of course problems began - with psychotic episodes where [my son] would become violent (have no recall of what happened and then have deep remorse) and we had to call the police - of course this was no use - it only made the spiral deeper and his self esteem lower.

(Carer, Mother, New South Wales, Submission #122)

My son is 19 and he has chronic schizophrenia and a drug abuse problem – he's been in the locked ward at Graylands for quite a while and I'm glad he's been locked up for that long because he can't cope outside the hospital. He lives with me and I worry about what will happen to him if he is released – he can't be accommodated anywhere and this is a human rights issue – there's unreasonable pressure on the family to provide care for really sick people like my son. But one of the big problems is how much people are charged to be in supported accommodation - 80% of a person's income for supported accommodation is too much because it just leaves enough for cigarettes. My son can't even get supported accommodation... These kids with comorbid problems like my son are becoming the new generation of homeless people.

(Carer, Mother, Western Australia, West Perth Forum #31)

Services are lacking to help consumers, of all ages, with combined drug addiction and mental illness. Drug and alcohol services and psychiatric services still work in isolation. This causes additional trauma to the sick person and families.

(ARAFMI Tasmania, Tasmania, Submission #245)

We believe that there should have been somewhere for [X] to be cared for ***safely and securely*** *while he was* ***stabilised*** *on the new drug regimen prescribed for his profoundly-depressed and suicidal condition.* ***Then*** *the Valium dependency could have been addressed. (author's emphasis)*

(Carer, Mother, Australian Capital Territory, Submission #288)

In all hospitals (four), supported accommodation facilities, and drug/alcohol services, there was failure to address the complex interaction between mental illness and substance abuse, with disastrous consequences. Integration of training, services, and philosophy between Mental Health and Drug & Alcohol Services should be a high priority!

(Carer, Mother, Victoria Submission #320)

Individuals who have a mental illness as well as a drug and alcohol problem are even more limited in their access to services. They face discrimination on both sides of the system. Drug and alcohol agencies are not set up to deal with issues of mental illness, and mental health agencies declare their work sites to be drug and alcohol free. People with a dual disability find themselves in a bind. There are services available that cater for them, but like most other organisations, they are under resourced and over burdened.

(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

4.3 PRIORITY 3: DEVELOPMENT OF A WIDER SPECTRUM OF ACUTE AND COMMUNITY-BASED CARE SETTINGS

As demand for acute care services increases and the cost of providing hospital services also rises, there is an urgent need to develop a range of service environments that provide appropriate alternatives to the most intensive forms of hospitalisation. Where there are insufficient alternatives, like stable housing or community-based clinical support, the pressure on acute hospital beds is exacerbated.

Over the last decade there has been a marked decline in hospital-based medium length stay and rehabilitation beds (National Mental Health Report 2004, Commonwealth Department of Health and Ageing, 2005). This has also contributed to increased pressure to discharge persons back to community-based care after relatively short periods in hospital.

A variety of complications may arise from premature discharge and inadequate community care, including early relapse, increased self-harm and increased pressure for readmission. The sense of a 'revolving door' system of care, rather than a coordinated spectrum of care was expressed strongly in many of the submissions.

There has been little or no realistic attempt to correct the lowering in the levels of acute beds across the state. In Victoria we not only closed the institutions but also substantially reduced the number of beds available for short term and acute admissions.

(Clinician, Victoria, Submission #123)

The move to community based services, while positive, has not been matched by attention to stratified and good quality accommodation options for persons with chronic mental illness who rarely can access supervised community accommodation. Disabled and disorganised patients flounder in unsupervised single accommodation, are cast onto the streets, or are involved in "revolving door" admissions to acute units, which are the only "accommodation" facilities remaining for them. A distressingly high number kill themselves.

(Public Sector Psychiatrists, New South Wales, Submission #297)

Supported and step down accommodation is desperately needed for clients requiring support after leaving acute care and for those people who have difficulty living by themselves or are too big a burden on their family members (often aged parents).

(ARAFMI Tasmania, Tasmania, Submission #245)

Consumers need a whole range of support systems not just 2 weeks or less in an inpatient service to then be dumped back into the community experiencing symptoms.

(Consumer Activist, New South Wales, Submission #257)

My son had schizophrenia… I'm a nurse and I understand why he wasn't kept in hospital – you can't just keep people like him in hospital. What he needed was a halfway house. We need more money spent on after care and pre care – something staged that people can access when they don't necessarily need to be in hospital.

(Carer, Mother, Queensland, Rockhampton Forum #9)

Currently there is no interim or step down facility in Alice Springs, although apparently there are plans to develop such a service. Currently the options are the acute ward in the hospital or being flown back to the community.

(Anonymous, Northern Territory, Submission #271)

The really sad thing is that people like my sister feel they are a burden on their families. There needs to be a place where they can go when they become unwell where they can get the care they need and the support they need. It's too late to wait until she is in a crisis for the system to respond to her – it's too late then! The support services that are in the community don't get the necessary increases in funding they need so they can't respond appropriately either.

(Carer, Victoria, Melbourne Forum #16)

Supported accommodation is in short supply. The Boarding House Reform program instigated by the NSW Government in 1996 has seemingly failed in its objectives. The standard care in those boarding houses remaining open is still poor and the number of beds available greatly reduced – where have all the previous residents gone? A lucky few were rehoused under the boarding house reform program into NGO run group homes. The bulk have possibly added to the majority of people accessing homeless shelters who have mental health problems, live on the streets or in unsupported private rental ghettoes. Seemingly no government department feels it is their responsibility to provide disability support and / or housing for people experiencing mental health problems…

(Clinician, New South Wales, Submission #197)

There is a consensus across human service agencies working with homeless young people with high and complex needs that the capacity of agencies to retain and work constructively with these clients needs to be developed. There is also a consensus that there is a need for a residential service that can manage and support these young people in extreme circumstances, as an alternative to hospitalisation or worse.

(Youth Affairs Council of South Australia, South Australia, Submission #38)

It is recognised that there is a need for sub-acute care services to be developed in the Northern Territory, to provide an alternative to hospitalisation and improve transition between inpatient and community care.

(Mental Health Program, Department of Health and Community Services, Northern Territory, Submission #259)

It is easier to recover from mental illness in hospital than at home. However, the average is about 3 days, and discharge from mental health care occurs far too early. Consumers have no option but to rely on hostels for accommodation, which cannot provide proper care or suitable environments for recovery.

(Consumer, South Australia, Submission #41)

When a patient is on a Community Treatment Order which has to be revoked because the patient has become unwell and in the absence of any intermediary facility requires hospitalisation. There is again often no bed available for them…

(Carer Advocate, Western Australia, Submission #339)

Lack of suitable accommodation (i.e. lower level care) following a stay in hospital is urgently needed to help the consumer adjust back to a normal life. The gap between hospital and normal life can be difficult to handle, and is of critical concern given that many patients are discharged prematurely.

(Peninsula Carers Council, Victoria, Submission #321)

Carers report that the current funding and provision of mental health care in WA is clearly inadequate to meet the level of need. This is demonstrated by: people unable to access community mental health services unless they are in crisis and are a threat to themselves or others; people presenting at hospital emergency departments requiring treatment for mental illness waiting in corridors as beds are not available in psychiatric hospitals; the lack of independent accommodation options for people with mental illness. There should be a range of options available and flexible to the individual needs of people with mental illness.

(Carers WA, Western Australia, Submission #277)

4.4 PRIORITY 4: SUPPORT FOR SERVICE DEVELOPMENT IN RURAL AND REGIONAL AREAS

Despite recognition by Commonwealth and State governments of the general difficulties faced by persons residing in rural and regional Australia, there was little sense that substantial improvements in mental health services were being achieved. There was, however, a sense that new services, or new policies or procedures, are being developed to give an impression that a service exists rather than to provide a real improvement in actual services. Submissions suggested that the emphasis was on providing an accessible point of contact, such as a new telephone triage service, rather than a real increase in access to actual services.

The submissions and consultations also suggest that the development of telepsychiatry services has had a marginal impact on access to specialist services. Neither government nor relevant professional bodies seem to be serious about addressing the tough issues of access to primary care and specialist services. On the other hand, increased emphasis appears to have been placed on securing appropriate transport to metropolitan services and ensuring the safety of staff, as opposed to consumers during this process. Consumers and carers continue to report inappropriate use of sedation and restraint for the purposes of transportation. It also seems that there has been greater use of police rather than ambulance services for transport of persons with mental illness.

We live in Devonport, 30,000 population. We have 1 psychiatrist at the service 1 day a week. It's not enough! They are beautiful people but they are under-resourced.

(Carer, Mother, Tasmania, Hobart Forum #15)

Of great concern is the attitude of Perth Metro area hospitals regarding the patients from the South West. Often the statements are we have "one of yours", our hospital is full of "your" patients and I was even told by a senior clinician that our patients were using up the beds in Perth funded by her tax money! There is a perception in the community and by the community mental health team that patients from the South West are discharged prematurely and without follow-up being arranged.

(Clinician, Western Australia, Submission #55)

The majority of medical services provided to these patients are provided by general practitioners. The provision of these services are largely unsupported and despite recent changes in the schedule are largely under funded for the time and resources needed to manage patients with long term mental health problems.

(Clinician in rural Victoria, Victoria, Submission #123)

The high levels of unemployment in Rockhampton contribute to the development of mental health problems. These people keep coming back and back but you see the deterioration – no support and no families – living in hostels.

(Anonymous, Queensland, Rockhampton Forum #17)

There is a lack of community outreach to rural areas and for specific programs such as child and adolescent, forensic. The focus is on inpatient care rather than community support.

(Anonymous, Tasmania, Submission #254)

…there has been ongoing debate regarding the mal-distribution of medical services in Australia… The majority of medical services have been concentrated in capital cities and major regional centres and have been quite limited in rural and remote areas. It has become increasingly difficult to recruit and retain general practitioners (GPs) in country areas and there is a long history of difficulties in the provision of specialist services outside large population centres. It is a fact that there are relatively few medical specialists living and working outside major regional centres… For example, in South Australia in 1997, only 1.1% of psychiatrists lived outside Adelaide.

(Clinician, South Australia, Submission #274)

There is a real need in Broken Hill for after hours care as there is not even a 1800 number that people can call to get assistance.

(Consumer, New South Wales, Broken Hill Forum #7)

Triage is a real problem in Broken Hill as there is constant confusion over who is responsible for assessment. This confusion makes it hard for consumers if they require immediate assistance… I have always presented to the hospital or to the mental health service but there seems to be no clear protocol amongst the staff about how to conduct an assessment when I am unwell. I have never been assessed by a psychiatrist and am normally assessed by the registrar on duty.

(Consumer, New South Wales, Broken Hill Forum #8)

You can't get care in the country. I travel 3.5 hours from the country to here (Melbourne) because I can get care… now I can't work because I need to travel down to here for care.

(Consumer Advocate, Victoria, VMIAC Forum #8)

In order to get an appointment with a psychiatrist I send my patients to Melbourne – but even this means about a 3 month wait.

(Clinician, Victoria, Morwell Forum #8)

The need is both dire and urgent, particularly on the South Coast of New South Wales. For persons with a mental illness the main issues are hospitalisation, rehabilitation places for persons leaving psychiatric hospital and not enough case workers. The closest hospital for acute treatment is at Chisholm Ross Hospital in Goulburn, a four to five hour trip from parts of the South Coast. Beds there are like hens teeth, accepting only the most acute cases; so with a degree of improvement, patients are discharged back into the community… Community resources are stretched to the maximum when a patient is required to be transported to Goulburn. This is costly in both money and workers time: such as police, local emergency hospital staff and community mental health workers. The South Coast is in desperate need. Money injected for projects now would both save lives, and save money in the long run.

(South Coast Mental Health Community Consultative Committee, New South Wales, Submission #244)

In the country you don't have a choice of psychiatrist, and there are no alternatives when it comes to what is available to help you. There is no therapy, little in the way of counselling and no choice but to do your own rehabilitation.

(Consumer, South Australia, Submission #77)

Human rights in regional and especially remote areas, are often infringed upon, because of lack of resources and very poor (if any) government funding. In fact in many areas services are being drastically reduced because of dramatic cuts in both Federal and State funding.

(Consumer Advocate, Queensland, Submission #16)

The Child and Adolescent Mental Health service in both Geraldton and Carnarvon has not been running for substantial periods of time over the past three years. This has left many children and adolescents at high risk of suicide. In Carnarvon a number of aboriginal adolescents have committed suicide.

(Clinician, Western Australia, Submission #333)

It is intended to fill the position with a person qualified in mental health. But one person doesn't make a team.
(Anonymous, Western Australia, Geraldton Forum #105)

4.5 PRIORITY 5: IMPLEMENTATION OF NATIONAL STANDARDS FOR MENTAL HEALTH SERVICES

The implementation of national standards for mental health services has been a top priority for the Mental Health Council of Australia and for most of the major national mental health non-government organisations. The most recent National Mental Health Report (2004) reported that less than half of the services had actually implemented the standards by the agreed date of June 2003. That date was some seven years after governments from all jurisdictions endorsed the National Standards for Mental Health Services (The Standards).

The key issue for users of services is whether the spirit of The Standards has translated to real effects on daily practices within the services. In the view of most mental health consumers, there are clear and ongoing examples of complete disregard for The Standards. While we have addressed these issues in detail elsewhere in the report, it is important to emphasise that this represents one of the major areas of non-compliance with the agreed implementation strategies of the second National Mental Health Plan (1998-2003). Universal implementation of The Standards, and ongoing monitoring of compliance, should be among the first steps towards any genuine commitment to improved quality and safety of specialist mental health services.

A major concern is the unwillingness of the hospital to initiate changes to organisational and clinical practices to meet standards set out by the National Standards for Mental Health (1996) based on the National Mental Health Policy (1992). (Excerpt from: Shanley (2001), Management of change in a psychiatric hospital using a 'bottom up'approach)
(Eamon Shanley, Professor of Mental Health Nursing, Western Australia, Submission #33)

At the same time the constant struggle to achieve best practice has been fraught with difficulties against a backdrop of increased accountability and devolution of administrative duties to clinical Staff. We have wonderful policies but no resources to implement them.
(Anonymous, Tasmania, Submission #254)

Mental health services are not implementing the National Standards for Mental Health Services and the Third Plan, despite government beliefs.
(Advocate, Australian Capital Territory, Canberra Forum #11)

There has been a failure to address issues identified by current Mental Health reporting. There has been no commitment to instigate long-term change when gaps have been identified. Lots of ideas – very little action.
(Anonymous, Tasmania, Submission #254)

The meeting agreed that an independent review of mental health services in the ACT against national service and workforce standards would be timely and merited.
(Mental Health Community Coalition Consumer and Carer Caucus,
Australian Capital Territory, Submission #342)

Australia's National Mental Health Strategy is in disarray and in urgent need of reform: in leadership, additional funding and delivery of services.
(SANE Australia, National, Submission #302)

Unfortunately, in more recent years positive change does not seem to have continued, and if anything, deterioration has taken place. Now, at least in Western Australia, there is a crisis in regard to provision of Mental Health Care within the community. (extract from a letter to Communications Manager, Mental Health Council of Australia)

(Clinician, Western Australia, Submission #24)

It is an unhealthy system that allows even a minority of its parts to operate in ways that are so hostile to its service users and against its own mandate.

(Health Consumers' Council WA, Western Australia, Submission #29)

The WA Office of Mental Health has established a Branch solely to examine reform and redesign issues, based on WA's Mental Health Strategic Plan 2004-08. Any action, however, will depend on the Gallop government which has been defensive and reluctant to commit itself seriously in this area.

(SANE Australia, National, Submission #302)

There are continuing problems in regard to the integration of the APU [Acute Psychiatric Unit] into the management structure of the Bunbury Regional Hospital. It is by no means clear that senior management staff have a good grasp of issues to do with mental health and psychiatric clinical service delivery. Despite principles of integration and mainstreaming there still is a tendency for psychiatry to be treated differently to other medical specialities… (extract from a letter to the Office of the Chief Psychiatrist)

(Clinician, Western Australia, Submission #24)

More money into mental health services will not make the difference without some changes to the fundamental assumptions that direct the current treatment paradigm.

(Health Consumers' Council WA, Western Australia, Submission #29)

Re-institutionalisation. The National Mental Health Strategy was launched in 1992 to transfer services from an institutional to a community setting. After 12 years, four of the five mainland States still have standalone psychiatric hospitals! These institutions continue to soak up around $420 million a year – 14% of the entire cost of mental health services of around $3 billion per annum. In several States, community-based services are being withdrawn onto hospital grounds to make short-term savings. Prisons are also becoming de facto psychiatric institutions – in NSW, for example, 46% of inmates at reception have a mental disorder, and the prevalence of psychosis is 30 times greater than the norm.

(SANE Australia, National, Submission #302)

[Report recommendation] Establishment of a National Mental Health Commission to monitor and report on effectiveness of mental health services.

(SANE Australia, National, Submission #302)

Despite welcoming the policy efforts and designated funding commitment of both state and federal governments, consumer agencies and community organisations are critical of their performance. It is argued that the failure of government to adequately resource its policy initiatives has lead to a chronic deterioration of care and support for mental health consumers. There is significant concern that because of the inability of services to provide preventative care this leads to delays and neglect in treatment, some of which creates irreversible damage in the mental health status of consumers. It also leads to an increased demand on an already overstretched mental health system.

(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

Both State and Federal Governments put considerable energy into devising lengthy and detailed mental health plans. Of what use are they if there is no funding with which to implement their recommendations? Human rights are not adequately addressed in these plans; there is no detailed documentation on accountability measures where rights are not upheld.

(Centre for Psychiatric Nursing Research and Practice, Victoria, Submission #323)

t may be timely to review the system – for many, it is complicated, convoluted and un-navigable with people seeking help being turned away, and falling through its cracks. There may be more effective, efficient, and user friendly ways of designing a mental health system.

(Australian Nursing Federation (Vic Branch), Victoria, Submission #322)

4.6 PRIORITY 6: SUPPORT FOR SERVICE DEVELOPMENT IN POORLY RESOURCED AREAS

On the basis of the submissions and presentations, it would appear that major areas of Australia have poorly resourced mental health services. This problem is commonly assumed to be confined to rural, remote or indigenous communities. In reality, many of the poorly resourced areas also lie in the outer suburbs of our major metropolitan or regional centres. Such areas typically have poor access to non-hospital based medical services, private hospital services and non-government service providers. Access to mental health specialists is often restricted in both the public and private sectors.

Difficulties in the distribution of specialist services have been long recognised by all levels of government and the relevant professional bodies but little substantial progress has been achieved. The under-resourcing spreads well beyond shortages in traditional hospital-based services and is particularly acute for many of the other community-based systems of clinical care or housing or welfare support.

Secondly in Australia, and notably in Melbourne, the distribution of public mental health services, private psychiatrists and high levels of quality primary care, is almost the direct inverse of the need for care. The affluent inner city areas have high levels of services of all kinds, while the growing or deprived outer suburban regions have minimal resources with inevitable consequences. The funding model was never valid and is now obsolete as well.

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

There's no crisis team in the area… There is differential access depending on which area you live in. For example, Fairfield, Camperdown and Bowral have no crisis assessment teams.

(Carer, Mother, New South Wales, Parramatta Forum #1)

The distribution of private psychiatrists … the practices of large numbers of private psychiatrists are concentrated in the capital cities. In Melbourne this situation is extreme. Within a fifteen kilometre radius of the Melbourne GPO can be found the highest concentration of private, practicing psychiatrists in the southern hemisphere and the second highest concentration in the world - second only to Manhattan, New York. The allowance of these capital city concentrations means that vast areas of Australia and thousands of people have virtually no access to psychiatry. This has to be seen as a demonstration of gross inequity given the fact medical undergraduate education and post-graduate psychiatric training are subsidized to such a high degree by tax payers.

(Anonymous, Victoria, Submission #318)

We only have one inpatient facility for the region – people of a low socio economic background find it very difficult to travel long distances to get care.

(Clinician, Victoria, Morwell Forum #11)

We have discovered that often the only way to access good mental health treatment in NSW is by constant hard lobbying by family or carers. The consequence of this is that adequate mental health care is frequently out of the reach of people from aboriginal and ethnic backgrounds, and those from lower socioeconomic areas.

(Carers, Parents, New South Wales, Submission #75)

There are not enough nurses, social workers and psychiatrists in the country where as in the city there are more. However, even in the city staffing in the mental illness field is less than satisfactory.

(Consumer, South Australia, Submission #77)

My son (33) has severe schizophrenia. We are from the North West Coast and we have a real lack of services, accommodation. There is nowhere that my son can go apart from home. There is a lack of rehab and recreational services. I see people going into hospital and then coming out but no support in community so they end up back in hospital. There is nothing for him to do to keep him occupied.

(Carer, Mother, Tasmania, Hobart Forum #15)

The resources need to be outsourced from the hospital. We need respite care, prevention education for the communities, it's too chemical.

(Anonymous, Northern Territory, Alice Springs Forum #21)

Follow up is then provided by a visiting psychiatrist and two community case managers who are funded to cover the entire southern area of NT and SA. This means that the focus of the service can only be crisis management at best. The ability for workers to provide ongoing support or any meaningful individual case planning is significantly impaired. Generally the workers will average a trip once a month to the region, which means even the larger communities may not see a worker for several months. The level of service is purely resource, rather than need, driven.

(Anonymous, Northern Territory, Submission #271)

The issues relevant to indigenous physical health outcomes are well documented. With the ongoing critical physical health needs of the community, staff are already at full capacity. In this context issues of mental health cannot be prioritised, unless there is an acute need for treatment.

(Anonymous, Northern Territory, Submission #271)

People have to drive 5 hours to get counselling. There are some acute fly-in services but these are highly medicalised. Access to acute services requires either a flight into Alice or to Perth. Often if they are taken they are then sent out – that's it.

(Anonymous, Northern Territory, Alice Springs Forum #10)

As people are often evacuated, without the support of family, relatives may have no contact with the treating team. They may not be given information or able to provide information to the treating team. If a person is admitted to hospital for a period of time the costs associated with family visits are prohibitive. In communities diesel can be up to $1.60 / litre, which means that doing 1000km round trips is beyond the capabilities of most. There is no public transport available on NPY Lands. This leads to extreme distress within families and communities. It also needs to be noted that due to the high level of chronic ill health within communities the burden on carers within families is often very high. Therefore it is important that health professional do not make assumptions about the level of family support available when making discharge plans.

(Anonymous, Northern Territory, Submission #271)

Our area has 12% of the population but receives 6% of the funding. We don't have anywhere near enough resources, enough staff or enough beds! We don't even have enough basic services!

(Carer, Mother, New South Wales, Parramatta Forum #1)

If the metro is $118 and Geraldton is $70 per capita, I would think that Dongara would be about $1.50 / capita… There is a lack of support for carers and acute clients.

(Anonymous, Western Australia, Geraldton Forum #108)

[Z], the other psychiatrist also contributing to the current roster, is reluctant to continue feeling that the role is not well supported and lacks parity with metropolitan arrangements. (extract from a letter to the Office of the Chief Psychiatrist)

(Clinician, Western Australia, Submission #24)

Transportation in regional areas is a real problem as many seriously ill patients have to go to Orange with the Royal Flying Doctors Service but then they have to make their own way home. Some people in Bourke have even been sent from Bourke to Orange in police cars.

(NGO worker, New South Wales, Broken Hill Forum #26)

4.7 PRIORITY 7: SUPPORT FOR PROGRAMS THAT PROMOTE ATTITUDINAL CHANGE AMONG MENTAL HEALTH WORKERS

Issues related to stigma and discrimination are still evident in many submissions and presentations and hence high on the community agenda. Within that broad agenda, however, the need for changes in the attitudes of health care providers are a high priority for users of the services. Accounts of highly negative, dismissive or stigmatising remarks by health staff towards persons with mental illness are still too common. Additionally, family members often feel discounted or ignored by health workers, even though they are expected to contribute greatly to ongoing care. Thus, while some attention has been directed to this issue in the past, it seems that there is little evidence now of a systematic response to inappropriate behaviour by mental health professionals.

It has been the experience of the VMIAC [Victorian Mental Illness Awareness Council] that more often than not, if you ask consumers if they could wave a magic wand and change something about the mental health system what would they change? The attitude of health professionals is the most frequent answer followed by access to services.

(Victorian Mental Illness Awareness Council, Victoria, Submission #332)

Many young people in the focus groups described their first experiences with health professionals and authority figures as unpleasant, frightening, coercive and humiliating, which subsequently had a profound effect on their attitudes to future dealings with health professionals. Young people said: …It broke my spirit… Humiliation… It took away my rights…

(NSW Association for Adolescent Health, New South Wales, Submission #98)

Prosperity and pleasantness are common causalities of severe mental illness. One would hope that psychiatrists, of all people, could accept this but like most doctors, psychiatrists rarely show enthusiasm for, or understanding of, patients who are neither cashed up nor personable.

(Clinician, Queensland, Submission #49)

Apart from the crucial issue of ease of local communal access, appropriate crisis and community care depends more on team attitudes than the site of services. But there is a widespread international consensus that it is much easier to generate and maintain the appropriate attitudes on a community site, rather than a hospital based site.

(Clinician, New South Wales, Submission #351)

The staff treating depressed inpatients should be educated about the potential adverse effect of negative comments on the patient's mental state. Education to staff that persons who attempt suicide can and do later succeed in suicide should be undertaken. (excerpt from a report prepared by an independent external reviewer)

(Carers, Parents, Australian Capital Territory, Submission #354)

In many settings there appears to be no multi-disciplinary approach to care, and in some cases, the seeking of care can be further stigmatised by the attitudes of the treating mental health care professionals.

(blueVoices, National, Submission #355)

Money alone can't buy service improvement… service provider "attitudes" can be a make or break factor. It emerged that many of these Consumer Consultants were often more immediately concerned and affected by the many ways that the cultures and environments of mental health services could be a supporting factor for consumer participation efforts, or the source of difficult and frustrating barriers. ***"Attitudes"*** *of service provider staff and managers towards consumers and receptivity to change were seen by some stakeholders as an important factor influencing outcomes. Consumer consultants spoke about a wide range of experiences at their local Area Mental health Services. (author's emphasis)*

(Consumer Advocate, Victoria, Submission #253)

Feedback we receive from people with a diagnosis of Personality Disorder suggest that they are being treated badly by staff (e.g., staff are irritable towards them, their concerns being dismissed as part of their illness, they are characterised as manipulative)… We request that the MHS considers conducting an evaluation to determine how people with a diagnosis of Personality Disorder experience ESMHP [Eastern Suburbs Mental Health Program] services, and address staff attitudes towards these consumers.

(Eastern Area Interagency NSW, New South Wales, Submission #100)

One day I asked [my psychiatrist] whether he had any patients with Borderline. He said he didn't like using that label because it brought such terrible consequences for people but, yes, he did see quite a lot of people who would fit into that category. I asked him what the treatment was and his immediate answer was to say, "the first thing I do is treat them nicely! This is a new experience for most of them".

(Consumer, New South Wales, Submission #327)

People, who doctors have decided have a 'personality disorder' are treated in the public system like [they] are not even human half the time – like dirt. My friend calls us ground feeders – we just pick up scraps of services that everyone else has discarded. How do we stop professionals judging us so badly?

(Consumer, New South Wales, Submission #205)

Better training for people working in mental health so there is not the "patronising put down" attitude that I have witnessed… An inclusive attitude for carers and families - where they are listened to and really heard and consulted more closely.

(Carers, Parents, Victoria, Submission #241)

Police need to have more MH [mental health] education / training. Ditto for Accident & Emergency staff including medical heads of dept about personality disordered people in crisis. I was told personally by a medical head of DEM [Department of Emergency Medicine] that 'they're arseholes' . So imagine the working culture if that view is held at the top.

(ARAFMI Hobart, Tasmania Submission #214)

At best, the mental health professionals we dealt with were genuinely concerned but were seemingly powerless within the system. At worst they were arrogant, inconsistent, disrespectful and uncaring. Above all, the mental health system failed to provide [X] with hope. Mental illness should not be terminal, and he wasn't beyond help.

(Anonymous, Australian Capital Territory, Submission #288)

I can understand how there are so many suicides in our community. Any hope for a normal life is minimal. Not only is the welfare of these people ignored there is positive discrimination against any progress they might want to make. More understanding and education is needed. The last government (and only) education campaign fell far below the mark required. Mental health sufferers need long term care and understanding. Not only by the general population but also (and more so) by the health industry and government.

(Carer, Western Australia, Submission #163)

4.8 PRIORITY 8: INCREASED SUPPORT FOR STIGMA REDUCTION CAMPAIGNS

General community attitudes towards persons with mental illness are difficult to change. Daily experiences of stigma and discrimination were reported repeatedly in the submissions and consultations. There was recognition that some progress had been made, particularly with regard to the non-psychotic disorders of depression and anxiety. However, consumers, carers and community groups reported that community attitudes towards persons with psychosis or substance abuse were still very negative. More importantly, it was also reported that little had been done in terms of planned and well-resourced community education programs. Community groups have argued for renewed efforts in this area as they are considered critical to achieving genuine social and vocational opportunity and recovery from mental illness.

Need to be aiming at inclusion not exclusion – I know of people who are banned from coming into shops because they have a mental illness. The stigma in our communities is still very bad. People are treated differently, badly because they have a mental illness.

(Carer, New South Wales, Sydney Forum #13)

A cousin who worked for the blue nurses in NSW was looking for work. She couldn't get work any more because of her mental illness and she ended up killing herself.

(Anonymous, Queensland, Rockhampton Forum #5)

[A] young man went off to have a cappuccino, and came back so quickly that [Y] asked him why and he told her that they'd said "Come back when there's no one here." That wouldn't happen there now, as a result of the Kew Regional Outreach Ministry.

(Carer, Mother, Victoria, Submission #211)

The belief exists that people with mental illness are inferior citizens who are best confined to certain areas, if not buildings, because they "would be happier there" and other citizens have a right not to be even mildly bothered by them. In fact people want them out of sight so that they do not have to deal with the reality of their existence.

(Carer, Australian Capital Territory, Submission #173)

Social isolation & loneliness are guaranteed triggers of episodes of mental illness, substance abuse, self harm & suicide. This happens, and it happens all the time. And in rural and isolated communities, where resources are even more scarce, the problems are much worse.

(Consumer Advocate, New South Wales, Submission #153)

It is scandalous and a national disgrace that there is no significant commitment by governments and the prevalence of community unawareness and apathy. There has to be a national campaign similar to that for AIDS if mental health is to successfully obtain government support etc.

(Carer, Son, New South Wales, Submission #120)

On one occasion when my son was ill he frightened some people in the town and when he was in hospital I put an advertisement in the paper to thank the police for their help but also to try to educate the community that he had received treatment and was not a threat to them. It didn't really help.

(Carer, South Australia, Murray Bridge Forum #10)

Finally I have lost some friends because they could not accept or cope with my mental illness. My new friends have their own mental illness and we meet to socialise and support each other but not in an integrated community way.

(Consumer, South Australia, Submission #77)

In respect to employment a person can have extended sick leave for a physical ailment or condition but if mentally ill it may be impossible to return to work. A period of mental illness is not looked on favourably by an employer. Applying for work knowing one has been mentally ill for ten years as is the case for me is exceedingly difficult because of stigma. It is assumed I cannot cope with daily life but if I had a broken leg or a bad heart no one would judge me in relation to coping with daily life let alone work. I don't have the right of a job or the right to suffer an illness without bias.

(Consumer, South Australia, Submission #77)

In my opinion there is considerable stigma attached to being mentally ill. The media often reports on certain mentally ill people as being dangerous and frightening. My mentally ill friends and myself are nether dangerous or frightening. Our society expects that people get physically sick but if a person becomes mentally ill for a time they are told unkindly to pull their self together. No understanding is entered into.

(Consumer, South Australia, Submission #77)

Stigma is a persistent issue in the NT. Some of the local media have repeatedly reported on anti-social behaviour by Aboriginal and Torres Strait Island people with mental illness in a way which blames those affected, rather than relate this to symptoms and lack of treatment, as they would with any other illness.

(SANE Australia, National, Submission #302)

There is a complete lack of understanding in the community that people may be able to function in some parts of their lives and not in others, or they may well for some part of the day / week / year and not others. This lack of understanding leads to unjustified criticism and discrimination.

(Carer, ACT, Submission #173)

The family never rings, or visit even though he has asked them to do so. Their excuse is that they are frightened.

(Carer, Father, Australian Capital Territory, Submission #208)

Community attitudes need to change, to move away from a fear of 'madness' and accept that mental illness is a common and serious condition, which has the capacity to ruin many lives if unacknowledged and untreated.

(Carer, Wife & Mother, Queensland, Submission #157)

Our research has proven to us that the root cause of inequity and social injustice is stigma. Therefore, as a society we need to continue with public awareness and education and to demonstrate our intolerance of stigma and discrimination in the workplace, the schoolyard and our health care system.

(blueVoices, National, Submission #355)

Human rights violations in mental health in Australia occur not just because of a few rotten apples in the barrel, or because of inadequate resources. Human rights violations are systemic and deeply embedded in how Australia responds to mental health. First, in the broader community, the stigma that surrounds mental health has to be seen as a deeply entrenched discrimination against madness that requires sustained, constructive measures to overcome. A clear and strong voice from consumer-survivors, in their own language, will be essential to this task. Second, within existing mental health services, this stigma and other discriminatory prejudices and practices are intrinsic to these services and central to the systemic human rights violations. Without a major overhaul of how we approach mental health, more resources will only further entrench and possibly worsen the current human rights abuses of mental health consumer and survivors.

(Insane Australia, Victoria, Submission #232)

At a public level, the association of violence and aggression with mental illness must be challenged whenever it appears. The public must be made aware that such violence is an exception, and that people who do have a psychiatric illness are much more likely to be on the receiving end of it rather than to be the perpetrators. All people with a psychiatric illness suffer at some level by the misperception that is created by sensationalist media reporting.

(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

4.9 PRIORITY 9: DEVELOPMENT OF SPECIFIC INTER-GOVERNMENTAL SERVICE AGREEMENTS (E.G. BETWEEN HEALTH, EDUCATION, HOUSING, EMPLOYMENT AND SOCIAL SECURITY)

Many submissions and presentations suggest that inter-government service coordination is poor. Mental health consumers report that the system is chaotic, disorganised and unresponsive to their wide range of needs.

To achieve a genuine improvement in health, social, welfare and emergency services, there is a clear need to identify the role and responsibilities of multiple government agencies. Unless clear inter-government agreements are in place and acted upon, there is little chance of on-the-ground service cooperation or coordination.

People living with a mental health problem are one of the most acutely disadvantaged groups in Australia. They are more likely to be living in poverty, with limited access to affordable and secure accommodation, to have low education and to be without employment. The ability of consumers to access service systems across the spectrum of care demands that government urgently increase their investment into services.

(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

The overwhelming conclusion from this research is the urgent need for an increased range and supply of support services to assist people with serious mental illness and their families to live successfully in the community. Deinstitutionalisation has not failed. What has failed is the political will to fund essential support services in the community… Ultimately, it is a failure of systems which is making people sick and forcing them into the costly acute care sector.

(Anglicare Tasmania, "Thin Ice: Living with Serious Mental Illness and Poverty in Tasmania", Tasmania, Submission #144)

In viewing health as indigenous people do, in holistic terms, it is impossible to overlook the enormous influence social factors have on the mental health of the people of Western Queensland. Poverty, inadequate housing and isolation rank high in the list of challenges to people's general health and well-being… Mental Health services which insist on providing individualized, clinical services cannot hope to be effective without also addressing the collective, environmental influences on mental health.

(Clinician, Queensland, Submission #285)

Many problems arise from the systems stasis of Mental Health, Social Security, Corrections, and Social Services, i.e. they serve the system, not the community, and as such constrain the development of appropriate, diverse, flexible and voluntary services and the growth of good relationships between staff, patients and people close to patients. Policy, political and societal will is as important as legislation here.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

We just don't have the resources to support these kids so the schools call the police. Yes we have other avenues, other services but how do we access these – the waiting lists are sometimes 18 months. These kids do not complete their education and they end up in a life of trouble – a horrendous situation – we have the mandate to keep the schools safe – but it's too hard.

(Teacher, South Australia, Murray Bridge Forum #17)

There are more fundamental issues that bear on mental health and mental health problems; there are issues around the priority given to mental health by all the human service and related systems. For example, look at the training of general nurses, and of the many of the specialities in medicine. In many of the latter mental health is critically important yet mental health does not feature in the training programmes, I am thinking especially of physicians and paediatricians. But there are others. The same could be said of lawyers and

police. Some of the most intractable problems I have found in caring for some young adults with mental illness are the way the justice system and police have treated them, and other systems like housing and income support.

(Anonymous, New South Wales, Submission #125)

The research uncovered a disturbing cycle of poverty and ill-health for many people with serious mental illness in Tasmania. Participants reported patterns of unstable housing, food insecurity, with a heavy reliance on emergency relief agencies, inadequate clothing, and regular disconnections from essentials such as telephones and electricity. Access to services such as general practitioners, the public dental service and public transport is made difficult by issues of cost. Without adequate support in the community to manage their accommodation, their finances and the tasks of everyday living, many found the stress of trying to survive alone exacerbated the symptoms of their illness, often resulting in relapse and re-hospitalisation.

(Anglicare Tasmania, "Thin Ice: Living with Serious Mental Illness and Poverty in Tasmania", Tasmania, Submission #144)

Collaborative service agreements between sectors that respond to the needs of people with dual diagnosis are required.

(Brain Injury Association of Queensland, Queensland, Submission #60)

Another thing I want to raise is the trauma and violence inflicted on carers and negotiating the systems such as Centrelink is extremely hard. This is not being recognised in the system. I have just been working with a Grandma who has been fighting for custody of her grandchild. She has no money and no support. We need a system to support these people who provide the care.

(Consumer, Victoria, Footscray Forum #6)

The closure of long term residential care beds in institutions, and the transfer of responsibility for care to families, has not been accompanied by the development and implementation of appropriate legislation and support for families to enable them to continue to care without severe emotional and financial distress.

(NSWCAG, New South Wales, Submission #273)

A new system of vocational recovery programs within public sector mental health / substance use services should be developed in conjunction with the Commonwealth and the business sector.

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

People with a psychiatric disability are on of the most disadvantaged groups in the labour market with an unemployment rate of 72% compared to a national rate of 5.7% (Australian Bureau of Statistics, 2001). These statistics reflect the enormous barriers people with a psychiatric disability face in gaining and keeping work. It also demonstrates that existing workplaces and employment agencies are clearly struggling to provide adequate support for this group.

(Disability Employment Action Centre, Victoria, Submission #209)

People with mental health concerns, or maybe dilemmas, who attempt to recreate or regain their lives through training and study are currently not given the support they need to do this adequately. Student support services are not able to adequately meet student's needs independently…

(Support and Equity Services, Charles Darwin University, Northern Territory, Submission #269)

One of the richest sources of expertise, in many districts helping with the recognition of depression and psychosis, the Aged Care Assessment Services, cannot intervene past the point of assessment. They are also poorly integrated with State-funded agencies in many instances.

(Clinician, Queensland, Submission #140)

4.10 PRIORITY 10: MORE GENUINE CONSUMER PARTICIPATION AT REGIONAL AND LOCAL SERVICE LEVELS

While the National Mental Health Policy places strong emphasis on the key roles of consumer and carer participation, it seems there is still a long way to go before such participation actually influences patterns of local service delivery. The impediments to this process appear to be both attitudinal as well as resource constraints. Traditional medical services appear to struggle to develop genuine service provider-consumer partnerships.

Mental health consumers are the great hope for the reform of mental health services in this state and no doubt elsewhere. … [U]ntil the users of mental health services are brought into the centre of the service delivery culture, there will be no change for the better. Consumer participation in meaningful and robust ways, will be the singlemost important accountability mechanism that will improve the safety and quality of mental health services in this state…

(Health Consumers' Council WA, Western Australia, Submission #29)

Many of these volunteers report that their time on these bodies was, at best, a complete waste but, more often, that they felt cheated and ripped-off – their contributions were rarely heard and virtually never acted upon.

(Insane Australia, Victoria, Submission #232)

It is still the case that dominant groups decide for consumers what kind of services should be provided, if any, without any meaningful consultations and when consumers are quite able to speak for themselves. This leads to a situation such as we have in Tasmania where consumers feel excluded and their different needs are overlooked or even worse dismissed. The anger and grief that results from such indifference then surfaces and very often labelling of those who complain then occurs.

(Anonymous, Tasmania, Submission #254)

There is a perception among consumers that more time and opportunities are given to consumers who are well, literate and not experiencing co-occurring disorders. Another concern is that consultation tends to focus on surveys, suggestion boxes and complaint forms.

(Anonymous, Tasmania, Submission #290)

Families are fed up. They've told their stories over and over again. What assurance can I give them that this will be any different. We simply tell our stories yet again and nothing gets done to address the problem.

(Carer, New South Wales, Parramatta Forum #1)

One of the problems with consumer employment and consumer advocates is the vast dearth of an actual skills base. As a trainer in consumer advocacy for a state organisation, I constantly talk to consumers whose only criteria for having been employed in a consumer position is the fact they're a consumer. Even though some consumers are more sensitive to the situations that many consumers find themselves in – training is a must and understanding the very, very specific role of consumer advocacy is imperative.

(Consumer and Consumer Advocate, New South Wales, Submission #8)

There's a need for a rural consultation in areas like Port Augusta… There's also a need for consumers, carers etc to be heard and to be supported with funding.

(Advocate, South Australia, Adelaide Forum #15)

There are many consumer advocates employed here in WA but the attitude is one of extreme paternalism by the office for mental health - when consumer advocates speak up and their position is in any way critical of the Government or the system, they are classed as being unwell.

(Consumer advocate, Western Australia, West Perth Forum #28)

Perhaps the greatest disconnection has occurred between the consumers, the providers and the decision makers. Consumers are no longer being consulted about their needs here.

(Clinician, Western Australia, Bunbury Forum #15)

I am constantly amazed at how many people in the community have experienced difficulties with the service over the years and it continues unabated, theirs and my constant frustration that nothing changes and that the treatment of consumers and carers remains poor. We have brought many issues up and were tired of our own voices and frustrations; we each have our own stories it just goes on…

(Anonymous, Queensland, Submission #113)

Consumers and carers continue to be largely denied effective participation in both their personal treatment and in the development of effective service delivery systems.

(Clinician, South Australia, Submission #56)

There is considerable support and some would say a growing "critical mass" of support, commitment and goodwill toward consumer participation among many service provider managers and staff and some genuine attempts to work in partnership and collaboration with consumers – as well as some quite entrenched pockets of doubts, resistance and "hangovers" from the institutional attitudes and approaches in some areas.

(Consumer Advocate, Victoria, Submission #253*)*

While some organisations appear to be genuinely committed to consumer participation, anecdotal reports from consumer consultants and consumer representatives persistently and consistently indicate that the attitudes of many service providers, managers and bureaucrats are that consumer participation exists because it has to rather than it needs to.

(VMIAC, Victoria, Submission #332)

This is the 4th community forum / report for mental health services in the NT – we are exposing ourselves.

(Carer, Mother, Northern Territory, Darwin Forum #2)

I have had an ongoing discussion with SANE about what I see as the invisibility of BPD [Borderline Personality Disorder] on their website and in their publications… on the Fact Sheet for BPD there is no emphasis on distress; rather, the whole emphasis is on people learning to manage their behaviour successfully. I hate this. The behaviour is as a result of something. It doesn't just jump out from nowhere. This is grossly unfair and judgemental.

(Consumer, Advocate, Victoria, Submission #166)

PART FIVE:
ANALYSIS OF ALL SUBMISSIONS AGAINST THE NATIONAL STANDARDS FOR MENTAL HEALTH SERVICES

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It was agreed by the MHCA, BMRI and HREOC, that the most useful framework for organising the vast amount of written and verbal data collected through the consultation process, was the *National Standards for Mental Health Services* (the Standards; see Appendix 8.7).

The information in this Part 5, and in Part 6, comes from the submissions and public consultations. The information represents a persuasive cumulation of personal experiences but it is not intended to suggest definitive proof or disproof of the implementation of the Standards. The data is analysed according to State and Territory (Parts 6.1-6.8), and then nationally (Part 6.9) for submissions received from national organisations.

In this section (Part 5), we summarise those common themes and provide a small sample of quotes that highlight personal experiences relevant to each Standard. The volume and consistency of the information gathered through this process demonstrates the gaps and the difficulties governments have had across Australia in meeting these Standards.

5.1 STANDARD 1: RIGHTS

The rights of people affected by mental disorders and/or mental health problems are upheld by the Mental Health Service (MHS).

Standard 1 is designed to generally promote and protect the rights of people with mental illness. The Standard is broken down into specific components which set out the criteria for meeting this principle in more detail (see Appendix 8.7).

There was universal concern about the implementation of this Standard across Australia. The concerns (see list below) indicate the continuing vulnerability of people with mental illness, continued exposure to abuse and a lack of access to complaints procedures to identify systemic failures and provide personal redress.

Carers and service providers noted flaws with complaints procedures that resulted in consumers and carers being afraid to lodge complaints. They described fears of retribution and withdrawal of services. Carers who had lodged complaints also felt that they were being 'fobbed off'.

There were also reports that mental health consumers were not being treated with dignity or respect. Experiences ranged from humiliating and degrading treatment in hospital settings to forced interactions with the police. Consumers and carers said that they were not being provided with information about their illness and treatment choices. They also complained that they were frequently denied the right to have others, such as carers and advocates, involved in their care.

Consumers from a Non-English Speaking Background (NESB) reported a denial of access to interpreters by services, which led to difficulties in accessing appropriate treatment and support services.

Another key area of concern was the protection of the rights of one of the most vulnerable groups of consumers - people with mental illness in the criminal justice system. This is a critical issue, given the rising rate of incarceration of people with mental illness (often due to the inability of consumers to access treatment and support services when needed).

In summary, the key issues relating to this Standard, across Australia, include:

- Consumers and their carers are not being provided with information about their rights (Standards 1.2, 1.3, 1.4)
- Consumers and their carers are not being provided with information about available mental health services, mental illness and available treatment and support services (Standard 1.8)
- Consumers from a NESB and their carers are not being provided with accessible information about available mental health services, mental illness and available treatment and support services and how to access them (Standards 1.7 and 1.8)
- Consumers are not being treated with dignity and respect (Standards 1.1 and 1.4)
- Lack of access to interpreters (Standard 1.7)
- Lack of access to advocates (Standard 1.6)
- Problems with complaints procedures (Standard 1.10)
- General failure to protect consumers rights (Standard 1.1)
- Denial of a consumer's right to have others involved in their care (Standards 1.5 and 1.6)
- Staff and services are not complying with relevant legislation, regulations and instruments protecting the rights of people with mental illness (Standard 1.1)
- Concern about the rights of people with mental illness in the criminal justice system (Standards 1.1 and 1.4)
- Concern about Ministerial discretion and the rights of people with mental illness (Standard 1.1)

The following selected quotes from community forums and submissions describe people's recent experiences of mental health services in the context of Standard 1. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Consumers and their carers not being provided with information about their rights

Failure to inform consumers of their rights. The recent review of the Mental Health Act 1996 revealed continued resistance amongst mental health workers to the philosophy and practice of informing mental health consumers of their rights, including review of orders, involuntary treatment second opinions, use of advocates. The provision of pamphlets listing consumers' rights is the most routine means of meeting the duty to inform. This is a minimum standard and considerable pressure needs to be applied to encourage verbal communication by staff about rights, at levels appropriate to consumer needs, at various times during hospitalisation or care in the community.

(Health Consumers' Council WA, Western Australia, Submission #29)

[X] was not informed of his rights as a Voluntary Patient and was not made aware that he had been made an 'Involuntary Patient'. This had been done without notification, oral or written. This was witnessed by us prior to [X] being placed in a drug induced sleep. He has not obtained or received copies of associated Forms relevant to this admission…. Management of [X]'s case, have violated his rights as a person with a mental illness.

(Carers, Western Australia, Submission #177)

Consumers not being treated with dignity and respect

A lack of dignity and respect in care received from mental health services are reported generally but in particular, forensic patients, young people and Aboriginal patients are reported to be treated poorly.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

Why in 2004 are our loved ones still suffering after policy documents from fancy government watchdogs have been released? Why aren't our loved receiving the same quality of care as people with physical illnesses? Are they not worthy of treatment? Where is the concern? There are huge problems with the system and some of the staff within the system. There is physical and sexual abuse still occurring. Why do we still use seclusion where there are no toilets, no water?

(Carer, New South Wales, Parramatta Forum #1)

I stayed in the Psychiatric Intensive Care Unit at the Royal Derwent Hospital – human rights regarding seclusion. There was no access to a toilet so I had to urinate in the corner of the room.

(Consumer, Tasmania, Hobart Forum #3)

By 15 December 2001, our daughter had developed severe oral thrush, her tongue being swollen preventing her from swallowing and talking without great distress. Unbelievably, her meals still comprised solid food (which she could not eat); this situation led to her subsequent malnutrition and severe dehydration which resulted in her losing 12 kilograms and being transferred to medical ward 2 East on 4 January 2002 for prompt life-saving intravenous and naso-gastric treatment… my wife saw our daughter drinking the toilet water to help relieve her dry and thickly-coated tongue, mouth and throat.

(Carers, Parents, New South Wales, Submission #106)

We are often required to transport these people but they are not criminals, they are ill.

(Police officer, Western Australia, Bunbury Forum #9)

Concern about protection of the rights of the mentally ill in the criminal justice system

Prison is an expensive housing option for the mentally ill: it is also a grave abuse of their human rights.

(Anonymous, Queensland, Submission #67)

In May 2001, as a consequence of that inadequate treatment, he was charged with malicious damage by arson and in April 2002 was found not guilty by reason of mental illness. From May 2001 until June 2003 our son was incarcerated in appalling conditions at Long Bay Prison Hospital. His behaviour throughout that period was exemplary. During all of that time, he was locked for at least 11 hours a day, and often longer, in solitary confinement in a prison cell and was not allowed to have a TV in his cell. He was frequently hungry, due to the poor quality of the food provided.

(Carers, Parents, New South Wales, Submission #75)

[Prisoners] are in a highly restricted environment, have no choice in provision of service, have far reduced access to their support network, have even greater problems in accessing any complaint or oversight body and in allowing such bodies to examine information that they request to be examined.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA),
New South Wales, Submission #349)

Problems with complaints procedures

95% of the reason why you don't get complaints – because they are exhausted and afraid of victimisation.

(Anonymous, Northern Territory, Darwin Forum #27)

I want to talk about what happens to patients if you complain about staff. If you complain you go from the frying pan to the fire! …You still need the treatment and the service so you don't complain.

(Consumer, Victoria, Morwell Forum #10)

People are afraid to complain. There's a fear of impact if they complain. Even when the evidence is overwhelming, there is still a real fear. The more serious the complaint, the more "they" will try to discredit the consumer. The culture is such that "they" never want to help the consumer.

(Consumer Advocate, Victoria, VMIAC Forum # 9)

A protocol needs to be developed for the dealing with complaints on a prompt basis whether it be from official agencies such as OCA or others including family, friends and carers. A responsible accountable system for dealing with complaints may well assist morale and confidence in the safe care provided by PSU. (Excerpt from Report of findings by the Chief Coroner)

(Carer, Partner, Australian Capital Territory, Submission #305)

…even numerous complaints to the WA Medical Board have been dismissed with such statements as 'time lessens the memory'..... sure, after they kept fobbing off meetings with them and letting time lapse. I went to every viable person in Perth only to crash into brick wall after brick wall. [Y], Head Psych for the state, told me I was just an emotive mother... too right I am!

(Carer, Mother, Western Australia, Submission #103)

Staff and services not complying with relevant legislation, regulations and instruments protecting the rights of people with mental illness

The hospital has reduced the Ward Clerk hours, which leaves her unable to provide the time needed to do the paperwork to comply with the Mental Health Act. Often when a patient is to have a review by the Mental Health Review Board, there is no paperwork ready, no psychiatrist in attendance and no report by the treating psychiatrist.

(Nurse, Western Australia, Submission #55)

Mental Health Review Board (MHRB) fails to uphold human rights of mental health consumers. The MHRB has consistently failed to work to the reasonable extent of the scope of its powers, by testing the attitudes and practices that lead to detention and forced treatment of consumers. The MHRB is widely regarded by mental health consumers with experience of the system as not being worth the effort of contacting. Reviews are routinely limited to 20 minutes, psychiatrists' reports are taken on face value and rarely challenged, procedural fairness is seen by most consumers and advocates as completely absent.

(Health Consumers' Council WA, Western Australia, Submission #29)

Lack of access to advocates

We have also found problems with the system's recognition of independent advocates, who having been specifically requested to act of behalf of a patient regarding a certain matter, are denied the ability to do so. This even occurs when the request has been in writing - demands are made for the request to be rewritten in a standardised format. This causes frustration in the patient and delay in resolving a problem.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA),
New South Wales, Submission #349)

To offset the abuse of human rights occurring on a daily basis, the need for advocacy services is stronger than ever before, and yet funding for these services has steadily diminished. Without access to independent, fully funded, fully trained advocates, human rights will continue to be breached and the effects will continue to be long lasting and impede the recovery of so many consumers. Independent advocacy can be very effective when used pro-actively in mental health service provision.

(Centre for Psychiatric Nursing Research and Practice, Victoria, Submission #323)

Lack of access to interpreters

The lack of interpreters is a real issue. Many of our people don't have carers, they are socially isolated and they have problems with the language. But they are told by many practitioners that they don't work with interpreters so they can't access adequate care.

(Service Provider, Western Australia, West Perth Forum #36)

Interpreter use of people with limited English. The Health Consumers' Council has assisted a Macedonian mental health consumer who was challenging the actions of mental health services to require him to submit to medication and involuntary hospitalisation. The clinical consultation during which the decision was made to place the consumer on an involuntary order occurred without an interpreter. We include an Advocacy report produced at the time of this consultation that highlights our concerns about the failure of mental health service clinicians to engage interpreters. Specific comment: The engagement of an interpreter should not be optional where action under the Mental Health Act is likely or possible.

(Health Consumers' Council WA, Western Australia, Submission #29)

Concern about Ministerial discretion and the rights of people with mental illness

The Minister is sitting on a request for a consumer to go home even after the Mental Health Tribunal has approved his release.

(Carer, New South Wales, Parramatta Forum #1)

During the period of our son's Forensic Order, we have not been satisfied with the 'due process' of administration of conditions of that order. The requirement that the NSW Minister for Health approve these conditions means that the process is inappropriately politicised. Decisions about transfer and leave for patients, seem to be made to appease community attitudes about mental illness and violence, which are steeped in stigma, rather than in the best interest of the patient.

(Carers, Parents, New South Wales, Submission #75)

5.2 STANDARD 2: SAFETY

The activities and environment of the MHS are safe for consumers, carers, families, staff and the community.

There was serious concern that mental health services are not providing treatment and support to ensure the safety of consumers, their families and the community. The lack of services to assist youth, in particular, was noted. Submissions indicated that many consumers are unable to access emergency services even when at risk of self-harm or harm to others.

Families and carers reported fear for their own safety and the safety of their family member, with no or little response from mental health services. Some consumers shared experiences where they were afraid in hospital treatment settings and provided examples where their safety was not adequately provided for.

Submissions and presentations provided examples of consumers dying while in hospital care, or soon after discharge. Some services responded to safety issues by employing security guards and limiting the freedom of inpatients. However, submissions indicate that this response did not improve safety and security, rather it exacerbated stigma issues and feelings that people with mental illness were criminals or "animals".

Fears for personal safety were also expressed by staff. The expressed a need for additional resources and staff support and training in order for mental health services to respond appropriately and ensure the safety of consumers, carers, staff and the community.

Nationally, the key issues raised regarding this Standard include:

- lack of response to family concerns of danger (Standard 2.3);
- excessive use of physical restraint, sedation and armed escort (Standard 2.3);
- excessive focus on security (Standards 2.1 and 2.3);
- problems with the use of security guards with inpatients (Standard 2.3);
- Consumers are not kept safe or protected from abuse in hospital and treatment settings (Standard 2.2);
- inappropriate staff responses to aggressive and difficult behaviour (Standard 2.4);
- need for staff training to respond appropriately to aggressive and difficult behaviour (Standard 2.4);
- safety concerns for children with mental illness (Standard 2.2);
- lack of services for children and youth with behaviour problems (Standard 2.2);
- lack of procedures in hospitals to ensure safety of consumers, carers and the community upon discharge (Standards 2.1 and 2.3);
- inadequate treatment and support services to ensure the safety of consumers, carers and the community (Standard 2.3);
- lack of support and services in the community to protect consumers from abuse (Standard 2.2);
- lack of trust in MHS to ensure safety for the community (Standard 2.3);
- occupational health and safety issues (Standard 2.3);
- safety concerns of staff (Standards 2.3 and 2.5);
- safety not ensured in supported accommodation environments (Standards 2.2 and 2.3);
- the MHS is not communicating vital information with other accommodation service providers to ensure the safety of staff and other residents (Standard 2.3);
- transport of consumers in a manner which is not 'safe and dignified' (Standard 2.3); and
- safety issues due to lack of resources (Standard 2.3).

The following selected quotes from community forums and submissions describe people's recent experiences of mental health services and their areas of concern under Standard 2. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Safety of people with mental illness not ensured

The only way the people I have mentioned will receive help is if they harm themselves severely or someone else which is more than likely and why should carers have to wait for such a result.

(Carer, Queensland, Submission #109)

Two consumers died at Xmas one who self harmed and took it too far – we referred him to the service as he was very distressed and out of control he was assessed by a case manager as OK but died within the following week; The second went to the service begging to go into the unit as he knew that when he got this depressed he was at risk – this was our experience in the past and he was hospitalised and kept safe; they refused on this occasion – he took his own life a couple of days later.

(Anonymous, Queensland, Submission #113)

Safety of families and carers not ensured

More than half of the time within 48 hours, to a week, of her release we would be back at the emergency room when the medication had worn off and the delusions had returned full force and often she had lashed out at myself or my grandparents.

(Anonymous, Queensland, Submission #82)

[X] subsequently stayed with us for 10 days even though he was clearly very unwell and should not have been released from hospital. He seemed to be getting worse staying with us and constantly paced through the house day and night. [X] became very aggressive towards his family and had problems with his thought processes. His condition was obviously deteriorating rapidly and we were very worried about safety issues, both his and our own.

(Carers, Parents, New South Wales, Submission #198)

Lack of services for children and youth with behaviour problems

I have staff using the expulsion / suspension guidelines to exclude these kids. I have staff being attacked by kids who are on drugs. Because of a lack of services there's nothing left but to exclude these kids. Actually they really need care.

(Teacher, South Australia, Murray Bridge Forum #17)

Safety not ensured in supported accommodation environments

Hostels like St. Bartholomew's House can no longer afford the risk of injury to staff and/or other residents from people who are not having adequate treatment and support from mental health services.

(St Bartholomew's House Inc, Western Australia, Submission #37)

Safety concerns of staff

As well as the serious implications this crisis has for patients, there are very real and unacceptable consequences for staff. In addition to the obvious risks associated with safety and aggression, there is the deleterious psychological impact on staff constantly frustrated in their attempts to deal humanely with these people in a system that is patently incapable of responding adequately to demand.

(Mental Health Workers Alliance, New South Wales, Submission #325)

Excessive focus on security

Some of these security measures convey to the public that the people behind the wire are animals that need to be constrained.

(Carer, New South Wales, Parramatta Forum #4)

Excessive use of physical restraint, sedation and armed escort

…it goes against the grain to see people being made to stay on a trolley, in a cubicle, usually sedated, occasionally mechanically restrained, just because the mental health system is overloaded and poorly resourced. This situation is chronic and untenable.

(Clinician, Victoria, Submission #201)

Generally if a person's level of distress is of such concern to the clinic staff, themselves, family and / or community, the person will be evacuated, generally by air, to Alice Springs for assessment. The distances involved and the use of planes mean that evacuation to the acute service often requires chemical and / or physical restraint. Clearly there are significant safety issues that are evaluated in each case, however it does mean that Anangu are more likely to be chemically and physically restrained during an acute episode.

(Anonymous, Northern Territory, Submission #271)

Problems with using security guards with inpatients

One of the most disturbing practices for me is the use of security guards from a private security firm to facilitate the care of inpatients, due to lack of proper facilities and staffing levels in Bunbury. The hospital regularly employs guards to "special" patients who are considered at risk of either self-harm or absconding. They often use the guards to boost the staffing levels in the unit to try and make the environment safe. This can often mean an untrained person, usually male, following around a very ill or deeply disturbed person in the medical ward of the hospital as well as the psychiatric unit, or is sitting around in full uniform in the psychiatric unit. This has a couple of very major concerns. Firstly, the patient often self discloses to the security guard their personal history… Secondly, it also gives the patient, visitors and other patients, the impression that the person with the guard is "trouble", i.e. violent, bad, etc.

(Clinician, Western Australia, Submission #55)

Consumers not kept safe or protected from abuse in hospital and treatment settings

I'm a patient in the hospital at the moment under an involuntary order and it was very difficult for me to get here to this forum today… It's a place where you can get away from the world but there's not much else. The situation is terrible and I can't even have a shower in private. I'm scared and I have no privacy.

(Consumer, Western Australia, Bunbury Forum #17)

In my last admission (one year ago) to a public hospital I was assaulted and many of my things were stolen and some jewellery was flushed down the toilet. I do not blame the other patient because she was very unwell but I expect to be safe when I get admitted to hospital.

(Consumer, Queensland, Submission #204)

I am writing to you in order to express how appalled I am to hear that, eighteen months after the release of the Bunbury Health Task Force Report major problems with clinical safety at the Bunbury Hospital Psychiatric Inpatient Unit still continue… I can only hope that now, with the release of yet another report, your Office and that of the State Wide Office of Mental Health will be able to insist upon change – before someone is seriously injured, killed or otherwise jeopardised… (extract from a letter to the Office of the Chief Psychiatrist)

(Clinician, Western Australia, Submission #24)

Need for staff training to respond appropriately to aggressive and difficult behaviour

As a nurse academic and educator, I am aware that it seems that nurses often adopt or are directed to adopt a zero tolerance to aggression and violence, creating an often adversarial stance with patients and thus increasing the possibility of an aggressive episode... This is avoidable and unacceptable workplace practice. Patients deserve better care, nurses deserve high quality ongoing education and support to provide them with the skills and knowledge to care for people with difficult behaviours.

(Academic, South Australia, Submission #142)

Safety issues due to lack of resources

…the increasing service resource crisis presents significant threats to the rights of mentally ill people. This occurs through compromising safety and increasing the risk of sub-standard treatment, undermining centres of clinical academic excellence, increasingly marginalising those with mental illnesses, and through a tendency when addressing clinical problems to rely increasingly on administrative and legal solutions rather than clinically led solutions.

(Public Sector Psychiatrists, New South Wales, Submission #297)

There is a crisis in attracting all disciplines to work in Mental Health due to lack of support/ training and poor working conditions and a lack of attractive career paths. This impacts on comprehensive care and there are recurrent safety issues due to staff dealing with potentially violent and dangerous situations, sometimes without any back up.

(Anonymous, Tasmania, Submission #254)

5.3 STANDARD 3: CONSUMER AND CARER PARTICIPATION

Consumers and carers are involved in the planning, implementation and evaluation of the MHS.

Across Australia there were concerns about the diminishing level, or complete abandonment, of consultation and engagement with consumers and carers in the planning, implementation and evaluation of service delivery. There were reports that critical service delivery decisions were being made without any consultation with consumers and carers. Nor were there attempts to communicate the ramifications of such decisions to this group.

Where such processes were still operating, they were frequently described as 'tokenistic' and consumers and carers did not feel valued. Continued withdrawal of funding and lack of resources to support consumer and carer participation programs was also reported. Consumers and carers described feelings of weariness and 'consultation fatigue.' They are sick of being ignored and frustrated by the futility of participation and lack of progress.

Concern was also expressed that representation is not inclusive of all consumers and carers; for example, the representation of people with Borderline Personality Disorder was noted as lacking.

Nationally, the key issues relating to this Standard include:

- abandonment of participation by consumers and carers in planning, implementation and evaluation processes by the MHS (Standards 3.1 and 3.2);
- lack of meaningful consultation (Standard 3.1);
- 'tokenistic' approach to consumer and carer participation (Standard 3.1);
- views of consumers and carers are not being heard (Standard 3.1);
- views of youth with mental illness and mental health problems are not being heard (Standards 3.1, 3.2 and 3.6);
- consumers with borderline personality disorder, in particular, are not being heard (Standard 3.6);
- lack of funding and resources to support consumer and carer participation (Standards 3.2, 3.3 and 3.4);
- concerns about lack of progress and 'consultation fatigue' (Standard 3.1); and
- need to address barriers to effective participation by consumers and carers (Standard 3.7).

The following selected quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 3. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Concerns about lack of progress and 'consultation fatigue'

The other thing the NSW government is good at is holding inquiry after inquiry, establishing one task force or select committee after each other – and all it is, is a big talk fest and we go around the same circle for the next 2-3 years or in Australia's case for the next 10 years.

(Consumer and Consumer Advocate, New South Wales, Submission #8)

My son and I have been involved with the Mental Health Association and been on lots of committees and attended many forums and consultations and where are we?

(Carer, Mother, Northern Territory, Alice Springs Forum #13)

Too many times over the years have many other people and I given information, been part of a consultation group, spoken up when asked to do so. Too many times have we been promised that something would be done? Too many times we have been let down. I am certain that somewhere in archives there is a plethora of information that has been collected and not activated on. I like many of my colleagues in the Mental Health System am sick and tired of being told that we have a voice only to find out that we have been fooled once again.

(Consumer, Victoria, Submission #112)

Lack of meaningful consultation

There is a rhetoric of inclusion of the consumer voice in mental health debates but the consumer-survivor experience of this, virtually unanimously, is that this rhetoric is lip-service not matched by any real commitment and certainly not by any meaningful resources to promote the inclusion of the consumer perspective…

(Insane Australia, Victoria, Submission #232)

Other Consumers Consultants, an apparently smaller group – who measured their situations in various different ways – said that the local Area Mental health Services where they worked remained apparently "resistant and entrenched" toward consumer perspectives, maintaining attitude barriers and "us and them" thinking, and sometimes taking a "pathologising" view of issues. A more subtle but still difficult situation was where consumers perceived that services seemed to be "saying all the right things" but were short on meaningful action – sometimes opting for quick fixes, tick-the-box checklists and "tokenistic" displays of consumer participation through Public Relations exercises, and ever more pamphlets.

(Consumer Advocate, Victoria, Submission #253)

Views of consumers and carers are not being heard

We're at no risk of being threatened for speaking out because we're not being heard at all!

(Advocate, South Australia, Adelaide Forum #15)

Unless people are heard then the government of the day whether it be State or Federal will do nothing.

(Carer, Wife, Australian Capital Territory, Submission #149)

Abandonment of participation by consumers and carers in planning, implementation and evaluation processes by the MHS

Only recently in July, Carers at a Carer Advocacy & Issues Forum in Bunbury met and expressed their frustration regarding the sudden closure of mental health services in their community. Specific concerns regarding the closure of services include: …The complete lack of consultation with carers, consumers and health professionals regarding the closure.

(Carers WA, Western Australia, Submission #277)

The Health Consumers' Council operated a Mental Health Consumer Advocacy Program for six years until this was de-funded in late 2003. This program supported consumer participation in service decision-making, trained consumers as public speakers on service standards and provided a Participation Payment scheme to assist consumer participation. The most promising feature of this program was the employment of mental health consumers as advocates for service reform. Consumers worked on a part-time basis in a team supporting a wide network of peers involved in service reform work. The cost to the state of this program was in the order of $130K per year – 4 workers, 200 consumer reps, 100 committees. The loss of this program was catastrophic for the emerging mental health consumer movement. Almost all progress against the National Mental Health Plan in respect to consumer participation in mental health services has stopped in Western Australia.

(Health Consumers' Council, Western Australia, Submission #29)

Lack of funding and resources to support consumer and carer participation

Let's talk about consumers being employed within the mental health system. Yes, I'm a consumer employee and I get paid for 30 hours and work close on 48 hours each week… What my gripe is that we have such minimal hours, that we simply cannot do half the stuff we're capable of and try to put into effect. More often than not we're not acknowledged as having any expertise, definitely expected (in my situation) to perform as a manger yet not paid accordingly. In other areas we're the most under utilised resource within a mental health service – and forget the voluntary crap – we deserve to be paid for a good day's work like any other person in the community.

(Consumer and Consumer Advocate, New South Wales, Submission #8)

To remove barriers to participation more resources need to be dedicated for consultation, organisational commitment and leadership and consumer participation.

(Anonymous, Tasmania, Submission #290)

Views of youth with mental illness and mental health problems are not being heard

While consumer participation has fixed some of the worst bits of the adult mental health system, it is virtually non-existent in youth and adolescent services.

(Youth Participation Worker, Victoria, Submission #255)

For a number of years, YACSA has recommended that the State Government establish and resource a youth health advisory mechanism to provide advice to the Department of Human Services on policy and strategic issues aimed at maximising health outcomes. With issues of mental health, sexual health, drug and alcohol abuse and access to services (particularly for young people in rural, regional and outer metropolitan South Australia), there is an urgent need to act on the implementation of an appropriate advisory structure to the Minister for Health. Given the Generational Health Review emphasis on regionalisation and community participation, YACSA recommends that the Department of Human Services establish a number of regional Youth Health Advisory Committees in key, strategic locations as determined through the process of decentralising the existing health system. YACSA envisages that the Committees would comprise relevant departmental officers and non-government stakeholders in the youth, community and mental health sectors, as well as representation from young people / consumers. YACSA further recommends that the structure of the Committees be based on the previously successful Youth Views young consumer participation model, with executive support to be provided by existing staff.

(Youth Affairs Council of South Australia, South Australia, Submission #38)

5.4 STANDARD 4: PROMOTING COMMUNITY ACCEPTANCE

The MHS promotes community acceptance and the reduction of stigma for people affected by mental disorders and / or mental health problems.

The submissions and consultations reveal ongoing concerns about the high level of stigma associated with mental illness in the community, the workplace and in treatment settings. These concerns indicate that stigma reduction activities and campaigns to-date have had little real impact.

Consumers and families report feeling completely isolated, lonely and ashamed. They feel like they have no support from anyone. Of particular note is the documentation relating to children of parents with mental illness.

There were submissions describing discrimination in the workplace and exclusion of people in social and community settings. Some of those experiences included people losing their job after they disclosed their illness and people physically distancing themselves from them in public social places (e.g. in pubs and cafes). Some described negative behaviour and remarks from mental health workers, police and accident and emergency staff.

It was highlighted that a lack of access to treatment and support services often results in deteriorating mental health, and this serves to exacerbate stigma-related issues for the community. Thus there is a vicious cycle that perpetuates myths, stereotypes and unnecessary fear. Many pointed out the role of the media in maintaining these myths and stereotypes, and urged for rapid changes in this area.

Nationally, the key issues relating to this Standard include:

- high levels of stigma still prevalent within the community (Standard 4.1);
- high levels of stigma still being experienced by people with mental illness and their children (Standard 4.1);
- social isolation experienced by consumers and their family (Standard 4.1);
- rejection by the community (Standard 4.1);
- offensive remarks by police and accident and emergency staff (Standard 4.2);
- discrimination in the workplace and the need to educate employers (Standard 4.2);
- lack of community acceptance and support (Standard 4.1);
- need for community education (Standard 4.2);
- non-acceptance by mental health workers (Standard 4.2);
- non-acceptance by family members (Standard 4.2);
- discrimination by real estate agents (Standard 4.2);
- problems with terminology and stigma for people with personality disorders (Standard 4.3);
- the impact of lack of access to services on stigma and stereotypes (Standard 4.3);
- stigma associated with 'therapy' as opposed to treatment by medication (Standard 4.1);
- stigma and stereotypes being perpetuated by the media (Standard 4.2); and
- diminishing use of the radio as a medium to promote community acceptance (Standard 4.1).

The following selected quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 4. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

High levels of stigma still prevalent within the community

I have 2 sons who have schizophrenia. [X] (eldest son) had a bad breakdown so we decided we would move to a small community to give him a better chance at life but the stigma here was very bad – when our sons went to the pub for a drink the locals would move away from them.

(Carer, South Australia, Murray Bridge Forum #10)

Stigma is also high in small communities like Broken Hill as people fear what they can't see. In discussions with legal advisors they have encouraged people not to disclose their illness. In addition, community attitudes are often dismissive of people with a mental illness.

(Consumer, Carer & Family Worker, New South Wales, Broken Hill Forum #23)

Admission to mental health facilities or contact with mental health professionals results in fear of consequences for community and professional standing and this fear has a realistic base.

(Support and Equity Services, Charles Darwin University, Northern Territory, Submission #269)

No one understands what is like to have a mental health problem in your family unless they are in the situation themselves. We live a silent pain. Ashamed. Embarrassed. In fear of our lives. Family destroyed. No one wants to help.

(Carer, Mother, New South Wales, Submission #90)

In every discussion held to date, stigma and discrimination have been raised as issues of concern. Unfortunately, the experience of stigma and discrimination is endemic, ranging from the common media portrayal of people with a psychiatric illness being violent and aggressive to discrimination in employment and even to how people are treated in mainstream medical services.

(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

Social isolation experienced by people with mental illness and their families

…three members of my family who have been diagnosed with Schizophrenia. This has had a devastating effect on not only the immediate family but also on extended family relationships, namely the isolation we have suffered since the diagnoses were made.

(Carer, Anonymous, Submission #224)

[X] finally lost all hope and on the 29th of May 1999 he laid himself on a train track… Because of the myths and stigma associated with mental illness his condition became worse. He had nobody to turn to about his problem, as mental illness is something that is not discussed in our society. I also did not have anyone to turn to. It was like something very shameful had hit our family.

(Carer, Mother, Queensland, Submission #81)

My son had schizophrenia and he's now dead as well - he committed suicide. The community didn't understand and when people found out he had a mental illness they dropped him like a hot potato.

(Carer, Mother, Queensland, Rockhampton Forum #9)

I think for those who are severely ill and are isolated in the community due to their illness they often have no form of support even from family or friends. For people like that they are in the community living like ghosts – they are dying alone.

(Consumer, Victoria, Footscray Forum #11)

My son had so many friends, his photo in the local paper every week, and captain of every team he was in, and as soon as the diagnosis came, he'd say "Any mail, mum?", "Any phone calls?", but there weren't any.

(Carer, Mother, Victoria, Submission #211).

Mental illness is a 'hidden' disability for families who are labelled and marginalised along with their unwell relative. Their predominant theme is loss - of the 'well' relative, a lifestyle, a rightful place in their community and their identity as spouse, parent, child or sibling.

(Carer, Wife & Mother, Queensland, Submission #157)

Lack of community acceptance and support

In Western Australia mental health problems are shrouded in ignorance. Few people ever think about the mental health needs of our communities and even less people think about the needs of mothers with mental illness and their children. The cost to our community is only counted in fiscal terms for the Health Department…

(Health Consumers' Council WA, Western Australia, Submission #29)

The impact of lack of access to services on stereotypes

When my son and others like him are unwell, their behaviour is their stigmata... this policy requires them to be different enough to draw attention to themselves in a totally negative way... thus under this policy the stigma of mental illness is propagated rather than alleviated. And let us not forget that this behaviour, not chosen behaviour, but behaviour dictated by the illness, is that which can cause them to lose accommodation, employment, friends and perhaps even family, thereby having their lives fall apart time and time again.

(Carer, Mother, Victoria, Submission #178)

Because my kids don't get any support, in fact they get teased about having a father who is mentally ill, they then come home and take it out on me; tell me I'm nuts or I'm a loony.

(Consumer, South Australia, Murray Bridge Forum #1)

Discrimination in the workplace

One client did eventually disclose her medical history three months after she got a job and then promptly lost that job.

(NGO Worker, New South Wales, Broken Hill Forum #21)

I am a nurse but I have been told that I will never get a job in this area because of my previous mental health condition.

(Consumer, Nurse, Western Australia, Bunbury Forum #2)

I also have a lot of contact with people who have had bad workplace and insurance issues. Also people who have been working and then need time off work and try to get income support have great difficulty. I also have many clients who have had depression and have lost their jobs because of their illness.

(Clinician, Queensland, Brisbane Forum #20)

There is discrimination in employment. You become ill, get the treatment on sick leave, get well again and are asked to leave.

(Carer, Mother, Northern Territory, Darwin Forum #5)

I took 3 months off from work on personal leave to recover from suicidal thoughts. When I came back, I had to deal with new management and new thinking. Previously, I had a supportive supervisor. I asked for a transfer to another section. The new management sought a psychiatric assessment of my illness. Their solution to the problem was to pension me off rather than look to work with me around the illness.

(Consumer, Australian Capital Territory, Canberra Forum #19)

A female client hospitalised with major depressive episode and a high suicide risk took sick leave from her job, only to be eventually fired due to her illness. This occurred despite the fact that she was planning on returning to work and was progressing well. She later returned to work with another company (she didn't disclose her history).

(Clinician, Queensland, Submission #105)

I advise clients not to disclose to their employer if they currently have or have had depression or any other mental health condition, as ignorance and stigma remain high in the general community and they are likely to be penalised for their honesty.

(Clinician, Queensland, Submission #105)

Stigma and stereotypes being perpetuated by the media

I'm from the bush and I have bipolar disorder. I agree with the previous speaker that there are many shocking articles in the media that shape the community's attitudes. Stigma is the biggest thing to fight.

(Anonymous, Queensland, Brisbane Forum #12)

While there has been some improvement in media coverage of mental illness, this is not sufficient to counter systemic stigma. Some newspapers and TV dramas also continue to portray mental illness in an inaccurate, sensationalised and disrespectful way. This can suit political leaders, as it displaces blame for the consequences of poor service delivery onto the mentally ill themselves.

(SANE Australia, National, Submission #302)

Discrimination by real estate agents

Housing is difficult – if you present to a real estate agency and declare that you are on a disability support pension you aren't assisted – you'll be rejected!

(Consumer, Queensland, Brisbane Forum #11)

…an eviction notice as he had not been paying his rent… I then contacted the rental agent from the Real Estate Agency and arranged to meet with her at my son's unit for an inspection and to arrange removal of his belongings. She arrived, followed by two police officers. There was no damage to the unit. I apologised for what had happened and was strongly rebuked by the agent for not having informed her that my son suffered from schizophrenia and added that she would have to inform all other rental agencies that he was an evictee along with my name as his next of kin. (Obviously this would make acquiring further accommodation for him very difficult).

(Carer, Mother, Victoria, Submission #178)

Problems with terminology and stigma for people with personality disorders

…the term, personality disorder, makes people sick… personality disorder implies that a person's problems are all that person's fault and responsibility… some clinicians use the term personality disorder indiscriminately as short hand for everything that presents as difficult to diagnose or socially construed.

(Consumers, Victoria, Submission #194)

Stigma associated with 'therapy' as opposed to treatment by medication

Intensive psychotherapy is extremely hard on everybody. The public image that it is somehow what privileged, overindulged, middle class women do to fill in the time needs challenging. I am very concerned that the efforts that have been made by SANE and other organisations to de-stigmatise mental illness have not even tried to do anything about de-stigmatising therapy in Australia

(Consumer, Victoria, Submission #203)

Non-acceptance by mental health workers

SANE Stigma Survey 2004:… Analysis of over 300 responses suggests that being treated unfairly and disrespectfully – by health professionals as well as the general community – is a regular occurrence for many Australians whose lives are affected by mental illness.

(SANE Australia, National, Submission #302)

5.5 STANDARD 5: PRIVACY AND CONFIDENTIALITY

The MHS ensures the privacy and confidentiality of consumers and carers.

Concerns were strongly expressed across all States and Territories regarding the misuse and incorrect application of policies and procedures designed to protect the privacy and confidentiality of consumers. The complexity of, and misunderstandings about, privacy laws and policies has hindered communication between consumers, carers and clinicians and has led to obstructions in the provision of treatment and support to consumers.

There many examples where mental health professionals have refused to communicate with carers and family even when consumers have expressed a desire, and provided specific authorisation, for others to be involved in their care.

Some carers report a 'double whammy' wherein the mental health care system expects them to assume and accept the responsibility of care but fails to involve them in the development of treatment plans or provide them with the information necessary to fulfil this role. Similarly, carers reported that clinicians were often not prepared to even 'listen' to their notifications regarding signs of relapse or fears for the personal safety of consumers or themselves under the pretext of 'privacy and confidentiality'.

There was also concern that often clinicians mistakenly assume that consumers lack the capacity to give informed consent and for this reason do not discuss these issues with consumers.

The need for culturally sensitive approaches to dealing with information, for Indigenous cultures in particular, was raised as an area of concern.

The privacy and confidentiality of information relating to consumers who are subject to the criminal justice system was also raised as a critical area of concern.

'Privacy', 'private space', control over that space and adequacy of physical care environments are also covered under this Standard. The diminishing importance of consumers having adequate privacy in residential and inpatient settings (both indoor and outdoor spaces) and control over their personal effects was noted. The generally poor condition of mental health inpatient and residential settings was described as being of a standard that would not be acceptable for those receiving care for physical health problems.

Nationally, the key issues relating to this Standard include:

- concerns about policies and procedures to protect confidentiality (Standards 5.1 and 5.2);
- concerns about privacy and confidentiality policies hindering communication with carers (Standards 5.1 and 5.2);

- staff applying privacy and confidentiality rule without authority, ignoring or not requesting permission from consumers to share information or involve carers (Standards 5.1, 5.2 and 5.4);
- the MHS denying consumers their right to have others involved in their care (Standard 5.3);
- reluctance by services to involve carers, even when permission is given by consumers (Standard 5.3);
- problems with access to databases and confidentiality (Standards 5.1 and 5.4);
- indigenous issues (Standards 5.3 and 5.4);
- prisoners and problems with information sharing between agencies (Standards 5.1 and 5.4);
- information sharing with the police (Standard 5.4);
- privacy laws and assisting youth to access care (Standards 5.1 and 5.3);
- rights of carers (carers not informed of discharge) (Standards 5.1, 5.2, 5.3 and 5.4);
- consequences that may follow for consumers and their relationship with carers or significant others if policies and procedures to protect the confidentiality and privacy of consumers are misunderstood (Standard 5.3);
- lack of privacy and outdoor physical space (Standards 5.5 and 5.7);
- concerns about lack of privacy and control over personal space (Standards 5.7 and 5.8);
- inadequate indoor physical care environment (Standards 5.7 and 5.9); and
- loss of personal effects (Standard 5.8).

The following limited selection of quotes from community consultations and submissions describe people's recent experiences of mental health services and areas of concern under Standard 5. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Concerns about policies and procedures to protect confidentiality

Family, friends and carers could provide information valuable for such a plan and they need to be involved on discharge of patients to be treated within the community. Information from family, friends and carers is important for treatment planning and risk assessment and for the continuation of treatment upon discharge. The problem of patient resistance to the involvement of family, friends and carers and privacy issues needs to be contended with. Best practice does involve this question. It did not happen here at an appropriate level… (Excerpt from Report of findings by the Chief Coroner)

(Carer, Partner, Australian Capital Territory, Submission #305)

…the laws are often given as an easy way to avoid talking about issues with people involved with the patient regardless of the appropriateness or otherwise of the request, and c) privacy laws are often attacked because they are inaccurately blamed for lack of social support, and general medical information about psychiatric disability comprehensible to the general public that people close to a patient might need… Generally, no matter what laws are enacted regarding them, the problems of information / privacy issues will always come down to the attitudes of all parties in the practical application of any such laws. These are complex relationship and social issues that have to be dealt with at the grass roots level and through three way learning between professionals, patients and people connected to patients.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA),
New South Wales, Submission #349)

'What is wrong with the CATT [Crisis Assessment Treatment Team] and the emergency processes? It's getting worse. They tell us they are short staffed. They tell us they can't talk to us that it's a matter of privacy and confidentiality, but surely when our lives and our safety are at risk, they must listen to us'.

(Mental Health Community Coalition Consumer and Carer Caucus,
Australian Capital Territory, Submission #342)

Staff applying privacy and confidentiality rule without authority, ignoring or not requesting permission from consumer to share information or involve carers

Family members reported that some clinicians are receptive to speaking with and listening to them but that others are not and will cite 'confidentiality' as a reason for not engaging with family members.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

Doctrines of confidentiality and privacy of adult patient information are often interpreted by some professionals and adhered to so strongly within that Carers are intentionally not provided with information about medication, treatment and progress. Also, they are frequently denied linkages with those treating the consumer, even though Carers are expected to support and manage the care of the consumer in the community. The reality is that care provided in the community by family members frequently occurs without recognition from the mental health system, the professionals, or the general health care and primary health care sectors.

(Carers Association of SA, South Australia, Submission #30)

Respondent F. spoke of her husband's in-patient psychiatrist as "abrupt, arrogant…I was supposed to defer to his 'expert' knowledge". Due to privacy legislation, most respondents felt they had not been given a full description of their relative's diagnosis. Respondent C. stated, "even my family doctor would not discuss my son's condition with me… how could I continue to care for him if I did not know what to expect?" Confidentiality considerations can be an excuse for lack of family members' inclusion in care planning.

(Carer, Wife & Mother, Queensland, Submission #157)

Concerns about privacy and confidentiality policies hindering communication with carers

The mental health system failed [X] in so many ways. In summary the key failings were: … the role of family members as carers was ignored: they would not listen to our input and apparently valued privacy requirements above everything else, including [X]'s welfare and even his life.

(Carer, Sister, Australian Capital Territory, Canberra Forum #9)

A common problem for carers is the impact of privacy laws and recognition of their role. Each State and Territory has different legislation governing rights of carers and the release of information to carers so that a three-tier system must be overcome prior to information being shared with the mental health service or recognition of their role being granted. This tiered system is comprised of the relevant State or Territory mental health legislation, State or Territory privacy or health legislation and the Federal privacy laws.

(Carers Australia, National, Submission #276)

We as a family were not allowed to be involved with my son's treatment ***because of the confidentiality law.*** *The law states, that my 19-year-old son - suffering mental illness and living at home - was deemed an adult so we were excluded from his treatment. This was thrown at me – **his mother** – in every direction and I tried extremely hard trying to contact my son's Doctor's, Psychiatrist and various organisations, but to no avail. (author's emphasis)*

(Carer, Mother, Queensland, Submission #81)

Carers continue to report that they feel there is minimal recognition of them by mental health services and minimal efforts to consider their views and/or involve them. Whilst Carers respect the need for confidentiality the lack of possible involvement of carers is a significant barrier to carers in providing care and support for their family members/friends with mental illness.

(Carers WA, Western Australia, Submission #277)

MHS reluctant to have others involved in the care of patients

I have power of attorney over my wife but when I ask for information about my wife they tell me they can't give it to me – until I slap the POA(Power of Attorney) in their hands.

(Carer, Husband, Victoria, Melbourne Forum #3)

Consequences of exclusion of carers and families

I was married to a paranoid schizophrenic and did not know… No Dr. would tell me – ethics, the result was, this "man" totally destroyed my life, and there was not a thing I could do about that legally… I am still trying to "pick myself up off the floor", but sadly never will.

(Carer, Wife, South Australia, Submission #148)

Capacity to provide consent

It should never be assumed that the person is incapable of considering a matter, forming an opinion and giving direction regarding the matter. This includes who is privy to information and who may be involved in admission, treatment, and discharge, in terms of Health and non-Health persons and the interaction of the two. There is generally a presumption that any patient with psychiatric disability lacks capacity. This is untrue.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

Rights of carers

…two issues which can cause enormous problems for carers and which I believe can create the greatest divisions in understanding between mental health professionals and carers. The first is 'confidentiality'… from personal experience and anecdotally, this has proved on many occasions to have the potential to put either the carer or the person with the illness at risk - even if that risk is simply to their personal health and well being, apart from the distinct possibility of far more serious consequences. It is small wonder that carers can often feel used and abused by the mental health system - it appears that there has been little thought given to the rights of carers, or rather their lack of rights; we are expected to accept responsibility for the continuity of care without even the right to be informed of hospital discharges without the patient's consent, and with currently minimal time spent in hospital, the matter of the person with the illness being able to make such important decisions in regard to their own welfare has proven to be highly questionable.

(Carer, Mother, Victoria, Submission #178)

Family carers indicate they have all responsibility but no rights. They are key players in caring for sick family members. The confidentiality / privacy act is an aberration. Carers observe a loved one's illness daily and can warn when episodes/relapses are imminent. Professionals deny themselves access to the wisdom of carers and hinder early diagnosis and accurate diagnosis.

(ARAFMI Tasmania, Tasmania, Submission #245)

The CONFIDENTIALTY LAW needs to be amended. There is no other illness in society that the medical profession do not involve the families or carers. However once a person has been diagnosed with mental illness the confidentiality law is used and abused to the detriment of the family and carers. An example of this abuse is if a person has been diagnosed with cancer, heart attacks, diabetes etc the whole family is involved however if a person who has been diagnosed with some form of mental illness the confidentiality/privacy act comes into play. SO WITH OR WITHOUT THE CONSENT of the person who has been diagnosed with mental illness we the families and carers who are the community care givers and providers MUST be involved, consulted and our opinions respected in determining the health and happiness of our loved ones. Exactly in the same way other illnesses are treated. (author's emphasis)

(White Wreath Association Inc, Queensland, Submission #81)

Indigenous issues

It is a necessity to recognise formally the Indigenous concepts of family, kinship and community, and to allow communities and individuals within the Indigenous communities to work out appropriate ways of dealing with information that affects the relationships within the Indigenous communities. Indigenous Cultures must be respected and Indigenous people must not be forced or pressured to reveal Cultural information. There are arrangements already existing that are supposed to be respected, such as the AHRC / NSW Health Partnership, to look into these issues and ensure that matters affecting Indigenous people(s) are dealt with at all law, policy and service levels in the appropriate and culturally respectful manner. It cannot be allowed to be done in ignorance of the rights and concerns of Indigenous peoples and without self determination. As these issues are already known to government and departments, a choice to ignore the issue and deny rights amounts to a deliberate decision which we contend must be examined with regard to the International Convention on Genocide. We also argue that these issues be examined in the light of the 2003 WHO guidelines on Mental Health Law and Human Rights regarding the protection of Indigenous ethnic groups and minorities.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

Prisoners and problems with information sharing between agencies

We wish to express here our absolute objection that prisoners, as an entire class of people, have by law no right to privacy due to recently passed laws. This discrimination is offensive in and of itself. It is also highly damaging to prisoners' wellbeing and relationships with medical staff and others. Prisoners' patient records have been given to the media, for example the X-rays of the hand of Ivan Milat. (We note that forensic patients' mental state and therapeutic relationship has also been released and discussed in the media, and that this is a nation-wide problem. Forensicare of Victoria is often considered exemplary in debates around forensic standards, but they are in no way immune from problems and have also revealed such personal information in an inappropriate and political manner.)

(Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

Problems with access to databases and confidentiality

We also completely object to NGO / Police access to databases and information sharing regarding the mental state and medical records of patients as suggested in submissions and hearings at the NSW Parliamentary Inquiry into Mental Health Services. This is an abuse of patient's private information and must not occur. NGO's and Police can contact Mental Health Teams if really necessary.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

Inadequate indoor physical care environment

Many people fear that ultimately Graylands Hospital will be closed down, as was Heathcote Hospital. It should always be born in mind that to replace beds in a facility like Graylands Hospital with its peaceful surrounds with extra beds in a general hospital like Royal Perth or SCGH [Sir Charles Gairdner Hospital] with their locked wards and lack of personal space is absolutely a huge step backward!

(Carers, Parents, Western Australia, Submission #76)

There have been complaints made to St Vincent's but nothing has been done about it. I think it's there to stay. The nurses lobbied for it and said they had it built to protect their patients and themselves from people coming in off the street. I'm not opposed to secure units at all. That's not what I mean. What I mean is that we need to give more thought about how we build secure units. They shouldn't look like cheap prisons. People, even high security people have a right to privacy and respect.

(Consumer Advocate, New South Wales, Parramatta Forum #3)

The James Fletcher Hospital is also frequently "dirty"… cleanliness could be upgraded to hospital standard. For example, the carpets are very dirty, which leaves patients with black feet. There was an example of food smeared on a window which was left for more than 3 weeks. A dead cockroach was left lying in a corridor for several days. There are frequently coffee stains left on the garden furniture. Overall, it is a very dirty environment, not what you would expect from a hospital. There is also no air-conditioning or fans and so no fresh air. The fans were removed after a patient attempted to hang themself. A plan for installation of air conditioning was developed 12 months ago, but no action has occurred yet. Furthermore, there is only one meal option available to patients, regardless of the individual's tastes or beliefs. There is often no privacy for patients using the telephone because if there is a staff meeting being held in the room housing the phone it is placed in the hallway… patients are treated as 2nd class citizens. They do not receive the same level of care you would receive in other health facilities.

(Anonymous, New South Wales, Submission #156)

5.6 STANDARD 6: PREVENTION AND MENTAL HEALTH PROMOTION

The MHS works with the defined community in prevention, early detection, early intervention and mental health promotion.

A recurrent theme at the community forums and in submissions received from consumers, carers, clinicians, academics, advocates and service providers was the concern about lack of resources and plans to support early intervention and prevention. Participants noted the serious negative consequences this has for consumers, carers and the community.

Submissions and representations described a failure to provide early intervention and implement prevention programs. Consumers, carers and providers also said access to care was practically impossible when people were becoming seriously unwell. Consumers are regularly told they can not access services until their health has deteriorated further. For example, one consumer was told he was 'not psychotic enough'.

For some consumers an inability to access timely services led to deteriorating mental health which, in turn, led to behaviour resulting in entry into the criminal justice system. Others entered a 'revolving door' pattern of admission for acute care due to a lack of rehabilitation programs and ongoing support.

Carers reported that clinicians need to engage with consumers and, with consent, their family members to develop plans to identify early warning signs of relapse. Family members then need to be heard and the information acted upon.

The lack of services for youth, and the implication this has for attempts to avert long-term negative life consequences, was highlighted as a particularly significant deficiency. Similar concerns were expressed about the lack of early intervention and prevention programs to deal concurrently with mental illness and substance abuse problems.

Reports were also received regarding the lack of effective mental health promotion strategies, particularly for children at school, for people who are hearing impaired and for those who come from a Non-English Speaking Background. A better promotion strategy would help consumers, carers and the community at large to identify early warning signs and assist in seeking the appropriate care. On the other hand, service providers noted that it is unfair to promote early intervention and prevention to the community when services do not have sufficient resources to respond to crises.

Nationally, the key issues relating to this Standard include:

- due to lack of access to services, no prevention or early intervention is happening (Standard 6.1);
- no attempts at and lack of focus on early intervention or prevention - reactive, crisis driven approach to service delivery (Standard 6.1 and Standards 6.4 – 6.8);
- lack of services for youth – no early intervention or mental health promotion possible (Standards 6.2 and 6.5);
- early intervention – families need to be heard (Standard 6.1 and 6.7);
- early intervention – involvement and role of GPs (Standard 6.5);
- early intervention - importance of open discussion and acceptance (Standards 6.2 and 6.3);
- more promotional strategies needed (Standards 6.2 and 6.3);
- lack of rehabilitation programs (Standard 6.8);
- social needs are not being met through the use of mainstream agencies (Standard 6.9);
- prevention – substance abuse and mental illness need to be tackled jointly (Standards 6.4, 6.5 and 6.6);
- preventing depression in older men (Standard 6.4);
- need for education campaigns in schools (Standard 6.2);
- lack of support for children of parents with mental illness (Standard 6.4);
- unfair to promote early intervention when services are failing to cope with current demand (Standards 6.1 and 6.10);
- need for more programs to promote mental health and prevent mental disorders in the deaf community (Standards 6.2 and 6.3); and
- need for more programs to promote mental health and early intervention to people from a non-English speaking background (Standard 6.3).

The following selected quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 6. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Due to lack of access to services, no prevention or early intervention is happening

Consumer relapse knowledge ignored. Consumers who feel themselves to be becoming unwell have little or no access to assistance from their treating team. It is not uncommon to contact a clinic on behalf of a consumer who feels the need for immediate intervention and be told that the referral will be placed on a list to be discussed at an 'intake' meeting at a later date… It is the experience of mental health consumers with early signs of relapse or episodes of need that the inability of services to respond to their needs pushes them towards crisis, disruption of their life and greater need to call on those same mental health services.

(Health Consumers' Council WA, Western Australia, Submission #29)

No attempts at and lack of focus on early intervention or prevention - reactive, crisis driven approach to service delivery

Despite the seriousness of the disorders, there is no philosophical or legal framework supporting a more assertive or early intervention approach, nor the funding capacity to support such a model. Indeed such an endeavour is still impeded by a residual moral dimension to understanding these disorders. The clinical focus is typically on advanced phases of disorder (even in young people) where treatment can no longer be withheld, yet when it may be much less effective.

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

Crisis Assessment and Treatment Services are variable in their response. Family carers seeking early intervention can find it difficult to get an assessment from the CAT service until their relative has deteriorated to a point where inpatient admission may be the only solution.

(ARAFEMI Victoria, Victoria, Submission #230)

In Canberra, I tried to get access to mental health care when I was becoming unwell. The doctor estimated that I wasn't psychotic enough. The doctor told me they couldn't help as they didn't have the resources, but if I was becoming more unwell and reached a point where I couldn't leave my apartment then I should "give him a call". If people are that unwell these things are beyond them!

(Consumer, Australian Capital Territory, Canberra Forum #21)

On 4 December 2001, my wife discussed our daughter's condition with her treating psychiatrist, the MHU [Mental Health Unit] Psychiatric Registrar and MHU nursing staff, who agreed that the MHU did not cater for our daughter's then current mental state – she was not psychotic. At the request of my wife, and our daughter's clinical psychologist, our daughter was placed in the MHU lock-up ward for her physical protection. It was not until four weeks later, when our daughter's condition had significantly deteriorated, that she was "specialled". We later discovered by accident that "specialling" is normal procedure for vulnerable patients. It seems reasonable that early "specialling" for our daughter would have significantly reduced the severity, duration and cost of her confinement and prevented her ongoing loss of hair and teeth problems from unnecessary malnutrition.

(Carers, Parents, New South Wales, Submission #106)

I would like to comment on the fact that people with a mental illness are being arrested because often it's the only way they can get any help. They have a right to get care, not be arrested. We've got to get access to early intervention programs but it doesn't happen – now my brother is in the court system, not because he's bad but because he's got a mental illness.

(Carer, Sister, Western Australia, Bunbury Forum #24)

Lack of services for youth – no early intervention or mental health promotion possible

Youth mental heath services… At the moment there's no access to services at all – previously there was a 6-months waiting list – so the notion of early intervention or prevention doesn't exist for this community.

(Western Australia, Bunbury Forum #8)

Early intervention – families need to be heard

What is acceptable about a clinician making an assessment in a 15 minute appointment whilst ignoring the information of these same carers who are in the position of being far more sensitive to the signs of deterioration in the person for whom they care?

(Carer, Mother, Victoria, Submission #178)

Early intervention – involvement and role of GPs

At the Forum in the Melbourne Town Hall on Monday, I picked up a card saying "Mental Health-GP Business", and I'd just like to be sure that GPs now can pick up mental illness symptoms in young people. When my son was suddenly diagnosed at 21 with chronic paranoid schizophrenia, which was such a shock, we heard from him later that at 15 he'd been seeing our GP, because he knew there was something wrong. (he always had great insight), the Doctor felt he looked so well and fit, he sent him off.

(Carer, Mother, Victoria, Submission #211)

Prevention – substance abuse and mental illness need to be tackled jointly

Significant substance abuse problems exist in Aboriginal remote communities, resulting in significant mental health problems. .

(Anonymous, Northern Territory Submission #188)

Most participants reported taking drugs at early ages (12-14 years) and experiencing psychotic episodes some years later. Commonly, they did not seek help or recognise that they needed help. They reported having a vague understanding of what schizophrenia is but they failed to associate their own experiences with such a mental illness. In most cases, the first episode of their mental illness was diagnosed when they were brought into hospital by police and assessed and hospitalised in the psychiatric ward.

(NSW Association for Adolescent Health, New South Wales, Submission #98)

Preventing depression in older men

Men need more support – because they don't ask for help. There's nothing in this town for men – no support. My partner phoned his parole officer to ask for help because there was nothing else for him.

(Consumer, New South Wales, Broken Hill Forum #24)

More promotional strategies needed

There is a general lack of awareness and information about mental illness, so that those affected and their friends and family members may not realise that they are becoming unwell.

(Health and Community Services Network, Murray Mallee Strategic Task Force, South Australia Submission #115)

Need for education campaigns in schools

[Y] added there needs to be more education about mental and physical illness and disabilities in schools. They have sex education and drug awareness and healthy eating education at his school but he hasn't been to a school that talks about mental illness.

(14 year old Consumer and Carer (Son), Young Carers Forum Canberra #2)

Lack of rehabilitation programs

The lack of ongoing rehabilitation programs also means that we see a lot of young people, especially, being discharged after treatment but then without the necessary support, quickly becoming unwell again and the cycle constantly being repeated.

(Carer, Mother, Tasmania Submission #315)

This means that as there is no follow up people return to their previous bad state and so these clients have to repeat the whole the process.

(NGO Worker, New South Wales, Broken Hill Forum #5)

He had support through Eureka. He looked forward to it – he did it for 2 years then they told him he had to stop because there wasn't enough funding and someone else had to have a go. He got very depressed, very ill and became very violent. He broke someone's arm and was arrested and taken to the hospital.

(Carer, Tasmania, Hobart Forum #22)

There's a real lack of services to help people get back into society to rehabilitate.

(Clinician, Queensland, Brisbane Forum #7)

We have a son... with a mild intellectual disability… 22 years of age and remained in that job for ten years feeling a 'normal' part of the community… Due to all this floundering over the past two years our son now 34 has regressed to a point where he is now in a community care unit seeming as though he has lost all hope of getting anywhere, his hygiene medication and budgeting skills at an all time low. My husband and I both 70 are no experts in mental health but feel had there been positive intervention in the beginning instead of lying about home he would be less reliant on the medical system now, plus the government spending good money into these job agencies which are totally dysfunctional.

(Carers, Queensland, Submission #150)

The Health System's main approach to people with Mental Illness is to get them medicated and then very little else. There are no serious rehabilitation facilities.

(Carer, Father, Victoria, Submission #231)

5.7 STANDARD 7: CULTURAL AWARENESS

The MHS delivers non-discriminatory treatment and support which are sensitive to the social and cultural values of the consumer and the consumer's family and community.

Concern was expressed regarding the lack of culturally sensitive treatment and support for Indigenous people and people from a Non-English Speaking Background (NESB). For Indigenous people, access to care was reported to be complicated by discriminatory attitudes by some clinicians who often refuse treatment on the basis of prevailing stereotypes (for example belief in intoxication or drug misuse as the only cause of the behaviour). There were also reports by clinicians and carers that some staff impose their own spiritual and cultural beliefs on consumers by ridiculing consumers or passing judgment. Further there seems to be a failure to consider service delivery in the context of global Indigenous disadvantage and community needs

The need for specific training and employment of mental health workers with relevant experience appears to be an essential missing ingredient.

Nationally, the key issues relating to this Standard include:

- lack of culturally appropriate practices for NESB consumers (Standards 7.2 and 7.3);
- lack of culturally appropriate treatment and support services for Indigenous consumers and their families (Standards 7.2 and 7.3);
- lack of treatment and support services for older immigrants and newly arrived young people (Standard 7.1);
- problems with treatment due to cultural barriers and intellectual disability (Standard 7.3);
- social and cultural prejudice by staff towards Indigenous people with mental illness (Standard 7.5);
- need for cultural competency training (Standard 7.5);
- need for training of interpreters on mental health issues (Standard 7.3);
- utilisation of staff and services with expertise to provide services to consumers from a NESB (Standard 7.4);
- staff imposing their own religious and cultural attitudes on consumers (Standard 7.5);
- cultural background not being respected and considered in the delivery of treatment and support (Standards 7.1- 7.4);
- lack of sensitivity to spiritual beliefs (Standard 7.3); and
- the need to understand issues associated with recent immigration (Standards 7.1 – 7.4).

The following selected quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 7. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Lack of culturally appropriate treatment and support services for Indigenous consumers and their families

My son committed suicide 2 years ago. There are a lot of deaths here amongst Indigenous youth. Before he killed himself my son went to the mental health unit and they told me he was suffering from behaviour problems – the perception was that because he was an Indigenous young man that he was 'sloshed out'. We were told that he wasn't suicidal.

(Carer, Mother, Queensland, Rockhampton Forum #3)

When Indigenous people become unwell they are all put in baskets, they either have a mental illness or a drug and alcohol problem. There's no holistic care. There have been 20 close deaths in my family.

(Anonymous, South Australia, Murray Bridge Forum #15)

If the current mental health system works at its optimum level, there are still critical and serious service provision gaps. Anangu do not have access to a spectrum of interventions that are culturally appropriate and responsive to individual and / or community need. There is no access to counselling, grief and trauma support, early intervention programmes or ongoing rehabilitation programmes if someone has been diagnosed with an ongoing disability.

(Anonymous, Northern Territory, Submission #271)

Underlying this submission are several assumptions of knowledge:

- *Indigenous Australians have significantly worse health outcomes than the general population, including higher rates of mental health concerns*
- *The mental health concerns of indigenous Australians need to be viewed in the context of global disadvantage including poverty, reduced life expectancy and chronic ill health, as well as issues of cultural dislocation, trauma and grief.*
- *Anangu view mental health issues as part of a general concept that includes the health of the individual, family, community and land in a cyclic view of past, present and future.*

(Anonymous, Northern Territory, Submission #271)

By far and away the most prominent mental health concern facing the communities to which I travel [remote communities in Central and North West Queensland] are those of accumulated grief and loss and the intergenerational consequences of such losses. The history of colonization and cultural oppression represents over and over as symptoms of trauma, depression, drug and alcohol abuse, relationship breakdown and self harm. Tragically, the current, mental health system seems ill-equipped to deal, in culturally appropriate ways, with the complexities of Indigenous health.

(Clinician, Queensland, Submission #285)

Lack of culturally appropriate practices for NESB consumers

People who do not speak English as their first language have very limited access and their linguistic and cultural needs are not met.

(NESB Consumer Advocate, New South Wales, Parramatta Forum #8)

Anecdotal evidence further suggests a disregard within the system for the cultural and religious beliefs of people in patient psychiatric settings. Such anecdotes include no attempts to meet the dietary requirements of religious and cultural groups, and a complete lack of sensitivity to exposure of parts of the body and / or nakedness.

(Australian Nursing Federation (Vic Branch), Victoria, Submission #322)

Need for cultural competency training

Cultural competence doesn't exist at the level it's needed. No cultural competence is taught. Unless we make it as a core competency, it won't happen.

(Anonymous, New South Wales, NESB Parramatta Forum #14)

Staff imposing their own religious and cultural attitudes on consumers

[I] attended the hospital with a friend who had attempted suicide. This was after hours. When I took her to the A and E she was initially checked over for any physical effects of the overdose she had taken. She also reported that she had been abused as a child. The consulting doctor then talked to her at length about religion indicating to her that people who commit suicide "go to hell". This greatly upset my friend who was already very upset. She said later it made her feel guilty about what she had done…An understanding and non-judgmental attitude would also have helped.

(Clinician, Western Australia, Submission #333)

Lack of sensitivity to spiritual beliefs of consumers

Also it's insulting to not believe the spirituality of the consumer. My daughter has been ridiculed about her belief in God and how prayer helps her. This occurred in our Psychiatric Hospital here in Bendigo.

(Carer, Victoria, Submission #199)

Need for training of interpreters on mental health issues

Language and cultural barriers are often not overcome because skilled and experienced interpreters are not available. Also interpreters will often have to play a role as a bi-cultural worker, to bridge the gap in cultural understanding.

(Melaleuca Refugee Centre, Northern Territory, Submission #191)

5.8 STANDARD 8: INTEGRATION

5.8.1 STANDARD 8.1: SERVICE INTEGRATION

The MHS is integrated and coordinated to provide a balanced mix of services which ensure continuity of care for the consumer.

Concerns were expressed across Australia from consumers, carers and clinicians alike that mental health services are not integrated and coordinated due to a lack of resources, staff and planning. There is a perception that the situation is progressively becoming worse.

Reports also suggest that the mental health system is unable to provide a mix of services to respond to consumer needs, even during a crisis. This results in a reliance on the police for a response. Even with police intervention and assistance in taking people to appropriate care facilities, consumers were often sent home again without any arrangements for treatment or follow-up.

Treatment and support services for children and youth with mental illness across Australia seem to be almost non-existent. Submissions suggest that there are either no services at all or extremely long waitlists (for example, a nine to ten month waiting list for children with mental illness to get into care). Thus the need for integrated and coordinated care for this group is particularly pressing.

Many General Practitioners spoke of their willingness to be involved in the provision of mental health treatment and support, but noted difficulties in doing this without the necessary professional support.

High staff turnover and frequent staff rotations between programs and sites was also mentioned as a difficulty in providing continuous and coordinated care. Consumers report that they are tired of repeating their story and frustrated at being passed from one doctor to another. Fragmented service delivery and breakdown of links with NGO service providers seems to be another consequence of the scarcity of resources.

Nationally, the key issues relating to this Standard include:

- MHS not integrated to provide the mix of services required to respond to consumer needs (Standard 8.1.1);
- MHS not providing continuity of care for consumers (Standard 8.1.5);
- more staff and resources are required for integrated service to respond effectively to crises (Standard 8.1.1);
- chronic under-resourcing of MHS resulting in inability to deliver integrated and coordinated care (Standards 8.1.1 and Standard 8.1.2);
- difficulties in organising integrated and coordinated care with components of the MHS (Standards 8.1.2 and 8.1.3);
- lack of staff and resources to provide integrated care to rural and remote communities (Standard 8.1.1);
- shortage of mental health staff to provide integrated care across settings and programs (Standards 8.1.2 and 8.1.3);
- difficulties accessing case managers (Standard 8.1.1);
- inability to provide coordinated continuous care due to high staff turnover and staff rotations, especially in rural and regional areas (Standard 8.1.4);
- no continuity of care leads to lack of communication (Standards 8.1.3 and 8.1.6);
- lack of cooperation within MHS leads to poor attitudes towards rural and regional patients and providers (Standards 8.1.1 and 8.1.6);
- lack of mental health services for children and youth (Standard 8.1.5);
- problems with continuity between adolescent and adult mental health services (Standard 8.1.5);
- problems with link between General Practitioners and mental health services (Standard 8.1.6);
- problems with integration with NGO services (Standard 8.1.5);
- general Practitioners lack the skills to treat people with mental illness or mental health problems. (Standard 8.1.5);
- inability of MHS to deliver coordinated and integrated services to consumers from a non-English speaking background (Standard 8.1.1);
- inability of mental health teams to provide services resulting in reliance on police force (Standard 8.1.1); and
- problems with Schedule II procedures and integrated and coordinated care (Standard 8.1.6).

The following limited selection of quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 8.1. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

MHS not integrated to provide the mix of services required to respond to consumer needs

[X]… is escorted to the emergency department of the local hospital… [Y]… assessed [X] to be at high risk of suicide. No admission and no follow-up is arranged. Additionally, no contact was made with the referring agency and according to [X], no request of discussion with the referring agency was sought by mental health services.

(Support and Equity Services, Charles Darwin University, Northern Territory, Submission #269)

Lack of communication and co-operative case management between inpatient and outpatient hospital staff can cause serious errors in treatment. At one time [X] was in hospital for 4-5 days before the inpatient staff knew what the treatment orders were!

(Carer, Mother, Victoria Submission #320)

Chronic under-resourcing of MHS resulting in inability to deliver integrated and coordinated care

This support is not being provided and has been progressively withdrawn over the last several years. The patients are constantly disappointed by the diminished level and duration of service as provided by the state funded public psychiatric system.

(Clinician, Victoria, Submission #123)

Some of the issues that matter are poor accessibility, lack of access to private practitioners, lack of bulk-billing GPs and lack of accessibility to counselling services particularly for people with high prevalence disorders.

(NGO worker, Victoria, Morwell Forum #7)

Lack of staff and resources to provide integrated care to rural and remote communities

I have been advocating for improved psychiatric services in this region for 8 years now. Over 1/3 of our GPs have undertaken additional training. But there's no psychiatrists East of Dandenong! As GPs we have little to no support from the specialist sector.

(Clinician, Victoria, Morwell Forum #8)

More staff and resources are required for integrated service to respond effectively to crises

4 weeks ago a young man came to see me. He was suicidal, he had several crises in his life he was trying to deal with and he had been self-medicating. I see many people like him – they are not bad people but people who need assistance from society. I managed to get him assessed by a crisis assessment service – that in itself was a really big win! But the crisis service was going to send him home with some phone numbers. Fortunately I had organised to see him and got irate and asked them how they would feel if this young man was dead in the morning.

(Clinician, Queensland, Brisbane Forum #7)

I have a friend who had a mental breakdown… I rang the mental health team and they couldn't see her for 5 days no appointment for 3 to 4 weeks. The GP tried to cope. Good clinicians took details but 3-4 weeks later was asked the same questions again. There is a lack of staff – the team in community and lack of coordinated services.

(Anonymous, Western Australia, Geraldton Forum #65)

The community staff are stretched to the maximum and their resort is to tell people to go to their GP or access an emergency service (was one very recent answering machine message I happen to hear when I was trying to contact a community health worker. Mind you, no information about how to contact the emergency service was part of the message.)

(Consumer and Consumer Advocate, New South Wales, Submission #8)

MATT (mobile assertive treatment team) – work with severely sick psychotic people to keep them out of hospital – only one team with 7 staff who see 70 clients for the Central Sydney area which has 5000 consumers, 500 of whom would benefit from seeing the MATT team, which provides intensive case management, support, counselling and supervision

*(*Consumer and Consumer Advocate, New South Wales, Submission #169*)*

Shortage of mental health staff to provide integrated care across settings and programs

[[X] went] to a psychologist just 2 months before he died - who referred [X] to a psychiatrist - but unfortunately the psychiatrist was away on holidays - so he couldn't get an appointment - in the detailed referral it was obvious to blind Harry that [X] was screaming out for help he had in a one hour session with the psychologist relayed every vital piece of information in regard to his condition. [X] should never have been allowed to leave that psychologist's office - in the referral it said he had a (suicide) plan - it wasn't the first time etc etc.

(Carer, Mother, New South Wales, Submission #122)

Lack of mental health services for children and youth

I've been on a few committees and it's not the service providers who are the problems; they are on our side. It's the politicians and our government that are negligent… There's a 9-10 month waiting list for mentally ill children to get into care.

(Consumer, Western Australia, West Perth Forum #41)

Problems with continuity between adolescent and adult mental health services

Young people 16-17 come and see us but we do some transitioning to the adult mental health service also. There is a period when there's nothing for young people during this transition.

(Clinician, South Australia, Murray Bridge Forum #14)

Inability to provide coordinated continuous care due to high staff turnover and staff rotations, especially in rural and regional areas

He has a different social worker every three months and suffers from psychotic episodes. He finds it difficult to trust people and the constant changes to the social worker assigned to his case are not helpful.

(17 year old Carer, Sister, Australian Capital Territory, Young Carers Forum Canberra #1)

The lack of consistency with being passed from one trainee doctor to another. Where we are the doctors change every three months

(Carer, Victoria, Submission #199)

More than once the police local have said that it is not their problem and we should call her mental health worker, who is 100kms away and never able to take our call because she is so busy she is rarely in the office. More often also, the mental health worker who is in charge of my mother's care, changes twice a year, and she is periodically moved between the West End Mental Health Clinic to the one at Ashgrove (I can never remember if it is Ashmore or Ashgrove).

(Anonymous, Queensland, Submission #82)

[Y] has depression and no longer accesses counsellors through ACT government services. [Y] explained the counsellors in the government system change a lot so he had to keep starting from the beginning and moving to a point in his story, when the counsellor would be replaced with another, and he would have to start again. [Y] said he found this really frustrating. [Y] said the counsellors in the government services didn't know why they were swapped around.

(14 year old Consumer and Carer (Son), Australian Capital Territory, Young Carers Forum Canberra #2)

Problems with link between general practitioners and mental health services

There were a number of GPs in Bunbury who wanted to be involved with the mental health unit but only if there was adequate support. We don't have that support anymore.

(Clinician, Western Australia, Bunbury Forum #19)

One can usually find a specialist physician or surgeon to follow up difficult cases, offering whatever support they can. As a GP, I find it frustrating when psychiatrists will not do likewise. It appears that psychiatry operates in a comfort zone that conveniently defines the most troublesome and least lucrative cases as outside their concern. I often diagnose a life-threatening personality disorder but can't arrange any specialist support.

(Clinician, Queensland, Submission #49)

MHS not providing continuity of care for consumers

The attempts to shore up the interfaces between GPs and specialist care are appropriate however most of their work is with so-called high prevalence or non-psychotic disorders, and sadly there is no longer expertise in the specialist system to help them to manage the more challenging of these disorders. In fact a team approach rather than a solo GP or even a solo private psychiatrist is needed for many of these cases.

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

However, GPs have limitations on the time they can spend with patients and the level of service that they can provide. Both of these areas are aspects of the system where GPs need support to provide home care and follow up services to patients being treated by the GP. This area has in the past been one where local public mental health services have been utilized.

(Clinician, Victoria, Submission #123)

Problems with integration with NGO services

The sector is currently very fragmented. Continuity of care between Government services and NGOs is difficult to maintain given the current restrictions of time and scarce resources.

(Anonymous, Tasmania, Submission #254)

There's a real breakdown between NGO and public services. The Government is happy to treat NGOs as extensions of services but not fund them accordingly. In fact the Government has cut funding to NGOs and still expects that the NGOs will carry the load. I have had to put a ban on all referrals from services. We're now in a position where we are rationalising our services. We don't like it but we have to run our service within the resources we have to work with… My service has a budget of $400,000 / year but our funding hasn't increased since early 1990s.

(Clinician, New South Wales, Sydney Forum #3)

Difficulties in organising integrated and coordinated care with components of the MHS

The mental health system failed [X] in so many ways. In summary the key failings were: Third, was lack of integration across the various mental health areas, such as the hospitals and the mental health crisis team, and related areas such as Drug and Alcohol services and accommodation facilities: we are a very "bureaucracy-literate" family and we had immense difficulty navigating the system.

(Carer, Sister, Australian Capital Territory, Canberra Forum #9)

I do not refer to Mental Health Services because of past experiences, particularly as they will not see people who have a drug problem. I use GRAMS [Geraldton Regional Aboriginal Medical Service] where possible.
(Anonymous, Western Australia, Geraldton Forum #94)

5.8.2 STANDARD 8.2: INTEGRATION WITH THE HEALTH SYSTEM

The MHS develops and maintains links with other health service providers at local, state and national levels to ensure specialised coordinated care and promote community integration for people with mental disorders and / or mental health problems.

Across Australia, there were concerns about the neglect of the physical health of people with mental illness. A focus solely on the mental health of many consumers resulted in holistic care being ignored, including in inpatient settings where patients are often required to be transferred to general hospital wards to address their deteriorating physical health conditions. Difficulties in obtaining physical health assessments and access to general practice were also noted.

Research identifying elevated death rates in all main causes of death for people with mental illness, compared with the general population, was noted as a critical indicator of this neglect.

There have been suggestions that comprehensive care is only available to those who can afford to 'purchase care' in the private sector.

It was also reported that for Indigenous people with mental illness and / or mental health problems, poor physical health meant that mental health care was not being addressed as a priority or at all.

Problems with access to General Practitioners (GPs), barriers between GPs and psychiatrists and interagency collaboration are all complicating the provision of comprehensive care.

Nationally, the key issues relating to this Standard include:

- physical health care neglected (Standard 8.2.1 and 8.2.5);
- physical health care neglected in inpatient settings (Standard 8.2.1 and 8.2.5);
- problems with integrated and continuous care when consumers are admitted to hospital for physical illnesses (Standards 8.2.1, 8.2.3 and 8.2.4);
- comprehensive care only obtainable from the private sector (Standard 8.2.1 and 8.2.5);
- comprehensive health care not promoted (Standard 8.2.1 – 8.2.4);
- inability of consumers to afford basic heath care (Standard 8.2.1 and 8.2.5);
- For Indigenous people, mental health care is neglected due to poor physical health (Standard 8.2.1 - 8.2.5);
- lack of access to services to meet physical health needs (Standard 8.2.1, 8.2.2 and 8.2.3);
- problems with accessing General Practice (Standard 8.2.4);
- the need to improve arrangements with Psychiatrists and General Practitioners (Standard 8.2.4); and
- problems with interagency collaboration (Standard 8.2.4).

The following limited selection of quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 8.2. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Physical health care neglected in inpatient settings

However on 4 January 2002 (following our threats to involve the media), she was transferred to a medical ward, having become psychotic and also because she had acquired dehydration, malnutrition, severe carpet thrush and split and bleeding heels. These four new conditions had developed in the MHU whilst she was under the "care" of staff. We believe that our daughter's mental and physical states are inseparable as regards duty of care, and we vigorously question the therapeutic efficacy of the Liverpool Hospital Mental Health Unit.

(Carers, Parents, New South Wales, Submission #106)

On three occasions my son [X] has been admitted with physical problems which either had not been noted on admission or were ignored even when they had been noted. On one occasion he went three days before the symptoms were properly addressed. The end result was an emergency operation for the removal of a salivary gland with embedded calcium stones.

(Carer, Wife and Mother, Queensland, Submission #52)

Physical health care neglected

Because [X] my wife was having active mental health problems with her schizophrenia and that she was poorly controlled while under the CTO [Community Treatment Order] a decision was made not to treat her with either chemotherapy or radiation to me that is a Human Rights issue, even the HSC [Health Services Commissioner] office told me that there 15 to 18 other such cases in Victoria like our case.

(Carer, Husband, Victoria, Submission #179)

Access to services will also be discussed below but it seems appropriate to raise the issue of general medical treatment here. It is reported, by people who have a psychiatric illness, that it can be very difficult to have physical illness concerns taken seriously by main stream health providers—too often their concerns are dismissed as 'just the symptoms of their mental illness'. One young woman who participated in the consultations spoke of the difficulty she had convincing her general practitioner that she was unwell—after a number of months she sought other advice and was diagnosed as having diabetes. Other consumers spoke of the difficulties they had experienced in emergency departments—as soon as doctors saw their file and read 'mental illness' consumers felt they were dismissed and some even reported having been sent home without speaking to a doctor. Discrimination is not something that is only experienced among the 'uneducated' broader community; it clearly even exists within the health and welfare community.

(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

Comprehensive care not promoted

Among a series of similar studies internationally, the crucial Duty to Care study from Western Australia (Coghlan et al 2001) showed that people with serious mental disorders, especially schizophrenia, had considerably elevated death rates from all main causes of death, with heart disease topping the list of causes ahead of suicide. Not only is the prevalence of these disorders increased, but they are diagnosed late and treated inadequately. This pattern of premature death and substandard medical care is characteristic of marginalised and disadvantaged sections of the community and demands urgent action.

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

Inability of consumers to afford basic heath care

Consumers and carers reported that the most basic of health care is often out of the reach of people experiencing mental illness and sometimes also out of the reach of members of their families. In particular, greater and free access to the following services and professionals is required: GPs; Specialists; Non-urgent, non-life threatening or elective procedures; Dental care; Foot care; Skin care; Optometrists, physiotherapists and psychologists etc.

(Mental Health Community Coalition Consumer and Carer Caucus,
Australian Capital Territory, Submission #342)

Lack of access to services to meet physical health needs

Since the closure of the institutions there has been a large influx of people into this community. But these people need access to other health services for their physical and mental health needs – they often get sent on buses and taxis to Adelaide for care.

(Police Officer, South Australia, Murray Bridge Forum #16)

There's also very poor access to physical health assessments for people with a mental illness.

(Clinician, Queensland, Brisbane Forum #7)

Problems with interagency collaboration

In defence of mental health services, there has been a big effort to liaise with NGOs – there have been significant efforts made in the last few years to get better community integration of mental health services. But the high turnover of staff it makes it very hard to establish those relationships and collaborations and hard to get the protocols right.

(NGO, New South Wales, Broken Hill Forum #10)

The need to improve arrangements with general practitioners

If people do attend for help for anxiety disorders or depression it is usually to the GP where the response is usually to offer medication only. GP's are generally unaware of other services that are available. People need to know the range of treatment options for their condition as one would expect with any physical illness. GP training in CBT [Cognitive Behavioural Therapy] is also useful and hopefully will mean earlier intervention for many people, however significant numbers of people with anxiety disorders and depression have complex histories and require longer and more specialised help.

(Clinical Service Provider, Victoria, Submission #268)

5.8.3 STANDARD 8.3: INTEGRATION WITH OTHER SECTORS

The MHS develops and maintains links with other sectors at local, state and national levels to ensure specialised coordinated care and promote community integration for people with mental disorders and / or mental health problems.

Concerns were expressed nationally that in order for the rights of people with mental illness to be protected and promoted, a whole-of-government approach was needed to tackle the myriad of problems facing consumers and their families.

Collaborative arrangements were identified as vital to enable consumers and their carers to participate socially, economically and politically in society. Many consumers required assistance beyond mental health care in a hospital. For example many mentally ill persons need financial support, access to home and community care (for those choosing to live independently, or with their family at home), or access to a range of short and long-term housing and supported accommodation options.

The large deficit in available housing and supported accommodation was cited as a critical barrier to successful rehabilitation and integration into community life for consumers and a critical burden on families who are not being compensated or supported to provide interim support.

The nexus between poverty and mental illness for consumers and their families was also cited repeatedly. Many consumers reported that they and their families living were below the poverty line and had insufficient money to pay for medication and food.

Consumers noted the scarce number of bulkbilling clinicians. They also highlighted the problems caused by an absence of Medicare rebates for psychologists.

For consumers, financial hardship was also often due to interrupted ability to work or difficulties in gaining and maintaining employment. Some of the barriers to employment include high levels of stigma and discrimination in the workplace and lack of workplace supports. To address this, the need for a whole-of-government approach to tackle employment and education-related issues was cited as an area requiring urgent attention.

For carers, the high burden of caring for a family member as a result of lack of access to treatment and support services also disrupted their ability to gain and maintain employment.

Intersectoral links and collaboration with police, court liaison and prison services were also cited as critical to provide appropriate alternatives for the increasing number of people with mental illness who are coming into contact with the police. Without better coordination there will be little success in diverting those who would otherwise enter the criminal justice system.

Youth, wards of the State, people requiring guardianship and people with disability are all disproportionately impacted by the failure to provide holistic care and integrated services for people with a mental illness.

The need for cross-border agreements was also raised to improve service delivery for consumers in rural and remote areas.

Nationally, the key issues relating to this Standard include:

- the need for a whole-of government response for consumers and families (Standards 8.3.1 and 8.3.3);
- the lack of housing and accommodation options for people with mental illness and mental health problems (Standards 8.3.2 and 8.3.3);
- the need for a whole-of government response for youth (Standard 8.3.1 – 8.3.3);
- lack of coordinated care across sectors for older people with mental illness (Standard 8.3.1 – 8.3.3);
- integration with police services and the criminal justice system (Standards 8.3.2 and 8.3.3);
- the need for a whole-of government response to tackle employment (Standard 8.3.3);
- whole-of-government approach needed to tackle poverty and mental illness (Standards 8.3.1 – 8.3.3);
- lack of support from Centrelink (Standard 8.3.3);
- Welfare support – problems with carer allowance and disability support pensions (Standards 8.3.1 – 8.3.3);
- lack of support for families (Standards 8.3.1 – 8.3.3);
- lack of access to home and community services (Standard 8.3.3);
- whole-of-government approach to specifically care for children who have become Wards of the State (Standards 8.3.1 – 8.3.3);
- the lack of cross border agreements (Standard 8.3.3);
- need to integrate mental health strategy with drug strategy (Standard 8.3.3);
- lack of support from departments dealing with disability (Standards 8.3.2 and 8.3.3);

- lack of support from departments dealing with community services (Standards 8.3.2 and 8.3.3);
- whole of government approaches needed to improve mental health outcomes for Indigenous communities (Standards 8.3.1 – 8.3.3);
- transport (Standard 8.3.3);
- education (Standards 8.3.1 – 8.3.3);
- higher education (Standards 8.3.1 – 8.3.3);
- guardianship (Standards 8.3.1 – 8.3.3);
- emergency services (Standards 8.3.1 – 8.3.3);
- medicare rebates (Standard 8.3.3);
- affordability of care – lack of bulk billing clinicians, cost of psychiatrists and psychologists, private health insurance and medication costs (Standard 8.3.3);
- national strategies to increase the number of mental health professionals (Standards 8.3.3);
- need to address training and support issues for mental health nurses and general practitioners (Standard 8.3.3); and
- national legislative reform of anti-discrimination legislation to cover vilification and harassment (Standard 8.3.3).

The following limited selection of quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 8.3. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

The need for a whole-of government response for consumers and families

People with a mental illness and long term disability resulting from such illness impact heavily on the justice, drug and alcohol, housing and welfare systems as well as the health system. The failure to provide adequate support services has resulted in an overrepresentation of people with a mental illness among the homeless and in the criminal justice system. MIFA calls for structural reform of services, which incorporates a whole of government approach to address the structural impediments and the failure to provide sufficient support systems to address the overrepresentation.

(Mental Illness Fellowship of Australia, National Submission #331)

My concern arises from the criminalisation of mental illness. Some people with a mental illness are being punished over and over again. Housing and support for these people has been so neglected that approximately 400 are now housed in mainstream prisons in south-east Queensland.

(Anonymous, Queensland, Submission #67)

NCOSS is extremely concerned about the poor coordination of mental health issues, which is occurring across Government agencies in NSW, including poor linkages between specialist mental health services and other Government services. Health consumers and community organisations participating in NCOSS forums have repeatedly raised the need for closer and more consistent integration between mental health services and other Government services.

(NCOSS, New South Wales, Submission #47)

I have also long advocated the need for Mental Health Impact Statements (analogous to Environmental Impact Statements) to be prepared as a component of planning services / projects. The purpose being to draw attention / make conscious the contribution (or lack thereof) of matters under consideration and to educate us all as to how pervasive is our neglect (or otherwise). Whether it be housing, fostering programs, recreational facilities / programs, religion based plans, setting up a business, claimed therapeutic practice, governmental proposals, or whatever. This may well get up a few noses, including our own, with benefit!

(Clinician, New South Wales, Submission #154)

Where is it? The organisation I work for has tried for the last decade to supply appropriate, affordable ***supported*** *accommodation for people with a mental illness / disability. We are exhausted, frustrated and generally confused by the inflexible poorly coordinated Government Departments that should be providing service to people with a mental illness. It seems to me that no single Department has the ability or inclination to play the lead role in the provision of service to this client group. (author's emphasis)*

(NGO Service Provider, Queensland, Submission #40)

People with mental health problems and their families do not go away if the government does not provide services for them. Instead they go or are brought to other service systems. This phenomenon is most obvious as people with mental health problems are stranded in the emergency departments of hospitals. However General Practitioners, Police, Schools, the Correctional system and Community Groups all report increasing numbers of people with mental health problems they encounter who cannot get adequate assistance.

(Health and Community Services Union, Victoria, Submission #220)

The lack of housing and accommodation options for people with mental illness and mental health problems

There's a high level of homelessness. People ring up and say I've got $35 left to last me for the week and my medications will cost me $38. I've got no food and I won't get my pension until next week. What should I do? How can I survive?

(Consumer Advocate, Victoria, VMIAC Forum #3)

Living on the street further complicates matters by making it difficult for mentally ill person to receive follow-up services. Without this and ongoing care, these individuals stop taking their medication and sooner or later, end up having a run in with law enforcement. It is at this point that, what was once the institution's mental health problem, now becomes a police problem.

(Police Association of New South Wales, New South Wales, Submission #59)

There's a real revolving door syndrome – people get admitted, they get treatment and then they get discharged but because there's no supported accommodation for them they keep coming back into the hospital.

(Clinician, South Australia, Murray Bridge Forum #5)

We have 12 houses and a boarding house for single men so we can take in 18 men. I have worked in human services for the last 16 years and I can tell you that we are now on a path to disaster – people are being 'dumped' on our service and on the streets because other people don't know what to do with them. They are sent here by the service or the hospital with no consultation with us – they are just told where to go, how to find us.

(Service Provider, Western Australia, Bunbury Forum #12)

In the inner suburbs of Melbourne some 'unofficial' rooming houses operate, offering sub-standard accommodation to vulnerable people living with a mental illness. The BSL provides services to some consumers who do not have access to reasonable bathroom or kitchen facilities, a situation that should not continue to exist today. Without access to stable, safe and affordable housing it makes it extremely difficult to treat people for their psychiatric illness. The Victorian Homeless Strategy 2002 reported that long term housing and support for people with a mental illness drastically reduces inpatient stays (VHS 2002,p.7) —providing this housing must be a government priority.

(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

People on a Disability Pension for Mental Illness, are paid an allowance and left to their own devices. There isn't enough funding for supported accommodation or even subsidized housing. If you want a Minister of Housing accommodation, it's a 12-18 YEAR! wait. What are people supposed to do in the meantime?

(Carer, Mother, Victoria, Submission #352)

Whole-of-government approach needed to tackle poverty and mental illness

This nexus between poverty and serious mental illness extended to the lives of the carers. The task of caring for people with serious mental illness tends to fall heavily on their families, usually parents. This research highlights the high toll taken in terms of their health in addition to their social, emotional and financial wellbeing. The dollar cost of care is no measure of the real price of anxiety and grief expressed by carers, yet it is a significant and largely unmeasured impost on families. This report documents the real cost for carers of providing accommodation, food, clothing and support to people with serious mental illness. This significant cost remains largely hidden, picked up by carers, who, if they are themselves on a low fixed income, may be forced on to income support, emergency relief services, charities, and crisis accommodation services. In addition to the financial impost of caring, carers report a critical lack of support in the form of community-based ser vices, clinical, counselling, information and respite options. In particular they identified the lack of appropriate supported accommodation which denied their adult son or daughter the chance to live a meaningful independent life.

(Anglicare Tasmania, "Thin Ice: Living with Serious Mental Illness and Poverty in Tasmania", Tasmania, Submission #144)

Lack of access to home and community services

Some support services such as some Home and Community Care programmes still discriminate against people with mental illnesses by denying them access to needed services for a range of reasons i.e. 1) lack of knowledge about mental illness and how to care for those effected 2) lack of understanding of their needs and the way in which certain conditions affect their ability to care for themselves, i.e. an attitude that a person is lazy when they lack the motivation to clean their home.

(Anonymous, Tasmania, Submission #254)

Lack of support for families

…plight of children who have one or both parents who suffer a mental illness. I would like to see more attention and assistance for these children, many of who have a very heavy load to bear, and are often quite isolated. There is great shortage of any help or accommodation for children when parents are unwell, or in hospital.

(Carer, Victoria, Submission #185)

Some programs require that carers pay for their own education and support. Families have in effect been told that they are part of the mental health workforce and indeed they save the federal government billions of dollars per year. Yet lack of direct funding for carers of people with a mental illness including for education programs, support services and carer consultants sends the message that carers' requirements are not valid in their own right and that it is up to them to deal with the fallout from de-institutionalisation.

(The Network for Carers Of People With A Mental Illness, Victoria, Submission #319)

Education sector

Our core business is education – we identify children with intellectual disability but not psychiatric disability. We are not funded to support these kids. We can provide inclusive resources but we can't really do it properly. Generally they are just piece meal packages. I have staff using the expulsion / suspension guidelines to exclude these kids… Because of a lack of services there's nothing left but to exclude these kids. Actually they really need care.

(Teacher, South Australia, Murray Bridge Forum #17)

Welfare support – problems with the Carer Allowance and Disability Support Pension

As a carer, I cope reasonably well, but being retired and on a pension, our income is limited, so I work part-time. At times I am stretched mentally and physically, and often feel depressed myself.

(Carer, Husband, Victoria, Submission #247)

They pay us an inadequate amount a fortnight to do a job they know we are unqualified and ill-equipped for, when they are the ones who should be providing us with the people and services to care for our families properly.

(Carer, Mother, Victoria, Submission #352)

Whole-of-government approach to specifically care for children who have become Wards of the State

…children were displaced into the adult mental health system and are still suffering from our incarceration, many of us were under the care and protection of the state, But unfortunately we were overlooked by the Forde inquiry because although we originated in children's homes and suffered there, we were thrown to the wolves! ,adult institutions were not part of the ford inquiry, which sucks because at thirteen wasn't I still a child with the right to be protected from rape, vicious attacks, exposure to violence and the incredible suffering of others, forced drug addiction, inhumane and degrading punishment, emotional and mental torture, terrifying treatment such as ECT chemical torture (servier dystonic reaction with bronchial collapse) what does this mean EXCRUCIATING PAIN AND MENTAL ANGUISH." (author's emphasis)

(Anonymous, Consumer, Queensland, Submission #300)

Lack of cross-border agreements

Lack of co-ordination between State Governments can lead to services gap and duplication. With the exception of the South Australian & Northern Territory agreement there is no coordination of services, increasing the risk of service duplication. It also means that more cost effective, co-ordinated, innovative service options are not explored.

(Anonymous, Northern Territory Submission #271)

The need for a whole-of government response to tackle employment

The Commonwealth should be seriously committed in assisting people with psychiatric disabilities in gaining employment and as a matter of urgency should consider: (1) new employment policies for people with psychiatric disabilities; (2) alternate employment models as a way of providing more appropriate assistance and choices; and (3) new measures to increase labourforce participation.

(Disability Employment Action Centre, Victorian Submission #209)

Integration with police services and the criminal justice system

The public mental health system and the criminal justice system must collaborate so that police officers have several alternatives, not just arrest or hospitalisation, when handling mentally ill persons in the community…

(Police Association of New South Wales, New South Wales, Submission #59)

Despite the existence of an official Memorandum Of Understanding between police and mental health services in the ACT, consumers and families reported that there appears to be a need for clarification of responsibilities on a daily basis and at 'ground zero'. It is reported that mental health services frequently refuse to act and families report they are told by mental health services to phone the police.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

Solicitors may have poor knowledge of mental health issues. A court liaison officer works at the Brisbane courts but mental health clients appearing at other courts have no access to this service.

(Anonymous, Queensland, Submission #67)

National legislative reform of anti-discrimination legislation to cover vilification and harassment

In most parts of Australia it is unlawful under anti-discrimination Acts to vilify people on the grounds of race, religion, sexuality or gender identity. In NSW it is also unlawful to vilify people with HIV / AIDS. Under current Australian legislation, however (apart from Tasmania), people with a psychiatric or other disability do not enjoy this protection. It is totally unacceptable that vilifying the mentally ill remains a legal activity in mainland Australia.

(SANE Australia, National, Submission #302)

Need to address training and support issues for mental health nurses and general practitioners

In 1993 in Victoria, the separate psychiatric nurse degree was abolished, and merged with the comprehensive nurse training degree. This has meant that the mental health component of undergraduate nurse training is as little as 3% in some courses… This has a direct impact on the quality of care offered to consumers, and the capacity of services to meet care needs with appropriately trained staff.

(Centre for Psychiatric Nursing Research and Practice, Victoria, Submission #323)

Affordability of care

There are noticeable differences between the private and parts of the public mental health systems with respect to attitudes to treatment. Money appears to be a major driver here although workforce culture and age profiles, differing financial controls and the evolution of new patterns of illness and new opportunities for treatment all play their part. We have reached a situation in this country where the public in-patient services are geared to short term, crisis management. These services are also restricted in the sense that by the population of patients that is receives treatment is essentially made up of persons with psychotic disorders and persons who are considered to be at risk of suicide. For too many this access to specialist treatment and care is also transient and upon discharge to private GPs enter the process. Issues like bulk billing, surgery hours, GP interest, geographic location of residency etc. then take their toll.

(Anonymous, Victoria, Submission #318)

5.9 STANDARD 9: SERVICE DEVELOPMENT

The MHS is managed effectively and efficiently to facilitate the delivery of coordinated and integrated services.

Problems with accountability and declining levels of consultation with consumers, carers, staff and service providers in the planning and delivery of care were noted as serious areas of concern across Australia. Sudden closure of community services and decisions to relocate community services back to hospital settings, without consultation, were cited as examples of this trend.

The lack of funding and resources and problems with the distribution of resources across metropolitan, regional and rural areas were described as critical factors in the inability of mental health services to deliver quality care. Consumers, carers and clinicians alike described services which were struggling to cope with increasing workloads without parallel increases in funding, staffing levels and resource allocation. Instead, reports were received that services were non-existent, inaccessible or declining in quality.

A significant number of carers reported increasing reliance on them as 'cheap resources' and 'slaves', there to provide the support to consumers that is not being provided by mental health services.

Many staff reported feelings of 'burnout'. High staff turnover and inability to recruit and retain staff were seen as indicators of the stress being experienced by staff due to lack of resources, funding and support to deliver services. This was acutely evident in rural and remote areas. The lack of community-based services and the model of care underpinning service delivery were also reported as factors inhibiting improved service delivery. The current model was described as overly emphasising the medical model of care, as focusing on crisis intervention and 'custody and control'. The perceived trend towards requiring consumers to pay for care was also noted by some as a key area of concern to be addressed.

Nationally, the key issues relating to this Standard include:

- the poor quality of existing services and the lack of appropriate services (Standards 9.22, 9.24, 9.28, 9.29, 9.30, 9.33 and 9.34);
- distribution of resources (Standard 9.14-9.16, 9.33. 9.34);
- service development issues in rural and regional areas (Standard 9.33 and 9.34);
- lack of resources, treatment and support services in rural, regional and remote areas (Standard 9.7-9.11, 9.14-9.16, 9.33, 9.34);
- services ever diminishing in rural and regional areas (Standard 9.7-9.11, 9.14-16, 9.29, 9.33 and 9.34);
- consumers, carers, staff and service providers not involved in planning and delivery of services (Standard 9.8);
- lack of planning to provide continuous care (Standards 9.4. 9.5, 9.7-11);
- lack of resources to deliver quality mental health care (Standards 9.14-9.16, 9.33, 9.34);
- lack of resources to support community-based care following deinstitutionalisation (Standards 9.14-9.16, 9.33, 9.34);
- a greater focus needed to meet the needs of Indigenous people with mental illness and mental health problems (Standards 9.4, 9.5, 9.14-9.16, 9.33, 9.34);
- low regard for psychogeriatric planning, policy development and funding (Standards 9.7-9.11, 9.14-9.16);
- lack of funding and services to meet the needs of young people (Standards 9.7-9.11, 9.14-9.16)
- more services required to support young carers (Standards 9.7-9.11);
- staffing issues including supply, education and training (Standards 9.16-9.21);
- low quality of services associated with staff shortage (Standard 9.4, 9.16, 9.17-9.21, 9.28, 9.29, 9.30, 9.33, 9.34);
- lack of resources and staff and the impact this has on staff and their work practices (Standard 9.8, 9.15, 9.16-9.21, 9.29);
- recruitment and retention of staff in rural and regional areas (Standards 9.6, 9.14-9.16, 9.29);
- staff recruitment and retention issues in general (Standards 9.6, 9.14-9.16, 9.29);
- lack of funding (Standards 9.14 and 9.15);
- funding model needs to change (Standards 9.14 and 9.15);
- lack of funding and support for critical services provided by NGO's (Standard 9.8, 9.14-9.16, 9.29);
- problems with funding arrangements for service providers (Standards 9.14-9.15);
- loss of clinical leadership (Standards 9.1-9.3 and 9.5);
- problems identified with the loss of a coherent vision and direction (Standard 9.1-9.5, 9.14, 9.15, 9.33, 9.34);

- the model of mental health care needs to change as there is an inappropriate focus on inpatient and crisis care (Standards 9.14, 9.15, 9.22, 9.24, 9.29, 9.30, 9.33, 9.34);
- lack of resources and services is resulting in reinstitutionalisation of people with mental illness (Standards 9.14 – 9.15);
- problem with 'custody and control' model of care (Standard 9.14 and 9.15);
- an inappropriate focus on the medical model for service delivery including concerns about the relocation of community based services back to hospital sites (Standards 9.7-9.10, 9.14-9.16, 9.29, 9.30);
- lack of community based support or prevention focus (crisis model of care) (Standards 9.7-9.10, 9.14-9.16, 9.29, 9.30);
- carers are shouldering the burden of services which should be provided by the MHS (Standard 9.15);
- staff attitudes (Standards 9.17-20);
- lack of skilled staff (Standards 9.16-20);
- staff training and development needed (Standards 9.17-9.20);
- lack of education and training of workforce (Standards 9.16 and 9.18);
- training programs for GPs (Standard 9.16 and 9.18);
- need for more graduate programs and supervision for mental health nurses (Standards 9.17-9.20);
- education and training of mental health staff (Standards 9.16-9.20);
- the dismantling and subsequent "imploding" of working services (Standards 9.1-9.3, 9.5, 9.8, 9.10, 9.14, 9.24, 9.29, 9.33, 9.34);
- lack of mechanisms to improve service delivery and accountability (Standards 9.1-9.6, 9.7-9.11, 9.14-9.15, 9.17-9.18, 9.24, 9.28, 9.29, 9.33, 9.34);
- problems with management, planning and accountability (Standards 9.1-9.6, 9.7-9.11, 9.14-9.15, 9.17-9.18, 9.24, 9.28, 9.29, 9.33, 9.34);
- the need for a national audit and an independent review to ensure strategic plan and services conform to national mental health policies (Standards 9.10, 9.11, 9.14, 9.25, 9.28, 9.29, 9.30, 9.33);
- lack of progress and quality improvement despite inquiries being conducted, reports released and recommendations being made (Standards 9.7-9.11, 9.14, 9.15, 9.30, 9.31, 9.33, 9.34);
- concerns about government and health bureaucracy (Standard 9.1-9.6);
- fear of repercussions for 'speaking out' on mental health issues (Standards 9.8-9.9, 9.29);
- affordability of care and access to psychiatrists and psychologists (Standard 9.4, 9.15, 9.29, 9.30);
- private versus public mental health services (Standard 9.22, 9.24, 9.30);
- the lack of support for research (Standard 9.31); and
- the need for more research (Standard 9.28-9.32).

The following selected quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 9. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Lack of resources to support community based care following deinstitutionalisation

Since the National Mental Health Policy was signed by the Australian Health Ministers in 1992 to deinstitutionalise mental health care and move treatment of mental illness to a community based system, the community has had to attempt to establish some system of care with insufficient funding resulting in a system lacking the basic ability to meet the needs of people with mental illness. In an interview between the Hon Peter Costello MP and Alan Jones on 23 September 2004, the Treasurer openly admitted in relation to this policy of moving treatment into the community 'I don't think that policy has been a great success'.

(Carers Australia, National, Submission #276)

Thin Ice is an examination of the failure of systems to support people with serious mental illness. It outlines how this systems failure ultimately makes people sick and forces them into the costly acute care sector. The conclusion of the report is the urgent need for an increased range and supply of support services in the community to support people and assist recovery.

(Anglicare Tasmania, Tasmania, Submission #144)

Lack of funding

…the issue of inadequate funding to mental health services is a major concern. Compared to other OECD [Organisation for Economic Co-operation and Development] countries Australia is falling behind in the level of funds to mental health and the distribution of those funds. As an example New Zealand has increased their overall funding to mental health by 174% in nominal terms over the last decade and by 6.8% in the year 2002 / 2003. 28% of funds go to services provided by NGOs and 69% of funds are spent on community services with only 31% spent on in-patient services. Australia urgently needs to increase the overall funding to mental health in line with best practice in OECD countries and to avoid being classed as having a 'banana republic mental health system'.

(Mental Illness Fellowship of Australia, National Submission #331)

Unless Australia increases its mental health budget from 5-7% to at least 17%; as recommended by the WHO [World Health Organisation], inadequacies will continue to plague the Mental Health System in years to come.

(Carer, Anonymous Submission #224)

Consumers, carers and staff not involved in planning and delivery of services

Until we erase the current culture of poor Health governance in W.A., unfortunately we will not move forward. For example, local doctors were excluded from participating on the local Hospital Board from the mid 1990's, and the Hospital and Health Department have ignored, or been unwilling to accept our advice on all matters medical, for many years… Government cannot continue to blame lack of staff for our current Mental Health care problems. Any money thrown at the current system without a fundamental change, as outlined, will not work.

(GP, Western Australia, Submission #326)

It is evident to clinical staff that contributions to policy formulation or micro-reform suggestions aimed at service improvement are not welcome. In the rare instances where consultation processes exist they are tokenistic, without power and their outcomes are not acted on. When suggestions / proposals are submitted they are ignored as a rule. If the person making suggestions, raising issues insists, s/he will be increasingly ignored, and should s/he persist, s/he will be marginalised, described as having a 'bee in his / her bonnet' or 'a chip on his / her shoulder'. This may gradually degenerate in outright denigration of his / her work or person on the part of managers, team leaders, including character assassination which outside of the Public Service would be subject to slander and libel laws.

(Clinician, South Australia, Submission #56)

Problems with management, planning and accountability

Those who wield the power need to take responsibility for their decisions and the outcomes of those decisions. They need to stop trying to silence those who complain and to engage in open and honest dialogue and shared projects identified by those who have an interest in developing them.

(Anonymous, Tasmania, Submission #254)

Unfortunately, no matter what clinicians say or do, it is managers within the various systems that control budgets and therefore the important resource requirements. The system in Western Australia now is such that it is as though a divide exists between managers on the one hand and clinicians on the other.

(extract from a letter to Communications Manager, Mental Health Council of Australia)
(Clinician, Western Australia, Submission #24)

The system doesn't reflect the clients' needs – the system is more interested in reflecting KPI's [Key Performance Indicators] / good outcomes / indicators so they don't deal with the difficult ones. These are the ones that are given the bus tickets from other places and they end up here in our community. I know this happens.

(Police Officer, South Australia, Murray Bridge Forum #16)

Concerns about government and health bureaucracy

It is unfortunate but a culture exists which places the protection of government, Ministers, bureaucrats, organisations, managements, clinicians, and service providers above the protection of patients, in particular those with a mental illness.

(VMIAC, Victoria, Submission #332)

...issues that are regularly presented to our offices… One of the dilemmas is the culture of the mental health system – "toxic" culture of the mental health system.

(Office of the Public Advocate, Queensland, Brisbane Forum #14)

Carers are shouldering the burden of services which should be provided by the MHS

Carers consistently report that mental health services are inadequate and their family members can't get access to services when needed. On these occasions the responsibility for care and management is transferred onto the family carer who tries their best to manage and provide the care and support that is not available through mental health and community services. Without this sustained contribution from carers, the mental health system which is already under extreme pressure would be placed in greater jeopardy.

(Carers WA, Western Australia, Submission #277)

Carers carry the burden of this system. They are used as cheap resources – this is wrong!

(Carer, Mother, New South Wales, Parramatta Forum #1)

Lack of resources and staff and the impact this has on staff and their work practices

Case managers are burned out and/or distressed by their inability to provide a quality service or simply join the fold and deliver a sub standard service.

(Anonymous, Queensland, Submission #113)

Mental health services in this State have been in crisis for a long time and the chronic under-resourcing of this sector is responsible for an unacceptable decline in working conditions for the police, ambulance officers, nurses, doctors, allied health staff and security officers who are attempting to provide safe care and humane treatment for this vulnerable group.

(Mental Health Workers Alliance, New South Wales, Submission #325)

I am a clinical psychologist and I left the mental health system because of burnout and the feeling that in my previous role I felt like I was perpetuating the abuse because I didn't have the resources I needed to do my job properly.

(Anonymous, South Australia, Adelaide Forum #12)

Public mental health services for in-patients operate exclusively on a crisis- management basis. This fact is contributing to very high levels of staff burn out, low levels of job satisfaction and an inability of public mental health services to attract young nurses. These services are chronically under-funded and the experiences of many medical staff, who spend time in the public system gaining training to become qualified psychiatrists, drives them into private practice as soon as they gain accreditation.

(Anonymous, Victoria, Submission #318)

Staff recruitment and retention issues in general

There is a crisis in attracting all disciplines to work in Mental Health due to lack of support/ training and poor working conditions and a lack of attractive career paths.

(Anonymous, Tasmania, Submission #254)

There are also real problems with the workforce. Medical graduates are just not going into mental health. Who can blame them if they see this as the model?

(Anonymous, New South Wales, Submission #303)

As I said before, the administrative burden has increased significantly at the same time as bed numbers have been reduced. It's a vicious circle, a negative feedback loop – the more people (clinicians etc) who leave the more the increased workloads fall on those who are left behind. Then of course, they leave! This is happening at a consultant and registrar level and it is compounded by the declining entry into psychiatry of trainees.

(Anonymous, New South Wales, Submission #303)

Junior nurses and doctors are discouraged from pursuing careers in mental health due to the disgraceful working conditions that staff are forced to endure. This only compounds the problems of staff shortages.

(Clinician, Western Australia, Submission #4)

Junior medical staff are voting with their feet, we've seen a dramatic reduction in the number of applicants psychiatry training. Also an increased drop-out rate once in and a massive shift towards immediate private practice post Fellowship…

(Consumer Advocate, Western Australia, Submission #338)

The shortage of psychiatric nurses and other mental health professionals is a major issue. Low recruitment and retention is due in part to perceived low status, inadequate training and extreme workloads.

- *Average age of a psychiatric nurse (2004) 46 years*
- *% of nursing graduates entering mental health system 4%*

The SANE Mental Health Report recommends that this workforce issue be urgently addressed at a national level.

(SANE Australia, National, Submission #302)

Lack of resources to deliver quality mental health care

Victoria provides dramatic proof that having a good model, good intentions and committed, innovative health professionals is still not enough to provide adequate mental health services…. if there is insufficient funding to implement services properly.

(SANE Australia, National, Submission #302)

We now have access to the lowest cost health service! Not only do we have to tolerate the closure of our mental health service but ever diminishing resources. My experience is that we have extremely diligent staff and GPs but there simply isn't enough money or resources to support them in delivering quality mental health care.

(Carer, Western Australia, Bunbury Forum #14)

As a result of our enquiries into this area, we were made increasingly aware of the incredible reduction in the amount of care in almost every area which affects mental health treatment. Doctors and nursing staff are struggling with ever mounting burdens of care, while working with continually decreasing resources in Graylands Hospital and the mental health clinics. When our son was first admitted to Graylands Hospital in 1990, there were approximately 300 beds available. Now, after several wards have been closed, there are only 197 beds, of which 30 are in a separate locked forensic ward (built in about 1995), and hence are not available to the general public!! As Perth has grown in leaps and bounds with an ever increasing population, and therefore by extension, ever increasing numbers of mentally ill people of all ages, the amount of available care has been significantly reduced by successive governments, and particularly so in the past few years.

(Carers, Parents, Western Australia, Submission #76)

Lack of resources to support community-based care following deinstitutionalisation

There was never enough funding to support the move from institutions to community based care. Very little funding for ongoing support followed the clients into the community. Mostly their needs were expected to be absorbed by the existing community resources. This placed enormous stress on the community sector in terms of accommodation, support services and Staff. While the policy, undoubtedly, had its merits, some people with mental illness and their families were left unsupported in the community, and without a range of meaningful activities to occupy their time. Some clients preferred the asylum that the old facilities had to offer. With the exit from the hospitals also went much of the State's responsibility to care for those most vulnerable. There is nowhere to go if a safe place is needed for any length of time.

(Anonymous, Tasmania, Submission #254)

Carers… [t]hey express frustration with the crisis driven care at the expense of community support and rehabilitation.

(Anonymous, Northern Territory, Submission #188)

The model of mental health care needs to change as there is an inappropriate focus on inpatient and crisis care

Quite interesting is that 95% of the resources go to 5% of the burden. If we looked at the date we only look at hospital admissions not where the real burden is. We need the resources to support the people in the communities who are doing the work anyway. I am actually encouraged by the strength of the response here but we don't support people well enough.

(Anonymous, Northern Territory, Alice Springs Forum #23)

Prior to the meeting I gave a lot of thought to the pattern of the previous ten years... lack of consultation about treatment plans or changes to treatment plans resulting in persistent relapses, not being given information and not having my information or concerns heeded, the Mental Health System not accepting the responsibility of maintaining my son's 'wellness' and then repeatedly expecting me to accept the responsibility for his care and rehabilitation.

(Carer, Mother, Victoria, Submission #178)

Our community could benefit from a return to the program of social health visitors initiated by Dr Brain Hennessy... Those selected received substantial training, were given a car, were at the call of, and assisted, psychiatrists, psychologists, doctors and social workers. [They] were mainly the first involved in crisis intervention and the main contact following up patients after their stay in psychiatric ward of the hospital. The difference in [their] position as compared with the other professionals was that [they] we were considered more as a friend to [consumers] and their family, someone on their side. Thus [they] were able to persuade clients to cooperate more fully with treatment plans. Gone are the social health visitors; the service has become more clinically oriented, replacing the human / personal involvement. This makes it more difficult for people to develop a good self image and experience hope for the future. In our endeavour to improve mental health we could do no better that re-examine Dr Brian Hennessy's approach and implement again the strategies that worked effectively in the past.

(Anonymous, Australian Capital Territory, Submission #132)

Lack of resources and services is resulting in reinstitutionalisation of people with mental illness

It is becoming obvious, that persons who previously were treated within the mental health system are increasingly being shunted into the criminal justice system. People with mental illness must not be criminalised as a result of inadequate funding for the mental health system.

(Police Association of New South Wales, New South Wales, Submission #59)

This institutional model extends into the prison system. The Chair of the SA Parole Board has drawn attention to the high number of people with a mental illness in the State's prisons, saying the government was using them as a 'sump' for people who should be cared for by mental health services.

(SANE Australia, National, Submission #302)

Lack of funding and support for critical services provided by NGO's

There has been a rapid devolution to NGOs in NSW but the degree of funding is very poor. In fact, what governments have devolved to NGOs is the problem! Such devolution is unacceptable if NGOs do not have the capacity nor the resources to deliver the necessary services. There are huge gaps in clinical services, case management.

(Consumer Advocate, New South Wales, Parramatta Forum #3)

Rather than calling for a return to hospital and institutional care, the Alliance calls for real investment in the community and in community-governed organisations. People with mental illness want to live in the community – not in hospitals. They have a right to housing, employment and to flexible treatment and support. Queensland has an urgent need to exploit the potential of the non-government sector in providing recovery-focused services, which are cost effective and respect the rights of people affected by mental illness.

(Queensland Alliance of Mental Illness and Psychiatric Disability Groups, Queensland, Submission #218)

Distribution of resources

…(people making decisions about the distribution of resources) need to ask challenging questions such as 'serious to whom?' and 'serious through whose eyes?'

(Consumers, Victoria, Submission #194)

Need for more graduate programs and supervision for mental health nurses

The situation with regards to training of mental health nurses is also of grave concern… There are too few new and younger graduates coming through the generic nursing degree streams, who either interested in, or have enough training for mental health nursing. As the population of mental health clients seems to be escalating, concurrently the population of trained and experienced staff to deal with them seems to be falling. If this situation continues the welfare of patients will be at risk and consequently, the community also.

(Clinician, Victoria, Submission #201)

Problem with 'custody and control' model of care

Culture of control, not therapeutic engagement. The WA mental health system has evolved within the treatment model, excessive use of medication and routine use of police in dealing with patients. There is room for debate on the attitudes and practices of mental health service workers and whether these social norms support punitive handling of mental health consumers.

(Health Consumers' Council WA, Western Australia, Submission #29)

Affordability of care and access to psychiatrists and psychologists

Another factor in mental health consumers 'missing out' on appropriate services and timely treatment is the users pays system. Many simply cannot afford the cost of luxury 'private' services and many cannot afford the cost of private health insurance. Health insurance is becoming more and more out of reach for the 'average' Australian, let alone for someone who tries to exist on a disability support pension.

(Clinician, Queensland, Submission #105)

Fear of repercussions for 'speaking out' on mental health issues

HACSU members, although acutely aware of the issues, are often unable to articulate the problems they confront on a daily basis as they attempt to provide mental health services. Government policy, conditions of employment and fear of negative repercussions often prevent workers speaking publicly about the difficulties they face.

(Health and Community Services Union, Victoria, Submission #220

5.10 STANDARD 10: DOCUMENTATION

Clinical activities and service development activities are documented to assist in the delivery of care and in the management of services.

Concern was expressed that documentation systems to assist in the delivery of care or in the improvement of service delivery are not being adhered to. Some consumers, carers, clinicians and service providers reported that sometimes clinical records and individual care plans are not comprehensive or reliable and that documentation systems are not accessible to allow continuity of care across settings, programs and time.

Furthermore, it was suggested that the information that is available is not used to inform decisions related to treatment and support. Instead decisions are made for 'economic reasons' rather than having a clinical basis.

Submissions also suggest that data collection is time consuming and that the administrative burden is increasing at the same time as staffing and resource levels are diminishing. This as appears to create further barriers to the completion of documentation as required by the Standard.

Consumers were frustrated that they were asked to continuously repeat their stories. This suggests that documentation is not being accessed to provide continuity of care, and therefore essential information is not being relayed back to clinicians.

Some submissions suggested that treatment plans are not being followed because they are not being recorded. Others reported that community treatment orders are being abandoned due to the amount of time to complete paperwork associated with such treatment plans.

Concern was raised with regard to inferences drawn from data collected to assist with the management and planning of service delivery. It was suggested that different indicators and outcomes need to be utilised as markers of improved service delivery and outcomes for consumers.

Nationally, the key issues relating to this Standard include:

- Lack of coordinated, comprehensive and accessible documentation systems (Standard 10.2 - 10.5);
- Lack of comprehensiveness of documentation (Standard 10.2, 10.3 and 0.6);
- Clinical documentation failing to provide a comprehensive, factual and sequential record of treatment and support (Standard 10.5 and 10.6);
- Problems with the management of documentation (Standard 10.1 and 10.2);
- Concerns about the type and quantity of data collected to assist in the delivery of care and management of services (Standard 10.9);
- Documentation systems not being utilised to corroborate carers' pleas for access (Standard 10.4);
- The system does not allow continuity of care across settings (Standard 10.2); and
- Lack of communication between services and programs to ensure continuity of care (Standard 10.8).

The following selected quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 10. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Concerns about the type and quantity of data collected to assist in the delivery of care and management of services

There is no reliable data collection program as yet, despite the time spent by clinicians collecting information. Decisions appear to be made based on economic rather than clinical reasons.

(Anonymous, Tasmania, Submission #254)

The administrative burden is ever increasing. I have worked for 30 years in the public system and there has been a steady creep of administrative duties but now it's out of control and on top of that there are fewer administrative staff to assist us.

(Anonymous, New South Wales, Submission #303)

My daughter recently left hospital and we had no contact from the hospital to inform us that our daughter had actually been discharged. I had no idea where she was or when she had been released. The authorities had placed a community treatment order on her for the next 12 months which we thought was a good thing because at least she would get some care however the psychiatrist took her off that order after 2.5 months complaining about the level of paperwork required as part of the process.

(Carer, Mother, Victoria, Footscray Forum #10)

Clinical documentation failing to provide a comprehensive, factual and sequential record of treatment and support

Treatments discussed were not acted because proper treatment notes were not recorded.

(Carers, Parents, New South Wales, Submission #106)

…there did not appear to be an updated, clear and continuous treatment plan for [X] in the period of admission prior to his death. …the availability of a continuously updated care and treatment plan with a multidisciplinary input is important. It must be clear, unequivocal and available to all persons who need access to it. (Excerpt from Report of findings by the Chief Coroner)

(Carer, Partner, Australian Capital Territory, Submission #305)

In one instance, a patient was on 15-minute sightings, which were noted in the file from 0900 to 1050. The problem was that the patient jumped in front of a train at 0910. No accountability occurred or fault was found. The parents were devastated especially after the police contacted them, they phoned the hospital and were told he was okay when in fact he was dead.

(VMIAC, Victoria, Submission #332)

Several months following the creation of the Coordination Committee there was an audit of the activities of the ward by a senior nurse manager and the professor of mental health nursing. It found that although some of the changes introduced have been maintained a number had been modified or abandoned… Hand-over sheets, information sheets to patients, allocation files, medication sheets, information boards were rarely used and not fully replenished or when used were not completed systematically or consistently.

(Professor of Mental Health Nursing, Western Australia, Submission #33)

Lack of coordinated, comprehensive and accessible documentation systems

My brother has done the hospital shopping in Perth looking for help. What this means is that his current case notes are not available, the person (Me) who supports and follows his medical care and history, has been until now unable to speak with doctors to share valuable, timesaving, costsaving information that would support my brother more effectively with his care.

(Carer, Sister, Western Australia, Submission #101)

The system does not allow continuity of care across settings

The system is stuffed and so difficult for consumers to navigate. People have to tell the stories over and over again to a range of different people. They should only have to tell their story once.

(NGO Worker, South Australia, Adelaide Forum #24)

The after hours psych services number in this region is switched through to a town 100km away, and then the consumer's issue is not referred back to the local nurses;

(Coordinator, Grampians disAbility Advocacy Association, Victoria, Submission #212)

Problems with the management of documentation

I do not like people keeping records about me behind my back that they share with absolutely everyone but me and the people I designate as my supporters. These things make recovery SO MUCH harder. (author's emphasis)

(Consumer, Australian Capital Territory, Submission #287)

Documentation systems not being utilised to corroborate carers' pleas for access

In the past I have gone to see CAT [Crisis Assessment and Triage] team Triage in hospital ER room where my file has not been available, when I know that this particular hospital Mental Health Triage was set up with access to a key in the ER to make files available as people are seen in crisis there.

(Consumer, Victoria, Submission #112)

5.11 STANDARD 11: DELIVERY OF CARE

Principles guiding the delivery of care: The care, treatment and support delivered by the mental health service is guided by: choice; social, cultural and developmental context; continuous and coordinated care; comprehensive care; individual care; least restriction.

Information received via submissions and via presentations at forums suggests that treatment and support services are not being delivered according to the six principles of care outlined under this Standard. Reports of lack of treatment and support services (see Standards 11.1-11.6) and limited access effectively meant that for many consumers there were no options to consider and hence no choice.

Additionally, options were further restricted due to lack of available clinicians, long waitlists and lack of bulkbilling clinicians. The scarcity or inability to afford to pay for psychologists also limited treatment and support options. Lack of supported accommodation and housing options also limited choices. These difficulties suggest that care is not comprehensive (i.e. not available throughout the lifespan and not available during onset, acute, rehabilitation, consolidation and recovery phases) and is not tailor-made to reflect each individual's needs. An inability to access services prior to the need for acute care also meant that many consumers were not able to select the most appropriate option in the most empowering setting.

Deteriorating mental health and the need for acute care often resulted in the need for sedation, restraint and seclusion; the maximum restriction of rights. Some consumers entered the criminal justice system due to an inability to access treatment and support services, also reflecting a maximum restriction of rights.

Lack of appropriate treatment and support services for youth, the elderly and the lack of culturally appropriate services for Indigenous people and people from a Non-English Speaking Background also suggests that some services are not being guided by the 'social, cultural and developmental context'.

Nationally, the key issues under this universal Standard outlining the principles underlying care, submissions and presentations indicate concerns about:

- lack of access to any care (and therefore no choice);
- the lack of individualised and continuous care in mental health services;
- lack of coordinated care (due to problems of services, limited resources and crisis response-driven access);
- lack of services for youth, the elderly, people from a non-English speaking background and Indigenous people;
- social and cultural needs of Indigenous communities are not guiding the delivery of care to Indigenous consumers and their families ;
- services unable to respond in a flexible manner to changing need or diverse needs for individuals;

- lack of comprehensive care (due to an inability for consumers to access services during the onset phase, lack of access to rehabilitation services, and an overall inability to access mental health services);
- reports of a focus on containment and control (treatment and support is not the least restrictive)
- restriction of rights;
- restrictive approaches in the least empowering settings; and
- the fragility of the 'whole package of treatment and support' needed to promote and protect the rights of people with mental illness to participate socially and economically in the community.

The following selected quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 11. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

The lack of individualised and continuous care in mental health services

I am writing to say how difficult it is as a carer to source appropriate and continuous support mechanisms within the public health system for the recovery of a mentally ill patient. That is to say that the medical and psychosocial models have to operate in parallel, not serially, and that the psychosocial rehabilitation infrastructure has to offer a level of service which provides continuity so that planned rehabilitation activities can be sustained instead of a scattergun approach.

(Carer, Mother, Victoria, Submission #280)

More funding to make it possible for programs to be developed and tailored to individualised needs to make it possible for suffers to become worthwhile participants in the community.

(Carers, Parents, Victoria, Submission #241)

We are a group of community workers with a vast experience in their area of mental health and mental health and the ageing… Since deinstitutionalisation occurred in the 1980s, we believe that the pendulum has swung to far in the other direction whereby a number of sufferers do not have options open to them if their illness is so severe that they are unable to sustain living in the community with medication only.

(Social Worker and Team Leader, Victoria, Submission #236)

Services unable to respond in a flexible manner to changing need or diverse needs for individuals

It seems that the decision of treatment is entirely taken out of the hands of the family or carer and left to the sufferer. In most cases to find their own cure. The Public Mental Health System at present - processes people – they do not treat patients individually with the good will and respect that they deserve. The system we have is only too willing to allow this process to continue. In my opinion no other method of treatment is considered, or recommended in the Public Health System. The exception being pharmaceutical methods where there is limited explanation of how much and how often to take the prescribed medication and their possible side affects. The message to us was that you can't help those who won't help themselves. Yet people suffering mental illness are less able to help themselves.

(Carer, Mother, Queensland, Submission #81)

Restrictive approaches in the least empowering settings

Restraint practices across the state appear to be often cruel harsh and in many cases, in breach of the WHO guidelines re least restrictive environment.

(Academic, South Australia, Submission #142)

Social and cultural needs of Indigenous communities are not guiding the delivery of care to Indigenous consumers and their families

Extreme stress on the resources available, allowing very little capacity to develop culturally appropriate and meaningful services, which are Anangu driven.

(Anonymous, Northern Territory, Submission #271)

Lack of coordinated care (due to problems of services, limited resources and crisis response-driven access)

They must be [an] emergency to be admitted, if not the already overburdened and underfunded / resourced community teams have to try and maintain them, but in reality it is more likely to be the family / carer and the GP. There is no room for innovation, just relentless grind: the culture of therapeutic nihilism is now deeply ingrained. Staff fight with staff, barriers to service access are getting higher and higher.

(Consumer Advocate, Western Australia, Submission #338)

Surely it would be better to keep mental health people here in this town where they are close to their family and support. This doesn't happen because there is not the facility for their care therefore they are sectioned and sent off.

(Anonymous, Western Australia, Geraldton Forum #96)

Lack of access to any care

Another unsatisfactory situation that exists is when someone 'phones the AC Team for advice regarding a psychotic patient, invariable the advice is 'phone the police'.

(Carer, Wife and Mother, Queensland, Submission #52)

I am concerned that I, who see my role as my daughter's protector and nurturer, had to call the police on my daughter, because she could not be treated by the mental health system. I am concerned that the Eastern Area Mental Health Service was totally inadequate in dealing with the situation and left the police and emergency services and casualty departments to deal with a mental health problem. I am amazed at the amount and cost of public resources that were consumer in 'managing' her behaviour while she was untreated – police, ambulances, lawyers, courts, accident and emergency rooms. You can add to this the resources used in supporting her family – private counselling, Victims of Crime, the court system. This is in stark contrast to the negligible resources used in addressing the situation and in treating her.

(Carer, Mother, Victoria, Submission #307)

Lack of comprehensive care (due to an inability for consumers to access services during the onset phase, lack of access to rehabilitation services, and an overall inability to access mental health services)

The standards of service vary from adequate to excellent in the major cities around this country, to almost nothing existing in rural Australia. When services can be accessed, the issue of the quality of the service offered has caused us some concern.

(blueVoices, National, Submission #355)

I have had session times allocated which were constantly being changed from 1/2 hour appt that were made to a 10 min. session… When I would say "you and I both have a copy of the letter stating duration of sessions" I was told "we don't care, we don't have the time"?

(Consumer, Victoria, Submission #112)

Like all health care, we have serious concerns about the adequacy of the mental health workforce and its ability to treat people in a timely and appropriate manner. The shortened length of stay all too often results in people being discharged, with referrals to all over stretched community mental health services. The burden on the individual and their family is huge, as the individual may not receive the type and quality of treatment required. Conditions remain untreated and the severity of the illness increased – at times with disastrous consequences.

(Australian Nursing Federation (Vic Branch), Victoria, Submission #322)

We are fortunate that she becomes a danger to herself and others when acutely unwell otherwise she would probably receive no treatment at all.

(Carer, Mother, Victoria, Submission #299)

Lack of services for youth, the elderly, people from a non-English speaking background and Indigenous people

Considering the high rate of suicide amongst young people in Australia I find it absolutely appalling that when people do seek treatment and assistance they are refused, given minimal attention or are treated poorly by being labelled as being malingerers

(Clinician, Queensland, Submission #105)

5.11.1 STANDARD 11.1: ACCESS

The MHS is accessible to the defined community.

Serious concerns were expressed in every State and Territory about the increasing inability of consumers to access mental health services when needed. It seems to be necessary to wait for a crisis to occur before treatment and support can be accessed. Of particular concern were reports of difficulties in obtaining assistance when consumers were at risk of self harm or injuring others. Often, a police response was the only response available. To this extent, the police were frequently referred to as the 'de facto mental health service'.

In rural and regional areas, reports described access difficulties of enormous proportions and reliance on the police was even higher due to diminishing services and increasing reliance on telephone triage. The combined factors of deteriorating mental health (due to the inability of consumers to access treatment and support) and increasing reliance on police was also reported to be contributing to the increasing representation of people with mental illness in the criminal justice system.

Access to services was reported to be limited, and in some cases non-existent, for certain consumers. For example, consumers with: intellectual disability; personality disorders; drug and alcohol problems; complex needs; dual disability; a history of past sexual abuse; or a past forensic status. Appropriate services were also reported to be limited for Indigenous consumers, consumers from a Non-English Speaking Background and consumers who were elderly. Access to psychiatrists, psychologists and rehabilitation services were also noted to be difficult.

Nationally, the key issues relating to this Standard include:

- inability to access services when needed (Standards 11.1.1-11.5, 11.1.8, 11.1.9);
- a crisis is required before services can be accessed (Standards 11.1.1-11.1.5);
- concerns about inability to access services during a crisis (Standard 11.1.4);
- access being limited to those with 'serious mental illness' (Standards 11.1.1 and 11.1.5);
- no or limited access to services in regional and rural areas (Standard 11.1.1-11.1.5);

- access problems in remote areas (Standard 11.1.2, 11.1.3 and 11.1.4);
- lack of access to care in regional areas – transportation issues (Standards 11.1.2-11.1.5);
- problems when phone service is the only contact with mental health services (including problems with telephone triage) (Standard 11.1.1 and 11.1.3-11.1.5);
- operational policies which limit access (opening hours and mode of contact) (Standard 11.1.4, 11.1.8 and 11.1.9);
- problems with access after hours (Standard 11.1.4);
- police response is the only response – police are the de facto mental health service (Standard 11.1.4, 11.1.8 and 11.1.9);
- lack of access to care - "right to get care, not be arrested" (Standard 11.1.1-11.1.5);
- lack of access to treatment resulting in entry into the criminal justice system (Standard 11.1.8 and 11.1.9) ;
- access denied due to past forensic status (Standard 11.1.1);
- access denied due to history of sexual abuse (Standard 11.1.1);
- access denied for consumers with intellectual disability (Standard 11.1.1);
- access denied if consumer has dual disability (Standard 11.1.1);
- access difficulties for people in detention centres (Standard 11.1.1, 11.1.2, 11.1.3 and 11.1.5);
- lack of access to treatment and support services for people with personality disorders (Standard 11.1.1);
- lack of services for people with mental illness and complex needs (Standard 11.1.1);
- concerns about attitudes towards Indigenous people (Standard 11.1.1, 11.1.2, 11.1.3 and 11.1.5);
- carers concerns are being ignored (Standard 11.1.2);
- long waitlists or no clinicians available at all (Standard 11.1.4 and 11.1.8 and 11.1.9);
- problems with access through emergency departments (Standard 11.1.2, 11.1.3, 11.1.4, 11.1.8, 11.1.9);
- lack of services for youth with drug and alcohol problems (Standard 11.1.1, 11.1.2, 11.1.5);
- general difficulties in accessing care if new to the system (Standard 11.1.1, 11.1.6, 11.1.8 and 11.1.9);
- accessing services 'out of area' (Standard 11.1.3);
- problems for consumers from a non-English speaking background (Standards 11.1.1 and 11.1.5);
- no access to treatment and support for consumers who are elderly (Standards 11.1.1 and 11.1.5);
- limited access to people from low socio-economic backgrounds (Standards 11.1.1 and 11.1.5);
- difficulty accessing psychiatrists and psychologists (Standard 11.1.1, 11.1.2, 11.1.3, 11.1.5 and 11.1.9);
- lack of access to psychologists for those who can not afford to purchase care in the private sector (Standard 11.1.1, 11.1.5, 11.1.8 and 11.1.9); and
- lack of access to private psychiatrists, GPs, counsellors and rehabilitation services (Standard 11.1.2 and 11.1.3).

The following selected quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 11.1. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

A crisis is required before services can be accessed

We do not know how many patients have committed suicide as a result of being denied a service, but we have heard reports of individuals who have successfully suicided shortly after being refused hospitalisation and being left to fend for themselves. Additionally, we have had quite a number of patients tell us that they took an overdose or slashed their wrists as a means of gaining hospitalisation. Our feedback also indicates that many patients are just left to deteriorate until such time as they finally get admitted in a much worse state than was necessary.

(VMIAC, Victoria, Submission #332)

Whenever I contact the CAT [Crisis Assessment and Treatment] team for one of our clients the response is always "are they at risk of harming themselves or someone else" and the answer is no. You can't get help then. If they aren't in crisis they don't get help.

(Carer and Disability Accommodation Service Provider, Victoria, Melbourne Forum #9)

I know of no other illness where we wait until the person needs the intensive care ward and their family is in chaos before we address it.

(Carer, Mother, Victoria, Submission #307)

Concerns about inability to access services during a crisis

…daughter-in-law who was seriously mentally ill but had difficulty accessing care. She attempted to jump off a moving ferry, she said the voices told her to jump off. She was finally transported to hospital at 10am and assessed by the mental health assessment team. She was then sent home in a taxi and murdered her nephew.

(Family Member, Queensland, Rockhampton Forum #2)

I was once a very depressed, suicidal individual and the government hospitals and health care systems did absolutely nothing to help me when I was screaming out for help at the time!

(Consumer, Queensland, Submission #73)

Inability to access services when needed

Throughout our consultations people have spoke of the difficulties they have accessing the mental health services they feel they need, both in acute and community care. In acute care, consumers have spoken of being refused hospital beds even though they were at a crisis point, only to be admitted a few days later in an acute psychotic state. They tell stories of fronting at emergency departments of hospitals, only to be turned away without being properly assessed by a doctor and without being given any advice or assistance. They speak of their general practitioners refusing to believe they were hearing voices and of CAT teams visiting and quickly leaving because they determined 'you're not going to hurt yourself or someone else'. There is a clear picture that emerges—help is reserved for the most psychotic episodes only and that prevention or early intervention is of a low priority. Acute psychiatric services are under-funded, rationing access to a point where people have to beg for assistance.

(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

Recently a friend of mine went to hospital willingly and was turned away. So out of sheer frustration with not being able to get help she picked up an ashtray and threw it at the window and smashed it. They called the police. They took her to the police station and called the Crisis Assessment Team (CAT) who then admitted her! It's a joke that someone has to do something like that to get care.

(Consumer Advocate, Victoria, VMIAC Forum #5)

Staff also describe a "Revolving Door Syndrome" where only short-term crises are dealt with and long-term structured support for clients is not obtainable.

(Anonymous, Tasmania, Submission #254)

Challenging behaviours – people are often turned away from the system and don't get care because of the 'behaviour problem' but often the behaviour is a result of the frustration of the consumer not getting care.

(Service Provider, Northern Territory, Alice Springs Forum #16)

A lot of my clients I see come to me with bad experiences they have had when trying to access care. It's a sad reflection on the system if it is making people more traumatised!

(Clinician, Queensland, Brisbane Forum #20)

Psych disability rehab support sector – our services are funded to provide support to a group of people – the demands on our services always exceed the target but in the past we have worked hard to deliver as much as we can. We have continually raised this with the mental health branch as a problem that needs addressing but we've had no success. So we have been left with no other option but to make the decision to work to target only. This is very difficult because now there are people who need our service and now can't access it. To not be able to access services is a breach of people's human rights.

(Anonymous, Victoria, Morwell Forum #4)

Police response is the only response – police are the de facto mental health service

The fact remains that police, being the 24 hour, 7 day a week, mobile and free public service that they are, usually means that the residual problems of the community are left for them to handle when they have neither the resources nor the knowledge to adequately do so.

(Police Association of New South Wales, New South Wales, Submission #59)

'On one occasion we were told to by the CATT to phone the police, the police came, two officers spent almost a day with my family members, gradually got him to cooperate and to agree to going to the PSU [Psychiatric Support Unit]. But at no stage during this day as far we know, did mental health services assist the police.'

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

A contradiction arises, however, because the police feel that their job is to step in only when action is deemed necessary, usually when someone is in danger or breaking the law. Police do not feel, and rightly so, that it is their role to provide psychotherapy, counselling or aid and comfort for the lonely and confused. This is the job of mental health professionals, a group whom police see to some extent, as abdicating their responsibilities. Police see the responsibilities thrust upon them as they are – they are being asked to shoulder duties no one else wants or can manage.

(Police Association of New South Wales, New South Wales, Submission #59)

As a carer of a daughter with a mental illness my husband and I were forced to call police for help because we couldn't get any other response. The police were wonderful but after an 8 hour wait to be assessed the local hospital said they couldn't deal with her and she was sent to Perth to a secure ward. She was very quickly discharged and now we are dealing with the same situation again. Where do we go for help when there is no help?

(Carer, Mother, Western Australia, Bunbury Forum #10)

Problems with access after hours

As to crisis services – what crisis services – consumers are usually told to have a cuppa and go to bed. The service closes at 10pm and consumers simply cannot revolve their crisis around mental health service timeframes, which we are continually expected to do. I've even had staff tell me the consumer can go to Life Line if they're in crisis, who happen to be volunteers are not clinicians and cannot make mental health assessments. If Life Line counsellors refer consumers back to the MHS the consumer within a couple of hours are back onto the phone with Life Line – because at least a Life Line counsellor will try and listen to what is actually happening to the consumer.

(Consumer and Consumer Advocate, New South Wales, Submission #8)

No or limited access to services in regional and rural areas

I took someone who was suicidal up to the mental health service and they didn't do anything – there didn't appear to be any protocols in place. Where are we supposed to take someone when they need care?

(Carer, New South Wales, Broken Hill Forum #11)

How much does it cost to transport a patient by Ambulance to Perth? There are no doctors available here in Bunbury on nights or weekends so they send us to Perth! What have we got for a MH system? Nothing, absolutely nothing!

(Consumer, Western Australia, Bunbury Forum #1)

I can support what the police office said earlier about people who have been transported by the police to Graylands hospital often beating the police back to Bunbury!

(Mother, Western Australia, Bunbury Forum #22)

Lack of access to care - "right to get care, not be arrested"

My brother suffers from bipolar disorder… But I would like to comment on the fact that people with a mental illness are being arrested because often it's the only way they can get any help. They have a right to get care, not be arrested. We've got to get access to early intervention programs but it doesn't happen – now my brother is in the court system, not because he's bad but because he's got a mental illness.

(Carer, Sister, Western Australia, Bunbury Forum #24)

He tried cutting down on his antidepressant tablets when he was living in Salisbury about five years ago. He was bed ridden and physically ill in his attempt. He was crying out for help. He rang Glenside a few times and tried to convey to them by phone his desperate situation. His frustration in being dismissed combined with his lack of verbal and social skills resulted in the opposite from obtaining help. Again [X] faced court and was charged with abusive language. The system that should have protected [X], failed him.

(Carer, Mother, South Australia, Submission #195)

Problems when phone service is the only contact with mental health services (including problems with telephone triage)

Carers in some of these remote rural areas have reported having a crisis at midnight on a Friday. When attempting to contact SW24 they have told me the service has advised them that their problem will be forwarded to the clinicians who they know will not be in the office until the following Tuesday. When they explain this they are often asked to take the person they are concerned about to the nearest health facility which will handle psychiatric emergencies. Again for many this may be Bunbury which is located over two hundred kilometres away, further should they be able to get to Bunbury they are often told they can not be seen and are sent onto Perth a further two hundred and forty kilometres. Should this not be possible their alternative is to contact the local police, who are for most at least fifty kilometres away and usually only have one officer on duty, who then has to choose between leaving a town with out a service for what may turn out to be a ten hour round trip to Perth or advise the family they can not attend and this leaves them to fend for themselves. Although on the surface a 24 hour call services appears to be an effective means of offering support to people it is in fact only able to offer information which in most cases the person is already aware of, but it has very limited if not non existent ability to offer "hands on" or "face to face" practical assistance."

(NGO Service Provider, Western Australia, Submission #45)

Problems with access through emergency departments

At the beginning of this year, I began to suffer debilitating depression and eating disorder symptoms. I sought help in the Emergency department of Flinders Medical Centre three times. The first time I sought help there, I waited well over 3 hours to be seen, then was admitted and left in "Extended Emergency Care Unit" for 3 days, then discharged because there were no beds available in the Psychiatric Ward. The second time I presented, I gave up after a day in the EECU. I was on the waiting list for a bed, and after a number of weeks and another presentation to FMC Emergency, I finally got admitted.

(Consumer, South Australia, Submission #158)

No access to treatment and support for consumers who are elderly

It is harder for older people to gain admission to a system which is responsive to danger and acute suicidality. If you are an older person at home quietly depressed and not eating and just fading away it's much harder to get an urgent admission.

(Anonymous, New South Wales, Submission #303)

Lack of access to treatment and support services for people with personality disorders

Assessment, treatment, engagement, case management and care for people diagnosed with borderline or thought to have personality disorder continues to be a failing of mental health services in the ACT. People with personality disorder are reported to be still frequently denied service. They are reported to be another group that frequently ends up in the criminal justice system.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

…people with Borderline Personality Disorder who have been chased, sometimes in seriously undignified and persecutory ways, out of the public mental health system that they are as entitled as anyone else to use.

(Consumer, Victoria, Submission #203)

Carers concerns are being ignored

In this regard it is a reactive system, whereby consumer's rights take precedence over their welfare to an utterly illogical extent and something bad has to happen before something can be done. It fails them, it fails carers and it fails the community. For my son and others, who, like him do not recognise when they are unwell it means that by the very nature of their illness, when they are unwell, they are unable to access, accept and use voluntarily available treatment. This leads me to the belief that a mentally ill person's fundamental right to treatment and care should transcend all other considerations even when they are not well enough to seek treatment themselves.

(Carer, Mother, Victoria, Submission #178)

Carers are often best placed to notice subtle changes in the person for whom they care, and usually the first to notice the early warning signs of a relapse. However health professionals usually do not recognize the value of this information, and in fact when carers try to pass on this information it is often ignored. This can lead to additional problems for carers and a full blown episode for the consumer often with devastating consequences. Unfortunately it is the carers who usually bear with the consequences of a relapse not the health professionals.

(Peninsula Carers Council, Victoria, Submission #321)

Access being limited to those with 'serious mental illness'

There are concerns that the Mental Health Act is often used as a convenient excuse to provide no service to a person in need of treatment, simply because they don't meet the criteria for coercive treatment.

(Eastern Area Interagency NSW, New South Wales, Submission #100)

Lack of services for people with mental illness and complex needs

People with more complex issues such as homelessness, drug and alcohol issues, being diagnosed with Borderline Personality Disorder or have aggressive behaviour find it more difficult to access support and clinical services. This difficulty can be due to services wanting to transfer the responsibility to other sectors, stating that the diagnosis does not fit their criteria (particularly BPD), or stating they do not have the capacity/flexibility to work with this population.

(Western Region Health Centre, Victoria, Submission #292)

5.11.2 STANDARD 11.2: ENTRY

The process of entry to the MHS meets the needs of the defined community and facilitates timely and ongoing assessment.

Concerns were expressed nationally about the increasingly difficult procedures associated with entry to mental health services. The result has been delays in assessment and assessments occurring in inappropriate settings. Reports were received that in some areas there are now only two real options for entry into the system: (1) entry via emergency departments or (2) telephone triage. Both options were described as problematic.

For entry via emergency departments, problems include: long wait times; the absence of appropriately qualified mental health professionals; and an inappropriate setting in which to conduct assessments.

For entry via a phone service (especially when this was the single point of entry), problems included: difficulties for people without phones or where mobile phone coverage did not exist; calls not being free of charge; forwarding of information to offices where clinicians would not be attendance for long periods of time (sometimes several days); and suggestions to callers to contact the police or to go to the closest emergency department.

Excessive wait times were also reported between time of referral and assessment, and assessment and diagnosis. Submissions indicated that initial assessments of urgent referrals are not commenced within one hour of initial contact as specified by this Standard.

Nationally, the key issues relating to this Standard include:

- problems with entry via Emergency Departments and triage services (Standard 11.2.4, 11.2.6, 11.2.7-11.2.12);
- concerns about long waits with entry via emergency departments (Standard 11.2.12);
- problems when a phone service is the only entry point to the system (Standard 11.2.3, 11.2.4, 11.2.5, 11.2.6, 11.2.7, 11.2.8, 11.2.9, 11.2.11, 11.2.12);
- excessive amount of time between time of referral and time of assessment (Standard 11.2.12);
- concerns about the amount of time between the assessment being undertaken and a diagnosis being made (Standard 11.2.11); and
- lack of appropriately qualified mental health professionals to assist with entry (Standard 11.2.6).

The following selected quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 11.2. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Problems with entry via Emergency Departments and triage services

People with a mental illness also have to go through the accident and emergency department – they have difficulty in getting assessed.

(Anonymous, Queensland, Rockhampton Forum #13)

When clients come through triage the client has to tell their story 5 or 6 times before they get to see a psychiatrist. I cannot, as a worker in the community, leave the client – they'll leave if I don't stay with them through the process – they have no other continuity.

(Clinician, Queensland, Rockhampton Forum #15)

Can you imagine going to emergency department with a Paranoid Psychotic patient who is being admitted involuntary, having to sit with open doors, [and the] TV is always on in the ED [Emergency Department] waiting room (my loved one receives messages via the TV; e.g. he's dead, he has killed someone, run over someone)? [He is] paranoid and suspicious of other people. He has lots of enemies. Isn't the trauma and stress great enough without this not being a safe place for both them and the other people in emergency?

(Carer, Mother, Victoria, Submission #242)

Concerns about the amount of time between the assessment being undertaken and a diagnosis being made

There is a single point of entry through the acute care team – they have an initial assessment and then a decision is made within a period of 4-5 weeks.

(Clinician, Queensland, Rockhampton Forum #7)

Problems when a phone service is the only entry point to the system

SouthWest 24 has been around for quite a while as a private company – it used to work reasonably well but the problems occurred earlier this year when it became the single point of entry into the system!

(Clinician, Western Australia, Bunbury Forum #19)

Lack of appropriately qualified mental health professionals to assist with entry

For an emergency you'd go to the hospital at Burnie and sit there for however long it takes. You've always got to go through casualty before you get into the service – even though he has a long history of mental illness. Then he sees a registrar who knows nothing about mental illness.

(Carer, Mother, Tasmania, Hobart Forum #15)

Concerns about long waits with entry via emergency departments

We knew by his symptoms and after talking with the staff in Monash Psychiatric Ward that there was nothing else that could be done except take him to Monash Hospital through the Emergency Department. The waiting room was packed with sick people and quite a few young children. After I had explained my son's problem we were told to take a seat and wait - we waited nearly five hours! Can you imagine waiting all that time with an acutely psychotic patient, who, for the first time in eighteen years recognised that he was very unwell and was making an attempt to 'hold himself together'? I'll never forget the experience. My son was so agitated. Several times he wheeled out the Emergency Entrance and tried to get in the Psychiatric Ward himself, with me in hot pursuit trying to tell him that he had to go through 'the right channels'… Whilst the doctor went off to arrange a trolley, my son made a frantic escape attempt and pulled the emergency ambulance door off it's hinges and was only saved from escaping and possibly harming himself by a very strong security guard… I believe that people with a psychiatric illness should be seen in a special emergency section reserved for them only - this could be attached (or very near) to the psychiatric ward of the particular public hospital. This would make it easier for the admitting psychiatrist to see the prospective patient in a quieter and less threatening environment and, hopefully, create a much smoother and quicker transition to the admittance procedure.

(Carer, Mother, Victoria, Submission #176)

The trend towards generalisation is such that now consumers have to wait for anything up to 4 days plus in the Emergency Department which is a totally inappropriate environment for consumers in an acute phase of illness, especially if suicidal or aggressive, to be in. There is simply not the space; the noise factor is high, lights continually on, plenty of instruments to harm oneself or another in Emergency Departments. God help you if you actually want to talk to a mental health clinician in an emergency department if it happens to be out of hours of the CNC [Clinical Nurse Consultant] who happens to work business hours and a five day week.

(Consumer and Consumer Advocate, New South Wales, Submission #8)

5.11.3 STANDARD 11.3: ASSESSMENT AND REVIEW

Consumers and their carers receive a comprehensive, timely and accurate assessment and a regular review of progress.

Concerns were expressed in all jurisdictions regarding the difficulties in obtaining comprehensive, timely and accurate assessments. Problems included the location of assessments (increasingly limited to emergency departments where the Standards specify a preference for home visits or a setting chosen by the consumer), excessive delays in organising assessments (up to 12 weeks), lack of appropriately qualified and experienced mental health professionals, and the disregard of information offered by carers and service providers.

Concerns were also expressed about assessments conducted over the phone and assessment procedures in rural and regional areas.

For consumers who were young, Indigenous or from a Non-English Speaking Background, concerns were raised about the appropriateness of the assessment tools used and the manner in which the assessments were conducted.

Reports were also received that assessments were continuously being conducted but accompanying treatment plans were not being developed and some assessments were focussing exclusively on "risk".

Concerns were also raised with regard to the review process and that assessments were not being continually reviewed and that reviews were not occurring prior to discharge.

Nationally, the key issues relating to this Standard include:

- no notification of arrival for assessment and use of force (Standard 11.3.3);
- concerns about the quality of the assessment and review process (11.3.1, 11.3.2, 11.3.5, 11.3.6, 11.3.11, 11.3.12, 11.3.14, 11.3.17, 11.3.18, 11.3.19, Standard 11.3.20 and 11.3.21);
- problems with assessments in emergency departments (Standard 11.3.1 and 11.3.2);
- assessments focussing on risk only (Standard 11.3.5);
- problems with the review process (Standards 11.3.14-11.3.18);
- concerns about assessments conducted over the phone (Standard 11.3.1, 11.3.2, 11.3.5, 11.3.6, 11.3.13);
- assessment, admission, and immediate discharge (Standard 11.3.5, 11.3.8, 11.3.12);
- continuous assessments without any treatment (Standard 11.3.5 and 11.3.12);
- extended police involvement once at hospital for assessment (Standard 11.3.2, 11.3.20, 11.3.21);
- assessment problems in rural and regional areas (Standard 11.3.1, 11.3.2, 11.3.5, 11.3.6, 11.3.13, 11.3.20, 11.3.21);

- assessment problems for children and youth under the age of 18 with mental illness or and/mental health problems (Standard 11.3.1, 11.3.5, 11.3.6, 11.3.7);
- lack of opportunity to obtain a second opinion (11.3.18);
- the exclusion of people with complex needs (Standard 11.3.1, 11.3.5, 11.3.6, 11.3.7, 11.3.20, 11.3.21);
- carers and service providers not being involved or listened to during the assessment process (Standard 11.3.5);
- assessment problems for Indigenous people with mental illness or and/mental health problems (Standard 11.3.1, 11.3.6, 11.3.7, 11.3.9, 11.3.10);
- assessment concerns for people from a non-English speaking background (Standard 11.3.1, 11.3.6, 11.3.7, 11.3.9, 11.3.10);
- the need for consumers to have an advocate (Standard 11.3.5);
- long periods of time between reviews of involuntary orders (Standard 11.3.14, 11.3.17, 11.3.18);
- problems with staff workload and management of work (Standard 11.3.19); and
- large staff caseloads (Standard 11.3.19).

The following selected quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 11.3. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Concerns about the quality of the assessment and review process

As a GP who does a lot of mental health work and knows a lot of people in the system, I can get an assessment in 2 weeks if I pull strings – otherwise it is 12 weeks to get someone assessed.

(Clinician, Queensland, Brisbane Forum #7)

We question the practice of conducting minimal assessments, (those conducted in a few minutes) - it is our view that assessments must be thorough, and that unwell consumers can manage to hold it together during short assessments when it is harder to do so if an assessment is conducted with more time devoted to speaking with the person.

(Eastern Area Interagency NSW, New South Wales, Submission #100)

When our son did finally get to see Dr [Z], within one hour of entering the clinic he was pronounced miraculously cured, his diagnosis was changed to a behavioural disorder, he was given a three month supply of anti psychotic medication, told to go for a C.T. [Computed Tomography] scan and advised that he would be managed by his local GP from there. This despite the fact his local GP had absolutely no experience with him. However after spending seven years dragging our son to a clinic and dealing with his frequent episodes unassisted, to be told he has no condition other than a behavioural problem, lowers the science of psychiatry into the realm of the black arts… At the time of writing this letter we have still not been able to get our son to the C.T. scan clinic. He is so agitated and not well. I rang Armadale Hospital and asked them what to do (they said they would speak to Dr [Z]) this was four weeks ago no one rang back.

(Carer, Mother, Western Australia, Submission #13)

Carers and service providers not being involved or listened to during the assessment process

We know of 5-6 cases over the past few months. We don't wish to target Logan but we do wish to ensure that all Psychiatric Services including Logan lift their game to prevent further deaths. We point out that there has been a number of murders, police shootings / deaths in custody as a result of the initial assessment services not listening to the patient, patient's family and the police attempting in good faith to get help for the patient.

(White Wreath Association Inc, Queensland, Submission #81)

I was horrified to see my DSM [Diagnostic and Statistical Manual] classification that my stress-induced disorder was classified as Bipolar… The psychiatrist would not listen to me, would not read my diaries. I saw the psychiatrist several times but he wouldn't listen. My GP rang the hospital 5 times about my work-related stress. My psychiatrist would not see through the public system, and I was paying $275 to be put on Lithium. I was put on medication after only 1 episode, but this should not occur before adequate assessment.

(Consumer, Australian Capital Territory, Canberra Forum #3)

Problems with assessments in emergency departments

Now the PET [Psychiatric Emergency Treatment] unit asks you to bring the [unwell] person to the hospital. Previously the mental health nurses would come to the person's home to provide assessment and assistance. If a person is acutely unwell, it can be impossible to convince them to go to hospital. This leaves the police as the only resort, which is embarrassing and inappropriate. When you get to the hospital, there is only a junior doctor [i.e. registrar] on duty, as there is no senior doctor at the hospital anymore.

(Anonymous, New South Wales, Submission #156)

Ultimately, OH&S and economy-of-scale arguments can be extended to banning all community health centres and all home visits. The appropriate path is to make community work as safe as possible, to screen and divert most assessments and initiation of treatment away from Emergency Departments, and then use Emergency Departments in exceptional, highly ambiguous or emergency circumstances only, or to assess mixed medical/psychiatric emergencies.

(Clinician, New South Wales, Submission #351)

Some Emergency Department medical practitioners rely on Level 2 nursing staff for mental health and psychiatric assessments. To the best of my knowledge this is not the case for medical or surgical emergency presentations. In my opinion, credentialing may need to be reviewed in the case of any medical practitioner unable to undertake a bio-psycho-social assessment including mental state examination, risk assessment and management plan development. All of these issues, really, raise important questions in regard to strong clinical governance… (extract from a letter to the Office of the Chief Psychiatrist)

(Clinician, Western Australia, Submission #24)

The need for consumers to have an advocate

Patients should not have to find an advocate before they are believed.

(Carers, Parents, Victoria, Submission #275)

5.11.4 STANDARD 11.4: TREATMENT AND SUPPORT

The defined community has access to a range of high quality mental health treatment and support services.

Across Australia, consumers, carers, clinicians, service providers and advocates alike expressed serious concerns about the lack of treatment and support services available to consumers (a) in the community and (b) when acute care was required.

Submissions indicate that mental health services have not ensured access to a comprehensive range of treatment and support services that are specialised in regard to a person's age and stage of development, the consumer's stage in the recovery process, dual diagnosis and other disability, or for those subject to the criminal justice system.

Submissions suggest that either no services at all, or a limited number of services, catered to the needs of the following groups of consumers: people with intellectual disability; people with drug and alcohol problems;

people with physical disability; people with hearing impairment; people with Acquired Brain Injury; people with personality disorders; people with eating disorders; people who were homeless; children and adolescents; the elderly; and refugees.

Many barriers and difficulties were also reported for Indigenous people and people from a Non-English Speaking Background.

For consumers and carers living in remote, rural and regional areas, services were reported to be diminishing and deteriorating (due to lack of resources and staff and overburdened services) rather than expanding and improving.

For people with mental illness in the criminal justice system, there were problems with access to appropriate treatment and support services at entry (for court diversion purposes), when incarcerated or under community treatment orders, and when in the community post release. However, a submission was received providing an analysis of the outcomes and benefits of a court diversion program in South Australia.

Due to an inability generally to access treatment and support services during the onset, rehabilitation and recovery phases, and descriptions that treatment was often only available for acute emergency care, suggests that some mental health services are not providing the least restrictive and least intrusive treatment and support possible as outlined under Standard 11.4. Reports were also received indicating that often treatment and support is not developed collaboratively with consumers and other persons nominated by consumers.

Nationally, the key issues relating to this Standard include:

- lack of treatment and support services - only available when in a crisis (Standard 11.4.1);
- lack of treatment and support services generally (Standards 11.4.3 - 11.4.8, 11.4.12 and 11.4.13);
- lack of services for people living in rural and regional areas (Standard 11.4.1, 11.4.3 - 11.4.8);
- lack of support services for consumers to live in the community (Standards 11.4.3 - 11.4.8);
- lack of treatment and support services for Indigenous consumers and their families living in remote communities (Standard 11.4.1, Standards 11.4.3 - 11.4.8);
- lack of services for people with dual diagnosis - intellectual disability (Standard 11.4.7);
- lack of services for consumers with dual diagnosis - drug and alcohol (Standard 11.4.7);
- lack of services for consumers with hearing impairment (Standard 11.4.x);
- lack of treatment and support services for consumers who are homeless (Standard 11.4.6);
- lack of treatment and support services for consumers who are elderly and homeless (Standard 11.4.3 and 11.4.6);
- lack of treatment and support services for people with eating disorders (Standards 11.4.1 and 11.4.7);
- lack of appropriate treatment and support services for consumers subject to the criminal justice system (Standards 11.4.7);
- lack of appropriate treatment and support services for consumers after release from prison (Standards 11.4.1, 11.4.6, 11.4.7);
- lack of treatment and support services for children and youth (Standard 11.4.3);
- lack of mental health services for the elderly (Standard 11.4.3);
- lack of services for people with Personality Disorders (Standards 11.4.1, 11.4.6 and 11.4.7);
- lack of services for people with Acquired Brain Injury (Standard 11.4.7);
- lack of services for people with mental illness and physical disability (Standards 11.4.6 and 11.4.7);

- lack of services for consumers with hearing or both hearing and vision impairment (Standard 11.4.7);
- lack of services for people with complex needs (Standards 11.4.1, 11.4.3, 11.4.6 and 11.4.7);
- lack of services for refugees (Standard 11.4.4, 11.4.6 and11.4.8);
- difficulties in accessing treatment and support for consumers from a non-English speaking background (NESB) (Standards 11.4.6 and 11.4.8);
- limiting access to treatment and support by diagnosis (Standards 11.4.1, 11.4.4);
- difficulties for community-based offenders with mental health problems (Standard 11.4.7);
- problems for consumers subject to the criminal justice system (Standard 11.4.7);
- problems with forensic care and new forensic units (Standard 11.4.1, 11.4.7 and 11.4.10);
- concerns about relocating the provision of community treatment and support services to hospital settings (Standards 11.4.5 and 11.4.10);
- concerns about restrictive and intrusive practices (Standards 11.4.5 and 11.4.10);
- carers not involved or informed with the development or review of the individual care plan (Standard 11.4.9);
- resistance to involving consumers and carers in the planning of treatment and care (Standard 11.4.9, 11.4.11-11.4.13); and
- individual care plans not discussed with consumers and carers (Standard 11.4.9 and 11.4.11).

The following selected quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 11.4. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Lack of treatment and support services - only available when in a crisis

Clinical services leave clients till they are so unwell that they have to been hospitalised.

(Anonymous, Northern Territory, Submission #188)

Lack of treatment and support services generally

The thing that concerns me most is that moral judgements are made about our illness and used to exclude us from treatments, yet we are told that our illnesses are like diabetes, but no one with diabetes is told to just convince themselves to fix their insulin levels.

(Consumer, Tasmania, Hobart Forum #21)

On three occasions I have been taken by ambulance to a hospital in Melbourne, Victoria, after taking an overdose of medication. On all three occasions I was discharged after recovery in the accident and emergency unit. I was still feeling suicidal, I live alone without family and with no available support. I can only supply you with these skeleton details now, as I am feeling too distressed to write more about the incidents in depth.

(Consumer, Victoria, Submission #84)

Please, if you are aware of any services I could access for my daughter or myself, could you let me know, as I cannot accept the answer I have been given by a number of health care professionals - that if my daughter survives into her twenties, I will have done well !

(Carer, Mother, New South Wales, Submission #92)

We're in a crisis here in NT, particularly indigenous suicides.

(Service Provider, Northern Territory, Darwin Forum #1)

For the 35 days that our daughter was in the MHU, we often experienced poor internal communication in the ward. We were given incorrect information about our daughter's medications and levels; the Psychiatric Registrars, Doctors [Y] and [Z], were reluctant to contribute to our twice-weekly case meetings, and items that were to be noted for our daughter's treatments were not actioned.

(Carers, Parents, New South Wales, Submission #106)

Lack of support services for consumers to live in the community

My brother suicided in a hospital… My brother is just an example of what will happen to others who are failed by the system. People are placing too much faith in institutions – people need access to good quality community care without having their human rights abused. My brother had care at Rozelle but he didn't really qualify for that catchment area so he then had to go back to St George but there wasn't anything for him to do there.

(Carer, Sister, New South Wales, Sydney Forum #7)

I live in fear for my life most days. But, I won't turn him on the streets to be homeless. I am not sure what the answer is, the prison system seems to be were they all end up. There is no help there for them. Actually it is the worse place they can go as they are treated like animals.

(Carer, Mother, New South Wales, Submission #90)

Effectively, CTOs extend involuntary status into the community, and yet in many instances community supports are fractured and insufficient to assist the consumer.

(Centre for Psychiatric Nursing Research and Practice, Victoria, Submission #323)

Sure staff are busy but service isn't there – particularly when there is a dual diagnosis. He's referred back and forth.

(Carer, Mother, Northern Territory, Darwin Forum #2)

Lack of treatment and support services for children and youth

Parents have difficulty accessing limited child psychiatrists and psychologists for their disturbed youngsters. Adult facilities are inappropriate, overburdened and inaccessible. Early intervention and accurate diagnosis, stressed as priorities in the National Mental Health Plan 2003 – 2008, remain as rhetoric instead of reality.

(ARAFMI Tasmania, Tasmania, Submission #245)

I work with young people aged 13-18 years, but this is getting pushed out to work with people as old as 25. I provided 24 hour support to a 21 year old recently who couldn't get care anywhere.

(Service Provider, Australian Capital Territory, Canberra Forum #20)

We are letting young people down by not dealing with them properly. We need to provide services in the prison system if that is where they are going to end up.

(Service Provider, Australian Capital Territory, Canberra Forum #20)

Lack of services for people with Personality Disorders

People who have a personality disorder are rarely treated by mental health services due to this condition not being identified as a mental illness. People with a personality disorder/s often fall between service delivery gaps and due to their behaviour, at times their housing and mental health / well being needs are not met.

(Colony 47, Tasmania, Submission #227)

Borderline Personality Disorder is not untreatable. This is a myth and one we should get rid of. … Resources need to be fed into providing services for people with Borderline.

(Consumer, Victoria, Submission #203)

Lack of mental health services for the elderly

Another problem is the lack of dedicated facilities for older people with psychiatric disorders requiring admission. Older people don't mix well with younger people, particularly those younger violent patients who are taking illicit drugs and are psychotic. There are strong arguments for separate for separate facilities.

(Anonymous, New South Wales, Submission #303)

Lack of services for consumers with dual diagnosis – drug and alcohol

There are real problems with the lack of partnerships in dual diagnosis. Because I have a mental illness and use drugs I can't get care from anywhere.

(Consumer, NGO member, Victoria, Footscray Forum #6)

It is ORYGEN's experience that the lack of integration between drug and alcohol and mental health services in Australia has significantly contributed to the poor detection and treatment of mental illness amongst young people with substance abuse. This results in waste of resources and long-term psychiatric and substance use problems for individuals who could otherwise be helped.

(ORYGEN Research Centre, Victoria, Submission #258)

Failure to address issues raised by a Dual Diagnosis has left thousands of young people with mental illness floundering, unemployed, uneducated, unskilled and many of them in gaol or homeless. As a group they seem to have been thrown on the Mental Health scrap heap, regarded as having developed an illness which easily becomes too entrenched to treat. A number of our younger daughter's friends have suicided which has added to her distress. And now the 'law of diminishing returns' applies - this being the way one senior clinician put it to me. He was discharging our schizophrenic daughter from HDU in an Acute Inpatient Unit directly onto the street after her sixth hospitalisation.

(Carer, Mother, Victoria, Submission #299)

Lack of services for people with dual diagnosis - Intellectual disability

In recent years, OPA (Office of the Public Advocate), and other support organisations and service providers have raised concerns about the failure of the existing service system to meet the needs of people with dual/multiple disabilities… OPA observes the following continuing difficulties:

- *Despite the existence of substantial research data to indicate that people with intellectual disabilities are more at risk of developing mental illness than the general population (Hudson & Chan, 2002); gaps in service provision for people with intellectual disability and mental illness remain. People who have an intellectual disability are less likely to receive assistance from mental health services because they are considered to have behavioural problems attributed to their intellectual disability rather than to their co-existing mental illness.*
- *Service boundary issues; people with dual intellectual disability/psychiatric disability have difficulty accessing the mental health system, and intellectual disability services are often left to support people with dual/multiple disabilities without funding and with non-specialist staff.*
- *People with presentations that cross behavioural, psychiatric and intellectual disability boundaries are often the subjects of service boundary disputes about which service should provide 'the' service to these clients.*

(Victorian Office of the Public Advocate, Victoria, Submission #284)

Lack of appropriate treatment and support services for consumers subject to the criminal justice system

As psychiatric services struggle to respond to the needs of the mentally ill the criminal justice system becomes a substitute. Prisons are now accommodation for more mentally ill people. How many will remain incorrectly diagnosed and return to the community without psychiatric treatment? Adolescents detained in Ashley detention centre present with mental health issues. The criminal justice system is a bleak future for their young lives.

(ARAFMI Tasmania, Tasmania, Submission #245)

My primary concerns in relation to mental health, are the extremely high rates of incarcerated women (and men) with both diagnosed and undiagnosed mental illness, and furthermore the treatment they receive from health services whilst in prison. There are also serious issues relating to treatment post release from community mental health services…I know I do not have to outline the issues related to dual diagnosis, which this client group exemplify. Particular problems also arise for this client group when a Borderline Personality diagnosis is given, which is very often.

(Service provider, Western Australia, Submission #14)

About 8 weeks ago my son was arrested and put in prison for 8 weeks for breaking a court order. He had been taking medication for years. While he was there he was not permitted to see a doctor or take his medication. While there he was bashed. He was released on strict conditions that he sees a psych. Again we are having difficulty as he does not work and can not afford a psychiatrist. There have been times when I have been to the hospital and spoken with the mental health teams and they have turned us away.

(Carer, Mother, New South Wales, Submission #90)

…if the incarceration of people with mental health disorders is to be reduced, the assessment, treatment and support services for offenders with mental illness/mental health issues (including intellectual disability) are not only required pre sentence and upon transition from gaol to the community, but additionally and predominantly for those who serve their entire sentence in the community.

(Community Offender Services, Probation and Parole Service, Department of Corrective Services, New South Wales, Submission #317)

Difficulties for community-based offenders with mental health problems

All offenders supervised by COS [Community Offender Services] are members of the community. While they may form a sub-group within the community, offenders should remain entitled to services from mainstream agencies that are funded to provide services to the community.

(Community Offender Services, Probation and Parole Service, Department of Corrective Services, New South Wales, Submission #317)

Resistance to involving consumers and carers in the planning of treatment and care

My other concern is for the carers they are told not to get involved but there's no one else to get involved. If the service doesn't want to involve carers then who do they think will provide the care once someone is discharged from a hospital? Who else is there?

(Clinician, Western Australia, Bunbury Forum #19)

… attitudes towards families generally within the system are very mixed. The impression one gets is that senior management are unsympathetic and find input from carers a nuisance - and too time consuming. The attitude seems to be that, if you are lucky enough to actually have a family, you are so far ahead of most consumers that you can look after yourself.

(Carer, Mother, Victoria, Submission #299)

5.11.4.A STANDARD 11.4.A: COMMUNITY LIVING

The MHS provides consumers with access to a range of treatment and support programs which maximise the consumer's quality of community living.

A consistent theme throughout many submissions and forums across Australia was the paucity of treatment and support services to enable consumers to maximise their quality of living and level of social and economic participation whilst living in the community. In particular, the lack of support for the family was described with access to family-centred approaches and support services being rarely offered. Without such support valued relationships were generally not strengthened and families took considerable strain. Some families wanting to be involved reported being "fobbed off" by mental health services. Children of parents with mental illness and young carers were also reported to be poorly supported and their needs ignored or not met. The decreasing availability of programs teaching self-care skills to enable consumers a choice to live independently was reported and consumers spoke of their desire to learn or relearn such skills.

Also reported to be diminishing were leisure, recreation and rehabilitation programs. These were described to be of critical importance in the reintegration process and rehabilitation phase. Withdrawal from such programs due to service reduction was reported to have catastrophic effects on some consumers and precipitated deteriorating events. Access to employment opportunities and education, training and work programs was also reported to be scarce.

Nationally, the key issues relating to this Standard include:

- lack of treatment and support services to maximise consumers' quality of living in the community without their health deteriorating (Standard 11.4.A.2, 11.4.A.4, 11.4.A.10, 11.4.A.11, 11.4.A.12);
- lack of community support services to maximise opportunities to live independently (Standard 11.4.A.13);
- lack of support services in community (Standard 11.4.A.2, 11.4.A.4, 11.4.A.10, 11.4.A.12, 11.4.A.13);
- difficulties accessing community based services (Standard 11.4.A.14 and 11.4.A.15);
- lack of support for consumers and their families in the community (Standard 11.4.A.2, 11.4.A.4, 11.4.A.10, 11.4.A.12, 11.4.A.13);
- Withdrawal of support from community mental health clinics (Standard 11.4.A.15);
- lack of education, training, work and employment programs (Standard 11.4.A.4 and 11.4.A.9);
- lack of vocational programs and employment opportunities (Standard 11.4.A.4, 11.4.A.6-11.4.A.8);
- lack of leisure, recreational, social and rehabilitation programs (Standards 11.4.A.4, 11.4.A.5, 11.4.A.10);
- lack of self care and living skills programs (Standards 11.4.A.1 and 11.4.A.2);
- access to leisure and recreation programs is being reduced (Standards 11.4.A.4, 11.4.A.5, 11.4.A.10, 11.4.A.14 and 11.4.A.15);
- more support needed to strengthen valued relationships (Standard 11.4.A.11);
- lack of family-centred approaches and support services (Standard 11.4.A.12);
- lack of support for children of parents with mental illness (Standard 11.4.A.12);
- lack of support for carers (Standard 11.4.A.12); and
- lack of recognition and support for young carers (Standard 11.4.A.12).

The following selected quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 11.4.A. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Lack of treatment and support services to maximise consumers' quality of living in the community without their health deteriorating

The impact of the erosion of community based rehabilitation services has been underestimated; as the networks of support so critical for the maintenance of stable mental health are removed, the burden upon the health system grows even larger. This again typifies a lack of understanding indeed an ignorance of the issues of those living with mental health conditions, as these programmes that offer social networks, education and recreation play a key role in the maintenance of mental health, community and social cohesion, and significantly contribute towards decreased admission rates, and burden upon the health care system.

(Clinician, New South Wales, Submission #197)

*MHCC's [*Mental Health Coordinating Council*] major concerns are related to the inadequate levels of community mental health services provided by the public health system and the shortage of psychosocial rehabilitation services. The latter services respond to a person's 'whole of life' needs in a community setting and include supported residential services, day centres which provide social and recreational activities and link clients to other such services in the community, outreach support services, vocational and employment services, and information and education services. Even though NSW Health has recently acknowledged in its draft document, NGOs and Mental Health: a Framework for Partnership, that these services are most appropriately provided by the non-government sector (NSW Health, 2002), there has been no indication that new funds will be allocated for this purpose.*

(Mental Health Coordinating Council, New South Wales, Submission #298)

There is no follow-up of medication or therapy to help people with a disability get back into society or become independent.

(Carer, Mother, Victoria, Submission #352)

Lack of self care and living skills programs

I came from the institution. I lived there from 7-21. I wasn't trained how to dress or how to wash. I am now 39 and I'm still trying to get over all my fears and anxieties. You need a lot of care and support and there is not a lot of that around.

(Consumer, Victoria, Morwell Forum #9)

We need a service here in Bunbury that teaches living skills. It is my understanding that there was someone here doing that once but not anymore. It seems that living skills are the last thing on the agenda for mental health services.

(Support Worker, Western Australia, Bunbury Forum #13)

Programs like living skills have been dropped out of NSW.

(Consumer Advocate, New South Wales, Parramatta Forum #3)

Lack of support for consumers and their families in the community

Single parents with a mental illness have very little help (if any) to care for their children and are usually forced to put them into state care. Sometimes the children are split up causing further trauma to both the parent and the children.

(Anonymous, Tasmania, Submission #254)

To obtain a comprehensive narrative, the author conducted a small research project focusing on the impact on nine family members of persons living with mental illness. The project identified a significant number of traumatic physical, mental and emotional impacts, which had a disabling effect on these relatives. Listening to the stories of spouses, parents, children and siblings it became obvious that all respondents felt the mental health 'system' had failed them and their relative living and/or dying with mental illness.

(Carer, Wife & Mother, Queensland, Submission #157)

Difficulties accessing community based services

We provide a comprehensive service. It is difficult to link mental health clients to get community based services… It seems to be a big problem with links to mental health clinicians linking in with the discharge planning. Mental health patients are not linked in to home help.

(Social worker, Western Australia, Geraldton Forum #84)

Lack of community support services to maximise opportunities to live independently

We are now seeing houses that are nothing short of disgusting! These houses are occupied by people who have been discharged from psychiatric institutions and they live like dogs because there's no follow-up care for them, they are not taught any basic living skills and most don't even know how to cook for themselves.

(NGO Employment Service Provider, Adelaide Forum #19)

Our families want a life, a job, accommodation. We can't get home care or meals on wheels for our loved ones. Why is this? When our children come out of hospital they are often severeley disabled, they can't remember how to cook or clean up after themselves. So why can't they get home help in these situations?

(Carer, Mother, New South Wales, Parramatta Forum #1)

We need more housing, accommodation and day programs to support people in the community. But there's a real lack of willingness to provide these services.

(Consumer, NGO member, Victoria, Footscray Forum #6)

Lack of leisure, recreational, social and rehabilitation programs

Apart from accommodation our biggest problem is the lack of recreation and rehabilitation programs available. [X] struggles at the best of times with no real motivation to do much at all and this coupled with constant tiredness leaves him incredibly bored for most of the time… There have been a couple of programs run over the last year by the Richmond Fellowship of Tasmania Inc. During these [X] would get to go out with the group twice a week. Not only did he really enjoy it and looked forward to it, but it was beneficial for him… the 'Kicking Goals Program' …the rapport he has built up with the coordinator has made such a difference to his behaviour and to our family unit.

(Carer, Mother, Tasmania, Submission #315)

I would like to know why mental health funding is dominated by the medical model when funding could be better used to develop mechanisms to provide assistance for when people are well. We need to give people an opportunity of a life worth living... The medical model is about risk management. We neglect people when we leave them out to rot – in front of a TV all day! I lost all my social skills… We need case workers who have no more than 8-10 clients and who can give due attention to people's long-term needs.

(Consumer, Victoria, Footscray Forum #3)

There are inadequate rehabilitation services for consumers who are trying to rebuild their lives. People recovering from heart surgery are automatically given a place on a rehabilitation program and access to professional assistance such as dieticians. Unfortunately the same cannot be said of psychiatric rehabilitation. In Frankston, Impact Services provide a quality Psycho-social rehabilitation service but due to long waiting lists, many consumers are unable to access this much needed type of service. At best the PDRS (Psychiatric Disability & Rehabilitation Service) offers a few hours of rehab per week leaving the carer with the responsibility for over 100 hours for the rest of the week to the carer. Rehabilitation services and support programs are essential for people with a mental illness many of whom have become socially isolated.

(Peninsula Carers Council, Victoria, Submission #321)

Lack of vocational programs and employment opportunities

My son has paranoid schizophrenia. He's on new medication and he's the best he has been for 20 years. He wants to work but we can't get any help.

(Carer, Mother, Ballarat, Melbourne Forum #11)

Lack of education, training, work and employment programs

There need to be more community based treatments available for mental health consumers (especially job placements), voluntary work, educational achievements (at TAFEs) (anything to keep the self-esteem of a mental health consumer as this will develop positive outcomes).

(Anonymous, Western Australia, Submission #243)

Lack of family-centred approaches and support services

Though the ACT Mental Health Services receive training in family sensitive practice, families report that they are frequently told by the clinical case-manager that they can't be involved or that the case-manager can't talk to them or tell them anything. Families reported feeling 'fobbed off'. Families and other carers pleaded to be taken seriously and for clinicians to understand their role and the difficult nature of that role.

(Mental Health Community Coalition Consumer and Carer Caucus,,
Australian Capital Territory, Submission #342)

Families not supported – we know entire families who are adrift.

(Consumer, Carer & Family Worker, New South Wales, Broken Hill Forum #23)

When we expressed our fear and worry about [X]'s premature discharge from the psychiatric unit after his first suicide attempt, we were told, "Family dynamics are not our concern."

(Carer, Sister, Australian Capital Territory, Canberra Forum #9)

Lack of support for carers

I coordinate family carer services. I focus mostly on urban carers. One of our carers has been a carer for a long time and I now advise carers to develop their own support because it's too frustrating to try and get anything from the system.

(Service Provider, Northern Territory, Alice Springs Forum #12)

I have no family or children so have had to cope on my own. Some good sound advice and suggestions from a mentor would be wonderful, but where can I go without it costing me an 'arm and a leg'.

(Carer, Wife, Australian Capital Territory, Submission #149)

Secondly, government policy states that carers have a right to appropriate education and training in order to fulfil their role, and yet our research indicates that carer support, education and training lacks the funding to administer comprehensive, timely and targeted support for carers in all regions .

(The Network for Carers Of People With A Mental Illness, Victoria, Submission #319)

5.11.4.B STANDARD 11.4.B: SUPPORTED ACCOMMODATION

Supported accommodation is provided and / or supported in a manner which promotes choice, safety, and maximum possible quality of life for the consumer.

Serious concerns were expressed across Australia about the decreasing level of available supported accommodation, especially in rural and regional areas. The lack of supported accommodation options in rural and regional areas effectively means that these consumers are forced to live away from their social and cultural supports.

Long wait lists (up to 3-4 years) were also reported by many service providers. Service providers also described the increasing number of consumers with complex needs who were requesting admission. Some NGO service providers described the increasing trend for their services to be used as "quasi-psychiatric" by mental health services without the requisite resources, funding and expertise.

Both these factors (lack of resources and increasing pressure to admit people with complex needs) are reportedly creating serious safety risks for consumers and staff. The need for a range of options was also voiced; in particular, the need for step-up and step-down facilities and facilities for consumers with drug and alcohol problems.

Access to a range of treatment and support for consumers living in supported accommodation was also reported to be limited and problematic. Support for accommodation service providers was also reported to be difficult to access, for example, after hours crisis support and medication supervision. The lack of respite options was also noted as a critical gap.

Nationally, the key issues relating to this Standard include:

- lack of housing and supported accommodation (Standards 11.4.B.1, 11.4.B.5, 11.4.B.6, 11.4.B.8-11.4.B.115);
- a necessary range of accommodation options is lacking (Standard 11.4.B.8);
- need for interim and step-down accommodations options (Standard 11.4.B.8);
- the need for step-up and step-down accommodation facilities for consumers with dual diagnosis (drug and alcohol) (Standards 11.4.B.6 and 11.4.B.8);
- lack of support for consumers and providers of supported accommodation (Standards 11.4.B.2-11.4.B.18);
- lack of supported accommodation options for people in rural and regional areas (Standards 11.4.B.8 and 11.4.B.9);
- lack of supported accommodation for people with complex needs (mental illness, drug and alcohol, homeless, elderly) (Standards 11.4.B.3, 11.4.B.5, 11.4.B.6 and 11.4.B.12);
- lack of supported accommodation options for young people (Standards 11.4.B.5, 11.4.B.9, 11.4.B.12);
- lack of support for homeless people with mental illness (Standards 11.4.B.5, 11.4.B.6, 11.4.B.8-11.4.B.12);
- lack of supported accommodation for offenders with mental illness or mental health problems (Standard 11.4.B.5);
- lack of supported accommodation options for consumers form a non-English speaking background (NESB) (Standards 11.4.B.5, 11.4.B.6, 11.4.B.9, 11.4.B.10, 11.4.B.12);

- lack of respite options (Standard 11.4.B.8);
- lack of respite options for parents with mental illness who have children (Standard 11.4.B.6 and 11.4.B.8);
- lack of funding and support for supported accommodation services (Standards 11.4.B.17 and 11.4.B.18); and
- lack of resources and support for NGO accommodation service providers (Standards 11.4.B.14-11.4.B.18).

The following selected quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 11.4.B. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Lack of housing and supported accommodation

St Bartholomew's [accommodation provider for homeless men] had found in 2001 in a situation where over 60% of its clients were potentially involved with mental health issues. It was utilised as a quasi-psychiatric service without any resources with respect to this aspect of care. Mental Health Services all over the area were discharging clients directly to St Bartholomew's… (excerpt from Coroner's Report, 2004)

(St Bartholomew's House Inc, Western Australia, Submission #37)

Homeless shelters, refuges and boarding houses are now functioning, defacto, as a major component of the accommodation provided by our society for thousands of Australians affected by Mental illness. This is completely unacceptable. It must have been acceptable because it has not changed. Homeless shelters are receiving more referrals from Acute Psychiatric Units to supply accommodation for their patients then ever before.

(NGO Service Provider, Queensland, Submission #40)

Brian Burdekin's 1993 report is just as valid today as it was eleven years ago and in some instances the situation is worse, e.g. with psychiatric clients losing case management support; and the decrease in housing stocks.

(Anonymous, Queensland, Submission #67)

The provision of suitable housing and accommodation available within Australia is appalling… When the large institutions were closed and patients moved into community care settings it allowed the Governments at all levels to neglect the accommodation for the mentally ill. They have taken this opportunity to neglect the provision of accommodation for the mentally ill with a zeal that they display in no other area of health care! We regret that this same level of enthusiasm is not evident in the area of service provision." Which level of government is responsible for housing?

(Clinician in rural Victoria, Victoria, Submission #123)

In addition to the financial impost of caring, carers report a critical lack of support in the form of community-based services, clinical, counselling, information and respite options. In particular they identified the lack of appropriate supported accommodation which denied their adult son or daughter the chance to live a meaningful independent life.

(Anglicare Tasmania, "Thin Ice: Living with Serious Mental Illness and Poverty in Tasmania", Tasmania, Submission #144)

I had a lady staying with me and she had a mental illness and I took her home and she had nowhere to go. I went on a holiday and when I came back she had killed herself. Her case worker and I tried to get someone – but no one would take her.

(Anonymous, Queensland, Rockhampton Forum #10)

We are still trying to find suitable accommodation for [X] after his release from hospital. It is very obvious to all that [X] needs to go into supported accommodation to help with his rehabilitation. He has shown that he can be very well, given the right set of circumstances, which include support of his family, psychiatrist and suitable supported accommodation. It is our greatest wish that [X] be well enough so that he may enjoy a useful and happy independent life.

(Carers, Parents, New South Wales, Submission #198)

I'm [X]'s carer and I feel for myself to cope so soon is very scary, walking on egg shells, mentally and physically very draining experience. I feel I can no longer cope with him living at home due to this illness. Bit there is nowhere for him to live. It's all unavailable. I would not want him locked away in an institution. But where can people with a mental illness live.

(Carer, Mother, Victoria, Submission #310)

There is a critical lack of suitable accommodation for suffers of mental illness. Large numbers are homeless or living with family who struggle to cope with the burden.

(Carer, Mother, Victoria, Submission #299)

Lack of support for consumers and providers of supported accommodation

NCOSS has received reports that supported accommodation providers are consistently unable to obtain necessary support services from mental health teams, including crisis response services, to assess and manage clients with mental disorders.

(NCOSS, New South Wales, Submission #47)

…is a non government organisation which provides housing and support to people with psychiatric disabilities in the Swan Region of Perth. We have been providing these services for 8 years now and have a waitlist for housing of between 40 and 50 people. It is almost an embarrassment to do an assessment for housing and then have to inform applicants that the waitlist is 3 to 4 years long… We are also now in the position where we are housing people when properties become available, without the capacity to support them in their housing.

(NGO Service Provider, Western Australia, Submission #18)

The closure of long term residential care beds in institutions has not been accompanied by the development of properly resourced and supported community accommodation. Sub-standard conditions in boarding houses are of great concern. In addition, placing consumers (people with mental illness) into public housing without ongoing supervision and support has lead to a deterioration in health of consumers and serious problems for other tenants in public housing.

(NSWCAG, New South Wales, Submission #273)

Lack of support for homeless people with mental illness

Tragically, the homeless people are the forgotten people. You won't hear from the homeless people even in a meeting like this.

(NGO Nurse Unit Manager, New South Wales, Sydney Forum #3)

A necessary range of accommodation options is lacking

Huge deficit in supported accommodation options: People who have recently been discharged after an acute episode usually require intensive support from both clinical care and social support services. However, the reality is that upon discharge, many people with a mental illness enter crisis accommodation services, or end up in police lock-ups or on the street. The alternative of being housed by their family often leaves the family vulnerable to emotional, physical and financial disruptions. Pressure on resources in hospitals means that patients have been discharged from hospital too early, placing a further strain on the family. Sometimes violence, financial demands and other factors associated with people with a mental illness prevent families from accepting their relative into the home.

(The Network for Carers Of People With A Mental Illness, Victoria, Submission #319)

Carers report that the current funding and provision of mental health care in WA is clearly inadequate to meet the level of need. This is demonstrated by: … [a] lack of independent accommodation options for people with mental illness. There should be a range of options available and flexible to the individual needs of people with mental illness.

(Carers WA, Western Australia, Submission #277)

Critical to the stabilisation and recovery of consumers is the availability of a flexible range of accommodation options. There are currently an inadequate number and range of residential rehabilitation programs offered to people with a mental illness in Victoria. Most of these offer psychosocial rehabilitation to people usually over 1-2 years. Yet longer-term residential rehabilitation programs lasting up to 6 or 7 years are needed to properly address the issues of clients with complex and chronic issues.

(The Network for Carers Of People With A Mental Illness, Victoria, Submission #319)

We go the extra mile in trying to provide accommodation for Mental Health Clients but are continually frustrated and concerned for both the client and ourselves at the lack of services and funding available. These are the same clients who cannot be accommodated more appropriately anywhere else.

(Darwin Red Shield Hostel, Northern Territory, Submission #217)

The mental health system failed [X] in so many ways. In summary the key failings were: … safe, secure accommodation was non-existent: there is nothing between the psychiatric unit and the charity-run refuges, which often have waiting lists and seem to pick up the pieces falling from the mental health system.

(Carer, Sister, Australian Capital Territory, Canberra Forum #9)

Many families, particularly elderly parents / carers, are being placed under a lot of stress because of the severe shortage of suitable assisted accommodation for their mentally ill adult children who are unable to manage on their own. Most of them are worried sick about what will happen to their children when the carer dies. Will the consumer end up on the streets? This is the biggest fear for the parents of these consumers. Many of these consumers COULD manage their own home IF they had the ongoing support of a case manager. And I mean a case manager who visits a minimum of once per week. So the problem of eliminating case managers also affects the ability of consumers to live in society independently of their family. (author's emphasis)

(Carer, Mother, Queensland, Submission #10)

This young man now has two fines which he will not pay. He needs a 'sheltered living hostel', a mentor, some work under supervision, like the Work for the Dole project. It is my contention that a program such as this is not more expensive than the present cost to the community and it may be good for him. He is a walking advertisement for the failure of Mental Health Services to support vulnerable people like him.

(Consumer Advocate, Western Australia, Submission #35

There is a lack of government funded long term supported housing for people who may not be able to live independently, or for people who may require supported housing long term before being able to sustain independent living

(Western Region Health Centre, Victoria, Submission #292)

Need for interim and step-down accommodations options

A huge area lacking in the mental health system overall is the lack of some form of interim accommodation like houses or hostels for patients who have recovered to the extent that they no longer require hospitalisation, but still require some overall supervision in a secure environment to give them their medication regularly and help to prepare them for release into the community. We have come across patients in Graylands hospital who have been there for many months, and have really nowhere to go where they can still be supervised and helped to rehabilitate.

(Carers, Parents, Western Australia, Submission #76)

Short term fully supported accommodation is needed to enable the development of living skills and rehabilitation back into the community. Families are often not best placed to provide such support - they are working to try to make ends meet.

(Carer, Mother, Victoria, Submission #299)

Lack of supported accommodation for offenders with mental illness or mental health problems

Undoubtedly, homelessness is a major issue for offenders with mental health issues… homeless mentally ill people are up to 40 times more likely to be arrested and 20 times more likely to be imprisoned than those with stable, suitable accommodation. While statistics are not available, there would appear to be no compelling reason why the situation would be different for mentally ill offenders in NSW. Incarceration appears to worsen post release accommodation issues… Further, offenders released with no stable accommodation were three times more likely to re-offend than those who had accommodation.

(Community Offender Services, Probation and Parole Service, Department of Corrective Services, New South Wales, Submission #317)

Lack of respite options

There is no available respite for families/carers of those people with mental health issues. However, for a carer of someone with an intellectual disability resources are available for respite. This raises another concern which is for that of the mental and physical health of the carer. (I have seen the health of carers and their families – including young children – deteriorate as they struggle to cope with their loved one).

(Anonymous, Western Australia, Submission #145)

5.11.4.C STANDARD 11.4.C: MEDICATION AND OTHER TECHNOLOGIES

Medication and other medical technologies are provided in a manner which promotes choice, safety and maximum possible quality of life for the consumer.

Across Australia, concern was expressed that there is an over-reliance and emphasis on medication as the only treatment option. There is a perception that therapies are omitted as a choice or are not available due to lack of services and clinicians. Concerns were also raised about the increasing use of Electro Convulsive Therapy (ECT) in both public and private hospitals and that consumers are not being given sufficient information to provide informed consent. The lack of opportunity to obtain a second opinion was also noted under this Standard.

Nationally, the key issues relating to this Standard include:

- concerns about the over reliance and emphasis on medication and medication as the only treatment option (Standard 11.4.C.1-11.4.C.4, 11.4.C.10-11.4.C.112);
- concern about the use of antidepressants for children (Standard 11.4.C.1, 11.4.C.2, 11.4.C.4 and 11.4.C.10);
- unsafe practices during treatment using Electro Convulsive Therapy (Standard 11.4.C.1, 11.4.C.2, 11.4.C.6, 11.4.C.9, 11.4.C.10, 11.4.C.11, 11.4.C.15 and 11.4.C.16);
- difficulties in accessing maintenance ECT (Electro Convulsive Therapy) treatment (Standard 11.4.C.1, 11.4.C.15 and 11.4.C.16); and
- the lack of opportunity to get a second opinion (Standard 11.4.C.12).

The following selected quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 11.4.C. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Concerns about the over-reliance and emphasis on medication and medication as the only treatment option

I'm also concerned that many people are treated for mental illness when the main treatment seems to be to whack them on large doses of medication – there is a lack of review of medication.

(Consumer, Queensland, Brisbane Forum #11)

By this time, [X] seemed as if he felt he didn't really need to attend the unit as Dr [Y] had provided him with a script with seven repeats! I didn't even think this was possible. Dr [Y] apparently also increased the dosage. This meant that [X] was not being seen by anyone at Mental Health so his deterioration was going undetected.

(Carer, Wife and Mother, Queensland, Submission #52)

Our son felt that the Psychiatrists and doctors in the Public Health System were not helping him. Either they don't know, don't want to know or their hands are tied because of government guide-lines. In fact their treatment was to heavily medicate our son and send him home, without any follow up treatment.

(Carer, Mother, Queensland, Submission #81)

Medication as the only treatment modality. Consumers of public mental health services, as in patients or in the community, rarely have an opportunity to 'talk through' the contents of their thoughts, their ideas about the causation of their illness, or the progressive processing or understanding they are developing about their condition. The structure of mental health services means that frequent turnover of staff leads to discontinuous relationships between consumers and doctors. Medication has become the primary treatment modality. Most consultations centre around negotiations on dose, medication type, combinations, side-effects, and consumer concerns about being on chemical treatments…

(Health Consumers' Council WA, Western Australia, Submission #29)

The ever-increasing reliance on medication to manage mental illness means there is an ever-increasing reliance on forcing people to take medication. As a result, involuntary orders have increased at the same time as people are crying out for treatment.

(Mental Health Legal Centre, Victoria, Submission #330)

Currently the focus of treatment is predominantly on medication. People who suffer from a mental illness, not only need medication but assistance and support to help deal with their situation. As well as medication they need counselling to help them deal with the difficulties of having a mental illness.

(Peninsula Carers Council, Victoria, Submission #321)

Medication is often inappropriately tailored to the individual's needs and poorly monitored with distressing results. Mental Health Workers do not take sufficient notice of consumers in this regard. I have seen my daughter faint onto a thinly carpeted concrete floor as a result of low blood pressure induced by medication whilst a psychiatric nurse looked on impassively as if she was 'putting it on'. She was once medicated so heavily that her voice sank to an almost inaudible whisper for 36 hours. She has suffered severe involuntary protrusions of the tongue and I have seen her endure a 10 minute wait at the nurses station in full view of all the other patients before Cogentin was administered. Such experiences are frightening, especially given that her medication is administered involuntarily.

(Carer, Mother, Victoria, Submission #299)

Unsafe practices during treatment using Electro Convulsive Therapy

ECT [Electro Convulsive Therapy] use is increasing in WA, in both public and private hospitals. There was a marked 25% increase in ECT hospitalisations in the financial year 2000 / 01 (618), compared with the previous year 1999 / 00 (495). 63% of these hospitalisations were in private hospitals. Why is this the case? …The majority of hospitalisations for ECT treatment in 2001 were female (70%)… There is no standard protocol for the administering of ECT over all hospitals. Individual hospitals have their own clinical protocols, including voltage, area of administration and number of treatments. While a standard protocol for public hospitals is being addressed, the private hospitals adhere to their own individual policies. Elderly patients (24% of ECT patients were over 65 years) are being given "maintenance ECT" with no other treatment, and no treatment plan. Patients are not fully informed of the multitude of side effects associated with ECT. There has been a move away from unilateral ECT (which was thought to minimise side effects) to bilateral ECT. A review of the literature indicates there is little agreement amongst ECT "Experts" about ECT procedures. Issues such as current, electrode placement, and number of treatments remain controversial. I do not believe the public are aware of the extent of ECT use. In my opinion, ECT is an unacceptable treatment. If it is used at all, ECT should be given as an absolute last resort, under the most stringent guidelines. Currently ECT is being given in an ad hoc manner.

(Giz Watson MLC, Western Australia, Submission #171)

Difficulties in accessing maintenance ECT

For this treatment to continue being successful it is essential that [X] receive regular maintenance ECTs. Although this was previously done at Dandenong for out patients, it is no longer the case. This means that [X] must book as an inpatient, taking a bed that could otherwise be used for someone else, or if no bed available, then her treatment is cancelled, as has happened with her last four sessions, which I am sure you would understand has had a negative affect on the benefits initially gained from her ongoing treatment. It is my understanding that outpatient maintenance ECTs are available at surrounding hospitals but we are "out of area", we and the many others who could benefit from this program are missing out.

(Carer, Husband, Victoria, Submission #348)

5.11.4.D STANDARD 11.4.D: THERAPIES

The consumer and consumer's family / carer have access to a range of safe and effective therapies

Concerns were expressed about the extremely limited availability of therapies throughout mental health services in Australia. Reports were received that non-pharmaceutical therapies are often not offered as a choice and there is an emphasis on medication as the only treatment option. Lack of access to psychologists in the public sector meant that only those who could afford to pay for such services in the private sector were able to access this form of treatment option. This situation was described as 'immoral' and 'incompatible with human rights'.

Nationally, the key issues relating to this Standard include:

- lack of access to a range of therapies – emphasis on medication (Standards 11.4.D.1 – 11.4.D.4);
- lack of access to Psychologists (Standards 11.4.D.1 – 11.4.D.4);
- lack of access to treatment programs for people with Borderline Personality Disorder (Standards 11.4.D.1 – 11.4.D.4); and
- concerns about the costs associated with therapies making this a limited option for many consumers (Standard 11.4.D.5).

The following selected quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 11.4.D. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Lack of access to a range of therapies – emphasis on medication

My husband was diagnosed with bipolar 40 years ago. On and off with depression. Treated every time with drugs, no cognitive behaviour therapy (CBT).

(Carer, Wife, Northern Territory, Darwin Forum #13)

Both consumers and carers reported that whilst a person is in hospital, very little 'therapy' or 'treatment', other then medication and injections, are available or provided.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

During the years I have been involved with the Rockhamptom Mental Health Unit the only option offered to consumers seems to be by way of medication. There is a real need for other options to be available instead of / or in conjunction with the use of medications.

(Carer, Wife and Mother, Queensland, Submission #52)

A predominant finding in our experience has been the difficulty in seeking non-pharmacological treatments for persons who experience Anxiety and Depression.

(blueVoices, National, Submission #355)

People with anxiety disorders and depression often have no idea how to access the services that are available. The majority of the people coming to see the psychologists at PADA (Panic, Anxiety and Depression Assistance) have had their anxiety disorder for many years – usually between four and ten years. This is outrageous for conditions that respond well to CBT (Cognitive Behaviour Therapy).

(Clinical Service Provider, Victoria, Submission #268)

Lack of access to psychologists

Psychologists are not available in the public health system. It's inaccessible and it's impossible to ask people to do that themselves. People with a mental illness don't get help to deal with normal life stress - they get their meds increased.

(Carer, Mother and NGO Service Provider, Tasmania, Hobart Forum #14)

The Burdekin report stated that "restriction to access to psychologists results in important treatment options being denied to many individuals affected by mental illness and that the lack of access is incompatible with human rights and is economically unsound". It seems immoral that in 2004 clinical psychologists are not routinely available to people suffering mental disorders.

(ARAFMI Tasmania, Tasmania, Submission #245)

Concerns about the costs associated with therapies making this a limited option for many consumers

It is almost impossible to see a psychologist or psychotherapist in the public mental health sector these days. This is a disaster. Where have they all gone and why? Why do those of us who desperately need counselling and other talking therapies always seem to come last?

(Consumer, Queensland, Submission #204)

Access to the combination of pharmacological prescription and therapeutic counselling is not available to people who cannot afford to pay full private price and for those who can, remains extremely limited.

(Support and Equity Services, Charles Darwin University, Northern Territory, Submission #269)

While living with a mental illness is hard, the fact is that if you have money you can get help. For example, with money you can access other forms of therapy (non-drug), which can help greatly but we can't access this care through Medicare.

(Carer , New South Wales, Sydney Forum #9)

For our members access to low cost counselling would be invaluable to assist with their recovery. Anecdotally we have worked with members who report the benefits of using local community counselling services to resolve the underlying causes of issues.

(Service Provider, Victoria, Submission #266)

My wife suffers from depression and I took her to the regional mental health unit in Wodonga. An initial interview was conducted with 2 people from this unit and their only advice was 'go and see a private psychologist, we don't have the resources here to help'. This news was devastating as we cannot afford the treatment required in private practice, and this has now tainted my wife's view of any help possible.

(Carer, Husband, Victoria, Submission #119)

5.11.4.E STANDARD 11.4.E: INPATIENT CARE

The MHS ensures access to high quality, safe and comfortable inpatient care for consumers.

Serious concerns were expressed about the quality of treatment and support currently being delivered in inpatient units in every Australian State and Territory. Reports of excessive use of sedation, restraint and seclusion and the increasing inappropriate use of security guards due to a shortage of secure beds were cited as areas of critical concern.

A chronic shortage of beds was also described as one of the main reasons for non-admission of consumers where acute care was urgently required. The pressure to vacate beds is also the cause of premature discharge.

Reports were received that a chronic shortage of resources and staff resulted in occasions when the safety of consumers was not ensured and when consumers harmed themselves or died while in care. Reports were also received of many consumers absconding from care and staff not adhering to protocols. There have also been illustrations of occasions when voluntary admissions were not promoted.

Also of serious concern were reports from consumers that they were frequently not involved in the development of their own treatment plans. Many inpatient units were described to be in very poor condition with minimum regard for privacy and increasingly inpatient units were being renovated to resemble prison enclosures.

Consumers also reported feeling scared and having nothing to do within inpatient facilities and that they were being treated as 'second class citizens' and receiving services of an inferior standard compared to other health facilities.

Transport to and between hospital settings with police vehicles also raised concerns that that this was not the most respectful mode of transport possible and suggests that people with mental illness are criminals.

Concern was also expressed that the impact of admission on the consumer's family is not minimised and that children of parents with mental illness are not always notified of admission and their needs may not be considered while their parent is in hospital.

Nationally, the key issues relating to this Standard include:

- care not being provided in the least restrictive environment (Standard 11.4.E.1);
- excessive use of restraint (chemical and physical) and seclusion (Standard 11.4.E.1);
- death while an inpatient (Standards 11.4.E.1, 11.4.E.14 - 11.4.E.16);
- concerns about consumers suiciding in hospital settings (Standards 11.4.E.1, 11.4.E.14 - 11.4.E.16);
- protection from harm not ensured (Standards 11.4.E.1, 11.4.E.14 - 11.4.E.16);
- patients absconding from hospitals and involvement of police (Standards 11.4.E.1 and 11.4.E.14 - 11.4.E.16);
- lack of beds (Standard 11.4.E.1, 11.4.E.2, 11.4.E.14 - 11.4.E.16);
- problems with increasing use of security guards in hospital settings due to a shortage of secure beds (Standards 11.4.E.1, 11.4.E.14 - 11.4.E.16);
- lack of access to professional mental health staff (Standard 11.4.E.5, 11.4.E.15-11.4.E.16);
- appropriate treatment and support not being provided in inpatient units (Standard 11.4.E.1, 11.4.E.4 and 11.4.E.5);
- voluntary admission not supported (Standard 11.4.E.2);
- transport to hospital is not occurring in the most respectful manner possible (Standard 11.4.E.3);
- use of police to transport consumers to and between hospitals (Standard 11.4.E.3);
- lack of supervision and adherence to protocols (Standards 11.4.E.15 and 11.4.E.16);
- consumers and carers are not being informed or involved in treatment plans (Standards 11.4.E.6, 11.4.E.11);
- impact of admission on consumers' family not minimised (Standard 11.4.E.7);
- lack of continuity of care and extreme distress for consumers and their families and carers when admission is required (Standard 11.4.E.5 and 11.4.E.7);
- children of parents with mental illness are not being notified of admission of parent or their needs considered while their parent is receiving inpatient treatment and support (Standard 11.4.E.7);
- need for separate psychogeriatric facilities (Standards 11.4.E.1, 11.4.E.11 and 11.4.E.16);
- inpatient units in poor condition (Standard 11.4.E.14); and
- lack of privacy and lack of choice (Standard 11.4.E.14).

The following selected quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 11.4.E. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Death while an inpatient

Attempts were made to locate a facility to meet the needs of my sister. It is my understanding that of all the hospitals with closed wards, there were no beds available that evening. Eventually after a long delay, she was transferred to the psychiatric unit at Royal Perth Hospital in the Perth CBD. She stayed there the night but was not in a locked ward. In the morning she walked out of the hospital. She walked less than 500m to a multilevel carpark on the corner of Wellington and Pier Streets. She went to the top floor and jumped to her death... It was unnecessary tragedy that could and should have been averted. There are many questions unanswered for my family: How can this happen? Who is accountable? Why are there insufficient resources when the problem is so evident? ...the system failed my sister and her family. It is unacceptable and these issues need to be voiced and addressed… I was unable to return to [my] job after my loss.

(Brother, Western Australia, Submission #89)

[Graylands Hospital[is a nightmare of mammoth proportions and at the moment I am writing a book showing such facts along with the death of my daughter there, along with other young adults. It is usual to go to a hospital to improve one's health... these young people are dying through neglect by hospital staff and not being listened to. Certainly no fault of their own. I have searched long and hard and if I honestly believed that my daughter and the others I know of had died through their own doing and with compassion behind them I would leave well alone. They didn't - they died in strange circumstances.

(Carer, Mother, Western Australia, Submission #103)

15 March, 2002. She said [X] was being sent out on unaccompanied leave that night. When asked had she read my letter, she said "yes" and made no further comment. I told her, at some length, that [X] was acutely paranoid and believed that stalkers were at her flat. She listened, made no reply, and noted these serious matters in the file as "allowed to ventilate"… When asked six weeks later if she had informed Dr [Y] of my fears and [X]'s paranoia, [she] said no. I called the ward at 2pm to say that [X] might kill herself if sent out without me. [X] was sent out. We stayed in contact by phone. She got through Friday night. 16 March. We were in contact by phone. [X] was not happy, but said she would stay. We spoke last at 8.30pm. At 11pm [X] jumped in front of a train and was killed instantly.

(Carer, Mother, Victoria, Submission #206)

Excessive use of restraint (chemical and physical) and seclusion

I am extremely concerned about the use of restraint and seclusion in SA hospitals. There have been frequent recent stories of psychiatric patients being shackled in the ED [Emergency Department] at central city hospitals, inappropriate use of seclusion (for staff convenience not patient care), the use of outmoded and banned restraint holds by nurses and patients not being treated with the care and respect they deserve.

(Academic, South Australia, Submission #142)

More extreme forms of physical abuse include being strip-searched, locked up and isolated, physically restrained by ward staff or restraining devices such as shackles.

(Insane Australia, Victoria, Submission #232)

I also want to talk about a story that was reported in the Penrith Press – the story is about patients being sedated for up to 5 days and being strapped to beds – they have no access to any therapeutic services - only TV or smoking.

(Advocate, New South Wales, Sydney Forum # 8).

When I asked patients in a research study about what they thought of seclusion, their answers were largely negative, they feel punished humiliated, bored and scared when in seclusion. This is not quality nursing care.

(Academic, South Australia, Submission #142)

The use of Seclusion Rooms and involuntary restraint is still continuing in NSW. Seclusion Rooms and involuntary restraint, which are often, degrading, inhumane and traumatic, are a normal form of 'treatment' in NSW Public hospitals. Why is it that in other parts of the World including the U.S., Prevention Programmes have greatly reduced the need for these abuses, yet in NSW this form of treatment is still seen as legitimate?

(Consumer Activist, New South Wales, Submission #257)

Further, nurses report that the workload results in their having no option but to adopt a custodial approach to patient care, rather than that of the development of therapeutic relationships. We learn of instances where restraint is used, with security guards and the police being called to emergency departments to restrain people who are acutely and severely unwell.

(Australian Nursing Federation (Vic Branch), Victoria, Submission #322)

Appropriate treatment and support not being provided in inpatient units

I was admitted to hospital one night. I had a serious overdose on drugs, trying to commit suicide, I explained this to the nurses in the Logan Hospital, they left me in a room by myself all night and released me at 6am the following morning and told me I was fine.

(Consumer, Queensland, Submission #73)

Treatment is typically brief and often people are released the next day; they are just kept in over night. This type of care is no good – it creates a revolving door – people just get sick again because they have been discharged early so the figures look good and someone else can have their bed. This is not good care.

(NGO worker, Queensland, Brisbane Forum #3)

I believe the public have a right to know about the dangerously inadequate psychiatric services currently available in Gippsland. As previously reported, people who are deemed in need of admission, & thus 24 hour care, are being cared for during the day in a highly stressed environment, where Nurses are often General Nurses, inexperienced in psychiatric care. At times there has only been one Psychiatric Nurse on duty, responsible for supervising a nursing team, comprising some for whom it was their first experience in an acute psychiatric ward. It is not surprising that some of these nurses have refused to return. Because the number of patients being admitted is higher than the number of available beds, it is correct that patients are sent to motels and caravan parks to sleep. As you can imagine any psychiatric ward can be and often is a place where highly charged emotions are expressed. Imagine the added effect of overcrowding and at times fearful inexperienced staff. This is a recipe for tragedy waiting to occur.

(Anonymous, Victoria, Submission #312)

[X] believes that patients are treated as 2nd class citizens. They do not receive the same level of care you would receive in other health facilities.

(Anonymous, New South Wales, Submission #156)

Lack of beds

… it is also worth noting that the Consultant Psychiatrist who admitted her had to almost beg for the last bed on the ward, otherwise the client, who was suicidal, would have been sent home with no support. The doctor informed me that on the previous day, he had wasted 3 hours of his clinic time chasing a bed for an extremely unwell patient. His other patients could not be seen due to this.

(Clinician, Western Australia, Submission #15)

Early discharge – people are moved from wards to overnight rehab beds so another patient can have their bed. This type of system is not in favour of patients or their family or staff. We have 56 patients in a 33 bed ward. Patients are often put on leave for a week because we have a bed shortage. Their clinical care is being determined not by their need but by the availability of resources! The ones who have families are the ones who are discharged more quickly.

(Service Provider, New South Wales, NESB Parramatta Forum #21)

There is a real shortage of beds and this results in a crisis occurring every weekend with respect to beds and community based care… What happens is that they get lined up in emergency departments, which are overfull in any case and ED staff are stressed and unhappy. Alternatively other patients are moved from the psych unit to general wards to make room for new admissions or people are sent home earlier than desirable clinically, with fingers crossed! This is really a system problem, not a clinician problem.

(Anonymous, New South Wales Submission #303)

Currently there is a catastrophic and cruel shortage of acute mental health beds in the state. I work in psychiatric triage, based in an Emergency Department and almost on a daily basis, my colleagues and I search for beds for people who have become acutely unwell and require hospitalisation. It is not uncommon for these people to have to wait 48 to 60 hours in the emergency department, amidst the noise and chaos of emergency, for a suitable bed. They are even unluckier if they require a High Dependency bed.

(Clinician, Victoria, Submission #201)

Nurses told me when a patient is in emergency needing a bed, they do "eenie, meenie, miny, mo" around the ward and decide who can be discharged – whether or not they are well. . On one occasion during the 6 month period my son was ill he was discharged and threatening staff while we were still standing in the ward waiting for his medication.

(Carer, Mother, Queensland, Submission #168)

The few who make it to an inpatient unit face the risk of premature discharge in order to 'free up' more beds for those in crisis awaiting admission. People are often discharged on the basis of who is the least risk rather than who is ready to return to their home.

(Health and Community Services Union, Victoria, Submission #220)

There are extended waiting times in Emergency Departments for Mental Health patients/clients, because there are limited beds; inpatient mental health services run above capacity most of the time. Deinstitutionalisation and mainstreaming have resulted in general hospitals having more contact with Mental Health patients/clients; Emergency Departments are the main access point for mental health emergencies. There is clear evidence that general hospital staff and systems are poorly equipped and resourced to provide mental health care to patients/clients with mental health concerns. The availability of meaningful assistance to general hospitals from mental health services varies dramatically. Psychiatric Emergency and Consultation-Liaison Psychiatry Services are inequitably distributed across the state and in many cases, virtually non-existent in country regions.

(ANZCMH Nurses Victorian Branch, Victoria, Submission #316)

Voluntary admission not supported

[X] was kept heavily sedated: [X] was in and out of drug induced sleep for approximately 18 hours until admission at Graylands Hospital. Surely this is way too long and unnecessary considering the fact that [X] was voluntarily seeking treatment! During the assessment stage at the Emergency Department of Bunbury Regional Hospital, [X] had been calm and fully compliant. No grounds were shown for involuntary admission witnessed by parents, security and nursing staff.

(Carers, Western Australia, Submission #177)

Transport to hospital is not occurring in the most respectful manner possible

The fact remains that these individuals should not be treated as offenders and as such it is inappropriate to be transporting them in police vehicles. Police have received complaints regarding this very point by concerned family members of these patients.

(Police Association of New South Wales, New South Wales, Submission #59)

Impact of admission on consumers' family not minimised

When admitted to an Adelaide hospital you become distant from your family and visiting is less affordable. Again no communication from the hospital to help families adjust and understand what is happening occurs.

(Consumer, South Australia, Submission #77)

5.11.5 STANDARD 11.5: PLANNING FOR EXIT

Consumers are assisted to plan for their exit from the MHS to ensure that ongoing follow-up is available if required.

Under this Standard, the prevailing concern at the national level was that discharge decisions are made according to the need to vacate beds rather than the health status of consumers. As such, reports were received of discharge frequently occurring with very little notice, without the review of individual care plans, without proper assessments and without adequate discharge plans being in place. Where attempts had been made to plan for exit, it seems that the lack of treatment and support services in the community and long wait lists, means there were few real options. Reports were also received of occasions when services were identified in plans but contact had not been established prior to exit, and arrangements for ongoing follow-up had not been made.

Nationally, the key issues relating to this Standard include:

- discharge occurring suddenly while consumer still unwell due to lack of resources (Standards 11.5.1 and 11.5.2);
- planning for exit on the basis of need to vacate beds (Standards 11.5.7 - 11.5.9);
- discharge being used as a threat with consumers (Standard 11.5.7);
- discharge without proper assessment (Standards 11.5.1 and 11.5. 2);
- individual care plans not being reviewed properly prior to exit (Standard 11.5. 2);
- discharge occurring without adequate planning (Standards 11.5.1 – 11.5.6);
- inadequate discharge plans (Standards 11.5.1 – 11.5.3);
- exit plans not authorised by medical staff (Standards 11.5.8 and 11.5.9);
- difficulty in coordinating community-based services when exiting mental health services (Standards 11.5.5 and 11.5.6);
- lack of services and options available to assist with delivery of treatment and support after discharge (Standards 11.5.4 – 11.5.6); and
- other service providers nominated on exit plan not informed prior to exit (Standards 11.5.5 and 11.5.6).

The following quotes from community forums and submissions describe some people's recent experiences of mental health services and areas of concern under Standard 11.5. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Planning for exit on the basis of need to vacate beds

It should be noted that discharge is largely driven by the assessment that another incoming client has a greater need rather than the client is ready for discharge.

(Anonymous, Tasmania, Submission #254)

Patients admitted with a mental illness are often discharged before they have sufficiently recovered, due to pressure on hospital beds. This can place an unnecessary burden on carers, who are untrained but are forced to care for someone who is still unwell. This can also put the consumer at risk, and in particular risk of suicide.

(Peninsula Carers Council, Victoria, Submission #321)

Discharge occurring without adequate planning

"The first time I was in hospital—on the day I was to be discharged and I didn't know it was going to be that day—I was given a sheet of paper with a list of boarding houses on it and told to find myself a place to stay because I was going to be discharged that afternoon. I lived under a train station for 2 weeks until I found somewhere to stay. I had just spent 8 weeks in hospital getting better and then they say you have to get out and they don't care where you go. They told me I could come back on Monday if I needed to". (BSL 2004 Focus groups with mental health consumers)

(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

But then they sedated him even though I told them I would transport him to Graylands. 20 hours later after being in a drug induced state in Graylands he was discharged (the next morning) without any explanation to him or to us.

(Mother, Western Australia, Bunbury Forum #22)

Patients admitted with a mental illness are often discharged without establishing whether they have appropriate accommodation arranged. This can mean that carers are unprepared for their loved one to return home, or that their loved one literally has nowhere to go.

(Peninsula Carers Council, Victoria, Submission #321)

Inadequate discharge plans

Psychiatric disability is ongoing, not fixed on release from hospital. There needs to be an adequate discharge plan available for people discharged from hospital. These plans don't always occur. Many plans are not adequate enough.

(Carer, Father, Australian Capital Territory, Canberra Forum #18)

Difficulty in coordinating community based services when exiting mental health services

We provide a comprehensive service. It is difficult to link mental health clients to get community based services. We have difficulty getting mental health staff to work in with discharge of patients. It seems to be a big problem with links to mental health clinicians linking in with the discharge planning. Mental health patients are not linked in to home help.

(Social Worker, Western Australia, Geraldton Forum #84)

The Hospital (eg RHH {Royal Hobart Hospital]) is outside the community mental health structure and therefore has no commitment to the care of clients once it perceives them as ready for discharge. Despite frequent attempts to establish coordinated discharge planning ("discharge planning begins on admission") the community services are still often left out of the loop and find the client has been discharged without proper arrangements for continued support.

(Anonymous, Tasmania, Submission #254)

5.11.6 STANDARD 11.6: EXIT AND RE-ENTRY

The MHS assists consumers to exit the service and ensures re-entry according to the consumer's needs.

Concerns were expressed across Australia that treatment, support and ongoing follow-up are not being arranged or reviewed prior to exit for many consumers. A result of this was that some consumers and carers felt that once they "walked out the door of the mental health service no one cared".

There were many reports of consumers committing suicide soon after discharge. Other reports illustrated and absence of follow-up arrangements or, if they were made, appointments were not kept by the mental health service.

The stories illustrate that discharge protocols are not in place in some mental health services or are inconsistently applied. There are seems to be insufficient procedures ensuring provision of adequate information to consumers and their carers about treatment and support, how to gain entry to the mental health service at a later date, how to identify early warning signs and who to contact.

Nationally, the key issues relating to this Standard include:

- consumers being discharged while still very ill with no arrangements for ongoing treatment and support (Standard 11.6.1);
- suicide soon after discharge (Standards 11.6.1 - 11.6.5);
- lack of involvement of carers on exit (Standards 11.6.3 and 11.6.5);
- no review of arrangements prior to exit (Standard 11.6.1); and
- inadequate or no follow-up (Standards 11.6.2 – 11.6.5).

The following selected quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 11.6. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Suicide soon after discharge (consumers being discharged while still very ill with no arrangements for ongoing treatment and support)

*On leaving the hospital with her son, the only information given to his mother was a copy of the discharge summary and four pages of "better sleep tips". Dr [Y], the discharging doctor, was asked if there was a discharge protocol. She replied that she did not use one and was unaware if one existed. Dr [Z] later agreed that there should have been a conference with the family before discharge… The standard of care provided for [X] left much to be desired. After considerable questioning, this was reluctantly conceded by some of the doctors who gave evidence at this inquest… [X] was discharged with a minimum of formality and no guidance or assistance to them or their son… (*excerpt from the Coroner's Report*)*

(Carers, Parents, New South Wales, Submission #137)

The thing I found is that once he walked out the door of the mental health service no one cared about him or what happened to him… They said he was okay and released him with no shoes, no where to go and blood all over him. I spoke to the Dr and [X] died 10 days later – he jumped. There are so many suiciding. Nobody to help me. I should have had more help, I couldn't do it… Everybody like that needs someone to care for them.

(Carer, Tasmania, Hobart Forum #22)

I saw my husband rapidly lose weight, lose sleep, lose more interest in things he loved to do and withdraw from me, and yet it never occurred to me that he would attempt suicide again. I had no idea on the high statistics of that happening. No-one told me anything. Especially the fact that a Mobile Crisis Team was available if I needed them to be at my beck and call. I didn't know of their existence until they came to see me after [X] died and they said to me, "your husband has fallen through the cracks. If you wanted to take further action I wouldn't blame you." My heart just sank. Apparently in the clinic they asked [X] if he thought he needed acute care????? What sort of a question is that to ask a suicidal patient? How in the hell would he know? During the whole 9 days after [X]'s discharge from the clinic he did not receive one follow up phone call or anything to check on his condition. That I find is appalling.

(Carer, Wife, New South Wales, Submission #126)

Consumers being discharged while still very ill with no arrangements for ongoing treatment and support

Then he was discharged while still obviously very psychotic, and 14 hours later his brother sat in an emergency room at the hospital for another 5 hours to have him re-admitted.

(Carer, Mother, Queensland, Submission #168)

Inadequate or no follow-up

After his discharge from hospital [X] had a couple of appointments with the psychiatrist at Swan Valley Centre, then was discharged form there and told to go his GP for his medication. So far [X] has gone twice to be issued with 6 month repeat prescriptions. There has been no other contact – not even a phone call to ask how he is doing.

(Carer, Mother, Western Australia, Submission #99).

I feel my main concerns are that there is: NO FOLLOW UP ON DISCHARGE, NO REHABILITATION ON DISCHARGE. [X] said to me when he came out of hospital 'Mum what am I going to do with my life? I didn't know what to say. (author's emphasis)

(Carer, Mother, Western Australia, Submission #99).

It is very difficult to be admitted to the facility and in many cases there is no follow up and / or case management is kept to a minimum. But this is not always the case, some people are taken up or case managed long-term that are far less ill than others.

(Anonymous, Queensland, Submission #113)

After I took the overdose I was admitted to hospital. I only saw the doctor on the day I was being discharged and he told me I would be assigned a case worker but still 4 weeks later I have had no contact.

(Consumer, New South Wales, Broken Hill Forum #3)

Lack of involvement of carers on exit

My son was discharged from hospital and we didn't even know he had been discharged until he turned up on our doorstep. No one tried to inform us even though they knew he would come back to us because we are his carers.

(Mother, Western Australia, Bunbury Forum #22)

My other concern is for the carers they are told not to get involved but there's no one else to get involved. If the service doesn't want to involve carers then who do they think will provide the care once someone is discharged from a hospital? Who else is there?

(GP, Western Australia, Bunbury Forum #19)

On discharge there is no discharge plan and the support received by the patient from the hospital ends with not even a phone call to see how you are.

(Consumer, South Australia, Submission #77)

Each time I have been hospitalised "no" follow-ups have occurred. You have to wait until you can "acquire" an appointment at the clinic. This can be 2-4 weeks later.

(Consumer, Victoria, Submission #112)

PART SIX:
ANALYSIS OF SUBMISSIONS AND FORUMS AGAINST THE NATIONAL STANDARDS FOR MENTAL HEALTH SERVICES

6.1 New South Wales 237

6.2 Victoria 356

6.3 Queensland 460

6.4 South Australia 527

6.5 Western Australia 584

6.6 Australian Capital Territory 669

6.7 Northern Territory 716

6.8 Tasmania 761

6.9 National 805

6.1 NEW SOUTH WALES

ANALYSIS OF SUBMISSIONS AND CONSULTATIONS FROM NEW SOUTH WALES AGAINST THE NATIONAL STANDARDS FOR MENTAL HEALTH SERVICES

In summary, information presented in this section was gathered from 82 submissions (see Appendix 8.3.1) and presentations made community forums attended by approximately 163 people (see Appendix 8.1). A draft copy of this report was sent to the Premier and Minister for Health for comment. An analysis of the response from the New South Wales Government (reproduced in Appendix 8.4.1) and an overall review of mental health service delivery in New South Wales is contained in Part 2.7.1.

6.1.1 STANDARD 1: RIGHTS

The rights of people affected by mental disorders and / or mental health problems are upheld by the MHS.

Under this Standard, submissions and presentations indicate concerns about:

- non-compliance with relevant instruments protecting the rights of people with mental illness;
- lack of information about treatment options;
- problems with the complaints process;
- consumers not being treated with dignity and respect;
- rights of people with mental illness in the criminal justice system;
- lack of access to advocates;
- lack of access to interpreters; and
- ministerial discretion and the rights of people with mental illness.

> *I would like to know if it is possible to take class action against NSW Government on behalf of the mentally ill people and their carers on the basis of discrimination demonstrated by the loss of big psychiatric hospitals such as Gladesville and Rozelle without proper compensation by provision of equivalent community and general hospital based services.*
>
> (Clinician, New South Wales, Submission #25)

6.1.1.1 Non-compliance with relevant instruments protecting the rights of people with mental illness

Concerns were expressed that staff of the MHS are not complying with relevant legislation, regulations and instruments protecting the rights of people affected by mental disorders and/or mental health problems (Standard 1.1). Included in the notes and examples for Standard 1.1 are: The Australian Health Ministers' Statement of Rights and Responsibilities, the UN Prinicples on the Protection of People with a Mental Illness and Improvement in Mental Health Care, departmental codes of conduct and mental health legislation.

Why in 2004 are our loved ones still suffering after policy documents from fancy government watchdogs have been released? Why aren't our loved ones receiving the same quality of care as people with physical illnesses? Are they not worthy of treatment? Where is the concern? There are huge problems with the system and some of the staff within the system. There is physical and sexual abuse still occurring. Why do we still use seclusion where there are no toilets, no water?

(Carer, New South Wales, Parramatta Forum #1)

...the basic human rights of people living with a mental illness are still being ignored. What about the voiceless sufferers of people with a mental illness.

(Carer New South Wales, Sydney Forum #2)

It must be recognised that the patient is the most disempowered person, the one whose input is most likely to be disregarded and put down as a symptom. As such it is necessary to ensure their rights.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

The Indigenous Social Justice Association (ISJA) and Justice Action (JA) also expressed concern regarding the frequent assumption that people with mental illness lack the capacity to consider matters, give opinion or give directions and that this lays the basis for many rights being denied:

We believe that it is vital to respect the patient as a person. It should never be assumed that the person is incapable of considering a matter, forming an opinion and giving direction regarding the matter. This includes who is privy to information and who may be involved in admission, treatment, and discharge, in terms of Health and non-Health persons and the interaction of the two. There is generally a presumption that any patient with psychiatric disability lacks capacity. This is untrue. It is also untrue that a lack of capacity regarding one issue means that the patient may be regarded as lacking capacity in another or all issues. Issues need to be looked at on a case by case basis.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

6.1.1.2 Lack of information about treatment options

Concern was expressed that mental health services are not providing consumers and their carers with information about available mental health services, mental disorders, mental health problems and available treatments and support services. Standard 1.8 states: 'The mental health service provides consumers and their carers with information about available mental health services, mental disorders, mental health problems and available treatments and support services'.

This is of serious concern on many levels with regards to consent, choice, the right of a person to know about their illness and the treatment plan (and any side-effects) and for carers to be informed regarding what is and will be happening and how they best support the consumer or access support for themselves. The following statement by a consumer at the Sydney forum indicates that despite frequent contact with the mental health service, very little information was provided about treatment options to allow the consumer to realise her range of options and elect to receive treatment in the least restrictive setting:

I have had 4 acute episodes but it was only during the last one that I found out that I could be treated at home if I had a support person.

(Consumer, New South Wales, Sydney Forum #11)

The worker left absolutely no information – not even a business card. No information was given about community services… The worker did not arrange any support services or give any information about them.

(Carer, New South Wales, Submission #48)

6.1.1.3 Problems with the complaints process

Carers who had used the complaints procedure reported feelings of anger with the process, of being ignored or their concerns trivialised or being fearful of losing everything they had. The descriptions provided by carers did not accord with a complaints procedure 'easily accessed, responsive and fair' (Standard 1.10). Failure to have in place a system which allows consumers and their families and carers to make complaints confidentially and ensure that complaints procedures are adhered and responded to weakens this right and fails to provide a mechanism by which to 'improve performance as a part of a quality improvement process' (Standard 1.12). Comments presented via submissions indicate that the complaints procedure is currently obstructive and futile. The complaints process does not allow for the identification of single or systemic failures and thereby does not allow for personal redress or systemic improvement. The following extracts from a number of submissions illustrate some of the frustration experienced by people when dealing with a dysfunctional system:

We have lost our son… There has not been a hearing yet, which we made a statement to say we wished to be present at. The Dr that was head of the [X] Dept made a comment to us as we left to something of the effect that we shouldn't pursue the matter any further as not having a lot we could lose all that we have. Our son was told he could not leave as he was too ill and was on 24 hour surveillance, and this happened… Dr [Z]… [h]e felt there was not enough done. I feel the medication he was on made him do what he did.

(Carer, Mother, New South Wales, Submission #135)

We had made a detailed complaint in writing to Mr [Y] (General Manager, X Hospital) on 23 December 2001 and were unsatisfied with his response which was inaccurate, glib and condescending.

(Carers, Parents, New South Wales, Submission #106)

My wife made a formal complaint about [nurse]'s behaviour, but there was no response from the hospital.

(Carers, Parents, New South Wales, Submission #106)

The health service will only flex a muscle when it feels threatened by actually appearing before a coroner's inquest or being sued.

(Consumer and Consumer Advocate, New South Wales, Submission #8)

There is not enough access to legal aid for those with a mental illness in terms of ongoing support. There seems to be a disparity in what can be accessed by those with a mental illness compared to those without a mental illness.

(Clinician, New South Wales, Broken Hill Forum #20)

People have the right to legal aid. I know from my husband that consumers have been refused legal aid and are put on community treatment orders because of their mental illness.

(Clinician, New South Wales, Broken Hill Forum #19)

I applied under the Freedom of Information Act to get access to files to lodge a complaint – we have been waiting for two months and haven't received any medical files. The mother recently suffered a stroke her sister is caring for her.

(NESB Consumer Advocate, New South Wales, Parramatta Forum #8)

During December 2001 and January 2002, we had a number of discussions and conferences with the MHU [Mental Health Unit] Psychiatric Registrars and with Dr [Y], Director MHU. Our experience with these people was that no follow-up occurred with some issues that we raised, treatments recommended by them were not carried out because they did not appear in the treatment notes, and official complaints were ignored.

(Carers, Parents, New South Wales, Submission #106)

I also wrote to the Health Complaints Commission who felt an internal investigation was warranted. Apparently as a result we have had the business cards of the clinic changed, as the number there was misleading to patients. [X] called it for help upon discharge and the phone had rung in the patients lounge and was answered by a patient. He wanted help and no-one was there. Also I think other smaller things have been changed with regard to patient care especially after an attempt at suicide. Not much in the scheme of things.

(Carer, Wife, New South Wales, Submission #126)

6.1.1.4 Consumers are not being treated with dignity and respect

Overall, many carers and consumers expressed concern that during their involvement with the MHS they were treated with disrespect and as citizens whose rights as described under the National Standards were ignored.

Consumers have a right to be treated with dignity and respect. It is our view that some staff are not acting appropriately in the way in which some consumers, carers and agencies are being treated.

(Eastern Area Interagency NSW, New South Wales, Submission #100)

Some people are transported around in paddy wagons for days because there's nowhere for the police to take them. Some people are held in seclusion for days on end for the same reason. Where is the humanity in this? People who are on community treatment orders are required to turn up at police stations to get their injections.

(Consumer, New South Wales, Parramatta Forum #5)

My wife and I are appalled at the social injustice and undignified treatment to which we and our daughter were subjected during our daughter's 35 days in the MHU.

(Carers, Parents, New South Wales Submission #106)

By 15 December 2001, our daughter had developed severe oral thrush, her tongue being swollen preventing her from swallowing and talking without great distress. Unbelievably, her meals still comprised solid food (which she could not eat); this situation led to her subsequent malnutrition and severe dehydration which resulted in her losing 12 kilograms and being transferred to medical ward 2 East on 4 January 2002 for prompt life-saving intravenous and naso-gastric treatment… We observed that MHU staff has no time or interest in addressing anything other than our daughter's mental state. Also on 15 December 2001, my wife saw our daughter drinking the toilet water to help relieve her dry and thickly-coated tongue, mouth and throat.

(Carers, Parents, New South Wales. Submission #106)

My brother suicided in a hospital… My brother is just an example of what will happen to others who are failed by the system. People are placing too much faith in institutions – people need access to good quality community care without having their human rights abused. My brother had care at Rozelle but he didn't really qualify for that catchment area so he then had to go back to St George but there wasn't anything for him to do there.

(Carer, Sister, New South Wales, Sydney Forum #7)

After 4 January 2002 when our daughter had been transferred from the MHU into medical ward 2East, she was immediately treated by the staff as a whole person with dignity, respect, compassion and empathy. We observed that the medical ward staff was a professional caring team at all times, even when our daughter was a handful They accepted the challenge with care, diligence, resourcefulness and a great team effort which achieved a great result in a short time in comparison with the five weeks that our daughter was in the MHU where she deteriorated badly. As parents, we are grateful for the clear concise and accurate information the medical ward team offered us, keeping us informed and assured that our daughter's medical treatment was on-track.

(Carers, Parents, New South Wales, Submission #106)

The clients… are the ones who end up 'falling between the gaps'. Even of their chosen lifestyle is non-conformist or they are 'difficult clients' they are still human beings who are entitled to be treated. And treated humanely.

(Walgett SAAP Services, New South Wales, Submission #63)

They did not send a letter of introduction with a request for contact prior to the first visit of three people to the home which came as a surprise to the client [aged person] and carer. No reason was given for this… At no stage did the worker [aged care assessment team] advise the client [aged person] when they would be arriving. They just had to let them in…

(Carer, New South Wales, Submission #48)

He was supposed to be sent to a hospital with a psychiatric ward but instead he was sent to Silver Water jail which does not have a psychiatric ward. At the jail he was sent into the general population area with no toothbrush, no glasses, no hearing aid. That is where he stayed for 2 months. We spent two months trying to get him his glasses and hearing aid

(Carer, Mother, Victoria, Footscray Forum #8)

6.1.1.5 Rights of people with mental illness in the criminal justice system

The Indigenous Social Justice Association (ISJA) and Justice Action (JA) raised concerns with regard to the rights of people with mental illness in the criminal justice system and the need to be particularly vigilant about protecting the rights of these consumers and their access to treatment and support services. Carers also raised concerns about conditions and treatment received by their children with mental illness while in prison:

They are in a highly restricted environment, have no choice in provision of service, have far reduced access to their support network, have even greater problems in accessing any complaint or oversight body and in allowing such bodies to examine information that they request to be examined.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

Prisoners must also be able to nominate friends / family / advocates as per below and have access to their information and control over who is allowed to have it like any other person.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

In May 2001, as a consequence of that inadequate treatment, he was charged with malicious damage by arson and in April 2002 was found not guilty by reason of mental illness. From May 2001 until June 2003 our son was incarcerated in appalling conditions at Long Bay Prison Hospital. His behaviour throughout that period was exemplary. During all of that time, he was locked for at least 11 hours a day, and often longer, in solitary confinement in a prison cell and was not allowed to have a TV in his cell. He was frequently hungry, due to the poor quality of the food provided.

(Carers, Parents, New South Wales, Submission #75)

We have been shocked by the use of prisons as surrogate mental health care and treatment facilities in NSW. We do not believe that this is an acceptable option in 2004. Furthermore we consider it is in contravention of the United Nations Declaration of Human Rights 1948.

(Carers, Parents, New South Wales, Submission #75)

Section 32 of the *Mental Health (Criminal Procedure) Act* 1990 (which commenced 14 February 2004) provides magistrates with the option to divert people with an intellectual disability or mental disorder into the 'human services sector' rather than convicting them of a criminal offence. Walgett SAAP Services noted its concern that people with a mental illness have been inappropriately incarcerated because they have been unable to get the documentation necessary to prove their illness:

Local solicitors have advised that it is difficult having client matters dealt with under s32 of the Mental Health Act due to the lack of necessary psychiatric reports. Consequently many clients are dealt with in the prison system.

(Walgett SAAP Services, New South Wales, Submission #63)

6.1.1.6 Access to advocates

Concern was expressed that consumers are not being made aware that they have a right to have 'an independent advocate or support person with them at any time during their involvement with the MHS' (Standard 1.6). This has resulted in support people, including nominated service providers, explicitly being refused involvement when consumers have specifically requested their co-attendance and support:

We have also found problems with the system's recognition of independent advocates, who having been specifically requested to act of behalf of a patient regarding a certain matter, are denied the ability to do so. This even occurs when the request has been in writing - demands are made for the request to be rewritten in a standardised format. This causes frustration in the patient and delay in resolving a problem. The form suggested above plus an expanded ability for friends, family, people in other close relationships and advocates to rapidly contact the Official Visitor and have them look into problems will also assist in this area of concern.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

We propose that communal self advocacy organisations be formally recognised and allowed to do individual patient advocacy on request, and systemic advocacy regarding the issues affecting their members.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

Appealing for a shy person with mental issues is extraordinarily difficult. At least there are hospital visitors for people in hospital. It would seem that there should be a system of advocacy whereby of there is an at home visiting by the ACAT [Aged Care Assessment Team] team there should be an independent advocate who makes contact – both for the carer and the client – who facilitates appeals and ensures the individuals fully understands the process. Unfortunately the client may not appeal because they just don't want the hassle – it is too much for them – there needs to be some way clients and carers can make their views known and taken into account.

(Carer, New South Wales, Submission #48)

6.1.1.7 Access to interpreters

For people who have a hearing impairment or speak a language other than English, access to mental health care is further complicated by communication and cultural barriers. These barriers may make it difficult for the consumer and their family and carers to understand mental disorders, mental health problems and available treatment and support services and how to navigate the system. In many cases a person may be socially isolated or reluctant to have family or friends involved as carers or act as an interpreter for reasons of confidentiality or stigma. Evidence presented at forums and submissions indicate that many consumers from a non-English speaking background (NESB) are not made aware of their rights and responsibilities in either a written or verbal manner as required by Standard 1.3 (e.g. written material in their language or via and interpreter). This failure to appropriately inform people of their overall rights means that consumers may be specifically unaware of their right to have access to an accredited interpreter (Standard 1.7). Additionally, it appears that some health professionals are either not aware of the right of consumers and carers to have access to accredited interpreters or they are specifically denying consumers and carers this right. The following quotes from a number of the community forums serve to illustrate these failures:

> *We tried to set up a telephone interpreter service in mental health services for the hearing impaired but we had no success. Services are not budgeting for interpreters. There are only 2 F/T hearing impaired community workers for the whole of NSW.*
>
> (Disability Community Worker, New South Wales, Parramatta Forum #2)

> *The use of interpreters is still a big problem. The services are not using interpreters when they should be.*
>
> (Multicultural Mental Health Worker, New South Wales, NESB Parramatta Forum #9)

> *People assume it's not their right to have an interpreter present. We've had dealings with services that simply don't inform people of their right to have an interpreter present. It can also be costly for the client. Phone interpreters were free for just five years.*
>
> (Anonymous, New South Wales, NESB Parramatta Forum #13)

> *Services are saying they don't work with interpreters. Bankstown will but Parramatta won't.*
>
> (Service Provider, New South Wales, NESB Parramatta Forum #21)

6.1.1.8 Ministerial discretion impeding rights

Carers expressed concern regarding Ministerial discretion when reviewing Forensic Orders and when the Mental Health Review Tribunal has made a decision regarding changes to treatment orders:

> *The Minister is sitting on a request for a consumer to go home even after the Mental Health Tribunal has approved his release.*
>
> (Carer, New South Wales, Parramatta Forum #1)

> *During the period of our son's Forensic Order, we have not been satisfied with the 'due process' of administration of conditions of that order. The requirement that the NSW Minister for Health approve these conditions means that the process is inappropriately politicised. Decisions about transfer and leave for patients, seem to be made to appease community attitudes about mental illness and violence, which are steeped in stigma, rather than in the best interest of the patient.*
>
> (Carers, Parents, New South Wales, Submission #75)

6.1.2 STANDARD 2: SAFETY

The activities and environment of the MHS are safe for consumers, carers, families, staff and the community.

> *…the increasing service resource crisis presents significant threats to the rights of mentally ill people. This occurs through compromising safety and increasing the risk of sub-standard treatment, undermining centres of clinical academic excellence, increasingly marginalising those with mental illnesses, and through a tendency when addressing clinical problems to rely increasingly on administrative and legal solutions rather than clinically led solutions. The adverse factors combine to make front-line public mental health professionals an endangered species."*
>
> (Public Sector Psychiatrists, New South Wales, Submission #297)

Under this Standard, submissions and presentations indicate concerns about:

- excessive focus on security;
- safety concerns for consumers in hospital settings;
- safety concerns of staff; and
- inadequate treatment and support services to ensure the safety of consumers, carers and the community.

6.1.2.1 Excessive focus on security

The NSW Police Association expressed a broad range of concerns with the system of mental healthcare in NSW. In particular, the Association highlighted the large number of people with mental health and drug and alcohol problems needing to be dealt with by the police. They regarded this as a clear failure of the mental health system:

> *A report released in June 1998 on police shootings showed that more than half the 41 people shot dead by Australian police officers since 1990 were under the influence of drugs or alcohol, and one third were depressed or had a history of psychiatric illness – a clear indication that the system is failing.*
>
> (Police Association of New South Wales, New South Wales, Submission #59)

Consumers, carers, NGOs and others expressed concerns with the increasing focus and emphasis on security. Many considered these approaches to superficially address safety in a way that increased fear and intimidation and dehumanised those in 'care':

> *Some of these security measures convey to the public that the people behind the wire are animals that need to be constrained.*
>
> (Carer, New South Wales, Parramatta Forum #4)

> *Everything is so security driven now – this is a real problem. There's increased gates and increased security.*
>
> (Consumer Consultant, New South Wales, Parramatta Forum #9)

> *Consumers are really intimidated by all the increased security. Even during tribunal hearings there might be two security guards present. Hospitals are not supposed to be prisons.*
>
> (Anonymous, New South Wales, Parramatta Forum #10)

It is not uncommon for people suffering a mental illness or acting irrationally, to feel threatened if confronted by a police officer…

(Police Association of New South Wales, New South Wales, Submission #59)

6.1.2.2 Safety concerns for consumers in hospital settings

Standard 2.3 states: 'Policies, procedures and resources are available to promote the safety of consumers, staff and the community'. Clinicians and carers expressed concern that policies and procedures were not in place to promote the safety of consumers, and that often this was due to a lack of resources:

These problems jeopardise patient safety. Every day, there are knife-edge situations that generally do not end in disaster, only because of the extraordinary efforts of frontline personnel. It is difficult to act in the patient's best interest when institutional pressures are so great.

(Public Sector Psychiatrists, New South Wales, Submission #297)

We observed the MHU staff working under considerable pressure, their services being under-resourced and their numbers inadequate for their patients' safety. We are hesitant to single out particular staff, but we believe that individually it is their responsibility to practice appropriate duty of care and nursing similar to that demanded in hospital medical wards.

(Carers, Parents, New South Wales, Submission #106)

My brother, like many others with a mental illness doesn't have a voice. My brother suicided in a hospital – I came from a modest European background. My parents believed that we would get care… Hospitals need to be safe – we need to make our hospitals places where it is not easy for people to die from suicide.

(Carer, Sister, New South Wales, Sydney Forum #7)

Around 14 December 2001, my wife saw that the hand basin in the MHU female toilets had been removed leaving the taps to flow directly onto the floor. Patients were still using the taps, in their altered mental state. A month later, my wife noticed that nothing had been done to fix this situation. We believe that this is negligent maintenance and also an OH&S issue, apart from giving carers no faith in the basic competence within the MHU.

(Carers, Parents, New South Wales, Submission #106)

Over three weeks from 9 January 2002, our daughter had a series of ECTs [Electro-Convulsive Therapy]. On 23 January 2002, we observed that no MHU staff accompanied her to the theatre. This was the second time that she was unaccompanied by MHU staff, whom we were told had this responsibility as duty of care, and this MHU delinquency angered the medical ward and theatre staff. We observed on this same day that MHU sent a patient to theatre who had had a drink, and she was rejected by theatre staff.

(Carers, Parents, New South Wales, Submission #106)

However, for [public hospitals] to be safe there needs to be more staff because understaffed, frantic places are ripe for further abuse. During these two stays in hospital in Sydney I saw three other patients assaulted by fellow inmates and one of them was not even believed when she tried to report it to staff. I was really angry on her behalf but I said nothing because I thought I might get a personality disorder back on my file if I attempted to stand up for her.

(Consumer, New South Wales, Submission #327)

6.1.2.3 Staff safety concerns

Concerns were also raised about current policies, procedures and resource allocation to ensure the safety of staff:

I now find it stressful being on call for a weekend. But the mix of patients has changed too. They are on the average more aggressive, more violent.

(Anonymous, New South Wales, Submission #303)

I want to talk about an incident that occurred recently which should indicate to you some of the problems we're faced with in the NGO sector. Two of my nursing staff were leaving work at night and were approached by a client. The client was upset at not being able to access accommodation because he was considered to be non-compliant with his treatment. He threw punches at the nurses and they had to run for their safety. One of the nurses managed to get her mobile phone out and phoned the police and then taken to a secure mental health unit. Within ½ hour he was assessed as being intoxicated and not scheduled – he was released onto the streets and was back outside our service wanting accommodation.

(Clinician, New South Wales, Sydney Forum #3)

Public attention rightly focuses on patient safety but not sufficiently on safety of mental health personnel, with regular assaults on staff being ignored in the media. Current services were not designed to accommodate highly dangerous patients or persons in social crisis who are violent. An overwhelming focus on safety issues ultimately will degrade the humanistic base of psychiatry, with fear driving a wedge between patients and personnel.

(Public Sector Psychiatrists, New South Wales, Submission #297)

Safety for staff is very important, but can be assured by other means (working in pairs to home visit unknown people, electronic safety and communication equipment, returning to a common community base at nights and on weekends, insisting on police involvement if there is the slightest hint of possible danger with ensured response dictated by memoranda of understanding with police, by not allowing any staff to see people in community centres alone at night, etc.).

(Clinician, New South Wales, Submission #351)

Ultimately, OH&S and economy-of-scale arguments can be extended to banning all community health centres and all home visits. The appropriate path is to make community work as safe as possible, to screen and divert most assessments and initiation of treatment away from Emergency Departments, and then use Emergency Departments in exceptional, highly ambiguous or emergency circumstances only, or to assess mixed medical/psychiatric emergencies.

(Clinician, New South Wales, Submission #351)

It is not too difficult in reality to accommodate OH&S concerns while maintaining community based services. We could be forgiven for suspecting that this concern is simply a screen for the dominant drive to economically rationalize services, and to realize assets occupied by mental health services for general health purposes.

(Clinician, New South Wales, Submission #351)

As well as the serious implications this crisis has for patients, there are very real and unacceptable consequences for staff. In addition to the obvious risks associated with safety and aggression, there is the deleterious psychological impact on staff constantly frustrated in their attempts to deal humanely with these people in a system that is patently incapable of responding adequately to demand.

(Mental Health Workers Alliance, New South Wales, Submission #325)

6.1.2.4 Inadequate treatment and support services to ensure the safety of consumers, carers and the community

As documented elsewhere in this Report, consumers, carers and staff also raised concerns about their inability to access treatment and support services during times of crisis, including when at risk of harm to self or others.

> *When released from hospital, they could do no more for him the hospital said, he proceeded to harass his wife. [X] was arrested and charged and sent to jail… he appealed and was out in five weeks. They did not let his wife know this… Last resort, he got a sledge hammer and at 4.30 am… 2004 smashed the back door of [wife]'s house, threatening to kill himself with knives he had, locking his small daughter in her room and held wife all day until Police arrived and arrested him. … Also his wife and children under constant fear, how do they cope, all having counselling now, how safe are they? All the mental hospitals tried to help but after some time just sent him home on medication when they were unable to succeed, hoping he would survive.*
>
> (Carer, Sister and Brother-in-Law, New South Wales, Submission #108)

> *There have been incidents where Mum was not covered by a CTO (Community Treatment Order), which meant my mother (under partial care) took to living on the streets and could not be picked up off the streets, even if it was for her own good. I even once tried calling an ambulance, when I saw her asleep on a bench hoping they would take her, alas they couldn't. I was constantly beside myself and scared for her safety.*
>
> (Carer, Daughter, New South Wales, Submission #134)

> *On drugs, malnourished and sick, and mentally disturbed [X] was taken in by my mother who is an invalid pensioner suffering from early dementia. This led to inevitable breakdown of my mother's health as she could not cope with such a disturbed individual who was threatening violence.*
>
> (Carer, Sister, New South Wales, Submission #104)

> *[X] subsequently stayed with us for 10 days even though he was clearly very unwell and should not have been released from hospital. He seemed to be getting worse staying with us and constantly paced through the house day and night. [X] became very aggressive towards his family and had problems with his thought processes. His condition was obviously deteriorating rapidly and we were very worried about safety issues, both his and our own.*
>
> (Carers, Parents, New South Wales, Submission #198)

6.1.3 STANDARD 3: CONSUMER AND CARER PARTICIPATION

Consumers and carers are involved in the planning, implementation and evaluation of the MHS.

> *The other thing the NSW govt. is good at is holding inquiry after inquiy, establishing task force or select committee after each other – and all it is, is a big talk fest and we go around the same circle for the next 2-3 years or in Australia's case for the next 10 years.*
>
> (Consumer and Consumer Advocate, New South Wales, Submission #8)

Under this Standard, submissions and presentations indicate concerns about:

- consumers and carers not being heard; and
- a tokenistic approach by the MHS to consumer and carer participation.

6.1.3.1 Consumers and carers not being heard

Consumers and carers expressed concerns that they are tired of telling their stories and not being heard and they have no avenues to give voice to these views so that they can be heard in a meaningful way. According to Standard 3.2: 'The MHS undertakes and supports a range of activities which maximise both consumer and carer participation in the service'. However, for those consumers and carers who gave evidence either verbally or by submission, their experiences did not reflect realisation of Standard 3.2:

> *Families are fed up. They've told their stories over and over again. What assurance can I give them that this will be any different. We simply tell our stories yet again and nothing gets done to address the problem.*
>
> (Carer, New South Wales, Parramatta Forum #1)

> *As far as I am concerned there is enough talking and too many different organisations drawing up reports. People with mental illness need access to better care – we know what needs to be done.*
>
> (Carer, New South Wales, Sydney Forum #2)

> *I have had Schizophrenic since 1976… The system doesn't handle people with a problem like mine. Nobody cares – no one is standing up and saying these people need care.*
>
> (Consumer, New South Wales, Sydney Forum #4)

One consumer felt some progress, although a long time in coming, has been made:

> *We have to tell our stories time and time again – but there have been improvements – though it's been a long time coming! I think we're getting a good response now.*
>
> (Consumer, New South Wales, Broken Hill Forum #4)

6.1.3.2 Tokenistic approach to consumer and carer participation

Standard 3.3 states: 'The MHS assists with training and support for consumers, carers and staff which maximise consumer and participation in the service' and Standard 3.4 states 'A process and methods exist for consumers and carers to be reimbursed for expenses and/or paid for their time and expertise where appropriate'. One consumer advocate expressed concern that the mental health system is not committed to consumer participation and that many of the activities and positions are 'tokenistic':

> *Let's talk about consumers being employed within the mental health system. Yes, I'm a consumer employee and I get paid for 30 hours and work close on 48 hours each week… What my gripe is that we have such minimal hours, that we simply cannot do half the stuff we're capable of and try to put into effect. More often than not we're not acknowledged as having any expertise, definitely expected (in my situation) to perform as a manger yet not paid accordingly. In other areas we're the most under utilised resource within a mental health service – and forget the voluntary crap – we deserve to be paid for a good day's work like any other person in the community.*
>
> (Consumer and Consumer Advocate, New South Wales, Submission #8)

> *One of the problems with consumer employment and consumer advocates is the vast dearth of an actual skills base. As a trainer in consumer advocacy for a state organisation, I constantly talk to consumers whose only criteria for having been employed in a consumer position is the fact they're a consumer. Even though some consumers are more sensitive to the situations that many consumers find themselves in – training is a must and understanding the very, very specific role of consumer advocacy is imperative.*
>
> (Consumer and Consumer Advocate, New South Wales, Submission #8)

Consumers are grossly under-utilised in Mental Health. There is a need for Independent Advocacy for Consumers by consumers.

(Consumer Activist, New South Wales, Submission #257)

6.1.4 STANDARD 4: PROMOTING COMMUNITY ACCEPTANCE

The MHS promotes community acceptance and the reduction of stigma for people affected by mental disorders and / or mental health problems.

Social isolation & loneliness are guaranteed triggers of episodes of mental illness, substance abuse, self harm & suicide. This happens, and it happens all the time. And in rural and isolated communities, where resources are even more scarce, the problems are much worse.

(Consumer Advocate, New South Wales, Submission #153)

Under this Standard, submissions and presentations indicate concerns about:

- feelings of isolation;
- high levels of stigma and discrimination; and
- discrimination in employment.

6.1.4.1 Feelings of isolation

Consumers and carers expressed concerns about the stigma that still surrounds mental illness and how all too often this results in friends and other members in the community distancing themselves from the consumer and the consumer's family. This would indicate that campaigns and activities by the mental health system to address community acceptance and reduce stigma to date (Standard 4.1) have not been able to turn community attitudes around. A lack of community acceptance is a key barrier to people with mental illness (and their family members) being able to participate socially, economically and politically in society.

As the following quotes highlight, social isolation, feelings of being a burden on family and friends, are the real outcomes for many people:

Now as a survivor of suicide I find I could probably count my good friends on one hand. Many others I have known over the years either because of their own fears, or because [X] didn't die of an accepted death, have chosen to ignore my family and I. But I have never been ashamed of my husband. He fought it as only he knew how and to this day I'm proud of him.

(Carer, Wife, New South Wales, Submission #126)

There is no such thing as community care because the community doesn't care.

(Carer, New South Wales, Sydney Forum #5)

Many people with a mental illness simply don't survive – I've questioned what sort of society we live in when people stand around and laugh and take photos of the homeless. You can see it happening when you walk down the streets!

(Carer, New South Wales, Sydney Forum #5)

I think it is disgusting what the government have done to the mentally ill people of Australia. No one understands what is like to have a mental health problem in your family unless they are in the situation them selves. We live a silent pain. Ashamed. Embarrassed. In fear of our lives. Family destroyed. No one wants to help.

(Carer, Mother, New South Wales, Submission #90)

6.1.4.2 High levels of stigma and prejudice

Consumers and carers spoke of the high levels of stigma associated with mental illness and prejudice experienced by both people with mental illness and their families. Community awareness campaigns to increase understanding of mental illness, acceptance of people with mental illness and information about how to support people with mental illness and their families and carers were described as being critical. The following extracts show how stigma is still causing immense pain in the lives of people with a mental illness and in their lives of their families:

Stigma is also high in small communities like Broken Hill as people fear what they can't see. In discussions with legal advisors they have encouraged people not to disclose their illness. In addition, community attitudes are often dismissive of people with a mental illness.

(Consumer, Carer & Family Worker, New South Wales, Broken Hill Forum #23)

Stigma is a big problem in this community – people fear what they don't understand. I've experienced a change in body language of a specialist when they ask you what medications you are on. I've been told by a solicitor not to tell anyone that – sometimes our integrity is questioned just because we have a mental illness – we might be unwell but that doesn't mean we're stupid.

(Consumer, New South Wales, Broken Hill Forum #24)

We need to create more awareness in the community. My brother was 27 when he died – that is far too young – it's a waste of life. He was incredibly talented.

(Carer, Teacher, New South Wales, Sydney Forum #7)

Need to be aiming at inclusion not exclusion – I know of people who are banned from coming into shops because they have a mental illness. The stigma in our communities is still very bad. People are treated differently, badly because they have a mental illness.

(Carer, New South Wales, Sydney Forum #13)

There's an Indian saying - it takes a whole village to raise a child. Our younger generation don't always get that support from our "village". There are too many people trying to struggle on their own to make sense of the way things are for them.

(Carer, Mother, New South Wales, Submission #122)

Given the stereotype of mentally disordered people as dangerous, citizens often call upon the police to "do something" in situations involving mentally ill individuals, particularly when they exhibit the more frightening and disturbing signs of mental disorder.

(Police Association of New South Wales, New South Wales, Submission #59)

One major consideration is the release of offenders with a history of mental health problems. Mentally ill people face significant social pressures; the prejudices they encounter are even greater if they have both a criminal history and mental illness. People with a criminal history and mental illness can be over rated for their risk of violence. Therefore they can find it very difficult to access mental health resources in the community.

(NSW Department of Corrective Services, New South Wales, Submission #295)

Community stigma is also a problem. People with mental illness are picked on in the community, but there is no community support from services until these people become very unwell.

(Anonymous, New South Wales, Submission #156)

It is scandalous and a national disgrace that there is no significant commitment by governments and the prevalence of community unawareness and apathy. There has to be a national campaign similar to that for AIDS if mental health is to successfully obtain government support etc.

(Carer, Son, New South Wales, Submission #120)

Do you think that anyone cares about anyone with a Mental Illness. The government definitely do not, not even 3/4 of Australia or any where else for that matter.

(Consumer, New South Wales, Submission #70)

There is also the public perception of "suicide" being some sort of crime or punishment, not as it should be, of a perception of loving care and understanding. I must say however, that this was an accidental overdose, but nevertheless, the end result is the same.

(Carer, Mother, New South Wales, Submission #88)

Why is mental illness such a social taboo? If it were a medical condition, I'm sure there would be no end of help.

(Carer, Mother, New South Wales, Submission #88)

6.1.4.3 Discrimination in employment

Employment and a supportive workplace are seen as key factors in preventing the rapid escalation of mental illness and as being essential in the process of rehabilitation and reintegration into society after a period of mental illness. Standard 4.2 states: 'The MHS provides understandable information to mainstream workers and the defined community about mental disorders and mental health problems'. However, acceptance and understanding of mental illness seem to be lacking in the workplace and, according to submissions received and evidence given at many of the forums, discrimination and high levels of stigma are still prevalent in the workplace:

I have 2 clients who have said that if they disclose that they have a mental illness when going for a job they would not have got the job.

(NGO Worker, New South Wales, Broken Hill Forum #21)

One client did eventually disclose her medical history three months after she got a job and then promptly lost that job.

(NGO Worker, New South Wales, Broken Hill Forum #21)

Where is the employment for our kids? Our children are being discriminated against by sophisticated means.

(Carer, New South Wales, Parramatta Forum #1)

Teacher, police officers etc would be very reluctant to tell their employers they have a mental health problem.

(Consumer, New South Wales, Broken Hill Forum #24)

Meanwhile sufferers continue to lose their jobs when employers discover they have an eating disorder…

(Anonymous, New South Wales, Submission #58)

6.1.5 STANDARD 5: PRIVACY AND CONFIDENTIALITY

The MHS ensures the privacy and confidentiality of consumers and carers.

Under this Standard, submissions and presentations indicate concerns about:

- lack of privacy and outdoor physical space;
- inadequate indoor physical care environment;
- staff applying privacy and confidentiality rule without authority or ignore or do not request permission from consumer to share information or involve carers;
- Indigenous issues;
- prisoners and problems with information sharing between agencies;
- information sharing with the police;
- privacy laws and assisting youth to access care; and
- rights of carers (carers not informed of discharge).

6.1.5.1 Lack of privacy and outdoor physical space

One consumer advocate expressed concern about the lack of private outdoor space in inpatient units. In particular, not only was this space described as being open to view by the public, but that it was unsafe in design (potential for suicide) and conveyed a sense to the consumers and to the public that mental illness equated to a criminal offence (20ft wire fences with a security guard). Standard 5.6 states: 'The location used for the delivery of mental health care provides an opportunity for sight and sound privacy' and Standard 5.7 states 'consumers have adequate space in regard to indoor and outdoor physical care environments'. Clearly though, as the following show, there are many problems with meeting this Standard:

> *I would like to talk about St Vincent's Hospital and the fence that surrounds that hospital. It's surrounded by a 20ft high wire fence! There's no privacy for consumers in the court yard or the ward. It is opposite a fashionable café where diners can view the inpatients clearly. The fence comes up and turns in at the top – not outward. It's a great place to hang oneself! There are also security guards sitting in the courtyard reading novels during the day. Compare this with Prof Pat McGorry's unit in Melbourne where they planted shrubs which have grown into hedges. It is a stark contrast.*
>
> (Consumer Advocate, New South Wales, Parramatta Forum #3)

> *There have been complaints made to St Vincent's but nothing has been done about it. I think it's there to stay. The nurses lobbied for it and said they had it built to protect their patients and themselves from people coming in off the street. I'm not opposed to secure units at all. That's not what I mean. What I mean is that we need to give more thought about how we build secure units. They shouldn't look like cheap prisons. People, even high security people have a right to privacy and respect.*
>
> (Consumer Advocate, New South Wales, Parramatta Forum #3)

6.1.5.2 Inadequate indoor physical care environment

Concern was also expressed about the poor standard of hygiene, cleanliness and ambience of inpatient units. Even though Standard 5.7 states that consumers should 'have adequate space in regard to indoor and outdoor physical care environments' it appears the reality for many consumers was far from this:

During December 2001 and January 2002, we observed that both the MHU wards (open and lock-up) were generally in a filthy state, and we saw numerous cockroaches everywhere. It was embarrassing, in fact, when we met with our daughter's clinical psychologist in the MHU lock-up ward and we all observed cockroaches on the wall; we turned blind eyes because they were the least of our worries. But, we ask, how can a hospital environment permit this? And what does it say about the professionalism of the ward management and staff, and their concern for patients?

(Carers, Parents, New South Wales, Submission #106)

Mental health services in this state, this city are shabby, dirty places. The walls have no posters or adornment. I really can't see the point of someone with a mental illness coming into an environment like that.

(Consumer Advocate, New South Wales, Parramatta Forum #3)

…we have lost our son in Carasta [Caritas] Mental Health Hospital (Branch of St Vincent Hospital Sydney)… They knew he was very sad, but when we saw the hospital where it happened it was so depressing. They told us that depressed people did not notice their surroundings.

(Carer, Mother, New South Wales, Submission #135)

The James Fletcher Hospital is also frequently "dirty"… cleanliness could be upgraded to hospital standard. For example, the carpets are very dirty, which leaves patients with black feet. There was an example of food smeared on a window which was left for more than 3 weeks. A dead cockroach was left lying in a corridor for several days. There are frequently coffee stains left on the garden furniture. Overall, it is a very dirty environment, not what you would expect from a hospital. There is also no air-conditioning or fans and so no fresh air. The fans were removed after a patient attempted to hang themself. A plan for installation of air conditioning was developed 12 months ago, but no action has occurred yet. Furthermore, there is only one meal option available to patients, regardless of the individual's tastes or beliefs. There is often no privacy for patients using the telephone because if there is a staff meeting being held in the room housing the phone it is placed in the hallway… patients are treated as 2nd class citizens. They do not receive the same level of care you would receive in other health facilities.

(Anonymous, New South Wales, Submission #156)

6.1.5.3 Staff applying privacy and confidentiality rule without authority or ignore or do not request permission from consumer to share information or involve carers

Both clinicians and carers expressed concerns that a misunderstanding of the Privacy Act and related policies and procedures to protect the confidentiality and privacy of consumers is hampering communication between consumers, carers and clinicians in the provision of treatment and the sharing of vital information. Furthermore, these concerns would suggest that these policies and procedures are not always being made available to consumers and carers in an understandable language and format (Standard 5.2) and that the mental health system is not encouraging and providing opportunities for consumers to involve others in their care (Standard 5.3):

One of my biggest gripes was the privacy law and how I as [X]'s wife was not told anything that could benefit him or myself. ([X] completed suicide 7 days after discharge)

(Carer, Wife, New South Wales, Submission #126)

We have received complaints that people close to a patient have been told by staff that the person has objected to notice and other information being given out and the patient has stated that they made no such objection. This is abuse of the law which could be guarded against by our suggested Advance Directives, admission procedures and creation of a information consent Form, but really it ought not occur for reasons of right conduct.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

…the laws are often given as an easy way to avoid talking about issues with people involved with the patient regardless of the appropriateness or otherwise of the request, and c) privacy laws are often attacked because they are inaccurately blamed for lack of social support, and general medical information about psychiatric disability comprehensible to the general public that people close to a patient might need… Generally, no matter what laws are enacted regarding them, the problems of information/privacy issues will always come down to the attitudes of all parties in the practical application of any such laws. These are complex relationship and social issues that have to be dealt with at the grass roots level and though three way learning between professionals, patients and people connected to patients.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

Having made these points we wish to state that we believe that legislatively and in practice, that there are problems with the definition and interpretation of classes of persons that are allowed to have/give information.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

No other class of people has their personal individual innermost thoughts so examined by others as psychiatric patients. Inspected, rejected, accepted, labelled, classified, dismissed, pathologised. Judged. It is crucial that they have some space to exist in as a person, and are accorded rights not to have their experience and thoughts blathered to all and sundry. That is a fundamental and profound issue of rights that can directly affect the survival of the person. It needs to be upheld for that reason, regardless of the fact that it is also 'therapeutic' and 'in accordance with privacy laws'. Patients must be informed of any disclosure to another party. They have a right to know what is happening with their information, and to whom it is given. To not abide by this principle is to create a situation of secrecy and actions carried out in an underhand manner.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

We contend that the maintenance of privacy of information must be upheld, and that the laws regarding information in no way accord too many rights to the patient as has been suggested. We oppose any degradation of rights of patients in regards to their information and privacy, and we contend that in many areas it needs to be strengthened. We support provision for discussion and mechanisms that allow for diverse relationships to be recognised and for information to be shared in non-abusive ways.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

It should never be assumed that the person is incapable of considering a matter, forming an opinion and giving direction regarding the matter. This includes who is privy to information and who may be involved in admission, treatment, and discharge, in terms of Health and non-Health persons and the interaction of the two. There is generally a presumption that any patient with psychiatric disability lacks capacity. This is untrue.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

I do not think that being over the age of 18 should stop doctors from letting families know more of their loved ones feelings so that they can understand.

(Carer, Mother, New South Wales, Submission #88)

One carer expressed concern that although the mental health system provides opportunities for consumers 'to involve others in their care' misunderstandings of laws and policies in relation to privacy and confidentiality are hindering carers from accessing care on behalf of the consumer when needed:

For a number of years, I have been trying to access mental health services for my daughter, who is now approaching 17… Throughout the last year, her mental state has deteriorated badly and I am no longer able to seek help for her because her age precludes it.

(Carer, Mother, New South Wales, Submission #92)

6.1.5.4 Indigenous Issues

The Indigenous Social Justice Association (ISJA) and Justice Action (JA) expressed concern that issues related to privacy and confidentiality for Indigenous people must also be addressed within a cultural context (and therefore related to Standard 7 – Cultural Awareness):

It is a necessity to recognise formally the Indigenous concepts of family, kinship and community, and to allow communities and individuals within the Indigenous communities to work out appropriate ways of dealing with information that affects the relationships within the Indigenous communities. Indigenous Cultures must be respected and Indigenous people must not be forced or pressured to reveal Cultural information. There are arrangements already existing that are supposed to be respected, such as the AHRC / NSW Health Partnership, to look into these issues and ensure that matters affecting Indigenous people(s) are dealt with at all law, policy and service levels in the appropriate and culturally respectful manner. It cannot be allowed to be done in ignorance of the rights and concerns of Indigenous peoples and without self determination. As these issues are already known to government and departments, a choice to ignore the issue and deny rights amounts to a deliberate decision which we contend must be examined with regard to the International Convention on Genocide. We also argue that these issues be examined in the light of the 2003 WHO guidelines on Mental Health Law and Human Rights regarding the protection of Indigenous *ethnic groups and minorities.*

(Indigenous Social Justice Association (ISJA) and Justice Action (JA),
New South Wales, Submission #349)

6.1.5.5 Prisoners and problems with information sharing between agencies

The Indigenous Social Justice Association (ISJA) and Justice Action (JA) also expressed concern about the right to privacy of prisoners with mental illness and how their privacy has not been respected and consumers have not given 'informed consent before their personal information is communicated to health professionals outside the MHS, to carers or other agencies or people' (Standard 5.4):

We wish to express here our absolute objection that prisoners, as an entire class of people, have by law no right to privacy due to recently passed laws. This discrimination is offensive in and of itself. It is also highly damaging to prisoners' wellbeing and relationships with medical staff and others. Prisoners' patient records have been given to the media, for example the X-rays of the hand of Ivan Milat. (We note that forensic patients' mental state and therapeutic relationship has also been released and discussed in the media, and that this is a nation-wide problem. Forensicare of Victoria is often considered exemplary in debates around forensic standards, but they are in no way immune from problems and have also revealed such personal information in an inappropriate and political manner.)

(Indigenous Social Justice Association (ISJA) and Justice Action (JA),
New South Wales, Submission #349)

We have received complaints directly from prisoners so affected about the new lack of privacy laws in NSW. We demand that the laws be repealed, and that prisoners be granted rights of medical privacy in accordance with other patients. Corrections should under no circumstances have the right to give out such information and Corrections is not the prisoner's 'carer'.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA),
New South Wales, Submission #349)

We have also described general privacy problems regarding medical treatment in jail and demand that prisoners seeking medical treatment be accorded respect and that their medical rights as a human being be upheld. Prisoners must also be able to nominate friends/family/advocates as per below and have access to their information and control over who is allowed to have it like any other person.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

We also completely object to NGO / Police access to databases and information sharing regarding the mental state and medical records of patients as suggested in submissions and hearings at the NSW Parliamentary Inquiry into Mental Health Services. This is an abuse of patient's private information and must not occur. NGO's and Police can contact Mental Health Teams if really necessary.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

6.1.5.6 Information sharing with the police

Concern was expressed by the police that due to the inability of consumers to access mental health services when required and increasing reliance by families and the community on the police to intervene and assist, that the police should have access to data about consumers in order to provide more appropriate responses. As mentioned above, Standard 5.4 states: 'Consumers give informed consent before their personal information is communicated to health professionals outside the MHS, to carers or other agencies or people'. While information may need to be shared in specific circumstances, in order to meet this Standard, and protect many rights of consumers beyond confidentiality, the appropriate response would be to first improve the response by the mental health service to minimise the need for police involvement on such a large scale:

Funding needs also to be provided for the establishment of a national health system for the identification purposes in relation to the medical history of those persons with mental illness or disorders with ready access to police to assist them in their encounters with these individuals.

(Police Association of New South Wales, New South Wales, Submission #59)

There needs to be a greater sharing of information by the health department to police in relation to a mental health issues. This could possibly take the form of a type of national database which could contain records of names of individuals who have been hospitalized, the types of mental illness they suffer etc so that when police come in contact with the individual, through the hospital they can be accurately informed as to their mental state, which would be of great assistance in helping police determine how they could be best treated.

(Police Association of New South Wales, New South Wales, Submission #59)

6.1.5.7 Rights of carers - carers not informed

One carer expressed her frustration that carers of consumers also have the right to information that impacts on them, and that it should not just be consumers who claim the right to withhold information:

I have four children and 3 with a serious mental illness. I want to outline an issue about the rights – the human rights of carers. My daughter was taken into care involuntarily – taken in as an involuntary patient and we weren't informed. I didn't know for 24 hours where my daughter was – I knew she was acutely ill but not where she was. When I approached the hospital they informed me that my daughter has exercised her right not to inform her family.

(Carer, New South Wales, Sydney Forum #9)

6.1.6 STANDARD 6: PREVENTION AND MENTAL HEALTH PROMOTION

The MHS works with the defined community in prevention, early detection, early intervention and mental health promotion.

> *On 4 December 2001, my wife discussed our daughter's condition with her treating psychiatrist, the MHU Psychiatric Registrar and MHU nursing staff, who agreed that the MHU did not cater for our daughter's then current mental state – she was not psychotic. At the request of my wife, and our daughter's clinical psychologist, our daughter was placed in the MHU lock-up ward for her physical protection. It was not until four weeks later, when our daughter's condition had significantly deteriorated, that she was "specialled". We later discovered by accident that "specialling" is normal procedure for vulnerable patients. It seems reasonable that early "specialling" for our daughter would have significantly reduced the severity, duration and cost of her confinement and prevented her ongoing loss of hair and teeth problems from unnecessary malnutrition.*
>
> (Carers, Parents, New South Wales, Submission #106)

Under this Standard, submissions and presentations indicated concerns about:

- a lack of focus on early intervention or prevention programs;
- unfairness of promoting early intervention when services are failing to cope with current demand;
- need for more programs to promote mental health and prevent mental disorders in the deaf community;
- need for more programs to promote mental health and early intervention to people from a non-English speaking background;
- preventing depression in older men; and
- substance abuse and mental illness need to be tackled jointly in mental health promotion programs with children and youth.

A sense of disbelief at how government funding was allocated was conveyed by many. This is aptly captured in the following quote:

> *I think it's terrible that the NSW Government can spend $1.2 million to put up a suicide barrier on a bridge but can't put money into improving access to mental health care.*
>
> (Consumer, New South Wales, Sydney Forum #4)

6.1.6.1 A lack of focus on early intervention or prevention programs

Standard 6.8 states: 'The MHS ensures that the consumer has access to rehabilitation programs which aim to minimise psychiatric disability and prevent relapse'. Concern was expressed however that the mental health system places little emphasis on rehabilitation programs or other programs to prevent relapse or promote recovery and instead waits for a crisis to occur before responding:

> *I work in a psychosocial rehabilitation unit. I think it's unbelievable that things haven't changed. I have met some very dedicated people in the hospital system but I've also seen the opposite. It all starts with the under-funding of services and this undervalues the problem. People are called the 'worried well' and turned away until they are in crisis. The system is structured in such a way that there's too much of a reliance on medication and not enough attention to the other important things like rehabilitation and psychosocial support, housing, etc.*
>
> (Mental Health Worker, New South Wales, Sydney Forum #10)

We require more support groups for people experiencing depression anxiety. There is no money going into programs that promote or enhance recovery.

(NGO worker, New South Wales, Sydney Forum # 8)

[There are] no early intervention programs

*(*Consumer and Consumer Advocate, New South Wales, Submission #169*)*

We support a population health model, with its emphasis on promotion, prevention and early intervention in mental health. Many of our organisations believe that the Eastern Suburbs Mental Health Program is falling far short of achieving systematic and strategic approaches to early intervention, often failing to respond effectively or provide any service at all, on many occasions when consumers in our services are in need of proper assessment and timely intervention… We request the implementation of National Standards as they relate to early intervention and continuity of care.

(Eastern Area Interagency NSW, New South Wales, Submission #100)

Closure of the Living Skills Centres has not been accompanied by any coherent implementation of Statewide, recovery-focused rehabilitation services.

(SANE Australia, National, Submission #302)

6.1.6.2 Unfair to promote early intervention when services are failing to cope with current demand

Although the policy shift to prevention and increasing community awareness of available interventions is laudable, an unforeseen consequence for existing services is the generation of more referrals in addition to providing services to "core" patients in high risk groups.

(Public Sector Psychiatrists, New South Wales, Submission #297)

Clinicians expressed concern that there are insufficient services, resources and committed funding to respond to increasing access demands as a result of mental health promotion programs. Clinicians stated that adequate funding and the structure of service delivery needs to be addressed to cope with current and increased future demand to intervene at the earliest possible moment. Standard 6.1 states: 'The MHS has policy, resources and plans that support mental health promotion, prevention of mental disorders and mental health problems, early detection and intervention'.

This means that as there is no follow up people return to their previous bad state and so these clients have to repeat the whole the process.

(NGO Worker, New South Wales, Broken Hill Forum #5)

The prevention 'push' often has encouraged the funding of short-term projects that risk increasing expectations without interventions being sustainable. Such funding enhancements generally have not generated ongoing new mental health services. In addition, other effective sources for referral have diminished. GPs are often too busy and funding constraints limit the availability of the private sector.

(Public Sector Psychiatrists, New South Wales, Submission #297)

Need to educate the community so they recognise the symptoms.

(Clinician, New South Wales, Broken Hill Forum #25)

6.1.6.3 Need for more programs to promote mental health and prevent mental disorders in the deaf community

As mentioned above, access to interpreters for people with hearing impairment is difficult and not all promotional strategies would successfully reach this community. Standard 6.4 states: 'The MHS has the capacity to identify and appropriately respond to the most vulnerable consumers and carers in the defined community'. Also Standard 6.2 states: 'The MHS works collaboratively with health promotion units and other organisations to conduct and mange activities which promote mental health and prevent the onset of mental disorders and/or mental health problems across the lifespan'. One community worker expressed concern that insufficient programs, strategies or funding are available to prevent mental disorders and psychiatric disability in the deaf community, particularly amongst the young:

> *The rate of young deaf people suiciding is very high. There's no funding to even enable us to print out emergency deaf cards. We would like the government to help us but it won't… it doesn't.*
>
> (Disability Community Worker, New South Wales, Parramatta Forum #2)

6.1.6.4 Need for more programs to promote mental health and early intervention to people from a non-English speaking background

Standard 6.3 states: 'The MHS provides information to mainstream workers and the defined community about mental disorders and mental health problems as well as information about factors that prevent mental disorders and/or mental health problems'. Included in the notes to this Standard are 'local community groups'. Given the cultural diversity of NSW this would include culturally and linguistically diverse communities. For these communities, many barriers present as a problem when discussing prevention and mental health promotion strategies including literacy skills in English and other languages spoken at home, knowledge of the health system and cultural barriers to acknowledging disability and accessing care. Concerns were expressed that insufficient support services and resources have been allocated to assist consumers from a non-English speaking background and refugees to recognise symptoms and access services as early as possible:

> *We have to continue to invest in this area. The messages need to be multi-level, and multi media - not just brochures. It takes a fair bit of resources and time. The short term funding that we get to develop and provide resources and supportive programs is a problem, we need long term funding so that we can have a meaningful impact.*
>
> (Mental Health Promotion Worker, New South Wales, NESB Parramatta Forum #11)

> *People in the NESB communities don't understand the system of mental healthcare. So they don't know what is available. They need to use NESB workers but these positions are disappearing, particularly difficult to find a worker who is fluent in the right language for the client. So for example, Polish people are assisting people from Arab backgrounds etc. Ethnic health workers are filling the gaps but these people have different skills and are not as appropriate as multicultural health workers. The rigid funding barriers make it worse.*
>
> (Multicultural Mental Health Worker, New South Wales, NESB Parramatta Forum #6)

> *We provide settlement services and aged care services for the Polish Community. The biggest issue/problem facing this community is mental health problems. The refugees in the 40-50 age group have a high level of post-war trauma that has not previously been dealt with properly. There's also a lot of people with dementia and other mental health issues and people presenting with personality disorders. These people have had these illnesses and been untreated for a very long time. They have developed survival techniques but they can't go on like that. They need help and support but it's not available.*
>
> (NESB Welfare Worker, New South Wales, NESB Parramatta Forum #2)

An off shoot of Temporary Protection Visa is long-term mental illness and stress. And family isolation contributes to mental illness.

(Anonymous, New South Wales, NESB Parramatta Forum #1)

6.1.6.5 Preventing depression in older men

Men need more support – because they don't ask for help. There's nothing in this town for men – no support. My partner phoned his parole officer to ask for help because there was nothing else for him.

(Consumer, Female, New South Wales, Broken Hill Forum #24)

Standard 6.5 states: 'The MHS has the capacity to identify and respond to people with mental disorders and/or mental health problems as early as possible'. However, the inequity of treatment and early access to services for different population and age groups was a key concern for some. For example, concerns were raised that the needs of older men who are at increased risk of developing depression were not being met by the mental health system:

A final point to be noted is that although a lot of money has gone into prevention of suicide among young people in Australia, there has been comparatively little attention to the continuing high suicide rate among men in late old age... we need to examine how best to help those whose depression is closely linked to painful or disabling physical illnesses.

(Clinician, New South Wales, Submission #264)

Broken Hill has got the highest suicide rate of older men in NSW. Morbidity is highest in New South Wales' far west. Broken Hill has an ageing population. There is a demographic shift in Broken Hill which means there is an increasing older population and decreasing younger population as many move away to seek higher education and build there lives in other places where they can find work and hope. We need more mental health first aid – looks like it empowers you. We need to educate the community so they recognise the symptoms.

(Clinician, New South Wales, Broken Hill Forum #25)

6.1.6.6 Prevention – substance abuse and mental illness need to be tackled jointly

Concerns were expressed regarding the need to address substance abuse and mental health problems jointly. This indicates greater attention to a preventive focus in the delivery of mental health services is required, as outlined by Standards 6.4 (capacity to identify and respond to the most vulnerable consumers n the community), 6.5 (capacity to identify and respond as early as possible) and 6.6 (treatment and support to occur in a community setting in preference to an institutional setting).

Given the known consequences of substance abuse, it is alarming that treatment and support services are not provided at the earliest possible moment to prevent deteriorating illness. Result of this failure can include deteriorating physical and mental health, risk of harm to self or others, unemployment and social withdrawal, and the need for acute care in restrictive settings with severe treatment regimes.

Excellent prevention strategies are in place in regard to tobacco smoking saving many lives and millions of dollars from the health budget. We need similar public health education and awareness campaigns in relation to marijuana abuse. For example a teenager who has a joint every weekend at a party (smokes cannabis 50 times or more before 18 years) has the following increased risk of serious harm: 6.7 times greater risk of developing schizophrenia (Andreasson et al. 1987; Zammit et al. 2002); 59 times greater risk of using other illicit drugs; Increased risk of depression and suicide; Greater risk of cancer cigarette for cigarette than tobacco cigarettes (50% greater tar burden)

(Clinician, New South Wales, Submission #181)

Lack of information was noted as a major problem for young people receiving care in the hospital system. Young people reported that the primary treatment offered was medication but were concerned about dependency and the lack of monitoring and aftercare by treating staff. Young people stressed that youth services and telephone counselling services were supportive but some young people did not know about them until too late.

(NSW Association for Adolescent Health, New South Wales, Submission #98)

Most participants reported taking drugs at early ages (12-14 years) and experiencing psychotic episodes some years later. Commonly, they did not seek help or recognise that they needed help. They reported having a vague understanding of what schizophrenia is but they failed to associate their own experiences with such a mental illness. In most cases, the first episode of their mental illness was diagnosed when they were brought into hospital by police and assessed and hospitalised in the psychiatric ward.

(NSW Association for Adolescent Health, New South Wales, Submission #98)

6.1.7 STANDARD 7: CULTURAL AWARENESS

The MHS delivers non-discriminatory treatment and support which are sensitive to the social and cultural values of the consumer and the consumer's family and community.

People who do not speak English as their first language have very limited access and their linguistic and cultural needs are not met.

(NESB Consumer Advocate, New South Wales, Parramatta Forum #8)

Under this Standard, submissions and presentations indicated concerns about:

- lack of culturally appropriate practices for consumers from a non-English speaking background;
- problems with treatment due to cultural barriers and intellectual disability;
- the need for cultural competency training of staff in the MHS; and
- utilisation of staff and services with expertise to provide services to consumers from a NESB.

6.1.7.1 Lack of culturally appropriate practices for consumers from a non-English speaking background

Comments were received which suggests that mental health services have not been planned and delivered in a manner which 'considers the needs and unique factors of social and cultural groups represented in the defined community and involves these groups in the planning and implementation of services' (Standard 7.2). Concern was expressed that in many instances staff were not accommodating the cultural need of consumers to have family present during assessment. Also, concern was expressed that even though culturally appropriate practices could be enhanced by employing staff from a variety of backgrounds, sufficient resources were not available to enable this to occur:

When our clients are assessed, the families want to be included but most of our staff are Australian. So language barriers are a problem. Staff are paid poorly so we take whoever we can get.

(NGO Service Provider, New South Wales, NESB Parramatta Forum #10)

Outcome based interventions don't necessarily work for CALD groups. We need to be able to be flexible with the delivery of interventions to NESB communities and tailor programs to the individual.

(Anonymous, New South Wales, NESB Parramatta Forum #16)

Concern was also expressed that staff of the mental health service may not have the requisite 'understanding of the social and historical factors' relevant to the current circumstances of social and cultural groups represented in the defined community (Standard 7.1):

> *We have people who are victims of concentration camp medical experiments. She was admitted to hospital but had PTSD [Posttraumatic Stress Disorder].*
>
> (NESB Welfare Worker, New South Wales, NESB Parramatta Forum #2)

6.1.7.2 Problems with treatment due to cultural barriers and intellectual disability

One consumer advocate expressed concern regarding the management of a person from a non-English speaking background with intellectual disability. It seems that many factors contributed to the infringement of this person's rights including: interpreter not involved; advocate or support person not involved; consumer or carer not being made aware of their rights and access to interpreters and advocates and information; staff social and cultural prejudice; and lack of disability awareness by staff:

> *There was a lady from Bosnia, a refugee, who has an intellectual disability. Because of her inappropriate assessment she was involuntarily admitted to hospital for a mental illness. She was considered to have PTSD but she didn't. Some people with an intellectual disability do have behavioural problems but not like a mental illness. I applied under the FOI [Freedom of Information] Act to get access to files to lodge a complaint – we have been waiting for two months and haven't received any medical files. The mother recently suffered a stroke her sister is caring for her.*
>
> (NESB Consumer Advocate, New South Wales, Parramatta Forum #8)

6.1.7.3 Need for cultural competency training

Standard 7.5 states: 'The MHS monitors and addresses issues associated with social and cultural prejudice in regard to its own staff'. Included in the notes to this Standard are 'cross cultural training for staff' and 'carers from a range of different social and cultural groups'. However, evidence presented suggested that in some cases this was not happening. It was suggested that staff of mental health services are in need of cultural competency training that will assist them to modify their attitudes and behaviours (decrease discrimination) when dealing with consumers from a non-English speaking background:

> *Cultural competence doesn't exist at the level it's needed. No cultural competence taught. Unless we make it as a core competency, it won't happen.*
>
> (New South Wales, NESB Parramatta Forum #14)

> *Multicultural courses are available but they are predominantly short courses and they are not mandatory. And these courses are often attended by the converted!*
>
> (Anonymous, New South Wales, NESB Parramatta Forum #15)

> *Staff development is really failing at a systematic level to deliver outcomes for people from a NESB. What do we need to do to improve the cultural competencies of the workers? We are seeing increasing institutional racism.*
>
> (NESB Consumer Advocate, New South Wales, NESB Parramatta Forum #7)

> *There is really inadequate training for consumer issues related to settlement.*
>
> (NESB Consumer Advocate, New South Wales, Parramatta Forum #8)

6.1.7.4 Utilisation of staff and services with expertise to provide services to consumers from a NESB

Standard 7.4 states: 'The MHS employs staff or develops links with other service providers/organisations with relevant experience in the provision of treatment and support to the specific social and cultural groups represented in the defined community'. Concerns were expressed from consumers, advocates, multicultural mental health workers, NGO service providers and clinicians that a sufficient number of skilled staff are not being employed to meet demands. Consequently, systemic problems exist with the operation of current policies and the interface between specialist and mainstream services for consumers from a NESB:

> *There's a systemic failing on a policy level and a marked reduction of providing multicultural workers because we are being mainstreamed.*
>
> (NESB Consumer Advocate, New South Wales, NESB Parramatta Forum #7)

> *I am 1 of 30 bilingual counsellors for NSW. We are not psychiatrists however we do feel the brunt of the community's need. I am aware of only one Spanish speaking psychiatrist. We need a review of bi-lingual psychiatrists.*
>
> (Multicultural Mental Health Worker, New South Wales, NESB Parramatta Forum #8)

> *There's no balance between the ethno-specific workers and mainstream workers.*
>
> (NGO Service Provider, New South Wales, NESB Parramatta Forum #10)

> *Pilots and one-off grants make it very difficult for us to reach out to the communities. Mostly now we don't apply for this money. It's not fair to build people's expectation.*
>
> (Clinician, Rehabilitation, New South Wales, NESB Parramatta Forum #17)

6.1.8 STANDARD 8: INTEGRATION

6.1.8.1 Service Integration

The MHS is integrated and coordinated to provide a balanced mix of services which ensure continuity of care for the consumer.

Under this Standard, submissions and presentations indicate concerns about:

- lack of coordinated care in rural and regional areas due to high staff turnover;
- chronic under-resourcing resulting in inability of MHS to deliver integrated and coordinated care;
- inability of MHS to deliver coordinated and integrated services to consumers from a non-English speaking background;
- links with NGO services;
- inability of mental health teams to provide services resulting in reliance on police force; and
- problems with Schedule II procedures and integrated and coordinated care.

6.8.1.1.1 Lack of coordinated care in rural and regional areas due to high staff turnover

According to Standard 8.1.4: 'Opportunity exists for the rotation of staff between settings and programs within the MHS, and which maintains continuity of care for the consumer'. Also Standard 8.1.1 states: 'There is an integrated MHS available to serve each defined community'. Reports of high staff turnover also concerned consumers in one regional area as this meant that consumers were not receiving continuous care:

There's no continuity of care or no time to establish relationships as staff move on very quickly in this area.
(Consumer, New South Wales, Broken Hill Forum #2)

With resident specialists so often on leave or moving on it is hard to have to re-tell your story to each new arrival. People with mental illness need to build relationships and trust. We can't do that here because we lose staff quickly.
(Consumer, New South Wales, Broken Hill Forum #2)

6.8.1.1.2 Chronic under-resourcing resulting in inability of MHS to deliver integrated and coordinated care

Concerns were also expressed with regard to the shortage of clinical staff in the sector to provide the required treatment and support when consumers were trying to access services or when clinicians were referring consumers for treatment. The shortage of psychologists and psychiatrists in the public sector was reported, as was the shortage of general practitioners who bulk-bill and who have adequate mental health training:

We need a link for people to refer to so people can access care. As there is very limited access to psychiatrists and long delays in seeing psychiatrists, it means many people have to return to GPs to try and get help. But access to GPs is not always easy given the decline in bulk billing.
(Family Support Services Worker, New South Wales, Broken Hill Forum #12)

There is a focus on clients presenting for the first time, at the expense of long-term clients. [X] believes this philosophy of the mental health services "means to me they have given up on the long term patients".
(Anonymous, New South Wales, Submission #156)

A person needs to be on the "acute board" to get a home visit from the mental health team. People at the acute stage of their illness are registered on an awareness / priority register for mental health nurses. Only the hospital doctor at the hospital can put a person on the board.
(Anonymous, New South Wales, Submission #156)

[X] went to a psychologist just 2 months before he died - who referred [X] to a psychiatrist - but unfortunately the psychiatrist was away on holidays - so he couldn't get an appointment - in the detailed referral it was obvious to blind Harry that [X] was screaming out for help he had in a one hour session with the psychologist relayed every vital piece of information in regard to his condition. [X] should never have been allowed to leave that psychologist's office - in the referral it said he had a (suicide) plan - it wasn't the first time etc etc.
(Carer, Mother, New South Wales, Submission #122)

Even this last hospital admission, with a CTO order in place took ridiculous co-ordination between Community Health Centres to ensure that Mum could get picked up. Mum had to be breached, the breached approved, approved to be faxed to the other centres, and then maybe she could be picked up. Meanwhile, you are starting to get nervous as your mother takes to the streets more, her mental health and hygiene slowly deteriorating. Trust me when I say that the catch me if you can game can take weeks, even months.
(Carer, Daughter, New South Wales, Submission #134)

Mental health services are shifting clients onto GPs. However, whilst GPs have now received some training in mental health, they don't have sufficient time to give to patients for mental health consultations. They also have limited training. For example, the GP for [X]'s wife is not fully up-to-date on medications.
(Anonymous, New South Wales, Submission #156)

I have had Schizophrenia since 1976… I go regularly to see a psychiatrist at Prince of Wales Hospital. Though there's now only 1 psychiatrist left out of the 8 that were there when I first started going years ago. 1 psychiatrist is hardly enough is it?
(Consumer, New South Wales, Sydney Forum #4)

[X] was identified by a psychologist as suicidal and referred to his doctor [GP]. After repeated attempts to get an appointment, he saw his doctor. Before the appointment occurred he attempted suicide. After keeping his doctors appointment which was only a half hour after the attempt, I was summonsed to drive him to the Emergency Section of our hospital. [X] was given a letter by his doctor in which the doctor stated that the Psychologist [X] had seen on the previous Monday had informed him that he thought [X] was suicidal. Yet, at NO time did [X]'s doctor call him as a matter of urgency to go and see him or to offer help in any way. Lack of duty of care as far as I'm concerned.

(Carer, Wife, New South Wales, Submission #126)

Mental Health staff report they do not have the resources and staff required to meet the demand for mental health services, and services in areas such as supported accommodation, outreach, self-help and rehabilitation are wholly inadequate. Mental health teams no longer provide long-term case management and are limited instead to 'episodic care', with short-term interventions followed by the referral of chronic mental health clients to general practitioners (GPs) for case management. Even so, mental health teams are struggling with caseload pressures.

(NCOSS, New South Wales, Submission #47)

MATT (mobile assertive treatment team) – work with severely sick psychotic people to keep them out of hospital – only one team with 7 staff who see 70 clients for the Central Sydney area which has 5000 consumers, 500 of whom would benefit from seeing the MATT team, which provides intensive case management, support, counselling and supervision

*(*Consumer and Consumer Advocate, New South Wales, Submission #169*)*

Case managers in the Community Health Centres are overloaded – have to manage too many consumers (30 each? e.g. 28 people for 1 day a week) – not enough time to work intensively with people. There is hardly any money for community treatment. Crisis teams do not have enough time to spend with consumers in crisis - only time to quickly check symptoms and medication, no time for counselling

*(*Consumer and Consumer Advocate, New South Wales, Submission #169*)*

Concern was also expressed regarding staff leaving without planning for continuity of care. The impact for one consumer of having to restart the care process without notification or transition time was devastating. Standard 8.1.4 states: 'Opportunity exists for the rotation of staff between settings and programs within the MHS, and which maintains continuity of care for the consumer'.

A few years ago she finally found a great doctor she trusted. Dr [Z] worked in a Western Sydney Hospital, and for a couple of years she was stable and quite normal, until one day she turned up to her appointed only to be told he had moved to America. EVER SINCE THIS DAY, we have been battling to keep her stable. This doctor had not arranged a transition time to a new line of help. He just left and did not care about the consequences. (author's emphasis)

(Carer, Sister, New South Wales, Submission #79)

6.1.8.1.3 Inability of MHS to deliver coordinated and integrated services to consumers from a non-English speaking background

Standard 8.1.1 states: 'There is an integrated MHS available to serve each defined community' and Standard 8.1.5 states 'the MHS has documented policies and procedures which are used to promote continuity of care across programs, sites, other services and lifespan'. As previously mentioned, many concerns were expressed about the ability of the mental health system to deliver coordinated treatment and care to consumers from a non-English speaking background as reported in the following quotes:

The bilingual counsellors do take the brunt. I am coming across this over and over again. We can do an assessment and see people for 6 sessions then we have to refer them on to mainstream services but they bounce back to us.

(Multicultural Mental Health Worker, New South Wales, NESB Parramatta Forum #9)

I was part of a major service re-educating GPs and developing shared care etc for NESB. It's taken about 5 years and there is evidence that it's working. Everyone puts in an effort but it's just not enough to help someone like me from an acute mental health service dealing with someone from Somalia for example.

(Mental Health Worker, New South Wales, NESB Parramatta Forum #12)

6.1.8.1.4 Breakdown in Links with NGO services

One clinician from an NGO service expressed concern about the lack of resources and breakdown between NGO service providers and the mental health service and not being able to work together to provide continuity of care in a coordinated and integrated manner as stated in Standard 8.1.5:

There's a real breakdown between NGO & public services. The Government is happy to treat NGO's as extensions of services but not fund them accordingly. In fact the Government has cut funding to NGOs and still expects that the NGO's will carry the load. I have had to put a ban on all referrals from services. We're now in a position where we are rationalising our services. We don't like it but we have to run our service within the resources we have to work with… My service has a budget of $400,000 / year but our funding hasn't increased since early 1990s.

(NGO Clinician, New South Wales, Sydney Forum #3)

6.1.8.1.5 Inability of mental health teams to provide services resulting in reliance on police force

Standard 8.1.1 states: 'There is an integrated MHS available to serve each defined community', including case management and crisis intervention. The under-resourcing of community based services led one consumer advocate and the Police Association of NSW to express concerns that coordinated care was not being provided and, as a result, police were required to become involved unnecessarily:

The community staff are stretched to the maximum and their resort is to tell people to go to their GP or access an emergency service (was one very recent answering machine message I happen to hear when I was trying to contact a community health worker. Mind you, no information about how to contact the emergency service was part of the message.)

(Consumer and Consumer Advocate, New South Wales, Submission #8)

Even though they claim to be available 24 hrs a day / 7 days a week through a 1800 telephone number, they are not providing a true 24/7 service… Currently, police are finding themselves being called prematurely and often unnecessarily to assist in the management of patients who have been released into the community or who are allegedly being treated while living in the community. They are also often being asked to retrieve AWL (Absent Without Leave) patients from the community without any attempt of the mental health teams to bring the patients back to hospital using their own resources…

(Police Association of New South Wales, New South Wales, Submission #59)

6.1.8.1.6 Problems with Schedule II procedures and integrated and coordinated care

The Police Association of NSW particularly expressed concern about the frequent and unnecessary involvement of the police in Schedule II procedures. Specifically, they expressed concern that mental health teams should co-attend when necessary and that general practitioners require additional training and information about when police involvement is necessary. Both these factors could result in fewer consumers coming into contact with the police thus treating 'persons with mental illness humanely and with dignity'.

> *Mental health teams should also be required to accompany police when attending a Schedule II, especially when the individual is not known to police. The police role in these scenarios (and they should only be used in the most extreme circumstances) should only be limited to police merely providing security for the mental health workers. Mental health units and the health system are failing in their duty of care to mentally ill patients released from hospitals… By working together, they can treat persons with mental illness humanely and with dignity and ensure that these subjects receive the most appropriate services available…*
>
> (Police Association of New South Wales, New South Wales, Submission #59)

> *A common complaint is that doctors seem to regularly and somewhat routinely sign the schedule that police are required as escorts in situations where they are definitely not required, for example, where the patient is drugged up…private practice doctors appear to have no idea when it comes to issuing a Schedule II requesting police assistance – they seem to do this almost routinely and appear unaware of any local MOUs [Memorandum of Understanding], largely due to the fact that private practitioners are not a group in partnership with such memorandum… At the moment, police have no say in the matter. If they refuse to comply with the doctor's request, they are liable to be prosecuted for neglect…*
>
> (Police Association of New South Wales, New South Wales, Submission #59)

6.1.8.2 Integration within the health system

The MHS develops and maintains links with other health service providers at local, state and national levels to ensure specialised coordinated care and promote community integration for people with mental disorders and / or mental health problems.

> *If you do not have a case worker you do not have particularly good care. Mental Health is not as integrated with other services as it should be.*
>
> (Consumer, Male, New South Wales, Broken Hill Forum #8)

Under this Standard, submissions and presentations indicate concerns with: neglect of consumers' physical health care needs in inpatient settings; and the lack of interagency collaboration.

6.1.8.2.1 Neglect of physical health care needs in inpatient settings

Standard 8.2.1 states: 'The MHS is part of the general health care system and promotes comprehensive health care for consumers, including access to specialist medical resources'. Concern was expressed that the mental health system is neglecting the physical health of consumers in inpatient settings:

> *However on 4 January 2002 (following our threats to involve the media), she was transferred to a medical ward, having become psychotic and also because she had acquired dehydration, malnutrition, severe carpet thrush and split and bleeding heels. These four new conditions had developed in the MHU [Mental Health Unit] whilst she was under the "care" of staff. We believe that our daughter's mental and physical states are inseparable as regards duty of care, and we vigorously question the therapeutic efficacy of the Liverpool Hospital Mental Health Unit.*

(Carers, Parents, New South Wales, Submission #106)

At no time did we find evidence of the MHU [Mental Health Unit] treating our daughter for her extensive bruising (suffered from falling over, punching walls and staff handling), yet these injuries were promptly addressed in the medical ward.

(Carers, Parents, New South Wales, Submission #106)

6.1.8.2.2 Problems with interagency collaboration

Standard 8.2.4 states: 'The MHS has formal processes to promote inter-agency collaboration'. However, once again many concerns were expressed that a lack of funding, high staff turnover in the mental health system and a lack of interagency collaboration and protocols is hindering the delivery of integrated and coordinated care:

In defence of mental health services, there has been a big effort to liaise with NGOs – there have been significant efforts made in the last few years to get better community integration of mental health services. But the high turnover of staff it makes it very hard to establish those relationships and collaborations and hard to get the protocols right.

(NGO worker, New South Wales, Broken Hill Forum #10)

The Mental Health First Aid Course has been very useful and 4 of our Lifeline positions were funded to do this by the mental health service. We previously had a MoU with the mental health service but it's no longer functional.

(NGO worker, New South Wales, Broken Hill Forum #10)

The Richmond Fellowship is a good model of community partnership but the mental health services are working in isolation and could be more integrated in community activities.

(Consumer, New South Wales, Broken Hill Forum #8)

6.1.8.3 Integration with other sectors

The MHS develops and maintains links with other sectors at local, state and national levels to ensure specialised coordinated care and promote community integration for people with mental disorders and / or mental health problems.

Under this Standard, submissions and presentations indicate concerns about:

- the need for whole-of-government approaches;
- housing and accommodation options;
- Department of Community Services (DOCS);
- guardianship;
- Centrelink;
- police and the criminal justice system;
- emergency services;
- employment;
- whole-of-government approach needed to improve outcomes for Indigenous communities;
- wards of the state;
- affordability of care – bulk billing clinicians, cost of psychologists and private health insurance;
- cross-border agreements;
- whole-of-government approach for youth; and
- national strategies to increase the number of mental health professionals.

6.1.8.3.1 The need for whole-of-government approaches

[X] was then discharged the next morning and on the drive on the way home with his friend he killed his friend because he was still sick and hallucinating. He was sent to jail… He was supposed to be sent to a hospital with a psychiatric ward but instead he was sent to Silver Water jail which does not have a psychiatric ward. At the jail he was sent into the general population area with no toothbrush, no glasses, no hearing aid. That is where he stayed for 2 months. We spent two months trying to get him his glasses and hearing aid… he became very suicidal. This was communicated to me and I informed and pleaded with the authorities to make them aware he was sick and suicidal. They informed me he would be put in a cell with another inmate who could watch him but in fact he was placed in a single cell on Friday 1 October and hung himself on the Friday night. I would like to know why he was failed by 3 Government departments. How did this happen? He wouldn't have killed anybody if he hadn't been put in that situation.

(Carer, Mother, Victoria, Footscray Forum #8)

Overall, the thrust of many submissions suggested a lack of integrated service delivery or whole-of-government approach to solve the complex support needs of many people with a mental illness and their families and carers. Their 'right' to live in the community in a dignified manner appeared a dream rather than a reality. These problems were reported with health, welfare, suicide prevention strategies, criminal justice, community services, disability services, legal, housing and disability services. Many submissions identified that a broader governmental, societal and community approach was urgently required:

The issues around mental health must not be seen as a problem solely of a mental health system. They simply are not. There are more fundamental issues that bear on mental health and mental health problems; there are issues around the priority given to mental health by all the human service and related systems.

(Anonymous, New South Wales, Submission #125)

Many problems arise from the systems stasis of Mental Health, Social Security, Corrections, and Social Services, i.e. they serve the system, not the community, and as such constrain the development of appropriate, diverse, flexible and voluntary services and the growth of good relationships between staff, patients and people close to patients. Policy, political and societal will is as important as legislation here.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

There is an increase in complex presentations, drug problems and violence, and the re-emergence of an alienated 'underclass' whose problems are passed off to psychiatry. Human service institutions (e.g. DOCS) increasingly expect public mental health to pick up the tab for social (rebadged as 'mental health') problems.

(Public Sector Psychiatrists, New South Wales, Submission #297)

There are more fundamental issues that bear on mental health and mental health problems; there are issues around the priority given to mental health by all the human service and related systems. For example, look at the training of general nurses, and of the many of the specialities in medicine. In many of the latter mental health is critically important yet mental health does not feature in the training programmes, I am thinking especially of physicians and paediatricians. But there are others. The same could be said of lawyers and police. Some of the most intractable problems I have found in caring for some young adults with mental illness are the way the justice system and police have treated them, and other systems like housing and income support.

(Anonymous, New South Wales, Submission #125)

To review mental health your purview it must span more widely than mental health services and examine social determinants, different intersecting influences on health and behaviour, and the material provisions for afflicted people and above all the priority accorded to mental health in the broad sense by politics, systems such as health and media.

(Anonymous, New South Wales, Submission #125)

In my mind as a carer, the worst kind of discrimination comes from NSW Government which instead of providing adequate comprehensive services to these people has consistently reduced its provision of services.

(Clinician, New South Wales, Submission #25)

[Stigma and isolation]… It is not surprising that they turn to drugs, and when they get into financial difficulties the answer should not be to evict them for arrears, but to assess them, and find another solution rather than putting them on the streets without funds or a roof over their heads. There should be some agency to which a mentally ill person can turn for help when things get out of control. Making them homeless when they fail to manage a rental situation is about as uncaring as a government agency can get.

(Carer, Sister, New South Wales, Submission #104)

NCOSS is extremely concerned about the poor coordination of mental health issues, which is occurring across Government agencies in NSW, including poor linkages between specialist mental health services and other Government services. Health consumers and community organisations participating in NCOSS forums have repeatedly raised the need for closer and more consistent integration between mental health services and other Government services.

(NCOSS, New South Wales, Submission #47)

The need for broader examinations of all planning projects from government departments to be examined for their impact on the mental health of the community was also suggested:

I have also long advocated the need for Mental Health Impact Statements (analogous to Environmental Impact Statements) to be prepared as a component of planning services / projects. The purpose being to draw attention/make conscious the contribution (or lack thereof) of matters under consideration and to educate us all as to how pervasive is our neglect (or otherwise). Whether it be housing, fostering programs, recreational facilities/ programs, religion based plans, setting up a business, claimed therapeutic practice, governmental proposals … This may well get up a few noses, including our own, with benefit! Rhonda Galbally was interested before she left VicHealth, but it was not taken up.

(Clinician, New South Wales, Submission #154)

It was good to hear the emphasis on the responsibility of the community as a whole and the need for leadership in government on the issues and the need for money being contributed in support of innovation and existing agency function… It did my almost broken heart good to hear the focus on the full picture and the recognition that it is not all the responsibility of the mental health services, or of the voluntary sector.

(Clinician, New South Wales, Submission #154)

6.1.8.3.2 Housing and accommodation options

The lack of available housing and accommodation options for people with mental illness was repeatedly raised as a critical gap in the attainment of mental, physical and social well-being. Concerns were expressed (as detailed in Standard 11.4.B Supported Accommodation) that the lack of available supported accommodation or other accommodation options resulted in people becoming homeless or remaining in care for longer periods of time than necessary because there were no viable alternatives. There was also considerable concern expressed that families bear the brunt of this gap.

Affordable and stable accommodation remains one of the greatest areas of unmet need, particularly for people in the large cities such as Sydney.

(Clinician, New South Wales, Submission #197)

Access to secure and safe accommodation is recognised in the National Standards as essential in the process of reintegration into the community and improved mental health. The lack of available housing and accommodation options and the process of deinstitutionalisation and consequent lack of increased community services have resulted in many people with mental illness becoming homeless, placing intolerable strain on families and contributed to declining health and quality of life:

The problem of finding suitable accommodation was a constant source of frustration for all those working in this industry. I don't believe that the community or the government fully understand the impact that lack of care and accommodation not only on the chronically ill but also to the cost to society.

(Social worker, Student, New South Wales, Submission #118)

Licensed boarding houses are an appalling infringement of people's human rights.

(Anonymous, New South Wales, NESB Parramatta Forum #20)

The move to community based services, while positive, has not been matched by attention to stratified and good quality accommodation options for persons with chronic mental illness who rarely can access supervised community accommodation. Disabled and disorganised patients flounder in unsupervised single accommodation, are cast onto the streets, or are involved in "revolving door" admissions to acute units, which are the only "accommodation" facilities remaining for them. A distressingly high number kill themselves.

(Public Sector Psychiatrists, New South Wales, Submission #297)

We do not consider service providers to be 'carers'. Noting cases of locked boarding houses that dole out huge doses of pills, and noting that Boarding Houses Inspection teams have been refused entry by those that run such places, we consider they should not be accorded any rights whatsoever, and should be stopped from incarcerating people and medicating people.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

Crisis, medium and long-term supported accommodation for offenders with mental health issues and intellectual disability is urgently needed for all community-based offenders (probationers and parolees) throughout the state.

(Community Offender Services, Probation and Parole Service, Department of Corrective Services, New South Wales, Submission #317)

There is a consistent lack of accommodation and community based services for women offenders with mental health issues. Additionally, if a woman is the primary carer of children it is even more difficult for that woman to find appropriate accommodation. Most women in custody are the primary carers of children.

(NSW Department of Corrective Services, New South Wales, Submission #295)

Living on the street further complicates matters by making it difficult for mentally ill person to receive follow-up services. Without this and ongoing care, these individuals stop taking their medication and sooner or later, end up having a run in with law enforcement. It is at this point that, what was once the institution's mental health problem, now becomes a police problem.

(Police Association of New South Wales, New South Wales, Submission #59)

Undoubtedly, homelessness is a major issue for offenders with mental health issues… homeless mentally ill people are up to 40 times more likely to be arrested and 20 times more likely to be imprisoned than those with stable, suitable accommodation. While statistics are not available, there would appear to be no compelling reason why the situation would be different for mentally ill offenders in NSW. Incarceration appears to worsen post release accommodation issues… Further, offenders released with no stable accommodation were three times more likely to re-offend than those who had accommodation.

(Community Offender Services, Probation and Parole Service, Department of Corrective Services, New South Wales, Submission #317)

As a result of Drug Summit reallocation of funding COS have been able to develop a limited crisis accommodation initiative for higher risk offenders who are at risk of drug relapse due to homelessness.

(Community Offender Services, Probation and Parole Service, Department of Corrective Services, New South Wales, Submission #317)

I am here today to represent the homeless people who are homeless because of their mental illness. There isn't enough crisis accommodation for homeless men. From my observations about 80% of homeless people have a mental illness, about 50% of those have a dual drug and alcohol diagnosis. We regularly have about 50-60 men sleeping in the laneways in the surrounding blocks to our accommodation service and at any one time you'll see about 100 "sleeping rough" on the streets.

(NGO Nurse Unit Manager, New South Wales, Sydney Forum #3)

Tragically, the homeless people are the forgotten people. You won't hear from the homeless people even in a meeting like this.

(NGO Nurse Unit Manager, New South Wales, Sydney Forum #3)

I am advocating a modern asylum model. The move to community care hasn't improved the situation. We need to target funding to meet the needs of the homeless. The homeless don't have friends or family. There are deaths all the time.

(NGO Nurse Unit Manager, New South Wales, Sydney Forum #3)

The change in vagrancy laws and the Richmond Report have greatly contributed to one of the changing face of the homeless, being mentally ill sufferers. The government tried to sell the proposal as the community helping the community.

(Carer, Daughter, New South Wales, Submission #134)

NCOSS has grave concerns about the impact of the social housing package reforms on people with a mental health issue. The creation of market rental bonds, renewable tenancies (rather than security of tenure), the need to prove that you are able to sustain a tenancy and the new policies around nuisance and annoyance will all have a negative impact on people with a mental health issues and are contrary to the recommendations within the mental health inquiry report… NCOSS is particularly concerned as the availability of support services is currently very limited and those services that are available are over-stretched…

(NCOSS, New South Wales, Submission #47)

I am aware there are no answers, but one would think that provision for housing for people with an incurable mental illness should be a basic requirement. When I spoke with an officer of the Dept. of Housing explaining the upcoming situation I was told that the mentally ill were not their problem and for [X] to fill in application papers and he can then go back on a waiting list.

(Carer, Sister, New South Wales, Submission #104)

In [X]'s case, The Dept. of Housing had knowledge that he was on a mental health pension, yet ordered him to not only pay enormous (and ultimately unjustifiable) renovation costs, but rental arrears. When he appealed to them for help, he was advised in writing he could not re apply for housing assistance from them without first providing them with a reference showing a six months good rental record in the private market. How absurd is that?

(Carer, Sister, New South Wales, Submission #104)

Supported accommodation is in short supply. The Boarding House Reform program instigated by the NSW Government in 1996 has seemingly failed in its objectives. The standard care in those boarding houses remaining open is still poor and the number of beds available greatly reduced – where have all the previous residents gone? A lucky few were rehoused under the boarding house reform program into NGO run group homes. The bulk have possibly added to the majority of people accessing homeless shelters who have mental health problems, live on the streets or in unsupported private rental ghettoes. Seemingly no government department feels it is their responsibility to provide disability support and / or housing for people experiencing mental health problems…

(Clinician, New South Wales, Submission #197)

…the Association recommends that: ...NAAH continues to work with the Youth Accommodation Association and other key bodies to advocate for more responsive supported accommodation programs for young people with a dual diagnosis in New South Wales; that this includes the consideration of specialist, short-term respite services for young people in accommodation services.

(NSW Association for Adolescent Health, New South Wales, Submission #98)

6.1.8.3.3 Department of Community Services (DOCS)

Concerns were raised at the forum for consumers from a non-English speaking background regarding the involvement of the Department of Community Services in the removal of children from parents with a mental illness. These descriptions suggest that cultural and language barriers complicated the protection of the rights of these parents and that these parents were potentially discriminated against both due to their mental illness and their ethnicity.

I had contact with DOCS. I was the case manager of a woman with schizophrenia. I was never given the opportunity to comment or to speak for my client. She lost her two children.

(Anonymous, New South Wales, NESB Parramatta Forum #4)

[X] and his wife both have a disability. When these problems occurred with the children a whole machine of DOCS came crushing down on the family. The problems started for the family when [X]'s wife developed post-natal depression. She had two kids then had the third child and all of a sudden a whole lot of people got interested in the family. But instead of people putting in place support, a whole lot of draconian child protection strategies where put in place. It is a nightmare! It took me three years to get legal aid for this family.

(NESB Advocate, New South Wales, NESB Parramatta Forum #3)

There is a woman from Macedonia who has chronic schizophrenia and has a brother with schizophrenia. Her mother has no disability. The daughter with schizophrenia has a 3 year old child and the child fell and injured herself. The family took the child to hospital and the case was reported and five people came to the house and took the child. The child was appointed a public guardian and even though we tried all avenues to correct this problem there was no success. This person's cultural and linguistic needs were not taken into consideration.

(NESB Consumer Advocate, New South Wales, Parramatta Forum #8)

6.1.8.3.4 Guardianship

One carer expressed concern regarding procedural problems and delays in obtaining guardianship for her son. This delay resulted in fears for the safety of all concerned: the consumer, family members and the community.

I begged and begged for my son to be admitted to hospital but they wouldn't because he wouldn't consent – I couldn't get guardianship. He then went on to another state – the police were the only ones who were sympathetic – it took me 4 months to get guardianship and I finally got him off the streets – his brothers were terrified of him, the local school was terrified of him.

(Carer, New South Wales, Sydney Forum #5)

6.1.8.3.5 Centrelink

The NSW Consumer Advisory Group Mental Health Inc expressed concern regarding the financial vulnerability of many consumers and their families and the need for increased access to welfare payments. Some families, as a result of being unable to access supported accommodation or other treatment and support services for their family member, are often unable to maintain employment and the family is forced to rely on payments from Centrelink.

> *The closure of long term residential care beds in institutions, and the transfer of responsibility for care to families, has not been accompanied by the development and implementation of appropriate legislation and support for families to enable them to continue to care without severe emotional and financial distress.*
>
> (NSWCAG, New South Wales, Submission #273)

Concern was also expressed regarding Centrelink's perceived unnecessary demands for excessive amounts of information and attempts to influence the medical treatment of consumers:

> *We have also received complaints regarding Centrelink demands to patients and persons close to them a) for very detailed medical information, including letters sent between Doctors… This is done on threat of termination of payment. It is not acceptable. A patient should not have to give yet more information than the already extensive amount that Centrelink is legally able to get, and in no way should Centrelink be directing patients' medical treatment… Centrelink is not a 'carer' or the patient or a practitioner.*
>
> (Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

6.1.8.3.6 Police and the criminal justice system

> *There is great disappointment that the promised 135- bed 'forensic hospital' turns out to be part of the new prison hospital at Long Bay – continuing to regard people as 'mentally ill prisoners' rather than forensic patients.*
>
> (SANE Australia, National, Submission #302)

Due to diminishing access to mental health services for consumers throughout their illness, police are increasingly being called to respond to issues relating to people with mental illness, especially in times of crisis. This places consumers at increased risk of coming into contact with the police and the distinct possibility of entering the criminal justice system. The Indigenous Social Justice Association and Justice Action expressed the view that a whole-of-government approach is needed to address the increasing number of people with mental illness who are being incarcerated. Such an approach then needs to take into account issues relating to access to care, crisis prevention and the protection of people's rights when and if they are at risk of entering the criminal justice system. Even though some Memoranda of Understanding have been developed and training has occurred, the presentations and submissions suggest that further consultation is required to more clearly define police involvement with people and acknowledge the limitations of their involvement. Additionally, involvement of police to assist with people with mental illness increases the stigma that ensues from police contact and may heighten community fears, in what should be a mental health response. These views are shared by the NSW Police Association:

> *The public mental health system and the criminal justice system must collaborate so that police officers have several alternatives, not just arrest or hospitalisation, when handling mentally ill persons in the community…*
>
> (Police Association of New South Wales, New South Wales, Submission #59)

Comparing the situations of people with psychiatric disabilities to the general population, despite being more likely a victim of crime without restitution, people with psychiatric disabilities are more likely to: have their actions come to the attention of the police, to be charged if suspects, to be remanded to custody, to be convicted, and to get heavier sentences - especially custodial. This does not necessarily mean that people so imprisoned are guilty. According to the then Police Minister Paul Whelan, "I think people would be shocked to find out how many people have been wrongly convicted." (SMH 8 Jun 2001). He attributed much to "unethical behaviour by police". There is also now a massive problem of false guilty pleas due to it being a worse situation to press for exposition of your innocence.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

People with psychiatric disabilities are at a disadvantage in terms of police interviews, defence, communications with lawyers, self representation, understanding and communicating during court and so on due to disability (including effects of medication and prejudice concerning credibility) which exists regardless of not being currently defined as meeting status of unfitness to plea or stand trial. More could have their charges simply dismissed under Mental Health (Criminal Procedure) Act Sec 32, and this Section should be made known and available for people to use if they want - but it does mean you can't have the case heard fully, and it depends on the 'bravery' of Magistrates to act against demands for guilties, zero tolerance, 'street cleaning' and harsh punishment.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

The depressing recalcitrance of the intractable Ministries related to the criminal justice system - as evidenced by governmental responses to HREOC Social Justice Reports, Parliamentary Inquiries such as SCIPP [Select Committee of Inquiry into Prisoner Population] or Crime Prevention through Social Support, and Reports on Kariong and State Wards – has meant that issues of anti-racism, social support, prison and criminal justice reform are lost, so community suffering, prison trauma, rates of psychiatric disability and the abuse of the rights of people with psychiatric disability continue. Evidence of widespread severe problems and unmet needs are answered with singular pilot program examples, denial and so on. We suggest that the Health Department's problems would be massively reduced if the government took seriously the evidence of the community put before Parliament and acted compassionately in response to the investigations of Inquiries & Reports.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

The feedback of our members strongly indicates to us that an enormous amount of their time is spent trying to make improvements in protocols involving police and mental health services responding to mental health issues.

(Police Association of New South Wales, New South Wales, Submission #59)

The overburdened role police have been forced to bear in relation to mental health would thus be shifted rightfully back to NSW health services where it belongs and where it can be best managed by specifically trained mental health professionals.

(Police Association of New South Wales, New South Wales, Submission #59)

…police are experiencing many instances of non-compliance with the MOU and local protocols by mental health staff and hospitals… it is open to interpretation which allows mental health professionals to be selective with what they choose to use from it to best suit their needs.

(Police Association of New South Wales, New South Wales, Submission #59)

…COS [Community Offender Services] can direct the offender to attend for treatment even if this is not a specific condition of a court or parole order. However, no provision exists for the service provider to accept the offender for treatment and, frequently, offenders experience barriers to treatment services from mainstream community agencies. Such problems occur for a variety of reasons including the philosophical issues of mandated treatment provision, the offender's particular diagnosis and/or failure of the offender to meet strict criteria for treatment provision, fear of potential harm to staff and apparent individual service interpretation of existing policy. Anecdotally, cooperative and coordinated approaches between COS and community treatment providers in dealing with mutual clients exist in some areas. However, there is a notable lack of consistency in terms of an integrative approach throughout the state.

(Community Offender Services, Probation and Parole Service, Department of Corrective Services, New South Wales, Submission #317)

Policies designed to address appropriate treatment plans for offenders with mental health issues, a commitment to the plan by treatment providers and addressing factors associated with greater risk of reoffending such as stable accommodation would also serve to increase the likelihood of suitability for all community sentencing options and assist in the diversion of the mentally ill from custody. Such services require a whole-of-government partnership approach to meeting the needs of offenders, in particular those with severe psychiatric disorders and those with co-morbid substance use disorders. Service delivery agreements between agencies would allow for such cooperative case management to be formalised.

(Community Offender Services, Probation and Parole Service, Department of Corrective Services, New South Wales, Submission #317)

The Police Association of NSW stated that police require more training in dealing with and recognising mental illness:

Training seems to have been improved with various courses containing segments relating to mental health, however, this does not go far enough. Despite training, police officers cannot be expected to be mental health experts. They are police men and women – not mental health professionals, and as such, their involvement with the mentally ill should be kept to a minimum…

(Police Association of New South Wales, New South Wales, Submission #59)

6.1.8.3.7 Emergency services

Emergency services receive many calls involving assistance with mentally ill consumers. The Police Association of New South Wales expressed concern that operating procedures for all emergency services need to be revised to ensure appropriate responses. Also, emergency numbers (e.g. '000') receive many repeated, unnecessary calls from people with mental illness who may be delusional or lonely or isolated, thus tying up valuable community resources. It was suggested that strategies need to be implemented to address this:

Revised Standard Operating Procedures (SOP's) with clearer instructions should also be created for the responsibilities of police, ambulance, mental health teams, hospitals and mental health team doctors who act as assessors.

(Police Association of New South Wales, New South Wales, Submission #59)

A network of phone-backs and communication between patients and nominated contact persons has minimised impact on the emergency service organizations of unwanted and irrelevant 000 calls… The Association recommends that the Department of Health looks towards establishing a system or process to alleviate the negative impact repeated telephone calls to 000 by the mentally ill and isolated continues to have on police responding to genuine emergency calls at the first opportunity.

(Police Association of New South Wales, New South Wales, Submission #59)

6.1.8.3.8 Employment

Access to welfare, the supported wage and finding suitable employment are all critical components in the process of social inclusion and living a meaningful life with dignity in the community. However, many concerns were raised regarding difficulties with the current welfare and employment systems and models in assisting consumers to remain in or access employment. As reported previously in this Report (Standard 4, Promoting Community Acceptance), concern was expressed regarding discrimination in employment settings:

> *There is a huge gap in Broken Hill in terms of opportunities for those with disabilities trying to access some form of work. Many people are also referred on to Nova from CRS Australia – the Australian Govt employment agency. A fundamental problem is that CRS will not help people that are unwell but they do not themselves recognise that employment is part of the recovery process. CRS therefore offer little or no assistance to those with psychiatric disability.*
>
> (Employment Service Provider, New South Wales, Broken Hill Forum #18)

> *Employers in Broken Hill have a large pool to choose from so temporary contracts of three month trials are commonplace so this situation also makes it harder for those with a mental illness. Through our experience we try to go out and canvass for work – when there is an ad there'd be 17-120 people applying for the job. The competition is high and because of the 3-month trial short-term employment seems to be the norm here.*
>
> (Employment Service Provider, New South Wales, Broken Hill Forum #22)

> *Liberal government has been trying to get people off DSP to save money – number of people on DSP has doubled in the last few years; plenty of older people with back and neck problems have been shifted to DSP, no programs for retraining; this has confused unemployment figures. Currently you can work up to 30 hours and keep part of your pension; under Howard's plan if you work up to 15 hours you will lose all of your DSP and only keep 15 hours pay; criteria would be are you capable of working more than 15 hours a week; if so, you would get cut off DSP. If someone has an episode at 19; gets better a few years later; if they are threatened with getting cut off if they can work more than 15 hours a week they have no incentive to work, encouraging them to simply do the easy thing and stay on DSP, rather than try and work and risk getting cut off, so they end up not trying to improve their lives, and the govt. ends up probably losing more money; people will get sick more often because they are not working (due to less self-esteem) which leads to more hospitalisations and more money spent*
>
> (Consumer and Consumer Advocate, New South Wales, Submission #169)

> *Unemployment rate for consumers of mental health services is 80%*
>
> (Consumer and Consumer Advocate, New South Wales, Submission #169)

6.1.8.3.9 Whole-of-government approach needed to improve outcomes for Indigenous communities

The Indigenous Social Justice Association and Justice Action raised concerns about the lack of progress on the Aboriginal Mental Health Policy and other health and related social policies to improve outcomes for the Indigenous communities and reduce discrimination and entry into the criminal justice system. Their concerns are outlined here:

We object to the lack of progress - noted by ISJA - on the Aboriginal Mental Health Policy that has been around since 1998. ISJA's President, Mr Ray Jackson, then of the Aboriginal Deaths in Custody Watch Committee, was part of the team that was assembled to work it up to an acceptable document (Long Bay forensic ward was also involved) and it is, we have been informed, still no nearer to completion or acceptance. The 1989 National Aboriginal Health Strategy, although it got to a stage of being "excellent" according to Tony McCartney of NACCHO, "but the government has failed to implement it" ("'Deadly': Indigenous Health Today", Aust. Nursing Federation, Oct 2004), which is a bad sign for the Aboriginal Mental Health Policy.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

The rate of Indigenous imprisonment has increased 205% for women and 95% for men over the last 8 years. The criminal justice system is highly discriminatory, especially in terms of race, culture and disability. As a marginalised, impoverished, disadvantaged group suffering public prejudice, over-policing and discriminatory laws and procedures, it is no surprise that people with psychiatric disabilities are so disproportionately imprisoned. This is not the fault of deinstitutionalisation, which has not been shown to have contributed to greater rates of offences by people with psychiatric disabilities.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

It must be recognised that many Indigenous people regard the Mental Health Act and associated services as another form of Policing, as being another form of 'Protector' / 'Welfare' role and as such as being abusive, and just another form of control, monitoring and interference (many others, especially from marginalised groups agree). The problem is acute at the intersection of Corrective Services and Health. This is not the peoples' attitudinal problem. It is an issue for Legislators and services to resolve to the satisfaction of the public they serve with particular regard for the rights of minorities and the disempowered. Laws and services that affect Indigenous people must be altered to recognise the rights and needs of Indigenous people. Community control and respect are vital. What is a social problem, what is a political problem, what is a cultural issue, what is an issue of trauma and grief, and what is a medical problem, and what are the solutions must be determined by Indigenous people. Ideas of individuality, family, kinship, community, land and spirituality must be respected. It is the duty of governments, departments and services to sincerely listen to, learn from and work with Indigenous people in the design and provision of law, policy and services. Every policy created through Indigenous community work has called for specific sorts of services that people not only will go to voluntarily, but that they actually want and think they need. It is a matter of self-determination, respect and justice, and it is an emergency.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

It is of great concern that the latest statistics set reported by the MHRT [Mental Health Review Tribunal] regarding involuntary treatment, CCOs [Community Counselling Order], CTOs [Community Treatment Order], ECT [Electroconvulsive Therapy] and forensic matters does not include Indigenous specific data, meaning trends can no longer be assessed and unmet needs for Indigenous specific services for people under the Act, and for the prevention of their coming under the Act, may be ignored.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

6.1.8.3.10 Wards of the State

One presentation at the forum in Sydney highlighted the need for the Government to adequately respond, through a whole-of-government approach, to the needs of children and adolescents placed in the State's care. As indicated in the following transcript, the claim was made that gaps existed in multiple areas and that the needs of these children and youth are ignored resulting in mental health problems and serious negative life consequences:

I'm representing a large group of people with a mental illness. I was first diagnosed with a mental illness at 7 and charged with being abandoned (people who have been in the care of the state and the churches). Burdekin didn't give us much of a mention… We state that 25 out of 1000 of children in state care attempt suicide. We are basically ignored by services. The problems are particularly acute when people leave the care of the state – thrown into their own resources after age of 18. Recommendation – audits done to see what happens to those who leave the care of the state – what is the government doing?

(NGO worker, New South Wales, Sydney Forum # 8)

6.1.8.3.11 Affordability of care – bulk billing clinicians, cost of psychologists and private health insurance

Concern was expressed throughout the consultation process that due to the lack of services available though the public mental health sector, consumers were increasingly forced to pay for care (to see psychiatrists and psychologists). Additionally, concerns were expressed that even those prepared to pay have difficulty accessing services due to long wait lists. Many people though are unable to consider such options for financial reasons, including inability to work or pay for private health insurance, and difficulties in finding clinicians prepared to bulk-bill:

…I was fortunate enough to have found a really experienced private psychiatrist who I clicked with and who was prepared to bulk bill. Before this, money was a major problem because my psychiatric disability meant that I have never been able to work full time. In the past I have tried to get some help from the private system but I could not afford private health insurance and most psychiatrists wanted to charge me more than I could possibly afford…

(Consumer, New South Wales, Submission #327)

6.1.8.3.12 Cross-border agreements

Concern was expressed with regard to agreements between NSW and the ACT and that consumers were "falling through the cracks". Such agreements could be used to the mutual benefit of all signatories and enhance access to scarce resources and enable consumers to receive continuous and coordinated care or treatment close to their social support networks.

Concern was also expressed about the difficulty in obtaining documentation (clinical records) to provide continuity of care from Victoria to NSW. Standard 10.4 states: 'A system exists by which the MHS uses the individual clinical record to promote continuity of care across settings, programs and time':

In December 2003… She was in a coma for about 3-4 days before she recovered. When she recovered, she went back to the Psychiatric ward at St Vincent's [Victoria]. I had several discussions with the Doctors at St Vincent's as it was coming up to Christmas, they said they could do no more for her there, they attempted to transfer her to Nolan House in Albury. But we couldn't get Nolan House to accept her, interstate red tape.

(Carer, Father, New South Wales, Submission #102)

We feel that [X] is a victim of the cross border problem existing between the ACT and NSW. There is a dispute that he is not an ACT resident, when clearly he had an extended period of rehabilitation in the ACT before going overseas, and then returning temporarily to stay with his family prior to getting employment organised in the ACT. It is obvious that [X] will fall through the cracks yet again if suitable supported accommodation isn't found upon his release from The Chisholm Ross Centre.

(Carers, Parents, New South Wales, Submission #198)

The hospital [X, NSW] needed to get his patient history from our normal hospital in Echuca [Victoria] but there was a delay in getting this information. I tried to get his medical history for them but couldn't.

(Carer, Mother, Victoria, Footscray Forum #8)

6.1.8.3.13 Whole-of-government approach for youth

In particular, many submissions and presentations identified the paucity of services and integrated services to assist young people with mental illness or mental health problems as a serious concern (See Standard 11.4 Treatment and Support). Such coordinated services are seen as essential from an early intervention perspective to halt spiralling negative life consequences which result in homelessness, suicide, entry into the criminal justice system or separation from the family. The need for integration with drug and alcohol initiatives was seen as critical:

…the Association recommends that: …An intergovernmental approach be developed to identify, support and build on the existing knowledge of agencies currently offering services to young people with dual diagnosis and their families / carers.

(NSW Association for Adolescent Health, New South Wales, Submission #98)

…the Association recommends that: …NSW Health embark on a comprehensive health promotion and education campaign on dual diagnosis which includes programs targeting police, health professionals and others who work with young people with dual diagnosis issues.

(NSW Association for Adolescent Health, New South Wales, Submission #98)

6.1.8.3.14 National strategies to increase the number of mental health professionals

Concern was expressed that initiatives to address the declining numbers of mental health professionals also needed to be tackled at a national level:

There is also an urgent need for the Federal Government to increase the number of training places for mental health nurses and psychiatrists, to alleviate the chronic shortage in the mental health workforce.

(Carers, Parents, New South Wales, Submission #75)

6.1.9 STANDARD 9: SERVICE DEVELOPMENT

The MHS is managed effectively and efficiently to facilitate the delivery of coordinated and integrated services.

I have worked in the mental health sector in 4 states in Australia over a period of 20 years… I have seen a steady decline in the situation in NSW.

(Consumer Advocate, New South Wales, Parramatta Forum #3)

Under this Standard, submissions and presentations indicate concerns about:

- the current state of mental health services in NSW;
- no progress despite inquiries being conducted, reports released and recommendations being made;
- problems identified with the loss of a coherent vision and direction;
- lack of appropriate services;
- poor quality of existing services;
- lack of funding and accountability;

- lack of funding for NGOs;
- an inappropriate focus on the medical model for service delivery;
- concern about relocation of community based services back to hospital sites;
- reinstitutionalisation;
- service development issues in rural and regional areas;
- low regard for psychogeriatric planning and funding;
- recruitment and retention of staff in rural and regional areas;
- loss of clinical leadership;
- staff issues as a result of lack of resources;
- addressing staff shortages;
- staff attitudes and practice;
- need for training for all mental health workers;
- lack of consultation with clinicians when planning and changing service delivery;
- lack of consultation with consumers, carers and community groups;
- the dismantling and subsequent "imploding" of working services;
- the lack of support for research;
- accountability; and
- fear of repercussions for 'speaking out' on mental health issues.

6.1.9.1 The current state of mental health services in NSW

Many submissions and presentation at forums conveyed feelings of anger that since the Burdekin Report, the closure of institutions and the promise of community care, services have been seriously declining and deteriorating. They did not observe any noteworthy improvements to improve service delivery or protect the rights of consumers. The following quotes highlight these problems:

> *All we are talking about now is more beds. We don't want more beds – we want a system of community based care. We want early intervention in the community. We have to move from talking to doing.*
>
> (Consumer Consultant, New South Wales, Parramatta Forum #9)

> *Everything is so security driven now – this is a real problem.*
>
> (Consumer Consultant, New South Wales, Parramatta Forum #9)

> *Carers carry the burden of this system. They are used as cheap resources – this is wrong!*
>
> (Carer, New South Wales, Parramatta Forum #1)

> *The Richmond Report was based on good intentions but failed to provide the alternative community-based services it promised and therefore left many persons with mental illness homeless and without services.*
>
> (Police Association of New South Wales, New South Wales, Submission #59)

> *It is becoming obvious, that persons who previously were treated within the mental health system are increasingly being shunted into the criminal justice system. People with mental illness must not be criminalised as a result of inadequate funding for the mental health system.*
>
> (Police Association of New South Wales, New South Wales, Submission #59)

> *…the blaring inadequacy of our mental health system in dealing with the often forgotten mentally ill. It seems nothing has changed.*
>
> (Police Association of New South Wales, New South Wales, Submission #59)

I've been in the system for 30 years and I've never seen it so demoralised. There must be better management.
(Anonymous, New South Wales, Submission #303)

I was at the last Burdekin Inquiry. We are facing very frightening times at the moment. We are in a system in crisis and there is an enormous amount of abuse going on. The MHCA brings together an enormous number of voices but we are far from getting our human rights met. The government has failed us - all the governments have failed us. We must be absolutely vigilant that there aren't more human rights abuses committed. We're not planning for increased demand either but we know that mental illness is increasing in prevalence. We are living in frightening times which impacts on people's mental health. We are also living in bad drought times and economic downturn. All these things are affecting communities, families and individuals but the system isn't coping now with the demand and it won't cope in the future unless something is changed.
(Consumer, New South Wales, Sydney Forum #14)

In every country and state like NSW where there has been a winding down of psychiatric services there has been an increase in the prison population. Such an outcome is logical and obvious and I believe that the failure to care about what is obvious is reprehensible.
(Clinician, New South Wales, Submission #26)

Public hospitals are not really therapeutic places these days so I learnt not to expect that. They are multi-roomed holding bays where you can be safely stored until your symptoms respond to medication.
(Consumer, New South Wales, Submission #327)

…the Burdekin Inquiry, and of course not enough resources have ever been put into the community. The situation is worse now than it was some years ago. And as well, there are not enough psych beds now …
(Family Member, New South Wales Submission #9)

Recent press statements are still saying the same things, that NSW and Australia, are allocating about 6% of the Health Budget compared to about 12% that other western countries allocate. Talk about the Lucky Country, which of course it is, provided that you ***Don't suffer from a Serious Mental Illness.*** *(author's emphasis)*
(Carers, Parents, New South Wales, Submission #17)

Mental health services are worse than 10 years ago
(Consumer and Consumer Advocate, New South Wales, Submission #169)

However, improvements (as well as areas still requiring attention) in the NSW mental health system were noted in the following submission:

There have been some significant improvements in the provision of services for people experiencing mental health problems since the Burdekin Report was published ion 1993.

- *Increasing development of community treatment options.*
- *Improvements in medications available and how they have been used.*
- *Recognition of the importance of and provision of psychological interventions (the beginnings of this).*
- *The beginnings of incorporating consumers / carers as partners in service development and provision.*
- *Greater awareness of mental health problems – health improvement projects such as "Beyondblue".*

However, there remain areas of great unmet need and neglect.

- *Crisis in acute care provision…*
- *Dual diagnosis…*
- *Accommodation…*
- *A move away from a social view of health…*

(Clinician, New South Wales, Submission #197)

6.1.9.2 No progress despite inquiries being conducted, reports being released and recommendations being made

Concern was expressed that despite a number of inquiries and reports being produced detailing problems with the delivery of mental health service, very little had changed, or indeed, services have deteriorated. One consumer reported being "sick to death of inquiries" and one clinician stated that the continual disregard by the NSW government of the "blight of the most vulnerable members of our community" was "discrimination of the worst kind":

> *Since the Richmond report these resources have been taken away from people with mental illness without establishing comprehensive community and general hospital based services of equivalent value as recommended in the report. Despite numerous government reviews of mental health services since then, NSW Government has failed to act on the recommendations and continues to ignore the blight of the most vulnerable members of our community. This is a great shame and morally wrong. It is discrimination of the worst kind and hence should be also legally wrong.*
>
> (Clinician, New South Wales, Submission #25)

> *Did the Burdekin Report do anything to really change consumers' lives and their experiences? Well, there was a lot of noise, a small injection of funding yet really things are worse than what they were.*
>
> (Consumer and Consumer Advocate, New South Wales, Submission #8)

> *I'm sick to death of inquiries, committees and the like who simply write and report, have a bit of fan fare and absolutely nothing changes. Oh let's write another policy. We don't need more policies. We need the one's we've got actually taken seriously and implanted and consequences for MHS and Staff and Directors who actually don't implant them.*
>
> (Consumer and Consumer Advocate, New South Wales, Submission #8)

> *There have been many Inquiries and Reports over the years, and yet the situation does not seem to have altered much.*
>
> (Carers, Parents, New South Wales, Submission #17)

> *Clearly, there has been little improvement, if not a further degradation of services since the Burdekin Report in 1993.*
>
> (Carers, Parents, New South Wales, Submission #75)

6.1.9.3 Loss of coherent vision and direction

The Comprehensive Area Service Psychiatrists (CASP) Group expressed concern that the mental health system has lost direction and is working in an ad hoc manner that is inconsistent with the aims and strategies enshrined in the National Mental Health Strategy and the National Standards for Mental Health Services. The CASP Submission particularly highlighted problems with:

- the inconsistency with the *direction of the National Mental Health Strategy, Standards and evidence;*
- *stalling and lack of completion of deinstitutionalisation. Stand alone institutions not integrated with local mental health services;*
- *knee-jerk planning;*
- *band-aiding of a failing system;*
- *acute bed planning rather than MHS system planning; and*
- *lack of protection and dismantling of core services*

(Comprehensive Area Service Psychiatrists (CASP) Group, New South Wales, Submission #350)

What is more alarming is the complete lack of vision and insight by Health in the pursuit of reducing costs above best practice research that offers solid support for resourced community teams, rather than hospital based services in reducing the impact upon the health system. The mental health system in NSW is a case in point…

(Clinician, New South Wales, Submission #197)

6.1.9.4 Lack of services

The lack of services, both in the community and to acute care services in hospitals across NSW, was reported extensively in most submissions and at the community consultations. As discussed in more detail later in this report (particularly Standard 11.4, treatment and Support), the lack of services to deliver treatment and support from the early intervention phase to recovery and rehabilitation for many mental health disorders and problems, across the life span and across NSW, impeded the delivery of coordinated and integrated mental health services to consumers and their families and carers. This would suggest that planning is not occurring 'through a process of consultation with staff, consumers, carers, other appropriate service providers and the defined community' (Standard 9.8) and that resources are not being allocated 'in a manner which follow the consumer and allows the MHS to respond promptly to the changing needs of the defined community' (Standard 9.15).

What is needed are PROPERLY RESOURCED community based services which provide social and emotional supports, peer support and advocacy - which return to people their humanity, their dignity, their self-respect. (author's emphasis)

(Consumer Advocate, New South Wales, Submission #153)

The government in NSW is totally focused on beds as they can count beds and have starved community mental health for years. So much so that consumers are increasingly becoming unwell to the point they need actual hospitalization, thereby placing more emphasis and demands on inpatient beds and the lack thereof. So, what's our erstwhile NSW Health Minister deciding to do – increase the number of beds? Nobody seems to be able to get through that if there were adequate community mental health services, the demand on inpatient beds would actually decrease via people able to remain well or only access an inpatient when in absolute necessity, and maybe even the length of stay might even be shorter for some people.

(Consumer and Consumer Advocate, New South Wales, Submission #8)

Even the mobile assessment teams have been reduced significantly. There's now only 1 team for the whole Central Sydney area – only 7 staff. Most of the new money announced recently by the Government was for hospital beds and forensic services. Bob Carr sees mental health as a law & order issue not a health issue. There was no money announced for community based mental health services.

(Consumer, Female, New South Wales, Sydney Forum #11)

Increasing the capacity of inpatient units and community services to guarantee 24 hour access to those in need of treatment.

(Mental Health Workers Alliance, New South Wales, Submission #325)

Appropriate crisis care, including 24 hour mental health expertise in emergency departments and community teams, to alleviate pressure on front line emergency services.

(Mental Health Workers Alliance, New South Wales, Submission #325)

Hospitals and Community Mental Health Services have to provide resources on a 24hr basis for emergency services. However these services are profoundly under-resourced and underpaid, the staff being forced to take time off in lieu rather than being paid for extended work hours. Staff on call, sometimes experiencing 6 call outs are still expected to work the next day as there are insufficient staff on the payroll.

(Social worker, Student, New South Wales, Submission #118)

6.1.9.5 Quality of services

Associated with the concerns expressed regarding the lack of services, staff and funding were reports regarding the quality of services received from those services which are operating.

We found that the therapeutic situation in the MHU [Mental Health Unit] is unacceptable in its overall treatment of people with mental illness… We found that the management of the MHU raises issues of delinquency or malpractice, whether by inadvertence, incompetence or deliberation. We observed the MHU staff working under considerable pressure, their services being under-resourced and their numbers inadequate for their patients' safety.

(Carers, Parents, New South Wales, Submission #106)

Safety issues and adverse confrontations with patients and families relate to inadequate resources and unrealistic expectations.

(Public Sector Psychiatrists, New South Wales, Submission #297)

Dr [Z]… who gave evidence at an inquest following the death of an adolescent 10 hours after discharge from a Mandala Psychiatric Unit, "…funding of mental health services was not the only limiting factor. An Australia wide shortage of psychiatric staff is a major problem".

(The Coroner's Report in Carers, Parents, New South Wales, Submission #137)

We live in what everyone around the world is known as "The Lucky Country". I myself have a long history with ear problems (22 years) and the care I have received has always been better that 100%. Yet for the first time in my life, I can honestly say, that I am truly unhappy with the care my fiancé ` and I have received.

(Carer, Partner, New South Wales, Submission #20)

It is also very well for various legislative Acts to decide relevant standards – and we agree that it is important to have standards – but it is extremely unreasonable for services to be expected to provide additional services without additional staff or funding.

(Walgett SAAP Services, New South Wales, Submission #63)

A case manager [Y] was involved in [X]'s care by visiting him at home. This is where I become angry, [Y] failed to turn up on a number of occasions and no explanation was given, indeed I had to contact Mental Health Services to inform them he failed to come… Despite stating to my son and I that he would see him "next week" he did not appear. This is disgusting, the people he deals with are mentally ill some may not have any family and they wait anxiously for a visit and they are left dangling, surely this could send some over the edge. My son was upset and felt he was not worth the effort for [Y] to see him. I have left messages for him before but I don't bother now as he rarely replies.

(Carer, Mother and Nurse, New South Wales, Submission #147)

My sister lives in Marrickville and sees the community centre physiatrist on bulk billing. We wanted to arrange the crisis care team (which the community centre initially told us was available) in the area to visit, at home, every couple of days to ensure things were going well that week and basically to have someone other than family provide care. BUT would you believe the response she got - they said she was a difficult case and the community centre basically did not recommend her for this service.

(Carer, Sister, New South Wales, Submission #79)

In February [2002], help was sought in a private hospital in Sydney as there was no adequate care in the public health system.

(Carer, Mother, New South Wales, Submission #88)

6.1.9.6 Lack of funding

Associated with the complaints of lack of available resources to deliver quality mental health services are requests and demands that the level and control of funding is changed in order that appropriate services are delivered and the rights of people with mental illness are protected. Funding issues were raised both with regard to Federal and State government contributions to the health budget and the provision of support services for people with mental illness and their families and carers. Claims were made that the MHS was focusing on beds (end crisis point) and not community services (early intervention) and resources were not being allocated to reflect national mental health policies (Standard 9.14) or in manner which allows the MHS to respond promptly to the changing needs of the defined community (Standard 9.15).

I have concluded that there is definitely cause for concern in New South Wales. There is good public policy but no resources to back it up.

(Consumer Advocate, New South Wales, Parramatta Forum #3)

There is a crisis in the NSW mental health system. It is under-resourced with inadequate community support programs for the mentally ill. More funding is needed in the area of mental health…

(Police Association of New South Wales, New South Wales, Submission #59)

Resources have continued to contract gradually and this has significant and lasting effects on the type of service we can offer.

(Anonymous, New South Wales, Submission #303)

Many of us don't find it rewarding work anymore. It's really stressful and we're expected to do more and more with less and less.

(Anonymous, New South Wales, Submission #303)

There's a really big problem with resources. In NSW we've the lowest funding of all States. We're far behind which badly impacts on our inpatients services and our community care.

(Anonymous, New South Wales, Submission #303)

Mental health is a medically neglected area. We only got about 8% of the health budget for mental health – comparable countries spend much more.

(Carer, New South Wales, Sydney Forum #13)

I want to know where will we go in the next 5-10 years? We need 9-20% of the budget for mental health. We need more money for community support. In the press release the NSW Health Department talked about community but we need the government to define what it means by community care.

(Consumer, New South Wales, Sydney Forum #15)

Current expenditure in Australia on mental health is about $3.1 billion / year – out of a total health budget of $66 billion. As of end 2002, national mental health spending fell from 6.6 to 4.5% of total health spending. This trend represents a visible lack of commitment to the mentally ill and their welfare. Available indices suggest that NSW public mental health services may be disproportionately underfunded, compared with the national picture.

(Public Sector Psychiatrists, New South Wales, Submission #297)

When I first joined the suicide prevention team I was associated with I used to ask the question - why doesn't mental health get any funding - we all used to hear about the mental health initiatives - but if there's no money, there's no treatment or care.

(Carer, Mother, New South Wales, Submission #122)

Appropriate funding for mental health by increasing the mental health proportion of the State Health Budget to at least 10%, as recommended by the National Mental Health Strategy, and for mental health expenditure to be transparent and quarantined.

(Mental Health Workers Alliance, New South Wales, Submission #325)

Insufficient Funding

- *Erosion of funding for core components of mental health services – waiting lists for case management rehabilitation and residentials*
- *Siphoning of budgets by general hospitals and Area Health Services*
- *Per capita recurrent funding and capital transfer and investment equivalent to New Zealand or at least Victoria required (Ref: Rosen and Manns, (2003) Who Owns Callan Park? A Cautionary Tale, Australasian Psychiatry)*

(Comprehensive Area Service Psychiatrists (CASP) Group, New South Wales, Submission #350)

You bet the mental health system has continually failed to meet the needs of mental health consumers – absolutely big time. However, in saying this, I also recognize the absolute starvation of mental health dollars being put into the system.

(Consumer and Consumer Advocate, New South Wales, Submission #8)

Increasing demand

- *comorbidity*
- *age demographics*
- *longer admissions*
- *increasing involuntary admission*
- *pressure on Emergency Departments*
- *pressure on shrinking community mental health services*
- *increasing demand on Consultation-Liaison Services*

(Comprehensive Area Service Psychiatrists (CASP) Group, New South Wales, Submission #350)

We need to be listened to and we can tell you what we want and need. One of them is funding.

(Consumer, New South Wales, Submission #70)

In particular, there is a chronic underfunding of community mental health teams and rehabilitation and support services.

(Carers, Parents, New South Wales, Submission #75)

It was abundantly clear though, that unless more resources are made available to our area, most of these issues will never be resolved.

(Eastern Area Interagency NSW, New South Wales, Submission #100)

There is a need for a significant increase in Federal Government funding to increase the percentage of the total health budget spent on mental health care. This percentage should be in line with comparable first world countries. Currently it is way below that.

(Carers, Parents, New South Wales, Submission #75)

% of health budget in Australia spent on mental health is 7% (in NZ 12%)

(Consumer and Consumer Advocate, New South Wales, Submission #169)

6.1.9.7 Lack of funding for NGO services

Concern was also expressed about the quantity of services the MHS has contracted out to a poorly-resourced NGO sector. As indicated in the following quotes, many feel that the Government is simply 'passing the buck' to the NGO sector:

There has been a rapid devolution to NGOs in NSW but the degree of funding is very poor. In fact, what governments have devolved to NGOs is the problem! Such devolution is unacceptable if NGOs do not have the capacity nor the resources to deliver the necessary services. There are huge gaps in clinical services, case management.

(Consumer Advocate, New South Wales, Parramatta Forum #3)

The Government is happy to treat NGO's as extensions of services but not fund them accordingly. In fact the Government has cut funding to NGOs and still expects that the NGO's will carry the load. I have had to put a ban on all referrals from services. We're now in a position where we are rationalising our services. We don't like it but we have to run our service within the resources we have to work with… My service has a budget of $400,000/year but our funding hasn't increased since early 1990s.

(NGO Clinician, New South Wales, Sydney Forum #3)

Better resourcing for the non-government sector and supported accommodation, with particular attention to the plight of the homeless mentally ill.

(Mental Health Workers Alliance, New South Wales, Submission #325)

NCOSS is concerned at the inadequate services for mental health care in the community and the low level of funding for mental health NGOs… NCOSS is receiving consistent reports of inadequate resources in specialist mental health services and in other services, which include people with a mental illness in their client group.

(NCOSS, New South Wales, Submission #47)

Governments are unwilling to fund additional positions. It appears that both state and federal governments are willing to fund 'new initiative' or to start new programs but are unwilling to provide funding for an additional staff member in an existing service – especially a NGO. Budgets just do not stretch far enough to allow additional employment.

(Walgett SAAP Services, New South Wales, Submission #63)

…the 'new initiatives' are often for 12 months. Short term programs are totally non-productive when dealing with Mental Health and AOD [Alcohol and Other Drugs] clients. It takes time to gain the trust of individuals. No sooner does a program start to achieve results, than the funding ceases. This attitude is only setting individuals up to fail – yet again.

(Walgett SAAP Services, New South Wales, Submission #63)

NGOs are most often the 'front-line' agencies who meet clients in their raw, most vulnerable state and who are expected to cope with a range of dysfunctional behaviours with little or no support. Respect from professionals would help.

(Walgett SAAP Services, New South Wales, Submission #63)

Dealing with our SAAP [Supported Accommodation and Assistance Program] clients is difficult because of the holistic approach we take to the individual. We no longer just provide them with a bed and a feed but endeavour to help them achieve their chosen quality of life… everyone is aware that prevention is better than cure and that early diagnosis is the preferred treatment option. Government departments to allow sufficient funding in NGO budgets for an on-site counsellor who can take the case-management role.

(Walgett SAAP Services, New South Wales, Submission #63)

6.1.9.8 Focus on the medical model for service delivery inadequate

Concerns were also expressed regarding the use of the medical model as the basis for the planning and delivery of treatment and support services and that this model was limiting the protection of the rights of people with mental illness:

THE MEDICAL MODEL RULES SUPREME. The focus is always FIRST on clinical interventions, usually focused on the crisis event, with community based services coming 2nd… Medical intervention is important, but in the long run, plays only a relatively small part in people regaining & retaining wellness. When too much emphasis is placed by government on clinical interventions, resources are disproportionately allocated to the clinical sector at the cost of too few resources finding their way into the community. The first priority should NOT be more funding for educating GPs, Help Lines or more clinical Services. (author's emphasis)

(Consumer Advocate, New South Wales, Submission #153)

One common response from the Liverpool Hospital was that soon a new facility would be built to house the Mental Health Unit, which would address our concerns. But a prudent mind will see that the new building is not the answer; it is the systems, the people and the resources that are the essential elements in order to comply with the National Mental Health Strategy and provide equity for people with mental illness and their families.

(Carers, Parents, New South Wales, Submission #106)

The trend towards medicalising further the realm of psychiatry away from the social and contextual experiences of clients continues to lead to the erosion of essential social, recreational and intensive rehabilitation based services for mental health clients.

(Clinician, New South Wales, Submission #197)

With the medicalisation of mental health services those most in need of social networks and support are left without essential services, and consequently as a community we have become increasingly dislocated, traumatised and impoverished.

(Clinician, New South Wales, Submission #197)

6.1.9.9 Concern about relocation of community based services back to hospital sites

There is a statewide drive to consolidate all community health services onto existing hospital sites in the name of "economy of scale" or the current health finance ideology of "capital-charging".

(Clinician, New South Wales, Submission #351)

Concerns were expressed regarding the recent pattern to relocate community based services to hospital sites primarily for financial reasons. It was suggested that this effectively "re-institutionalises" services and works against all the aims of community based service delivery and emphasises the medical model of mental health. Evidence was presented that suggested that this approach results in less face-to-face consultation and home visits, reduced ability of clinicians to go into the community, less communal access, and will divert people to assessments in emergency departments and hospitalised based treatments. This pattern will contradict stigma reduction campaigns and do little to assist with access to a variety of treatment and support services in the community or the promotion of the rights of people with mental illness to participate socially and economically.

At the same time, it is concluded that simply converting buildings on hospital sites does not constitute a community base.

(Clinician, New South Wales, Submission #351)

Implementation of the National Mental Health Strategy has always been problematic in NSW because of the fragmentation into largely autonomous Area Health Services. While it is hoped the 2004 reform will improve this situation, things currently look bad in the State. Community-based mental health services are in retreat, with widespread funding restrictions, cutting of 24-hour crisis services to office hours only, and pulling back of resources into the hospital system so that so-called 'community services' are in reality 'outpatient departments'.

(SANE Australia, National, Submission #302)

Apart from the crucial issue of ease of local communal access, appropriate crisis and community care depends more on team attitudes than the site of services. But there is a widespread international consensus that it is much easier to generate and maintain the appropriate attitudes on a community site, rather than a hospital based site. Further, international expert opinion concludes that a balance needs to be struck between local physical access, and critical density of staff to provide a) cover for leave, absence and professional training and b) a range of service options.

(Clinician, New South Wales, Submission #351)

Newcastle Mental Health Services have received a new director in recent years. This has brought changes, which now see a more top heavy, less operative approach to mental health in the area. There are now less staff for face-to-face consultations and so less home visits. There is now a centre-based service with reduced ability to go into the community.

(Anonymous, New South Wales, Submission #156)

I was notified late on 15 September 2004, that Northern Sydney Area Health Service now favours a proposal to transfer all the staff and facilities of Cremorne and Chatswood Mental Health Centres, Westview Consumer Services, and our Assertive Rehabilitation/Recovery service as soon as possible to a defunct paediatric ward on the Royal North Shore Hospital site. This temporary placement will last 5 – 10 years and then NSAHS's plan is to move the entire Lower North Shore Community Mental Health Service into a generic community health precinct on hospital grounds…

(Clinician, New South Wales, Submission #351)

This is planned ostensibly because NSW Department of Health and NSAHS do not wish to spend the $4 million required to refurbish or rebuild the Chatswood site to a reasonable standard, nor will they consider retaining the Cremorne site. It is clear that NSW Department of Health and NSAHS wishes to sell the Chatswood and Cremorne Community Mental Health sites, worth respectively upwards of $10-12 million and $3 – 5 million at conservative estimates provided to NSAHS. Only a small fraction of this will be spent on merging and squeezing existing Community Mental Health facilities into a generic community health hospital precinct. Capital resources presently dedicated to Mental Health will be reabsorbed into NSAHS's contribution to its general hospital redevelopment funds. This is similar to the loss by stealth over the last 15 years of Gladesville and Macquarie psychiatric hospital sites to general health administration, etc. This has occurred without recompense to Mental Health, and without reprovision of the full range of community and general hospital based acute, residential and day rehabilitation facilities which are missing from most catchments in NSW, but are present throughout Victoria (see Report on Site Visit to Victorian MHS and "Who Owns Callan Park", attached).

(Clinician, New South Wales, Submission #351)

Our NSAMHS Area Director argues that siting Ryde CMHS on the edge of a hospital site has not compromised its operation. However… it will no longer provide the degree of communal access that Professor Jim Lawson envisaged – for instance when he acquired the Chatswood site – in a residential setting near major shopping, bus and train hubs, or with the Cremorne site, straddled between residential and shopping zones on a major local transport route.

(Clinician, New South Wales, Submission #351)

Ultimately, OH&S and economy-of-scale arguments can be extended to banning all community health centres and all home visits. The appropriate path is to make community work as safe as possible, to screen and divert most assessments and initiation of treatment away from Emergency Departments, and then use Emergency Departments in exceptional, highly ambiguous or emergency circumstances only, or to assess mixed medical / psychiatric emergencies.

(Clinician, New South Wales, Submission #351)

It is not too difficult in reality to accommodate OH&S concerns while maintaining community based services. We could be forgiven for suspecting that this concern is simply a screen for the dominant drive to economically rationalise services, and to realise assets occupied by mental health services for general health purposes.

(Clinician, New South Wales, Submission #351)

The randomised control evidence clearly favours community and home based mobile extended hours crisis services over hospital based assessment and initiated treatment (see references). We are told by our Director of MHS, NSAHS that all the arguments for having community mental health services on community sites are purely "ideological". Well, no one side of such a debate has a monopoly on ideology. Further, although some of the evidence for local community siting is indirect, there is no evidence-base whatsoever for siting all community mental health services in hospitals. Wherever a difference can be inferred directly or indirectly from the evidence, it is in favour of community-based teams. Though it is important to be cautious and not to overclaim in extrapolating from the literature, this general trend is fairly consistent and not "in contention" as stated by our Area Mental Health Director.

(Clinician, New South Wales, Submission #351)

In fact, continuing capital investment in dedicated mental health facilities ensures the continuing existence of mental health services, rather than their continual erosion, dilution and ultimate merging again with generic outpatient services.

(Clinician, New South Wales, Submission #351)

Meanwhile, mental health services do not have sufficient resources to bring the fabric of community mental health centres up to acceptable community standards. They are generally left in poor repair until they rot and become unsafe. Then there is a sudden but predictable panic to bring these services back to a hospital site. Neither are capital resources allotted to providing the range of community based residential drop-in, rehabilitation, residential, dual disorder, personality disorder and forensic facilities that are provided locally or regionally throughout Victoria and New Zealand.

(Clinician, New South Wales, Submission #351)

On the very local level at the Lower North Shore, the decision to close Cremorne Mental Health Centre means a loss of badly needed community based mental health services. If NSW Government had adequately funded the service the Centre would be offering a comprehensive program supporting recovery and independent living in the community to consumers and their carers. Instead the Centre has lost 10 members of staff due to lack of funding and service users are expected to travel long distances by public transport to a new temporary centre (temporary at the cost of $ 4.6 million) that is to be built in Chatswood. Many consumers are not well enough to travel long distances, frequently not even short distances by public transport. This means that the carers have to drive them or service providers have to visit them at home on a continuous basis. Neither one of these alternatives foster independence but dependency and poor self image. It also adds to the burden of caring. It is another obstacle to access the services.

(Clinician, New South Wales, Submission #25)

6.1.9.10 Reinstitutionalisation: more acute beds and forensic facilities and less community based care

Concern was expressed about the focus on increasing the number of acute beds, the building of a forensic unit at Long Bay Gaol and the recent pattern to relocate community based services to hospital sites primarily for financial reasons. It was suggested that this effectively "re-institutionalises" services and works against all the aims of community based service delivery and emphasises the medical model of mental health.

The crisis in community mental health services is misrepresented by politicians and the media as a 'bed crisis,' leading to creeping reinstitutionalisation as the Health Department knee-jerks with more beds as the principal response.

(SANE Australia, National, Submission #302)

Latest funding announcement for NSW Mental Health announced $241 million - most was for inpatient services. Most were already announced funds, and most was allocated to building a forensic unit at Long Bay Gaol - thus NSW put more priority on gaoling consumers with psychotic illnesses rather than for health facilities in the community - Bob Carr treating mental illness as a law & order issue, not a health issue.

(Consumer and Consumer Advocate, New South Wales, Submission #169)

6.1.9.11 Service development issues in rural and regional areas

Many concerns were raised at the forum in Broken Hill regarding the lack of services in rural and regional areas of NSW. Many consumers and carers spoke of the absence of any services to access, especially after hours, and their only options were at a great distance away; due to the scarce number of services and clinicians, these services were also difficult to access (e.g. long waitlists). Concerns were also raised that planning and resource allocation for services located in rural and regional areas needs to consider a multiplicity of factors that may hinder the operation of such plans or not cater appropriately for the differing needs of those communities. For example, as mentioned above, the recruitment and retention of staff in rural areas, higher rates of unemployment and the ageing population:

Our area has 12% of the population but receives 6% of the funding. We don't have anywhere near enough resources, enough staff or enough beds! We don't even have enough basic services!

(Carer, New South Wales, Parramatta Forum #1)

Murray, Judd et al (2004) have recently demonstrated in Australian rural settings that locations of mental health services with greater access to services and social interaction were statistically associated with higher levels of subjective wellbeing or resilience dimensions for individuals with mental illness.

(Clinician, New South Wales, Submission #351)

In Broken Hill the mental health services and the counselling services are combined which is the only area in NSW where the services are combined. The model is not the problems it the fragility of the location - the service could be good one moment and then in crisis the next.

(Clinician, New South Wales, Broken Hill Forum #16)

There are 4 teams operating in the local area including Broken Hill, Deaton, Bourke and Lightening Ridge. Broken Hill is probably the best as access to supporting services is much worse in the other locations.

(Clinician, New South Wales, Broken Hill Forum #16)

The Richmond Fellowship has been helpful for people with disabilities and housing. Certainly problems in employment, particularly in rural areas, make it more difficult for local people.

(Clinician, New South Wales, Broken Hill Forum #17)

Broken Hill has an ageing population. There is a demographic shift in Broken Hill which means there is an increasing older population and decreasing younger population as many move away to seek higher education and build there lives in other places where they can find work and hope.

(Clinician, New South Wales, Broken Hill Forum #25)

I would hate to see [X]'s death be in vain, I would like to see an inquiry into the mental health system in country areas, the type of things addressed would be a decentralised mental health facility to deal with long term problems. Specifically set up in major country areas.

(Carer, Father, New South Wales, Submission #102)

6.1.9.12 Psychogeriatric planning and funding

A number of clinicians expressed their concerns that the level of funding allocated to the provision of mental health services to the aged population across NSW was particularly poor and there was inadequate psychogeriatric needs assessments or planning in NSW:

I have concerns about the relative lack of attention that has been given to the needs of older people in Australia who have mental disorders or problems.

(Clinician, New South Wales, Submission #264)

There is a lack of financial equity. The elderly make up 13% of the population. It is hard to obtain accurate figures but it appears that in most Areas, older people do not receive their 13% share of the budget.

(Anonymous, New South Wales, Submission #303)

One reason for the relative lack of attention is that surveys of Australians (such as the Mental Health and Wellbeing survey conducted in 1997, published 1998) have used investigative schedules that are not appropriate for questioning older people. What's more, that large and expensive Mental Health and Wellbeing survey was methodologically flawed… In spite of the flaws, governments in Australia have cited the survey as evidence that older people are less likely to need mental health services than younger people. For example, the survey has been quoted in NSW Department of Health literature concerning the allocation of resources.

(Clinician, New South Wales, Submission #264)

There was a Mental Health for Older People Committee convened by the Centre for Mental Health, which produced a 250 page report in 1998. This report never saw daylight and was shelved. A 24 page summary policy was developed before the 1999 election, but sadly did not reflect the large report.

(Anonymous, New South Wales, Submission #303)

It is true that some areas don't have old age psychiatrists but this is not because of a shortage of them; it is because some areas have tried to get away without creating specialist positions specifically for old age psychiatrists, possibly again because of conclusions from flawed studies. However, there are certainly too few nurse and social worker and occupational therapist positions in old age psychiatry teams…

(Clinician, New South Wales, Submission #264)

Another NSW committee has been formed including some excellent clinicians and bureaucrats. Hopefully soon we will see some more resources eventuate. One initiative has been the establishment of Areas Coordinators Of Specialist Mental Health Services For Older People, with $1.6 million across NSW to fund these positions. We are yet to see what these positions will achieve but it is at least one small but positive step.

(Anonymous, New South Wales, Submission #303)

Despite all of this, NSW still does not have a good psychogeriatric plan. VIC and QLD are doing much better. VIC spends more per capita on mental health in general and for older people in particular. VIC has psychogeriatric homes. We had the 9 Cade homes previously but 2 closed so we're only left with 7.

(Anonymous, New South Wales, Submission #303)

…some administrators have argued that Mental Health should not be responsible for dealing with cases of dementia. They have argued that dementia is not a mental disorder… In my view, psychiatry should look after people referred for specialist assessment and/or care because of dementia unless they are non-ambulant and have other reasons for needing the involvement of geriatric services.

(Clinician, New South Wales, Submission #264)

I think there is real potential for the Commonwealth and State Governments to work together and put in joint funding, which is what VIC is doing. VIC has also put a lot of funding into memory clinics.

(Anonymous, New South Wales, Submission #303)

Another deficiency in our system… is the lack of availability of old age psychiatry teams to be involved in psychiatric and behavioural programmes in aged care facilities. We wanted to set up such an arrangement in our sector in Sydney, but when the money was allocated to our area it was diverted to paying for another half-time old age psychiatrist.

(Clinician, New South Wales, Submission #264)

6.1.9.13 Recruitment and retention of staff in rural and regional areas

Lack of funding and resources were identified as part of a package of problems in recruiting staff to fill vacancies in rural and regional areas. Inability to attract and retain staff in rural and regional areas was also identified as a significant problem for continuity of care (See Standard 8.1):

It is acknowledged that the people currently employed are very good but it is hard to get staff to locate to Broken Hill. Overall the system in Broken Hill needs more people with more training.

(Carer, New South Wales, Broken Hill Forum #1)

Recruitment and retention of staff is very hard as the service can not afford the high wages and benefits required to attract people to come and stay to work in Broken Hill.

(Service Provider – representing the Director of Mental Health in the Far West, New South Wales, Broken Hill Forum #14)

Not many staff that come out to Broken Hill actually stay for a long period of time. They have managed to attract some resident psychiatrists to Broken Hill but they all seem to leave as soon as they have completed their residency. The service is attempting to increase the specialist mental health workforce and hope to have increased numbers in the future.

(Service Provider – representing the Director of Mental Health in the Far West, New South Wales, Broken Hill Forum #14)

The recruitment of staff is a huge problem – we can't offer staff incentives to work in this rural area – we get quite a lot of intern psychologists and then they leave after 12 months. We hope to offer some training incentives.

(Service Provider – representing the Director of Mental Health in the Far West, New South Wales, Broken Hill Forum #14)

Staffing levels are probably at the best for the last 6 or 7 years however about 6 of the team are in their first 18 months of work so they are young team.

(Clinician, New South Wales, Broken Hill Forum #15)

Normally the mental health worker works as a specialist working in a consultative role. The mental health worker would consult with other specialists to address a specific area of expertise and need. We are considering how we can encourage some workers to develop a second area of expertise and we are hoping the Department of Health for NSW would provide some funding for this to happen. There is a tour of duty mentality for workers in Broken Hill where they come, do their time in a rural area and leave.

(Clinician, New South Wales, Broken Hill Forum #16)

6.1.9.14 Loss of clinical leadership

The Comprehensive Area Service Psychiatrists (CASP) Group also expressed concern that there has been a trend, which the group believes is likely to continue, to destabilise many permanent Directors or Clinical Directors and that this is resulting in unnecessary resignations and the loss of clinical leadership:

Loss of psychiatrists as permanent Director or Clinical Director (f/t or substantial p/t) in many sectors / areas of NSW, including:

1. *Prince of Wales / Eastern Suburbs*
2. *St Vincent's / Kings Cross*
3. *St Georges*
4. *Manly / Northern Beaches*
5. *Bankstown*
6. *Wollongong / Illawarra*
7. *Campbelltown*
8. *Albury*
9. *Gosford / Central Coast Area / Sector*
10. *Hornsby-Kuringai Hospital and Sector*

Other directors / clinical directors are currently being destabilised, and are likely to resign if this does not cease.

(Comprehensive Area Service Psychiatrists (CASP) Group, New South Wales, Submission #350)

6.1.9.15 Staff issues as a result of lack of resources

There are also real problems with the workforce. Medical graduates are just not going into mental health. Who can blame them if they see this as the model?

(Anonymous, New South Wales, Submission #303)

Lack of resources, high demand and overstretched staff is also seen to be contributing to high staff turnover, low morale and impacting on attitudes and behaviour of staff. All of these factors impact on the ability of the MHS to deliver 'a range of high quality mental health treatment and support services (Standard 11.4) and protect the rights of people with mental illness and mental health problems'.

Because of the budgetary restrictions that have been imposed on us there's a freeze on new positions. What this means is that I can't be critical of staff who may not be ideal because if they leave we can't replace them! What do we do?

(Anonymous, New South Wales, Submission #303)

Many times it is a case of identifying good workers and targeting them for assistance as you know they will try and do their best. This puts a drain on these workers but people in need really are in crisis and they need help.

(NGO Worker, New South Wales, Broken Hill Forum #5)

As I said before, the administrative burden has increased significantly at the same time as bed numbers have been reduced. It's a vicious circle, a negative feedback loop – the more people (clinicians etc) who leave the more the increased workloads fall on those who are left behind. Then of course, they leave! This is happening at a consultant and registrar level and it is compounded by the declining entry into psychiatry of trainees.

(Anonymous, New South Wales, Submission #303)

Staff on call, sometimes experiencing 6 call outs are still expected to work the next day as there are insufficient staff on the payroll. Therefore high turnover rates are also a problem. Those that work in this industry are those that are compassionately aware of their clients needs and quite often feel helpless in being able to assist."

(Social worker, Student, New South Wales, Submission #118)

Don't get me wrong it's not that I think all government workers and hospital staff are incompetent, they are bound by a resource strapped, inefficient bureaucratic framework.

(Carer, Daughter, New South Wales, Submission #134)

Committed workforce becoming demoralized and leaving:

- *loss of medical directors / psychiatrists / registrars*
- *loss and aging of mental health trained nursing staff*
- *hospitals removing RMO's [Resident Medical Officer] from working in Psychiatry – loss of replacement recruiting ground*
- *unreasonable and destructive bureaucratic pressures upon clinical practice and leadership*
- *perceived media and government fuelled "blame" culture and "lock-em-up" mentality*

(Comprehensive Area Service Psychiatrists (CASP) Group, New South Wales, Submission #350)

Mental health services in this State have been in crisis for a long time and the chronic under-resourcing of this sector is responsible for an unacceptable decline in working conditions for the police, ambulance officers, nurses, doctors, allied health staff and security officers who are attempting to provide safe care and humane treatment for this vulnerable group.

(Mental Health Workers Alliance, New South Wales, Submission #325)

We have experience of working with a social worker dealing with people with mental health problems and this social worker was burnt out in 3 weeks due to the demand on their time.

(NGO Service Provider, New South Wales, Broken Hill Forum #13)

…less staff than 10 years ago, worse attitudes towards patients among staff (from nursing staff and consumer representatives); morale in mental health services is very low, due to bad conditions and lack of funding

(Consumer and Consumer Advocate, New South Wales, Submission #169)

6.1.9.16 Addressing staff shortages

Concern was expressed about the shortage of supply of mental health professionals, loss of key staff and retaining those currently employed. Concern was also expressed about the current strategy to address recruitment and retention problems by hiring Visiting Medical Officers (VMO's) and that the broader picture of service delivery and other strategies need to be examined.

Visiting Medical Officers

- *Loss of supervising and system building psychiatrists*
- *Can't build service out of fragments of VMO time, doing only direct clinical work. Even major metropolitan services are now trying to limp along with poorly coordinated "VMO de jour" arrangements.*
- *Often no regular communication, peer review or calibration of clinical practices*
- *Need wide job description encompassing full range of work required.*
- *Can't retain staff specialists as attracted to more lucrative VMO sessions advertised in some areas.*
- *If service has to rely increasingly on VMO's, funding for other staff shrinks*

(Comprehensive Area Service Psychiatrists (CASP) Group, New South Wales, Submission #350)

Addressing the problems of recruitment and retention in the sector by providing incentives to enter employment, enter training schemes, supporting learning and development.

(Mental Health Workers Alliance, New South Wales, Submission #325)

Loss of key staff is an urgent problem in NSW, brought about by demoralisation and 'ageing out'. Immediate action is required to recruit and retain psychiatrists, nurses and other mental health professionals – including creating a positive, recovery-focused environment in which to work.

(SANE Australia, National, Submission #302)

6.1.9.17 Staff attitudes and practice

Concerns were expressed about poor staff attitudes towards consumers and carers indicating that staff may be in need of training in order to change their attitudes and behaviours and be more supportive when dealing with people with a mental illness:

Encountered rude and uncaring attitudes by staff.

(Carers, Parents, New South Wales, Submission #106)

There are many accounts of stigmatising and inappropriate treatment of mental health clients by some staff within the ESMHP [Eastern Suburbs Mental Health Program]. The manner in which people are spoken to, comments and remarks made are suggestive of a significant problem within the service.

(Eastern Area Interagency NSW, New South Wales, Submission #100)

We believe that staff must receive training from consumers and carers, designed to raise awareness of perspectives of their care, attitudes, and practices.

(Eastern Area Interagency NSW, New South Wales, Submission #100)

We need to charge the attitudes of the people who are providing care.

(Former consumer of mental health services, New South Wales, Sydney Forum #12)

Lack of communication between staff, and with parents.

(Carers, Parents, New South Wales, Submission #106)

Most mental health staff don't like working with a lot of older people so admitting them to general psychiatric wards does not result in good treatment as those staff become resentful at the number of older patients. This is another reason for having separate dedicated psychogeriatric wards.

(Anonymous, New South Wales, Submission #303)

Also no amount of dollars equates to good staff practice and there are many, many instances where the situations that consumers find themselves in have more to do with actual poor staff practice than inadequate funding.

(Consumer and Consumer Advocate, New South Wales, Submission #8)

Feedback we receive from people with a diagnosis of Personality Disorder suggest that they are being treated badly by staff (e.g., staff are irritable towards them, their concerns being dismissed as part of their illness, they are characterised as manipulative)… We request that the MHS considers conducting an evaluation to determine how people with a diagnosis of Personality Disorder experience ESMHP services, and address staff attitudes towards these consumers.

(Eastern Area Interagency NSW, New South Wales, Submission #100)

[My psychiatrist] did lots of things that were useful. These included showing me my file everyday… Staff felt a bit threatened I am sure but it meant that people had to take greater responsibility for the language that they used and this was really beneficial for me. He also took up issues for me and treated my complaints, even the very little ones, seriously…

(Consumer, New South Wales, Submission #327)

Many young people in the focus groups described their first experiences with health professionals and authority figures as unpleasant, frightening, coercive and humiliating, which subsequently had a profound effect on their attitudes to future dealings with health professionals. Young people said:

…It broke my spirit…
...Humiliation…
…It took away my rights…

(NSW Association for Adolescent Health, New South Wales, Submission #98)

6.1.9.18 Need for training for all mental health workers

Standard 9.17 states: 'The MHS regularly identifies training and development needs of its staff' (for example with reference to industry-validated core competencies for mental health staff) and Standard 9.18 states 'The MHS ensures that staff participate in education and professional development programs'. Concerns were expressed regarding the lack of comprehensive, standardised training for all mental health workers and problems with service demands to release staff to attend training based on identified needs or professional development.

I would like to raise an issue that I believe has contributed significantly to the decline of the standard of service provision in MH facilities (community and inpatient): the absence of a comprehensive, standardised training program for all MH workers.

(Anonymous, New South Wales, Submission #71)

Other than training provided at undergraduate level (which is known to be very limited and variable in quality and quantity for all disciplines), or short distance-based post-graduate courses, there is no comprehensive, skills based training program for non-medical staff working in MH. The only long-term programs are available through the stand-alone facilities such as Rozelle and Macquarie, and are limited to staff employed there. The bulk of staff accepting employment in MHS in NSW do not have a baseline of core knowledge, and are required to attain this on the job. The variability of opportunities for mentoring and models of practice on the job means that someone could be working in MH for some years without fundamental training in the principles and practice of MH care. This means that shared standards of practice and conceptual frameworks amongst and between disciplines is non-existent, resulting in inconsistencies in practice and outcomes.

(Anonymous, New South Wales, Submission #71)

I believe the Centre for MH should commission a training organisation (?Institute of Psychiatry) to develop a standardised training program aligned to the one provided for Psychiatric registrars, that would provide the baseline training for all staff working in MHS in NSW.

(Anonymous, New South Wales, Submission #71)

Numbers of trained and experienced staff have been critically reduced, a trend which has been superimposed on chronic understaffing. This is so for most categories of mental health professionals, but particularly psychiatrists, psychiatric registrars and nurses. An additional problem is the limited pool of professionals that can be recruited to the field, even if money were available. As a consequence of these factors, viability of overtime rosters is in jeopardy, risking the safety of patients and registrars. Also, rosters are becoming increasingly onerous for consultants.

(Public Sector Psychiatrists, New South Wales, Submission #297)

There are more fundamental issues that bear on mental health and mental health problems; there are issues around the priority given to mental health by all the human service and related systems. For example, look at the training of general nurses, and of the many of the specialities in medicine. In many of the latter mental health is critically important yet mental health does not feature in the training programmes, I am thinking especially of physicians and paediatricians. But there are others. The same could be said of lawyers and police. Some of the most intractable problems I have found in caring for some young adults with mental illness are the way the justice system and police have treated them, and other systems like housing and income support.

(Anonymous, New South Wales, Submission #125)

Service demands (e.g. registrar rosters) jeopardise training requirements.

(Public Sector Psychiatrists, New South Wales, Submission #297)

There is a lack of diversity in work experiences.

(Public Sector Psychiatrists, New South Wales, Submission #297)

Barely workable registrar rosters jeopardise registrars' training requirements and / or mental health, leading to resignations, negative perceptions of psychiatry, and problems with recruitment and retention. The current pattern poses a growing risk to a sustainable, home-grown psychiatric workforce for the public sector in the future.

(Public Sector Psychiatrists, New South Wales, Submission #297)

6.1.9.19 Lack of consultation with clinicians and service providers when planning and changing service delivery

Concerns were also expressed that clinicians and service providers are not being consulted about key changes to service delivery even when they are directly responsible for associated budgets and delivery of such services. Standard 9.8 states 'The strategic plan is developed and reviewed through a process of consultation with staff, consumers, carers, other appropriate service providers and the defined community'. However, as the following quotes highlight, this is not always occurring:

There must be better management. We are carrying all the responsibility but no authority for budgets. We only know when it gets cut.

(Anonymous, New South Wales, Submission #303)

I was not notified about the nature of and was not included in the [Y] Area meeting… which made this decision, although I was on duty and available to participate … Such unfortunate decisions have enormous clinical implications for the operation of our mental health services, and should not be made administratively without the input and agreement of the clinical director of our service.

(Clinician, New South Wales, Submission #351)

In her conceptual diagram of the new Acute Mental Health Service Models at a combined Northern Sydney – Central Coast Area workshop at Hornsby RSL Club on 30th July 2004, Consultant [y] proposed that Emergency Dept. Mental Health Triage and Assessment Team, and the Psychiatric Crisis and Acute community care teams, a Psychiatric Emergency Suite should be concentrated within Emergency Departments. Central Coast MHS have already operationalised such a plan, apparently to meet severe Emergency Department pressures, having had to concentrate their "front end" crisis services in Emergency Department at the expense of their so-called "back-end" (continuity of care and rehabilitation services) which they have sorely depleted. [Y] has not amended this hospital centred model in the consultative document September 2004, despite detailed concerns expressed at and since this workshop.

(Clinician, New South Wales, Submission #351)

Agencies in this community are wondering, when we have shown a willingness to advocate for more funding and better resources for mental health services in this area, why we have encountered strong resistance from the ESMHP [Eastern Suburbs Mental Health Program] to work with us in direct and open partnership; address inadequacies, creating better outcomes for consumers, their families and friends, and the community generally.

(Eastern Area Interagency NSW, New South Wales, Submission #100)

We request more direct communication from the ESMHP, so we can have more direct involvement in creating effective and timely strategies to address early intervention and continuity of care issues for people living with mental illness in our area.

(Eastern Area Interagency NSW, New South Wales, Submission #100)

We are attempting to work collaboratively with the ESMHP, in accordance with National and State policies, to address individual and systemic issues. We want to do this effectively, and we want this collaboration to commence now. We are requesting the ESMHP to select senior representatives to meet with us on a monthly and ongoing basis, to address issues, and to establish a transparent and accountable process of joint consultation.

(Eastern Area Interagency NSW, New South Wales, Submission #100)

6.1.9.20 Lack of consultation with consumers, carers and community groups

Concerns were also expressed that consumers, carers and community groups are not being listened to (and that they have a right to be heard) and are tired of consultations which result in no changes and are not meaningful. Standard 9.8 states 'The strategic plan is developed and reviewed through a process of consultation with staff, consumers, carers, other appropriate service providers and the defined community' and Standard 9.9 describes the process for such a plan (e.g. consumer and community needs analysis and a service evaluation plan including the measurement of health outcomes for individual consumers). These concerns suggest that even when consumers and carers are involved such processes are not being adhered to in a meaningful way and also indicate that criteria listed under Standard 3 (Consumer and Carer Participation) are not being met.

The decision to close Cremorne Mental Health Centre illustrates NSW Government attitude towards people with mental illness and their carers; they don't matter. This same attitude was demonstrated by [the Director of … Area Health Services] today when he called the representatives of concerned community groups as rubble rousers to their face and warned them not to kick a fuss or they might be worse off.

(Clinician, New South Wales, Submission #25)

We request that the ESMHP is more inclusive of consumers, carers and service agencies, in relation to the development of future Strategic Plans.

(Eastern Area Interagency NSW, New South Wales, Submission #100)

6.1.9.21 The dismantling and subsequent "imploding" of working services

The Comprehensive Area Service Psychiatrists (CASP) Group expressed concern that the government is dismantling and "imploding" functional services, thus reducing the capacity of the mental health system to deliver treatment and support services to consumers and their carers and families. The CASP Group gave the following as examples:

The dismantling and subsequent "imploding" of Working Services

- *South-Eastern Sydney*
- *St. Vincent's / King's Cross: loss of virtually all psychiatrists, registrars, resident medical officer*
- *St. Georges: loss of psychiatrists*
- *Illawarra: closing mobile crisis services after 9 – 5, M-F*
- *Northern Sydney – Amalgamation, merging and contracting of RNS and Ryde award-winning nationally renowned services. - loss of community staff*
- *Central Sydney, Northern Sydney, Central Coast, Far West etc: Retreat from community sites to hospital sites for community mental health services*
- *Cumberland Hospital and Community Services - staff shortages – working to clinical standards*
- *Nepean Hospital and Community MHS - demoralised and administratively harassed staff*

(Comprehensive Area Service Psychiatrists (CASP) Group, New South Wales, Submission #350)

A good example of services being driven by administrative efficiencies not by consumer focus is the centralisation of services in the Northern Sydney Area of Mental Health including reduction in community based mental health services. Whilst a huge area of Central Coast is added to the Northern Sydney Area of Health including Mental Health this Area becomes the biggest in NSW with a population well over 1 million. At the same time Lower North Shore and Ryde Sectors of Mental Health are amalgamated. It is said that these are only administrative moves. Not so, they bring more hierarchy to the structure, making it more top heavy and more funds has to be directed from the coal face to administration. There is no way that this would not have an effect on the service delivery.

(Clinician, New South Wales, Submission #25)

6.1.9.22 Lack of support for research

Two submissions expressed the view that more funding needs to be allocated to research to improve the mental health of the community. According tho Standard 9.31, 'The MHS conducts or participates in appropriate research activities' and Standard 9.30 states 'The MHS routinely monitors health outcomes for individual consumers using a combination of accepted quantitative and qualitative methods'.

…lip service is paid to supporting research in the public health system, This is a real problem too. For example, we don't have proper space for our own research – we have to inspire graduates somewhere! We are given little recognition for the research that we do and it seems to be viewed by some as detracting from the real, i.e. clinical, work.

(Anonymous, New South Wales, Submission #303)

…the Association recommends that: …Further Australian specific research be funded into the epidemiology and aetiology of dual diagnosis with specific focus on young people, and including the issues for culturally and linguistically diverse (CALD) background, same sex attracted and Indigenous *Australian populations..*

(NSW Association for Adolescent Health, New South Wales, Submission #98)

6.1.9.23 Problems with accountability

The Comprehensive Area Service Psychiatrists (CASP) Group expressed concerns with the culture of cover-up in the NSW mental health system and that existing monitoring systems were being misused. Concerns were also expressed by Eastern Area Interagency NSW and NCOSS:

Culture of Cover-Up in NSW Mental Health Services

- *Clinical Leaders are necessary focused on providing the best possible quality of clinical services.*
- *There is pressure from Area Administrations to cover-up shortfalls in clinical services, which come as result of diversion of resources to area administrative positions.*
- *Administrative Managers have been increased and highly committed clinical leaders have/are being extruded from the mental health service system. Administrative managers are under pressure to sanitise or downplay the deficiencies in local mental health services.*
- *Clinical leaders are either ignored or bullied and disciplined for speaking up internally within their Area Health Service about the adverse impact of area management's decisions on clinical services.*

(Comprehensive Area Service Psychiatrists (CASP) Group, New South Wales, Submission #350)

We, local service agencies, have encountered, over a significant period of time, a culture of defensiveness; aggression; lack of communication; personal retribution; refusal to answer reasonable questions; refusal to work with us; and totally inadequate complaints procedures from our local mental health service.

(Eastern Area Interagency NSW, New South Wales, Submission #100)

Abuse and Misuse of Existing Monitoring Systems

- *Misuse and abuse of the Australian Health Care Standards Accreditation process and of the National Mental Health Standards, and annual National Mental Health Reports, allowing the dismantling of local 24 hour mobile community mental health services, and the reclassification and reporting of increasingly sedentary "psychiatric out-patients" as "community mental health care"*

(Comprehensive Area Service Psychiatrists (CASP) Group, New South Wales, Submission #350)

There are many concerns that many of the National Standards for Mental Health Services are not being implemented by the ESMHP, as indicated by actual outcomes for consumers, carers and relevant services within the community. We are deeply concerned that there appears to be a culture of non-reporting to the community about the progress of National Standards implementation; and the results of any independent evaluations of the ESMHP's performance against the National Standards (eg EQUIP Survey).

(Eastern Area Interagency NSW, New South Wales, Submission #100)

NCOSS receives regular reports that money ear marked as mental health funds has been spend on other areas. In some cases this is a transfer of funds, in others it occurs through disparity in the overheads charged to mental health and other Area Health Service activities. These overheads range from 25% - 45%.

(NCOSS, New South Wales, Submission #47)

Finally now, in 2001, 2002, and 2004 more deaths and abuse of patients by administrative psychiatry has been exposed in a Parliamentary inquiry. The reckless behaviour of management in reducing mental services to a hazardous level is in my eyes tantamount to the tortuous notion of 'negligence by omission to act'.

(Clinician, New South Wales, Submission #26)

These episodes are arguably the result of the Richmond Report delivered in NSW being run to its terminal point and beyond, accompanied by blind acceptance by empire building administrators and ignorant politicians with the able assistance of some psychiatrists. I realised that major bed shortage has been the widespread result in western countries of the application of economic rationalism. However NSW had more than a simple shortage by 2001 and continuing into 2004.

(Clinician, New South Wales, Submission #26)

We request access to the current Strategic Plan for ESMHP, including information regarding the budget and expenditures for the last two years.

(Eastern Area Interagency NSW, New South Wales, Submission #100)

6.1.9.24 Fear of repercussions for 'speaking out' on mental health issues

Concern was expressed that if service providers "speak out about mental health issues" then their clients will be denied acute care services. :

> *There is a strong perception that if local Services speak out about mental health issues, they are being denied acute care service for their clients. Agency staff are often not trained mental health workers, but feel that they are left to manage acute care because the ESMHP does not take responsibility for providing a timely service when it is needed.*
>
> (Eastern Area Interagency NSW, New South Wales, Submission #100)

6.1.10 STANDARD 10: DOCUMENTATION

Clinical activities and service development activities are documented to assist in the delivery of care and in the management of services.

> *Neither should a patient or close person have to take out an FOI [Freedom of Information] to get information regarding treatment as we have suggested such things should be available to the patient at MHRT [Mental Health Review Tribunal] hearings and so on.*
>
> (Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

Under this Standard, submissions and presentations indicate concerns that:

- often clinical documentation fails to provide a comprehensive, factual and sequential record of treatment and support.

The above concern also indicates that individual care plans are not being developed with or being made available to the consumer according to Standard 11.4.8 ('there is a current care plan for each consumer, which is constructed and regularly reviewed with the consumer and, with the consumer's informed consent, their carers and is available to them').

6.1.10.1 Documentation is not comprehensive

Standard 10.5 states: 'Documentation is a comprehensive, factual and sequential record of the consumer's condition and the treatment and support offered' and Standard 10.6 states 'each consumer has an individual care plan within their individual clinical record which documents the consumer's relevant history, assessment, investigations, diagnosis, treatment and support services required, other service providers, progress, follow-up details and outcomes'. Concerns however were expressed that documentation was not comprehensive and treatment plans were often not acted upon as the plans were not recorded in the treatment notes.

> *Treatments discussed were not acted because proper treatment notes were not recorded.*
>
> (Carers, Parents, New South Wales, Submission #106)

> *He made notes of the first meeting but not the second as he said he did not have enough time to do so. Statement made by treating doctor of events during inpatient care at Mandala Psychiatric Unit after admission of [X] after two suicide attempts and prior to discharge (and suicide 10 hours after discharge.*
>
> (The Coroner's Report in Carers, Parents, New South Wales, Submission #137)

During December 2001 and January 2002, we had a number of discussions and conferences with the MHU Psychiatric Registrars and with Dr [Y], Director MHU. Our experience with these people was that no follow-up occurred with some issues that we raised, treatments recommended by them were not carried out because they did not appear in the treatment notes, and official complaints were ignored.

(Carers, Parents, New South Wales, Submission #106)

On 8 January 2002 at the case meeting, my wife suggested to Psychiatric Registrar Dr [Y] that it might be a good opportunity to get a catheter into my daughter for a urine sample while she is under anaesthetic on 9 January 2002 for an ECT. Dr [Y] agreed that this would be done. On 9 January 2002, no attempt was made for the urine sample because nothing had been written in the treatment notes for the theatre staff.

(Carers, Parents, New South Wales, Submission #106)

One anonymous submission indicated that lack of staff and resources is contributing to the inability of staff to keep up with the administrative tasks that are ever-increasing.

The administrative burden is ever increasing. I have worked for 30 years in the public system and there has been a steady creep of administrative duties but now it's out of control and on top of that there are fewer administrative staff to assist us.

(Anonymous, New South Wales, Submission #303)

6.1.11 STANDARD 11: DELIVERY OF CARE

Principles guiding the delivery of care: The care, treatment and support delivered by the mental health service is guided by: choice; social, cultural and developmental context; continuous and coordinated care; comprehensive care; individual care; least restriction.

In mental health we are completely discriminated against. Other health areas get different, better treatment responses.

(Carer, New South Wales, Parramatta Forum #1)

Under this Standard outlining the principles underlying the provision of care, submissions and presentations indicate concerns about:

- lack of choice;
- lack of comprehensive care;
- lack of individual care; and
- restriction of rights.

Living on the street, suicide or being shot by the police are the options available to people with mental illness. Care isn't an option most of the time.

(Carer, New South Wales, Sydney Forum #5)

I came along today because my wife might end up a mental case herself because of her daughter. There's nowhere for someone who is mentally sick to go, there's nowhere for her daughter to get care. The police are nice and try to be helpful but they are not the health service.

(Carer, New South Wales, Sydney Forum #6)

I've just stopped going because of the poor standard of care in the system. It was making me even sicker to go there. So I've decided I don't need it. I need to surround myself with people who are better than me so I can get better also.

(Former Consumer of mental health services, New South Wales, Sydney Forum #12)

Many activities seem to be offered on a group only basis, and don't make provision for individual needs. Do activities such as computer recreation offer opportunities at the skill and interest level of the consumers?
(Eastern Area Interagency NSW, New South Wales, Submission #100)

6.1.11.1 Access

The MHS is accessible to the defined community.

Under this Standard, submissions and presentations indicate concerns about:

- the lack of access to services during a crisis;
- lack of access to care;
- police acting as the de facto mental health service;
- difficulties in accessing care in rural and regional areas;
- general difficulties in accessing care if 'new to the system' or from an Indigenous, NESB or low socio-economic background;
- accessing services 'out of area';
- inequality of access on the basis of older age;
- inequality of access on the basis of past forensic status;
- problems for consumers from a non-English speaking background; and
- denied access for people with Borderline Personality Disorder.

I have a daughter with schizo-affective disorder – as her Mother the stress of her illness and the difficulties we have experienced in trying to access care for her has driven me to a suicide attempt. It wasn't until after I went to the newspapers and politicians that my daughter was finally admitted.
(Carer, New South Wales, Sydney Forum #2)

Problems with access to treatment and support services, both within the community and inpatient care settings, resulted in a whole series of rights being infringed for consumers, carers and the community. For the consumer, these problems ranged from increasing disability and hence consequent inability to care for oneself or others, participate socially or work or study, and in some cases, the potential for harm to self or others, incarceration, or becoming homeless and poor.

There is a lack of resources to ensure good quality mental health care in NSW. Our son was unable to access early intervention and rehabilitation. Instead his condition was left to deteriorate, resulting in gross violations of his human rights on his imprisonment at Long Bay Hospital. His future prognosis has been compromised by the years of neglect by the system and his level of disability is worse that it would have been, had he received the treatment he required.
(Carers, Parents, New South Wales, Submission #75)

Similarly, increased burdens on carers disrupted their ability to participate socially and work when their family member became increasingly ill and required increasing care. The inability to access care for their family member resulted in deteriorating mental health for carers as evidenced by the suicide attempt of one carer. Increasing disability also exposed the consumer, and their family, to discrimination and social exclusion. This often resulted in the further deterioration of the consumers' mental illness. For consumers in rural and smaller regional areas, their ability to access care often required long trips to metropolitan or large regional centres and social dislocation if hospitalisation was required.

6.1.11.1.1 Inability to access services during a crisis

One of our families today is severely traumatised because their daughter died. She committed suicide after being refused care.

(Carer, New South Wales, Parramatta Forum #1)

A constant theme throughout many submissions was not only an inability to access services when needed throughout the course of illness, but that access was also difficult when consumers were at risk of self harm or harm to others. According to this information it would appear that Standards 11.1.4 'the MHS is available on a 24 hours basis, 7 days per week' and 11.1.2 'the community to be served is defined, its needs regularly identified and services are planned and delivered to meet those needs' are not being met:

There's no crisis team in the area… There is differential access depending on which area you live in. For example, Fairfield, Camperdown and Bowral have no crisis assessment teams.

(Carer, Mother, New South Wales, Parramatta Forum #1)

Some people are transported around in paddy wagons for days because there's nowhere for the police to take them.

(Consumer, New South Wales, Parramatta Forum #5)

As to crisis services – what crisis services – consumers are usually told to have a cuppa and go to bed. The services close at 10pm and consumers simply cannot revolve their crisis around mental health service timeframes, which we are continually expected to do. I've even had staff tell me the consumer can go to Life Line if they're in crisis, who happen to be volunteers are not clinicians and cannot make mental health assessments. If Life Line counsellors refer consumers back to the MHS the consumer within a couple of hours are back onto the phone with Life Line – because at least a Life Line counsellor will try and listen to what is actually happening to the consumer.

(Consumer and Consumer Advocate, New South Wales, Submission #8)

We're dumped, virtually told in every which way, unless it's absolute life & death then don't bother contacting us in a crisis. The crisis teams are under huge stress to try and meet the demands, especially with the MOU between Police & Health.

(Consumer and Consumer Advocate, New South Wales, Submission #8)

6 weeks ago I was taken to the mental health service by my parole officer. I needed help. They said they'd get in contact with me but they didn't. I took an overdose 2 weeks after that. They told me I'd have a case worker – but I haven't got one. I'm not getting the care I need.

(Consumer, New South Wales, Broken Hill Forum #3)

I took someone who was suicidal up to the mental health service and they didn't do anything – there didn't appear to be any protocols in place. Where are we supposed to take someone when they need care?

(Carer, New South Wales, Broken Hill Forum #11)

For years I tried to have him assessed or committed. The police tried on several occasions only to find the mental health unit would say he was OK after an hour and release him. I pleaded to the mental health unit to take him and was turned away. He was very violent and suicidal. As a parent it is so sad to see your children in so much pain and not to be able to help. The police told me they had no faith in the mental health units and I understand why.

(Carer, Mother, New South Wales, Submission #90)

[X] stated there is difficulty in getting after hours care from the mental health team due to lack of staff. On weekdays there is 1 person servicing the Newcastle area from 5:00pm to 8:30am. On weekends, there is 1 person working an 8:00am to 4:00pm shift, which overlaps with another person working a 2:00pm to 10:00pm shift (approximate times). There is no longer a 24 hour system.

(Anonymous, New South Wales, Submission #156)

There is a real shortage of beds and this results in a crisis occurring every weekend with respect to beds and community based care. Last weekend when I was on call there were no beds available. It was a fairly typical Saturday where we saw a range of patients who were quite disturbed with comorbid mental health and drug and alcohol issues – they are either a danger to themselves or to others.

(Anonymous, New South Wales, Submission #303)

We also have complaints regarding severe trauma being caused to family of patients who have been unable to prevent abuse by the system, and whose requests for community assistance for the patient, especially for shelter and counselling were all rejected up to and including the time at which the patient was forcibly scheduled against the family wishes, with the family being made complicit in abusive treatment that they actually had objected to.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

Our members have also noticed that juvenile mental health is also becoming a big problem and is in need of major attention, particularly in country areas. In many cases, juveniles whom police have attempted to schedule have been flat out refused on the basis that no accommodation was available for the person which in turn places strain on the families etc…

(Police Association of New South Wales, New South Wales, Submission #59)

I sought help from Mona Vale Hospital Psychiatric Officer, but was told unless [X] actually committed violence they could do nothing…

(Carer, Sister, New South Wales, Submission #104)

I have been informed that a male person committed suicide on Thursday night. The person… was an outpatient of Bunya, a Parramatta forensic facility. He was living in the community under conditional release. As I understand it he presented himself at Bunya for readmittance as he was "relapsing" (episodic symptoms). However, sadly, Bunya had no beds. He was taken home by the Sydney Mental Health Community Support Team and left there alone being told that they would be back in a few hours. While he was alone he killed himself by taking poison. Tragic that he must have wanted "pain relief" so badly that he chose suicide as the way of terminating his pain and life.

(Anonymous, Victoria, Submission #272)

At the beginning of July, 2004, he admitted to his wife, [Y], that he was not well and said that he wanted to be readmitted to the Lindsay Madew Ward at Hornsby Hospital. He phoned the hospital and they sent two people to his home. His request to them for admission to hospital was refused, and they said they would monitor him at his home. They immediately increased his medication to 800 mg. daily, indicating that the 400 mg. dose was far too low. On their second visit, he again asked to be readmitted to hospital, but again was refused… From memory, the home visits by Hornsby Hospital staff were made on Friday 2nd, and Saturday 3rd of July, 2004. They phoned him on Sunday 4th and again on Monday, 5th. On that Monday and also on Tuesday 6th, he went to his workplace in the city. On his way home on Tuesday evening, he fell / jumped from a suburban train. He was admitted to St. Vincent's Hospital, and died the next morning, Wednesday, 7th, without regaining consciousness. In effect, within days of Hornsby Hospital's refusal of his request for admittance to hospital, and the doubling of his medication, [X] was dead. As laymen, we cannot help feeling that he would be alive today –

- *had he been readmitted as requested, to the secure psychiatric ward at Hornsby Hospital.*
- *had his condition been monitored regularly after his first episode, which we are now told is normal procedure.*
- *had his daily medication of Epilim not been reduced from 1000 mg. to 400 mg. when at the Sydney Adventist Hospital in 2002.*

We feel the system failed us – and [our son]…

(Family Member, Father, New South Wales, Submission #346)

6.1.11.1.2 Lack of access to care – resulting in entry into the criminal justice system

As mentioned previously, failure to access services when needed in some instances resulted in consumers entering the criminal justice system purely because of their escalating and untreated mental illness. In extreme cases, criminal acts, including serious assault and homicide, were committed. The Police Association New South Wales expressed concern that often, as a result of their inability to assist consumers to access care; they feel they are left with no other choice than to 'proceed by charge':

When these individuals are refused to be scheduled on the basis of being affected by drugs or alcohol or if they are deemed to have behavioural disorders, they are being let down by the health system..Police then have only one avenue available to them in their duty of care, and that is to proceed by charge when inappropriate… In order to provide protection to the mentally ill person and the community, for example to stop further criminal acts, breaches of the peace and self-harming, police feel they have no alternative but to go around the mental health system who are currently not doing their job.

(Police Association of New South Wales, New South Wales, Submission #59)

At another service it was reported to me that a client, who had a long standing serious mental illness and a long history of spending his time between SAAP [Supported Accommodation and Assistance Program] services and correctional facilities, was approached by a welfare case worker to commence planning his discharge from the SAAP service… The case worker was assaulted. When the police transported the client to the local mental health service, he was assessed and deemed not mentally ill enough for admission. He was released back to the care of the SAAP service. Within two hours, he had assaulted another welfare worker and was again transported by police to another psychiatric facility. He was not admitted as he was deemed not mentally ill enough and was considered "out of area". He was returned to the SAAP service. Within the hour, he had walked to the local police station and assaulted the officer who had been transporting him to the psychiatric facilities. He was charged with assault and held in custody. It is of major concern to HomelessnessNSW.ACT that mental health services are failing to provide proper mental health care to people with some of the most complex health issues.

(HomelessnessNSW.ACT, New South Wales, Submission #27)

6.1.11.1.3 Police acting as the de facto mental health service

There's nowhere for someone who is mentally sick to go… there's nowhere… to get care. The police are nice and try to be helpful but they are not the health service.

(Carer, New South Wales, Sydney Forum #6)

Due to the inability of consumers and carers to access mental health services during times of crisis, police are called as a last resort as they are available 24 hours a day 7 days a week. The Police Association of New South Wales stated that they have 'neither the resources nor the knowledge' to fulfil this role. As stated above Standard 11.1.4 states: 'The MHS is available on a 24 hour basis, 7 days per week'. Included in the notes to this Standard are crisis teams, extended hours teams and 'cooperative arrangements with other appropriately skilled service providers and community agencies including General Practitioners, private psychiatrists, general hospitals'.

The police are already, if reluctantly, in the front line of caring for people with severe mental illness.

(Police Association of New South Wales, New South Wales, Submission #59)

The fact remains that police, being the 24 hour, 7 day a week, mobile and free public service that they are, usually means that the residual problems of the community are left for them to handle when they have neither the resources nor the knowledge to adequately do so.

(Police Association of New South Wales, New South Wales, Submission #59)

Police, by virtue of their position, become the only emergency response agency to which the public can turn in times of crisis, whatever that crisis might be. The police are turned to for help – it is the only agency available 24 hours a day and the only service that can be relied upon to turn u within minutes of being called.

(Police Association of New South Wales, New South Wales, Submission #59)

Concerns that upon calling the MHS for emergency assistance, people are often simply told to just call the police. We believe this is a totally unsatisfactory approach to mental health emergencies, and is in breach of the MOU. There is concern that Police, by default, are being used as quasi-mental health workers. (We know how they feel!)

(Eastern Area Interagency NSW, New South Wales, Submission #100)

For in the end, it is the police who are called on to handle mental health system "rejects", the people often cited as "bad patients" or poor treatment cases with little perceived chance of recover. You will invariably find that these are frequently people with multiple hospital admissions and court appearances. Police see that as adding to their workload – as unnecessary burdens which should be sorted out elsewhere.

(Police Association of New South Wales, New South Wales, Submission #59)

A contradiction arises, however, because the police feel that their job is to step in only when action is deemed necessary, usually when someone is in danger or breaking the law. Police do not feel, and rightly so, that it is their role to provide psychotherapy, counselling or aid and comfort for the lonely and confused. This is the job of mental health professionals, a group whom police see to some extent, as abdicating their responsibilities. Police see the responsibilities thrust upon them as they are – they are being asked to shoulder duties no one else wants or can manage.

(Police Association of New South Wales, New South Wales, Submission #59)

With the mental health system the way it is, police are being thrust with responsibility in an area which is time consuming and which they argue, is not a proper police function, except in a first response situation. But when limited or no assistance is obtainable from other agencies, police have little choice but to continue to carry the burden of a lack of effective government policy and lack of funding in mental health services.

(Police Association of New South Wales, New South Wales, Submission #59)

6.1.11.1.4 Difficulties in accessing care in rural and regional areas

The vast geographical areas in regional and rural areas of NSW poses serious challenges to the planning and delivery of services to meet Standards 11.1.3 ('mental health services are provided in a convenient and local manner and linked to the consumer's nominated primary care provider') and 11.1.5 ('the MHS ensures effective and equitable access to services for each person in the defined community'). For people living in many areas of NSW, there are very few services that were considered to be convenient and local (Standard 11.1.3). For many people, access to care involved travelling long distances by car, creating significant difficulties for those who are not so readily mobile or have their own transport, sedation and transportation with the Royal Flying Doctor Service or escorted by the police. Concerns were also expressed with treatment and support mediated by a telephone triage service:

There is a general lack of responsiveness from the mental health services and there is a real need in Broken Hill for face-to-face counselling for those people in the country.

(Consumer, New South Wales, Broken Hill Forum #7)

There is a real need in Broken Hill for after hours care as there is not even a 1800 number that people can call to get assistance.

(Consumer, New South Wales, Broken Hill Forum #7)

The level of telephone care in Broken Hill is not good enough and often people are told by mental health services that they will get back in touch with them but the service is not responsive in a time of crisis. An example might be that you call the service on a Friday night but you would get no follow up call and so it is left up to the client to take responsibility to do the following up. This is not easy when people are ill and in crisis.

(Consumer, New South Wales, Broken Hill Forum #7)

I strongly feel a need for after-hours care – not a 1800 number where you just got a few regular questions – but real help. For example, I rang on a Friday night and had a really poor response weeks later. People need face-to-face counselling.

(Consumer, New South Wales, Broken Hill Forum #7)

There have been times when a family member is ill and we're told that there is a bed but it's in a hospital well outside our community. For example, we have been told that we could send our family member to them to a hospital in Orange. The other alternative put to us was that we could take them home and accept the clinical responsibility for them while they are heavily sedated!

(Carer, New South Wales, Parramatta Forum #6)

Transportation in regional areas is a real problem as many seriously ill patients have to go to Orange with the Royal Flying Doctors Service but then they have to make their own way home. Some people in Bourke have even been sent from Bourke to Orange in police cars.

(NGO Worker, New South Wales, Broken Hill Forum #26)

Many of our clients use drugs and alcohol as a means of self medication to cope with their unresolved mental health issues. The Court sends them to local rehabilitation services that are in remote locations where it is difficult to gain access to mental health workers. When they return home the same issues exist and the cycle begins again.

(Walgett SAAP Services, New South Wales, Submission #63)

The Far West Area Health Service (Upper Western Sector) Mental Health and Counselling team is based in Lightning Ridge which is approximately 45 minutes away. The professionals in this team are extremely obliging but naturally they each have local case loads. When an emergency arrives at Walgett SAAP Services, it is often quite some time before the client can be assessed by a professional.

(Walgett SAAP Services, New South Wales, Submission #63)

The need is both dire and urgent, particularly on the South Coast of New South Wales. For persons with a mental illness the main issues are Hospitalisation, rehabilitation places for persons leaving psychiatric hospital, not enough case workers. The closest hospital for acute treatment is at Chisholm Ross Hospital in Goulburn, a four to five hour trip from parts of the South Coast. Beds there are like hens teeth, accepting only the most acute cases; so with a degree of improvement, patients are discharged back into the community… Community resources are stretched to the max. when a patient is required to be transported to Goulburn. This is costly in both money and workers time: such as police, local emergency hospital staff and community mental health workers. The South Coast is in desperate need. Money injected for projects now would both save lives, and save money in the long run.

(South Coast Mental Health Community Consultative Committee, New South Wales, Submission #244).

I would say that the level of expertise in relation to [X]'s problems is limited in the Albury / Wodonga area or really non-existent. To actually see a psychiatrist in this area you would have to wait up to 2 to 3 months.

(Carer, Father, New South Wales, Submission #102)

The facilities are to say the least poor. Because Nolan House is a short term facility it was never an option for [X] to stay. The only option was for [X] to go to Sydney or Melbourne for treatment. They are just inadequate to deal with local problems, when you go to Melbourne, most of the children are form the country.

(Carer, Father, New South Wales, Submission #102)

6.1.11.1.5 General difficulties in accessing care if 'new to the system' or from an Indigenous, NESB or low socio-economic background

Concern was also expressed in one submission that consumers new to the system find access to services even more difficult than those known to the service. Concern was expressed in another submission that 'good mental health treatment' is only accessed by hard lobbying by families and carers or people who could navigate or knew how to work the system. It was suggested that this could disadvantage Indigenous people, people from a non-English speaking background or people from low socio-economic backgrounds making access inequitable:

But for 'first timers' or those new to the system it is very difficult to get help.

(Anonymous, New South Wales, Submission #156)

We have discovered that often the only way to access good mental health treatment in NSW is by constant hard lobbying by family or carers. The consequence of this is that adequate mental health care is frequently out of the reach of people from aboriginal and ethnic backgrounds, and those from lower socioeconomic areas.

(Carers, Parents, New South Wales, Submission #75)

6.1.11.1.6 Accessing services 'out of area'

One carer expressed concern that hospitals were not assisting consumers who were attempting to voluntarily admit themselves (Standard 11.4.E.3 'where admission to an involuntary facility is required, the MHS makes every attempt to promote voluntary admission for the consumer') by granting access and making subsequent arrangements:

We encouraged him to admit himself voluntarily into Waratah House, the mental health unit attached to Campbelltown Hospital. (Incidentally, he had tried to admit himself into Cumberland Hospital on a couple of occasions and was not allowed due to the fact that he would be "out of area.")

(Carer, Mother, New South Wales, Submission #12)

6.1.11.1.7 Inequality of access on the basis of older age

Standard 11.1.1 states: 'The MHS ensures equality in the delivery of treatment and support regardless of consumer's age …'. However, one extensive submission detailed concerns that older people had difficulty in accessing appropriate services.

> *Nursing home patients are discriminated against. This is a policy problem. Psychiatric services don't always provide the same treatment access to older people living in residential care as they do for older people living in the community.*
>
> (Anonymous, New South Wales, Submission #303)

> *For many older people with dementia and mental health problems there is nowhere for them to go except to the geriatric wards. We wouldn't accept physicians looking after 40 or 50 year olds with mental health problems so why should we accept this for older people.*
>
> (Anonymous, New South Wales, Submission #303)

> *It is harder for older people to gain admission to a system which is responsive to danger and acute suicidality. If you are an older person at home quietly depressed and not eating and just fading away it's much harder to get an urgent admission.*
>
> (Anonymous, New South Wales, Submission #303)

6.1.11.1.8 Inequality of access on the basis of past forensic status

According to Standard 11.1.1 discrimination by the MHS against consumers on the basis of past forensic or current "offender" status is not to occur and such consumers are not to be diverted to other services. Instead, the Standard states that: 'The MHS ensures equality in the delivery of treatment and support regardless of… past forensic status...'. However, there is a perception that some consumers are being discriminated against:

> *Generally, offenders with mental health problems are regarded as the responsibility of Corrections and Justice Health. However, as noted above, the majority of offenders are in the community where they compete with more compliant, law abiding citizens for scarce community health resources. An offender who is unable to access mental health and associated services such as accommodation, within the community is likely to be incarcerated either as a result of further offending and/or as a result of failure to comply with current conditions of a court order or a parole order.*
>
> (Community Offender Services, Probation and Parole Service, Department of Corrective Services, New South Wales, Submission #317)

6.1.11.1.9 Problems for consumers from a non-English speaking background

Concerns were also expressed regarding access difficulties for consumers from a non-English speaking background. Standard 11.1.1 states: 'The MHS ensures equality in the delivery of treatment and support regardless of consumer's … culture…'

> *I have 60 clients and 80% of these people have a mental illness. Unfortunately most of them don't get the care they need.*
>
> (NESB Consumer Advocate, New South Wales, Parramatta Forum #8)

> *A lot of people fall between the gaps. We have cases of people who have died at home. Their life is like hell.*
>
> (NESB Welfare Worker, New South Wales, NESB Parramatta Forum #2)

If someone is 65+ it's really difficult to get them any care. We have clients who are diagnosed with dementia but they don't have dementia but we can't get them in to see a psychogeriatrician. There's a 3-5 year waiting list!

(NESB Welfare Worker, New South Wales, NESB Parramatta Forum #2)

6.1.11.1.10 Access denied if consumer has personality disorder

Concern was also expressed that a diagnosis of 'personality disorder' resulted in an inability to access treatment and support services form the MHS. Standard 11.1.1 states: 'The MHS ensures equality in the delivery of treatment and support regardless of consumer's… previous psychiatric diagnosis… or other disability'. Concerns were also raised that access was being limited to those meeting criteria under the Mental Health Act and not, as stated in Standard 11.1.5 'equitable access to services for each person in the defined community'.

We are concerned that on the basis of a diagnosis of Personality Disorder, people are being denied access to case management.

(Eastern Area Interagency NSW, New South Wales, Submission #100)

There are concerns that the Mental Health Act is often used as a convenient excuse to provide no service to a person in need of treatment, simply because they don't meet the criteria for coercive treatment.

(Eastern Area Interagency NSW, New South Wales, Submission #100)

I have had 14 different diagnoses… The different diagnoses have different consequences within the mental health system. Some bring rewards like more services or legitimacy within the system. Some bring shame and guilt and institutional ignorance. The one that has hurt me the most is 'Borderline Personality Disorder'… People, who have been diagnosed as having 'Borderline Personality Disorder', for an example of a more common Axis II diagnosis or 'disorder', are at awful risk of being denied services, and treated with contempt by a system which completely fails them…

(Consumer, New South Wales, Submission #205)

6.1.11.2 Entry

The process of entry to the MHS meets the needs of the defined community and facilitates timely and ongoing assessment.

Under this Standard, submissions and presentations indicate concerns about:

- long waits with entry via emergency departments and the lack of appropriately qualified mental health professionals.

6.1.11.2.1 Long waits with entry via emergency departments and lack of appropriately qualified mental health professionals

Concerns were expressed about entry via hospital emergency departments including problems with the assessment process and consumers having to repeat their stories many times. According to Standard 11.2.4: 'The entry process to the MHS can be undertaken in a variety of ways which are sensitive to the needs of the consumer, their carers and the defined community'. Notes to this Standard state that this process should be non-traumatic and non-damaging. Standard 11.2.6 further states 'An appropriately qualified and experienced mental health professional is available at all times to assist consumers to enter into mental health care'. Concern was expressed that often appropriately qualified mental health professionals are not available:

The trend towards generalisation is such that now consumers have to wait for anything up to 4 days plus in the Emergency Department which is a totally inappropriate environment for consumers in an acute phase of illness, especially if suicidal or aggressive, to be in. There is simply not the space; the noise factor is high, lights continually on, plenty of instruments to harm oneself or another in Emergency Departments. God help you if you actually want to talk to a mental health clinician in an emergency department if it happens to be out of hours of the CNC (Clinical Nurse Consultant) who happens to work business hours and a five day week.

(Consumer and Consumer Advocate, New South Wales, Submission #8)

The event I want to tell you about occurred about three months ago… We encouraged him to admit himself voluntarily into Waratah House, the mental health unit attached to Campbelltown Hospital… On the afternoon in question, I drove him down to Waratah House. We tried to enter the door and it was locked. A nurse came to the door and told us that we could not be admitted there, we had to go through general admission in the emergency section of the hospital. When I remonstrated with him and told him it had been difficult enough to get my son down to admit himself, he called a security guard and they both told us that we had the choice of going away or going to the emergency section – both my son and myself were upset by the incident. We walked down to the emergency section of the hospital – there were quite a few people down there. I asked at the reception area for help for my son… we were told that he would have to be assessed by the triage nurse… she... told him he would have to have a physical examination… At about 11.30pm, my son was shown into a cubicle. He had a short physical by a resident doctor and we were told to wait for the resident psychiatrist. At about quarter past midnight, another doctor arrived. He told us he was not a psychiatrist but had had some experience in the area. He told my son that he was allowed to admit himself as a voluntary patient but as there were no beds in Waratah House, he would have to go to Banks House, (part of Bankstown Hospital). We again waited for about half an hour. Then we were told that because my son was a voluntary patient there was no transport for him and we would have to take him to Banks House ourselves. We had a nightmare trip over there, by this time my son was quite distressed and disturbed. He was finally admitted at about 1.30am or thereabouts.

(Carer, Mother, New South Wales, Submission #12)

6.1.11.3 Assessment and Review

Consumers and their carers receive a comprehensive, timely and accurate assessment and a regular review of progress.

Under this Standard, submissions and presentations indicate concerns about:

- problems with assessments in emergency departments;
- assessment problems in rural and regional areas;
- extended police involvement once at hospital for assessment;
- management of large staff caseloads;
- assessment concerns for people from a non-English speaking background; and
- assessments are not comprehensive and reviews not being conducted.

When you read the literature it makes it sound like everyone gets unproblematic, non-changing, helpful diagnoses of what is wrong with them… This has not been my experience at all. In eight year in the system in Sydney and Brisbane I managed to gather nine different diagnoses…

(Consumer, Male, New South Wales, Submission #327)

6.1.11.3.1 Problems with assessments in emergency departments

Carers and clinicians expressed concern about the increasing trend to conduct assessments only in emergency departments often after lengthy delays (up to eleven hours). According to Standard 11.2.12: 'The MHS has a system which ensures that the initial assessment of an urgent referral is commenced within one hour of initial contact'. Not only were these reported assessments not conducted in a 'comprehensive and timely manner', consumers and carers commented on the inappropriateness of this setting and its negative impact on consumers. Standard 11.3.2 states: 'Wherever possible, the assessment is conducted in a setting chosen by the consumer. The choice of setting is negotiated by the consumer and the MHS and considers the safety of those people involved'. Included in the notes to this Standard: 'The MHS provides a home visit rather than expecting the consumer to attend the community mental health centre, emergency department or psychiatric unit'. Clearly, as seen in the quotes below, this is not always the case.

For example, the authors of the following submission reported that they and their daughter waited four and a half hours for an assessment; on a previous occasion they waited 11 hours in the Accident and Emergency department of a hospital without being admitted:

> *…it implies that perhaps only imminent death is the criterion for Dr [Y] to admit patients to the Liverpool hospital MHU [Mental Health Unit]. This is unacceptable in today's climate where emphasis is on preventing the deaths of young people.*
>
> (Carers, Parents, New South Wales, Submission #106)

> *Every day our members are faced with pressures and accountabilities that are entirely unreasonable given the gross resource deficiencies throughout the system. The chaos that surrounds the assessment of these patients in public hospital emergency departments is the most obvious example, but there are many others.*
>
> (Mental Health Workers Alliance, New South Wales, Submission #325)

> *Now the PET [Psychiatric Emergency Treatment] unit asks you to bring the [unwell] person to the hospital. Previously the mental health nurses would come to the person's home to provide assessment and assistance. If a person is acutely unwell, it can be impossible to convince them to go to hospital. This leaves the police as the only resort, which is embarrassing and inappropriate. When you get to the hospital, there is only a junior doctor [i.e. registrar] on duty, as there is no senior doctor at the hospital anymore.*
>
> (Anonymous, New South Wales, Submission #156)

> *This trend towards Emergency Department assessments is occurring in many places ostensibly on an Occupational Health and Safety basis. But it can also be construed as part of the erosion and retreat of community teams back into hospitals increasingly turning them into out-patient mental health services. I see this happening in both city and rural / remote services. As services become more hospital based, medical matters (bed availability, symptoms and signs) take precedence. Our experience is that as community crisis assessment and other mental health services get put back in hospitals:*
>
> *I. people present at Emergency Departments with more amplified clinical symptoms than life problems as currency to get attended to in a hospital;*
> *II. In Emergency Departments, life crises become confused with psychiatric emergencies. People get unnecessarily and more expensively treated as psychiatric emergencies for acute technical treatment, whereas if they were assessed in the community, life stressors and relationship difficulties fuelling the crisis could be sorted out in a more low-key and practical way;*
> *III. Community mental health teams get diverted to become handmaidens to admission and discharge pressures and hospital doctors' priorities (e.g. clearing out Emergency Department of non-psychiatric social and D&A problems). Of course Emergency Departments will initially love you for this, until the consequent depletion of coherent 24 hour community-based crisis and continuity of care MHS results in ever-increasing demands upon and presentations at Emergency Departments;*

- *teams based in hospitals become more sedentary, and home visits become infrequent;*
- *coherence and funding for distinct community teams evaporate, leaving a few staff to arrange "follow-up" from hospital only.*

(Clinician, New South Wales, Submission #351)

Ultimately, OH&S [Occupational Health and Safety] and economy-of-scale arguments can be extended to banning all community health centres and all home visits. The appropriate path is to make community work as safe as possible, to screen and divert most assessments and initiation of treatment away from Emergency Departments, and then use Emergency Departments in exceptional, highly ambiguous or emergency circumstances only, or to assess mixed medical / psychiatric emergencies.

(Clinician, New South Wales, Submission #351)

6.1.11.3.2 Assessment problems in rural and regional areas

Access to assessment and appropriate assessment procedures in rural and regional areas was an area of common concern. One consumer stated that in Broken Hill there is confusion as to who is responsible for conducting a psychiatric assessment:

Triage is a real problem in Broken Hill as there is constant confusion over who is responsible for assessment. This confusion makes it hard for consumers if they require immediate assistance… I have always presented to the hospital or to the mental health service but there seems to be no clear protocol amongst the staff about how to conduct an assessment when I am unwell. I have never been assessed by a psychiatrist and am normally assessed by the registrar on duty.

(Consumer, New South Wales, Broken Hill Forum #8)

6.1.11.3.3 Extended police involvement once at hospital for assessment

The Police Association of New South Wales also reported lengthy delays occurring before consumers were assessed after arriving at an emergency department or psychiatric unit. These delays unnecessarily tie up considerable police resources while they wait for an assessment to be conducted. According to Standard 11.2.12 'The MHS has a system which ensures that the initial assessment of an urgent referral is commenced within one hour of initial contact'.

In regards to the amount of time… this is generally due to the fact that there are not enough accredited persons to perform this role.

(Police Association of New South Wales, New South Wales, Submission #59)

Section 24 Orders – The problem faced by police in relation to this section of the Act, involves the amount of time police are forced to sit around at hospital waiting for relevant staff to make a decision on whether or not to schedule patient… Examples our members have provided, include it being the norm for two officers to sit in a particular western metro hospital for 3 hours whilst waiting on a decision to schedule or not to schedule… In another western metro suburb, this can mean that there are no police cars at all available to do other jobs at certain times of the day.

(Police Association of New South Wales, New South Wales, Submission #59)

Considering the stages in procedure as just described, it's not surprising that the entire process takes anywhere between 2 to 4 hours and even longer in some cases. Recently, two police officers were required to wait at a certain western suburbs hospital for 7 hours before medical clearance could be given so that the person could be scheduled. The time delay unfortunately impacts on the number of police on the streets, the amount of time it takes to police to get to other jobs and their response times, which remains a source of community frustration for those touched by crime.

(Police Association of New South Wales, New South Wales, Submission #59)

Police are frustrated and angered by the misuse of Section 24 of the Act by mental health professionals, who are fully aware of a police officer's duty of care. Duty of care essentially dictates that a police officer must do all within their power to take a person o a place of safety. Mental health professionals abuse the fact that once police bring in a person on a Section 24, they then cannot simply leave due to their duty of care to the individual concerned. Hence whilst the decision is being made on whether or not to schedule a patient, police continue to remain with the patient, their role in effect changing from a policing role to a mental health role. Once the individual is delivered to the hospital by police, they enter into the health system and from this point on, should cease to be the responsibility of the police.

(Police Association of New South Wales, New South Wales, Submission #59)

Another problem that needs addressing, involves the transferring of patients between hospitals. What generally happens, is that at the time they are originally assessed at the first hospital and consequently may be classified as being mentally ill or mentally disordered, by the time they are transferred to another hospital and are again assessed.

(Police Association of New South Wales, New South Wales, Submission #59)

6.1.11.3.4 Management of large staff caseloads

Many submissions acknowledged that the failure to deliver quality treatment and support services was not the fault of individual staff but more related to broader systemic issues such as increasing workloads, management of work and overall lack of resources that restricted the ability of clinician ability to deliver timely and accessible quality care. This indicates a failure to meet the requirements of Standard 11.3.19 which states: 'The MHS has a system for the routine monitoring of staff case loads in terms of number and mix of cases, frequency of contact and outcomes of care':

Another social worker arrived and they burnt out quickly also which reflects the demands on their time. The staff need support – there needs to be a system that can back these people up.

(NGO Service Provider, New South Wales, Broken Hill Forum #13)

6.1.11.3.5 Assessment concerns for people from a non-English speaking background

Even though Standard 11.3.9 states: 'There is opportunity for the assessment to be conducted in the preferred language of the consumer and their carers' and Standard 11.3.10 states 'Staff are aware of, and sensitive to, language and cultural issues which may affect the assessment', there were some who did not perceive this be the case. For example, concern was expressed about the potential misdiagnosis of a person from a non-English speaking background, which could indicate problems with the assessment process:

She has been informed that she has a mental health problem and in my opinion she doesn't. She had been wrongly diagnosed. After the assault she had been arrested three times by police. This is not uncommon – people from NESB backgrounds are often misdiagnosed.

(Legal Counsellor and Multicultural Mental Health Service worker, New South Wales, NESB Parramatta Forum #5)

6.1.11.3.6 Assessment process is not comprehensive and reviews not being conducted

Concern was expressed that during the assessment process, sufficient information was not being considered for the assessment to be called 'comprehensive' and appropriate conclusions to be drawn with regard to diagnosis, risk or review of progress. Standard 11.3.5 states: 'The assessment process is comprehensive and, with the consumer's informed consent, includes the consumer's carers (including children), other service providers and other people nominated by the consumer'. Included in the notes and examples to Standard 11.3.5 is the following: 'multidisciplinary assessment which includes physical, social and psychological strengths, risks, family and functional components' and 'information is gathered from a number of sources including, with the consumer's informed consent, the General Practitioner':

> *We question the practice of conducting minimal assessments, (those conducted in a few minutes) - it is our view that assessments must be thorough, and that unwell consumers can manage to hold it together during short assessments when it is harder to do so if an assessment is conducted with more time devoted to speaking with the person.*
>
> (Eastern Area Interagency NSW, New South Wales, Submission #100)

> *There is a concern that when an assessment has been conducted, and the Acute Care Team is subsequently informed of a further deterioration in the person's condition, they will not come out to conduct subsequent assessments.*
>
> (Eastern Area Interagency NSW, New South Wales, Submission #100)

6.1.11.4 Treatment and Support

The defined community has access to a range of high quality mental health treatment and support services.

Under this Standard, submissions and presentations indicate concerns about:

- the lack of care, treatment and support being provided by the mental health system;
- individual care plans not discussed with consumers and carers;
- concerns about relocating the provision of community treatment and support services to hospital settings;
- lack of services for youth;
- lack of services for people with dual diagnosis - drug and alcohol;
- lack of mental health services for the aged;
- lack of services for consumers with hearing or both hearing and vision impairment;
- difficulties in accessing treatment and support for consumers from a non-English speaking background (NESB);
- difficulties for community-based offenders with mental health problems;
- problems for consumers subject to the criminal justice system;
- lack of treatment and support for people with mental illness after release from prison;
- lack of services for people with personality disorders;
- lack of treatment and support services for consumers who are homeless;
- limiting access to treatment and support by diagnosis;
- lack of treatment and support services for people with eating disorders;
- lack of treatment and support in rural and remote areas; and
- lack of treatment and support for people with Acquired Brain Injury.

6.1.11.4.1 No care, no treatment and no support being provided by the MHS

Many consumers and carers expressed feelings of despair and frustration at being unable to access any care, treatment or support form the MHS and feeling horrified at some of the responses they had been given when seeking care:

There is a lack of response – the mental health service thought the doctors were looking after me and the hospital thought the mental health service was looking after me – actually nobody was. I just wanted to kill myself.

(Consumer, New South Wales, Broken Hill Forum #3)

The problems encountered in "the system" over the years have been both terrifying and frustrating. The feeling that no one cares, and that this is "your cross to bear".

(Carer, Mother, New South Wales, Submission #97)

Please, if you are aware of any services I could access for my daughter or myself, could you let me know, as I cannot accept the answer I have been given by a number of health care professionals – that if my daughter survives into her twenties, I will have done well !

(Carer, Mother, New South Wales, Submission #92)

I live in fear for my life most days. But, I won't turn him on the streets to be homeless. I am not sure what the answer is, the prison system seems to be were they all end up. There is no help there for them. Actually it is the worse place they can go as they are treated like animals.

(Carer, Mother, New South Wales, Submission #90)

I came along today because my wife might end up a mental case herself because of her daughter. There's nowhere for someone who is mentally sick to go, there's nowhere for her daughter to get care. The police are nice and try to be helpful but they are not the health service.

(Carer, New South Wales, Sydney Forum #6)

I have had Schizophrenia since 1976 … When I was sick in 2000 I called in the acute care response team – they gave me Valium, the next day they again gave me Valium – every time I've gone for care the system has failed me.

(Consumer, New South Wales, Sydney Forum #4)

The incident that occurred recently when the police shot dead that young student who was stabbing someone is a good example of how badly our system is failing people who have a mental illness. The student went to a mental health service to seek care but was turned away and told he was okay. He wasn't okay but he didn't deserve to die.

(Carer, New South Wales, Sydney Forum #5)

Consumers need a whole range of support systems not just 2 weeks or less in an inpatient service to then be dumped back into the community experiencing symptoms.

(Consumer Activist, New South Wales, Submission #257)

…my daughter, [X] who passed away in March 2002 as a result I think, of inadequate mental health care. [X] had a history of depression and Obsessive Compulsive Disorder. For the last 12 months of her life, [X] sought unsuccessfully for help to control her depression and OCD… As [X] became more and more depressed and anxious, she developed an eating disorder and worried about being fat, even though she was only 52 kilos. After attending a local doctor, whom I don't know, she was prescribed Duromine, a weight loss tablet I knew nothing of this. [X] also sought help from an OCD clinic near Newcastle and one in Sydney, but was put on a "waiting list". We are now left with the grief of a child we will never see again. There was nowhere to get help for this terrible nightmare we found ourselves in and we had to watch her waste away before our eyes. On the morning of March 24, [X] was found dead by her 9 and 10 year old daughters as an interaction of these lethal drugs when too many are taken. These little girls are now in my care and I blame the "system" for my daughter's death and the children not having a mother.

(Carer, Mother, New South Wales, Submission #88)

Crisis in Acute Care provision: There is definite crisis in the availability of appropriate care for people experiencing episodes of acute illness. This includes the availability of treatment options in hospital and in the community. The results of this include early and poorly planned discharge; long waiting times in emergency departments; increasing pressure and stress placed on carers; involvement of the police and emergency workers to address mental health issues; increasing use of Community Treatment Orders; imprisonment of mentally disordered offenders.

(Clinician, New South Wales, Submission #197)

6.1.11.4.2 Individual care plans not discussed with consumers and carers

Despite Standard 11.4.9 acknowledging the involvement of consumers and carers ('there is a current individual care plan for each consumer, which is constructed and regularly reviewed with the consumer and, with the consumer's informed consent, their carers and is available to them'), reports were received suggesting that both consumers are carers are repeatedly being excluded from assessment and treatment planning. Given the reported problems with access and limited services available in the community, practices which involve carers to assist with the delivery of care and achieve the best possible outcomes for consumers would both help recovery and protect many of the rights of people with mental illness.

For the 35 days that our daughter was in the MHU, we often experienced poor internal communication in the ward. We were given incorrect information about our daughter's medications and levels; the Psychiatric Registrars, Doctors [Y] and [Z], were reluctant to contribute to our twice-weekly case meetings, and items that were to be noted for our daughter's treatments were not actioned.

(Carers, Parents, New South Wales, Submission #106)

Neither should a patient or close person have to take out an FOI to get information regarding treatment as we have suggested such things should be available to the patient at MHRT hearings and so on.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

We have clients who are 16 and 17 year old adolescents who live with their parents. Often the child may not be responsive to the mental health services but as the parents are left out of the treatment circle it makes communication between that family and the service extremely hard.

(Family Support Services Worker, New South Wales, Broken Hill Forum #6)

6.1.11.4.3 Concerns about relocating the provision of community treatment and support services to hospital settings

An underlying theme in many submissions was that treatment and support services were not available for consumers in the community to address their mental illness and assist with recovery, rehabilitation and

integration back into the community. Standards 11.4.3 – 11.4.8 state that the MHS will 'ensure' or 'provide' 'access to a comprehensive range of treatment and support services' which are specialised with regard to age, stage in the recovery process, dual diagnosis, cultural factors, and which address 'the physical, social, cultural, emotional, spiritual, gender and lifestyle aspects of the consumer' (11.4.6). Additionally, Standard 11.4.10 states 'The MHS provides the least restrictive and least intrusive treatment and support possible in the environment and manner most helpful to, and most respectful to, the consumer'. Concerns were also expressed regarding the location of community based services within hospital settings and the preference for these to be located in the community.

> *There is a good reason for us to have a better community focus. Services at the moment are focused internally which is located in the hospital. To the Broken Hill people it may seem like just another hospital service.*
>
> (Clinician, New South Wales, Broken Hill Forum #9)

> *The randomised control evidence clearly favours community and home based mobile extended hours crisis services over hospital based assessment and initiated treatment (see references). We are told by our Director of MHS, NSAHS that all the arguments for having community mental health services on community sites are purely "ideological". Well, no one side of such a debate has a monopoly on ideology. Further, although some of the evidence for local community siting is indirect, there is no evidence-base whatsoever for siting all community mental health services in hospitals. Wherever a difference can be inferred directly or indirectly from the evidence, it is in favour of community-based teams. Though it is important to be cautious and not to overclaim in extrapolating from the literature, this general trend is fairly consistent and not "in contention" as stated by our Area Mental Health Director.*
>
> (Clinician, New South Wales, Submission #351)

> *Just because it is becoming more common to relocate such community-based services in Emergency Departments and elsewhere on acute hospital sites, doesn't imply that this is the most effective deployment at all. This retreat to a "fortress" hospital mentality is ostensibly due to administrative staff OH&S concerns. However it is really due to Health Executives' "land hunger", plus the perceived need to make shortsighted attempts to assuage general hospital clinical pressures, eclipsing the real need for community based services which prioritise the best possible outcomes for service users and their families.*
>
> (Clinician, New South Wales, Submission #351)

6.1.11.4.4 Lack of services for youth

Carers expressed concern at the paucity of services for youth and indicated that services need to be broader in their approach than treatment just for 'mental illness' as other mental health problems and life crises were generally associated with this age group. Standard 11.4.3 ensures access to a 'comprehensive range of treatment and support services which are, wherever possible, specialised in regard to a person's age and stage of development'.

> *For a number of years, I have been trying to access mental health services for my daughter, who is now approaching 17. She suffers an array of mental health issues, including obsessive / compulsive traits, depression, and self-abuse. Unfortunately, it seems that adolescent health support is sadly lacking, and I am unable to find anyone who will take my daughter's difficulties seriously. As a parent, it is absolutely heart-breaking and soul-destroying to watch my child gradually self-destruct. Throughout the last year, her mental state has deteriorated badly and I am no longer able to seek help for her because her age precludes it.*
>
> (Carer, Mother, New South Wales, Submission #92)

> *Department of Ageing, Disability and Home Care can't find somewhere for a young boy to go so he is being held at Bankstown.*
>
> (Carer, New South Wales, Parramatta Forum #1)

The main point I want to make is that is was so difficult for me to get any help for [X] because he was over 17. He realised just before he died he really wanted to turn his life around and we thought he was just about there when he suddenly decided to end his life. Parents need to be heard - young people can't alway help themselves to get the right treatment. Although having said that now (too late for us) but there are web sites / phone lines and help now available."

(Carer, Mother, New South Wales, Submission #122)

My experience is that getting young people with debilitating mental health issues into the NSW Health system's care, namely the child and adolescent mental health services, is very difficult as the child virtually has to be actually self-harming or close to it. Not only is this turning our back on these young people and their families, it is woefully inefficient, with mounting costs in the areas of the following over extended periods of the young person's later life: unemployment benefits, ongoing mental health treatments and their bodily concomitants, problem gambling / alcohol abuse costs to society and treatment program costs, and legal / punitive services costs, costs of marriage breakdown etc.

(Clinician, New South Wales, Submission #5)

A partnership between the Richmond Fellowship of NSW and South Sydney Youth Services resulted in a pilot service that provided support, information and education for young people with a dual diagnosis. The program sought to motivate participants to more readily contemplate and reduce their substance use. Preliminary evaluation findings indicated a high level of engagement of clients, with evidence that young people responded well through practical support (Walker 2002)…

(NSW Association for Adolescent Health, New South Wales, Submission #98)

It is clear that for young people with a dual diagnosis, their families and carers, the key issues are:

- *Timely and appropriate access to treatment that is able to engage young people in addressing both mental health disorders and substance misuse or abuse,*
- *Continuity of care with access to appropriate support and information.*

For young people with a dual diagnosis they are…

- ***Caught in the gap** between child and adult services, neither of which are appropriate,*
- ***Caught in the gap** between mental health and AOD services with differing philosophies, assessment processes and treatment models.*
- ***Caught in the current gap** in research and evidence based models to direct best practice in working with young people with a dual diagnosis. (author's emphasis)*

(NSW Association for Adolescent Health, New South Wales, Submission #98)

…the Association recommends that: …Age and developmentally appropriate services for young people are provided in mental health and AOD (Alcohol and Other Drugs) services.

(NSW Association for Adolescent Health, New South Wales, Submission #98)

6.1.11.4.5 Lack of services for people with dual diagnosis - drug and alcohol

Standard 11.4.7 states: 'The MHS ensures access to a comprehensive range of services which are, wherever possible, specialised in regard to dual diagnosis…' In the notes to this Standard, this includes dual case management with alcohol and other drug services. Concern was expressed that there are an insufficient number of such services to provide treatment and support to these consumers with complex needs:

The major problem is the lack of skilled follow up and supervised accommodation. My son spends time living with me, which always ends in violence, drugs in the house and the availability of more money for drugs, because everything is "laid on" at home for him. Police are involved due to threats (usually towards my husband), and the removal from the home. This makes us feel really guilty and depressed.

(Carer, Mother, New South Wales, Submission #97)

My son [X] committed suicide 2 years ago - he was 26. He was extremely intelligent, creative and a good athlete. His story started when he was 17 and started smoking marijuana and became quite depressed. My husband and I encouraged him to go to the local mental health service - where he saw [Y] and was encouraged by [Y] not to "prostitute" his ideals or lifestyle choices. I also went to see [Y] separately (as did my husband) who more or less said it was none of my business - he's 17… Anyway – [X] started drinking and smoking at the age of 21 (before that he didn't like alcohol) then of course problems began - with psychotic episodes where [X] would become violent (have no recall of what happened and then have deep remorse) and we had to call the police - of course this was no use - it only made the spiral deeper and his self esteem lower.

(Carer, Mother, New South Wales, Submission #122)

To be a consumer with a mental illness and, for example, drug or alcohol abuse problems or a compulsive gambling problem is to find yourself falling between the cracks. Whose responsibility are you? Lack of integrated services means the system is failing consumers with co-morbidity issues.

(NSWCAG, New South Wales, Submission #273)

…conventional MH systems still consistently fail the needs of:

3) *those naughty people who take alcohol or other drugs, or at least who tell the MH staff about it, and*
4) *those who have complex jumbled pictures, esp with two or more of the above. We need a far more integrated MH and D&A treatment / management system, and we need at least double the current budget.*

(Clinician, New South Wales, Submission #128

[There is] confusion about what to so with people with dual diagnosis

(Consumer and Consumer Advocate, New South Wales, Submission #169)

I have watched with grave concern the impact of cannabis abuse on the mental health of many of my clients and heard too many news items with the following scenario: A client with mental health problems becomes actively psychotic and a risk to his family, often smoking cannabis heavily aggravates this psychotic episode. The family, or the client himself, seek admission and treatment for the psychotic client and are refused. The client goes out and kills or seriously injures someone and gets free treatment, detoxification and medication in jail for many years. Generally cannabis abuse has made a significant contribution to the tragic scenario – possibly precipitating schizophrenia or drug induced psychosis in the first place and then aggravating it and hindering recovery in the long term. The murder of a four year old girl recently was a tragic example of this scenario. Doubly tragic as it was so avoidable.

(Clinician, New South Wales, Submission #181)

Recognition of cannabis abuse and dependency as a problem that can be treated needs to be heightened. Most people would be able to find a Quit group for smoking quickly and easily, however there is very limited availability of Quit groups for cannabis and no public health messages as to where to find them. Access to inpatient psychiatric care should be much more readily available to those who need it. Compulsory treatment should be enforced where necessary. (I will not submit in detail on these topics but strongly support increased availability of treatment and realistic and workable conditions for compulsory treatment where necessary).

(Clinician, New South Wales, Submission #181)

Cannabis abuse needs to be carefully assessed and treated. Treatment will help the client come 'out of the fog' and face life issues (like getting a job and communicating with family members). Treatment will also dramatically reduce the risk of progressing to heroin use. Cannabis use may be particularly dangerous for psychiatric and dual diagnosis clients. These clients especially should be clearly advised of the risks they face if they continue to use cannabis and offered good assessment and treatment.

(Clinician, New South Wales, Submission #181)

Cannabis use is associated with greater psychotic symptoms and increased depression. Previous research has found raised levels of psychopathological syndromes and higher relapse and readmission rates among people with schizophrenia who abuse cannabis… Cannabis use, and years of cannabis use, was associated with increased levels of psychotic and non-psychotic symptoms, including depression and paranoid ideation.

(Clinician, New South Wales, Submission #181)

The provision of co-ordinated and comprehensive services for people who experience mental health problems and drug and alcohol problems remains an area of great need. Services continue to be provided by separately funded and managed government agencies with some extremely limited flexible services being run by NGOs. The presentation to mental health services of people experiencing mental health problems and significant drug and alcohol problems has continued to increase significantly since 1993.

(Clinician, New South Wales, Submission #197)

6.1.11.4.6 Lack of mental health services for the aged

Standard 11.4.3 ensures access to a 'comprehensive range of treatment and support services which are, wherever possible, specialised in regard to a person's age and stage of development'. However, concerns were raised with regards to the many difficulties in providing services to this age group. Behaviour problems were cited as a difficulty both in terms of settings where treatment is provided for other patients (e.g. acute care and mix of consumers, aged residential setting) and staff.

Another problem is the lack of dedicated facilities for older people with psychiatric disorders requiring admission. Older people don't mix well with younger people, particularly those younger violent patients who are taking illicit drugs and are psychotic. There are strong arguments for separate for separate facilities.

(Anonymous, New South Wales, Submission #303)

…the problem is that geriatric services are not set up or trained for providing appropriate treatment for people with dementia who display disturbed behaviour (BPSD) or who have co-morbid depression or anxiety or paranoid states. Commonly, dementia first presents with depression or paranoid ideas… The ideal arrangement is a close liaison between geriatric and psychiatric services for older people, so that they can work together for those who have both psychiatric problems (e.g. dementia, depression, paranoid states) and physical problems.

(Clinician, New South Wales, Submission #264)

Another deficiency in our system… is the lack of availability of old age psychiatry teams to be involved in psychiatric and behavioural programmes in aged care facilities.

(Clinician, New South Wales, Submission #264)

There's no policy for behavioural problems in the elderly. The funding formula devised by the Centre for Mental Health in NSW, MHCCP, does not (yet?) provide for dementia. We can only admit patients with dementia into care if they have a fully formed psychosis, but not if they have behavioural problems not accompanied by a psychiatric diagnosis. Further nurses often don't want to admit people with dementia and behavioural problems because they fear the facilities are not suitable for them or they do not have sufficient staff or sufficient male staff.

(Anonymous, New South Wales, Submission #303)

6.1.11.4.7 Lack of services for consumers with hearing or both hearing and vision impairment

Included in Standard 11.4.7 with regard to the delivery of services to people with dual diagnosis are people with 'other disability'. One Disability Community Worker expressed concerns that people with hearing impairment or dual hearing and vision impairment were experiencing difficulty in accessing services and are being discriminated against. Standard 11 (Access), states that: 'The MHS ensures equality in the delivery of treatment and support regardless of… physical or other disability' and Standard 11.1.7 states 'the MHS, wherever possible, is located to promote ease of physical access with special attention being given to those people with physical disabilities…'.

> *I also want to talk about improving access to services for children with a hearing impairment. The resources in Australia, in this State, are extremely poor for hearing impaired children. The children become so isolated and disconnected from their communities. There are so many issues from a community justice point of view. We are desperately trying to train mental health services to become more accessible, responsive and understanding of the needs of people with a hearing impairment. We know many young people with a hearing impairment who are depressed and frightened. I don't have qualifications in psychology – we refer them on but they usually get fobbed off and fobbed off.*
>
> (Disability Community Worker, New South Wales, Parramatta Forum #2)

> *Then if you can imagine how bad it is for people who are both deaf and blind and have a mental illness. Some deaf people get progressively blind and there are absolutely no services for these people. They are so disabled – it has a huge impact on their mental health and nobody knows what to do with them or how to work with them.*
>
> (Disability Community Worker, New South Wales, Parramatta Forum #2)

> *[X] (NSW). [X] uses Auslan and is the only deaf person in her family. She was 24 when she first saw a mental health service provider. When asked to describe her experience, she says, "felt so great. I could get out of my chest which I couldn't express my feelings / experience to my family" (due to limited communication). She experienced counselling in Auslan, with an interpreter and without and interpreter. She says, "if the professional could [be] able [to] do [the counselling] with sign language, then it [would] be excellent!" She felt that having the interpreter (a third person) made it harder for her to express her feelings. She encourages counsellors to: (a) get an interpreter if the deaf person would prefer this; (b) use very clear and plain English when talking or in written communication; (c) to be aware of the different education levels of deaf people "not all the same"; (d) "be patient if deaf people do repeat again". [From: Improving access to mental health services for young deaf Australians - Step by step]*
>
> (Deaf Society of NSW, New South Wales, Submission #291)

6.1.11.4.8 Difficulties in accessing treatment and support for consumers from a non-English speaking background (NESB)

Concerns were expressed that consumers from a NESB are experiencing difficulties in accessing appropriate treatment and support services. Standard 11.4.8 states: 'The MHS ensures access to a comprehensive range of treatment and support services which are, wherever possible, specialised in addressing the particular needs of people of ethnic backgrounds'.

> *People with Post Traumatic Stress Disorder referred to our service don't get care. The waiting lists are long - sometimes up to a year. We need substantially more funding for trauma services.*
>
> (Multicultural Mental Health Worker, New South Wales, NESB Parramatta Forum #9)

> *All we can provide is a referral service but where can we refer them to? There are no services available.*
>
> (NGO Service Provider, New South Wales, NESB Parramatta Forum #10)

It is extremely difficult to get assistance or any type of care for those people who have a dual diagnosis and come from a NESB – there's not a lot of expertise to help these people. People are overmedicated by and large. A guy was having bad side effects from his medication but he was not believed because he had an intellectual disability and was from a NESB.

(NESB Consumer Advocate, New South Wales, NESB Parramatta Forum #7)

6.1.11.4.9 Difficulties for community-based offenders with mental health problems

All offenders supervised by COS are members of the community. While they may form a sub-group within the community, offenders should remain entitled to services from mainstream agencies that are funded to provide services to the community.

(Community Offender Services, Probation and Parole Service, Department of Corrective Services, New South Wales, Submission #317)

Concerns were expressed regarding the difficulties community-based offenders with mental health issues were experiencing in accessing treatment and support services. These services are seen as vital in diverting consumers from incarceration and this group are seen as having 'the most to gain from successful mental health intervention and support services'. Integrated and coordinated service delivery is seen as essential in diverting these consumers from incarceration.

Anecdotally, few offenders with mental health issues are suitable for such diversions from custody due to lack of treatment and other supports necessary for successful completion of such orders.

(Community Offender Services, Probation and Parole Service, Department of Corrective Services, New South Wales, Submission #317)

Community-based offenders should be seen as a priority for mental health treatment providers and support services such as accommodation providers since this group pose the greatest risk to the community, have fewer social supports and have the most to gain from successful mental health intervention and support services.

(Community Offender Services, Probation and Parole Service, Department of Corrective Services, New South Wales, Submission #317)

The custodial environment manages the mental health problems of offenders, with a combination of medical services and offender management interventions. For the continuing mental health of those who are released back into the community, the services of the Community Mental Health sector are essential.

(NSW Department of Corrective Services, New South Wales, Submission #295)

An offender who is unable to access mental health and associated services such as accommodation, within the community is likely to be incarcerated either as a result of further offending and/or as a result of failure to comply with current conditions of a court order or a parole order. COS can only effectively supervise offenders with mental health issues, or divert offenders from custody, if a treatment provider is willing and committed to providing the treatment within a partnership approach.

(Community Offender Services, Probation and Parole Service, Department of Corrective Services, New South Wales, Submission #317)

There is a lack of research on the numbers of community-based offenders with mental health issues, including drug and alcohol disorders. Such epidemiological data is urgently needed if problems relating to mental health, intellectual disability and drug and alcohol disorders are to be addressed.

(Community Offender Services, Probation and Parole Service, Department of Corrective Services, New South Wales, Submission #317)

6.1.11.4.10 Problems for consumers subject to the criminal justice system

Standard 11.4.7 states: 'The MHS ensures access to a comprehensive range of treatment and support services which are, wherever possible, specialised in regard to… consumers who are subject to the criminal justice system'.

Most people will not have full forensic procedures (and we could not recommend general extension of this due to the current system's injustices, apart from the fact that choice should be involved).

(Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

Women's mental health issues are of major significance for service providers in the criminal justice system. There are important differences in the mental health issues of female and male offenders. Female offenders differ from their male counterparts in the prevalence of certain disorders, the age of onset, the presentation and diversity of symptoms, the course and severity of the disorder, responses to interventions and known risk factors. Most women offenders have significant mental health issues and a high rate of co-morbid disorders such as substance abuse and personality disorders, and are poly-drug users.

(NSW Department of Corrective Services, New South Wales, Submission #295)

Important figures (Butler & Milner – 2001 NSW Inmate Health Survey):

- *Women were more likely than men to be currently taking psychiatric medication (24% vs. 1%).*
- *A doctor at had diagnosed 54% of women vs. 39% of men sometime in the past with having a psychiatric problem. Large numbers of women's psychiatric problems consisted of depression, drug dependence, anxiety and personality disorders.*
- *30% of women and 20% of men had made a past suicide attempt and women were more likely to have made multiple suicide attempts.*
- *21% of women vs. 12% of men had deliberately self-harmed or injured themselves at some time in the past.*

(NSW Department of Corrective Services, New South Wales, Submission #295)

About 8 weeks ago my son was arrested and put in prison for 8 weeks for breaking a court order. He had been taking medication for years. While he was there he was not permitted to see a doctor or take his medication. While there he was bashed. He was released on strict conditions that he sees a psych. Again we are having difficulty as he does not work and can not afford a psychiatrist. There have been times when I have been to the hospital and spoken with the mental health teams and they have turned us away.

(Carer, Mother, New South Wales, Submission #90)

It is the experience of correctional centre personnel that a significant offender management challenge is posed by a range of symptoms consistent with mental health disorders. These symptoms can be responsive to medication and interpersonal services, and they can be responsive to more behavioural interventions. In either situation, inmate symptomatic presentations provide a significant challenge to this department and to its allied medical services.

(NSW Department of Corrective Services, New South Wales, Submission #295)

In research conducted in NSW prisons, Butler and Allnutt (2003), found that 78.2% of male inmates and 90.1% of female inmates at reception into gaol had experienced a major psychiatric disorder in the past 12 months. These figures would appear to reflect both the lack of treatment services available in the community and the lack of stable accommodation. It is unclear what percentage of these remand inmates are later not convicted. However, according to data collected by the Department (Thompson 2001), of those offenders held in custody on remand, some 56% are discharged without a custodial sentence.

(Community Offender Services, Probation and Parole Service, Department of Corrective Services, New South Wales, Submission #317)

…if the incarceration of people with mental health disorders is to be reduced, the assessment, treatment and support services for offenders with mental illness/mental health issues (including intellectual disability) are not only required pre sentence and upon transition from gaol to the community, but additionally and predominantly for those who serve their entire sentence in the community.

(Community Offender Services, Probation and Parole Service, Department of Corrective Services, New South Wales, Submission #317)

They are in a highly restricted environment, have no choice in provision of service, have far reduced access to their support network, have even greater problems in accessing any complaint or oversight body and in allowing such bodies to examine information that they request to be examined.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

As you can see a man with a mental problem to end up in jail is <u>not</u> the place for him but somekind [sic] of mental institution where he can receive long term care and not be able to harm himself or others. Also his wife and children under constant fear, how do they cope, all having counselling now, how safe are they? All the mental hospitals tried to help but after some time just sent him home on medication when they were unable to succeed, hoping he would survive. (author's emphasis)

(Carers, Sister and Brother-in-law, New South Wales Submission #108)

People with psychiatric disabilities suffer discrimination in terms of bail, parole, jail security classification (they get isolation and 'protection' which is very dangerous for prisoners), and access to outside contact and visitors and activities / work / education / rehab programs.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

The new lack of Visiting Justices compounds their problems regarding defence to Corrections 'in-jail' charges on disciplinary proceedings, which often are actually brought against someone for symptoms of disability. Simultaneously imputed disability is used in these unexamined disciplinary proceedings to punish prisoners with the medication and isolation that results from that label. Discipline is at the discretion of the Commissioner, and the Ombudsman has no power to ask him to show evidence of an offence.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

The 2003 NSW Corrections Health Service (now Justice Health) Report on Mental Illness Among NSW Prisoners states that the 12 month prevalence of any psychiatric disorder in prison is 74%, compared to 22% in the general community, and while this includes substance disorder the high rate cannot be attributed to that alone. The twelve-month prevalence of psychosis in NSW inmates was thirty times higher than in the Australian community. The most common disorder was an anxiety disorder with the most common anxiety disorder being Post Traumatic (which can be very severe and disabling and indicates the horrors that many prisoners have experienced prior to and in jail). One in twenty prisoners had attempted suicide in the twelve months prior to interview. This study only touches the surface of evaluation and statistics of the nitty-gritty of what's going on - it excluded many people, including those "too unwell" to be interviewed. It also reflects the attitude of the professional, but considering that we regard 'labelling' to be covered by the term 'psychiatric disability' we consider the report of great use. This outrageously disproportionate situation arises from both prison conditions and the discriminatory nature of the criminal justice system.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA), New South Wales, Submission #349)

In relation to the 2002 and 2004 situation, some psychiatrists and other professionals working for both the prison services and the Department of Health have been responsible for the reckless indifference. Many professionals were forced to participate in disgraceful practices against their better judgement. Forensic psychiatrists and some general psychiatrists have played the role of whistle blowers as psychiatrists have in times past… In NSW corrections continue to bulge with psychiatric patients and a survey indicated 60% have a psychiatric diagnosis and 30-40 % have a psychotic illness many going untreated.

(Clinician, New South Wales, Submission #26)

2003 NSW young people in custody health survey: summary of findings [242 young people (223 males, 19 females) representing 76% of all young people in custody]; … 84% (178) reported symptoms consistent with a clinical disorder; … 37% (78) had mild, moderate or severe symptoms consistent with a personality disorder; … 73% (156) reported mild, moderate or severe symptoms consistent with psychosocial problems.

(Anonymous, New South Wales, Submission #64)

The CTOs [Community Treatment Orders] were a great step forward and a boon to the management of chronic schizophrenia when they were included in the Mental Health Act. The extension to six months before review was a needed improvement. BUT, it should be made possible, in the case of a chronic sufferer from schizophrenia who has previously been on CTOs on three or more occasions, for a <u>new</u> CTO to be ordered while the patient remains <u>in the community</u>. Currently, for a new CTO to be ordered, a hospital admission is necessary. It is very difficult to get a schedule for an admission now, partly because of a lack of beds, and partly because of policy that is probably influenced by resources (even when the arguments under the act can be made out -the policy extends the severity of illness required). So the chronic sufferer begins to decompensate and friends and family watch the condition of the sufferer deteriorate over long periods, sometimes to destitution, and the sufferer disappears and cruises around the country, and unless picked up by police for causing an affray and taken to hospital, it can be many months before treatment is resumed and a schedule to hospital happens. It would be far better not to allow this excessive deterioration to occur. In such cases, a CTO from the community would also cost a great deal less. (author's emphasis)

(Family Member, New South Wales Submission #9)

6.1.11.4.11 Lack of treatment and support for people with mental illness after release from prison

The lack of coordinated treatment and support services for people with mental illness post release was previously mentioned under Standard 8.3 with regard to the need for whole-of-government approaches to circumvent poor release outcomes. In particular, advocacy and support while in prison and transition planning are critical areas of concern that could promote and protect the rights of prisoners with mental illness while in prison and immediately post release:

When he is released [from prison] he will once again go unsupervised relying on a pension. Once again as he has no other place to which to return he will stay with our mother. [X]'s condition is not one which permits us to supervise him. He does not accept family interference in his life except for monetary assistance when he gets into financial difficulty, and we fear that within a very short period of time the previous scenario will repeat itself. … That the mentally ill feel they cannot cope and commit suicide or violence in those circumstances is not surprising. When a caring family feel that prison is 'good' and release is feared – it is a testament to how desperate things have become.

(Carer, Sister, New South Wales, Submission #104)

6.1.11.4.12 Lack of services for people with personality disorders

The Department of Corrective Services and the Police Association of New South Wales also raised concerns about the inability to access treatment and support services for people with personality disorder due to definition of "mental illness" under the Mental Health Act (1990). Both argued that this is a serious gap which results in no treatment or support services being available to many people with personality and behaviour disorders who come into contact with the police and in the criminal justice system positive results can be achieved from treatment to people with this disorder.

> *The problem for police is that many of the people they come in contact with who appear to be suffering from a form of mental illness, are being deemed by mental health professionals as not fitting the legislated criteria of a mental health disorder or illness – it is deemed to be behavioural, and as such, whilst these people are being assessed, they are being refused to be scheduled even though it is obvious they are not well… This is a clear example of the difficulties being faced by police. There appears to police, to be a gap in the legislation in regards to behaviour and personality disorders. These people are not criminals but many are continual self-harmers.*
>
> (Police Association of New South Wales, New South Wales, Submission #59)

> *While mental health treatment is sometimes available for those with illnesses that fall under the Mental Health (Criminal Procedure) Act 1990, such a definition excludes those with personality disorders. There is a very high prevalence of severe personality disorders within the offending population and a major gap in service provision is commonly acknowledged for such individuals. Individuals with personality disorders are frequently not recognised as being "mentally ill". Consequently, Probation and Parole Officers are unable to obtain assistance from treatment providers to manage highly disturbed, and erratic "acting out" individuals, who often display self-injurious behaviour.*
>
> (Community Offender Services, Probation and Parole Service, Department of Corrective Services, New South Wales, Submission #317)

> *Many behavioural problems among men and women in custody are consistent with symptoms of personality disorders. Until recently, there have been little evidence-based interventions for these more personality based disorders. But Dialectical Behaviour Therapy has emerged as a treatment choice for women with Borderline Personality Disorder and has shown good results in community based treatment programs.*
>
> (NSW Department of Corrective Services, New South Wales, Submission #295)

> *…but my complaint is that within services you get treated very, very differently depending on the diagnoses you have at the time… Twice I have tried to escape from my psychiatric records by moving to a new city… But I found out that even if I added things to my file (which you are allowed to do) you can't take things out. The language was awful and the information inaccurate… I wanted all references to Borderline Personality Disorder expunged from my life and my file.*
>
> (Consumer, New South Wales, Submission #327)

> *One day I asked [my psychiatrist] whether he had any patients with Borderline. He said he didn't like using that label because it brought such terrible consequences for people but, yes, he did see quite a lot of people who would fit into that category. I asked him what the treatment was and his immediate answer was to say, "the first thing I do is treat them nicely! This is a new experience for most of them".*
>
> (Consumer, New South Wales, Submission #327)

> *People who doctors have decided have a 'personality disorder' are treated in the public system like we are not even human half the time – like dirt. My friend calls us ground feeders – we just pick up scraps of services that everyone else has discarded. How do we stop professionals judging us so badly?*
>
> (Consumer, New South Wales, Submission #205)

*The response of the system to crisis is appalling. It would have been so much more healthy for me if I had been able to say, "if I can't find somewhere safe for a while all hell is going to break loose and I am going to hurt myself" and then have that responded to with respect and dignity as an assertive act of self-help. Instead of being able to say this and have it acted on I always 'knew' (like so many consumers with a 'Borderline' diagnosis 'know') how the system works. We 'know' that the system will **only** roll into gear after the cutting has happened and then in a judgemental way that is supposed to stop you doing it again. It doesn't. (author's emphasis)*

(Consumer, New South Wales, Submission #205)

My experience with this particular label [Borderline Personality Disorder] has left me soured… I did end up admitted twice after I returned to Sydney in 2001… On the whole these were slightly more bearable experiences for a number of reasons. Primarily they were better because I had a diagnosis of a 'real' mental illness (Bi-Polar Affective Disorder) and this meant that staff treated me a bit better. That's not to say it was great but there is something about being seen to be legitimately sick which makes staff more compassionate, more respectful and more tolerant of your quirks and strangness's.

(Consumer, New South Wales, Submission #327)

What I'm trying to convey is the frustration and isolation that we feel with insufficient support for [X] and myself. I live with the terror that he may take his life at any time. The medication takes time to work but no support therapy is offered while you are in this frightening situation…

(Carer, Mother and Nurse, New South Wales, Submission #147)

6.1.11.4.13 Lack of treatment and support services for consumers who are homeless

Concerns were expressed regarding the lack of treatment and support services for consumers who are homeless. The increasing number of people who are homeless and who have a mental illness and/or mental health problems has also risen with deinstitutionalisation and the subsequent lack of community based treatment and support services to meet the community's needs. Standard 11.4.6 states: 'The MHS ensure access to a comprehensive range of treatment and support services which address physical, social, cultural, emotional, spiritual, gender and lifestyle aspects of the consumer'.

*It is the City's view that a number of people who are homeless and who have a mental illness are suffering from significant **neglect** of their mental health conditions. This contravenes the right of people who are mentally ill to receive adequate treatment and care. (author's emphasis)*

(City of Sydney, New South Wales, Submission #345)

Most people who are homeless and who experience a mental illness pose no threat to the public. In too many instances, witnessed by workers in the City's Homelessness services, their mental health conditions remain inadequately treated. Out-patient mental health services, designed for people living in their own homes within the community are a poor model for the provision of treatment for people who are long term and episodically homeless. Significantly more long term rehabilitation and community based supported accommodation options need to be developed to meet current need.

(City of Sydney, New South Wales, Submission #345)

6.1.11.4.14 Limiting access to treatment and support by diagnosis

Concern was raised regarding treatment and support only being provided to a limited group of people with mental illness or mental health problems:

We believe that the ESMHP [Eastern Suburbs Mental Health Program] needs to adopt a less narrow approach to provision of treatment and support – especially given that the vast majority of people who experience mental illness are not treated under the provisions of this legislation [NSW Mental Health Act 1990] anyway. This attitude is blatant on the JGOs committee (Joint Guarantee of Service between Health and Housing), and offered as an excuse for not even considering alternative options or solutions to consumer issues.

(Eastern Area Interagency NSW, New South Wales, Submission #100)

I am sure I will not be the first or only person to note that conventional MH systems still consistently fail the needs of:

1. *those who "only" have anxiety,*
2. *those who have personality disorders, who may get admitted to hospital but rarely get more than acute services*

(Clinician, New South Wales, Submission #128)

6.1.11.4.15 Lack of treatment and support services for people with eating disorders

Concern was expressed about the lack of availability and quality of treatment and support services for people with eating disorders:

…consumers or carers affected by eating disorders. I have been very involved with families affected by these insidious illnesses for more than ten years and have seen the discrimination and the refusal of governments to provide funding for treatment and dissemination of information.

(Anonymous, New South Wales, Submission #58)

Meanwhile… family finances are being over-stretched to meet psychologists' fees because there are very few with E.D. [Eating Disorder] expertise in the public sector; and most important and painful of all, our young people are dying or suffering severe physical and psychological health problems.

(Anonymous, New South Wales, Submission #58)

6.1.11.4.16 Lack of treatment and support in regional and remote areas

The vast geographical area in Far West NSW poses serious challenges to the planning and delivery of services to meet Standards 11.1.3 ('mental health services are provided in a convenient and local manner and linked to the consumer's nominated primary care provider') and 11.1.5 ('the MHS ensures effective and equitable access to services for each person in the defined community'). For people living in many areas of NSW there are few services and generally no services which are convenient and local. Access to care involves long distances by car, a significant barrier for those who are not so readily mobile or have their own transport.

The latest incident was of a client that had been bailed by the Local Court to be assessed by the visiting psychiatrist after attacking his mother. This client was scheduled and sent to the nearest psychiatric facility. The client was dropped off at their local railway station upon release, became intoxicated and was returned to the hospital as he was very distressed, only to be released with no follow up two days later. This client is now homeless as the family has grave fears for their safety and there was nowhere in Lightning Ridge, Walgett or Dubbo to place him. Undoubtedly he will end up in the prison system.

(Walgett SAAP Services, New South Wales, Submission #63)

A local GP recently stated that he preferred to send a mental health client to Walgett SAAP Services as they were understaffed at the local hospital and stated that hospital staff were uncomfortable with handling mental health clients.

(Walgett SAAP Services, New South Wales, Submission #63)

Clients who are violent or threatening self harm are sometimes scheduled after a great deal of difficulty. They are transported at great expense of time and money to the nearest psychiatric hospital. Two days later, the client is sent – not collected or taken – back to Walgett with a note attached that says, "There is nothing wrong with this fellow." When he arrives back in Walgett he immediately becomes a major problem for the Mental Health team, the local GPs, the police, the hospital, the community, the family and Walgett SAAP Services. None of these services or individuals is configured to deal with violent clients. It has become such a problem of late, that GPs and the Mental Health team are extremely reluctant to schedule a patient because they know it will be a useless exercise.

(Walgett SAAP Services, New South Wales, Submission #63)

6.1.11.4.17 Lack of treatment and support for people with Acquired Brain Injury

The lack of mental health services to provide treatment and support for people with Acquired Brain Injury (ABI) was raised by one NGO service provider. In particular, it was noted that people with ABI have very complex needs in addition to mental health problems (e.g. intellectual disability as a result of the brain injury) and that many consumers with ABI "fall through the cracks" due to eligibility criteria. Standard 11.4.7 states: 'The MHS ensures access to a comprehensive range of services which are, wherever possible, specialised in regard to dual diagnosis …'.

[X] was involved in a motor vehicle and suffered head trauma… [X]'s financial affairs are managed by the Office of the Protective Commission… As a consequence of the head trauma she has suffered, [X] is probe to mood swings. She can be very anti social, abusive and sometimes violent. Lake Macquarie Mental Health will attend her home only in pairs and with a police escort… Through face-to-face dealings with [X] in her own home, we have become very concerned for her wellbeing, both physical and mental… Lake Macquarie Mental Health say that while [X] does have mental incapacity because it was caused by head trauma, she does not come under the charter of the Mental Health Act. As a result she is left without supervision to fend for herself… Commonsense suggests that if a person or organisation could be found that could by regular face-to-face contact "case manage" [X]'s basic needs, i.e. provision of regular hot meals… advice on pain management… home maintenance… transport… psychological counselling… then the quality of life for [X] could be improved dramatically and as a consequence her anti social activities may improve… Another alternative would be for the Mental Health Act to be amended in order to include in [their] services the many people like [X] who currently "fall through the cracks".

(NGO Service Provider, New South Wales, Submission #129)

6.1.11.4.A Community Living

The MHS provides consumers with access to a range of treatment and support programs which maximise the consumer's quality of community living.

Under this Standard, submissions and presentations indicate concerns about:

- need for programs which teach self-care skills;
- lack of access to education, training, work and employment programs;
- lack of community support services;
- lack of access to family centred approaches; and
- lack of social and recreational programs.

6.1.11.4.A.1 Need for programs which teach self-care skills

Living skills and self care programs would enable consumers to live with dignity in society and are seen as critical. Standard 11.4.A.13 states: 'The MHS provides a range of treatment and support which maximises opportunities for consumers to live independently in their own accommodation' and 11.4.A.2 states: 'Self care programs or interventions provide sufficient scope and balance so that consumers develop or redevelop the necessary competence to meet their own everyday community living needs.' As reported in many submissions and presentations, a lack of availability of supported accommodation forces many consumers to return to live with their families. In many instances, this placed strain on families as they waited for places to become available. Additionally, the lack of self care and living skills programs reported meant that consumers were not able to gain the necessary skills to live independently and move out.

> *Programs like living skills have been dropped out of NSW.*
>
> (Consumer Advocate, New South Wales, Parramatta Forum #3)

> *Our families want a life, a job, accommodation. We can't get home care or meals on wheels for our loved ones. Why is this? When our children come out of hospital they are often severeley disabled, they can't remember how to cook or clean up after themselves. So why can't they get home help in these situations?*
>
> (Carer, New South Wales, Parramatta Forum #1)

> *I have been a carer of my son for the last 15 years. He became ill in his final year of high school and he still lives his life as a child. He has no adult life experiences so he lives his life as a child. There are no opportunities for rehabilitation or recovery for him. He has to rely on me to look after him but what will happen to him if I can't look after him anymore?*
>
> (Carer, New South Wales, Sydney Forum #13)

6.1.11.4.A.2 Lack of access to education, training, work and employment programs

Access to education, training, work and employment programs are seen as critical for consumers to reintegrate and live in the community with opportunities to participate socially and economically. Concerns were expressed regarding access to such opportunities. Standards 11.4.A.4 to 11.4.A.9 aim to ensure access to a wide variety of programs, activities and agencies to maximise the consumer's success in these endeavours. Specifically Standard 11.4.A.6 states: 'The MHS provides access to, and/or support for consumers in employment and work'.

> *Why are consumers lacking equal access to employment, poor health outcomes, access to education. 76% with a mental illness are unemployed.*
>
> (Consumer, Carer & Consumer Consultant, New South Wales, Sydney Forum #1)

> *There is no Employment Agencies for people with Mental Illness. There is only a few. Care Employment in Enfield has closed.*
>
> (Consumer and Consumer Consultant, New South Wales, Submission #226)

6.1.11.4.A.3 Lack of community support services

> *I lost my brother 5 years ago. My brother, like many others with a mental illness doesn't have a voice. My brother suicided in a hospital… My brother is just an example of what will happen to others who are failed by the system. People are placing too much faith in institutions – people need access to good quality community care without having their human rights abused. My brother had care at Rozelle but he didn't really qualify for that catchment area so he then had to go back to St George but there wasn't anything for him to do there.*
>
> (Carer and Teacher, New South Wales, Sydney Forum #7)

The aim of deinstitutionalisation was to provide treatment and support in the least restrictive setting, which for most people means living in the community. However, as discussed above, the necessary treatment and support services and effective systems have not materialised. This is true for both people with serious mental illness living in the community and people who, as a consequence of failure to access treatment and support services at the onset of illness, develop significant disability and require additional community support services to live independently or with their family.

> *These services once delivered by Health have increasingly been privatised and excised form health interventions. This has led to poorly resourced, and in this area, the closure of essential Living Skills Centres due to cessation of funding and the abdication of all responsibility by Health in providing fundamental social and recreational services. There is good argument for the continued review and improvement of services aimed at helping people experiencing mental illness to remain active members of their communities.*
>
> (Clinician, New South Wales, Submission #197)

> *My dad and my brother both need home care support at the moment. The hospital told us they would just lock them in a room so we would be better off taking them home. I don't know how to explain to you how it feels when you are told to take these people home. The pressure is enormous.*
>
> (Disability Community Worker, New South Wales, Parramatta Forum #2)

> *…there is no community support from services until these people become very unwell.*
>
> (Anonymous, New South Wales, Submission #156)

> *Almost everything I have to do is hard, but I don't let on because I don't want people to think I'm crazy. Finding where I have to go for appointments is hard, figuring out which bus & where to catch it is hard. I put off making a psychiatrist appointment because I didn't know where to go. Getting to my therapist was my main priority & anything that involves thinking exhausts me. I sleep a lot. I have people ring & I don't know who they are or they leave messages & I can't ring them back because I can't find their number… My therapist has given me her mobile number, but I feel reluctant to use it because sometimes all I need is reassurance. Sorry to rave on, but it just really gets me down sometimes & I feel really alone.*
>
> (Consumer, New South Wales, Submission #69)

> *I think we urgently need respite for single mothers.*
>
> (Consumer Consultant, New South Wales, Parramatta Forum #9)

> *Support to maintain independent living is another area of great unmet need.*
>
> (Clinician, New South Wales, Submission #197)

6.1.11.4.A.4 Lack of access to family centred approaches

Many reports were received from carers, NGO and family workers describing the incredible strain that has been placed on families. In particular, a lack of access to family centred approaches and support groups was repeatedly mentioned. Standard 11.4.A.12 states: 'The MHS ensures that the consumer and their family have access to a range of family-centred approaches to treatment and support' and Standard 11.4.A.11 states: 'The consumer has the opportunity to strengthen their valued relationships through the treatment and support effected by the MHS'.

> *We need to nurture the family unit and we need services to nuture the family unit.*
>
> (Carer, New South Wales, Parramatta Forum #1)

> *Furthermore, there seems to be no support network for parents of mentally ill teenagers, and my 'coping' abilities are being sorely tested.*
>
> (Carer, Mother, New South Wales, Submission #92)

As a worker working with vulnerable families – it's the same problem we see – there's no follow up. I spend a lot of time with clients and it is often hard for them to tell their stories time and time again. Often case workers tell them they will contact them but this does not happen. We take them up again and again. They need to see somebody who's specialised.

(Clinician, New South Wales, Submission #5)

People with mental illness often present with families. When people present their carers often have no input into the care planning – this situation really needs to change. It's the people who are closest to the consumer that know best. For women who have un-well children it is hard if they are not informed of the child's treatment care plan. Families are not supported and there is a general lack of information.

(Consumer, Carer & Family Worker, New South Wales, Broken Hill Forum #23)

Families not supported – we know entire families who are adrift.

(Consumer, Carer & Family Worker, New South Wales, Broken Hill Forum #23)

Families and friends of people with mental illnesses are similarly under increasing pressure to fill the gaps in necessary care and support. Family support groups frequently bemoan the lack of response from emergency and case management services and the lack of access to psycho-social rehabilitation services. Assessment of the capacity of carers to support consumers and their inclusion in planning care programs needs to be formalised. The impact of caring for a family member or friend experiencing mental illness can, itself create mental health problems in carers. Carers may experience fear, anxiety, guilt and depression and may in some circumstances have real concerns for their personal safety. There is currently inadequate consideration and support given to carers of people experiencing mental health problems.

(Mental Health Coordinating Council, New South Wales, Submission #298)

6.1.11.4.A.5 Lack of social and recreational programs

Access to day programs to meet the needs for leisure, recreation and employment (Standard 11.4.A.4) were also reported to be declining. Access to such programs is seen as critical for consumers to reintegrate and live in the community with opportunities to participate socially and economically and to prevent relapse. Concerns were expressed regarding the lack of access to such programs and that consumers in the community have no opportunity to develop any skills. Standards 11.4.A.4-11.4.A.9 ensure access to a wide variety of programs, activities and agencies to maximise the consumer's success in these endeavours.

The impact of the erosion of community based rehabilitation services has been underestimated, as the networks of support so critical for the maintenance of stable mental health are removed, the burden upon the health system grows even larger. This again typifies a lack of understanding indeed an ignorance of the issues of those living with mental health conditions, as these programmes that offer social networks, education and recreation play a key role in the maintenance of mental health, community and social cohesion, and significantly contribute towards decreased admission rates, and burden upon the health care system.

(Clinician, New South Wales, Submission #197)

[X] needs something to keep him occupied as he is unable to work. Why there are no day centres for menta health sufferers to make them feel useful and valued in our community. He is a human being and deserves to be looked after just as a cancer or heart attack suffer does.

(Carer, Mother, and Nurse, New South Wales, Submission #147)

The MHCC strongly supports a community focussed, non-institutional system of mental health care… MHCC's major concerns are related to the inadequate levels of community mental health services provided by the public health system and the shortage of psychosocial rehabilitation services. The latter services respond to a person's 'whole of life' needs in a community setting and include supported residential services, day centres which provide social and recreational activities and link clients to other such services in the community, outreach support services, vocational and employment services, and information and education services. Even though NSW Health has recently acknowledged in its draft document, NGOs and Mental Health: a Framework for Partnership, that these services are most appropriately provided by the non-government sector (NSW Health, 2002), there has been no indication that new funds will be allocated for this purpose.

(Mental Health Coordinating Council, New South Wales, Submission #298)

6.1.11.4.B Supported Accommodation

Supported accommodation is provided and / or supported in a manner which promotes choice, safety, and maximum possible quality of life for the consumer.

Tragically, the homeless people are the forgotten people. You won't hear from the homeless people even in a meeting like this.

(NGO Nurse Unit Manager, New South Wales, Sydney Forum #3)

The move to community-based care initiated under the Richmond Report has resulted in increased numbers of people with mental illness who are homeless. "The change in vagrancy laws and the Richmond Report have greatly contributed to one of the changing face of the homeless, being mentally ill sufferers. The government tried to sell the proposal as the community helping the community."

(Carer, Daughter, New South Wales, Submission #134)

Under this Standard, submissions and presentations indicate concerns about:

- the lack of supported accommodation;
- lack of supported accommodation for offenders with mental illness or mental health problems;
- lack of supported accommodation options for consumers form a non-English speaking background (NESB); and
- lack of resources and support services for NGO supported accommodation providers.

6.1.11.4.B.1 Lack of supported accommodation

As noted previously in this Report (8.3 Integration), the lack of housing and accommodation options, and supported accommodation options in particular, for people with mental illness is a serious barrier to consumers attaining the 'maximum possible quality of life' and integrating and contributing to the community. Many consumers who could not access supported accommodation became homeless, complicating access to treatment and support and increasing the likelihood of entry into the criminal justice system. An indication of the lack of available supported accommodation in NSW was the report by one carer in Sydney who was offered a place for her mother in Goulburn. Standard 11.4.B.9 states: 'Where desired, consumers are accommodated in the proximity of their social and cultural supports'.

I am advocating a modern asylum model. The move to community care hasn't improved the situation. We need to target funding to meet the needs of the homeless. The homeless don't have friends or family. There are deaths all the time.

(NGO Nurse Unit Manager, New South Wales, Sydney Forum #3)

In her recent and still current admission, the various workers who are involved with my mother called me into a meeting and proposed that I consider an option of permanent hospitalisation for my mother, based on how well she responds to the structured environment of the hospital and how well she was on "Clozapine". Of course, I needed to think about the proposal but I knew it would mean that Mum would be safe off the streets and in an environment that she seems to respond to. The corker of the situation is, that my mother comes under the Eastern Suburbs area, and the closest option for my mother is to be based in Goulburn, which apparently is not really a long-term stay facility.

(Carer, Daughter, New South Wales, Submission #134)

There isn't enough crisis accommodation for homeless men. From my observations about 80% of homeless people have a mental illness, about 50% of those have a dual drug and alcohol diagnosis. We regularly have about 50-60 men sleeping in the laneways in the surrounding blocks to our accommodation service and at any one time you'll see about 100 "sleeping rough" on the streets.

(NGO Nurse Unit Manager, New South Wales, Sydney Forum #3)

The problem of finding suitable accommodation was a constant source of frustration for all those working in this industry. I don't believe that the community or the government fully understand the impact that lack of care and accommodation not only on the chronically ill but also to the cost to society.

(Social worker, Student, New South Wales, Submission #118)

The move to community based services, while positive, has not been matched by attention to stratified and good quality accommodation options for persons with chronic mental illness who rarely can access supervised community accommodation. Disabled and disorganised patients flounder in unsupervised single accommodation, are cast onto the streets, or are involved in "revolving door" admissions to acute units, which are the only "accommodation" facilities remaining for them. A distressingly high number kill themselves.

(Public Sector Psychiatrists, New South Wales, Submission #297)

Living on the street further complicates matters by making it difficult for mentally ill person to receive follow-up services. Without this and ongoing care, these individuals stop taking their medication and sooner or later, end up having a run in with law enforcement. It is at this point that, what was once the institution's mental health problem, now becomes a police problem.

(Police Association of New South Wales, New South Wales, Submission #59)

[X] has been placed on Clozapine, which requires regular blood testing as a health precaution. Also, problems can occur is she comes off the medication. This is difficult as she is regularly non-compliant and homeless.

(Carer, Daughter, New South Wales, Submission #134)

[X] was in a dreadful mental state and got in arrears with his rental, and his carer (who was a druggie friend) caused complaints from neighbours. This resulted in [X] being evicted and becoming homeless, and losing all his possessions as he had no place to store them. He also was charged with two offences and went before the court where THEY FINED HIM… (author's emphasis)

(Carer, Sister, New South Wales, Submission #104)

The closure of long term residential care beds in institutions has not been accompanied by the development of properly resourced and supported community accommodation. Sub-standard conditions in boarding houses are of great concern. In addition, placing consumers (people with mental illness) into public housing without ongoing supervision and support has lead to a deterioration in health of consumers and serious problems for other tenants in public housing.

(NSWCAG, New South Wales, Submission #273)

The Richmond Fellowship (providing supported accommodation for people with schizophrenia) has waiting lists of up to 2 years - cannot take on any more clients

(Consumer and Consumer Advocate, New South Wales, Submission #169)

We have been told that there is nowhere suitable for [X] to be released to after leaving the Chisholm Ross Centre. The extended care unit at Goulburn has a 6 month waiting period and that the most we can hope for is that [X] will be able to move into an unsupported community house on his own in Queanbeyan. We believe this to be unsuitable and to pose an unacceptable risk to [X]. We believe that the health authorities have a duty to keep [X] safe, and wish to record our concern, based on recent history as outlined above, that this is not being achieved in an effective manner.

(Carers, Parents, New South Wales, Submission #198)

We are still trying to find suitable accommodation for [X] after his release from hospital. It is very obvious to all that [X] needs to go into supported accommodation to help with his rehabilitation. He has shown that he can be very well, given the right set of circumstances, which include support of his family, psychiatrist and suitable supported accommodation. It is our greatest wish that [X] be well enough so that he may enjoy a useful and happy independent life.

(Carers, Parents, New South Wales, Submission #198)

We have been told that there is a 4 month wait for a bed, and that interim arrangements are not possible. We find this very frustrating and have not had a very satisfactory explanation as to what strategy is being put in place to get [X] back to Hennessey House.

(Carers, Parents, New South Wales, Submission #198)

One submission was received highlighting the positive outcomes that can be achieved when supported accommodation is available and support is provided which maximum quality of life for the person with mental illness:

After my mother's death in 1999, I went to live in a room for 12 months up until the end of 2002. Then I was fortunate enough to be offered a place at Irene Luth Cottages at Carlingford in April, 2003, where I have lived happily for about 15 months now. We have four carers / support staff who look after us, and one of them is "on call" 24 hrs a day in case of any emergencies. There are 21 residents in two complexes at Carlingford. This includes two houses & 16 separate units. There are 2 people in our house, and 3 in the other one. We have men and women living here… I haven't had a further breakdown [schizophrenia] since 1976, and I am trying very hard, with the help of my medication not to have one. I keep myself pretty busy, with grocery shopping, walking & occasionally going for a swim in a heated pool at Northmead. Also I go on "little adventures" as my friend [Z] calls them… Occasionally I do some voluntary work… I find there is still a "stigma" attached to people with a mental illness…

(Consumer, New South Wales, Submission #308)

6.1.11.4.B.2 Lack of supported accommodation for offenders with mental illness or mental health problems

The Department of Corrective Services expressed concern at the lack of crisis, medium and long-term supported accommodation options for offenders with mental illness and / or mental health problems. The Department of Corrective Services noted the importance of such accommodation as many offenders may have intellectual disability and many female offenders are the primary carers of children.

Crisis, medium and long-term supported accommodation for offenders with mental health issues and intellectual disability is urgently needed for all community-based offenders (probationers and parolees) throughout the state.

(Community Offender Services, Probation and Parole Service, Department of Corrective Services, New South Wales, Submission #317)

There is a consistent lack of accommodation and community based services for women offenders with mental health issues. Additionally, if a woman is the primary carer of children it is even more difficult for that woman to find appropriate accommodation. Most women in custody are the primary carers of children.

(NSW Department of Corrective Services, New South Wales, Submission #295)

Undoubtedly, homelessness is a major issue for offenders with mental health issues… homeless mentally ill people are up to 40 times more likely to be arrested and 20 times more likely to be imprisoned than those with stable, suitable accommodation. While statistics are not available, there would appear to be no compelling reason why the situation would be different for mentally ill offenders in NSW. Incarceration appears to worsen post release accommodation issues… Further, offenders released with no stable accommodation were three times more likely to re-offend than those who had accommodation.

(Community Offender Services, Probation and Parole Service, Department of Corrective Services, New South Wales, Submission #317)

As a result of Drug Summit reallocation of funding COS have been able to develop a limited crisis accommodation initiative for higher risk offenders who are at risk of drug relapse due to homelessness.

(Community Offender Services, Probation and Parole Service, Department of Corrective Services, New South Wales, Submission #317)

6.1.11.4.B.3 Lack of supported accommodation options for consumers form a non-English speaking background (NESB)

One clinician expressed concern at the lack of accommodation options for people from a NESB. Standard 11.4.B.12 states: 'Wherever possible and appropriate, the cultural, language, gender and preferred lifestyle requirements of the consumer are met'.

Structured and supported accommodation services for people with a mental illness and aged care is in crisis. Some people from a NESB believe they are responsible to care for their family member. The problem is that when we finally convince them to accept support them they find there are no services.

(Clinician, New South Wales, NESB Parramatta Forum #17)

6.1.11.4.B.4 Lack of resources and support services for NGO supported accommodation providers

Concern was expressed that NGO services providing accommodation are unable to access support from mental health services when required, even during a crisis, placing consumers at risk. Standard 11.4.B.14 sates: 'The MHS support consumers in their own accommodation and supports accommodation providers in order to promote the above criteria' [11.4.B.1 – 11.4.B.13]:

NCOSS has received reports that supported accommodation providers are consistently unable to obtain necessary support services from mental health teams, including crisis response services, to assess and manage clients with mental disorders.

(NCOSS, New South Wales, Submission #47)

Walgett SAAP Services is receiving more and more clients referred by the court system and the mental health team… It is important to emphasise here, that Naomi House is a Non Government Organisation. The staff are caring and supportive but are not trained professionals. They do the best that they can, but the role of Naomi House and Walgett SAAP Services is that of referral to professionals. Walgett SAAP Services is dealing with clients who are non-conformist in the extreme. If Walgett SAAP Services does not / cannot take the client, often the only alternative is a jail cell.

(Walgett SAAP Services, New South Wales, Submission #63)

6.1.11.4.C Medication and Other medical technologies

Medication and other medical technologies are provided in a manner which promotes choice, safety and maximum possible quality of life for the consumer.

Under this Standard, submissions and presentations indicate concerns about:

- the emphasis on medication; and
- unsafe practices during treatment using Electro Convulsive Therapy.

6.1.11.4.C.1 Emphasis on medication

Concern was expressed that the major focus of treatment for mental illness is a reliance on medication without consideration for other necessary treatment and supports and overall well-being.

> *The system is structured in such a way that there's too much of a reliance on medication and not enough attention to the other important things like rehabilitation and psychosocial support, housing, etc.*
>
> (Mental Health Worker, New South Wales, Sydney Forum #10)

> *I lost my brother 5 years ago… [X] had a dual diagnosis (mental illness & drug and alcohol) – he suffered for 11 years from the age 16. As many carers would know most people with a mental illness need large doses of medication – they do take the drugs but they need more.*
>
> (Carer and Teacher, New South Wales, Sydney Forum #7)

> *Inpatient Care is often characterised by an over-reliance on medication as the only form of treatment. While there are often some groups being run in inpatient areas, these are usually very scant on weekends, and consumers often report they spent a week in the inpatient area and no nurses talked to them the whole time. Admittedly, this is mainly the old-guard mental health nurses, the younger ones usually have a better attitude and often do talk to consumers.*
>
> (Consumer Activist, New South Wales, Submission #257)

> *Since then I believe there has been improvements in the medications being used and how they are used. I believe also there has been a growing interest in consumer participation in deciding suitable drug use.*
>
> (Clinician, New South Wales, Submission #356)

6.1.11.4.C.2 Unsafe practices during treatment using Electro Convulsive Therapy (ECT)

Carers expressed concern regarding the apparent lack of regard for the safety of their daughter by staff during treatment using ECT. However, a clinician noted use of this therapy has improved.

> *Over three weeks from 9 January 2002, our daughter had a series of ECTs. On 23 January 2002, we observed that no MHU staff accompanied her to the theatre. This was the second time that she was unaccompanied by MHU staff, whom we were told had this responsibility as duty of care, and this MHU delinquency angered the medical ward and theatre staff. We observed on this same day that MHU sent a patient to theatre who had had a drink, and she was rejected by theatre staff.*
>
> (Carers, Parents, New South Wales, Submission #106)

> *The use of ECT has improved over the years with the most recent being a lowering of the electrical current used to produce a more effective seizure that is safe and has fewer undesirable SEF's.*
>
> (Clinician, New South Wales, Submission #356)

6.1.11.4.D Therapies

The consumer and consumer's family / carer have access to a range of safe and effective therapies

Under this Standard, a presentation indicated concerns about:

- the costs associated with accessing therapies making this a limited option for many consumers.

6.1.11.4.D.1 Lack of access to a range of accepted therapies

According to Standard 11.4.D.2: 'The MHS provides access to a range of accepted therapies according to the needs of the consumer and their carers'. However, concern was expressed that many people can not afford to access such therapies as access via the public mental health system is difficult, bulk-billing psychiatrists are few and Medicare is not available for psychologists.

> *While living with a mental illness is hard, the fact is that if you have money you can get help. For example, with money you can access other forms of therapy (non-drug), which can help greatly but we can't access this care through Medicare.*
>
> (Carer, New South Wales, Sydney Forum #9)

6.1.11.4.E Inpatient care

The MHS ensures access to high quality, safe and comfortable inpatient care for consumers.

> *[X] believes that patients are treated as 2nd class citizens. They do not receive the same level of care you would receive in other health facilities.*
>
> (Anonymous, New South Wales, Submission #156)

Under this standard, submissions and presentations indicate concerns about:

- consumers suiciding in hospital settings;
- lack of beds;
- excessive use of restraint;
- protection from harm not ensured;
- need for separate psychogeriatric facilities;
- inpatient units in poor condition;
- lack of privacy and lack of choice;
- patients absconding from hospitals and involvement of police; and
- use of police to transport consumers to and between hospitals.

> *Early discharge – people are moved from wards to overnight rehab beds so another patient can have their bed. This type of system is not in favour of patients or their family or staff. We have 56 patients in a 33 bed ward. Patients are often put on leave for a week because we have a bed shortage. Their clinical care is being determined not by their need but by the availability of resources! The ones who have families are the ones who are discharged more quickly.*
>
> (Service Provider, New South Wales, NESB Parramatta Forum #21)

6.1.11.4.E.1 Death while an inpatient

Of most serious concern were reports of deaths of consumers while an inpatient and that hospitals did not provide safe settings or have adequate policies and procedures to ensure safety. Reports were also received of consumers who died very soon after discharge (see Standard 11.6).

> *…we have lost our son in Carasta [Caritas] Mental Health Hospital (Branch of St Vincent Hospital Sydney). It happened on the 16th of June 2003. We are devastated as we thought he would be safe and looked after in hospital. We made several calls to Dr [Y] (second name slips my memory) and the nurses who where looking after our son. I also told them to get in touch with Dr [Z] who had seen our son 18 months prior. He was willing to speak to them. Our darling son had written a letter and if you read it, he didn't want to die. I don't know how he could manage to get a sheet, plait and wet it and hang himself in the corridor without being noticed. They knew he was very sad, but when we saw the hospital where it happened it was so depressing. They told us that depressed people did not notice their surroundings. Also it was 12 hours before the police (not the hospital) called us. We kept him on life support for 10 days and in that time felt the staff, especially [W] and [V] kept very tight ranks on the matter. There are so many bazaar happenings and as we both were shocked and devastated we felt we should have stayed on and pursued it more… Our son was told he could not leave as he was too ill and was on 24 hour surveillance, and this happened… Dr [Z]… He felt there was not enough done. I feel the medication he was on made him do what he did. So much to say, but I think you would know.*
>
> (Carer, Mother, New South Wales, Submission #135)

> *I lost my brother 5 years ago. My brother, like many others with a mental illness doesn't have a voice. My brother suicided in a hospital – I came from a modest European background. My parents believed that we would get care. [X] had a dual diagnosis (mental illness & drug and alcohol)… My brother had care at Rozelle but he didn't really qualify for that catchment area so he then had to go back to St George but there wasn't anything for him to do there.*
>
> (Carer, Sister, New South Wales, Sydney Forum #7)

6.1.11.4.E.2 Lack of beds

The lack of available beds for acute care was also cited as a serious concern. As discussed previously, access to these beds for consumers in rural and regional areas was particularly problematical. Patients requiring admission were generally in desperate need of medical care, often life-saving medical care. It appears that the demand far exceeds the number of beds available which results in a whole series of other decisions which jeopardise the safety and rights of consumers including: non-admission and returned 'home', admission and someone else who is still unwell is discharged to vacate a bed, lengthy waits in emergency departments, being held in seclusion, or admission to other wards with the use of sedation or security guards.

> *In this area we have 30 beds for 900,000 people. We need at least 90 beds. What we have is a rolling door of people in and out of hosital. They are frequently discharged too early to make way for others.*
>
> (Carer, New South Wales, Parramatta Forum #1)

> *On 4 January 2002, after a case meeting, MHU staff helped us remove my daughter from the floor of the isolation room where she'd put herself, into a self-contained room in the MHU ward. She could hardly walk, (because of her state of mind and her cracked and bleeding heels), a wheelchair was unavailable and so she was carried; another female patient who was recovering from an ECT had to be removed from the bed for my daughter's occupation. I would be very displeased if I were the father of that patient.*
>
> (Carers, Parents, New South Wales, Submission #106)

The inpatient system comprises a small number of beds in psychiatric hospitals, and a large number of scattered small acute admission units in general hospitals. For those at the coalface, there is an insurmountable, overwhelming daily challenge searching for beds, arising from a state-wide bed gridlock. Registrars in particular get 'chewed up' trying to find beds. Associated community services have generally contracted and community rehabilitation positions have been lost, resulting in increased pressure on beds and emergency departments. These services are swamped by inexorably increasing caseloads and demands. It is impractical to explore and provide innovative, 'best practice' models of service delivery in such an environment.

(Public Sector Psychiatrists, New South Wales, Submission #297)

There is a real shortage of beds and this results in a crisis occurring every weekend with respect to beds and community based care… What happens is that they get lined up in emergency departments, which are overfull in any case and ED staff are stressed and unhappy. Alternatively other patients are moved from the psych unit to general wards to make room for new admissions or people are sent home earlier than desirable clinically, with fingers crossed! This is really a system problem, not a clinician problem.

(Anonymous, New South Wales, Submission #303)

The bed problem is out of control. Previously we had 121 at our hospitals and now we have less than 54. We had 10 neuropsychiatry beds and now there are 2!

(Anonymous, New South Wales, Submission #303)

It is reasonable to ask why the law permits the release of mentally ill individuals and why chronic community problems are not kept in hospitals for longer periods of time…

(Police Association of New South Wales, New South Wales, Submission #59)

Lack of community support leads to 'revolving door' admissions – leads to no spare beds in hospitals. Huge shortage of mental health nurses. In Manly, 5 patients were being looked after in emergency by security guards.

(Consumer and Consumer Advocate, New South Wales, Submission #169)

6.1.11.4.E.3 Excessive use of restraint

Standard 11.4.E.1 states: 'The MHS offers less restrictive alternatives to inpatient treatment and support provided that it adds value to the consumer's life and with consideration being given to the consumer's preference, demands on carers, availability of support and safety of those involved'. Excessive use of restraint, sedation and seclusion infringes on many consumer rights, as described in the submission below. The unnecessary use of such practices is also problematical given the scarcity of early intervention and treatment options in the community setting, necessitating consumers to reach crisis point before access to treatment is allowed, and then they are 'punished'.

I also want to talk about a story that was reported in the Penrith Press. The story is about patients being sedated for up to 5 days and being strapped to beds – they have no access to any therapeutic services, only TV or smoking.

(NGO worker, New South Wales, Sydney Forum # 8)

The use of Seclusion Rooms and involuntary restraint is still continuing in NSW. Seclusion Rooms and involuntary restraint, which are often, degrading, inhumane and traumatic, are a normal form of 'treatment' in NSW Public hospitals. Why is it that in other parts of the World including the U.S., Prevention Programmes have greatly reduced the need for these abuses, yet in NSW this form of treatment is still seen as legitimate?

(Consumer Activist, New South Wales, Submission #257)

6.1.11.4.E.4 Protection from harm not ensured

Concerns were expressed that protection from harm while an inpatient is not being ensured. Standard 11.4.E.15 states: 'The MHS provides a physical environment for inpatient care that ensures protection form harm, adequate indoor and outdoor space, privacy and choice'. Included in the notes to this Standard are: separate space for consumers with acute and sub-acute disorders, segregation/specialised units in the basis of gender and/or age and monitored seclusion.

> *[X]'s biggest complaint is that there are only 4 wards at the James Fletcher Hospital, and one of these wards is used for acute patients as well as forensic patients. While admitted to the locked ward, [X]'s wife was locked up with potentially aggressive men and / or criminals. There should be separate wards for males and females. Acutely psychotic patients, particularly large men can be very intimidating and not conducive to recovery when unwell.*
>
> (Anonymous, New South Wales, Submission #156)

> *We are also seeing a situation where there is an amalgamation of acute units with secure/involuntary wards. This means that patients are now being locked up in the same wards as involuntary patients.*
>
> (Carer, New South Wales, Parramatta Forum #11)

> *Previously it was rare to have very difficult and violent patients, but now we have many. I attribute this to increased illicit drug use and a lack of resources in the community.*
>
> (Anonymous, New South Wales, Submission #303)

> *Because the MHU ward is un-segregated according to patients' age, sex and degree of illness, we believe that our daughter unnecessarily became psychotic, which led to her body malfunctioning and thus to her having to be revived in a medical ward, and finally to her total duration in hospital of 8 weeks. We observed that MHU staff numbers only allowed ¼ of a person to each patient in the lock-up area, which we believe is inadequate supervision to guarantee a vulnerable patient's safety.*
>
> (Carers, Parents, New South Wales, Submission #106)

6.1.11.4.E.5 Need for separate psychogeriatric facilities

As noted above, Standard 11.4.E.15 states: 'The MHS provides a physical environment for inpatient care that ensures protection form harm, adequate indoor and outdoor space, privacy and choice'. Included in the notes to this Standard are: segregation/specialised units in the basis of gender and / or age. Concern was expressed the need for separate psychogeriatric facilities.

> *Another problem is the lack of dedicated facilities for older people with psychiatric disorders requiring admission. Older people don't mix well with younger people, particularly those younger violent patients who are taking illicit drugs and are psychotic. There are strong arguments for separate for separate facilities.*
>
> (Anonymous, New South Wales, Submission #303)

> *Not all psychiatric wards have a team approach to patient management. Old age psychiatry in particular needs a team approach.*
>
> (Anonymous, New South Wales, Submission #303)

6.1.11.4.E.6 Inpatient units in poor condition

Concerns were expressed (and noted previously in this report under Standard 1 – Rights) regarding the frequent poor condition and 'filthy' state of many inpatient units.

The James Fletcher Hospital is also frequently "dirty". [X] qualified that statement to say that "cleanliness could be upgraded to hospital standard". For example, the carpets are very dirty, which leaves patients with black feet. There was an example of food smeared on a window which was left for more than 3 weeks. A dead cockroach was left lying in a corridor for several days. There are frequently coffee stains left on the garden furniture. Overall, it is a very dirty environment, not what you would expect from a hospital.

(Anonymous, New South Wales, Submission #156)

During December 2001 and January 2002, we observed that both the MHU wards (open and lock-up) were generally in a filthy state, and we saw numerous cockroaches everywhere.

(Carers, Parents, New South Wales, Submission #106)

6.1.11.4.E.7 Lack of privacy and lack of choice

As stated above, Standard 11.4.E.14 stated that the MHS provides a physical environment that ensures privacy. Concern was expressed that a place for private telephone conversations was not available. Also, concern was expressed at the lack of any choice with regard to meal options.

… there is only one meal option available to patients, regardless of the individual's tastes or beliefs. There is often no privacy for patients using the telephone because if there is a staff meeting being held in the room housing the phone it is placed in the hallway.

(Anonymous, New South Wales, Submission #156)

6.1.11.4.E.8 Patients absconding from hospitals and involvement of police

The Police Association of New South Wales expressed concern regarding the high number of consumers, both voluntary and involuntary, who abscond from hospital. This is of serious concern for the safety of the consumer and the community. Additionally, the Police Association alleges that failure of hospitals to provide appropriate policies, procedures and resources to ensure the safety of consumers, results in the use of considerable police resources.

The problem for police, is that poor security and practices of mental health centres allows patients to leave care all too easily. Police must then use already sparse resources to return those patients to the centres and hospitals… The first concern relates to the welfare and safety of patients who are Absent Without Leave...

(Police Association of New South Wales, New South Wales, Submission #59)

Secondly, police are concerned with the fact that they continue to expend considerable resources recording and investigating AWL [Absent Without Leave] reports, regularly escorting AWL patients back to Mental Health Units. On occasions, police have recorded up to 2 hours attending various locations and conducting patrols to locate patients, only to return the patient and have them leave the unit again, sometimes within hours. Thirdly, police are concerned with preserving the dignity of the patient. This brings up the issue of the inappropriateness of placing a patient suffering a mental health illness into the back of a police truck which is the least suitable vehicle for transport (this issue will be discussed in greater depth later in the submission)…

(Police Association of New South Wales, New South Wales, Submission #59)

Police officers there are complaining that almost on a daily basis, both voluntary and involuntary patients are managing to leave the facility without the permission of staff. Little effort appears to be made by the staff there to return the patient other than on some occasions making a telephone call to the local police station advising them of the missing patient's name and description…

(Police Association of New South Wales, New South Wales, Submission #59)

6.1.11.4.E.9 Transport to and between hospitals

Whilst we're talking about the police, numerous consumers have complained about the way the police have handled them on transporting them to hospital. Major education of police – if they're to be the transport service, which they shouldn't be, needs to take place.

(Consumer and Consumer Advocate, New South Wales, Submission #8)

Concern was expressed from one consumer advocate regarding the often unnecessary use of the police to transport consumers to hospitals and treatment. The Police Association of New South Wales also expressed many concerns regarding the use of police to convey consumers to hospital. Standard 11.4.E.3 states: The MHS ensures that a consumer who requires involuntary admission is conveyed to the hospital in the safest and most respectful manner possible'. Police expressed concerns that they are being used indiscriminately, in effect, as a "taxi service".

A problem has developed for police whereby mental health crisis teams are relying on them to transport mentally ill patients in contravention of the MOU. The fact is, mentally ill persons are a health issue, not a police issue…

(Police Association of New South Wales, New South Wales, Submission #59)

A common complaint made by our members, is that there the use of police is being abused and that increasingly they are being used as a taxi service… police are having to convey patients for example, from a hospital in a western metro area to a hospital in an inner metro area under schedule II, with no alternatives even being tried by doctors, which is effectively wasting police resources… that medical staff are either ignorant of or disregarding of the MOU and local arrangements.

(Police Association of New South Wales, New South Wales, Submission #59)

The Association does not see this as a solution, however, as there are many occupational health and safety (OH&S) issues with placing the mentally ill and mentally disordered in the back of an ambulance. … using police escorts in ambulances is also a concern due to other issues such as weapons safety and the return of police to the origin of the trip…

(Police Association of New South Wales, New South Wales, Submission #59)

The fact remains that these individuals should not be treated as offenders and as such it is inappropriate to be transporting them in police vehicles. Police have received complaints regarding this very point by concerned family members of these patients…

(Police Association of New South Wales, New South Wales, Submission #59)

The distance and time factors, particularly in country NSW with the limited number of mental health facilities and cost implications in police travel and escorting patients should be considered…

(Police Association of New South Wales, New South Wales, Submission #59)

Hospitals are using police vehicles under the guise of Schedule II escorts as a cost-cutting measure as it means that they do not have to pay for ambulance transports…

(Police Association of New South Wales, New South Wales, Submission #59)

What is desperately required is the establishment of a specialist service transport unit to take up this role…

(Police Association of New South Wales, New South Wales, Submission #59)

6.1.11.5 Planning for Exit

Consumers are assisted to plan for their exit from the MHS to ensure that ongoing follow-up is available if required.

Under this Standard, submissions indicate concerns about discharge without adequate planning.

6.1.11.5.1 Discharge without adequate planning prior to discharge

One submission raised serious concerns about the inadequacy of discharge plans, and that sometimes they are not even instigated. Specifically, the allegation suggests that discharge plans have not been developed in collaboration with the consumer (Standard 11.5.2), that understandable information about the range of relevant services and supports have not been provided (Standard 11.5.4) and that consumers have not established contact with the service providers prior to exit (Standard 11.5.6).

> *Around this stage [July 2004], someone from the hospital telephoned and spoke to [X]'s wife, [Y], and asked hadn't they been monitoring him since his discharge from Hornsby Hospital in 2001. They indicated that he should have been monitored, initially weekly, then extending to monthly, and eventually quarterly, and that he should not have been discharged without arrangements in place for ongoing visits to a psychiatrist. When told that none of this had happened, the reply was that he must have "slipped through the cracks".*
>
> (Family Member, Father, New South Wales, Submission #346)

6.1.11.6 Exit and re-entry

The MHS assists consumers to exit the service and ensures re-entry according to the consumer's needs.

Under this Standard, submissions and presentations indicate concerns about:

- suicide or homicide soon after exit;
- lack of follow up despite promises; and
- quick discharge without adequate planning prior to discharge.

6.1.11.6.1 Suicide or homicide soon after exit

Concern was expressed regarding the inappropriate discharge of consumers when they were still unwell. Such concerns were reinforced by the reports below from carers whose sons and daughters were discharged and either committed homicide or suicided soon after exit.

He said he didn't feel very well on his injections - and one night started hallucinating. He was on a trip with a friend in NSW and so he was taken to a large country town and was admitted to the hospital. The hospital called me to let me know what had happened and I was assured he would be ok. The nurse put him on the phone to me and he sobbed like a baby. The nurse said they would look after him. I kept phoning all day. It was like a panic button had gone off in me. At the hospital in NSW the Psychiatric Consultant who examined [X] phoned me and told me he was going to be discharged as he was only homesick. I pleaded with him not to discharge him as he was really sick and needed help. The Consultant said he was ok to be discharged. I begged him to keep my son in hospital. Eventually the Consultant agreed he could be kept in overnight but he told me he would then be discharged early the next day. I asked him if he would do another examination in the morning and he said he would not and that no further examination would take place from mid afternoon until he was discharged. [X] was then discharged the next morning and on the drive on the way home with his friend he killed his friend because he was still sick and hallucinating.

(Carer, Mother, Victoria, Footscray Forum #8)

My 30 year old daughter committed suicide on the first March 2004. She had been depressed for eighteen years. [X] has been in both private and public hospitals - St Vincent's [Victoria] and Nolan House at Albury Base Hospital let her go to her death… In February 2004 [X] was then transferred and scheduled to Nolan House… a court order was made for [X] to stay for 14 days… I told him she shouldn't be allowed out. I was told by [Z] that she had been approached by the head of Nolan House and asked if [she] was happy to take care of [X] 24/7. [Z] told him no. He didn't reply to [Z] and told her [X] could go. [X] left with [Z]… I spoke with [X] over the next two weeks… one incident… [X] rang me in tears… I then again spoke to her to go back out and stay at a friend [W]'s place… She said she would. This was the last time I spoke with [X]… The heads psychiatrist at Nolan House in Albury would have known that he was sending her out to commit suicide, the village idiot would have known that.

(Carer, Father, New South Wales, Submission #102)

In January 2002, [X] took an overdose and was taken to hospital when found by myself. The hospital kept her in overnight and discharged her the next morning. [X] and her two daughters came to live with me until her passing in March [2002].

(Carer, Mother, New South Wales, Submission #88)

6.1.11.6.2 Discharge while still unwell

Concerns were expressed that discharge was occurring while consumers were still unwell and without carers being notified. One carer reported that their son was discharged while very ill, which indicates that that an individual care plan had not been devised, and an exit plan (Standard 11.5.1) and a clinical review of the consumer had not been conducted prior to discharge (Standard 11.3.18).

During this time there was a lot of pressure put upon our family to provide accommodation for him on release. It was obvious to his family that e wasn't well enough to be released because he displayed delusional thoughts and behaviour. However, [X] was released to a men's refuge in Queanbeyan without his family being told. He rang us up and told us where he was and asked us to pick up his car.

(Carers, Parents, New South Wales, Submission #198)

6.1.11.6.3 Lack of follow-up despite promises

Concerns were also expressed about the lack of follow-up, even if discharge plans were arranged:

> *In my agreement I was only allowed to stay a maximum of 5 days. The psychiatrist I saw in hospital was very nice & agreed with my therapist that I should have a case manager temporarily, however he wasn't there the day I was discharged & his registrar discharged me. I asked her if she could arrange for someone to help me as I was happy to go home but I didn't know where home was or how to do a lot of things. She said I'd remember when I got home.*
>
> (Consumer, New South Wales, Submission #69)

> *A couple of days later I found the phone number for the mht [Mental Health Team] near me & phoned to request help. I was told that some one would ring me back, when no-one did I tried another day with no luck. I asked my therapist to help & she spoke to them in my presence & was told they would call me Monday to sort out a time. That was a week ago & I still haven't heard anything. I have given up on getting any help.*
>
> (Consumer, New South Wales, Submission #69)

> *I saw my husband rapidly lose weight, lose sleep, lose more interest in things he loved to do and withdraw from me, and yet it never occurred to me that he would attempt suicide again. I had no idea on the high statistics of that happening. No-one told me anything. Especially the fact that a Mobile Crisis Team was available if I needed them to be at my beck and call. I didn't know of their existence until they came to see me after [X] died and they said to me, "your husband has fallen through the cracks. If you wanted to take further action I wouldn't blame you." My heart just sank. Apparently in the clinic they asked [X] if he thought he needed acute care????? What sort of a question is that to ask a suicidal patient? How in the hell would he know? During the whole 9 days after [X]'s discharge from the clinic he did not receive one follow up phone call or anything to check on his condition. That I find is appalling.*
>
> (Carer, Wife, New South Wales, Submission #126)

> *He is supposed to have a case manager who should be dropping by to see how he is coping at home. I think he has been visited on one occasion only.*
>
> (Carer, Mother, New South Wales, Submission #12)

> *After I took the overdose I was admitted to hospital. I only saw the doctor on the day I was being discharged and he told me I would be assigned a case worker but still 4 weeks later I have had no contact.*
>
> (Consumer, New South Wales, Broken Hill Forum #3)

6.1.11.6.4 Quick discharge without adequate planning prior to discharge

Many submissions from carers highlighted serious concerns about the inadequacy and sometimes absence of discharge plans. One report indicates that a discharge plan had not been developed in collaboration with the consumer or carer (Standard 11.5.2), that understandable information about the range of relevant services and supports had not been provided (Standard 11.5.4) and established contact with the service providers had not been arranged prior to discharge (Standard 11.5.6):

> *My son was, at one stage, discharged from hospital whilst we were in the process of moving house and there was nowhere for him to go. They gave us no warning of discharged, as previously promised. He was just thrown out "cured", onto the street. We weren't even told.*
>
> (Carer, Mother, New South Wales, Submission #97)

6.1.12 STORIES OF HOMICIDE AND SUICIDE IN NSW

I am a Carer from country Victoria who had a middle aged son called [X] who used to live at home and was cared for by the family. [X] suffered from schizophrenia. He was a good boy with his medication and he was good to us. He did more for us than we did for him. He was a loving, caring person. For many years he lived with the family but after many years he decided he wanted to try something new. I think he felt he was a burden on us and he decided he would move out. Not long after he moved out he stopped taking his medication – he said he didn't feel very well on his injections - and one night started hallucinating. He was on a trip with a friend in NSW and so he was taken to a large country town and was admitted to the hospital.

The hospital called me to let me know what had happened and I was assured he would be ok. The nurse put him on the phone to me and he sobbed like a baby. The nurse said they would look after him. I kept phoning all day. It was like a panic button had gone off in me. The hospital [X] was at needed to get his patient history from our normal hospital in Echuca but there was a delay in getting this information. I tried to get his medical history for them but couldn't.

At the hospital in NSW the Psychiatric Consultant who examined [X] phoned me and told me he was going to be discharged as he was only homesick. I pleaded with him not to discharge him as he was really sick and needed help. The Consultant said he was ok to be discharged. I begged him to keep my son in hospital. Eventually the Consultant agreed he could be kept in overnight but he told me he would then be discharged early the next day. I asked him if he would do another examination in the morning and he said he would not and that no further examination would take place from mid afternoon until he was discharged.

[X] was then discharged the next morning and on the drive on the way home with his friend he killed his friend because he was still sick and hallucinating. He was sent to jail and had his glasses and hearing aid removed and not returned. He was supposed to be sent to a hospital with a psychiatric ward but instead he was sent to Silver Water jail which does not have a psychiatric ward. At the jail he was sent into the general population area with no toothbrush, no glasses, no hearing aid. That is where he stayed for 2 months. We spent two months trying to get him his glasses and hearing aid. He didn't phone on Father's Day and none of us knew where he was or what was happening.

Eventually we were informed his court hearing was to be held on a certain Monday but we were worried as no contact had been received from him by the Tuesday. As it happened and without telling the family he had been moved to Long Bay Jail where he was supposed to undergo a psychiatric assessment prior to his court hearing. On the day of the assessment the doctor never turned up on the Friday to conduct the assessment and neither did the solicitor who was acting on his behalf. As such the hearing never took place and as a result he became very suicidal. This was communicated to me and I informed and pleaded with the authorities to make them aware he was sick and suicidal. They informed me he would be put in a cell with another inmate who could watch him but in fact he was placed in a single cell on Friday 1 October and hung himself on the Friday night.

I would like to know why he was failed by 3 Government departments. How did this happen? He wouldn't have killed anybody if he hadn't been put in that situation.

I think more consultation with patients is required in terms of medication and more checking if the medication works. I think the prison system does not know how to handle or cope with those with a mental illness. I would also like to say that nearly two and a half months after the police arrested him in NSW we have not heard a thing from the NSW police regarding his possessions and if they are going to return his possessions.

(Carer, Mother, Victoria, Footscray Forum #8)

One of our families today is severely traumatised because their daughter died. She committed suicide after being refused care.

(Carer, New South Wales, Parramatta Forum #1)

The incident that occurred recently when the police shot dead that young student who was stabbing someone is a good example of how badly our system is failing people who have a mental illness. The student went to a mental health service to seek care but was turned away and told he was okay. He wasn't okay but he didn't deserve to die.

(Carer, New South Wales, Sydney Forum #5)

My brother, like many others with a mental illness doesn't have a voice. My brother suicided in a hospital – I came from a modest European background. My parents believed that we would get care.

(Carer, Sister, New South Wales, Sydney Forum #7)

My son [X] committed suicide 2 years ago - he was 26. He was extremely intelligent, creative and a good athlete. His story started when he was 17 and started smoking marijuana and became quite depressed. My husband and I encouraged him to go to the local mental health service – where he saw [Y] and was encouraged by [Y] not to "prostitute" his ideals or lifestyle choices. I also went to see [Y] separately (as did my husband) who more or less said it was none of my business - he's 17… admitted to Cumberland Hospital after stabbing himself in the stomach 3 times in front of us (not long before he died) and being assured by the psychiatrist that this time they would keep him there and he would get help - but because he was smart and presented well - he was out in 3 days - obviously not a well boy - but the system is overloaded - people don't care - just move on. The main point I want to make is that is was so difficult for me to get any help for [X] because he was over 17. He realised just before he died he really wanted to turn his life around and we thought he was just about there when he suddenly decided to end his life. Parents need to be heard – young people can't alway help themselves to get the right treatment. Although having said that now (too late for us) but there are web sites / phone lines and help now available.

(Carer, Mother, New South Wales, Submission #122)

We are devastated as we thought he would be safe and looked after in hospital. We made several calls to [DR1] and the nurses who where looking after our son. I also told them to get in touch with [DR2] who had seen our son 18 months prior. He was willing to speak to them. Our darling son had written a letter and if you read it, he didn't want to die. I don't know how he could manage to get a sheet, plait and wet it and hang himself in the corridor without being noticed. They knew he was very sad, but when we saw the hospital where it happened it was so depressing. They told us that depressed people did not notice their surroundings. Also it was 12 hours before the police (not the hospital) called us. We kept him on life support for 10 days and in that time felt the staff… kept very tight ranks on the matter. There has not been a hearing yet, which we made a statement to say we wished to be present at… Our son was told he could not leave as he was too ill and was on 24 hour surveillance, and this happened.

(Carer, Mother, New South Wales, Submission #135)

Author's son, [X], completed suicide in December 2002, 10 hours after being discharged from the Mandala Psychiatric Unit on the Central Coast. He made 2 suicide attempts prior to admission. [X] was released from the unit after 36 hours in the hospital. "We strongly feel that [X] was not given the chance to want his life to go on. Mental health robbed him of that chance by not giving him the proper care that was required. [X] was released far too early for any counselling or medication to alter his thought pattern, so that he could have made his life worthwhile… Dr [Y] stated to us that his judgement was wrong in releasing [X]. We were not given any information as to how we could help [X] in any shape or form, nothing. We had not heard of the acute care team until [X]'s inquest, this I find appalling, as we were [X]'s carers and foremost parents. If we had more information on how to help our son things could have been different for us and most importantly [X]. We feel that Mandada should be accountable for the lack of care that [X] received at Mandala.

(Carers, Parents, New South Wales, Submission #137)

He was put into the local mental health clinic that evening and discharged on the following Saturday 19th April. Upon discharge I was told nothing about who to call should I need help or advice. [X] was told to wait until the Luvox "kicked in" and then see the psychiatrist who had been attending to him. As well as Luvox, he was given Valium to counteract the anxiety the Luvox caused. I asked why they didn't change his medication, they replied, "Doctor wants to persevere." I knew no better, so thought this must be right. From that moment on, until [X] made his final successful attempt on April 26th, I saw my husband rapidly lose weight, lose sleep, lose more interest in things he loved to do and withdraw from me, and yet it never occurred to me that he would attempt suicide again. I had no idea on the high statistics of that happening. No-one told me anything. Especially the fact that a Mobile Crisis Team was available if I needed them to be at my beck and call. I didn't know of their existence until they came to see me after [X] died and they said to me, "your husband has fallen through the cracks. If you wanted to take further action I wouldn't blame you." My heart just sank. Apparently in the clinic they asked [X] if he thought he needed acute care????? What sort of a question is that to ask a suicidal patient? How in the hell would he know? During the whole 9 days after [X]'s discharge from the clinic he did not receive one follow up phone call or anything to check on his condition. That I find is appalling.

(Carer, Wife, New South Wales, Submission #126)

…we have lost our son in Carasta [Caritas] Mental Health Hospital (Branch of St Vincent Hospital Sydney). It happened on the 16th of June 2003. We are devastated as we thought he would be safe and looked after in hospital. We made several calls to Dr [Y] (second name slips my memory) and the nurses who where looking after our son. I also told them to get in touch with Dr [Z] who had seen our son 18 months prior. He was willing to speak to them. Our darling son had written a letter and if you read it, he didn't want to die. I don't know how he could manage to get a sheet, plait and wet it and hang himself in the corridor without being noticed. They knew he was very sad, but when we saw the hospital where it happened it was so depressing. They told us that depressed people did not notice their surroundings. Also it was 12 hours before the police (not the hospital) called us. We kept him on life support for 10 days and in that time felt the staff, especially [W] and [V] kept very tight ranks on the matter. There are so many bazaar happenings and as we both were shocked and devastated we felt we should have stayed on and pursued it more.

There has not been a hearing yet, which we made a statement to say we wished to be present at. The Dr that was head of … made a comment to us as we left to something of the effect that we shouldn't pursue the matter any further as not having a lot we could lose all that we have.

Our son was told he could not leave as he was too ill and was on 24 hour surveillance, and this happened… Dr [Z]. He felt there was not enough done. I feel the medication he was on made him do what he did. So much to say, but I think you would know.

(Carer, Mother, New South Wales, Submission #135)

Whilst she was in care of the Health Dept Newcastle a few years later, and having some contact with the children, I received two concurrent letters from her, the first stated she was going to jump of the cliff at Nobbys and the second stated 'disregard the first letter' I copied the letters, got in touch with the Health Dept and her case worker and notified them of the letters, they assured me she was OK the Doctor she was seeing had reduced her medication she was doing so well, and all was fine. About 3 months later she through herself under a train at Adamstown. I imagine my experience is not that unusual, but it is a disgrace. Little help that she was to me raising the children, it was at least something, but it left me with no support as a single dad for a good ten years and the children with no Mum.

(Carer, Husband, New South Wales, Submission #160)

I have been informed that a male person committed suicide on Thursday night. The person… was an outpatient of Bunya, a Parramatta forensic facility. He was living in the community under conditional release. As I understand it he presented himself at Bunya for readmittance as he was "relapsing" (episodic symptoms). However, sadly, Bunya had no beds. He was taken home by the Sydney Mental Health Community Support Team and left there alone being told that they would be back in a few hours. While he was alone he killed himself by taking poison. Tragic that he must have wanted "pain relief" so badly that he chose suicide as the way of terminating his pain and life.

(Anonymous, Victoria, Submission #272)

At the beginning of July, 2004, he admitted to his wife, [Y], that he was not well and said that he wanted to be readmitted to the Lindsay Madew Ward at Hornsby Hospital. He phoned the hospital and they sent two people to his home. His request to them for admission to hospital was refused, and they said they would monitor him at his home. They immediately increased his medication to 800 mg. daily, indicating that the 400 mg. dose was far too low. On their second visit, he again asked to be readmitted to hospital, but again was refused… From memory, the home visits by Hornsby Hospital staff were made on Friday 2nd, and Saturday 3rd of July, 2004. They phoned him on Sunday 4th and again on Monday, 5th. On that Monday and also on Tuesday 6th, he went to his workplace in the city. On his way home on Tuesday evening, he fell / jumped from a suburban train. He was admitted to St. Vincent's Hospital, and died the next morning, Wednesday, 7th, without regaining consciousness. In effect, within days of Hornsby Hospital's refusal of his request for admittance to hospital, and the doubling of his medication, Andrew was dead. As laymen, we cannot help feeling that he would be alive today –

- *had he been readmitted as requested, to the secure psychiatric ward at Hornsby Hospital.*
- *had his condition been monitored regularly after his first episode, which we are now told is normal procedure.*
- *had his daily medication of Epilim not been reduced from 1000 mg. to 400 mg. when at the Sydney Adventist Hospital in 2002.*

We feel the system failed us – and [our son] …

(Carer, Father, New South Wales, Submission #346)

…my daughter, [X] who passed away in March 2002 as a result I think, of inadequate mental health care. [X] had a history of depression and Obsessive Compulsive Disorder. For the last 12 months of her life, [X] sought unsuccessfully for help to control her depression and OCD… As [X] became more and more depressed and anxious, she developed an eating disorder and worried about being fat, even though she was only 52 kilos. After attending a local doctor, whom I don't know, she was prescribed Duromine, a weight loss tablet I knew nothing of this. [X] also sought help from an OCD clinic near Newcastle and one in Sydney, but was put on a "waiting list". We are now left with the grief of a child we will never see again. There was nowhere to get help for this terrible nightmare we found ourselves in and we had to watch her waste away before our eyes. On the morning of March 24, [X] was found dead by her 9 and 10 year old daughters as an interaction of these lethal drugs when too many are taken. These little girls are now in my care and I blame the "system" for my daughter's death and the children not having a mother.

(Carer, Mother, New South Wales, Submission #88)

My 30 year old daughter committed suicide on the first March 2004. She had been depressed for eighteen years. Melinda has been in both private and public hospitals - St Vincent's [Victoria] and Nolan House at Albury Base Hospital let her go to her death… In February 2004 [X] was then transferred and scheduled to Nolan House. … a court order was made for [X] to stay for 14 days… I told him she shouldn't be allowed out. I was told by [Z] that she had been approached by the head of Nolan House and asked if [she] was happy to take care of [X] 24/7. [Z] told him no. He didn't reply to [Z] and told her [X] could go. [X] left with [Z]… I spoke with [X] over the next two weeks… one incident… [X] rang me in tears… I then again spoke to her to go back out and stay at a friend [W]'s place… She said she would. This was the last time I spoke with [X]… The heads psychiatrist at Nolan House in Albury would have known that he was sending her out to commit suicide, the village idiot would have known that.

(Carer, Father, New South Wales, Submission #102)

Author's son, [X], completed suicide in December 2002, 10 hours after being discharged from the Mandala Psychiatric Unit on the Central Coast. He made 2 suicide attempts prior to admission. [X] was released from the unit after 36 hours in the hospital. The coroner stated "It seems to me clear that staff were over anxious to discharge [X] due to the perennial shortage of beds at Mandala and that this is one of many cases which highlight Government neglect in the area of mental health facilities. Many promises are made but many do not eventuate or are delayed excessively. This is causing needless deaths in the community. The mental health beds at Wyong hospital have been promised for some time but are still not available. The public are entitled to expect that the mentally ill will be properly cared for by government funded services… The standard of care provided for [X] left much to be desired. After considerable questioning, this was reluctantly conceded by some of the doctors who gave evidence at this inquest… [X] was discharged with a minimum of formality and no guidance or assistance…

(The coroner's report in Carers, Parents, New South Wales, Submission #137)

On leaving the hospital with her son, the only information given to his mother was a copy of the discharge summary and four pages of "better sleep tips". Dr [Y], the discharging doctor, was asked if there was a discharge protocol. She replied that she did not use one and was unaware if one existed. Dr [Z] later agreed that there should have been a conference with the family before discharge… The standard of care provided for [X] left much to be desired. After considerable questioning, this was reluctantly conceded by some of the doctors who gave evidence at this inquest… [X] was discharged with a minimum of formality and no guidance or assistance to them or their son…

(The coroner's report in Carers, Parents, New South Wales, Submission #137)

6.2 VICTORIA

ANALYSIS OF SUBMISSIONS AND CONSULTATIONS FROM VICTORIA AGAINST THE NATIONAL STANDARDS FOR MENTAL HEALTH SERVICES

In summary, information presented in this section was gathered from 93 submissions (see Appendix 8.3.2) and presentations made at community forums attended by approximately 210 people (see Appendix 8.1). A draft copy of this report was sent to the Premier and Minister for Health for comment. An analysis of the response from the Victorian Government (reproduced in Appendix 8.4.2) and an overall review of mental health service delivery in Victoria is contained in Part 2.7.2.

6.2.1 STANDARD 1: RIGHTS

The rights of people affected by mental disorders and / or mental health problems are upheld by the MHS.

Under this Standard, submissions and presentations indicate concerns about:

- provision of information about rights;
- complaints procedures;
- access to advocates;
- provision of information about the consumer's mental illness, treatment and services available;
- consumers are not being treated with dignity and respect;
- the rights of carers;
- access to Auslan interpreters;
- rights of people with mental illness subject to the criminal justice system;
- non-compliance with relevant instruments protecting the rights of people with mental illness; and
- provision of information about mental health and how to access services for people from a non-English speaking background.

6.2.1.1 Provision of information about rights

> *We have been providing support to a man from Iraq who has a mental illness. He was a political prisoner. After September 11 he started experiencing racist remarks. He became depressed and went to hospital for care. He was admitted and was given medication. He wasn't given any other information so he said he wanted to leave. They said he couldn't go and put him in seclusion. When he woke up it was the next morning and he was in seclusion – he'd obviously been sedated but then they discharged him that morning. If he was well enough to leave that morning why didn't they let him go home the night before and why did they put him in seclusion? He was discriminated against, that's why.*
>
> (Consumer Advocate, Victoria, VMIAC Consultation #19)

The above report raises many concerns about the rights of people with mental illness: lack of provision of information about rights as soon as possible (Standards 1.2 and 11.4.E.6) in a manner that is understandable (Standard 1.3 and 11.4.E.6); lack of provision of information about mental disorders and available treatments and supports (Standard 1.8); lack of awareness of a right to have an independent advocate or support person (Standards 1.6 and 11.4.E.6); least restrictive alternative (Standard 11.4.E.1); possible lack of informed consent to medication (Standard 1.4.C.3) and equitable access (Standard 7 and Standard 11.1.1).

One consumer advocate expressed concern that the problem with the provision of information about rights (Standard 1.2) may lie with misunderstandings between staff about whose responsibility this is. Standard 1.12 (documented policies and procedures exist and are used to achieve the criteria) should address these roles and responsibilities to ensure there is not confusion.

> *Consumers' rights were explained to them in a way that they could understand – very few doctors and nurses know whose job it is to explain to patients what their rights are.*
>
> (Anonymous, Victoria, VMIAC Consultation #13)

6.2.1.2 Problems with the complaints procedures

> *Complaints diffusion is a big problem. People are afraid to complain. There's a fear of impact if they complain. Even when the evidence is overwhelming, there is still a real fear. The more serious the complaint, the more "they" will try to discredit the consumer. The culture is such that "they" never want to help the consumer.*
>
> (Consumer Advocate, Victoria, VMIAC Consultation # 9)

Overall, many people reported that they were afraid that services would be withdrawn if a complaint was lodged. Others reported that their complaints were ignored or inappropriately dealt with. This would imply that the complaints procedures were not easily accessed, responsive and fair (Standard 1.10). One consumer advocate reported that the process has improved with the ability to lodge complaints with the Health Complaints Commission. A well functioning complaints procedure, as described by Standard 1.10, also provides a mechanism by which to 'improve performance as a part of a quality improvement process' (Standard 1.12) and allow for the identification of single or systemic problems and thereby allow personal redress or systemic improvement.

> *I want to talk about what happens to patients if you complain about staff. If you complain you go from the frying pan to the fire! …You still need the treatment and the service so you don't complain.*
>
> (Consumer, Victoria, Morwell Forum #10)

> *One of the major difficulties is that if you have a mental illness almost everything you say can be discredited. The policies are fine but it's the practices.*
>
> (Consumer Advocate, Victoria, VMIAC Consultation #14)

> *Complaints are still problematic but things have improved because of the Health Complaints Commission. All complaints now go to conciliation. The conciliation process is a very good thing because it gives the consumer the chance to get natural justice – to say how they felt.*
>
> (Consumer Advocate, Victoria, VMIAC Consultation #15)

> *…we expected this to be an informal meeting before the hospital enquiry into [X]'s death. I was told by Dr [Y] however, that the hospital enquiry was over. I queried how this could be, since no-one had contacted me. He said, "I spoke to people who had spoken to you and they knew of your concerns. These words may be seen as a metaphor for what is being perpetuated in this institution and what has been part of [X]'s life for her last weeks; a lack of communication, a lack of respect, a seeming lack of humanity.*
>
> (Carer, Mother, ex-nurse, Victoria, Submission #206)

> *In 1999 I put our complaint into HREOC federal it took them just on 9 months for their finding, I think it was put in the too hard basket, the outcome from HREOC was that it was a medical problem. Because [X] my wife was having active mental health problems with her schizophrenia and that she was poorly controlled while under the CTO [Community Treatment Order] a decision was made not to treat her with either chemotherapy or radiation to me that is a Human Rights issue, even the HSC [Health Services Commissioner] office told me that there 15 to 18 other such cases in Victoria like our case. When I was told this I got [lawyer] to ring the HSC office he was told the same thing I have his notes fro the phone conversation to the HSC office again a*

HREOC issues I think. The whole process of getting answers on complaints is unfair and one sided to the Government side. Government Departments fully funded Government groups which are fully or partly funded will not really go in and bat for the person with the illness or the carer because they fear they will loose their funding or will not be able to win tenders for services plus the groups play games with each other, I have seen it, plus they all know it them selves.

(Carer, Husband, Victoria, Submission #179)

The provision of HACC [Home and Community Care] services is a real problem – people with a mental illness don't get HACC services. Also if you are a person with a mental illness and have a bad interaction with the service you are almost immediately excluded from further care… I took it to the Minister through VICCAG [Victorian Community Advisory Group].

(Anonymous, Victoria, Morwell Forum #3)

Given the feedback the VMIAC has received from patients who have experienced seclusion we would have to conclude that this practice is one of the most damaging treatment modalities in psychiatry… When patients try to talk about the experience or complain about it, defensive reasoning takes over and the issue of the impact of the experience on the patient is ignored and reflective practice negated.

(Victorian Mental Illness Awareness Council, Victoria, Submission #332)

A just and responsive mental health system needs complaint handling processes at all levels where consumers interact with the system. The MHLC [Mental Health Legal Centre] hears from consumers all the time who are unsatisfied with the way their complaints are being handled. It is only through learning how to investigate consumers claims of abuse and neglect within the system with good will and a lack of defensiveness that we are really going to 'de-institutionalise the system' At present the system remains bound by old values which mistrust consumers views, which pathologise people who complain, which makes people go on a bureaucratic paper chase and which perceives disputes that are not resolved for consumers as satisfactorily closed This will continue to breed the mistrust and sometimes hatred between people who use the system (often by force) and people who work in the system. Both groups (but particularly workers) are at risk of 'blaming the system' for things that are actually habitual ways of 'playing the game' practiced by individual providers. There needs to be transparency in complaints handling processes and management held responsible for their practice and the practice of the staff who work under them. Such accountability may mean having recourse to the Courts, which in now only an option in a narrow set of circumstances.

(Mental Health Legal Centre, Victoria, Submission #330)

Both my daughter and myself complained saying the procedure had not been fully explained to us and we were, misled. My daughter pleaded with the nurse to phone the psychiatrist 'on call' and ask them to come out that evening. (Which could have been done 3 weeks prior on the 26th September). Luckily for us she agreed and my daughter was finally seen at 8.30pm that night. The psychiatrist decided it would be detrimental to place her in the psychiatric ward and sent her home in my care. – I did make a formal complaint to the Dandenong Hospital a week later – I still have had no response [18.01.2005].

(Carer, Mother, Victoria, Submission #352)

Ombudsman / Independent Mental Health Commission - Given the number of consumers who do have very negative experiences as a result of their condition, whether it is within the healthcare system, in the workplace or as they deal with government services and agencies, a permanent National body should be established to monitor the situation. States would then replicate the National body. This would enable consumers to access an independent umpire and advocate specific to their circumstances when needed. This body would need trained Consumer Commissioner roles. (See New Zealand Mental Health Commission website)

(Centre for Psychiatric Nursing Research and Practice, Victoria, Submission #323)

6.2.1.3 Lack of access to advocates

Concern was expressed that consumers are not able to access advocates as advocacy services are diminishing due to decreased funding. The Centre for Psychiatric Nursing Research and Practice argued that there is a pressing need for such services in order to promote and protect the rights of people with mental illness. Standard 1.6 states: 'Independent advocacy services and support services are actively promoted by the MHS and consumers are made aware of their right to have an independent or support person with them at any time during their involvement with the MHS'.

> *To offset the abuse of human rights occurring on a daily basis, the need for advocacy services is stronger than ever before, and yet funding for these services has steadily diminished. Without access to independent, fully funded, fully trained advocates, human rights will continue to be breached and the effects will continue to be long lasting and impede the recovery of so many consumers. Independent advocacy can be very effective when used pro-actively in mental health service provision.*
>
> (Centre for Psychiatric Nursing Research and Practice, Victoria, Submission #323)

6.2.1.4 Information about the consumer's mental illness, treatment and services available not provided

Many carers stated that they did not receive adequate information about the consumer's recently diagnosed illness or treatments available. Furthermore, many carers stated that they were not given information about services available. Standard 1.8 states: 'The MHS provides consumers and their carers with information about available mental health services, mental disorders, mental health problems and available treatments and support services'. This is of serious concern on many levels; consent, choice, the right of a person to know about their illness and the treatment plan (and any side-effects) and for carers to be informed regarding what is and will be happening and how they best support the consumer or access support for themselves. The following quotes well illustrate this point:

> *When the first diagnosis comes, we'd like to see families/carers given information about the illness they're suddenly dealing with, and all the resources available to help them and their loved one. When we were suddenly given the diagnosis "chronic paranoid schizophrenia", which was such a surprise, we were left with the diagnosis as if it was the flu.*
>
> (Carer, Mother, Victoria, Submission #211)

> *And support groups help families too. Being at the courses and support groups helps families realise they're not the only ones this has happened to, and they stop feeling alone. So it would be good if they were told about all that's available when it suddenly happens.*
>
> (Carer, Mother, Victoria, Submission #211)

> *I've recently been to a conference in Denmark WSOP – Human Rights, not resources, are the biggest issue. In mental health it's the only area of health where we are denied the right to refuse treatment. Forced treatment has to be seen as a failure.*
>
> (Consumer, Victoria, Melbourne Forum #4)

> *Despite the improvement in the amount of information about Mental Illness and the resources which are available, it is often not easy to access. This is particularly true for people who are in the private system. Private psychiatrists do not appear to provide this information to patients, nor do they pass on information to carers.*
>
> (Peninsula Carers Council, Victoria, Submission #321)

For carers faced with trying to learn about Mental Illness and with trying to find out about services which are available for consumers and carers, it is very difficult to know where to start.

(Peninsula Carers Council, Victoria, Submission #321)

The failure to provide information as detailed in the above examples, also implies that these consumers and carers were not provided with a written or verbal statement of their rights and responsibilities as required by Standard 1.2 (Consumers and their carers are provided with a written and verbal statement of their rights and responsibilities as soon as possible after entering the MHS).

6.2.1.5 Consumers are not being treated with dignity and respect

Overall, consumers, carers, organisations and workers expressed concern that during their involvement with the MHS consumers were treated with disrespect and as citizens whose rights as described under the National Standards were ignored.

Asking questions, seeking explanations, and especially making complaints are often seen as 'difficult behaviour' that is often dismissed as symptomatic of our illness or, as many consumers have often heard, as 'the illness speaking' – this is extremely offensive and, for many, traumatising.

(Insane Australia, Victoria, Submission #232)

Over all our contact with the Mental Health System has been one of frustration, Our observations are that Mental Health Patients are treated as second rate citizens and the carers are over reacting nuisances. It appears staff are under trained for compassion, Patients are quickly threatened with seclusion for minor requests or for voicing their opinion.

(Carers, Parents, Victoria, Submission #246)

I have also been patronised, infantalised, spoken to rudely, made a scapegoat to save staff getting into trouble. There have been good experiences too but too often these staff are either too junior or too intimidated to stick up publicly for humane practice. I have learnt that some people working in the system are fantastic but too often they have to do the "good stuff" surreptitiously and behind the backs of senior clinicians who continue to have too much power.

(Consumer, Victoria, Submission #240)

Young people in the mental health system are extremely vulnerable and disempowered. They are much less likely to be listened to than adults and are often not even told what is going on with their own treatment. Their opinion is frequently discredited and their wishes ignored.

(Youth Participation Worker, Victoria, Submission #255)

6.2.1.6 The rights of carers

The Peninsula Carers Council raised concerns about the treatment and rights of carers. They argued that mental health services need to help and support carers as much as possible and treat cares with respect. As much of the care for people with mental illness is provided in the community by families, the need for mental health services to develop a comprehensive policy on the role and function of carers to define their rights is argued so that the rights of carers are formally recognised:

Members of the PCC have consistently heard stories of carers being dismissed, treated with disrespect and not listened to by health professionals. Not only do carers need the help and support of health professionals for the difficult job they are doing, but they are entitled to be treated with respect.

(Peninsula Carers Council, Victoria, Submission #321)

6.2.1.7 Lack of access to Auslan interpreters

One case manager expressed concern regarding the lack of access to interpreters for people with mental illness who have hearing impairment. This barrier results in additional stress for both the consumer and their case manager, who then have to try and find funding and a service that can provide an interpreter. Standard 1.7 states: 'The MHS upholds the right of the consumer and their carers to have access to accredited interpreters'.

> *The GP prescribed antidepressants and made a referral to a local counselling service. [Z] took referral information from the doctor and myself and took almost 2 weeks to come to the decision that they were unable to provide a service to my client solely on the basis that they had no funding for an interpreter. [X] is deaf and requires an auslan interpreter for her counselling sessions. [Z] agreed that they were the most appropriate local service for my client but none the less were unable to offer service. I was and remain outraged by this clear discrimination of my client. I am now looking at funding options to try to obtain money for an interpreter for the counselling sessions, as well as looking at other services in the region who I can refer [X] to who will provide an interpreter, but all this is time consuming which causes additional stress on [X] while they wait for supports.*
>
> (Case Manager, Victoria, Submission #337)

6.2.1.8 Rights of people with mental illness subject to the criminal justice system

VMIAC raised concerns with regard to the rights of people with mental illness in the criminal justice system and the need to be particularly vigilant about protecting the rights of these consumers and their access to treatment and support services. VMIAC raised concern that the rights of people with mental illness are not being protected:

> *A recent example perhaps best describes how politics influences decision making rather than standards of treatment and care. A forensic patient put in an application to the Forensic Leave Panel for unescorted leave. His treating team, the Panel judge, psychiatrist and community member supported the leave application. The member from the Office of the Chief Psychiatrist however did not support the leave. The reason given - What if you are out on leave and someone recognised you and phoned the Herald Sun. What does it say about the independence of the Office of Chief Psychiatrists when it allows the Herald Sun to influence the Office's duty to standards of treatment, care and rehabilitation?*
>
> (VMIAC, Victoria, Submission #332)

6.2.1.9 Non-compliance with relevant instruments protecting the rights of people with mental illness

Concerns were expressed by the Mental Health Legal Centre, Insane and the Brotherhood of St. Laurence and Catholic Social Services Victoria that due to a lack of resources, human rights issues are being "ignored, overlooked, diminished and minimised". As a result, people with mental illness and their families are "one of the most acutely disadvantaged groups in Australia".

Standard 1, as noted above, states: 'The rights of people affected by mental disorders and / or mental health problems are upheld by the MHS'. Further, Standard 1.1 state: 'Staff of the MHS comply with relevant legislation, regulations and instruments protecting the rights of people affected by mental disorders and / or mental health problems'. Included in the notes to Standard 1.1 are: The Australian Health Ministers' Statement of Rights and Responsibilities, the UN Prinicples on the Protection of People with a Mental Illness and Improvement in Mental Health Care, departmental codes of conduct and mental health legislation. According to the following quotes, the human rights of people with mental illness and their families and carers are not being upheld:

There is anecdotal data to suggest that despite the consumer having the right to participate in their treatment planning, in many instances, this is not happening. This has serious consequences when CTO's [Community Treatment Orders]] are simply resigned every 6 months.

(Centre for Psychiatric Nursing Research and Practice, Victoria, Submission #323)

It is our experience that because resources are limited, there is a reluctance to allow rights to be a focus. There is a sense that treatment, or the lack of it, is the most important thing to focus on and that any issues which divert from this focus are an attempt to divert precious resources. As a result, we believe that rights are constantly ignored, overlooked, diminished and minimised as not important. This spills over into accountabilities and the quality of and transparency of decision-making in relation to service delivery. We understand that mental health service delivery and rights are a complex set of competing and complimentary issues that need to be delicately handled. However, we do not believe that that balance is right and as a result, human rights are constantly being trampled.

(Mental Health Legal Centre, Victoria, Submission #330)

The current, limited public debate on mental health in Australia today focuses largely on the appalling lack of resources for mental health services. At Insane we agree that mental health services are grossly neglected in this country and that many people are dying, mostly through suicide, from this neglect. This neglect needs to be seen as not just a failure to resource an essential service but as a violation of our fundamental human rights.

(Insane Australia, Victoria, Submission #232)

People living with a mental health problem are one of the most acutely disadvantaged groups in Australia. They are more likely to be living in poverty, with limited access to affordable and secure accommodation, to have low education and to be without employment. Sadly we have the knowledge and abilities to treat people. However, the failure of governments to adequately resource services and the lack of commitment to genuine reform have lead to a chronic deterioration of care and support to consumers, their families and carers. It is not acceptable that people seeking relief from the symptoms of their mental illness are unable to receive the help that will preserve their rights and dignity. The ability of consumers to access service systems across the spectrum of care demands that government urgently increase their investment into services.

(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

6.2.1.10 Lack of information about mental health and how to access services available for people from a non-English speaking background (NESB)

Concern was expressed that some community groups that do not speak English have very little access to information about mental health, mental illness, how to access services and the right to an interpreter. This knowledge is critical for service access and the promotion and protection of the rights of people with mental illness who speak a language other than English:

There are some areas of problems that the Polish community has to face:

1) *There is a lack of information about mental health issues available in Polish and what is available is difficult to locate and it is not distributed to the community. Most Poles are unfamiliar with how to locate this information in Polish.*
2) *There is a lack of prevention and early intervention programs for Polish people, which contribute to the high admission rate to mental health services at the crisis stage.*
3) *The Polish community is not familiar with mainstream mental health services or whether any provide culturally and linguistically appropriate support.*
4) *The stigma around mental illness for the Polish community prevents seeking assistance if people are aware of services.*

5) *We have conducted research to identify the understanding of and that measures the level of depression among the Polish community. 174 people participated and 32% self identified as experiencing from depression. 52% are not aware of any services they can access, 30% would seek assistance from their GP. These figures show that the majority of Polish people would not know where to ask for help and the chances that they need help to deal with depression is high.*

(Australian Polish Community Services, Victoria, Submission #329)

6.2.2 STANDARD 2: SAFETY

The activities and environment of the MHS are safe for consumers, carers, families, staff and the community.

Under this Standard, submissions and presentations indicate concerns about:

- consumers not being protected from abuse in hospitals;
- lack of support and services in the community to protect consumers from abuse;
- carers feeing unsafe due to lack of services and support in the community; and
- safety concerns of staff.

6.2.2.1 Lack of safety in hospitals – consumers not protected from abuse

Standard 2.2 states: 'Treatment and support offered by the MHS ensure that the consumer is protected from abuse and exploitation'. The following quotes express concern that consumers were not protected from abuse in treatment settings. This also indicates that in these particular situations, 'policies, procedures and resources' were not available to promote the safety of consumers (Standard 2.3) in hospital settings.

…it goes against the grain to see people being made to stay on a trolley, in a cubicle, usually sedated, occasionally mechanically restrained, just because the mental health system is overloaded and poorly resourced. This situation is chronic and untenable.

(Clinician, Victoria, Submission #201)

There is a staggering amount of sufferers of mental conditions who have been sexually abused… Some go to private therapy which they can ill afford. They are handling 2 stigmas while trying to get justice. Another problem is when hospitalised they are often put into a group situation, some patients with sexual desires often prevalent in mania can abuse unwittingly. But my concern is the lack of security in these wards, staff sit in their box while unsecured areas are unsupervised, we need more staff on the floor. Sleeping arrangements also are a worry in some hospitals I believe. Our rights are that we should feel safe, but quite often this is abused. Thank you for bearing with me.

(Consumer, Victoria, Submission #193)

I'm now treated for post-traumatic disorder and that trauma happened in hospital. Sometimes hospitals make you sick.

(Consumer, Advocate, Victoria, Melbourne Forum #14)

The lack of proactive preventative measures that exist in mental health services generally, but in particular in in-patient facilities, to ensure the safety of all patients is of major concern. Policies seem to only exist to guide staff about what to do after an event rather than before an event. It is our view that it is the right of every patient to not only be safe, but also to feel safe.

(VMIAC, Victoria, Submission #332)

I have been a patient in the mental health system for twenty years… During that time I have learnt that many people working in the system get habituated to violence. The psychiatric hospital is not safe. I have been assaulted. I have had my belongings stolen. I have been abused. I have not been protected by staff. Sometimes staff are the worst perpetrators of this violence.

(Consumer, Victoria, Submission #240)

The specialist forensic hospital is unable to offer beds to area mental health services coping with violent inpatients, leading to an increase in the level of violence and assault in the general hospital psychiatric units. The rights of the mentally ill offender to receive treatment and care for their mental illness and the rights of people in the inpatient units of general hospitals to treatment and care in a safe environment are being compromised.

(ARAFEMI Victoria, Victoria, Submission #230)

6.2.2.2 Lack of support and services in the community to protect consumers from abuse

Not only were concerns raised regarding the safety of consumers in hospital settings, but concerns were also raised with regard to consumers not being protected from abuse in the community. One clinician cited the reason for this as the failure to implement the necessary community treatment and support services, including supported accommodation post-deinstitutionalisation:

One of the problems when we moved patients from long term care into the community was that a lot of abuse has occurred because we have never had the community system built to the level it's needed.

(Regional GP, Victoria, Morwell Forum #8)

6.2.2.3 Carers feeing unsafe due to lack of services and support

[Y] died… apparently driven to suicide after living with her husband who was diagnosed with bipolar disorder. He was often non-compliant and when not taking his medication, threatened to kill her and [their child] if she tried to leave him. She could not get adequate support from Psych services or obtain emergency housing so that she could be safe to leave.

(Anonymous, Victoria, Submission # 306)

Standard 2.3 states 'Policies, procedures and resources are available to promote the safety of consumers, carers, staff and the community.' The helpline dialogue described below shows how attempts to contact the police and the mental health service when a consumer repeatedly attacked his parents resulted in nothing more than the consumer being assessed and then returned to his home on the same day:

A young woman rang the Helpline I'm on, and said her 18-year-old cousin was attacking his parents every week. Each time the parents rang the Police, they came and took him to the mental health place, and brought him back and said he was fine. She felt he was in danger of murdering his parents.

(Carer, Mother, Victoria, Submission #211)

This 'revolving door' type of 'care' was commonly reported by consumers and carers alike.

> *I have been forced to leave my home because of his constant violent outbursts and damage to my home. I was living in fear all the time when I lived with my son. My home has had every window in it smashed and there are holes that have been punched or kicked in most of the walls. I have telephoned the C.A.T [Crisis Assessment and Treatment] team on many occasions when my son has been having an explosive outburst and at other times when he was just depressed and anxious. The C.A.T team say that they will not come and that I should call the police. The police tell me I should ring the C.A.T team!!!!*
>
> (Carer, Mother, Victoria, Submission #296)

6.2.2.4 Safety concerns of staff

One clinician also expressed concern that staff do not always feel safe when dealing with some consumers, in particular, with consumers who are using drugs. This suggests that Standard 2.3 ('Policies, procedures and resources are available to promote the safety of consumers, carers, staff and the community') has not been adequately met and/or that staff may have been insufficiently trained to 'understand and appropriately and safely respond to aggressive and other difficult behaviours' (Standard 2.4):

> *What we are faced with now is a cohort of people who have a mental illness and are using drugs. People – my colleagues – are frightened.*
>
> (Clinician, Victoria, Footscray Forum #5)

> *It is our view that there appears to be a shortage of experienced staff, which again not only impacts on the stress levels of staff, but on patients as well. It has not been uncommon for patients to express concern about the stress levels of staff. We believe patients have enough to worry about without having to be concerned about staff. On some occasions when we have mentioned these concerns to individual managers the response is often that the "staff put patients up to this." This sort of defensive reasoning does nothing to solve the problem – it just facilitates its continuance. It also demonstrates a lack of concern about staff and / or ignorance about the problems within their organisation and their responsibility to take care of their staff and address issues of concern.*
>
> (VMIAC, Victoria, Submission #332)

Concern was also raised regarding staff bullying and the impact this has both on the wellbeing of staff and their ability to provide quality services to consumers:

> *There are also going concerns, and an increasing body of evidence to suggest that bullying of staff by staff (often managers but not exclusively) is very common impacting on staff wellbeing and their ability to be therapeutic with patients / clients.*
>
> (ANZCMH Nurses Victorian Branch, Victoria, Submission #316)

6.2.3 STANDARD 3: CONSUMER AND CARER PARTICIPATION

Consumers and carers are involved in the planning, implementation and evaluation of the MHS.

> *Even though the First National Mental Health Strategy was controversial and flawed it was very strong on consumer participation and very exciting in terms of making gutsy changes to some of the taken-for-granted assumptions of the 'mental illness establishment'.*
>
> (Consumer, Advocate, Victoria, Submission #166)

Under this Standard, submissions and presentations indicate concerns that:

- the views of consumers and carers are not being heard' and
- attitudes of staff and service providers are hindering participation by consumers and carers;
- insufficient resources to support consumer participation;
- the voice of consumers with Borderline Personality Disorder, in particular, are not being heard; and
- voice of adolescents with mental illness or mental health problems not heard.

6.2.3.1 Consumers and carers not being heard

Consumers and carers expressed concerns that their views are not being heard and they have no avenues to give voice to these views so that they can be heard in a meaningful way. According to Standard 3.2 'The MHS undertakes and supports a range of activities which maximise both consumer and care participation in the service'. Many consumers and carers feel that these activities are not being supported by the MHS:

> *Too many times over the years have many other people and I given information, been part of a consultation group, spoken up when asked to do so. Too many times have we been promised that something would be done? Too many times we have been let down. I am certain that somewhere in archives there is a plethora of information that has been collected and not activated on. I like many of my colleagues in the Mental Health System am sick and tired of being told that we have a voice only to find out that we have been fooled once again.*
>
> (Consumer, Victoria, Submission #112)

> *As a worker I have credibility, as a carer I have none.*
>
> (Carer, and Disability Accommodation Service Provider, Victoria, Melbourne Forum #9)

> *The consumer voice has to be heard. The discussion about having another Burdekin Enquiry is not sufficient and there is sorry business in mental health and it needs to be attended to. Apologies need to be made and there needs to be restitution in some cases. Nothing about us without us is our motto.*
>
> (Consumer, Victoria, Melbourne Forum #4)

> *Carers get no consideration, they really don't.*
>
> (Carer, Victoria, Melbourne Forum #3)

> *Many of these volunteers report that their time on these bodies was, at best, a complete waste but, more often, that they felt cheated and ripped-off – their contributions were rarely heard and virtually never acted upon.*
>
> (Insane Australia, Victoria, Submission #232)

> *I implore you please do something for these suffering souls look at the state of "Mental Health" needs and talk to those who know what the needs are mostly the "Wife" "Partner" "Parents" those at the coal face not the so called experts.*
>
> (Carer, Wife, Victoria, Submission #248)

Some presentations and submissions, however, spoke of the positive impact and work which results from consumer and carer involvement in the mental health sector. The following quotes exemplify this:

> *The majority of the people I work with are very committed to their role and go out of their way to help.*
>
> (Consumer, Paid Consumer Consultant, Victoria, Morwell Forum #5)

I work for Latrobe Hospital as a consumer consultant. We still need assistance with care.

(Consumer, Consultant, Victoria, Morwell Forum #1)

In 1999 the Commonwealth funded a very interesting series of weekend workshops. They were attended by representatives of the umbrella organisations for each of the discipline groups that play a major role in servicing the mental health sector: mental health nurses, psychologists, psychiatrists, occupational therapists and social workers. Also invited to these workshops were a critical mass of consumers and a critical mass of carers… The most interesting thing that happened however was that as these workshops progressed this funny defensive humour was slowly replaced by the realisation that the consumer body of expertise (the lived experience of 'mental illness') was actually as important as each professional group's accumulated wisdom. Many professionals who experienced these workshops tell vivid stories of how they were challenged and how they changed through the experience. Several people went back to their home cities and proceeded to initiate projects and programs, which came directly out of their learning in Canberra. Some consumers came away feeling that, at last, we were involved in a way that was not just tokenistic.

(Consumer, Advocate, Victoria, Submission #166)

A significant finding of the research project – reverberating throughout the accounts given by most informants – is that even with marked limitations in resources for consumer participation activities, a great deal of service improvement and innovation is being brought about in many local clinical mental health service systems.

(Consumer Advocate, Victoria, Submission #253)

There is considerable support and some would say a growing "critical mass" of support, commitment and goodwill toward consumer participation among many service provider managers and staff and some genuine attempts to work in partnership and collaboration with consumers – as well as some quite entrenched pockets of doubts, resistance and "hangovers" from the institutional attitudes and approaches in some areas.

(Consumer Advocate, Victoria, Submission #253*)*

A Ministerial Advisory Committee on Mental Health was announced in August 2004, giving consumers, carers, non-government organisations and clinical leaders input to policy decision-making at a State level.

(SANE Australia, National, Submission #302)

Carer Consultant positions are being established alongside Consumer Consultants to articulate concerns of family and other carers at an Area level.

(SANE Australia, National, Submission #302)

6.2.3.2 Attitudes of staff and service providers are hindering participation by consumers and carers

Concern was expressed that one of the main obstacles to meaningful participation by consumers and carers was the attitude of many service providers, managers and bureaucrats. For example. the Centre for Psychiatric Nursing Research and Practice suggested that "unless we mandate consumer perspective in the training and education of all mental health practitioners" this situation will not change and the rhetoric of inclusion of the consumer voice will not be translated into meaningful participation with real commitment:

While some organisations appear to be genuinely committed to consumer participation, anecdotal reports from consumer consultants and consumer representatives persistently and consistently indicate that the attitudes of many service providers, managers and bureaucrats are that consumer participation exists because it has to rather than it needs to.

(VMIAC, Victoria, Submission #332)

There is a rhetoric of inclusion of the consumer voice in mental health debates but the consumer-survivor experience of this, virtually unanimously, is that this rhetoric is lip-service not matched by any real commitment and certainly not by any meaningful resources to promote the inclusion of the consumer perspective…

(Insane Australia, Victoria, Submission #232)

Other Consumers Consultants, an apparently smaller group – who measured their situations in various different ways – said that the local Area Mental health Services where they worked remained apparently "resistant and entrenched" toward consumer perspectives, maintaining attitude barriers and "us and them" thinking, and sometimes taking a "pathologising" view of issues. A more subtle but still difficult situation was where consumers perceived that services seemed to be "saying all the right things" but were short on meaningful action – sometimes opting for quick fixes, tick-the-box checklists and "tokenistic" displays of consumer participation through Public Relations exercises, and ever more pamphlets.

(Consumer Advocate, Victoria, Submission #253)

Money alone can't buy service improvement… service provider "attitudes" can be a make or break factor. It emerged that many of these Consumer Consultants were often more immediately concerned and affected by the many ways that the cultures and environments of mental health services could be a supporting factor for consumer participation efforts, or the source of difficult and frustrating barriers. ***"Attitudes"*** *of service provider staff and managers towards consumers and receptivity to change were seen by some stakeholders as an important factor influencing outcomes. Consumer consultants spoke about a wide range of experiences at their local Area Mental health Services. (author's emphasis)*

(Consumer Advocate, Victoria, Submission #253)

All of our mental health plans support consumer participation. This is occurring in different ways, to different degrees across Australia. However, we are only just skimming the surface of what can truly be achieved unless we mandate consumer perspective in the training and education of all mental health practitioners, especially Psychiatrists and Registrars.

(Centre for Psychiatric Nursing Research and Practice, Victoria, Submission #323)

6.2.3.3 Insufficient resources to support consumer participation

Concern was also expressed that insufficient funding is also preventing genuine participation by consumers:

Consumer self advocacy groups, organisations and individuals have insufficient funding to provide the overwhelming support needs of consumers whose rights have been abused. Nor do we have funding to provide the kinds of alternative supports that we know will work for many of us. Nor do we have funding to allow us to hold forums, conferences, communicate with each other. Without funding we remain voiceless and disconnected. Without funding we cannot participate in any of the ways that our mental health policies tell us we should be participating.

(Insane Australia, Victoria, Submission #232)

The consumer movement in Australia needs to be adequately resourced to bring the genuine consumer voice into mental health policies in ways that are more than the current lip-service.

(Insane Australia, Victoria, Submission #232)

Considerable evidence emerged from the research indicating that limited resourcing is a major factor preventing many of these projects from reaching their full, (and supporters of consumer participation would argue) ***deserved*** *potential. (author's emphasis)*

(Consumer Advocate, Victoria, Submission #253)

There are also widespread accounts of Consumer Consultants trying to maintain large outputs of work, within an already complex and demanding role, with limited resources, putting in large amounts of extra voluntary time, in some cases striving to personally "bridge" service gaps, and often facing costs to their own health and wellbeing.

(Consumer Advocate, Victoria, Submission #253)

6.2.3.4 Voice of consumers with Borderline Personality Disorder not heard

One consumer expressed concern that people with Borderline Personality Disorder, in particular, are not being heard at any level and therefore their needs are not being lobbied for or considered in the planning and implementation of services:

I have had an ongoing discussion with SANE about what I see as the invisibility of BPD on their website and in their publications… on the Fact Sheet for BPD there is no emphasis on distress; rather, the whole emphasis is on people learning to manage their behaviour successfully. I hate this. The behaviour is as a result of something. It doesn't just jump out from nowhere. This is grossly unfair and judgemental.

(Consumer, Advocate, Victoria, Submission #166)

In some ways the MHCA simply reflects the political lobbying power of its constituent member organisations. Therefore, we shouldn't be either surprised or too critical of the fact that it has thus far not engaged publicly (that I know of) in promoting issues at a national level that are of central importance to those of us who care deeply about people who have been labelled as having BPD. In many ways it is a reflection of our own incapacity to organise ourselves into a coherent public voice and demand representation on the MHCA Board.

(Consumer, Advocate, Victoria, Submission #166)

6.2.3.5 Voice of adolescents with mental illness or mental health problems not heard

A youth participation worker emphasised the importance of participation by youth in reform processes to maximise health outcomes for children and young people:

While consumer participation has fixed some of the worst bits of the adult mental health system, it is virtually non-existent in youth and adolescent services.

(Youth Participation Worker, Victoria, Submission #255)

6.2.4 STANDARD 4: PROMOTING COMMUNITY ACCEPTANCE

The MHS promotes community acceptance and the reduction of stigma for people affected by mental disorders and/or mental health problems.

Under this Standard, submissions and presentations raise concerns about:

- stigma and the need for community education;
- discrimination in employment settings;
- stigma and stereotypes perpetuated by the media;
- social isolation;
- rejection by the community;
- non-acceptance by mental health workers;
- non-acceptance by family members;

- discrimination by real estate agents;
- problems with terminology and stigma for people with Personality Disorders;
- the impact of lack of access to services on stigma; and
- stigma associated with 'therapy' as opposed to treatment by medication.

6.2.4.1 Stigma and the need for community education

Standard 4.1 states: 'The MHS works collaboratively with the defined community to initiate and participate in a range of activities designed to promote acceptance of people with mental disorders and / or mental health problems by reducing stigma in the community'. Consumers expressed concerns about the high level of stigma and ostracism still being experienced by people with mental illness, to the extent that the rights and needs of the people with mental illness who are homeless or in the criminal justice system are being ignored by society. These high levels of stigma would indicate that campaigns and activities to date to address community acceptance and reduce stigma have not been able to turn community attitudes around.

As described below, a lack of community acceptance is a key barrier to people with mental illness from accessing treatment and gaining employment or having a voice and thus being able to participate socially, economically and politically in society. Without community education, not only will community acceptance and understanding not be forthcoming, but fears based on myths, stereotypes and inaccurate information will continue. This will further perpetuate stigma and discrimination and support an unwarranted call for seclusion and restraint and the curtailment of rights of people with mental illness:

> *But we at Insane regard this failure to resource mental health as a second-order issue. Human rights violations in mental health in Australia occur not just because of a few rotten apples in the barrel, or because of inadequate resources. Human rights violations are systemic and deeply embedded in how Australia responds to mental health. First, in the broader community, the stigma that surrounds mental health has to be seen as a deeply entrenched discrimination against madness that requires sustained, constructive measures to overcome. A clear and strong voice from consumer-survivors, in their own language, will be essential to this task. Second, within existing mental health services, this stigma and other discriminatory prejudices and practices are intrinsic to these services and central to the systemic human rights violations. Without a major overhaul of how we approach mental health, more resources will only further entrench and possibly worsen the current human rights abuses of mental health consumer and survivors. Again, the voices of consumer-survivors must be heard if these systemic human rights violations are to be addressed.*
>
> (Insane Australia, Victoria, Submission #232)

> *Stigma: Some people with a mental illness are not willing to engage in a psychiatric rehabilitation service because of personal and community attitudes. These services are not viewed as being attractive to potential users i.e. youth.*
>
> (Service Provider, Victoria, Submission #266)

> *There are those who consider that people with a mental illness do not have disabilities like others with (say) chronic physical pain, and loss of limbs, hearing, vision, speech et al. …There is still an attitude about mental illness which requires addressing, and, importantly, when considering protocols for various government programs such as SAAP [Supported Accommodation and Assistance Program].*
>
> (Anonymous, Victoria, Submission #272)

> *In every discussion held to date, stigma and discrimination have been raised as issues of concern. Unfortunately, the experience of stigma and discrimination is endemic, ranging from the common media portrayal of people with a psychiatric illness being violent and aggressive to discrimination in employment and even to how people are treated in mainstream medical services.*
>
> (Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

6.2.4.2 Discrimination in employment settings

Concerns were expressed about discriminatory practices in employment settings which preclude people with mental illness from participating successfully in the workplace. These included problems with disclosure, lack of support when employed and termination as a result of mental illness.

Many of these problems could be addressed by activities associated with Standard 4.2 'The MHS provides understandable information to mainstream workers and the defined community about mental disorders and mental health problems'. Employment and support in the workplace by managers and other employees are seen as critical in the rehabilitation phase, reducing the impact of illness in the long-term and successful reintegration into society at a social and financial level.

> *Employment is where many consumers feel they are particularly vulnerable to discrimination. Broader issues of employment are discussed below but it is useful to quote a young man's personal experience here to highlight how hard your work life can be if you are perceived to be different:*
>
> *"I haven't disclosed anything about my illness to my employer, though I'm sure they know there is something going on. Initially, I had a shared office, which was really hard—I avoided going in to the office whenever I could (I work part time and have a fair bit of flexibility). We just didn't get on very well—but my employer was accommodating and found me another place where I could be by myself. But they have gone to the extreme—I have a whole level to myself and there is no one else around. I don't get to see anyone—it's weird but I get a sense that I'm there because they think I'm weird. Work is now very lonely".*
>
> *(BSL 2004 Focus groups with mental health consumers)*
>
> (Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

> *The majority of consumers spoken to during the consultation were not working, but many had in the past and wished to do so again in the future. They, however, acknowledged the great barriers that would have to be overcome if they were ever to achieve their aims.*
>
> *"I started having problems with depression and I didn't understand that anxiety was part of it—I didn't understand how it was affecting me. It is hard to get the right help and the right medication and to keep functioning at the same time. I ended up losing 12 jobs in a row—falling in a heap and not being able to concentrate. It's like the last 20 years of my life has been just one big nightmare—I've lost family, I've lost friends, I've lost property, I've lost just about everything I've owned. I've lost a lot of hope and it has taken me a long time to get that back. And I still don't know if I've got the wherewithal to work. I still have problems with concentration and memory—am I employable? And is an employer going to understand if I have a relapse? I'd like to work but I'm not sure I would trust myself or the workplace".*
>
> *"What I've found is that if your boss knows you have a mental illness he'll play on it. He thinks he is doing you a favour by hiring you and will expect you to do the things he won't ask other people—or he'll start picking on the quality of your work".*
>
> *"Do you tell people that you have a mental illness? If you tell them when you are applying for the job you won't get it. They won't say that's why they didn't give it to you though".*
> *(BSL 2004 Focus groups with mental health consumers)*
>
> (Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

6.2.4.3 Stigma and stereotypes perpetuated by the media

Concerns were also raised that any activities by the MHS to reduce stigma in the community must also address education of media personnel to modify their portrayal of people with mental illness and comparative references.

At a public level, the association of violence and aggression with mental illness must be challenged whenever it appears. The public must be made aware that such violence is an exception, and that people who do have a psychiatric illness are much more likely to be on the receiving end of it rather than to be the perpetrators. All people with a psychiatric illness suffer at some level by the misperception that is created by sensationalist media reporting.

(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

6.2.4.4 Social isolation

Consumers and carers expressed concern at the increasing number of people with mental illness who, for a variety of reasons, including stigma, are isolated in the community and have no social supports:

My son is fortunate because he has me but plenty of people don't have anyone.

(Carer, Mother and Disability Accommodation Service Provider, Victoria, Melbourne Forum #9)

I have always had access to very supportive family members who have been there for me when I needed it but a lot of people don't have that so they have no-one or nowhere to go.

(Consumer, Paid Consumer Consultant, Victoria, Morwell Forum #5)

6.2.4.5 Feelings of isolation – rejection by the community

Empathy is a big thing – support from one human being to another human being.

(Anonymous, Victoria, Morwell Forum #19)

Consumers and carers expressed concerns about the stigma that still surrounds mental illness and how this resulted in friends and other members in the community distancing themselves from the consumer and the family. This would indicate that campaigns and activities under the National Mental Health Strategy to address community acceptance and reduce stigma to date (Standard 4.1) have not yet successfully changed community attitudes to mental illness.

Discrimination and lack of community acceptance are key barriers to people with mental illness (and their family members) being able to participate socially, economically and politically in society. Consumers and carers reported social isolation, feelings of being a burden on family and friends, and 'living like ghosts' and 'dying alone' are the result.

I think for those who are severely ill and are isolated in the community due to their illness they often have no form of support even from family or friends. For people like that they are in the community living like ghosts – they are dying alone.

(Consumer, Victoria, Footscray Forum #11)

My son had so many friends, his photo in the local paper every week, and captain of every team he was in, and as soon as the diagnosis came, he'd say "Any mail, mum?", "Any phone calls?", but there weren't any.

(Carer, Mother, Victoria, Submission #211).

…a young man went off to have a cappuccino, and came back so quickly that [Y] asked him why and he told her that they'd said "Come back when there's no one here." That wouldn't happen there now, as a result of the Kew Regional Outreach Ministry.

(Carer, Mother, Victoria, Submission #211)

The really sad thing is that people like my sister feel they are a burden on their families.

(Carer, Victoria, Melbourne Forum #16)

It is unfortunate that the vilification of people who have attracted a diagnosis of Borderline still seems to be OK. Much money and effort has been put into trying to de-stigmatise people with psychotic illness and depression however we see no sign of s similar campaign being organised either by governments or Non-government organisations to change the dominant and inaccurate community understanding of and betrayal of those with Borderline Personality Disorder.

(Consumers, Victoria, Submission #194)

Lack of community support and understanding.

(WIRE-Women's Information, Victoria, Submission #182)

Out of what can be many different labels they say things like; "mention I have been diagnosed with Schizophrenia and Depression but please don't say anything about Borderline."

(Consumer, Advocate, Victoria, Submission #166)

You start to cry and you can't seem to stop – you begin to question yourself and then others begin to question you, some even judge you, some start avoiding you, and some stop calling around.

(Carer, Mother, Victoria, Submission #242)

Dealing with Mental Illness you need people to care and share with you our problems and it takes patience to allow our bodies and mind to heal because it will not happen overnight.

(Consumer, Victoria, Submission #328)

6.2.4.6 Non-acceptance by mental health workers

The campaign largely fails to take up the issue of discrimination within mental health systems themselves. Consumers often report that the worst discrimination comes from inside services and is particularly targeted at people labelled as having personality disorders.

(Consumer, Advocate, Victoria, Submission #166)

Many consumers and carers also expressed concerns about the lack of acceptance and understanding and what they labelled as discriminatory attitudes shown by some service providers. This is of particular concern given that consumers must come directly into contact with mental health service providers and their views impact directly upon them and their carers:

Some services and carers are unsympathetic and unresponsive.

(Coordinator, Grampians disAbility Advocacy Association, Victoria, Submission #212)

…one member found it offensive to be told by a community nurse that "you're not mentally ill, you have a living problem"; and the solution is?

(Coordinator, Grampians disAbility Advocacy Association, Victoria, Submission #212)

Two women have come into the Fellowship and each told us that a psychologist said to their son, who'd had schizophrenia for some time, "You haven't got schizophrenia. You've just got a difficult mother".

(Carer, Mother, Victoria, Submission #211).

Borderline, on the other hand, tends to be one that people are really ashamed of and the shaming in the system that follows the diagnosis just intensifies some people's self hate in my experience.

(Consumer, Advocate, Victoria, Submission #166)

6.2.4.7 Non-acceptance by family

As the following quotes indicate, the need for activities to promote community acceptance not only for the community but for family members is critical.

> *I think culture plays a big part in our society especially in terms of lack of family support due to family non-acceptance of their illness. This is certainly true for non-English speaking families. Sometimes consumers are made to feel that they are an embarrassment to their families. So they live very isolated lives. We need further education to address stigma and discrimination. We are reasonably ahead of the pack in Australia but we've still got a long way to go.*
>
> (Consumer, Victoria, Footscray Forum #12)

> *A young woman rang the Helpline and said her husband had suddenly been diagnosed with schizophrenia. His parents said to her "He was fine when you married him". The doctors listened to them, and didn't allow her to visit him I hospital*.
>
> (Carer, Mother, Victoria, Submission #211)

6.2.4.8 Discrimination by real estate agents

One carer described a series of negative repercussions that resulted when she disclosed to the real estate agent that her son had a mental illness, including the unnecessary involvement of the police to accompany an inspection of the premises.

> *…an eviction notice as he had not been paying his rent… I then contacted the rental agent from the Real Estate Agency and arranged to meet with her at my son's unit for an inspection and to arrange removal of his belongings. She arrived, followed by two police officers. There was no damage to the unit. I apologised for what had happened and was strongly rebuked by the agent for not having informed her that my son suffered from schizophrenia and added that she would have to inform all other rental agencies that he was an evictee along with my name as his next of kin. Obviously this would make acquiring further accommodation for him very difficult.*
>
> (Carer, Mother, Victoria, Submission #178)

6.2.4.9 Problems with terminology and stigma for people with Personality Disorders

Two of the submissions received strongly argued for community acceptance campaigns that include education about personality disorders. The contributors argued that unless this was addressed, commonly held myths and stereotypes about people with personality disorders will continue to significantly and negatively impact on consumers' lives:

> *Outrageously, ideas about mental health literacy completely fail to even broach the issues that are central to the lives of all of us who have been crudely thrown around or out of the public system because someone has decided we just have a personality disorder (or 2 or 3).*
>
> (Consumers, Victoria, Submission #194)

> *…the term, personality disorder, makes people sick… personality disorder implies that a person's problems are all that person's fault and responsibility… some clinicians use the term personality disorder indiscriminately as short hand for everything that presents as difficult to diagnose or socially construed.*
>
> (Consumers, Victoria, Submission #194)

At the very least I think we should be letting people we have labelled in this way know something about the history of the term because without an explanation it is very easy to come to all sorts of conclusions about what it means. However, even beyond this the term is horrible.

(Consumer, Advocate, Victoria, Submission #166)

Consumers argue strongly that the best way to arrest the defamation that so often follows this label is to emphasise the very close correlation between adult experiences which get labelled Borderline Personality Disorder and childhood experiences of abuse and neglect… Others argue that that it is not useful because there are about 10% of people with this diagnosis who don't have personal histories of abuse and/or neglect. Others argue that it needs to be placed within a spectrum of conditions that could be called 'Trauma Spectrum Disorders' (including Dissociative Identity Disorder (DID) and Post Traumatic Stress Disorder (PTSD).

(Consumer, Advocate, Victoria, Submission #166)

Consumers are no less influenced by the 'mad' / 'bad' dichotomy as anyone else. Many consumers distance themselves from people who are labelled as having BPD because they believe that in some way collective political lobbying will put the anti-stigma message back as one important plank of the agenda has been the message that 'madness is not badness'… Some consumers have been frightened by the way people labelled as having BPD have demonstrated their distress. Self-harm can be quite frightening for others to witness particularly if it is in an acute unit and you are already having a rotten time yourself.

(Consumer, Advocate, Victoria, Submission #166)

The most important anti-discrimination knowledge that many people who have been labelled with BPD want to get out to the public is that their so-called 'behaviour' comes from somewhere – it is not 'badness'. This is particularly true for women who hurt themselves. This 'behaviour' is more likely to be as a result of the badness of others when they were young. Not being out there and fair dinkum about this relationship between growing up and being 'mad' is discrimination.

(Consumer, Advocate, Victoria, Submission #166)

6.2.4.10 Impact of lack of access to services on stigma

Many carers raised their concerns about the mode of crisis care currently in operation. The fact that consumers can only access services when they are in crisis reportedly makes it extremely difficult for consumers to be accepted into the community and to overcome the community's stigmatising attitudes and negative perceptions about mental illness.

When my son and others like him are unwell, their behaviour is their stigmata... this policy requires them to be different enough to draw attention to themselves in a totally negative way... thus under this policy the stigma of mental illness is propagated rather than alleviated. And let us not forget that this behaviour, not chosen behaviour, but behaviour dictated by the illness, is that which can cause them to lose accommodation, employment, friends and perhaps even family, thereby having their lives fall apart time and time again.

(Carer, Mother, Victoria, Submission #178)

6.2.4.11 Stigma associated with 'therapy' as opposed to treatment by medication

One consumer expressed concern that not only does stigma directly associated with mental disorders and mental health problems have to be addressed, but also stigma associated with "therapy" as opposed to treatment by medication which is acceptable.

Intensive psychotherapy is extremely hard on everybody. The public image that it is somehow what privileged, overindulged, middle class women do to fill in the time needs challenging. I am very concerned that the efforts that have been made by SANE and other organisations to de-stigmatise mental illness have not even tried to do anything about de-stigmatising therapy in Australia

(Consumer, Victoria, Submission #203)

6.2.5 STANDARD 5: PRIVACY AND CONFIDENTIALITY

The MHS ensures the privacy and confidentiality of consumers and carers.

Under this Standard, submissions and presentations indicate concerns about the reluctance by services to involve carers, even when permission is given by consumers.

6.2.5.1 Reluctance of services to involve carers, even when permission is given by consumers

Many carers expressed concerns that the policies and procedures to protect the confidentiality and privacy of consumers is hampering communication between consumers, carers and clinicians in the provision of treatment and jeopardising the safety of consumers. Carers expressed feelings of frustration in some clinicians being very resistant to discussing anything with them and, in one instance, this resulted in a carer having to 'slap the power of attorney in their hands'. These concerns would indicate that policies and procedures related to privacy and confidentiality are not being made available to consumers and carers in an understandable language and format (Standard 5.2) and that the MHS is not encouraging and providing opportunities for consumers to involve others in their care (Standard 5.3).

I have power of attorney over my wife but when I ask for information about my wife they tell me they can't give it to me – until I slap the POA in their hands.

(Carer, Husband, Victoria, Melbourne Forum #3)

…two issues which can cause enormous problems for carers and which I believe can create the greatest divisions in understanding between mental health professionals and carers. The first is 'confidentiality'....from personal experience and anecdotally, this has proved on many occasions to have the potential to put either the carer or the person with the illness at risk - even if that risk is simply to their personal health and well being, apart from the distinct possibility of far more serious consequences. It is small wonder that carers can often feel used and abused by the mental health system - it appears that there has been little thought given to the rights of carers, or rather their lack of rights; we are expected to accept responsibility for the continuity of care without even the right to be informed of hospital discharges without the patient's consent, and with currently minimal time spent in hospital, the matter of the person with the illness being able to make such important decisions in regard to their own welfare has proven to be highly questionable.

(Carer, Mother, Victoria, Submission #178)

She had a job doing volunteer work. I thought we were doing really well but at the same time the private psychiatrist was reducing her medication. Now she's gone again and I can't find out where she is. Section 28 doesn't seem to take into consideration carers at all. This illness is destroying her and destroying us. I've got her bills, unpaid bills and I can't get any information from Centrelink. We don't know whether she's dead or alive so what do you do?

(Carer, Mother, Victoria, Melbourne Forum #7)

My daughter recently left hospital and we had no contact from the hospital to inform us that our daughter had actually been discharged. I had no idea where she was or when she had been released. The authorities had placed a community treatment order on her for the next 12 months which we thought was a good thing because at least she would get some care however the psychiatrist took her off that order after 2.5 months complaining about the level of paperwork required as part of the process.

(Carer, Mother, Victoria, Footscray Forum #10)

Even now when I can tell she isn't doing so well I am reluctant to contact her case manager (If she still has one) because I cannot be assured of confidentiality and my concerns may reach my mother. This of course causes more problems. The lack of communication between the 'services' and the families of those who are ill is deplorable. I understand about rights to privacy but surely some consultation / involvement is required - even information about how we as a family can assist. Another example of this concerned a time when Mum's medication was reduced and she subsequently relapsed… it would have been beneficial to be aware of this situation and to have been involved in helping to monitor any changes and to communicate with her doctors etc.

(Carer, Daughter, Victoria, Submission #265)

Many carers contact us at a point of desperation, when they have not been able to communicate with or be listened to by clinical and other services who regard the mentally ill person as the client whose privacy needs to be protected. Carers are very confused as to what rights they have in this situation- where they are the ones who provide the ongoing support in the community and whose lives and safety are affected by the illness and decisions made.

(Carers Victoria, Victoria, Submission #270)

6.2.6 STANDARD 6: PREVENTION AND MENTAL HEALTH PROMOTION

The MHS works with the defined community in prevention, early detection, early intervention and mental health promotion.

What is acceptable about refusing to carry out early intervention until the person is 'acutely' unwell, which leads to a very distressing forceful intervention, then having to administer extremely strong dosages of medication which induce obvious physical side effects which take months to subside? … What is acceptable about not keeping people with a mental illness as well as they can possibly be, thus reaching and maintaining their full potential within the illness?

(Carer, Mother, Victoria, Submission #178)

Under this Standard, submissions and presentations indicated concerns about the lack of prevention and early intervention strategies. In particular, people raised concerns about:

- mental health services making no attempt at early intervention and instead waiting for a crisis to occur before intervening;
- the lack of willingness by services to listen to families;
- the need for increased involvement of general practitioners;
- the importance of open discussion and acceptance;
- the need for more promotional strategies; and
- lack of rehabilitation programs.

Despite the seriousness of the disorders, there is no philosophical or legal framework supporting a more assertive or early intervention approach, nor the funding capacity to support such a model. Indeed such an endeavour is still impeded by a residual moral dimension to understanding these disorders. The clinical focus is typically on advanced phases of disorder (even in young people) where treatment can no longer be withheld, yet when it may be much less effective.

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

6.2.6.1 No attempts at early intervention – wait for a crisis to occur

In our region people have the choice of living in the community and only have access to public hospitals when they become critically unwell. This leads to increased strain on family members who are coping with little support. Critical incidents can follow which feeds into community perceptions of people with a mental illness and setbacks the person with a mental illness. The alternative of earlier and timely interventions are desirable but seemingly not possible under the current funding and care model.

(Service Provider, Victoria, Submission #266)

Many carers and one academic expressed serious concerns about the lack of a preventive focus in the delivery of mental health services, despite the emphasis of such an approach in Standards 6.4 (capacity to identify and respond to the most vulnerable consumers in the community), 6.5 (capacity to identify and respond as early as possible) and 6.6 (treatment and support to occur in a community setting in preference to an institutional setting).

In particular, all mentioned how unacceptable it was, on many levels, for treatment and support services not to be provided at the earliest possible moment to prevent deteriorating illness until the consumer was at risk of harming themselves or others, and the rest of their life had also deteriorated (e.g. employment, social withdrawal), and required acute care often in restrictive settings and severe treatment regimes. Professor McGorry further stated that intervention at this point can often not reverse the damage that has been done.

Many submissions also pointed out the discriminatory aspects such approaches to mental health. They suggest that this approach would be unacceptable for the treatment of physical illness where early intervention is emphasised, demanded by the public and supported by the Health Department. The worst result of a failure to intervene early is death, as reported by one carer.

…although she was visited by Crisis Assessment Teams, she remained essentially untreated. In September 1994, she made a serious attempt to kill herself, was admitted to hospital and, finally, taken into the system. I cannot but connect [X]'s two years of untreated psychosis with her subsequent and, even at her best, permanent paranoia and eventual death [in 2002].

(Carer, Mother, Victoria, Submission #206)

Bearing in mind that to my knowledge he has twice attempted suicide, I was naturally very concerned and spoke to several people at the Mental Health Clinic on a number of occasions but was told that there was nothing that they could do until a 'crisis situation' occurred as his rights must be respected.

(Carer, Mother, Victoria, Submission #178)

Those who are conscious of the practical and economic problems in providing care to over half the population at some point and up to a quarter within a 12 month period, have argued that a diagnosis should be associated with substantial functional disability before treatment should be funded and accessed (Regier et al 1998, Spitzer et al 1998). This is superficially attractive, however it means that people are required to become functionally disabled by their symptoms before they can be offered help. Such disability is usually hard to reverse even when treatment is effective… Restricting access in this way is antithetical to preventive and early intervention approaches, would be completely unacceptable in general medical care where people with mild disorders, such as a viral illness, can gain ready access, and may prevent the most cost-effective phase of serious illness from being treated. Mild disorders should be able to access treatment of some kind for all these reasons (Kessler 2003).

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

What is acceptable about condoning and ensuring the inevitable pattern of relapses resulting in lives falling apart time and time again rather than practicing early intervention?

(Carer, Mother, Victoria, Submission #178)

Regarding 'involuntary intervention'; although the Mental Health System espouses 'early intervention' and carers are encouraged to practice this, the constraints surrounding 'involuntary intervention' can make 'early intervention' impossible. From personal experience, it means that intervention will not be carried out without the consumer's consent until that person is acutely unwell and a 'crisis situation' arises. Although it will then, still be without the consumer's consent, probably even more so, and will probably mean a more forceful intervention, somehow this policy is considered more humane… As ridiculous as it sounds, it means that the behaviour of the unwell person has to disturb, alarm or frighten a member of the public enough to bring it to the attention of the police or the Mental Health Service - a carer's word that the person is at risk is not enough… and we talk about reducing the stigma of mental illness.

(Carer, Mother, Victoria, Submission #178)

On occasions when I have sought intervention before these far more damaging and sometimes dangerous 'crisis situations' occur, I have been told that my son's right to make his own decisions must be respected and that it is not appropriate for me to judge anyone else's quality of life, even if that life, (or more appropriately, existence) consists of physically hiding in darkness and isolation. To my knowledge my son has attempted suicide twice, therefore, far from being an hysterical alarmist, these are the times when I am most fearful as are many other carers when in similar situations.

(Carer, Mother, Victoria, Submission #178)

This is a plea for early intervention in mental illness and for a more compassionate and consultative, less rigid mental health service. This story concerns my daughter whom I shall call [X], who was diagnosed with schizophrenia in October 2001. I am concerned that it took so long to diagnose [X]. It took 18 months from March 2000 to October 2001, during which time she was at extreme risk, wandering around Melbourne, acutely disturbed, terrified (we later learnt), sometimes suicidal. It was also 18 months of anguish and extreme risk for her family. That trauma is still with her and with us.

(Carer, Mother, Victoria, Submission #307)

One carer described her elation at finding an organisation which specialised in the early detection and prevention of psychotic episodes only to discover that her family did not live within the catchment area of the service:

There was one meeting I attended whereat we were addressed by a guest speaker from an organisation that specialised in the early detection and prevention of psychotic episodes – they informed the meeting of the exciting programs they had in place, they spoke of the great successes they had enjoyed with their clients and families, the hope they instilled in me, will truly never be forgotten. I came home from that meeting quite elated and optimistic. The very next day I gave them a call – firstly they briefed me about their organisation and what assistance they could offer - they then asked me to answer a questionnaire over the phone to make certain that my set of circumstances fit into their selection criteria – we worked through a series of questions which I answered with baited breath, I was finally able to expel my breath with a great sigh of relief when I was informed that yes, they could help me – I recall weeping with delight. I was then asked my mailing address so as they could forward information out to me – after informing them of my mailing address and then confirming this to also be my home address – my elation was brought to a screeching halt as they spoke the words: "I am so sorry, but you will not be able to be a part of our program…." To which I replied: "excuse me, I don't think I heard you correctly…" They then said: "I'm afraid this program is only available to the western suburbs…"

(Carer, Mother, Victoria, Submission #155)

6.2.6.2 Early intervention – families need to be heard

Carers also indicated that greater involvement of carers would assist clinicians to comprehend the mental health care needs of the consumer so that an early intervention treatment program could be discussed with the consumer and treatment and support services could be initiated.

And even when the family knows there's something wrong, but their loved one doesn't want to admit it, it would help if they were listened to.

(Carer, Mother, Victoria, Submission #211)

What is acceptable about a clinician making an assessment in a 15 minute appointment whilst ignoring the information of these same carers who are in the position of being far more sensitive to the signs of deterioration in the person for whom they care?

(Carer, Mother, Victoria, Submission #178)

Crisis Assessment and Treatment Services are variable in their response. Family carers seeking early intervention can find it difficult to get an assessment from the CAT service until their relative has deteriorated to a point where inpatient admission may be the only solution.

(ARAFEMI Victoria, Victoria, Submission #230)

6.2.6.3 Early intervention – involvement and role of GPs

One carer supported the recent emphasis on general practitioners becoming increasingly involved in mental health care and saw that they could play a pivotal role in early detection and early intervention programs. The carer indicated that further education of general practitioners could assist in this regard:

At the Forum in the Melbourne Town Hall on Monday, I picked up a card saying "Mental Health-GP Business", and I'd just like to be sure that GP's now can pick up mental illness symptoms in young people. When my son was suddenly diagnosed at 21 with chronic paranoid schizophrenia, which was such a shock, we heard from him later that at 15 he'd been seeing our GP, because he knew there was something wrong (he always had great insight), the Doctor felt he looked so well and fit, he sent him off.

(Carer, Mother, Victoria, Submission #211)

6.2.6.4 Early intervention - importance of open discussion and acceptance

Concerns were also expressed that one of the major obstacles to consumers seeking and obtaining appropriate and treatment at the earliest possible moment is stigma and discrimination. If consumers felt their concerns could be spoken about in an open, accepting and supportive manner, this would assist with interventions and supports being provided early.

> *I hadn't known that my mother's family had depression in it. When our youngest daughter came home from school at 13 and said "I felt so dreadful in school today. I never want to feel like that again", by then I knew what she was talking about. Early intervention can make such a difference.*
>
> (Carer, Victoria, Submission #211)

> *Sartorius (1998) argues that stigma and prejudice are the very first obstacles that must be tackled if the quality of life and of care is to improve for people with mental illness. Whether people with mental disorders get appropriate help is the end result of a series of processes… Firstly there is the issue of awareness of the problem and whether it is recognised as illness, or even as a problem… On the canvas of this background level of knowledge and probably prejudice, the person with emerging subjective or behavioural change and distress and / or disability may or may not recognise that they have a problem… It is common to feel shame, weakness, helplessness and an urge to withdraw from others, not only due to stigma, but also through the distorting effects of the change in mental state, the illness itself, on self-esteem, cognition, energy, judgement and crucially, on social relationships. What is difficult in this process is how to share distress and personal problems with strangers, such as the local GP that governments insist must be the first port of call. It requires a high level of trust, a leap of faith. This leap is frequently not taken without encouragement and "brokerage"… Shame mixed with desperation is what I have perceived in the frequent, often furtive, telephone calls I have received from mature, often successful and assertive people trying to obtain help for someone, a relative or friend, they know is unwell, or for themselves. This brokerage and advocacy is a crucial element especially when the illness itself has impaired awareness of the need for care or immobilised the person involved. What is lacking is the next step where prominent or ordinary citizens will talk openly among their friends and colleagues about the illnesses they have encountered or experienced, just as they do when someone has had an asthma attack or developed diabetes.*
>
> (Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

6.2.6.5 More promotional strategies needed

In support of all the concerns expressed above, a consumer and consumer advocate suggested more promotional strategies, funding and resources are needed, and these need the support of the health bureaucracy.

> *Nothing is done for mental health. There's a lot of apathy. Kids with cancer get on the front page of the paper and they get funding for their cause. Now I'm not saying that they are not important but I'm saying that we should get the same response for mental health but we don't!*
>
> (Consumer Advocate, Victoria, VMIAC Consultation #2)

> *During mental health week we are given $15,000 from the mental health branch for this premier event. We're facing organisational burnout trying to keep mental health week going. Bronwyn Pike now unavailable to launch mental health week.*
>
> (Consumer, Victoria, Melbourne Forum #8)

6.2.6.6 Lack of rehabilitation programs

Rehabilitation programs are a critical step for both reintegrating back into full life after a period of illness and preventing relapse for many people with mental illness. Such programs would include living skills programs, respite and social programs. Access to rehabilitation programs is covered under Standard 6.8 "The MHS ensures that the consumer has access to rehabilitation programs which aim to minimise psychiatric disability and prevent relapse'.

Concern was expressed however that Victorian mental health services place insufficient emphasis on rehabilitation programs or other programs to prevent relapse or promote recovery as no rehabilitation programs are available for consumers to access. These programs are essential to promote and protect the social and economic participation rights of consumers.

> *The Health System's main approach to people with Mental Illness is to get them medicated and then very little else. There are no serious rehabilitation facilities.*
>
> (Carer, Father, Victoria, Submission #231)

6.2.7 STANDARD 7: CULTURAL AWARENESS

The MHS delivers non-discriminatory treatment and support which are sensitive to the social and cultural values of the consumer and the consumer's family and community.

Under this Standard, submissions and presentations indicated concerns about:

- the lack of sensitivity to spiritual, religious and cultural beliefs; and
- the lack of understanding of issues associated with recent immigration.

In some cases the mismatch between bureaucratic rhetoric and the day-to-day experiences of those who use the system was marked. Yet, those working within the system argued the opposite:

> *The Department has been very proactive in providing services for the Indigenous people in the region.*
>
> (Clinician, Victoria, Morwell Forum #11)

6.2.7.1 Lack of sensitivity to spiritual, religious and cultural beliefs

Standard 7.3 states: 'The MHS delivers treatment and support in a manner which is sensitive to the social and cultural beliefs, values and cultural practices of the consumer and carers'. In the notes to this Standard, this includes religious practices. One carer expressed concern that her daughter's spiritual beliefs were ridiculed by mental health staff. Such attitudes by staff would indicate the need for further cultural awareness training.

> *Also it's insulting to not believe the spirituality of the consumer. My daughter has been ridiculed about her belief in God and how prayer helps her. This occurred in our Psychiatric Hospital here in Bendigo.*
>
> (Carer, Victoria, Submission #199)

Concern was also expressed by the Victorian Branch of the Australian Nurses Federation that cultural and religious beliefs of people with mental illness are not being respected or considered in the delivery of treatment and support by mental health services:

> *Anecdotal evidence further suggests a disregard within the system for the cultural and religious beliefs of people in patient psychiatric settings. Such anecdotes include no attempts to meet the dietary requirements of religious and cultural groups, and a complete lack of sensitivity to exposure of parts of the body and / or nakedness.*
>
> (Australian Nursing Federation (Vic Branch), Victoria, Submission #322)

6.2.7.2 Understanding issues associated with recent immigration

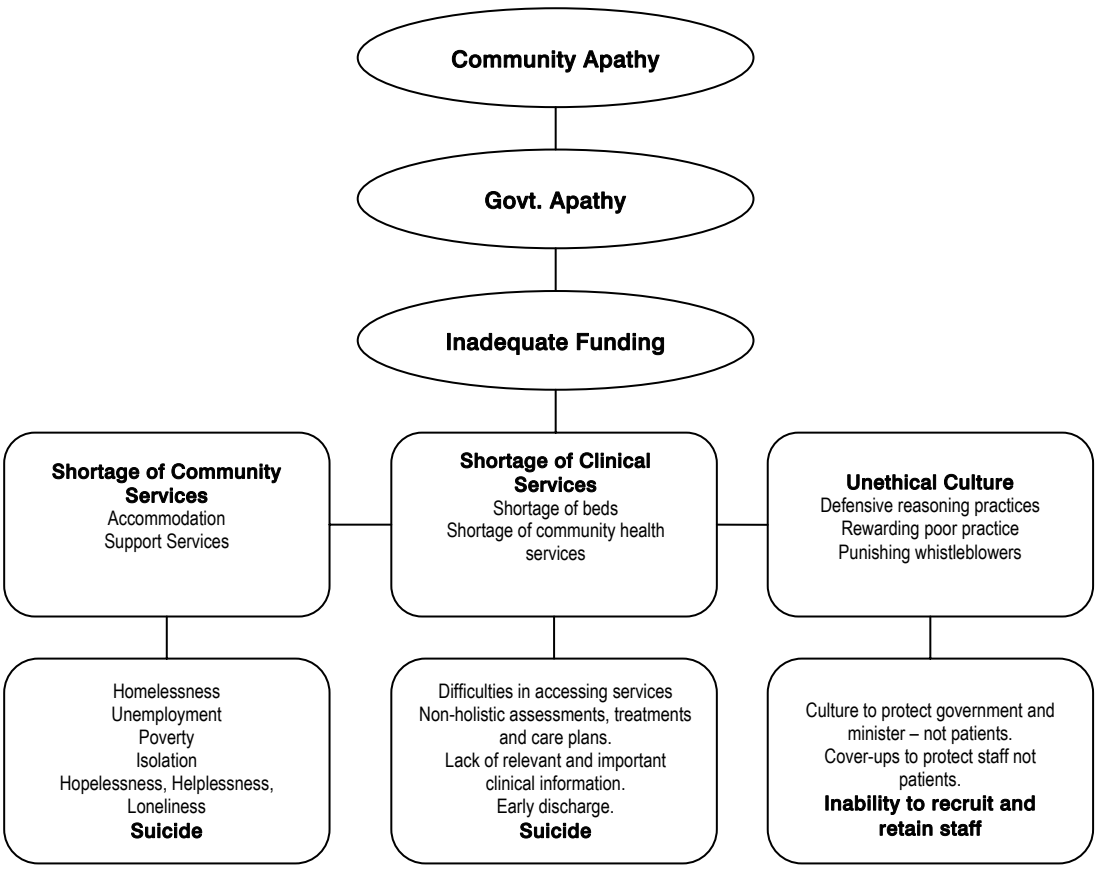
Concern was also expressed that issues associated with migration and cultural difference need to be considered in the planning of treatment and support for newly arrived immigrants. Standard 7.1 states: 'Staff of the MHS have knowledge of the social and cultural groups represented in the defined community and an understanding of those social and historical factors relevant to their current circumstances'.

> *Migration / cultural impact on mental health e.g. newly arrived migrant recently given birth who does not speak English and is experiencing post natal depression.*
>
> (WIRE-Women's Information, Victoria, Submission #182)

6.2.8 STANDARD 8: INTEGRATION

The Victorian Mental Illness Awareness Council (VMIAC) submitted the following diagram to describe its concerns as to why integrated services, across the board, are not able to provide a balanced mix of services to ensure continuity of care and the best possible life outcomes for the consumer. VMIAC contend that impediments at each level must be addressed in order to ensure that treatment and support services are delivered at the earliest possible moment in order to promote and protect the rights of people with mental illness to participate socially and economically in society.

> *We (VMIAC members) feel that the following diagram highlights the main issues concerning people with a mental health problem.*
>
> (Consumer Advocate, *Victoria, VMIAC Consultation #1)*



6.2.8.1 Service Integration

The MHS is integrated and coordinated to provide a balanced mix of services which ensure continuity of care for the consumer.

Under this Standard, submissions and presentations indicate concerns about:

- the lack of integrated service to respond to crises;
- the shortage of mental health professionals to provide integrated care across settings;
- high staff turnover; and
- a lack of communication hindering continuity of care.

6.2.8.1.1 Lack of integrated service to respond to changing needs, including crises

One carer expressed her concern at the inability of the mental health service to respond to a crisis, and that their response was for her to call the police. According to Standard 8.1.1 'There is an integrated MHS available to serve each defined community'. Included in the notes to this Standard is 'crisis intervention'.

> *When I turn up there and they are in crisis, I call the Crisis Assessment Team and they tell me to call the police! I want to know why I'm standing there alone and nobody is coming to help me.*
>
> (Carer, Mother, Victoria, Footscray Forum #1)

> *The ad hoc, uncoordinated and unsatisfactory handling of her illness has rendered her 'resistant to treatment' and entrenched in her cannabis habit. The Mental Health Service seems only able to respond to crises as they arise. In effect, case management is provided by me and involves trying to encourage activities to prevent complete social withdrawal and constant drug use.*
>
> (Carer, Mother, Victoria, Submission #299)

6.2.8.1.2 Shortage of mental health professionals and lack of resources to provide integrated care across settings

> *This support is not being provided and has been progressively withdrawn over the last several years. The patients are constantly disappointed by the diminished level and duration of service as provided by the state funded public psychiatric system.*
>
> (GP, Victoria, Submission #123)

Concerns were also expressed with regard to the shortage of clinical staff in the sector to provide the required treatment and support when consumers were trying to access services or when clinicians were referring consumers for treatment. The shortage of psychologists and psychiatrists in the public sector was noted, as was the shortage of bulk-billing general practitioners and psychiatrists as many people can not afford to pay for treatment in the private sector.

> *Some of the issues that matter are poor accessibility, lack of access to private practitioners, lack of bulk-billing GPs and lack of accessibility to counselling services particularly for people with high prevalence disorders.*
>
> (NGO worker, Victoria, Morwell Forum #7)

> *I have had session times allocated which were constantly being changed from 1/2 hour appt that were made to a 10 min. session… When I would say "you and I both have a copy of the letter stating duration of sessions" I was told "we don't care, we don't have the time"?*
>
> (Consumer, Victoria, Submission #112)

Community-based services are also chronically under-funded. People seeking case management are often forced to wait for long periods before receiving assistance:

> *"It's hard getting the treatment [case management] you need in the country. First we have to meet the very tight criteria and then you get put on a list and have to wait until someone else drops off and you can take the place. They don't look at the waiting list and say 'maybe we need another worker'".*
>
> *(BSL 2004 Focus groups with mental health consumers)*
>
> (Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

Services are very quick to try to cross consumers off their books before there is adequate proof that they are truly 'recovered'. Carers often feel under pressure to pick up more responsibility because the services are so stretched and under pressure, especially when case managers take leave for sickness or annual leave. Other case managers then add that load to their own and spread their services even more thinly… and the carer picks up the slack!

(Peninsula Carers Council, Victoria, Submission #321)

…a very good psychiatrist in Melbourne who he has been seeing ever since – he sees him at bulk billing rates. Because he has been seeing this doctor I was told on several occasions by workers in Ballarat that [X[was not in the system so not entitled to any help of any kind in Ballarat.

(Carers, Parents, Victoria, Submission #241)

…those severely afflicted, if receiving collaborative sympathetic counsel from skilled psychologists, who can also advise carers and families are able to achieve medication compliance and improved quality of life for loved ones. It involves giving respect to them, gaining trust and listening to their chaotic belief systems. Light in dark tunnels can be found and partnership agreements built with much improved outcomes for many. However, there are no adjunct psychology counselling systems in place to support the medical ones and at $80 plus a session for psychologists, few can dream of affording this support. Unless there is a will to include referral psychologists and funding assistance as part of the mental health system, no improvement of the current crisis situation is to be expected and the costly revolving door system grinds on.

(Anonymous, Victoria, Submission #216)

One of the things that really does worry me though is the relationship between private and public health systems in Australia. From my understanding there are almost no psychotherapists around in the public system any more. The implications of this are far reaching. It means that for people with Borderline mostly can't get what they need and this is further accentuated by the fact that people like me need quite intense psychotherapy for several years… We need governments and bureaucracies to start facing the facts in regard to this. You are not going to get a quick fix... rhetoric of unworthiness that gets attached to those illnesses that are treated with talking therapies rather than drugs.

(Consumer, Victoria, Submission #203)

Outreach services such as ERMHA [Eastern Regions Mental Health Association] *have a 12-18 month waiting pool just to be assessed, before you have to wait again for a case-worker.*

(Carer, Mother, Victoria, Submission #352)

6.2.8.1.3 High staff turnover

Reports of high staff turnover were received, indicating a barrier to continuous care. According to Standard 8.1.4 'Opportunity exists for the rotation of staff between settings and programs within the MHS, and which maintains continuity of care for the consumer'.

The lack of consistency with being passed from one trainee doctor to another. Where we are the doctors change every three months

(Carer, Victoria, Submission #199)

The context in which patients / clients are being cared for creates some significant difficulties. The inpatient settings often run on high levels of casual nurses which has implications for the continuity of care of patients. It also becomes a stressful environment for nurses working in the area not knowing the capabilities of nurses that they are working with, and the regular nurses providing the continuity of care for increased numbers of patients / clients.

(ANZCMH Nurses Victorian Branch, Victoria, Submission #316)

Contact with Community Mental Health service is too intermittent to enable the development of trust - the entire focus is on medication. Our daughter has had more than a dozen different treating psychiatrists in the 8 years since she was diagnosed

(Carer, Mother, Victoria, Submission #299)

The treatment offered by the services does not give consumers enough time nor is the contact frequent enough. Frequent changes in case managers and doctors mean lack of continuity for consumers and carers.

(Peninsula Carers Council, Victoria, Submission #321)

6.2.8.1.4 No continuity of care – lack of communication

A concern was also expressed that important information is not being communicated between settings to ensure continuity of care. Standard 8.1.5 states: 'The MHS has documented policies and procedures which are used to promote continuity of care across programs, sites, other services and lifespan'. According to one carer, there were problems with communication between the outreach worker, carer and the nurse and doctor at Waiora Mental Health Clinic prior to an admission in 2002.

No doctor at Waiora was told that [X] was off Clozapin. No doctor saw her until after her admission.

(Carer, Mother, Victoria, Submission #206)

Lack of communication and co-operative case management between inpatient and outpatient hospital staff can cause serious errors in treatment. At one time [X] was in hospital for 4-5 days before the inpatient staff knew what the treatment orders were!

(Carer, Mother, Victoria Submission #320)

Recommendations from service provider and users: … Clearer communication between crisis care, clinic and rehabilitation services to assist a person access to services following an acute episode.

(Service Provider, Victoria, Submission #266)

6.2.8.2 Integration within the Health System

The MHS develops and maintains links with other health service providers at local, state and national levels to ensure specialised coordinated care and promote community integration for people with mental disorders and / or mental health problems.

Under this Standard, submissions and presentations indicate concerns about:

- the neglect of the physical health of people with mental illness; and
- arrangements between psychiatrists and general practitioners in the provision of care to people with mental illness.

6.2.8.2.1 Physical health care neglected

Many reports were received about the neglect of the physical health of people with mental illness. Evidence was also presented to support concerns that people with serious mental illness have elevated death rates from all main causes of death, for example heart disease. General practitioners and carers described the difficulties they had in organising appropriate care for consumers' physical illnesses. The lack of sufficiently trained services in hospital was also noted.

> *It's really difficult to get appropriate physical care for patients with mental illness.*
>
> (Regional GP, Victoria, Morwell Forum #8)

> *…checking their physical health is important. I wasn't allowed to ask any questions about my son's physical health.*
>
> (Carer, Mother, Victoria, Submission #211)

> *Among a series of similar studies internationally, the crucial Duty to Care study from Western Australia (Coghlan et al 2001) showed that people with serious mental disorders, especially schizophrenia, had considerably elevated death rates from all main causes of death, with heart disease topping the list of causes ahead of suicide. Not only is the prevalence of these disorders increased, but they are diagnosed late and treated inadequately. This pattern of premature death and substandard medical care is characteristic of marginalised and disadvantaged sections of the community and demands urgent action.*
>
> (Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

> *Because [X] my wife was having active mental health problems with her schizophrenia and that she was poorly controlled while under the CTO [Community Treatment Order] a decision was made not to treat her with either chemotherapy or radiation to me that is a Human Rights issue, even the HSC office told me that there are 15 to 18 other such cases in Victoria like our case.*
>
> (Carer, Husband, Victoria, Submission #179)

> *There's also a real lack of sufficiently trained services in our hospitals.*
>
> (Regional GP, Victoria, Morwell Forum #8)

> *Access to services will also be discussed below but it seems appropriate to raise the issue of general medical treatment here. It is reported, by people who have a psychiatric illness, that it can be very difficult to have physical illness concerns taken seriously by main stream health providers—too often their concerns are dismissed as 'just the symptoms of their mental illness'. One young woman who participated in the consultations spoke of the difficulty she had convincing her general practitioner that she was unwell—after a number of months she sought other advice and was diagnosed as having diabetes. Other consumers spoke of the difficulties they had experienced in emergency departments—as soon as doctors saw their file and read 'mental illness' consumers felt they were dismissed and some even reported having been sent home without speaking to a doctor. Discrimination is not something that is only experienced among the 'uneducated' broader community; it clearly even exists within the health and welfare community.*
>
> (Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

6.2.8.2.2 Arrangements between psychiatrists and general practitioners

In the following quotes, a psychiatrist and a general practitioner raise concerns about how both groups of service providers could work together more efficiently to ensure specialised and coordinated care for people with mental illness and mental health problems:

The attempts to shore up the interfaces between GP's and specialist care are appropriate however most of their work is with so-called high prevalence or non-psychotic disorders, and sadly there is no longer expertise in the specialist system to help them to manage the more challenging of these disorders. In fact a team approach rather than a solo GP or even a solo private psychiatrist is needed for many of these cases.

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

However, GP's have limitations on the time they can spend with patients and the level of service that they can provide. Both of these areas are aspects of the system where GP's need support to provide home care and follow up services to patients being treated by the GP. This area has in the past been one where local public mental health services have been utilised.

(GP, Victoria, Submission #123)

I have been advocating for improved psychiatric services in this region for 8 years now. Over 1/3 of our GPs have undertaken additional training. But there are no psychiatrists east of Dandenong! As GPs we have little to no support from the specialist sector.

(GP, Victoria, Morwell Forum #8)

If people do attend for help for anxiety disorders or depression it is usually to the GP where the response is usually to offer medication only. GP's are generally unaware of other services that are available. People need to know the range of treatment options for their condition as one would expect with any physical illness. GP training in CBT [Cognitive Behavioural Therapy] is also useful and hopefully will mean earlier intervention for many people, however significant numbers of people with anxiety disorders and depression have complex histories and require longer and more specialised help.

(Clinical Service Provider, Victoria, Submission #268)

The Primary Mental Health Care teams that have been initiated in Victoria are an inadequate response to the problem of anxiety and depression as no direct service is provided - secondary consultation only! This is of no assistance to the community health services that are already providing counselling in these areas.

(Clinical Service Provider, Victoria, Submission #268)

One general practitioner from a rural area did comment that in that area, there was good liaison between the Division of General Practice and other services in that area. Such support would greatly assist with integrated and coordinated delivery of services. Standard 8.2.4 states 'The MHS has formal processes to promote inter-agency collaboration.

There is good liaison between our Division of General Practice and other services.

(Regional GP, Victoria, Morwell Forum #8)

6.2.8.3 Integration with other sectors

The MHS develops and maintains links with other sectors at local, state and national levels to ensure specialised coordinated care and promote community integration for people with mental disorders and / or mental health problems.

Under this Standard, submissions and presentations indicate concerns about:

- the lack of housing options for people with mental illness and mental health problems;
- the need for a whole-of-government response for consumers and families;
- the need for a whole-of government response for youth;
- the need for services and supports for families and carers after suicide;

- police and the criminal justice system;
- Medicare rebates;
- employment;
- Centrelink support for consumers and carers;
- public transport;
- training of nurses; and
- public versus private mental health services

6.2.8.3.1 Lack of housing options for people with mental illness

A lack of available housing and accommodation options for people with mental illness was repeatedly raised as a critical gap in the process of integrating people with mental illness in the community and improved mental health (see Standard 11.4.B Supported Accommodation). The lack of available housing and accommodation options and the process of deinstitutionalisation and consequent lack of increased community services reportedly have led to an increase in the proportion of people who are homeless who have a mental illness:

> *Housing and homelessness are big issues affecting people with a mental illness. Recently we've become aware of a policy in Victoria which is in effect virtually banning people with a mental illness from getting housing.*
>
> (Consumer, Victoria, Footscray Forum #12)

> *There's a high level of homelessness. People ring up and say I've got $35 left to last me for the week and my medications will cost me $38. I've got no food and I won't get my pension until next week. What should I do? How can I survive?*
>
> (Consumer Advocate, Victoria, VMIAC Consultation #3)

> *Lack of access to safe, secure, and affordable housing*
>
> (WIRE-Women's Information, Victoria, Submission #182)

> *There is a serious shortage of both affordable housing in Victoria, leaving many people in 'housing stress': their housing costs so great that they are not left with a sufficient income to meet other basic needs. People with a mental illness form a significant part of this group who struggle, and often fail, to keep a roof over their head.*
>
> (Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

> *Consumers interviewed in our consultation process speak of the difficulty they have in obtaining affordable housing, either in Melbourne or in rural cities and towns. Public housing waiting lists are currently measured in terms of years, not months, with some consumers being told that they are unlikely to ever obtain a public housing unit. Private rental is one of their few options, but the cost of it leaves very little income on which to survive, even in rural and regional areas. Two consumers from a town in central Victoria commented:*
>
> *"After rent I've got $60 per week to live on—to pay for my food, electricity, transport, clothes—there just isn't any money to go out. The stress of living this way compounds any mental health issues you have".*
>
> *"I rent a house privately—the public housing waiting list is about 5 years—but the place isn't in very good condition. The floor sags and there is grass growing between the floor and walls and in the window ledges but I can't afford anything better. My kids live with me and help me with the rent—I pay $160 per week". (BSL 2004 Focus groups with mental health consumers)*
>
> (Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

The cost of accommodation is expensive. Governments need to provide housing from existing public housing stock to help NGOs. The recurrent costs are high for insurance premiums, training and education of staff, employment of trained staff, administrative costs in running supportive accommodation projects (utility costs, maintenance, foods, furnishings, clothing, activities, wages and allowances, tax payments et al), and there are the administration costs of the specific NGO overall in conducting all of its activities.

(Anonymous, Victoria, Submission #272)

The PDRSS Housing and Support programs have limited opportunities to offer housing due to no or very limited replacement stock through Office of Housing when clients within the housing have stabilized and do not require ongoing support

(Western Region Health Centre, Victoria, Submission #292)

Housing services use tenancy 'rules' as an avenue to evict people from housing when the issue is related to mental illness, as an easier option of relocating

(Western Region Health Centre, Victoria, Submission #292)

People on a Disability Pension for Mental Illness, are paid an allowance and left to their own devices. There isn't enough funding for supported accommodation or even subsidized housing. If you want a Minister of Housing accommodation, it's a 12-18 YEAR! wait. What are people supposed to do in the meantime?

(Carer, Mother, Victoria, Submission #352)

In the inner suburbs of Melbourne some 'unofficial' rooming houses operate, offering sub-standard accommodation to vulnerable people living with a mental illness. The BSL provides services to some consumers who do not have access to reasonable bathroom or kitchen facilities, a situation that should not continue to exist today. Without access to stable, safe and affordable housing it makes it extremely difficult to treat people for their psychiatric illness. The Victorian Homeless Strategy 2002 reported that long term housing and support for people with a mental illness drastically reduces inpatient stays (VHS 2002,p.7) - providing this housing must be a government priority.

(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

6.2.8.3.2 Whole-of government response needed for consumers and families

Many submissions and presentations noted a lack, and expressed the need for, a whole-of-government approach to solve the complex support needs required for people with mental illness and their families and carers to live in the community in a dignified manner with the opportunity to participate socially and contribute economically. As described below, problems were reported about housing, employment, education, police and the criminal justice system. Many submissions identified that a broader governmental, societal and community approach was required:

A new system of vocational recovery programs within public sector mental health / substance use services should be developed in conjunction with the Commonwealth and the business sector.

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

In government we tend to departmentalise things and we need to realise that things overlap. If a person has a range of issues, things they need, then the police should take a leadership role. But at the same time we need to build the capacity of the community rather than simply focussing on what the police alone can achieve. I think there needs to be government departmental sub-groups which are linked across sectors – drug and alcohol, youth, housing, etc.

(Victorian Police Officer, Victoria, Footscray Forum #4)

Link between domestic violence and mental health and well-being of women e.g. anxiety, depression and suicidal behaviour linked to violence.

(WIRE-Women's Information, Victoria, Submission #182)

…plight of children who have one or both parents who suffer a mental illness. I would like to see more attention and assistance for these children, many of who have a very heavy load to bear, and are often quite isolated. There is great shortage of any help or accommodation for children when parents are unwell, or in hospital.

(Carer, Victoria, Submission #185)

Another thing I want to raise is the trauma and violence inflicted on carers and negotiating the systems such as Centrelink is extremely hard. This is not being recognised in the system. I have just been working with a Grandma who has been fighting for custody of her grandchild. She has no money and no support. We need a system to support these people who provide the care.

(Consumer, & Mental Illness Fellowship in Victoria, Victoria, Footscray Forum #6)

People with mental health problems and their families do not go away if the government does not provide services for them. Instead they go or are brought to other service systems. This phenomenon is most obvious as people with mental health problems are stranded in the emergency departments of hospitals. However General Practitioners, Police, Schools, the Correctional system and Community Groups all report increasing numbers of people with mental health problems they encounter who cannot get adequate assistance.

(Health and Community Services Union, Victoria, Submission #220)

6.2.8.3.3 Whole-of-government approach for youth

In particular, many submissions and presentations identified the paucity of services and integrated services to assist young people with mental illness or mental health problems as a serious concern (See Standard 11.4 Treatment and Support). Such coordinated services are seen as essential from an early intervention perspective to halt spiralling negative life consequences which result in homelessness, suicide, entry into the criminal justice system or separation from the family. The need for integration with drug and alcohol initiatives was also seen as critical:

A new model of integrated care linking adolescent and young adult psychiatry resources with substance abuse services and primary care for young people should be engineered and mainstreamed with educational, vocational, sports and leisure programs in key locations across all capital cities and regional centres.

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

Linking between hospitals and schools to improve the transition from hospital back to school is not adequate.

(Carer, Mother, Victoria Submission #320)

Concerns were also raised about the need to integrate service delivery with Child Protection Workers for the mental health needs of all children and youth they may come into contact with. Also, training for Child Protection Workers was also suggested with regard to children of parents with mental illness:

Child Protective services closed the case… because [the father] was stable at the time. He has since stopped taking his medication and is not receiving any psychiatric supervision but Child Protective Services have no authority to act until [the child] is in immediate danger, which may be too late.

(Anonymous, Victoria, Submission # 306)

We believe there is a serious lack of skilled Child Protection Workers, especially those who deal with children who have a parent or parents with mental illness. There is an urgent need for a special unit to be set up within the Department of Human Services to provide trained workers who understand the risks and issues involved for children living with mentally ill parents and can make informed decisions.

(Anonymous, Victoria, Submission # 306)

Legislation needs to be changed to provide more protection to children requiring mentally ill parents to be regularly monitored by a psychiatrist and case manager or lose custody. Mental illness is managed, not cured. Supervision should not be voluntary when children's lives and wellbeing are at stake.

(Anonymous, Victoria, Submission # 306)

6.2.8.3.4 Police and the criminal justice system

Due to diminishing access to mental health services for consumers throughout their illness, police are increasingly being called to respond to issues relating to people with mental illness, especially in times of crisis. This places consumers at increased risk of coming into contact with the police and the distinct possibility of entering the criminal justice system.

Brotherhood of St. Laurence and Catholic Social Services Victoria expressed the view that a whole-of-government approach is needed to address to divert people with mental illness from being incarcerated. Such an approach also needs to take into account issues relating to access to care, crisis prevention and the protection of people's rights when and if they are at risk of entering the criminal justice system.

A Victorian police officer suggested that further consultation is required to more clearly define police involvement with people and acknowledge the limitations of their involvement. Additionally, involvement of police to assist with people with mental illness increases the stigma that ensues from police contact and may heighten community fears, in what should be a mental health response.

We know issues in the police force are there and I can say they are being worked through. I think many decisions the police deal with relate to Section 10 of the Victorian Mental Health Act which allows people to be transported involuntary. I believe Police polices have to reflect both city and country areas and that is what we are attempting to do. A lot of our dealings with people with mental illness are governed by the Mental Health Act. One of the difficulties with a State police force is that it's impossible to make policy that is workable for the whole state. Transportation is one issue but the use of restraints is another case in point.

(Victorian Police Officer, Victoria, Footscray Forum #4)

It is our position that all prisoners with a mental health problem have access to appropriate care and treatment. We also believe it crucial that the police and courts execute diversionary options for offenders with a mental illness, recognising that a sympathetic response is required.

(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

6.2.8.3.5 Medicare rebates

Submissions expressed concern with the length of time it takes to get the Medicare rebate after seeing a psychiatrist in the private sector. Another submission raised concerns regarding the inability to access treatment from psychologists as their services do not come under the Medicare rebate scheme. As such, people from a low socio-economic background are disadvantaged as they can not afford to access private services and there are too few psychologists on the public sector.

…there are no adjunct psychology counselling systems in place to support the medical ones and at $80 plus a session for psychologists, few can dream of affording this support. Unless there is a will to include referral psychologists and funding assistance as part of the mental health system, no improvement of the current crisis situation is to be expected and the costly revolving door system grinds on.

(Anonymous, Victoria, Submission #216)

It takes too long to get the Medicare rebate for a visit to a private psychiatrist ($150 fee for service, $120 rebate, but you have to wait six weeks it).

(Coordinator, Grampians disAbility Advocacy Association, Victoria, Submission #212)

A general practitioner also raised concerns with regard to the length of time required to provide treatment and support to consumers with complex needs and that the Medicare Benefits Schedule rebate to consumers does not adequately recognise and reimburse practitioners for this time:

The majority of medical services provided to these patients are provided by general practitioners. The provision of these services are largely unsupported and despite recent changes in the schedule are largely under funded for the time and resources needed to manage patients with long term mental health problems.

(GP in rural Victoria, Victoria, Submission #123)

6.2.8.3.6 Employment

My son has paranoid schizophrenia. He's on new medication and he's the best he has been for 20 years. He wants to work but we can't get any help. I got on John Fay's program to discuss this and within 5 minutes the Minister was on air talking about funding.

(Carer, Mother, Ballarat, Victoria, Melbourne Forum #11)

Access to welfare, the supported wage and finding suitable employment are all critical components in the process of social inclusion and living a meaningful life with dignity in the community. However, many concerns were raised regarding difficulties with the current welfare and employment systems and models:

Workers with psychiatric disabilities have traditionally been faced with limited work options because of discrimination in the open labour market or because of a lack of meaningful employment service models.

(Disability Employment Action Centre, Victoria, Submission #209)

The exclusion of people with a disability in the Australian labourforce will increasingly become more expensive if government does not develop new employment policies that value diversity and inclusivity. The under-utilisation of people with a disability in the workforce is estimated to costing the community $18.8 billion, or $5000 for each taxpayer[1].

(Disability Employment Action Centre, Victoria, Submission #209)

The Commonwealth should be seriously committed in assisting people with psychiatric disabilities in gaining employment and as a matter of urgency should consider: (1) new employment policies for people with psychiatric disabilities; (2) alternate employment models as a way of providing more appropriate assistance and choices; and (3) new measures to increase labourforce participation.

(Disability Employment Action Centre, Victoria, Submission #209)

In the last 20 years there has been no significant development in providing employment assistance to people with a disability.

(Disability Employment Action Centre, Victoria, Submission #209)

[1] http://www.work.asn.au/disability/people/index.cfm, 31 March 2004

DEAC is of the view that to increase the participation rates of people with a psychiatric disability in employment the Commonwealth should put in place the following:

1. *Remove the funding cap to the disability services program to fund more places in disability employment services thus alleviating current waiting lists.*
2. *Research and fund alternative employment assistance models for workers with a psychiatric disability such as the Social Firm Model.*
3. *Increase employer incentives to hire employees with psychiatric disabilities by doubling the current employer subsidy to $2,800.*
4. *Review income support benefits for people with a psychiatric disability to foster a greater sense of independence. A new and more flexible income support system is needed to encourage workforce participation.*
5. *Reverse current Public sector employment trends for people with a disability by drafting new and effective affirmative action policies.*

(Disability Employment Action Centre, Victoria, Submission #209)

Work impairment is one of the major adverse consequences of mental disorder costing more than the costs of successful treatment (Beeharry et al 2002). Thomas and Morris (2003) estimated the cost of this lost productivity to be 23 times the costs falling to the health service in the UK. In addition to "days out of role", even when depressed people are at work, their performance is reduced, and this "work cutback" or "presentism" contributes further to the "hidden" disability of mental disorders. Productivity gains following effective depression treatment far exceed direct treatment costs.

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

People with a psychiatric disability are one of the most disadvantaged groups in the labour market with an unemployment rate of 72% compared to a national rate of 5.7% (Australian Bureau of Statistics, 2001). These statistics reflect the enormous barriers people with a psychiatric disability face in gaining and keeping work. It also demonstrates that existing workplaces and employment agencies are clearly struggling to provide adequate support for this group.

(Disability Employment Action Centre, Victoria, Submission #209)

In relation to government reforms the trend data is indicating that people with mental illness are the group least likely to receive employment assistance. As a policy point in the UK and to some extent in the USA, there are incentives for employers to take on people with a mental illness. The availability of services is there for the general community. Participation in the workforce is an important part of someone's recovery. A research activity undertaken in Mount Druitt in NSW undertaken by the NSW Premier's Department found there was no ongoing support or linkages across services. This is true for most if not all places in Australia. Employment is very important for those with a psychiatric disability as it provides linkages for their health, education, housing, and more. Often, people with a mental illness can't find friends or employment or somewhere to call home. With employment comes wellness!

(Employment Service Provider, Victoria, Footscray Forum #2)

Employment programs to encourage and train people who are able and willing to work again and to educate and compensate employers willing to help.

(Carers, Parents, Victoria, Submission #241)

6.2.8.3.7 Centrelink – lack of support for consumers and carers

With limited access to mental health services, supported accommodation and access to early intervention treatment and support, the burden on families and carers to provide long-term and crisis support is immense. This often impacts on the financial income of the family by a reduced ability of carers to work. The shifting of care by governments to carers fails to recognise that carers are providing a significant cost-free service that is not being shouldered by the community.

Concerns were also raised with regard to the financial hardship experienced by carers due to the lack of services in the community to provide appropriate treatment and support to people with mental illness and / or mental health problems:

> *I have an 89 year old father, blind and with severe dementia, and have lost my part time job due to the amount of time I was needing to take off to tackle crises.*
>
> (Carer, Mother, Victoria, Submission #299)

> *Some programs require that carers pay for their own education and support. Families have in effect been told that they are part of the mental health workforce and indeed they save the federal government billions of dollars per year. Yet lack of direct funding for carers of people with a mental illness including for education programs, support services and carer consultants sends the message that carers' requirements are not valid in their own right and that it is up to them to deal with the fallout from de-institutionalisation.*
>
> (The Network for Carers Of People With A Mental Illness, Victoria, Submission #319)

> *As a carer, I cope reasonably well, but being retired and on a pension, our income is limited, so I work part-time. At times I am stretched mentally and physically, and often feel depressed myself.*
>
> (Carer, Husband, Victoria, Submission #247)

> *They pay us an inadequate amount a fortnight to do a job they know we are unqualified and ill-equipped for, when they are the ones who should be providing us with the people and services to care for our families properly.*
>
> (Carer, Mother, Victoria, Submission #352)

Concerns were also expressed about the insufficient level of financial support available for people with mental illness:

> *The majority of consumers with whom we have consulted have been living on the Disability Support Pension, and have spoken of the difficulties of getting through each fortnight, until the next payment. Housing costs, as discussed earlier, 'eat a large hole' into what they get, leaving little to survive. Consumers report:*
>
> > *"There is just not enough money to live on, so what you do is rob Peter to pay Paul. Your electricity is going to be cut off so you go into a cycle of debt—you borrow from friends and family and then you borrow from someone else to pay it back. It ends up borrowing and borrowing and borrowing, and you are a burden on the people you know and they start avoiding you because you always need something…you start feeling like a leech. And then you don't want to be seen in the supermarket buying food because you still owe someone money. You wear out your family, you wear out your friends, and you start avoiding people and they start avoiding you. It adds to your exclusion and the other awful thing that follows quickly is that it is very hard to fight the bitterness and the resentment that you start to feel about everything".*
> >
> > *"I'm quite lucky as my mum helps me out with money and groceries when I really need it (but it's every second week before I get my pension)—if you don't have the support of family you really are in trouble because you can't live on the Centrelink payment".*
> >
> > *"The rental housing market has gone crazy. You get your money on pension day and go pay some bills, get some cigarettes and get some groceries—and before you know it you have no money left and end up getting food vouchers to get by".*
> > *(BSL 2004 Focus groups with mental health consumers)*
>
> (Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

Living like this is hard and would put a strain on most people's mental health and wellbeing. Unfortunately, meeting the expenses of basic necessities means that many people have no money to participate in leisure and social activities, a situation that isolates them further:

> *"It's awful when you look at someone else and start to resent their happiness—resent it." (BSL 2004 Focus groups with mental health consumers)*

Providing people with a sufficient income to allow them to live with some dignity must be a priority in a wealthy and civilised society.

(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

6.2.8.3.8 Public transport

Another related but indirect problem with regard to access to services is transport. This concern was raised by a service provider that for many consumers, for a myriad of reasons, reliance on public transport and location of services is critical. Collaboration with local transport providers may also be an essential link to be made to enable access to services without discrimination for all consumers.

Staff and members discussed availability and cost of public transport as an issue that impedes access to services, it impacts on people already isolated in the community. Our lack of resources mean we are unable to provide transport as frequently as it requested to assist engagement into the service.

(Service Provider, Victoria, Submission #266)

6.2.8.3.9 Training of Nurses

The Centre for Psychiatric Nursing Research and Practice expressed concern regarding training of nurses and the impact this has on the capability of health services to respond to the needs of people with mental illness and mental health problems. This will also impact on the diminishing number of mental health professionals available for recruitment:

In 1993 in Victoria, the separate psychiatric nurse degree was abolished, and merged with the comprehensive nurse training degree. This has meant that the mental health component of undergraduate nurse training is as little as 3% in some courses… This has a direct impact on the quality of care offered to consumers, and the capacity of services to meet care needs with appropriately trained staff.

(Centre for Psychiatric Nursing Research and Practice, Victoria, Submission #323)

6.2.8.3.10 Public versus private mental health services

Concern was also expressed regarding access and type of care in both the public and private sectors, affordability of care and concerns for the future:

One of the ongoing themes in the various debates that are being held about the responsibility of governments with respect to health services is the possibility that two levels of health care might evolve as a consequence of government policy. The fact is that in the mental health area, two levels of care already exist. These two levels of health care for the mentally ill overlay the existing split between the public and private provision of services.

(Anonymous, Victoria, Submission #318)

There are noticeable differences between the private and parts of the public mental health systems with respect to attitudes to treatment. Money appears to be a major driver here although workforce culture and age profiles, differing financial controls and the evolution of new patterns of illness and new opportunities for treatment all play their part. We have reached a situation in this country where the public in-patient services are geared to short term, crisis management. These services are also restricted in the sense that by the population of patients that is receives treatment is essentially made up of persons with psychotic disorders and persons who are considered to be at risk of suicide. For too many this access to specialist treatment and care is also transient and upon discharge to private GPs enter the process. Issues like bulk billing, surgery hours, GP interest, geographic location of residency etc. then take their toll.

(Anonymous, Victoria, Submission #318)

As already described, the population of in-patients in the public mental health units is essentially made up of persons with psychotic disorders. This is in marked contrast to the private clinics where sick people with the full range of mental illnesses will be receiving specialist care and treatment and this is continued after patient discharge.

(Anonymous, Victoria, Submission #318)

6.2.9 STANDARD 9: SERVICE DEVELOPMENT

The MHS is managed effectively and efficiently to facilitate the delivery of coordinated and integrated services.

I would like to finish with a quotation from a worker in the mental health field… "We have to put a fence at the top of this cliff rather than an ambulance at the bottom".

(Carer, Mother, Victoria, Submission #178)

Under this Standard, submissions and presentations indicate concerns about:

- the current state of mental health services in Victoria;
- involvement of the Victorian government and health bureaucracy;
- the lack of services;
- quality of care;
- staff shortages;
- lack of funding;
- distribution of resources;
- the medical model;
- education and training of mental health staff;
- staff attitudes;
- accountability and barriers to service reform and quality improvement; and
- re-institutionalisation.

6.2.9.1 Concerns about the current state of mental health services in Victoria

Other endemic forces were characterised by David Goldberg under the acronym ACE. A is for austerity, meaning that reform needs money, and budgetary stasis, and even progressive budget cuts, such as we have seen in inpatient settings over the past 10 years, are unlikely to be associated with improvements for patients, especially given the massive new challenges faced by such units. C is for criticism and refers to the culture of blame, usually devolved downwards, which persecutes those at the sharp end of the problem for inevitable errors or for whistleblowing and advocacy. E is for enmity which involves the lack of collegial support and factionalism which has often been seen across services and academic units, between disciplines and even between the components of our so-called integrated mental health services. This has been augmented by the disaggregation of the public mental health system when mainstreaming occurred. We need to find ways to come back together as a functional system of care.

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

While the majority of this Report documents a variety of concerns regarding the current state of mental health services in Victoria, the following quotes also capture comparative perspectives and current perceptions:

Things are now worse than they were 12 years ago.

(Carer, Victoria, Melbourne Forum #2)

In my view the mental health system has improved markedly from 20 years ago but a lot still needs to be done.

(Anonymous, Victoria, Morwell Forum #19)

While being under-resourced, Victoria continues to provide a model for the other States and Territories. If adequate funding were in place, Victoria's mental health services could provide an international example of best practice.

(SANE Australia, National, Submission #302)

I have been a psych nurse for 22 years. I have been part of and witnessed the change from institutional care to community based care. We do the best we can with what we have. But we only achieve 60-80% of the guidelines. We sometimes feel that we are only providing band-aid therapy.

(Clinician, Victoria, Footscray Forum #5)

The State's specialist services – for example in early psychosis intervention (EPPIC), dual diagnosis (SUMMIT), borderline personality disorder (Spectrum) and forensic treatment (Forensicare) – are highly regarded in Australia and overseas.

(SANE Australia, National, Submission #302)

Is it acceptable that many of the people who were deinstitutionalised now number among the homeless and the prison population?

(Carer, Mother, Victoria, Submission #178)

When we moved patients from institutions and subsequently closed the institutions why did we not anticipate the increase in demand for short term admission and accommodation requirements? *It was after all entirely predictable but there is no provision for it. There has been little or no realistic attempt to correct the lowering in the levels of acute beds across the state. In Victoria we not only closed the institutions but also substantially reduced the number of beds available for short term and acute admissions. (author's emphasis)*

(GP in rural Victoria, Victoria, Submission #123)

A couple of days after he was admitted, when I rang, a doctor told me that my son would be discharged in a weeks time. I expressed surprise that he could possibly be well enough by then. She suggested that perhaps I should have a meeting with the head psychiatrist at the hospital and her to discuss the matter. I readily agreed. Prior to the meeting I gave a lot of thought to the pattern of the previous ten years… lack of consultation about treatment plans or changes to treatment plans resulting in persistent relapses, not being given information and not having my information or concerns heeded, the Mental Health System not accepting the responsibility of maintaining my son's 'wellness' and then repeatedly expecting me to accept the responsibility for his care and rehabilitation.

(Carer, Mother, Victoria, Submission #178)

Since de-institutionalisation carers have born the brunt, along with our seriously ill family members, of serious under funding of Mental Health services, particularly well integrated community supports. 'Out of hospital, out of mind' still resonates in Victoria.

(Carer, Mother, Victoria, Submission #299)

The mental health system is in crisis. There is a shortage of psychiatric nurses because they are overworked and under resourced. There are not enough available beds in psychiatric hospitals, particularly in country areas.

(Anonymous, Victoria, Submission # 306)

There are increasing numbers of people in the community living with mental illness, accessing under-resourced services and facilities. This in itself is an abuse of human rights when we consider that Australia has a universal healthcare system, which is supposed to guarantee healthcare to all those in need. Yet we continually hear stories of people requiring assistance remaining untreated, or under-treated through lack of resources, or inadequate mental health training of medical and healthcare professionals.

(Centre for Psychiatric Nursing Research and Practice, Victoria, Submission #323)

The Burdekin Report uncovered a great deal in terms of issues and recommendations, but more needs to be done. Unless steps are taken now to adequately investigate the true state of mental health care in Australia via both a HREOC investigate and a Senate Standing Committee Inquiry, the situation will get much worse before it gets better, and it will be predominantly consumers who will suffer the consequences.

(Centre for Psychiatric Nursing Research and Practice, Victoria, Submission #323)

Despite welcoming the policy efforts and designated funding commitment of both state and federal governments, consumer agencies and community organisations are critical of their performance. It is argued that the failure of government to adequately resource its policy initiatives has lead to a chronic deterioration of care and support for mental health consumers. There is significant concern that because of the inability of services to provide preventative care this leads to delays and neglect in treatment, some of which creates irreversible damage in the mental health status of consumers. It also leads to an increased demand on an already overstretched mental health system.

(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

The politicians need to pull their fingers out & recognise Mental Illness for what it is and meet the people's needs. We are Desperate!

(Carer, Mother, Victoria, Submission #352)

Victoria, at one stage, was arguably amongst the leading States in Australia in regard to the delivery of mental health services. However, in recent years, a mounting groundswell of community concern has led many to question this notion. Issues of ease of access to services, especially in crisis situations, overloaded case management systems and insufficient acute beds are all now widely recognised problems. Demand for mental health services is growing exponentially and service provision is not keeping up. Not only is this leading to people 'missing out' on help when they need it but those who have engaged the system are not getting the level of help they need. The 'right to treatment' is effectively not always available.

(Health and Community Services Union, Victoria, Submission #220)

6.2.9.2 Involvement of the Victorian Government and health bureaucracy

Certainly its segregation from mainstream health care continues to perpetuate the stigmatisation of mental illness.

(Australian Nursing Federation (Vic Branch), Victoria, Submission #322)

Concerns were also expressed regarding the impact of initiatives and direction from the Victorian Government on the delivery of mental health services. Specifically, concerns were expressed that the reform process has stagnated, consumers have ceased to be the focus of service delivery and much energy is expended in protecting the government. These concerns indicate that many processes which exist or were in the process of implementation which could assist with the protection and promotion of the rights of people with mental illness are at risk of being abandoned.

Due to the lack of continuing reform momentum, the new model has become steadily institutionalised with patchy leadership and poor morale, and consequently non-consumer focused work practices.

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

In the Office of the Chief Psychiatrist they are there to protect the Minister – not the consumer. They can never carry out their job in the manner in which they should when there is no separation from government.

(Consumer Advocate, Victoria, VMIAC Consultation #12)

It's all about protecting the government. The patient is not the focus.

(Consumer Advocate, Victoria, Victoria, VMIAC Consultation #17)

I watched Minister Pike on TV reading off an idiot sheet but she didn't know what she was talking about. She needs to get into the system to find out herself what's happening.

(Carer, Victoria, Melbourne Forum #3)

Workforce review program was to be put out to the public by September last year but it's still not released.

(Anonymous, Victoria, Morwell Forum #19)

Auditor General's report was blown out of the water but I was working in the AG's office and it was valid.

(Victoria, Melbourne Forum #10)

6.2.9.3 Lack of services

The lack of services, both in the community and to acute care services in hospitals across Victoria, was reported extensively in most submissions and at the community consultations. As discussed in more detail later in this report (particularly Standard 11.4, Treatment and Support), the lack of services to deliver treatment and support from the early intervention phase to recovery and rehabilitation for many mental health disorders and problems, across the life span and across Victoria, impeded the delivery of coordinated and integrated mental health services to consumers and their families and carers. This would suggest that planning is not occurring 'through a process of consultation with staff, consumers, carers, other appropriate service providers and the defined community' (Standard 9.8) and that resources are not being allocated 'in a manner which follow the consumer and allows the MHS to respond promptly to the changing needs of the defined community' (Standard 9.15).

Only a fraction even of the most seriously mentally ill can gain secure tenure in this system. So even with a system heavily targeted to chronic schizophrenia, only a minority even of these cases gain appropriate coverage. The rest are referred back to unsupported GP's after the latest patch-up job otherwise called "episode of care".

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

Lack of appropriate, affordable support services eg: counselling and after hours support (has resulted in pressure on after hours telephone services)

(WIRE-Women's Information, Victoria, Submission #182)

Psych disability rehab support sector – our services are funded to provide support to a group of people – the demands on our services always exceed the target but in the past we have worked hard to deliver as much as we can. We have continually raised this with Mental Health branch as a problem that needs addressing but we've had no success.

(Psychiatric Disability Rehabilitation Support Worker, Victoria, Morwell Forum #4)

We don't have a funded consultation liaison service for patients with comorbid drug and alcohol and mental health services.

(Psychiatrist and Clinical Director, Victoria, Morwell Forum #18)

As the mental health system seems to operate in a state of 'overload' many agencies find themselves acting as substitute mental health service providers, without the necessary skills and knowledge.

(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

6.2.9.4 Quality of care

Associated with the concerns expressed regarding the lack of services, staff and funding, were reports regarding the quality of services received from those services which are operating:

There is an increasing number of people accessing mental health services which dilutes the quality of existing services – so with the quality of existing services being poor already you can see we are heading for a disaster.

(Psychiatric Disability Rehabilitation Support Worker, Victoria, Morwell Forum #4)

Quality of care is highly variable and well below what is achievable for a nation like Australia. There is a massive efficacy-effectiveness gap (EEG), that is the real world outcomes of intervention are much worse than can be achieved under optimal conditions. This EEG is almost certainly a more serious problem for mental disorders than physical illnesses.

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

People are unhappy with the level of service received;

(Coordinator, Grampians disAbility Advocacy Association, Victoria, Submission #212)

The new inpatient units are under severe pressure. They have to manage those acute patients who cannot be treated intensively in the community and such patients uniformly need highly intensive care. This work is highly challenging yet receives insufficient recognition and resources. The clinical leadership, morale, nursing numbers and skill levels, and the specific environmental conditions required for this challenge have fallen well short. Smaller units of 8 –12 beds as found in Scandinavia, seen here as uneconomic, are urgently required, together with much greater capacity for 1:1 nursing. This can be achieved by subdividing wards into functional subunits, though few have been designed this way.

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

It is true also to say that mental health services may find themselves often preoccupied with coping with day-to-day crises of an overloaded service system faced with burgeoning demands for services and limitations on resources.

(Consumer Advocate, Victoria, Submission #253)

6.2.9.5 Staff shortage

Associated with the lack of services are reports of an excessive demand for the services that exist, and reports that these services often had difficulties recruiting and retaining staff.

…the large turn over of staff in the services, which is no doubt due to the enormous pressure placed on them due to staff shortages. This lack of staffing continuity is quite serious, not only for the carer, but all members of the treatment team.

(Carer, Victoria, Submission #185)

The case loads for staff are very high.

(Consumer, Paid Consumer Consultant, Victoria, Morwell Forum #5)

…concerns about caseworkers going on leave and no-one being there for the consumer during that period.

(Coordinator, Grampians disAbility Advocacy Association, Victoria, Submission #212)

There's a real shortage of mental health nurses worldwide not just here in Australia and our average age is 42-45.

(Clinician, Victoria, Footscray Forum #5)

But we need to acknowledge that there is a world wide shortage of psychiatrists – Gippsland has managed to solve that to some extent – now we have 10 public psychs so it is improving.

(Psychiatrist and Clinical Director, Victoria, Morwell Forum #18)

I also receive a lot of comments about the cultural and language barriers of the Drs that come to this area. Many of the consumers have great difficulty understanding the heavy accents of Doctors from other countries – but they are the doctors we get in this rural area so there's not much we can do about it!

(Consumer, Paid Consumer Consultant, Victoria, Morwell Forum #5)

Trained staff – unfortunately there are too few trained psych nurses.

(Psychiatrist and Clinical Director, Victoria, Morwell Forum #18)

Public mental health services for in-patients operate exclusively on a crisis- management basis. This fact is contributing to very high levels of staff burn out, low levels of job satisfaction and an inability of public mental health services to attract young nurses. These services are chronically under-funded and the experiences of many medical staff, who spend time in the public system gaining training to become qualified psychiatrists, drives them into private practice as soon as they gain accreditation.

(Anonymous, Victoria, Submission #318)

A system that gives incentives to psychiatrists to move to country areas. At present we believe there are too many whose command of English is such that it is difficult for sufferers and carers, and I am sure a source of frustration for the doctors themselves

(Carers, Parents, Victoria, Submission #241)

6.2.9.6 Lack of funding

Associated with the complaints of lack of available resources to deliver quality mental health services are requests and demands that the level and control of funding needs to change in order that appropriate services are delivered and the rights of people with mental illness are protected. Funding issues were raised both with regard to Federal and State Government contributions to the health budget and the provision of support services for people with mental illness and their families and carers:

> *The level of services to the mentally ill in Australia has decreased since they were moved into the community.* ***This is not because the model is wrong but because the level and control of the funding for these services is inadequate. This will be the case until we establish single source funding with the associated single source responsibility for the funding of these essential services.*** *As a service provider the errors in the system are clear and obvious and considerable effort and clear thinking will be needed to reverse them. This is our challenge into the future and it will only be met with constant and public scrutiny of the system responsible for their care. (author's emphasis)*
>
> (GP in rural Victoria, Victoria, Submission #123)

> *Victoria provides dramatic proof that having a good model, good intentions and committed, innovative health professionals is still not enough to provide adequate mental health services…. if there is insufficient funding to implement services properly.*
>
> (SANE Australia, National, Submission #302)

> *Andrews has attempted to calculate how much of the burden associated with psychiatric disorders is avertable with modern evidence-based treatments (Andrews 2000). While it seems clear he has underestimated this for schizophrenia (Goldberg 2003, Warner 2003), his general conclusions seem to be that much of this burden, up to 40% on average across a range of disorders is potentially avertable. If evidence based treatment were made available and coverage were increased we could avert nearly 30% of the burden in contrast to the present 13%. Andrews had originally argued that greater efficiency should be the priority so as to allow greater coverage. He now appears to concede that it would be more feasible for greater efficiency (i.e. a narrowing of the EEG [Efficacy-Effectiveness Gap]) to be pursued in parallel with greater coverage, which will inevitably require an increase in resources. It actually costs more money to reduce the EEG as well as to provide services to more people. Squeezing an already fragile and pressured system harder to try to achieve these goals is already proving counter-productive.*
>
> (Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

> *The difference for the MH services we cover the whole of Gippsland. The resources are structured differently to physical health services. The way funds are given is on a program basis and we have to account for those funds.*
>
> (Psychiatrist and Clinical Director, Victoria, Morwell Forum #13)

> *The Federal Government has put in over a $1million into the system but the Sate Government has effectively reduced its funding by $1.2m. We do all this work, we go to Canberra and get the money, we fight for reform and in the end we get nowhere.*
>
> (Regional GP, Victoria, Morwell Forum #8)

> *However the funding split between hospital and community care is essentially a state/federal one and it has proved difficult to grow the state-funded community-continuing care sector outside of acute phase care. Hence the repeated call for more beds (more clearly a State responsibility) rather than more community care, which is actually the main deficiency. Finally the modus operandi of most continuing care teams is office-based rather than mobile assertive outreach. This is a further weakness in the model which inflates the apparent need for beds.*
>
> (Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

Australian Federal and State Governments are turning their backs on severe mental illness support systems. It is time to catch up with other civilised countries such as New Zealand which provides double the budget per capita on mental health and psycho social support.

(Anonymous, Victoria, Submission #216)

I came from New Zealand and I don't think our system here is that different. Like all mental health services it is under-resourced so the way funding is distributed is a problem. Compared to the rest of the health system in mental health we miss out.

(Psychiatrist and Clinical Director, Victoria, Morwell Forum #18)

…reform needs money… budgetary stasis, and even progressive budget cuts, such as we have seen in inpatient settings over the past 10 years, are unlikely to be associated with improvements for patients, especially given the massive new challenges faced by such units.

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

Further allied health resources should be allocated directly to a range of primary care settings via the Medicare scheme.

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

Serious incentives should be created for psychiatrists to work more closely with primary care.

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

…(people making decisions about the distribution of resources) need to ask challenging questions such as 'serious to whom?' and 'serious through whose eyes?'

(Consumers, Victoria, Submission #194)

There is increased funding for GPs to provide care for those people with high prevalence disorders but we have a huge problem treating people with serious mental illnesses.

(GP, Victoria, Morwell Forum #8)

As someone who has a mental illness, I generally feel abandoned and thrown to the waste dump by the government, who refuses to commit more funding to mental health care.

(Consumer, Victoria, Submission #84)

There needs to be recognition of true need in the community. Currently, one in five Australians experiences a mental illness, but only 7% of the health budget goes to mental health. There is therefore a 13% gap in terms of actual need, and funding provision. Australia has not kept abreast of other comparable developed nations when it comes to expenditure on mental health – we spend half that of some other nations in percentage / per capita terms.

(Centre for Psychiatric Nursing Research and Practice, Victoria, Submission #323)

Support for mental health services has genuinely increased in recent years, but so has demand. In the period 1997-2001, for example, the number of consumers registered with mental health services increased by 20%, and there is no reason to think this trend has decreased. Promotion and prevention strategies and improved liaison with primary care and non-government agencies mean that unmet need translates into demand and increased pressure on services. In other words, people affected by mental illness are being diagnosed and referred to services more effectively. The net effect of increased funding, therefore, may be that things do not improve but remain the same rather than worsen… or worsen at a slower rate than otherwise. Some Areas are also far better funded than others for historical reasons and this needs to be addressed.

(SANE Australia, National, Submission #302)

I would also like to remind the HREOC and the MHCA of the pitiful government funding that is still deemed acceptable for services in the Alcohol and Drug sector.

(Clinical Service Provider, Victoria, Submission #268)

Both State and Federal Governments put considerable energy into devising lengthy and detailed mental health plans. Of what use are they if there is no funding with which to implement their recommendations? Human rights are not adequately addressed in these plans; there is no detailed documentation on accountability measures where rights are not upheld.

(Centre for Psychiatric Nursing Research and Practice, Victoria, Submission #323)

Real monetary investment is needed to support our mental health services. Without this support, consumer's experiences of trying to access services will remain problematic. There is a real need to increase funding so as to ensure timely and appropriate responses within the mental health system.

(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

6.2.9.7 Distribution of resources

You can't get care in the country. I travel 3.5 hours from the country to here (Melbourne) because I can get care here. I can't get care in the country but now I can't work because I need to travel down to here for care.

(Consumer Advocate, Victoria, VMIAC Consultation #8)

Professor McGorry also expressed concern regarding the distribution of resources across metropolitan, rural and regional areas and access to services by people from low socioeconomic background or who live in disadvantaged areas.

Secondly in Australia, and notably in Melbourne, the distribution of public mental health services, private psychiatrists and high levels of quality primary care, is almost the direct inverse of the need for care. The affluent inner city areas have high levels of services of all kinds, while the growing or deprived outer suburban regions have minimal resources with inevitable consequences. The funding model was never valid and is now obsolete as well.

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

Thirdly, while this may be true to an extent in general healthcare, in psychiatry it is even more discriminatory than is realised. This is because services are tightly catchmented. So you cannot "shop around" either for acute care or for aftercare in the public sector. In effect you can be marooned in your own underresourced outer metropolitan or rural sector, where there are few if any private sector options. It is possible for people to move beyond these catchments for private psychiatric care, for example by visiting a private psychiatrist in another part of the city. However apart from the geographical barriers, there are large cost barriers for disadvantaged people here since most private psychiatrists, like all specialists, now charge well above the scheduled fee and rarely bulk bill. As a result rates of treatment for high prevalence disorders are almost certainly much lower in disadvantaged areas. This scenario, which would pertain across most regions of Australia, has not been honestly acknowledged by health planners.

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

The funding for public mental health services in rural regions is generally well under that needed to account for the additional costs in operating a service in a widespread and distant region. This means that the face top face service provision is limited. Some services attempt to correct this deficit with the provision of substandard and poor quality video or telephone consultations. While these are far better than no choice they are very much a second rate service that would not be tolerated by our city patients. The new Medicare item numbers for this service are complex to administer and difficult to access they take little or no account of line costs for the provision of the service and do not cover the costs of the enforced one in four face to face visits.

(GP in rural Victoria, Victoria, Submission #123)

Concern was also expressed about the level of funding allocated to the poorly-resourced NGO sector, especially in rural and regional areas:

Funding to community-based mental health services is also inadequate, with rural and regional consumers being particularly disadvantaged.

(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

6.2.9.8 The medical model is a problem

Concerns were also expressed regarding the use of the medical model as the basis for the planning and delivery of treatment and support services and that this model was impeding the protection of the rights of people with mental illness.

The excessive medicalisation of mental health is a human rights issue.

(Consumer, Victoria, Melbourne Forum #4)

We have a medical model that contributes to people's deaths.

(Consumer Advocate, Victoria, VMIAC Consultation #16)

The adult system remains predominantly an acute care model for people with chronic psychotic illness, translocated from the "bins" to the general hospital system. A hidden expectation of mainstreaming is that outside of acute care that the same arrangements as for other medical disorders should apply, namely GP follow up. There is no research evidence whatsoever for the effectiveness of this model in psychiatry, hence it is a default model and in no way evidence-based.

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

I am writing to say how difficult it is as a carer to source appropriate and continuous support mechanisms within the public health system for the recovery of a mentally ill patient. That is to say that the medical and psychosocial models have to operate in parallel, not serially, and that the psychosocial rehabilitation infrastructure has to offer a level of service which provides continuity so that planned rehabilitation activities can be sustained instead of a scattergun approach.

(Carer (mother), Victoria, Submission #280)

…the forensic mental health system… the tragic outcomes of cases that perhaps could have been avoided had more services been involved at an earlier stage to better manage their mental illness and provide support to families. The cost to the community is far greater in the long run if adequate resources are not available when needed most.

(Anonymous, Victoria, Submission # 306)

6.2.9.9 Education and training

Standard 9.17 states: 'The MHS regularly identifies training and development needs of its staff' (for example with reference to industry-validated core competencies for mental health staff) and Standard 9.18 states 'The MHS ensures that staff participate in education and professional development programs'. Reports were received concerning the number of trained mental health nurses available and the type of training being received by mental health nurses. The increase in training being received by general practitioners was noted:

In particular, I believe that the education and training needs of triage nurses have been entirely neglected, and given that these practitioners comprise 79% of the MH triage workforce this seems a gross oversight. In order to create quality service provision, specific, high quality education and support must be directed towards triage practitioners.

(Anonymous, Victoria, Submission #174)

The nurses really need educating – we've written letters to the Commissioner and the Chief Psychiatrist but we got no answer.

(Carer, Victoria, Melbourne Forum #3)

The number of trained staff is also a big problem for us in this region – unfortunately there are too few trained psych nurses.

(Psychiatrist and Clinical Director, Victoria, Morwell Forum #18)

The situation with regards to training of mental health nurses is also of grave concern. … There are too few new and younger graduates coming through the generic nursing degree streams, who either interested in, or have enough training for mental health nursing. As the population of mental health clients seems to be escalating, concurrently the population of trained and experienced staff to deal with them seems to be falling. If this situation continues the welfare of patients will be at risk and consequently, the community also.

(Clinician, Victoria, Submission #201)

A nurse especially should have an intimate understanding of how the patient is feeling but this doesn't happen anymore.

(Consumer Advocate, Victoria, Victoria, VMIAC Consultation #17)

People have left the MH service and people have lost confidence. I think they're in danger of real problems because they are not getting care. Some of the problems can be a personality clash between some of the staff and some consumers.

(Anonymous, Victoria, Morwell Forum #3)

People with serious mental illness don't feel they are being understood by providers.

(Anonymous, Victoria, Morwell Forum #3)

Is it acceptable that the 'Carer Perspective' is not, in general, included in the training of all Mental Health professionals?

(Carer, Mother, Victoria, Submission #178)

GPs are now getting much more training so that's been helpful.

(NGO worker, Victoria, Morwell Forum #7)

6.2.9.10 Staff attitudes

Similarly, concerns were expressed about poor staff attitudes towards consumers indicating that staff were in need of training in order to change their attitudes and behaviours (decrease discrimination) and be more supportive when dealing with people with a mental illness:

One member found it offensive to be told by a community nurse that "you're not mentally ill, you have a living problem"; and the solution is?

(Coordinator, Grampians disAbility Advocacy Association, Victoria, Submission #212)

Psych services wipe you off the books when they feel like it

(Coordinator, Grampians disAbility Advocacy Association, Victoria, Submission #212)

I have experienced and heard of far worse, but it does raise issues of entrenched attitudes, lack of understanding and on occasions, even arrogance, whilst at the same time, in fairness, acknowledging the fact that there are some enlightened 'carer sensitive' clinicians within the system.

(Carer, Mother, Victoria, Submission #178)

> I have been told by a CAT [Crisis Assessment and Treatment] team member on Triage duty at Public hospital ER (within the last few years time, date, name, recorded) "go out and see if the moon is up will you" As far as I am aware he is still working in the same position and nothing was done.
>
> (Consumer, Victoria, Submission #112)

> *WE SEE AS UNACCEPTABLE: Indifferent attitudes of psychiatrists / lack of sensitivity of staff / lack of skilled people in the profession / general lack of knowledge. (author's emphasis)*
>
> (Carer, Husband, Victoria, Submission #247)

> *It has been the experience of the VMIAC that more often than not, if you ask consumers if they could wave a magic wand and change something about the mental health system what would they change? The attitude of health professionals is the most frequent answer followed by access to services.*
>
> (VMIAC, Victoria, Submission #332)

> *Better training for people working in mental health so there is not the "patronising put down" attitude that I have witnessed*
>
> (Carers, Parents, Victoria, Submission #241)

> *An inclusive attitude for carers and families - where they are listened to and really heard and consulted more closely*
>
> (Carers, Parents, Victoria, Submission #241)

The following quote by Professor McGorry provides some explanation as to the reasons for the concerns expressed above by consumers and carers. Lack of resources, high demand and overstretched staff would also contribute to low service morale and impact on attitudes and behaviour of staff towards consumers and their carers and families.

> *A related point is the level of negative emotion that clinicians are exposed to on a daily basis. Once again this contrasts greatly with other health care settings. The patients can in no way be blamed for this, however the effects of this in services on morale have been underestimated. This is partly responsible for the perceived endemic lack of warmth and flexibility frequently highlighted by consumers and their families in clinical settings. Many staff become detached and burned out. This is not their fault and yet these effects are by no means inevitable.*
>
> (Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

Nonetheless, it could be argued that an appropriate increase in resources to the mental health sector could indeed overcome many of the problems outlined by Professor McGorry.

6.2.9.11 Accountability and barriers to service reform and quality improvement – protection of government and administrators and staff fears of negative repercussions for comments on service delivery

Concern was expressed that a culture exists at government and administration levels that impedes the identification of systemic or individual problems to be addressed to improve service delivery and promote and protect the rights of people with mental illness:

> *It is unfortunate but a culture exists which places the protection of government, Ministers, bureaucrats, organisations, managements, clinicians, and service providers above the protection of patients, in particular those with a mental illness.*
>
> (VMIAC, Victoria, Submission #332)

HACSU members, although acutely aware of the issues, are often unable to articulate the problems they confront on a daily basis as they attempt to provide mental health services. Government policy, conditions of employment and fear of negative repercussions often prevent workers speaking publicly about the difficulties they face.

(Health and Community Services Union, Victoria, Submission #220)

6.2.9.12 Re-institutionalisation

Concern was also expressed that the lack of treatment and support services, focus on acute care and rising rate of people with mental illness in the criminal justice system is effectively "re-institutionalising" people with mental illness.

As each institution has been able to be closed, it has also been able to be sold off with the realisation of tens of millions of dollars. Instead of this money being directed to provide appropriate facilities within communities, it has been re-directed away from the mental health system. Governments have been able to away with this because they have been able to exploit the generosity, good will and emotions of families and carers who are close to each person suffering chronic mental illness. A consequence of this chain of events has been the emergence of new forms of incarceration, particularly for persons without family or carer support. These new institutions take the form of prisons, rooming houses, squats, parks and large drains.

(Anonymous, Victoria, Submission #318)

6.2.10 STANDARD 10: DOCUMENTATION

Clinical activities and service development activities are documented to assist in the delivery of care and in the management of services.

In one instance, a patient was on 15-minute sightings, which were noted in the file from 0900 to 1050. The problem was that the patient jumped in front of a train at 0910. No accountability occurred or fault was found. The parents were devastated especially after the police contacted them, they phoned the hospital and were told he was okay when in fact he was dead.

(VMIAC, Victoria, Submission #332)

Under this Standard, submissions and presentations indicate concerns about:

- the lack of communication between services and programs to ensure continuity of care;
- the lack of comprehensiveness of documentation;
- problems with the management of documentation; and
- the documentation system not being accessible.

6.2.10.1 Lack of communication between services and programs to ensure continuity of care

Standard 10.2 states: 'Treatment and support provided by the MS are recorded in an individual clinical record which is accessible throughout the components of the MHS' and Standard 10.4 states 'A system exists by which the MHS uses the individual record to promote continuity of care across settings, programs and time'. Reports were received that systems were not allowing for documentation to be accessed across settings thus impeding the delivery of coordinated and integrated treatment and support:

My wife is ill. The biggest problem in hospitals is communication. Once, when taken in by an ambulance, she was sent home. It happened within the last couple of months.

(Carer, Husband, Victoria, Melbourne Forum #3)

The after hours psych services number in this region is switched through to a town 100km away, and then the consumer's issue is not referred back to the local nurses;

(Coordinator, Grampians disAbility Advocacy Association, Victoria, Submission #212)

6.2.10.2 Documentation is not comprehensive

Standard 10.5 states: 'Documentation is a comprehensive, factual and sequential record of the consumer's condition and the treatment and support offered' and Standard 10.6 states 'Each consumer has an individual care plan within their individual clinical record which documents the consumer's relevant history, assessment, investigations, diagnosis, treatment and support services required, other service providers, progress, follow-up details and outcomes'. Concerns however were expressed that documentation was not comprehensive

There is no evidence from the file that the mother's concerns were conveyed to the inpatient consultant or registrar. (In the 'Root Cause Analysis, a document required by the Department of Human Services after the death of a patient)

(Carer, Mother, Victoria, Submission #206)

…I estimate… that about half the day shifts passed without attempts at engagement with [X] being made, or recorded.

(Carer, Mother, ex-nurse, Victoria, Submission #206)

6.2.10.3 Problems with the management of documentation

Concerns were also expressed indicating that decisions were being made that were not consistent with care plans and that the excessive amount of paperwork required of providers often resulted in a good care plan being abandoned:

Psych services wipe you off the books when they feel like it

(Coordinator, Grampians disAbility Advocacy Association, Victoria, Submission #212)

My daughter recently left hospital and we had no contact from the hospital to inform us that our daughter had actually been discharged. I had no idea where she was or when she had been released. The authorities had placed a community treatment order on her for the next 12 months which we thought was a good thing because at least she would get some care however the psychiatrist took her off that order after 2.5 months complaining about the level of paperwork required as part of the process.

(Carer, Mother, Victoria, Footscray Forum #10)

6.2.10.4 Documentation system is not accessible

Concern was expressed by one consumer that the documentation system is often not accessible and clinical records can not be retrieved to assist with continuity of care. Standard 10.2 states: 'Treatment and support provided by the MHS are recorded in an individual clinical record which is accessible throughout the components of the MHS'.

In the past I have gone to see CAT [Crisis Assessment and Triage] team Triage in hospital ER room where my file has not been available, when I know that this particular hospital Mental Health Triage was set up with access to a key in the ER to make files available as people are seen in crisis there.

(Consumer, Victoria, Submission #112)

6.2.11 STANDARD 11: DELIVERY OF CARE

Principles guiding the delivery of care: The care, treatment and support delivered by the mental health service is guided by: choice; social, cultural and developmental context; continuous and coordinated care; comprehensive care; individual care; least restriction.

I am concerned that I, who see my role as my daughter's protector and nurturer, had to call the police on my daughter, because she could not be treated by the mental health system. I am concerned that the Eastern Area Mental Health Service was totally inadequate in dealing with the situation and left the police and emergency services and casualty departments to deal with a mental health problem. I am amazed at the amount and cost of public resources that were consumer in 'managing' her behaviour while she was untreated – police, ambulances, lawyers, courts, accident and emergency rooms. You can add to this the resources used in supporting her family – private counselling, Victims of Crime, the court system. This is in stark contrast to the negligible resources used in addressing the situation and in treating her.

(Carer, Mother, Victoria, Submission #307)

Under this global Standard outlining the principles underlying care, submissions and presentations indicate concerns about:

- the lack of individual, continuous and coordinated care;
- lack of comprehensive care;
- restrictive approaches in the least empowering settings;
- lack of choice; and
- lack of individualised care.

Below are selected examples of concerns against the principles guiding the delivery of care.

6.2.11.1 Lack of individual, continuous and coordinated care

Concerns from consumer advocates indicate that treatment and support are not devised on an individual basis or provided in a continuous or coordinated manner as evidenced by the fact that consumers are absconding from care to suicide or self-medicating with alcohol or drugs because they can not access care.

The month after people are discharged is when people are at the highest risk. There are reports about people absconding from care to suicide – nobody is asking the question as to why people are absconding from care to kill themselves. Is being in care that intolerable for some people?

(Consumer Advocate, Victoria, VMIAC Consultation #18)

Self medication with drugs and alcohol in order to cope with lack of support and resources.

(WIRE-Women's Information, Victoria, Submission #182)

Like all health care, we have serious concerns about the adequacy of the mental health workforce and its ability to treat people in a timely and appropriate manner. The shortened length of stay all too often results in people being discharged, with referrals to all over stretched community mental health services. The burden on the individual and their family is huge, as the individual may not receive the type and quality of treatment required. Conditions remain untreated and the severity of the illness increased – at times with disastrous consequences.

(Australian Nursing Federation (Vic Branch), Victoria, Submission #322)

6.2.11.2 Lack of comprehensive care

Concern was also expressed that treatment and support is not available to meet consumers' 'specific needs during the onset, acute, rehabilitation, consolidation and recovery phases…' as there are insufficient services, those operating are overstretched and people are being case managed for very short periods of time.

In general the Mental Health services are inadequate and stretched, and this often results in ineffective treatment. Ineffective treatment can mean that consumers' wellness is often not maintained to a satisfactory level, and this in turn creates an increased load for carers.

(Peninsula Carers Council, Victoria, Submission #321)

People are case managed for a very short period of time.

(Anonymous, Victoria, Morwell Forum #16)

Care may be available freely to those who damage property or other people but my submission is that more funds should be available for support of the mentally ill so that they have the very best opportunity to reach independence and their full potential which incidentally may save taxpayer's funds in the long term.

(Carer, Mother, Victoria, Submission #238)

6.2.11.3 Restrictive approaches in the least empowering setting

The principles of choice and least restriction appear not to be upheld according to practices of sedation and restraint due to an inability to access services earlier in the illness cycle and the acute system is poorly resourced.

…it goes against the grain to see people being made to stay on a trolley, in a cubicle, usually sedated, occasionally mechanically restrained, just because the mental health system is overloaded and poorly resourced. This situation is chronic and untenable.

(Clinician, Victoria, Submission #201)

6.2.11.4 Lack of choice

Concern was expressed that enforcement of boundaries of catchment areas was further limiting choice and access to care:

Boundaries: Catchment areas of area mental health services limit member's choices of accessing mental health services closer to their homes. Boundaries often take in a number of confusing routes.

(Service Provider, Victoria, Submission #266)

6.2.11.5 Lack of individualised care

Concern was expressed that due to insufficient resources and lack of services, the guiding principle of individual care 'specialised mental health treatment and support are tailor-made for each individual' can not be realised:

> *More funding to make it possible for programs to be developed and tailored to individualised needs to make it possible for suffers to become worthwhile participants in the community.*
>
> (Carers, Parents, Victoria, Submission #241)

6.2.11.1 Access

The MHS is accessible to the defined community.

> *We need a clinic we can walk into just like a 24 hr clinic you would attend for the flu. Why can't we have it? Why do I need to self harm myself to receive relief? Why do I need to overdose to receive attention? Do I and many, many more need to die before we attend to what we preach that mental illness is like a physical illness?*
>
> (Consumer, Victoria, Submission #202)

Under this Standard, submissions and presentations indicate concerns about:

- access not possible even if there is risk of harm to self or others;
- carers need to be heard;
- problems with phone triage;
- lack of access to private psychiatrists, GPs, counsellors and rehabilitation services;
- access denied if consumer has a diagnosis of 'personality disorder';
- difficulties accessing services for people with mental illness and drug and alcohol problems; and
- lack of access to care resulting in entry into the criminal justice system.

> *What is acceptable about not keeping people with a mental illness as well as they can possibly be, thus reaching and maintaining their full potential within the illness?*
>
> (Carer, Mother, Victoria, Submission #178)

The community consultations pointed to an inability for consumers to access treatment and support services, both within the community and inpatient care, which resulted in a whole series of rights being infringed for consumers, carers and the community. For the consumer, the consequences of these infringements can include increasing disability and hence consequent inability to care for oneself or others, inability to participate socially or work or study, in some cases the potential for harm to self or others, and becoming homeless and poor.

Increasing disability also exposed the consumer and their family to discrimination and social exclusion further compounding their illness. For children and youth, failure to gain access to services at this time of their life placed their future life course at risk as they were expelled from school, their problems behaviours increased which further disrupted relationships with their peers.

Similarly, increased burdens on carers disrupted their ability to participate socially and work when their family member became increasingly ill and required increasing care. Family isolation and increasing instability were also frequently reported due to the lack of community support and acceptance (high levels of stigma and discrimination) and lack of family-centred approached to treatment and support. For the community, rights to safety were infringed upon and social and economic cohesion disrupted.

6.2.11.1.1 Access not possible even if there is risk of harm to self or others

We do not know how many patients have committed suicide as a result of being denied a service, but we have heard reports of individuals who have successfully suicided shortly after being refused hospitalisation and being left to fend for themselves. Additionally, we have had quite a number of patients tell us that they took an overdose or slashed their wrists as a means of gaining hospitalisation. Our feedback also indicates that many patients are just left to deteriorate until such time as they finally get admitted in a much worse state than was necessary.

(VMIAC, Victoria, Submission #332)

My sister had suffered with bi polar disorder for 30 years… Sadly she took her life on 18th June 2004. On that day I was going to take her shopping but she didn't feel well. She said to me what about Psychiatric Services. But she always presented so well when they interviewed her that I knew they wouldn't take her in, so I took her home. She said she felt better just talking to me on the way over to our place. And many times over the years I would bring her home for a few days or a week to help her get over her depression. The next day I was going to be home at 2:00pm from work. That morning she took her life. What a waste of life. If only the system had a more open door policy. I wouldn't feel so guilty for leaving her that day.

(Carer, Sister, Victoria, Submission #286)

A constant theme throughout many submissions was not only an inability to access services when needed, but that access was also difficult when consumers were at risk of self harm or harm to others. According to this information it would appear that standards 11.1.4 'The MHS is available on a 24 hours basis, 7 days per week' and 11.1.2 'The community to be served is defined, its needs regularly identified and services are planned and delivered to meet those needs' are not being met.

Whenever I contact the CAT [Crisis Assessment and Treatment] team for one of our clients the response is always "are they at risk of harming themselves or someone else" and the answer is no. You can't get help then. If they aren't in crisis they don't get help.

(Carer and Disability Accommodation Service Provider, Victoria, Melbourne Forum #9)

When you phone up Lifeline or Personal Emergency it sometimes take\'s anywhere from 3 to 23+ times to get through. When you are in emergency condition, or crisis, whom' is going to reach out 23+ times to get help?

(Consumer, Victoria, Submission #112)

The situation in trying to access care is appalling. If you have depression and you think you might harm yourself or even someone else – forget it! You won't get help. But if you are already hurting yourself or someone else then the chances are that you'll get help. The problem is that most people don't get care until they really are in a crisis.

(Consumer Advocate, Consumer Advocate, Victoria, VMIAC Consultation #4)

Recently a friend of mine went to hospital willingly and was turned away. So out of sheer frustration with not being able to get help she picked up an ashtray and threw it at the window and smashed it. They called the police. They took her to the police station and called the Crisis Assessment Team (CAT) who then admitted her! It's a joke that someone has to do something like that to get care.

(Consumer Advocate, Victoria, VMIAC Consultation #5)

When I turn up there and they are in crisis, I call the Crisis Assessment Team and they tell me to call the police! I want to know why I'm standing there alone and nobody is coming to help me… I don't have the education required to be a social worker – I don't even know what the right thing to say is without creating more damage to me or to them.

(Carer, Mother, Victoria, Footscray Forum #1)

Lack of response to notifications re suicide

(Coordinator, Grampians disAbility Advocacy Association, Victoria, Submission #212)

A person has to be considered "acute" to see a psychiatrist from Grampians Psychiatric Services;

(Coordinator, Grampians disAbility Advocacy Association, Victoria, Submission #212)

What is humanely acceptable about a system which withholds treatment for people with a mental illness who do not recognise when they are unwell, until a 'crisis situation' occurs, when that 'crisis' may possibly mean suicide or involvement in other tragedies (which always seem to make the headlines) and which, apart from the profound anguish and pain of the families concerned, is surely another impediment in eliminating the stigma of mental illness?

(Carer, Mother, Victoria, Submission #178)

I know of no other illness where we wait until the person needs the intensive care ward and their family is in chaos before we address it.

(Carer, Mother, Victoria, Submission #307)

My son has presented himself at casualty on a number of occasions because he WANTS help and does not WANT to be the way he is. He cannot control his moods swings or the violent outbursts. He has also been taken to casualty by the police on several occasions although he usually goes with them willingly. The police have been called to my home several times, either by myself or my neighbours, when my son has been behaving violently in the home. Although the police have always been very good when they have attended, they really can not do much other than transport him to the hospital and leave him there to wait, often for up to five hours to be assessed. On some occasions my son has walked out after waiting many hours without being seen.

(Carer, Mother, Victoria, Submission #296)

In the past I have been told by CAT team members whilst in crisis. You know more about your diagnosis than we do, Call us back if you can't get it under control. In those days control usually meant I would SM. so badly I would have to sew or patch myself up. How far does a person have to go to say I need help and I need it now? (author's emphasis)

(Consumer, Victoria, Submission #112)

Throughout our consultations people have spoke of the difficulties they have accessing the mental health services they feel they need, both in acute and community care. In acute care, consumers have spoken of being refused hospital beds even though they were at a crisis point, only to be admitted a few days later in an acute psychotic state. They tell stories of fronting at emergency departments of hospitals, only to be turned away without being properly assessed by a doctor and without being given any advice or assistance. They speak of their general practitioners refusing to believe they were hearing voices and of CAT teams visiting and quickly leaving because they determined 'you're not going to hurt yourself or someone else'. There is a clear picture that emerges—help is reserved for the most psychotic episodes only and that prevention or early intervention is of a low priority. Acute psychiatric services are under-funded, rationing access to a point where people have to beg for assistance.

(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

A chronic shortage of acute inpatient beds leave crisis and assessment teams (CAT) in the situation of having to decide who will be admitted and who will not, based on who is 'most at risk'. Whether the consumer would 'benefit' from an admission is not enough to guarantee access to an acute inpatient bed. There are simply not enough beds for those who need them. In addition the option of intensive home treatment declines as CAT teams more and more struggle to meet the increasing demand for assessment.

(Health and Community Services Union, Victoria, Submission #220)

But on the 14th October [2004] she cut herself again in the early hours of the morning. I called the C.A.T Team to record the incident. I was told they would get back to me the following day. I'm still waiting.

(Carer, Mother, Victoria, Submission #352)

We are fortunate that she becomes a danger to herself and others when acutely unwell otherwise she would probably receive no treatment at all.

(Carer, Mother, Victoria, Submission #299)

It may be timely to review the system – for many, it is complicated, convoluted and un-navigable with people seeking help being turned away, and falling through its cracks. There may be more effective, efficient, and user friendly ways of designing a mental health system.

(Australian Nursing Federation (Vic Branch), Victoria, Submission #322)

Crisis time: I called the CAT team. The CAT team would not come until the police came. This was because of an intervention order that had been put on him at one stage when he had relapsed & substituted speed. [X] heard police mentioned & disappeared. After the police left, I phoned my brother. He came. I answered a knock at the door. It was [X]. Blood was pouring from his forehead, he was quivering, drenched in blood and sweat! I just held him in my arms while he was telling me he had to dig the brain chip out of his head. We took him to Clayton's Hospital emergency department. He was admitted to the psych ward as an involuntary patient.

(Carer, Mother, Victoria, Submission #353)

When my son has been assessed at casualty all they say is that he can't be admitted because he doesn't meet "the criteria" and send him home with valium! This is just a band aid solution and gets him out of their hair for the moment, but his behaviour is the same again within hours.

(Carer, Mother, Victoria, Submission #296)

1. Never enough beds in Upton House or other mental health hospitals. 2. Never enough members on the C.A.T. team therefore they can't come for many nights. 3. Nowhere for people with a mental illness to live, not enough is provided for … the last time he was admitted to hospital not long ago (July-August) there were no beds vacant so he had to go to Box Hill emergency until there was a bed available. (author's emphasis)

(Carer, Mother, Victoria, Submission #310)

6.2.11.1.2 Carers need to be heard

In this regard it is a reactive system, whereby consumer's rights take precedence over their welfare to an utterly illogical extent and something bad has to happen before something can be done. It fails them, it fails carers and it fails the community. For my son and others, who, like him do not recognise when they are unwell it means that by the very nature of their illness, when they are unwell, they are unable to access, accept and use voluntarily available treatment. This leads me to the belief that a mentally ill person's fundamental right to treatment and care should transcend all other considerations even when they are not well enough to seek treatment themselves.

(Carer, Mother, Victoria, Submission #178)

Another example supporting claims that a crisis is required before services are provided is that carers may be unable to initiate a response from services or are not heard. One mother highlighted this as a matter of serious concern for her son as he is incapable of seeking treatment when he is unwell.

Is it acceptable to place the responsibility for seeking treatment upon a person who is paranoid and delusional and totally incapable of seeking that treatment?

(Carer, Mother, Victoria, Submission #178)

It is exhausting to be on 24-hour alert with our family member, but to be ignored, disregarded or invalidated when we call for help is destructive to our confidence to continue in the role of carer year after year, decade after decade. Such scant assurance that services will indeed be available when we have been pushed to our limits leaves us anxious, exhausted and despondently wondering where to turn. Our need to rely upon services that evidently are not adequately informed in mental health treatment and therefore begrudging in the response places further stress on us as carers and merely adds to our load.

(Carer on behalf of group, Victoria, Submission #283).

Carers are often best placed to notice subtle changes in the person for whom they care, and usually the first to notice the early warning signs of a relapse. However health professionals usually do not recognize the value of this information, and in fact when carers try to pass on this information it is often ignored. This can lead to additional problems for carers and a full blown episode for the consumer often with devastating consequences. Unfortunately it is the carers who usually bear with the consequences of a relapse not the health professionals.

(Peninsula Carers Council, Victoria, Submission #321)

The CAT team came but only after my insistence. The workers were excellent, stated that the new medication did not seem to be helping and that this feeling would probably pass. Meanwhile he should continue to seek help and not do anything 'silly'. They contacted the psychiatrist for him and the medication was changed back to the old one. The CAT team continued to come for 3 days until the mood and thoughts began to turn away from suicide and become more normal. It has taken several months to restore his confidence in his ability to cope with life. This lack of confidence was acerbated by the refusal of the triage nurse to take his own words seriously. The treatment for CAT was an excellent and effective intervention.

(Carers, Parents, Victoria, Submission #275)

Gaining access to drug detox and rehabilitation services requires a level of life management that is beyond the capacity of a mentally ill, addicted young person. While the procedures may provide a reasonable test of motivation for those without mental illness, the chaotic life of a person with schizophrenia presents major obstacles to obtaining the necessary assistance.

(Carer, Mother, Victoria Submission #320)

6.2.11.1.3 Problems with phone triage

Concerns were also expressed with treatment and support mediated by a telephone triage service.

The phone triage service has real problems I think. Once recently when I phoned the triage service for help I was told that I was "Not for Service".

(Consumer, La Trobe Regional Hospital, Victoria, Morwell Forum #17)

The after hours psych services number in this region is switched through to a town 100km away, and then the consumer's issue is not referred back to the local nurses;

(Coordinator, Grampians disAbility Advocacy Association, Victoria, Submission #212)

Untimely and inappropriate responses due to lack of resources: We have struggled for 10 years to persuade our elder daughter with Bipolar Disorder … to connect with psychiatric services … Finally, in the middle of a manic episode in 2003, she rang a CMHC in SW Melbourne during business hours and got an answering machine. She left her name and telephone number but got no response. Two weeks later she was so unwell that I called the clinic to complain that they had not responded to her call - apparently her neighbours had also complained to the police. Two nights later she received a knock on the door at 9.45pm and was confronted by two men who said they were mental health workers from the CAT Team. She was living by herself in a rented house (her house mate had left) and was very frightened and ordered them off the property. She heard nothing further from the clinic and it was another three months before we finally managed to connect her with a private psychiatrist and get her onto medication - by this time she had lost her licence, her job and her accommodation and was forced to move home with us.

(Carer, Mother, Victoria, Submission #299)

6.2.11.1.4 Lack of access to private psychiatrists, GPs, counsellors and rehabilitation services

Reports were also received regarding the lack of adequate staff levels and services to meet the needs of the community, especially in rural and remote areas. This was evidenced by long wait lists for access to available staff, or no staff or services to meet the needs of special groups. Standard 11.1.2 states: 'The community to be serviced is defined, its needs regularly identified and services are planned and delivered to meet those needs'. In particular, one submission highlighted that an inability for the consumer to access services earlier in the course of their illness, may make their illness less responsive to treatment at the later stage.

Depending on the nature, severity and urgency of the problem, other barriers may then come into play, such as "closed books", waiting lists, reluctance of specialist services to get involved (a mix of work practice and funding barriers) or the frightening and uninviting nature of such environments. This means that people typically present late in their illness course, and may be much less personally accessible and responsive to treatment. Treatment often gets off on the wrong foot and there is much collateral damage to repair.

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

Some of the issues that matter are poor accessibility, lack of access to private practitioners, lack of bulk-billing GPs and lack of accessibility to counselling services particularly for people with high prevalence disorders.

(NGO worker, Victoria, Morwell Forum #7)

Psych disability rehab support sector – our services are funded to provide support to a group of people – the demands on our services always exceed the target but in the past we have worked hard to deliver as much as we can. We have continually raised this with the mental health branch as a problem that needs addressing but we've had no success. So we have been left with no other option but to make the decision to work to target only. This is very difficult because now there are people who need our service and now can't access it. To not be able to access services is a breach of people's human rights.

(Anonymous, Victoria, Morwell Forum #4)

The distribution of private psychiatrists … the practices of large numbers of private psychiatrists are concentrated in the capital cities. In Melbourne this situation is extreme. Within a fifteen kilometre radius of the Melbourne GPO can be found the highest concentration of private, practicing psychiatrist in the southern hemisphere and the second highest concentration in the world - second only to Manhattan, New York. The allowance of these capital city concentrations means that vast areas of Australia and thousand of people have virtually no access to psychiatry. This has to be seen as a demonstration of gross inequity given the fact medial undergraduate education and post-graduate psychiatric training are subsidized to such a high degree by tax payers.

(Anonymous, Victoria, Submission #318)

6.2.11.1.5 Access denied if consumer has a diagnosis of 'personality disorder'

Concern was also expressed that a diagnosis of 'personality disorder' resulted in an inability to access treatment and support services form the MHS. Standard 11.1.1 states: 'The MHS ensures equality in the delivery of treatment and support regardless of consumer's… previous psychiatric diagnosis… or other disability'. For many people with personality disorder, failure to access treatment resulted in deteriorating mental health and entry into the criminal justice system.

> *Axis II disorders: The Mental Health Legal Centre also hears from people with serious mental health problems who are denied services. Sometimes these people are not deemed serious enough (yet) and sometimes they carry the 'wrong' diagnosis – often Axis II diagnoses. Human rights abuses are as much about neglect as they are about being involuntarily detained. The MHLC supports the idea that resources urgently need to be channelled into services for people labelled as having Axis II diagnoses. If the way to do this is not through a mental health system then an alternative needs to be found and found quickly. However we would argue that a less medical model mental health system would be more humane, more accessible, more aware of issues to do with human rights AND more inclusive of all psyche distress. This would have big advantages for people who have been labelled as having both Axis I and Axis II disorders. Our experience is that many people have multiple diagnoses, which change through time and circumstance so that an attempt to realistically separate Personality Disorders from mental illness will probably fail.*
>
> (Mental Health Legal Centre, Victoria, Submission #330)

> *People with more complex issues such as homelessness, drug and alcohol issues, being diagnosed with Borderline Personality Disorder or have aggressive behaviour find it more difficult to access support and clinical services. This difficulty can be due to services wanting to transfer the responsibility to other sectors, stating that the diagnosis does not fit their criteria (particularly BPD), or stating they do not have the capacity/flexibility to work with this population.*
>
> (Western Region Health Centre, Victoria, Submission #292)

> *… my daughter who is 25 years old and has been diagnosed with B.P.D. (Borderline Personality Disorder) and depression – began cutting herself, and was at risk. I had to wait three weeks before she could see her psychiatrist, who told me to call the C.A.T Team (Crisis Assessment Team) and take her into Emergency at my local Dandenong Hospital if needed. I called the C.A.T Team who attended the first time, after 24 hrs of calling, to tell me they couldn't do anything to help because my daughter wouldn't accept any at the time … What did they expect? But told me to ring them again if I needed to. What for I don't know!*
>
> (Carer, Mother, Victoria, Submission #352)

6.2.11.1.6 Difficulties accessing services for people with mental illness and drug and alcohol problems

Concern was also expressed regarding the difficulties in accessing the few services that provide treatment and support for people with mental illness and drug and alcohol problems:

> *Poor accessibility of drug and alcohol services for people with mental illness and few services which treat drug and alcohol abuse and mental health issues simultaneously.*
>
> (Victorian Office of the Public Advocate, Victoria, Submission #284)

> *There is evidence to suggest that at least 46 per cent of females and 25 per sent of males reporting drug use also experience mental illness. There is also evidence to suggest that people who use drugs, and in particular, illicit drugs have poorer heath outcomes which is exacerbated by a lack of access to health services.*
>
> (Anex, Victoria, Submission #314)

Research and practitioner feedback indicate that especially for the vulnerable and marginalized sub-populations of people who use drugs (eg. street-based injecting drug users), there is a lack of accessible services that could address their mental health needs.

(Anex, Victoria, Submission #314)

It is further submitted that given "the chasm between the drug-using community and health and welfare providers" which results in services being less readily available and accessible for this group of people, there is a serious concern as to whether the right to health for this group of people is being substantively met.

(Anex, Victoria, Submission #314)

Among homeless persons, 62 per cent of respondents in a study conducted in Melbourne reported having special needs in addition to their drug- and alcohol- related problems. Of these, 50 per cent reported a psychiatric disorder including depression, schizophrenia and personality disorder (Horn, 1999).

(Anex, Victoria, Submission #314)

6.2.11.1.7 Lack of access to care – resulting in entry into the criminal justice system

As mentioned previously, failure to access services when needed in some instances resulted in consumers entering the criminal justice system purely because of their escalating and untreated mental illness.

The inability of people living in poverty to access the mental health system in a time of crisis predisposes them to the risk of offending and potential incarceration. One of the many concerns we have is the overrepresentation of poor people with a mental illness in prison.

(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

6.2.11.2 Entry

The process of entry to the MHS meets the needs of the defined community and facilitates timely and ongoing assessment.

Under this Standard, submissions and presentations indicate concerns about:

- problems with entry via Emergency Departments; and
- triage services.

6.2.11.2.1 Problems with entry via Emergency Departments

Concerns were expressed about entry via emergency departments regarding problems with the assessment process and consumers having to repeat their stories many times. According to Standard 11.2.4: 'The entry process to the MHS can be undertaken in a variety of ways which are sensitive to the needs of the consumer, their carers and the defined community'. Notes to this Standard state that this process should be non-traumatic and non-damaging.

There are many injustices done to the mentally ill and their carers but I would like to tell you about one specific area that particularly concerns me. That is the situation that exists in all public hospitals where people who wish (or their carers wish) them to be admitted to a public psychiatric ward have to be admitted through the general emergency section. This, I strongly believe, is so wrong!

(Carer, Mother, Victoria, Submission #176)

We knew by his symptoms and after talking with the staff in Monash Psychiatric Ward that there was nothing else that could be done except take him to Monash Hospital through the Emergency Department. The waiting room was packed with sick people and quite a few young children. After I had explained my son's problem we were told to take a seat and wait - we waited nearly five hours! Can you imagine waiting all that time with an acutely psychotic patient, who, for the first time in eighteen years recognised that he was very unwell and was making an attempt to 'hold himself together'? I'll never forget the experience. My son was so agitated. Several times he wheeled out the Emergency Entrance and tried to get in the Psychiatric Ward himself with me in hot pursuit trying to tell him that he had to go through 'the right channels'… Whilst the doctor went off to arrange a trolley, my son made a frantic escape attempt and pulled the emergency ambulance door off it's hinges and was only saved from escaping and possibly harming himself by a very strong security guard.

(Carer, Mother, Victoria, Submission #176)

I believe that people with a psychiatric illness should be seen in a special emergency section reserved for them only - this could be attached (or very near) to the psychiatric ward of the particular public hospital. This would make it easier for the admitting psychiatrist to see the prospective patient in a quieter and less threatening environment and, hopefully, create a much smoother and quicker transition to the admittance procedure.

(Carer, Mother, Victoria, Submission #176)

Can you imagine going to emergency department with a Paranoid Psychotic patient who is being admitted involuntary, having to sit with open doors, TV is always on in ED waiting room (my loved one receives messages via the TV; e.g. he's dead, he has killed someone, run over someone)? Paranoid and suspicious of other people. He has lots of enemies. Isn't the trauma and stress great enough without this not being a safe place for both them and the other people in emergency?

(Carer, Mother, Victoria, Submission #242)

6.2.11.2.2 Triage services

Mixed reports were received with regards to triage in general.

I have also had comments about triage being difficult to deal with.

(Consumer, Paid Consumer Consultant, Victoria, Morwell Forum #5)

Yes the triage system is a gateway that gets it right more times that it gets it wrong.

(Funding body, Victoria, Morwell Forum #15)

Triage works well for what it is.

(Anonymous, Victoria, Morwell Forum #16)

6.2.11.3 Assessment and Review

Consumers and their carers receive a comprehensive, timely and accurate assessment and a regular review of progress.

Under this Standard, submissions and presentations indicate concerns about:

- assessments conducted over the phone;
- continuous assessments without any treatment; and
- the need for a consumer to have an advocate.

6.2.11.3.1 Assessments conducted over phone

Concern was expressed by one carer regarding the inappropriateness of an assessment over the phone.

> *When a person has a history of a mental illness this should come into consideration. When my daughter was ill the CAT team wanted to conduct an assessment over the phone. What good is a phone assessment when someone is that ill? It's ridiculous! The Mental Health Act needs to be reviewed and modified.*
>
> (Carer, Mother, Victoria, Melbourne Forum #2)

6.2.11.3.2 Continuous assessment, no treatment

Reports were also received about consumers being assessed, but not receiving any treatment and support services that were tied in with the assessments:

> *My partner decided to come off her medication. It took 12 months and she was okay initially but then she became suicidal so I brought her down here to the city (Melbourne). She was assessed at the Broadmeadows clinic late at night and then sent home! 2 weeks later they did another assessment. But the problem was she wasn't getting the care she needed - it was just assessments.*
>
> (Consumer Advocate, Victoria, VMIAC Consultation #7)

> *Attempted suicides are assessed by a CAT team and then they go back into the community and often the environment they go back to is not a good environment – there's no support for them.*
>
> (Clinician, Victoria, Morwell Forum #11)

> *…as the Victorian Auditor General's report shows, the CATT teams have become increasingly embattled and are all too often reluctant to assess and treat people comprehensively in their home and community environments. There has been an excessive reliance by CATT teams on police in crisis situations. With the establishment of the eCATT model in Victoria, which saw psychiatric assessment resources located in many emergency departments, there has been an increasing tendency to direct new assessments into these stressed environments, even during normal hours.*
>
> (Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

6.2.11.3.3 Consumer perspective not heard without an advocate

One carer expressed concern that the views of people with mental illness are often not taken into account during the assessment process and that without an advocate, consumers are often not believed. The lack of access to advocates (as noted under Standard 1 – Rights) further compounds this problem:

> *Patients should not have to find an advocate before they are believed.*
>
> (Carers, Parents, Victoria, Submission #275)

6.2.11.4 Treatment and Support

The defined community has access to a range of high quality mental health treatment and support services.

Like the major physical illnesses, notably cancers and cardiovascular disease, a substantial proportion of the death and damage caused by mental disorders is already avertable with existing knowledge (Andrews et al 2004). It isn't being used. It isn't available to most people who need it. Even individual wealth cannot buy it. The rich and powerful might be able to buy new organs but chances are they can't buy quality mental health care or better outcomes.

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

Under this Standard, submissions and presentations indicate concerns about:

- lack of services for youth;
- lack of services for people with dual diagnosis - drug and alcohol;
- lack of services for people with dual diagnosis –mental illness and 'other disability';
- lack of services for people with complex needs;
- lack of treatment and support in the community for people on Community Treatment Orders (CTO's) or in crisis;
- lack of services for people living in rural and regional areas;
- lack of services for people with personality disorders;
- the lack of involvement of carers;
- lack of mental health services for the aged;
- consumers subject to the criminal justice system; and
- lack of treatment and support available to consumers after release from prison.

On three occasions I have been taken by ambulance to a hospital in Melbourne, Victoria, after taking an overdose of medication. On all three occasions I was discharged after recovery in the accident and emergency unit. I was still feeling suicidal, I live alone without family and with no available support. I can only supply you with these skeleton details now, as I am feeling too distressed to write more about the incidents in depth.

(Consumer, Victoria, Submission #84)

6.2.11.4.1 Lack of services for youth

Submissions indicated that the services for youth need to be approached in multiple integrated ways as other mental health problems and life crises were generally associated with this age group (e.g. drug and alcohol abuse). In particular, the necessity to intervene at this early stage was noted and figures were presented indicating the magnitude of the problem and ramifications of failure to provide services to this vulnerable group of consumers. Standard 11.4.3 ensures access to a 'comprehensive range of treatment and support services which are, wherever possible, specialised in regard to a person's age and stage of development'.

At Orygen youth health, we do have the capacity to treat around 600 new 15 –25 year olds with non-psychotic disorder each year, however we still have to refer out large numbers of patients (1400 referrals p.a.) who really need a specialist approach (as one index of this, 25% of those we are unable to accept have attempted suicide recently and are clearly significantly impaired). Moreover, we have no consultation-liaison team to work with GP's or counsellors to manage these and other cases.

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

Mental disorders are the most important single group of disorders in late adolescence-early adulthood, after which the relative contribution from these disorders decreases at older ages. Mental disorders are also less common before adolescence, though much of the preventable risk for later illness is probably generated during this period of life… These patterns across the lifespan raise the issue of cost-effectiveness, a key basis for carrying out burden of disease studies in the first place, and consequently the greater potential value of interventions earlier in life. Indeed Murray and Lopez addressed this issue placing the maximum weighting for the unit of disease burden, the DALY (disability adjusted life year), around the age of 22 (Figure 2). Yet this early adult period is in fact the weakest link in our whole health system for detection and treatment of mental disorders in both primary and specialist care.

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

When Professor McGorry started the Pace Clinic, I wrote and thanked him because at that stage young people like my son could be put on to him. [The PACE Clinic supports young people (aged 14-30) who may be at risk of developing psychosis.]

(Carer, Mother, Victoria, Submission #211)

Treatment in the Adolescent Psychiatric Unit at Monash Medical Centre was excellent, and the design of the facility showed an understanding of the personal and social needs of patients and visitors.

(Carer, Mother, Victoria Submission #320)

Concern was also expressed for carers of youth with mental illness and their need for support services:

Carers of children with a mental illness, even though their child doesn't voluntarily want to enter into programs there should be more support given to carers. We see more and more children self medicating and then becoming violent toward their families.

(Clinician, Victoria, Morwell Forum #11)

6.2.11.4.2 Lack of services for people with dual diagnosis - drug and alcohol

I am concerned about people with a dual diagnosis, lack of their treatment options is a real problem. People are unable to receive treatment.

(Anonymous, Victoria, Melbourne Forum #5)

NGOs look after our psychiatric and physical needs. Where do people with a dual disability go? There is nowhere.

(Consumer, Victoria, Morwell Forum #9)

Standard 11.4.7 states: 'The MHS ensures access to a comprehensive range of services which are, wherever possible, specialised in regard to dual diagnosis…' The notes to this Standard indicate that this includes dual case management with alcohol and other drug services. Concern was expressed that there were an insufficient number of such services to provide treatment and support to these consumers with complex needs:

It is ORYGEN's experience that the lack of integration between drug and alcohol and mental health services in Australia has significantly contributed to the poor detection and treatment of mental illness amongst young people with substance abuse. This results in waste of resources and long-term psychiatric and substance use problems for individuals who could otherwise be helped.

(ORYGEN Research Centre, Victoria, Submission #258)

There are real problems with the lack of partnerships in dual diagnosis. Because I have a mental illness and use drugs I can't get care from anywhere.

(Consumer, Victoria, Footscray Forum #6)

We don't have a funded consultation liaison service for patients with comorbid drug and alcohol and mental health services.

(Psychiatrist and Clinical Director, Victoria, Morwell Forum #18)

Substance use and mental disorders overlap more than ever before, yet in Australia, we have managed to separate the systems of care intended to respond to them so that now we have evolved two underfunded parallel systems with poorly compatible models and territorial attitudes. Embryonic programs have been developed to bridge this gap but the solution requires much more radical surgery and regrowth.

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

Drug and alcohol services also operate on the basis of "evidence" that these severe, persistent and life-threatening illnesses will respond to brief, almost trivial, interventions just as well as longer-term ones. One suspects that neither type of intervention is having much impact on the untreated or natural course. Indeed this type of evidence has been used to assert that very little of the burden of disease associated with drug and alcohol problems is avertable with current knowledge (Andrews et al 2004).

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

In all hospitals (four), supported accommodation facilities, and drug/alcohol services, there was failure to address the complex interaction between mental illness and substance abuse, with disastrous consequences. Integration of training, services, and philosophy between Mental Health and Drug & Alcohol Services should be a high priority!

(Carer, Mother, Victoria Submission #320)

Failure to address issues raised by a Dual Diagnosis has left thousands of young people with mental illness floundering, unemployed, uneducated, unskilled and many of them in gaol or homeless. As a group they seem to have been thrown on the Mental Health scrap heap, regarded as having developed an illness which easily becomes too entrenched to treat. A number of our younger daughter's friends have suicided which has added to her distress. And now the 'law of diminishing returns' applies - this being the way one senior clinician put it to me. He was discharging our schizophrenic daughter from HDU in an Acute Inpatient Unit directly onto the street after her sixth hospitalisation.

(Carer, Mother, Victoria, Submission #299)

Our younger daughter called Drug & Alcohol Services on one occasion - about four years ago - and asked for assistance to quit cannabis, She was told: "you sound as if you are doing just fine" - end of story! It was an opportunity missed and unfortunately she is not doing fine - she has been hospitalised at least three times since then for periods of more than a month and is now reaching an age when she is past qualifying for any intervention at all because the emphasis in Victoria has switched to early intervention and less serious illnesses that can be treated by a GP with six sessions of psychological counselling.

(Carer, Mother, Victoria, Submission #299)

From personal experience and discussion with others a psychiatric tag prevents or delays the substance abuser from addressing the problem – excess – and seeking the solution – abstinence. Furthermore – lithium carbonate – usually prescribed for bi-polar can have harmful effects. From experience, many practitioners do not take adequate care with monitoring blood levels. Nephrology departments are encountering increased cases of lithium toxicity [leading to] renal failure. … Tragically, after 25 years of lithium treatment for a bipolar disorder, I finally encountered a doctor who rejected the tag and ceased lithium carbonate. I have maintained sobriety which has given me the strength and esteem to deal with the consequences: dialysis to transplantation. This is not uncommon (author's emphaisis).

(Consumer, Victoria, Submission #143)

Individuals who have a mental illness as well as a drug and alcohol problem are even more limited in their access to services. They face discrimination on both sides of the system. Drug and alcohol agencies are not set up to deal with issues of mental illness, and mental health agencies declare their work sites to be drug and alcohol free. People with a dual disability find themselves in a bind. There are services available that cater for them, but like most other organisations, they are under resourced and over burdened.

(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

Returning to Melbourne in early 2001, [X] was admitted to supported accommodation provided by Psychiatric Disability Rehabilitation Services. Although progress was made, she suffered a severe psychotic episode, which eventually led to hospitalisation for a change of medication. During the long hospital stay that followed, the extreme failure of services to meet the needs of mentally ill patients with drug addiction became painfully clear, as illustrated by the following developments:

- *She used heroin.*
- *She had a heroin-related nerve injury, while sleeping in the lounge of the hospital, which resulted in a six-month partial paralysis of her right hand.*
- *She refused urine screening.*
- *She committed a heroin-related crime while on day leave.*
- *She was not provided with drug rehabilitation services.*
- *She was excluded from her PDRS accommodation, where budget cuts were leading to reduced hours of supervision.*

(Carer, Mother, Victoria Submission #320)

6.2.11.4.3 Lack of services for people with dual diagnosis – mental illness and 'other disability'

Standard 11.4.7 states: 'The MHS ensures access to a comprehensive range of services which are, wherever possible, specialised in regard to dual diagnosis, other disability…' In the notes to this Standard is 'collaborative treatment with… disability services'. Concern was expressed with regard to the lack of treatment and support for people with disability, including intellectual disability, physical disability and Aspergers Syndrome:

In recent years, OPA, and other support organisations and service providers have raised concerns about the failure of the existing service system to meet the needs of people with dual/multiple disabilities… OPA observes the following continuing difficulties:

- *Despite the existence of substantial research data to indicate that people with intellectual disabilities are more at risk of developing mental illness than the general population (Hudson & Chan, 2002); gaps in service provision for people with intellectual disability and mental illness remain. People who have an intellectual disability are less likely to receive assistance from mental health services because they are considered to have behavioural problems attributed to their intellectual disability rather than to their co-existing mental illness.*
- *Service boundary issues; people with dual intellectual disability/psychiatric disability have difficulty accessing the mental health system, and intellectual disability services are often left to support people with dual/multiple disabilities without funding and with non-specialist staff.*
- *People with presentations that cross behavioural, psychiatric and intellectual disability boundaries are often the subjects of service boundary disputes about which service should provide 'the' service to these clients.*

(Victorian Office of the Public Advocate, Victoria, Submission #284)

There are a number of patients/clients with physical and psychiatric co morbidity with significant unmet needs. The lack of understanding of these complex needs by federal and state governments leads to a subsequent lack of resource allocation to assist, this results in increased morbidity, resource usage, significant distress and mortality. In addition, patients/clients awaiting psychiatric beds are being cared for in sub-optimal conditions in Emergency Departments and medical/surgical wards and this can result in increased use of mechanical restraint and sedation and a delay in the commencement of appropriate psychiatric treatment.

(ANZCMH Nurses Victorian Branch, Victoria, Submission #316)

[He has major depression and recently diagnosed Aspergers Syndrome] The public mental health system is only willing to consider treating him if he is clearly psychotic, although they admit he must have deteriorated considerably since he was employed. … It is not just that someone displaying this level of illness and dysfunction, showing poor memory, disorganisation and other cognitive loss and alienation, should be unable to access services in the public mental health system. I fear that he will become as disabled as the other son before effective treatment is given and may not be so lucky as to fail to succeed at suicide or serious physical damage to another person. We fear that the mental health service will continue to fail him and that, if he does not suicide, he may well end up in the revolving door of the criminal justice system wherein there will be no effective treatment for his condition and in which he will suffer physical and sexual abuse while within "the care" of the State.

(Carers, Parents, Victoria, Submission #275)

In recent years, OPA, and other support organisations and service providers have raised concerns about the failure of the existing service system to meet the needs of people with dual/multiple disabilities… OPA observes the following continuing difficulties:

- *Service deficits for people with Huntington's disease - behavioural issues associated with the illness can preclude people with Huntington's disease from accessing nursing homes and other disability services.*
- *Few service provisions for people with multiple disabilities who, as a result of their mental illness are unable to 'comply' with treatment and care plans.*

(Victorian Office of the Public Advocate, Victoria, Submission #284)

6.2.11.4.4 Lack of services for people with complex needs

Concerns were expressed regarding the lack of treatment and support services for consumers who have complex needs, including dual diagnosis (disability or drug and alcohol problems) and homelessness. The increasing number of people who are homeless and who have a mental illness and/or mental health problems has also risen with deinstitutionalisation and the subsequent lack of community based treatment and support services to meet the community's needs. Standard 11.4.6 states: 'The MHS ensure access to a comprehensive range of treatment and support services which address physical, social, cultural, emotional, spiritual, gender and lifestyle aspects of the consumer'. Standard 11.4.7 states: 'The MHS ensures access to a comprehensive range of services which are, wherever possible, specialised in regard to dual diagnosis …' The notes to this Standard include 'dual case management with alcohol and other drug services'. Concern was expressed that there are an insufficient number of services to provide the appropriate treatment and support for these consumers with complex needs:

A central concern is the lack of training in dual diagnosis in the mental health system. While this is gradually changing, there are still relatively few places that can effectively support people with complex needs. Many are excluded from residential rehabilitation services because of a potential negative impact on other residents, because they have a dual diagnosis or other complications. Many people with complex care needs lose contact with their families and join the large number of homeless or transient people accessing crisis accommodation services. In these environments, people with complex needs become incredibly vulnerable and can be a danger to themselves and others. Some are evicted for not conforming to the service and thus fall through the gaps in the service system. Intensive Home-Based Outreach Services providing support to people with a mental illness at risk of homelessness need to be extended.

(The Network for Carers Of People With A Mental Illness, Victoria, Submission #319)

One of the positive changes in the sector in the last 4 years is that there has been a growth in services, particularly focused on people with more complex needs such as homelessness, and drug and/or alcohol dependence. These service models have been designed to be more flexible to meet the needs of the consumer population. However, the centre continues to identify key areas for further attention:

- *Housing – chronic shortage*
- *Support Services; and*
- *Access to services.*

(Western Region Health Centre, Victoria, Submission #292)

Community Mental Health services for a homeless mentally ill person cease when the "homeless" person passes from one area to another (St. Kilda to Melbourne CBD), carrying her belongings in a plastic bag.

(Carer, Mother, Victoria Submission #320)

Homelessness leads to a deterioration of psychological functioning and general health, raises the risk of substance abuse, and increases the likelihood that the person affected will need to return to emergency services for more intensive treatment.

(The Network for Carers Of People With A Mental Illness, Victoria, Submission #319)

6.2.11.4.5 Lack of treatment and support in the community for people on Community Treatment Orders (CTO's) or in crisis

Concern was expressed regarding the general lack of treatment and support to ensure comprehensive care for people on Community Treatment Orders or to respond to people contemplating suicide:

Effectively, CTOs extend involuntary status into the community, and yet in many instances community supports are fractured and insufficient to assist the consumer.

(Centre for Psychiatric Nursing Research and Practice, Victoria, Submission #323)

I have recently begun forming and facilitating a support group for women suffering from depression, the idea coming from the high number of cases of women I was seeing in my role as a Counsellor and the lack of our Mental Health service to adequately respond to suicidal ideation and ongoing support.

(Clinician, Victoria, Submission #234)

6.2.11.4.6 Lack of services for people living in rural and regional areas

In Victoria, many submissions indicated problems with access to services in rural and regional areas and that Standards 11.1.3 ('mental health services are provided in a convenient and local manner and linked to the consumer's nominated primary care provider') and 11.1.5 ('The MHS ensures effective and equitable access to services for each person in the defined community') were not being met for many consumers in these communities. For people living in many areas of Victoria there were no services which were convenient and local. Access to care involved long distances by car; a very significant difficulty for those who are not so readily mobile or are from low socio economic backgrounds. Even if consumers were prepared to travel, there were problems with long wait lists and the time required for appointments often seriously disrupted employment commitments. Also, if admission to hospital or long-term care was required, the consumer was isolated from their social and support networks.

We only have one inpatient facility for the region – people of a low socio economic background find it very difficult to travel long distances to get care.

(Clinician, Victoria, Morwell Forum #11)

I travel to Melbourne for care because there's no private psychiatrists in this area.

(Consumer, Consultant Victoria, Morwell Forum #1)

In order to get an appointment with a psychiatrist I send my patients to Melbourne – but even this means about a 3 month wait.

(GP, Victoria, Morwell Forum #8)

There's a real difficulty with the location and resourcing of hospitals. There's only one hospital in our area that will take mental health patients. This creates enormous problems for consumers being taken out of their local support systems.

(GP, Victoria, Morwell Forum #8)

You can't get care in the country. I travel 3.5 hours from the country to here (Melbourne) because I can get care here. I can't get care in the country but now I can't work because I need to travel down to here for care.

(Consumer Advocate, Victoria, VMIAC Consultation #8)

Lack of resources: lack of beds for short term and acute admissions; lack of supported accommodation… those services and beds available are usually distant from friends and family

(GP in rural Victoria, Victoria, Submission #123)

In rural regions there are minimal levels of services provided. Usually hospital beds, when available, are distant from the towns in which the people live and there are few or no specialist services. This lack of specialist services results in a direct and calculable reduction in Medicare funding for the provision of services. In our region the level of this deficit is in the order of 3.2 million dollars. If the specialist services are not available then surely some way can be found that this money is available for service provision.

(GP in rural Victoria, Victoria, Submission #123)

If supported accommodation is available it is generally far from the patients support network and available only for short and inadequate periods of time.

(GP in rural Victoria, Victoria, Submission #123)

6.2.11.4.7 Lack of services for people with personality disorders

> *…people with Borderline Personality Disorder who have been chased, sometimes in seriously undignified and persecutory ways, out of the public mental health system that they are as entitled as anyone else to use.*
>
> (Consumer, Female, Victoria, Submission #203)

Consumers and advocates also raised concerns about the lack of services for people with personality disorder and problems associated with the disorder not being recognised or acknowledged by some clinicians and services. Evidence was presented indicating the positive results that can be achieved both at a personal and societal level from providing treatment to people with this disorder. Two submissions were received applauding the new service SPECTRUM for people with personality disorder but suggested that while it was a good start, it could not meet current level of demand.

Submissions reported that the disorder is not recognised and acknowledged:

> *…some people think I don't have a real mental illness and they make it obvious that they will perhaps listen to me, or pretend to listen to me, but will actually not take any notice of anything I am trying to say. It is extremely hard to get heard anywhere if you have this dreadful diagnosis…. Many of us who have been diagnosed (in the end) with this unflattering diagnosis have been around I the system; going in and out and in and out of hospital; having people tell us we are 'slashers'; having staff tell us that we are taking up beds that belong to really sick people; having people tell us that we are cutting up to attract attention to ourselves or monopolise staff time, for a very long time.*
>
> (Consumer, Female, Victoria, Submission #203)

> *I have had ten different diagnoses. [X] has had seven different diagnoses. At times we have both been considered to have real mental illnesses and at other times we have both been seen to have more dubious titles like personality disorders.*
>
> (Consumers, Victoria, Submission #194)

> *We die and for the community that is a solution to a problem of the pesky people who keep intruding into the medical sieving process where they don't belong.*
>
> (Consumer, Female, Victoria, Submission #203)

> *…we also need resources or the system will continue to fail people with a history of trauma… those of us with personality disorders should not be institutionally discriminated against.*
>
> (Consumers, Victoria, Submission #194)

> *…if we are going to have a respectful, competent and inclusive mental health system how can we distribute services and resources in a way that is fair and respectful of the human rights of the maximum number of deserving people? Present delineations of 'neediness' are totally unacceptable. It is predominantly based on diagnosis, which discriminates very strongly against people with Borderline.*
>
> (Consumers, Victoria, Submission #194)

> *In challenging the existence of 'mental illness' at all they extinguish the belief that Axis I diagnoses are somehow more legitimate and more important than Axis II diagnoses. If there is no 'mental illness' then it doesn't matter if you've only got a disorder. One of the outcomes of this political position is that all forms of mental distress start to be seen as equally valid and equally deserving of society's resources and the emphasis is on the distress and self determination rather than arguing about validity.*
>
> (Consumer, Advocate, Victoria, Submission #166)

…the jargon of 'low prevalence' and 'high prevalence' disorders in their arguments about where money should be channelled. I am really concerned about us using this framework because it continues to totally exclude groups with Axis II diagnoses such as 'Borderline'. In the large epidemiological surveys that were carried out nationally in the late 1990s and which drive the debates about resource distribution Borderline Personality Disorder was excluded completely.

(Consumer, Advocate, Victoria, Submission # 166)

The population prevalence of Borderline Personality Disorder in Australia is approximately 1%. This is similar to the population prevalence of Schizophrenia. Both of these disorders are disabling and serious. Both have high rates of reported suicide. And yet, there is no comparison between the ways these two disorders are understood in the sector or 'sold' to the public by the sector. Within the sector Schizophrenia is seen as tragic, difficult but absolutely legitimate and 'BPD' is seen as difficult and a pain in the neck (and the public purse) – to be avoided except for those individuals who, quite literally, cannot be avoided.

(Consumer, Advocate, Victoria, Submission #166)

After everything that has happened these past six weeks my daughter has lost all faith and trust in the system & her psychiatrist and has refused to see him again. I don't know if I can get to see anyone in the future, which means she will be denied the help and care she greatly needs to recover and live a full and happy life.

(Carer, Mother, Victoria, Submission #352)

Difficulty accessing services because of diagnosis:

The first criterion for involuntary admission is that the person concerned appears to be mentally ill as defined by the Victorian Act: "'Mental disorder' includes 'mental illness', plus a range of conditions which are not mental illness for the purposes of the Act. Some mental disorders, such as personality disorders, are not 'mental illnesses' under the Act and cannot usually be the basis for involuntary treatment." …It is extremely difficult to argue that a group of people (who are not deemed to be 'mentally ill' under the Act) are still a group with substantial and legitimate needs in the system. With the everyday shorthand use of the term 'mental illness' to describe the target population of everything, people who aren't mentally ill (in terms of the Act) can easily get left out…

(Consumer, Advocate, Victoria, Submission #166)

The political reality is that the mental health system still uses the metaphor of 'the bed' to work out how it will distribute resources. The usual induction into a public service is through a stay in an acute unit. People go from an acute 'bed' to backup community services. So, those disorders (not illnesses) that are seen to not 'deserve' 'beds' will, unintentionally perhaps, be disadvantaged in a system, which relies on system-determined need criteria to distribute resources. This will be the case except when the system and services are put under an enormous amount of pressure by specific individuals who cannot be ignored.

(Consumer, Advocate, Victoria, Submission #166)

I have had Psychiatrists do dummy spits on me. The full repeated-in the seat out of the seat-raised voice. . "We treat serious illness here yours does not constitute that, Schizophrenia and Bi-Polar. What your diagnosis is (I have been diagnosed with (BPD, Clinical depression and P.T.S.D.) you are wasting our time and energies which could be spent elsewhere! You are not getting time lost from previous appointments and I am not going to treat you any more. I will be handing your case in at the next staff meeting. What are you going to do now, are you going to go running to the management?" I didn't want to disappoint her, so I did go to management– again.

(Consumer, Victoria, Submission #112)

Treatment for Borderline Personality Disorder which is working:

[My psychiatrist] sees me twice a week which sounds excessive but if you compare it to the unproductive , tumultuous, emergency service utilising, and personally destructive stuff that went on before you would not worry about the fact that I have two appointments a week. Because of this I can now work part time and I have even picked up one subject of my university studies. My psychiatrist is determined to keep me out of hospital and we have achieved this.

(Consumer, Victoria, Submission #203)

Borderline Personality Disorder is not untreatable. This is a myth and one we should get rid of… Resources need to be fed into providing services for people with Borderline.

(Consumer, Victoria, Submission #203)

I have also been reading about Spectrum in Melbourne which is the State-wide Borderline Personality Disorder Service. It is so good that, at last, people are starting to put just a little money into people with Borderline.

(Consumer, Victoria, Submission #203)

Victoria has a statewide personality disorder service. This has come after a realisation that the State had to do something! It is very useful but it is insufficient. They cannot possibly cover all the need across the State. It would be like having one State-wide Schizophrenia service.

(Consumer, Advocate, Victoria, Submission #166)

6.2.11.4.8 Lack of involvement of carers

Despite Standard 11.4.9 acknowledging the involvement of carers ('There is a current individual care plan for each consumer, which is constructed and regularly reviewed with the consumer and, with the consumer's informed consent, their carers and is available to them'), carers repeatedly reported being excluded and feeling frustrated. Given the reported problems with access and limited services available in the community, practices which involve carers to assist with the delivery of care and achieve the best possible outcomes for consumers would both help recovery and protect many rights of people with mental illness.

If carers were listened to, and included in the treatment team, that would make a big difference, as we are the ones who know the patients, and can recognise changes in them, and want to protect them from doing something they would regret, or the family would regret.

(Carer, Mother, Victoria, Submission #211)

I feel that I must mention here that I am most definitely not a belligerent confrontationalist. I tend far more toward a process of conciliation and negotiation, but at the end of that conversation, I found myself shaking and began crying from sheer frustration, disbelief and unvoiced anger.

(Carer, Mother, Victoria, Submission #178)

I spoke to both of [X]'s doctors about this and my concern about an adverse reaction to the drug. This matter was not pursued, as far as I know, and [X] was started on Clozapine again. A few days after reaching full dose, [X] had a hypotensive attack with transient total hearing loss (never investigated).

(Carer, Mother, Victoria, Submission #206)

The most serious problem of these weeks was a lack of communication: (a) between [X] and her consulting psychiatrist, (b) between [X] and her psychiatric registrar, (c) between [X] and many of her nurses, (d) between her consultant psychiatrist and me. Despite my efforts to speak to him in person or on the phone, I was able to obtain only 15 minutes of his time.

(Carer, Mother, Victoria, Submission #206)

How can it possibly be acceptable that carers are not included in the treatment plans for the people for whom they care and are simply 'used' by the Mental Health System?

(Carer, Mother, Victoria, Submission #178)

During this time of trying to obtain help for my son, I received a phone call from someone from the clinic informing me that my son was discharged from the service. When I asked how this could be when it was on record that my son was most unwell and that I had been reporting this for some time, his answer was "That's how it is, there is nothing that you can do about it, but of course we will do something if and when he comes to our attention". In other words my bringing it to their attention was worthless, once again it would require my son behaving in such a way that would bring him to the attention of the police or perhaps something far worse happening.

(Carer, Mother, Victoria, Submission #178)

Knowing that by then my son would be intensely paranoid and delusional and from past experiences, would surely be considered to be 'at risk', I went to the clinic and asked that they intervene before he disappeared again and was told that the only thing that I could do was to provide them with 'proof' that my son was 'acutely unwell' and even then, they may not be able to do anything. I asked what 'proof' I could provide and it was suggested that I go to the neighbours and have them write letters attesting to the fact that they had concerns about my son. Only one neighbour was at home and she agreed to write a letter which I took to the clinic… and I contacted the motel owner and explained the situation… She asked whether it would be of any help if she rang the clinic and expressed her concerns. I said that perhaps that could initiate some action. She did so and eventually the police and a CAT team arrived and he was hospitalised.

(Carer, Mother, Victoria, Submission #178)

Listening to family would of helped in this instance for information on the patients history. It was as if no one knew from one Dr to the next the patient's history or situation and each started from scratch in the meantime the patient getting more frustrated confused and losing hope.

(Family member, Victoria, Submission #170)

…no matter what our background, confidence, insight, carers of the mentally ill are often not heard by the doctors and nurses of their children. If I could not make staff at the Alfred Hospital take into account my knowledge of [X]'s condition, how do carers who are not at ease with hospitals and medical personnel make their concerns known? We are the advocate for our sons and daughters, who are often unable or too fearful to speak for themselves. We ought to be listened to for we know those in our care…We are ignored at the peril of our children's lives. And some of us are left standing helpless as we watch our sons and daughters die, one after another after another.

(Carer, Mother, ex-neurology nurse, Victoria, Submission #206)

[T]he hundreds of carers who contact our Care Line, seek counselling or attend our education sessions continue to speak of being excluded from information and from involvement in care management discussions and decisions that are vital to their ongoing support of their ill relative, that person's recovery and wellbeing, and the carer/family's own safety and wellbeing.

(Carers Victoria, Victoria, Submission #270)

There is too little opportunity for collaboration between family carers and supported accommodation services, whereby the overall supervision and care could be significantly improved.

(Carer, Mother, Victoria Submission #320)

We, her family, are never asked for our input regarding medication despite now having far more experience, regarding what has helped and what has not, than a changing series of psychiatrists.

(Carer, Mother, Victoria, Submission #299)

…attitudes towards families generally within the system are very mixed. The impression one gets is that senior management are unsympathetic and find input from carers a nuisance - and too time consuming. The attitude seems to be that, if you are lucky enough to actually have a family, you are so far ahead of most consumers that you can look after yourself.

(Carer, Mother, Victoria, Submission #299)

Despite policies which recommend the involvement of carers and families in the treatment of consumers, there does not appear to be any systematic or consistent approach; it appears to be at best ad hoc and depend on the inclination of individual health professionals. The council is aware of widespread dissatisfaction with the lack of consultation of families and carers. Carers are often not consulted or informed about treatment plans or changes in treatment plans. Consumers are often discharged without notifying carers which can result in consumers being without planned accommodation and at risk. … Involvement of the family or carers in treatment is more likely to provide a better outcome for the consumer and is more likely to keep the support environment for them in tact. (i.e. family / carers)

(Peninsula Carers Council, Victoria, Submission #321)

6.2.11.4.9 Lack of mental health services for the aged

Standard 11.4.3 ensures access to a 'comprehensive range of treatment and support services which are, wherever possible, specialised in regard to a person's age and stage of development'. However, concerns were raised with regard to the paucity of treatment and support available for this age group:

We are a group of community workers with a vast experience in their area of mental health and mental health and the ageing… Since deinstitutionalisation occurred in the 1980s, we believe that the pendulum has swung to far in the other direction whereby a number of sufferers do not have options open to them if their illness is so severe that they are unable to sustain living in the community with medication only.

(Social Worker and Team Leader, Victoria, Submission #236)

I am writing to plead my case for more funding to allow people like my husband to have access to more care. He as been suffering Depression, Anxiety and Panic Disorder for three and half years and because he is aged there is no facilities for him as he isn't "Dementia" or "Alzheimer's". (author's emphasis)

(Carer, Wife, Victoria, Submission #248)

6.2.11.4.10 Consumers subject to the criminal justice system

Standard 11.4.7 states: 'The MHS ensures access to a comprehensive range of treatment and support services which are, wherever possible, specialised in regard to… consumers who are subject to the criminal justice system'. Concern was expressed regarding the rising rate of people with mental illness being incarcerated and that for many of these people, access to treatment in prison was better than the treatment available in the community. Concern was also expressed regarding the variability of treatment available within the criminal justice system:

I am concerned that [X] had to go through the courts and the forensic system, in short, to be treated like a criminal, as the pathway to getting help for her mental illness. This is craziness. It is ironic that the forensic system… actually treated [X] more compassionately and effectively than the community mental health service.

(Carer, Mother, Victoria, Submission #307)

It is an indictment on our society that it was only in prison that this young woman with serious mental illness was able to withdraw from heroin and begin her long journey back to health. She had some very helpful attention from the prison psychiatrist, and there were attempts to help her with drug rehabilitation, but the resources in this area were woefully inadequate. She lived in fear of some of the other inmates, and in general the prison experience left terrible scars.

(Carer, Mother, Victoria Submission #320)

Given the high number of inmates who are substance abusers, priority should be placed on drug rehabilitation in the prison.

(Carer, Mother, Victoria Submission #320)

A recent survey found that 60% of prison admissions have an active mental illness. In 2000-2001, the total recurrent cost of prisons in Victoria was $188.36 million. By contrast, only $69.53 million was spent on mental health. Ex-prisoners who return to prison point to the lack of appropriate housing as having been a key factor in their inability to reintegrate into the community. This problem is likely to be greater still for those with a mental illness. Small Non-Government Organisations provide the bulk of transitional services for ex-prisoners. … The present deficit in appropriate housing and support highlighted above is likely to contribute to ongoing incarceration, which further traumatises people with a mental illness. The danger is that we as a community run the risk of using prisons as de facto asylums.

(The Network for Carers Of People With A Mental Illness, Victoria, Submission #319)

It is acknowledged that services for prisoners are generally limited. This unfortunately leads to a deficiency in treatment for those needing psychiatric care and support. The experience of prison also makes managing the illness more challenging.

(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

We have been told that it is not uncommon for prisons to 'wetcell' prisoners to manage acute episodes. This practice of seclusion can go on for weeks under the supervision of unqualified staff, until the 'issue' has resolved. It is absurd that such primitive regimes continue when we have the knowledge and skills to treat people in humane and decent ways.

(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

The increased number of people entering prison drug affected further exacerbates the difficulties associated with having a mental health problem and the ability of the prison system to manage their treatment appropriately.

(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

During the past decade, there has been a 50% expansion in the Australian prison system yet those close to grassroots services argue that much of the recent increase in the Australian prison population can be explained by unmet mental health needs, subsequent illegal use of drugs as a form of self-medication, and the eventual intervention of the criminal justice system .

(The Network for Carers Of People With A Mental Illness, Victoria, Submission #319)

6.2.11.4.11 Lack of treatment and support available to consumers after release from prison

Concern was expressed regarding the lack of treatment and support services available for people with mental illness after they have been released from prison. One carer noted that her daughter had been refused care due to her past criminal episode:

Upon release from prison in early 2000 [X] was ready for a therapeutic community and was motivated to live a wholesome life. She needed to be sheltered from environments where illicit drugs were being used, and she needed a simplified life style where she could find support and purpose. She also needed supervision regarding her antipsychotic medication and reduction of other prescribed medication. She had missed her opportunity at one rehabilitation community, another refused her because of her mental illness, another said no because of her past criminal episode.

(Carer, Mother, Victoria Submission #320)

With no data being maintained about prisoners' post-release housing options, it is assumed that some ex-prisoners are accessing generic housing services through the Supported Accommodation Assistance Program. However, prisoners need to become homeless again before being able to apply for housing services. A small pilot of the Office of Housing and the Office of the Correctional Services Commissioner provides 61 transitional places for ex-prisoners in Victoria. This is a good start but in no way represents an adequate level of support for this population. The fact that Victoria is viewed as a leading model in this regard raises grave concerns about the level of services in other states.

(The Network for Carers Of People With A Mental Illness, Victoria, Submission #319)

When people are discharged either from forensic care or the prison system this can also have a major impact on services due to the complexities of the consumers needs.

(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

6.2.11.4.A Community living

The MHS provides consumers with access to a range of treatment and support programs which maximise the consumer's quality of community living.

Under this Standard, submissions and presentations indicate concerns about:

- the lack of support services in the community;
- withdrawal of support from community mental health clinics;
- need for more leisure, recreation, education and employment programs;
- the need for self-care programs; and
- lack of family centred approaches.

6.2.11.4.A.1 Lack of support services in community

If family members fail to support the one who is ill, and some have reached the stage where they are stressed out, burned out, then the situation is at crisis point.

(Carer, Mother, Victoria, Submission #242)

The aim of de-institutionalisation was to provide treatment and support in the least restrictive setting, which for most people means living in the community. However, as discussed above, the necessary treatment and support services and effective systems on the submissions provided does not appear to have not materialised. This is true for people with serious mental illness living in the community and also for people who, as a consequence of failure to access treatment and support services at the onset of illness, develop significant disability and require additional community support services to live independently or with their family. The impact of dependence on families and carers was also reported to be problematic with carers describing their own health as failing and that they are also being 'denied opportunities to lead rich and fulfilling lives':

The really sad thing is that people like my sister feel they are a burden on their families. There needs to be a place where they can go when they become unwell where they can get the care they need and the support they need. It's too late to wait until she is in a crisis for the system to respond to her – it's too late then! The support services that are in the community don't get the necessary increases in funding they need so they can't respond appropriately either.

(Carer, Victoria, Melbourne Forum #16)

The provision of HACC services is a real problem – people with a mental illness don't get HACC services. Also if you are a person with a mental illness and have a bad interaction with the service you are almost immediately excluded from further care.

(Anonymous, Victoria, Morwell Forum #3)

My daughter was diagnosed with Schizophrenia about 10 years ago and has been on disability support pension for the last 5 years… She lives with another girl who has Bipolar Disorder. She's a very smart girl who used to work for Telstra. I have been to the house where they live which is in not very nice as they spend all their money on the pokies, drink, taxi. I have turned up there when they have both been in crisis. They ring because they are hungry or they don't have any cigarettes.

(Carer, Mother, Victoria, Footscray Forum #1)

…as the Victorian Auditor General's report shows, the CATT teams have become increasingly embattled and are all too often reluctant to assess and treat people comprehensively in their home and community environments.

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

Attempted suicides are assessed by a CAT team and then they go back into the community and often the environment they go back to is not a good environment – there's no support for them.

(Clinician, Victoria, Morwell Forum #11)

The second son is now 33. He has major depression and recently diagnosed Aspergers Syndrome. These difficulties contribute to his sudden explosions of anger and harm to himself and others. He has now been unemployed for 4 years but previously held a full-time job for 10 years. He has moved six times in the past three years, with short periods of homelessness. Private landlords will not rent to an unemployed person. He is paranoid, without social contacts or any reserve funds. He has presented on several occasions to public mental health services following these incidents and at other times. He is told that he has a mental illness, depression, he has Aspergers syndrome, he should learn to control his anger yet any referrals made to help with this anger turn out to be for people in relationships and he cannot form one, to use a private psychiatrist or GP. However he is not organised enough to keep appointments and often does not know what day of the week it is.

(Carers, Parents, Victoria, Submission #275)

Not only does the evidence support the contention that the system has failed, and continues to fail, people with mental illness, it also fails their families, who often have no option but to assume the role of full time care giver and custodian. They too are denied opportunities to lead rich and fulfilling lives.

(Australian Nursing Federation (Vic Branch), Victoria, Submission #322)

When I asked for help he was taking medication inappropriately. … We believe suffers of mental illness need access to: … in the early stages of developing the illness, somewhere that medication can be supervised to the point of dispensing it on a daily basis

(Carers, Parents, Victoria, Submission #241)

6.2.11.4.A.2 Withdrawal of support from community mental health clinic

One carer described in detail how well her son was doing while on a community treatment order and receiving support from the mental health clinic. He was living independently and integrating very well socially. However, despite a ten year history of non-compliance, support was withdrawn and the consumer became increasing ill, angry and aggressive and was evicted from his apartment.

> *The past has proved that my son maintains a high standard of 'wellness' when he is on the once a fortnight Depo injection programme. He is gentle, 'easy going', law abiding and lives comfortably and independently within the community. He is meticulous in paying his rent and other living expenses. He maintains very good relationships with his family, friends and neighbours… Despite his 10 year record of non-compliance, lack of insight into the illness, even strong indications of denial, after 12 months the CTO was removed and once again he was allowed to self-medicate. As in the past: He felt well therefore ceased medication. Rapidly became unwell. Ceased contact with me within weeks, as in his mind I then become part of the conspiracy against him and therefore he does not wish to see me. Became angry, belligerent and aggressive with the few people remaining in his life, ordering them off the property which he was renting. Became more and more reclusive. Eventually lived in virtual darkness and isolation only going out late at night for food when there were few people around… serve an eviction notice as he had not been paying his rent… a couple of elderly neighbours came and spoke to me. They were quite distressed (not for themselves, but for my son) and asked what was happening. I explained that my son had a mental illness, had suffered a relapse and that I had been unable to acquire treatment for him. They said that he had been a friendly, caring, helpful neighbour and that they had felt very safe with him there, but had become a little alarmed when he began abusing visitors, and that they had become increasingly concerned about his welfare but didn't know what they could do. A final comment from one of the elderly ladies was "We treat animals better than that" and from the other "How can this be allowed to happen? There is something terribly wrong when decent young people like your son end up in such a dreadful situation.*
>
> (Carer, Mother, Victoria, Submission #178)

6.2.11.4.A.3 Need for more leisure, recreation, education and employment programs

> *Australia's record of implementing systems which assist the person with a mental illness in entering, returning to or remaining in the workforce remains very poor. These people are denied opportunities of training/retraining and employment, with the result that they are denied opportunities to lead challenging and rewarding lives. Too often social isolation and unhealthy lifestyles remain the dominant features of someone who has a history of psychiatric disorder/illness.*
>
> (Australian Nursing Federation (Vic Branch), Victoria, Submission #322)

Access to rehabilitation and day programs to meet the needs for leisure, recreation, education and employment (Standard 11.4.A.4) were also reported to be declining. Access to such programs are seen as critical for consumers to reintegrate and live in the community, with opportunities to participate socially and economically.

> *We need more housing, accommodation and day programs to support people in the community. But there's a real lack of willingness to provide these services.*
>
> (Consumer, Victoria, Footscray Forum #6)

> *And we'd like to put our ill relatives on to support groups for them, recreation such as the Clubhouses and other structured day programs, and find out how to help them get work. [Y] who was with the Fellowship, arranges the sort of employment people coping with mental illness need, and gives talks on "Why Work Works", because it does.*
>
> (Carer, Mother, Victoria, Submission #211)

My son has paranoid schizophrenia. He's on new medication and he's the best he has been for 20 years. He wants to work but we can't get any help.

(Carer, Mother, Ballarat, Victoria, Melbourne Forum #11)

There are specialist employment agencies here but no private mental health services to help people to assist them through their difficulties. In this area there's a real absence of people who can provide a good assessment.

(NGO Worker, Victoria, Morwell Forum #7)

I have seen some good outcomes where people with a mental illness get jobs but only a few. Mental Health services need to work more closely with employment agencies.

(Clinician, Victoria, Footscray Forum #5)

And we'd like to put our ill relatives on to support groups for them, recreation such as the Clubhouses and other structured day programs, and find out how to help them get work. [Y] who was with the Fellowship, arranges the sort of employment people coping with mental illness need, and gives talks on "Why Work Works", because it does.

(Carer, Mother, Victoria, Submission #211)

When I asked the case manager to help her daughter to get work she was told it was "early days". Employment situation is a nation-wide scandal.

(Part time Carer & on ARAFMI Board, Victoria, Melbourne Forum #6)

In the absence of <u>any</u> available rehabilitation in Victoria, we pleaded our case with the State Minister for Health, but he was not able to help. The solution was provided by another small and very caring Christian community in rural Victoria, where for two years [X] gained stability, confidence, work skills, and a variety of work and social experience in a beautiful setting. In July 2004 she moved to … community in … Tasmania … where she continues to benefit from an extraordinary level of support and where she is for the first time engaged in a full-time course (TAFE certificate) and building hopes of eventual employment. Although she continues to have some mild symptoms of schizophrenia, she manages her own medication, she is happy, and she has friends. We have daily contact, and we are able to visit each other. It is now 18 months since she used any illicit drug. It is almost 8 years since she was diagnosed with schizophrenia. (author's emphasis)

(Carer, Mother, Victoria Submission #320)

There are inadequate rehabilitation services for consumers who are trying to rebuild their lives. People recovering from heart surgery are automatically given a place on a rehabilitation program and access to professional assistance such as dieticians. Unfortunately the same cannot be said of psychiatric rehabilitation. In Frankston, Impact Services provide a quality Psycho-social rehabilitation service but due to long waiting lists, many consumers are unable to access this much needed type of service. At best the PDRS (Psychiatric Disability & Rehabilitation Service) offers a few hours of rehab per week leaving the carer with the responsibility for over 100 hours for the rest of the week to the carer. Rehabilitation services and support programs are essential for people with a mental illness many of whom have become socially isolated.

(Peninsula Carers Council, Victoria, Submission #321)

[X[is now part of the Centacare Housing and Rehabilitation program and currently has accommodation in one of their houses. He is on new medication "Seroquel" which has had an amazing affect on him. He is back to normal weight, sleeps normal hours and eating normally, but there are no suitable programs to relieve his boredom – not sufficient funding.

(Carers, Parents, Victoria, Submission #241)

Extra resources are needed to strengthen the commitment to both community-based services and to preventative care. Consumers in both Melbourne and regional areas also spoke of the need for increased access to drop-in and general support services:

- *"My biggest frustration as a carer [in regional Victoria] is that there is no drop-in centre for the consumer—they need somewhere they can meet 4 or 5 days per week".*
- *"In this area there is only an outreach service…there is no place for people to just drop in—for day programs or groups or just to talk with friends".*

(BSL 2004 Focus groups with mental health consumers)

Consumers who were able to access a drop-in centre spoke highly of the benefits they obtained.
(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

Many of the consumers had been working when they became unwell but often had lost their job, usually due to their illness, before they obtained a diagnosis. Getting back into work after a major illness was proving difficult for those who wanted to work. The exceptions to this were some people who said they had received good employment assistance from disability employment agencies.

- *"I'm with…and they got me a job. They are very supportive. I made a decision to tell them about my illness and they told my employer who is understanding and asks how I am going? Do I need any time off?"*
- *"Working can be tough sometimes but my job is like organising my own business. That's how it's been organised for me. There's really no supervision; I really just plan my own days; I'm quite able to leave when I want to which takes the pressure off. Working part time means I can keep working".*

(BSL 2004 Focus groups with mental health consumers)
(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

Rehabilitative programs that centre on consumers re-entering the workplace need to be made a priority within the mental health system. Programs do already exist, but they, like many services are limited by a lack of funding and high demand. To help alleviate the barriers that consumers face, there is a definite need for increased funding and support in this area.
(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

There is no follow-up of medication or therapy to help people with a disability get back into society or become independent.
(Carer, Mother, Victoria, Submission #352)

6.2.11.4.A.4 Need for programs that teach self-care skills

Living skills and self care programs would enable consumers to live with dignity in society and are seen as critical. Standard 11.4.A.13 states: 'The MHS provides a range of treatment and support which maximises opportunities for consumers to live independently in their own accommodation' and 11.4.A.2 states: 'Self care programs or interventions provide sufficient scope and balance so that consumers develop or redevelop the necessary competence to meet their own everyday community living needs'.

A number of submissions and presentations pointed to a lack of availability of supported accommodation, many consumers been forced to return to live with their families. In many instances, this placed intolerable strain on families as they waited for places to become available. Additionally, the lack of self care and living skills programs meant that consumers were also not able to gain the necessary skills to live independently and move out. As indicated by one consumer, some people have not had opportunities in the past to learn these skills, and do not have family from which to learn or relearn these skills now.

I came from the institution. I lived there from 7-21. I wasn't trained how to dress or how to wash. I am now 39 and I'm still trying to get over all my fears and anxieties. You need a lot of care and support and there is not a lot of that around.

(Consumer, Victoria, Morwell Forum #9)

6.2.11.4.A.5 Lack of family centred approaches

As reported throughout this Report, concern was expressed about the incredible strain that has been placed on families as a result of an inability to access treatment and support at the earliest possible stage of onset of illness. For families, this was often further compounded by the lack of housing and accommodation options available for their family members.

Reports received also indicate a lack of family-centred approaches to treatment and support. Standard 11.4.A.12 states: 'The MHS ensures that the consumer and their family have access to a range of family-centred approaches to treatment and support'. Included in the notes to this standard are: family education regarding the relevant mental disorder(s), training in communication and problem solving skills, family counselling and ongoing support and contact with relevant support / self help groups. Further, Standard 11.4.A.11 states: 'The consumer has the opportunity to strengthen their valued relationships through the treatment and support effected by the MHS'.

The lack of access to other support services (e.g. respite, leisure, recreation, education, training, work, employment, respite, home and community care) also contributed to this strain for consumers and their families.

Secondly, government policy states that carers have a right to appropriate education and training in order to fulfil their role, and yet our research indicates that carer support, education and training lacks the funding to administer comprehensive, timely and targeted support for carers in all regions .

(The Network for Carers Of People With A Mental Illness, Victoria, Submission #319)

Further, I'm alarmed increasingly at the neglect of hard working carers (I have been one for 40 years). Please consider in practical ways of supporting these brave and loyal folks, a grand majority whose own health is suffering. I think respite care most urgently needs priority funding.

(Carer, Victoria, Submission #248)

6.2.11.4.B Supported accommodation

Supported accommodation is provided and/or supported in a manner which promotes choice, safety, and maximum possible quality of life for the consumer.

Submissions and presentations indicated concerns about:

- lack of supported accommodation;
- the need for interim (step-up and step down) accommodation for consumers;
- the need for step-up and step down accommodation facilities for consumers with dual diagnosis (drug and alcohol); and
- lack of supported accommodation options for people with mental illness and drug and alcohol problems.

6.2.11.4.B.1 Lack of supported accommodation

Fortunately I had met the psychiatrist on a number of occasions and knew him to be 'carer sensitive'. When he asked if my son could come home with me after discharge, I felt able to tell him that I had decided that the series of events leading up to this latest hospitalisation had driven me to a point where I was no longer prepared to be a part of this repetitive pattern. It was apparent that finding accommodation for him was going to be extremely difficult in the future due to the rental ramifications of this latest relapse and that as he wanted to be independent as much as I wanted that for him, I said that from now on I was placing the responsibility for his accommodation and rehabilitation upon the Mental Health System.

(Carer, Mother, Victoria, Submission #178)

As indicated by this carer, extra stresses and demands are being put on supported accommodation because the requisite support needed for people to live independently is not there. It was suggested that people who are able to live independently with support are seeking supported accommodation.

As noted previously in this Report (8.3 Integration), the lack of housing and accommodation options, and supported accommodation options in particular, for people with mental illness is of serious barrier to consumers attaining the 'maximum possible quality of life' and integrating and contributing to the community.

I'm [X]'s carer and I feel for myself to cope so soon is very scary, walking on egg shells, mentally and physically very draining experience. I feel I can no longer cope with him living at home due to this illness. Bit there is nowhere for him to live. It's all unavailable. I would <u>not</u> want him locked away in an institution. But where can people with a mental illness live. (author's emphasis)

(Carer, Mother, Victoria, Submission #310)

So much supported residential accommodation in Boroondara has been closed, and several of the residents have had to move away, which puts them out of contact with the Kew Regional Minister… who works hard to help them feel part of a community, and runs a monthly service for them in Kew… We would like to see more funding for supported residential accommodation throughout Boroondara.

(Carer, Mother, Victoria, Submission #211)

The provision of suitable housing and accommodation available within Australia is appalling… When the large institutions were closed and patients moved into community care settings it allowed the Governments at all levels to neglect the accommodation for the mentally ill. ***They have taken this opportunity to neglect the provision of accommodation for the mentally ill with a zeal that they display in no other area of health care!*** *We regret that this same level of enthusiasm is not evident in the area of service provision. Which level of government is responsible for housing? (author's emphasis)*

(GP in rural Victoria, Victoria, Submission #123)

Because of decisions to direct Commonwealth housing dollars to subsidising private rental through rent assistance, there has been a significant decline in the possibility of a person with a mental illness accessing secure and affordable housing through the State public housing programs. Waiting lists for people meeting the criteria for homelessness (Segment 1) are upwards of two years in some areas and for accommodation with support (Segment 2) can be from two to three years. The waiting list for people requesting accommodation and support from our own agency continue to climb, with little prospect of our being able to offer accommodation.

(ARAFEMI Victoria, Victoria, Submission #230)

There is a critical lack of suitable accommodation for suffers of mental illness. Large numbers are homeless or living with family who struggle to cope with the burden.

(Carer, Mother, Victoria, Submission #299)

Huge deficit in supported accommodation options: People who have recently been discharged after an acute episode usually require intensive support from both clinical care and social support services. However, the reality is that upon discharge, many people with a mental illness enter crisis accommodation services, or end up in police lock-ups or on the street. The alternative of being housed by their family often leaves the family vulnerable to emotional, physical and financial disruptions. Pressure on resources in hospitals means that patients have been discharged from hospital too early, placing a further strain on the family. Sometimes violence, financial demands and other factors associated with people with a mental illness prevent families from accepting their relative into the home.

(The Network for Carers Of People With A Mental Illness, Victoria, Submission #319)

More housing and support options attached to people with a mental illness are urgently needed. 30 to 50% of those people in crisis accommodation and Supported Residential Services or boarding houses have significant mental health problems.

(The Network for Carers Of People With A Mental Illness, Victoria, Submission #319)

There is a lack of government funded long term supported housing for people who may not be able to live independently, or for people who may require supported housing long term before being able to sustain independent living

(Western Region Health Centre, Victoria, Submission #292)

There is a lack of different housing models available to meet individual needs based on gender, age, support needs, affordability etc.

(Western Region Health Centre, Victoria, Submission #292)

The shortage of accommodation options for people with long term support needs is the most pressing need observed by guardians and Community Visitors. Community Visitors are aware of people with mental illness living in accommodation where there is inadequate support for their needs and an inappropriate mix of residents. The stress inherent in these types of living environments heightens the potential risk of relapse into acute phases of mental illness and hence, more admissions to acute inpatient facilities. In the financial year 2003-04, OPA received several complaints from relatives of people in community care units being asked to move to alternate community living facilities that relatives believed could not provide the level of support required by their mentally ill family member. The lengthy delay in the establishment of the sub-acute beds announced in the 2002 budget is of serious concern to OPA. The 20 beds to be established in metropolitan Melbourne - 12 in Springvale and eight in Box Hill - are still not yet operational. However, Community Visitors have reported very favourably regarding the new 24-hour prevention and recovery unit in Shepparton which has eight beds and two day clients. Sixty-six clients have accessed the service since 22 September 2003, when the first participant was accepted.

(Office of the Public Advocate, Victoria, Submission #284)

There is a limited availability of specialist accommodation for people with a severe mental illness who require long term support. For example, few long term accommodation options outside of secure extended care exist for this group. The secure extended care that does exist is limited to hostels, nursing homes, or Thomas Embling Forensic Hospital. The specific long term care needs of people with mental illness assessed as having a 'low rehabilitation potential' are not being catered for by the service system. The Willows program in Beechworth is a successful example of an appropriate accommodation option that could be provided.

(Office of the Public Advocate, Victoria, Submission #284)

Supported housing, where available, is useful to some consumers but sharing with 3 or 4 other people can be difficult. There is, however, an insufficient supply of such housing that results in many people not receiving the support that would be beneficial to their wellbeing.

(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

Rooming houses and Supported Residential Services (SRS) have become home to many people with a mental illness but such facilities are often ill equipped to provide the support many residents require. The Victorian Homeless Strategy (VHS) 2002 reported research which had found that 47 per cent of people living in crisis accommodation, SRS or boarding houses had significant mental health problem (VHS 2002, p6).

(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

Assessing residents for relocations due to closures, WRHC staff identified a range of issues for the residents including:

- *Lack of notice to residents for proper assessments of needs*
- *Shortage of accommodation options resulting in unsuitable relocations or people relocating out of area*
- *Residents losing contact with family and family being inadequately informed of closures and relocation plans*
- *Loss of residents' records*
- *Inadequate management and documentation of residents' financial affairs*
- *Poor health status of many residents; and*
- *Lack of access to specialist psychiatric treatment, including clinical review of medications*

(Western Region Health Centre, Victoria, Submission #292)

6.2.11.4.B.2 The need for interim (step-up and step down) accommodation for consumers

Many submissions argued that a range of accommodation options were needed and that these needed to be flexible, for example, interim step-up and step-down facilities.

But there's nowhere to go when you get out of Flynn. There's no step-up or step-down care.

(Consumer, Paid Consumer Consultant, Victoria, Morwell Forum #5)

Over the 12 years that my daughter was ill there was only one period of peace of mind when my daughter was hospitalised in Sydney. There should be interim accommodation when people don't need hospitalisation.

(Carer, Mother, Victoria, Melbourne Forum #2)

Short term fully supported accommodation is needed to enable the development of living skills and rehabilitation back into the community. Families are often not best placed to provide such support - they are working to try to make ends meet.

(Carer, Mother, Victoria, Submission #299)

Critical to the stabilisation and recovery of consumers is the availability of a flexible range of accommodation options. There are currently an inadequate number and range of residential rehabilitation programs offered to people with a mental illness in Victoria. Most of these offer psychosocial rehabilitation to people usually over 1-2 years. Yet longer-term residential rehabilitation programs lasting up to 6 or 7 years are needed to properly address the issues of clients with complex and chronic issues.

(The Network for Carers Of People With A Mental Illness, Victoria, Submission #319)

Lack of suitable accommodation (i.e. lower level care) following a stay in hospital is urgently needed to help the consumer adjust back to a normal life. The gap between hospital and normal life can be difficult to handle, and is of critical concern given that many patients are discharged prematurely.

(Peninsula Carers Council, Victoria, Submission #321)

New 'step up/ step down' residential programs are being piloted, to prevent the need for admission to acute wards and facilitate discharge.

(SANE Australia, National, Submission #302)

6.2.11.4.B.3 Need for step-up, step down and long-term accommodation facilities for consumers with dual diagnosis (drug and alcohol)

Concern was also expressed regarding the need for specific accommodation facilities for consumers with complex needs (mental illness and drug and alcohol). Additionally it was suggested that in order to achieve the best possible outcomes of reintegration into the community for these consumers, such facilities should also provide access to rehabilitation programs.

> *A large proportion of our clients are chronically unwell and have little or no family support, and often have polysubstance abuse as well. They frequently live in crisis accommodation or boarding houses which add to their isolation, contact with drugs and increased sense of loneliness and hopelessness. We have let them down by no longer creating" asylum" ie, places of refuge, as we used to when we had large institutional psychiatric hospitals. I believe there will always be people with mental illness who need "asylum" in the caring sense of the world. Community care has let them down, there are so few CCU / Rehabilitation beds it is a joke! Just when someone is improving we tend to send them back to live alone, such is the pressure on beds in the system. I have always believed that we need a system that is midway between what we had when I trained and what we have now, somewhere permanent where those that will never be well or cope alone can feel safe, protected and have some gainful activities and be monitored for symptom change.*
>
> (Clinician, Victoria, Submission #201)

> *I self-medicated with heroin for about 4 years. I spent time in rehabilitation and detox as a voluntary and involuntary patient. The better rehabs are residential and longer term. There needs to be more step up / step down community housing as 9–11 day stays as the average stay in hospital is not long enough for those people who are seriously ill and are trying to get back on their feet. They should also have strong peer support and active programs of group therapy, cooking, living skills – contrast that to a hospital ward and you are bored stupid – basically you are waiting for the drug trolley to come around and you just watch TV. Consumers like me with a dual diagnosis are just ping-ponged between services. We need to talk about the community of consumers helping each other. We also need to talk about the desperate need for and benefits of appropriate step-up and step-down facilities.*
>
> (Consumer, Victoria, Footscray Forum #7)

6.2.11.4.B.4 Lack of supported accommodation options for people with mental illness and drug and alcohol problems

Concern was expressed regarding the lack of longer term supported accommodation options for people with mental illness and drug and alcohol problems:

> *Longer term housing/small apartments in clusters where informal supervision and assistance can be provided are also needed. Almost none exist. We are providing independent accommodation for one daughter but she would benefit from nine to eighteen months in a facility where she could quit her drug dependencies and learn some living skills amongst others at various stages of recovery.*
>
> (Carer, Mother, Victoria, Submission #299)

> *His lack of self care and money management problems mean that his ability to live independently is severely impaired. I am very concerned about accommodation for him in the long term. I am very aware that accommodation for people with mental illness is in extreme short supply. However, because of his substance abuse he is ineligible for the limited amount that is available.*
>
> (Carer, Mother, Victoria, Submission #229)

There are particular difficulties for young people accessing supported housing when they have a dual diagnosis. Their support needs are greater than can be met by youth housing programs and they lose their housing. It is difficult to accommodate young people in some of the existing supported housing for people who have experienced mental health problems because of their drug usage and clash of life styles with older clients.

(ARAFEMI Victoria, Victoria, Submission #230)

An exhaustive search for appropriate supported accommodation was unsuccessful. [X] had too many obstacles--mental illness, some lapses into drug use, a criminal history, and finally one obstacle that should have been a strength: since she had caring parents who were prepared to continue as caregivers while she lived independently, her need was not considered to be great enough to qualify for assistance from a major service provider.

(Carer, Mother, Victoria Submission #320)

People with mental illness and other complex issues such as drug and/or alcohol usage or behavioural issues often cannot sustain tenancies due to conflict with neighbours in high density housing or lack of tolerance or understanding by housing services

(Western Region Health Centre, Victoria, Submission #292)

6.2.11.4.C Medication and other medical technologies

Medication and other medical technologies are provided in a manner which promotes choice, safety and maximum possible quality of life for the consumer.

Under this Standard, submissions and presentations indicate concerns about:

- emphasis on medication:
- the lack of opportunity to get a second opinion; and
- changes to policy for consumers receiving maintenance ECT (Electro Convulsive Therapy) treatment.

6.2.11.4.C.1 Emphasis on medication

Concern was expressed that the major focus of treatment for mental illness is a reliance on medication without consideration for other necessary treatment and supports and overall well-being:

The ever-increasing reliance on medication to manage mental illness means there is an ever-increasing reliance on forcing people to take medication. As a result, involuntary orders have increased at the same time as people are crying out for treatment.

(Mental Health Legal Centre, Victoria, Submission #330)

Currently the focus of treatment is predominantly on medication. People who suffer from a mental illness, not only need medication but assistance and support to help deal with their situation. As well as medication they need counselling to help them deal with the difficulties of having a mental illness.

(Peninsula Carers Council, Victoria, Submission #321)

Medication is often inappropriately tailored to the individual's needs and poorly monitored with distressing results. Mental Health Workers do not take sufficient notice of consumers in this regard. I have seen my daughter faint onto a thinly carpeted concrete floor as a result of low blood pressure induced by medication whilst a psychiatric nurse looked on impassively as if she was 'putting it on'. She was once medicated so heavily that her voice sank to an almost inaudible whisper for 36 hours. She has suffered severe involuntary protrusions of the tongue and I have seen her endure a 10 minute wait at the nurses station in full view of all the other patients before Cogentin was administered. Such experiences are frightening, especially given that her medication is administered involuntarily.

(Carer, Mother, Victoria, Submission #299)

6.2.11.4.C.2 Lack of opportunity to get a second opinion

Standard 11.4.C.12 states: 'the consumer's right to seek an opinion and/or treatment from another qualified person is acknowledged and facilitated and the MHS promotes continuity of care by working effectively with other service providers'. Due to the scarcity of services and difficulty in accessing those that exist, it was suggested that there is a lack of opportunity to get a second opinion.

A GP might prescribe you some medications or you might be referred to a psychologist on the public mental health services. GPs are now getting much more training so that's been helpful. But there's a real lack of opportunity to get a 2nd opinion - people need options.

(NGO worker, Victoria, Morwell Forum #7)

6.2.11.4.C.3 Difficulties in accessing maintenance ECT (Electro Convulsive Therapy) treatment

Concern was expressed regarding changes to policies and procedures in order to receive maintenance ECT and the negative impact this has had for one consumer in particular:

For this treatment to continue being successful it is essential that [X] receive regular maintenance ECTs. Although this was previously done at Dandenong for out patients, it is no longer the case. This means that [X] must book as an inpatient, taking a bed that could otherwise be used for someone else, or if no bed available, then her treatment is cancelled, as has happened with her last four sessions, which I am sure you would understand has had a negative affect on the benefits initially gained from her ongoing treatment. It is my understanding that outpatient maintenance ECTs are available at surrounding hospitals but we are "out of area", we and the many others who could benefit from this program are missing out.

(Carer, Husband, Victoria, Submission #348)

6.2.11.4.D Therapies

The consumer and consumer's family/carer have access to a range of safe and effective therapies

Under this Standard, submissions indicate concerns about lack of access to a range of accepted therapies.

6.2.11.4.D.1 Lack of access to a range of accepted therapies

According to Standard 11.4.D.2: 'The MHS provides access to a range of accepted therapies according to the needs of the consumer and their carers'. However, concern was expressed that there is an over reliance on medication and access to such therapies in the public mental health system is difficult. It was suggested that lack of access to therapies resulted in consumers not being able to recover appropriately and therefore often requiring re-admission.

Approx 50% of schizophrenia, bipolar and dual diagnosis sufferers are in a 'revolving door system', i.e. in and out of our overstretched and under-funded hospitals, receiving repeated diagnosis, medication, stabilisation, then out again until the pattern is repeated because there is no ongoing psychological counsel follow-up to assist with these patients' lack of insight and neuropsychological deficit.

(Anonymous, Victoria, Submission #216)

…those severely afflicted, if receiving collaborative sympathetic counsel from skilled psychologists, who can also advise carers and families are able to achieve medication compliance and improved quality of life for loved ones… However, there are no adjunct psychology counselling systems in place to support the medical ones and at $80 plus a session for psychologists, few can dream of affording this support.

(Anonymous, Victoria, Submission #216)

Supportive counselling after the event to talk through the trauma of hospitalisation and to discuss the side effects of medications is not offered although overseas research indicates it can help in developing insight.

(Carer, Mother, Victoria, Submission #299)

For our members access to low cost counselling would be invaluable to assist with their recovery. Anecdotally we have worked with members who report the benefits of using local community counselling services to resolve the underlying causes of issues.

(Service Provider, Victoria, Submission #266)

People with anxiety disorders and depression often have no idea how to access the services that are available. The majority of the people coming to see the psychologists at PADA have had their anxiety disorder for many years – usually between four and ten years. This is outrageous for conditions that respond well to CBT (Cognitive Behaviour Therapy).

(Clinical Service Provider, Victoria, Submission #268)

My wife suffers from depression and I took her to the regional mental health unit in Wodonga. An initial interview was conducted with 2 people from this unit and their only advice was 'go and see a private psychologist, we don't have the resources here to help'. This news was devastating as we cannot afford the treatment required in private practice, and this has now tainted my wife's view of any help possible.

(Carer, Husband, Victoria, Submission #119)

1. There are simply not enough specialist services for people with anxiety disorders and depression. 2. Most community health services provide some services for people with anxiety and depression, and are to be commended for doing so, however, are limited in the number of sessions that practitioners are able to provide, usually have long waiting lists and some smaller and/or regional CHS's do not have adequately qualified staff.

(Clinical Service Provider, Victoria, Submission #268)

6.2.11.4.E Inpatient care

The MHS ensures access to high quality, safe and comfortable inpatient care for consumers.

Under this Standard, submissions and presentations indicate concerns about:

- death while an inpatient;
- lack of beds;
- transportation is not in the most respectful manner possible;
- use of restraint; and
- lack of communication with consumers (consumers not involved in treatment plan).

6.2.11.4.E.1 Death while an inpatient

Of most serious concern were reports of deaths of consumers while an inpatient and that hospitals did not provide safe settings or have adequate policies and procedures to ensure safety.

> *The patient remained in care at a local hospital until transfer could be given on the Tuesday. The patient took their life on the Friday… Points of system failure. Unsecure safety watch. Not a high enough level of observation. Patient was not protected from harming themselves. It was not like the staff did not know the extent of the situation. Should of been in a secure ward or watched properly. The patient was calling out for help.*
>
> (Family member, Victoria, Submission #170)

> *There are matters concerning her care, and death while 'held in care' at the Alfred Hospital, which are of deep concern to me and my family…*
>
> (Carer, Mother, Victoria, Submission #206)

> *15 March, 2002. She said [X] was being sent out on unaccompanied leave that night. When asked had she read my letter, she said "yes" and made no further comment. I told her, at some length, that [X] was acutely paranoid and believed that stalkers were at her flat. She listened, made no reply, and noted these serious matters in the file as 'allowed to ventilate'… When asked six weeks later if she had informed Dr [Y] of my fears and [X]'s paranoia, [she] said no. I called the ward at 2pm to say that [X] might kill herself if sent out without me. [X] was sent out We stayed in contact by phone. She got through Friday night. 16 March. We were in contact by phone. [X] was not happy, but said she would stay. We spoke last at 8.30pm. At 11pm [X] jumped in front of a train and was killed instantly.*
>
> (Carer, Mother, Victoria, Submission #206)

> *The month after people are discharged is when people are at the highest risk. There are reports about people absconding from care to suicide – nobody is asking the question as to why people are absconding from care to kill themselves. Is being in care that intolerable for some people?*
>
> (Consumer Advocate, Victoria, VMIAC Consultation #18)

6.2.11.4.E.2 Lack of beds

The lack of available beds for acute care was also cited as a serious concern. As discussed previously, access to these beds for consumers in rural and regional areas was particularly problematical. Patients requiring admission were generally in desperate need of medical care, often life-saving medical care. It appears that the demand far exceeds the number of beds available which results in a whole series of other decisions which jeopardise the safety and rights of consumers including: non-admission and being returned 'home', admission and someone else who is still unwell is discharged to vacate a bed, lengthy waits in emergency departments and admission to other wards with the use of sedation or security guards.

> *Currently there is a catastrophic and cruel shortage of acute mental health beds in the state. I work in psychiatric triage, based in an Emergency Department and almost on a daily basis, my colleagues and I search for beds for people who have become acutely unwell and require hospitalisation. It is not uncommon for these people to have to wait 48 to 60 hours in the emergency department, amidst the noise and chaos of emergency, for a suitable bed. They are even unluckier if they require a High Dependency bed.*
>
> (Clinician, Victoria, Submission #201)

> *I have several patients who need long term acute care (1 per week) and you simply can't get that acute care. There are insufficient beds and insufficient government funding.*
>
> (Regional GP, Victoria, Morwell Forum #8)

… a metropolitan hospital in the outer Eastern suburbs of Melbourne. … I am pleased and proud of our Emergency Department's advances in reducing the waiting time people with mental health issues experience before being seen by psychiatric staff … I have, however, very severe personal, moral and professional concerns for a particular group of patients whom I think our system fails in every possible way. Our failure is unacceptable and wrong. It affects the most vulnerable group of people; the informal and involuntary patients who require an acute mental health admission and for whom there is no available psychiatric bed available. These people may be required to wait in the Emergency Department for a psychiatric bed for anywhere up to seven days, and in our region, we have experienced up to twelve severely ill people waiting for a bed at the same time. If these people were elderly, or waiting surgery for seven days in an Emergency Department, our community would not allow it; but we do, because these people are without a voice and often without a vote.

(Clinician, Victoria, Submission #223)

My job was created because of the large number of people waiting for beds. Talking about Human Rights and my job causes me a great deal of distress. We aren't able to respond in the way we need to be responding and this is clearly a resource issue. The DHS has done a lot of hard work to try to relieve the issue but it's not enough. It is not uncommon for me to spend up to 1.5 hours or more looking for beds when I could be providing care. It's because of this that I don't get sufficient time to devote to the people I was employed to help.

(Clinician, Victoria, Melbourne Forum #15)

The few who make it to an inpatient unit face the risk of premature discharge in order to 'free up' more beds for those in crisis awaiting admission. People are often discharged on the basis of who is the least risk rather than who is ready to return to their home.

(Health and Community Services Union, Victoria, Submission #220)

There are extended waiting times in Emergency Departments for Mental Health patients/clients, because there are limited beds; inpatient mental health services run above capacity most of the time. Deinstitutionalisation and mainstreaming have resulted in general hospitals having more contact with Mental Health patients/clients; Emergency Departments are the main access point for mental health emergencies. There is clear evidence that general hospital staff and systems are poorly equipped and resourced to provide mental health care to patients/clients with mental health concerns. The availability of meaningful assistance to general hospitals from mental health services varies dramatically. Psychiatric Emergency and Consultation-Liaison Psychiatry Services are inequitably distributed across the state and in many cases, virtually non-existent in country regions.

(ANZCMH Nurses Victorian Branch, Victoria, Submission #316)

When we were finally seen by the Psychiatric Registrar he was very understanding and knew my son needed to be admitted. He went off to find him a trolley to sleep on until late morning after telling us that he had checked all Melbourne hospitals and discovered there was not one single bed vacant!

(Carer, Mother, Victoria, Submission #176)

The optimistic predictions of community care are dented by the continuing need for inpatient service and the paucity of beds. The inpatient units in the general hospitals are under pressure to deny admission and to discharge as quickly as possible.

(ARAFEMI Victoria, Victoria, Submission #230)

People report that it is increasingly difficult to get access to an in-patient bed and that the length of stay is not long enough to assist people to stablilise their mental health.

(Western Region Health Centre, Victoria, Submission #292)

I believe the public have a right to know about the dangerously inadequate psychiatric services currently available in Gippsland. As previously reported, people who are deemed in need of admission, & thus 24 hour care, are being cared for during the day in a highly stressed environment, where nurses are often General Nurses, inexperienced in psychiatric care. At time there has only been one Psychiatric Nurse on duty, responsible for supervising a nursing team, comprising some for whom it was their first experience in an acute psychiatric ward. It is not surprising that some of these nurses have refused to return. Because the number of patient being admitted is higher than the number of available beds, it is correct that patients are sent to motels and caravan parks to sleep. As you can imagine any psychiatric ward can be and often is a place where highly charged emotions are expressed. Imagine the added effect of overcrowding and at times fearful inexperienced staff. This is a recipe for tragedy waiting to occur.

(Anonymous, Victoria, Submission #312)

6.2.11.4.E.3 Transportation is not in the most respectful manner possible

Standard 11.4.3.E states: 'The MHS ensures that a consumer who requires involuntary admission is conveyed to hospital in the safest and most respectful manner possible'. Concern was expressed that being escorted in the back of police paddy wagons like a criminal is not in the most respectful manner possible.

Can anything be done to stop supposed very sick people being man-handled into paddy-wagons and taken off like criminals. The fear they go through plus the illness must be unbearable for them

(Carer, Victoria, Submission #199)

Most people come to our department in a police van.

(Clinician, Victoria, Melbourne Forum #15)

6.2.11.4.E.4 Use of restraints

Such practices would presumably not be accordance with Standard 11.4.E.1 which states: 'The MHS offers less restrictive alternatives to inpatient treatment and support provided that it adds value to the consumer's life and with consideration being given to the consumer's preference, demands on carers, availability of support and safety of those involved'. Excessive use of restraint, sedation and seclusion may infringe on many consumer rights, as described below. The unnecessary use of such practices is also problematical given the scarcity of early intervention and treatment options in the community setting, necessitating consumers to reach crisis point before access to treatment is allowed, and then they are 'punished'.

I also want to talk about shackling – ultimately the medical officers make the decisions about shackling. Most people come to our department in a police van.

(Clinician, Victoria, Melbourne Forum #15)

We made strong recommendations 15 years ago that seclusion practices should cease but they are still being perpetuated.

(Consumer Advocate, Victoria, VMIAC Consultation #10)

There are some good people in the system but there are practices like this still being perpetuated.

(Consumer Advocate, Victoria, VMIAC Consultation #11)

Whilst guidelines and practice suggest that seclusion should be a last resort measure and only occur when the patient is at risk absconding, or of harming themself or others, our feedback and in some instances direct observation is that it is a first resort. To be "grabbed" by up to six people, taken against your will to a room, stripped naked in some instances in the most insensitive way, injected and left in the room only to be observed through a window at 15 minutely intervals would be humiliating and traumatic for anyone. Yet, patients' reactions and in particular, their feelings about the above experience are largely ignored from a humanistic point of view. When patients try to talk about the experience or complain about it, defensive reasoning takes over and the issue of the impact of the experience on the patient is ignored and reflective practice negated.

(VMIAC, Victoria, Submission #332)

The intensive care units were designed for small numbers and can only function if these numbers are kept low. In practice, they are overcrowded, highly stimulating and consequently characterised by restraint and over-medication.

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

More extreme forms of physical abuse include being strip-searched, locked up and isolated, physically restrained by ward staff or restraining devices such as shackles.

(Insane Australia, Victoria, Submission #232)

Further, nurses report that the workload results in their having no option but to adopt a custodial approach to patient care, rather than that of the development of therapeutic relationships. We learn of instances where restraint is used, with security guards and the police being called to emergency departments to restrain people who are acutely and severely unwell.

(Australian Nursing Federation (Vic Branch), Victoria, Submission #322)

6.2.11.4.E.5 Lack of communication with consumers - consumers not involved in treatment plan

One submission was received which described the events prior to the suicide of a family member. Included in the description were references to the consumers' growing agitation at not knowing what decisions had been made about treatment and lack of involvement in the care plan, about being 'left in the dark' and lack if continuity of care with treating doctors.

The patient remained in care at a local hospital until transfer could be given on the Tuesday. The patient took their life on the Friday… Points of system failure… No communication in the days of being at the hospital was given to the patient as to what decisions had been made about continuing treatment with the original Dr. Patient left in the dark and only wanted to know what they were deciding. A person in such a state should of been seen immediately. This patient needed professional help ASAP and apart from brief talks with prior program organiser (who is a Dr), the first treatment session was on the Friday morning, of the Friday night of taking their life. This was a new Dr the patient had not seen before. There are so many things that should of been better…

(Family member, Victoria, Submission #170)

6.2.11.5 Planning for exit

Consumers are assisted to plan for their exit from the MHS to ensure that ongoing follow-up is available if required.

For healers and carers, the discharge of patients should depend on their health status, not upon the 'bed status'. My dear daughter [X], should have had, as her right as someone 'held in care', a secure, contained environment provided in which her condition could improve.

(Carer, Mother, Victoria, Submission #206)

Under this Standard, submissions and presentations indicate concerns about:

- planning for exit on the basis of need to vacate beds;
- exit plans not authorised by medical staff; and
- inadequate planning prior to discharge.

6.2.11.5.1 Planning for exit on the basis of need to vacate beds

Concerns were expressed that discharge was not occurring to an agreed exit plan or health status of the consumer but rather according to the need to vacate beds for new admissions. Such exits could jeopardise the safety of the consumer, especially as entry is almost always on the basis of risk of actual self-harm, or harm to others, and frequently results in almost immediate readmission. According to Standard 11.5.2: 'The exit plan is reviewed in collaboration with the consumer, and with the consumer's informed consent, their carer's at each contact and as part of each review of the individual care plan'. Also, according to Standard 11.3.18, a review should be conducted when the consumer is going to exit the MHS, presumably to ensure that exit is occurring at and appropriate stage of the recovery process.

I was told by several people in [X]'s last week that beds had to be emptied before Easter, which was two weeks away.

(Carer, Mother, Victoria, Submission #206)

(Patient progress notes has entry 15/03/02) Dr [Y] unable to work towards definite discharge date due to unknown bed status.

(Carer, Mother, Victoria, Submission #206)

On 14 March [X] called me in a distressed state because Dr [Y] had said "you know, if someone sick comes in I can discharge you immediately. ([X] suicided 16 March)

(Carer, Mother, Victoria, Submission #206)

Patients admitted with a mental illness are often discharged before they have sufficiently recovered, due to pressure on hospital beds. This can place an unnecessary burden on carers, who are untrained but are forced to care for someone who is still unwell. This can also put the consumer at risk, and in particular risk of suicide.

(Peninsula Carers Council, Victoria, Submission #321)

6.2.11.5.2 Exit plans not authorised by medical staff

One carer reported the events leading to the discharge of her daughter which preceded her death. Concern was expressed by the mother that the exit plan was not authorised by medical staff.

The 'Plan' has all the professionalism of something written hastily on the back of an envelope, and the interpolations do nothing to add to its seeming lack of serious purpose. Upon such a clearly non-planned document rested my daughter's life, for, once it was written and filed, it seemed to acquire some inexorable life of its own; Wednesday's unsuccessful leave must be ignored, the 'Plan' must be adhered to, [X] must be sent to her flat alone. In the 'Root Cause Analysis (a document required by the Department of Human Services after the death of a patient) it was documented "A leave plan was documented in the file by the community case manager on 15 March", which is subsequently referred to by inpatient nursing staff, but this does not

appear to have been finally approved by the medical staff. A discharge plan written by the case manager is on a plain sheet of paper neither signed nor dated. Responsibility for both appears to have been delegated to the community case manager… There is a reasonable amount of information in the file regarding the patient's care and her mother's concerns but it is not clear how this information was communicated to the treating team. The file does not give a sense of how this information was put together to form a clinical opinion and there is no evidence of a summary of her progress which may have highlighted these issues.

(Carer, Mother, Victoria, Submission #206)

6.1.11.5.3 Discharge without adequate planning prior to discharge

One submission raised serious concerns about the inadequacy of discharge plans, and that sometimes they are not even instigated. Specifically, the allegation suggests that discharge plans have not been developed in collaboration with the consumer (Standard 11.5.2), that understandable information about the range of relevant services and supports has not been provided (Standard 11.5.4) and that consumers have not established contact with the service providers prior to exit (Standard 11.5.6).

"The first time I was in hospital—on the day I was to be discharged and I didn't know it was going to be that day—I was given a sheet of paper with a list of boarding houses on it and told to find myself a place to stay because I was going to be discharged that afternoon. I lived under a train station for 2 weeks until I found somewhere to stay. I had just spent 8 weeks in hospital getting better and then they say you have to get out and they don't care where you go. They told me I could come back on Monday if I needed to". (BSL 2004 Focus groups with mental health consumers)

(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

Again a shortage of staff – nursing, medical and allied health – may result in inadequate discharge planning and follow up in the community.

(Australian Nursing Federation (Vic Branch), Victoria, Submission #322)

Patients admitted with a mental illness are often discharged without establishing whether they have appropriate accommodation arranged. This can mean that carers are unprepared for their loved one to return home, or that their loved one literally has nowhere to go.

(Peninsula Carers Council, Victoria, Submission #321)

6.2.11.6 Exit and re-entry

The MHS assists consumers to exit the service and ensures re-entry according to the consumer's needs.

Under this Standard, submissions and presentations indicate concerns about:

- death soon after discharge;
- lack of involvement of carers on exit; and
- lack of engagement with consumer after exiting inpatient care and no review of arrangements prior to exit.

6.2.11.6.1 Death soon after discharge

Concern was expressed regarding the inappropriate discharge of consumers when they were still unwell. Such concerns were reinforced by the reports below from carers whose sons and daughters were discharged and committed suicide soon after exit.

His family, who all work, and his doctor, were effectively excluded. When we asked about making arrangements for supported accommodation, in preparation for his discharge, we were told "There will be another meeting later. There will be plenty of time before it's needed." There was no such meeting. … [X]'s doctor & family ignored. Worse, we were not informed that his bupromorphin had been stopped. It had been prescribed to protect him from heroin. The meeting that we were told would be arranged did not happen. Just a phone call during dinner one night, to say he was being released into the care of the girl who'd been visiting him. No time was allowed to make plans for supported accommodation, of which we'd found three. [X] had already indicated earlier, he was interested in going back to the Arc House. [X] was released just before the Easter break, into the care of the person who he said had "latched" onto him. No urine tests were done to establish his status as an addict, even though on the phone I was told they would do this. I had requested it. He came to me, desperate to get back onto the bupromorphin. He was in withdrawal. I phoned Dr. [Z], who was going on holidays, but said he'd wait for us. He was extremely angry at the hospital! [X] told him he'd been using while in the hospital. He said he'd been set back 8 years. Dealers had got to him in the psych ward. That was the last time I saw my son. … He was found dead ten days later.

(Carer, Mother, Victoria, Submission #353)

12 months ago I buried my partner after he successfully suicided. He had received treatment from this service, and received ECT therapy. He was also a private patient of the psychiatrist in Shepparton. He took him off his medication, just after the treatment finished. In another couple of weeks he had completed suicide.

(Carer, Partner, Victoria, Submission #127)

6.2.11.6.2 Lack of involvement of carers on exit

Carers expressed frustration that they were not notified of the consumer's discharge from the MHS, especially as they were expected to assume responsibility of care upon exit from the MHS. This left carers with feelings of extreme stress and fear for the safety of their family member with mental illness:

Parents sometimes ring the Helpline and say their son has been let out of hospital, but they weren't told, and they can't find him.

(Carer, Mother, Victoria, Submission #211)

At the meeting the head psychiatrist apologised for the misunderstanding and acknowledged the potential risks which were involved and when I said that as a carer, I believed that I have the right, even if not under the legislation but simply as a human being, to be given information about important issues which strongly impact on my own personal health and wellbeing, my son's new psychiatrist said "Well, I'm telling you that you that you certainly do not have that right."

(Carer, Mother, Victoria, Submission #178)

It is small wonder that carers can often feel used and abused by the mental health system – it appears that there has been little thought given to the rights of carers, or rather their lack of rights; we are expected to accept responsibility for the continuity of care without even the right to be informed of hospital discharges…

(Carer, Mother, Victoria, Submission #178)

Patients admitted with a mental illness are often discharged without notifying carers. If the consumer is hostile towards the carer (perhaps due to involuntary hospitalization); this can put the carer in a difficult situation and sometimes even at risk.

(Peninsula Carers Council, Victoria, Submission #321)

6.2.11.6.3 Lack of engagement with consumer after discharge and no review of arrangements prior to discharge

One carer commented that although an arrangement had been made for the dispensing of medication, there was no other contact from the mental health service after discharge from an acute admission to ensure the health and safety of the consumer. This was particularly problematic because the consumer had no accommodation arrangements on exit. Another carer expressed concern that no attempts had been made to re-engage with a consumer who did not keep the planned follow-up arrangements as required by Standard 11.6.4:

> *For the entire month that he was with me I saw no signs of 'organisational skills' whatsoever, he was virtually totally dependant on me, and until he 'turned up' for his injection no one from the hospital or clinic knew where or how he was.*
>
> (Carer, Mother, Victoria, Submission #178)

> *The case workers don't come out and see you if you don't keep your appointments.*
>
> (Carer, Victoria, Footscray Forum #1)

Another carer expressed concern that accommodation arrangements for her son had not been reviewed prior to discharge from hospital care. According to Standard 11.6.1: 'staff review the outcomes of treatment and support as well as ongoing follow-up arrangements for each consumer prior to their exit from the mental health service'.

> *I requested that I be notified of his discharge, partly as I was storing his belongings and the psychiatrist agreed… When I rang the hospital at 3 o'clock one afternoon on a bitterly cold, wet winter's day to inquire after my son… doctor and she informed me that he had been discharged that morning… I asked what type of accommodation had been organised and she brightly said "Oh, he organised it himself which is wonderful because it shows that his organisational skills are returning." I asked whether the accommodation he had organised was furnished as I was storing his belongings. She said "I can't possibly tell you anything about his accommodation, you will have to contact his case manager and he will let you know what and if anything is required." It was dark by 5:30 that afternoon and at 6 o'clock there was a knock on my front door. It was my son. At first I was alarmed because I thought he was there for a confrontation as has happened before. He had a very bad head cold, was cold, wet, exhausted and looked absolutely dreadful. He said "Mum, can I come home for a couple of nights, I've been driving around since early this morning trying to get into a caravan park?"*
>
> (Carer, Mother, Victoria, Submission #178)

> *Each time I have been hospitalised "no" follow-ups have occurred. You have to wait until you can "acquire" an appointment at the clinic. This can be 2-4 weeks later.*
>
> (Consumer, Victoria, Submission #112)

6.2.12 STORIES OF HOMICIDE AND SUICIDE IN VICTORIA

…several members of my suicide support group are convinced that the suicide wouldn't have happened if they'd been listened to, contacted, if there'd been adequate funding for emergency beds.

(Carer, Mother, Victoria, Submission #211)

My sister [X] was diagnosed with Bi-polar Disorder after the death of our father. Just in January this year my sister tried to take her own life. The system does not take people unless they are really in crisis. My sister was turned away from care when she really needed it. My sister came to my place for help and I told her and the service that if anything happened to her I would hold the service responsible. She was then admitted. After [X] came home from hospital she was working at the local school helping kids to read. She came to our place and she kept telling us that she didn't feel well. She took her life in June and I found her dead at home. The really sad thing is that people like my sister feel they are a burden on their families. There needs to be a place where they can go when they become unwell where they can get the care they need and the support they need. It's too late to wait until she is in a crisis for the system to respond to her – it's too late then! The support services that are in the community don't get the necessary increases in funding they need so they can't respond appropriately either.

(Carer, Victoria, Melbourne Forum #16)

My sister had suffered with bi polar disorder for 30 years… Sadly she took her life on 18th June 2004. On that day I was going to take her shopping but she didn't feel well. She said to me what about Psychiatric Services. But she always presented so well when they interviewed her that I knew they wouldn't take her in, so I took her home. She said she felt better just talking to me on the way over to our place. And many times over the years I would bring her home for a few days or a week to help her get over her depression. The next day I was going to be home at 2:00pm from work. That morning she took her life. What a waste of life. If only the system had a more open door policy. I wouldn't feel so guilty for leaving her that day.

(Carer, Sister, Victoria, Submission #286)

I believe my daughter killed herself two years ago while an involuntary patient at the Alfred Hospital Melbourne. I believe that there were grave breaches of duty if care at that place and that her human rights were abused because the clinicians ignored me, the one person she told her deepest fears to. 15 March, 2002. She said [X] was being sent out on unaccompanied leave that night. When asked had she read my letter, she said "yes" and made no further comment. I told her, at some length, that [X] was acutely paranoid and believed that stalkers were at her flat. She listened, made no reply, and noted these serious matters in the file as 'allowed to ventilate'… When asked six weeks later if she had informed Dr [Y] of my fears and [X]'s paranoia, [she] said no. I called the ward at 2pm to say that [X] might kill herself if sent out without me. [X] was sent out. We stayed in contact by phone. She got though Friday night. 16 March. We were in contact by phone. [X] was not happy, but said she would stay. We spoke last at 8.30pm. At 11pm [X] jumped in front of a train and was killed instantly.

(Carer, Mother, Victoria, Submission #206)

I have experienced the mental health care system indirectly. A family member had ill mental health. The family were desperate to get help as protection of the family members safety was beyond our reach. The treatment resulted in suicide. The suicide occurred at the institute where mental health care was being given. The patient went to the institute asking for help. They had been having counselling months prior. The counselling was due to end and the patient was not stable to be ending but the program did not allow for this so arrangements were to be made to continue but with different Dr's. This was like starting again for the patient. The patient returned home. Evident to the staff that the patient had suggested suicide. The patient returned home and attempted suicide. From here the patient returned now to the hospital of the institute. The event at home was on a Sunday. The patient remained in care at a local hospital until transfer could be given on the Tuesday. The patient took their life on the Friday.

(Family member, Victoria, Submission #170)

12 months ago I buried my partner after he successfully suicided. He had received treatment from this service, and received ECT therapy. He was also a private patient of the psychiatrist in Shepparton. He took him off his medication, just after the treatment finished. In another couple of weeks he had completed suicide.

(Carer, Partner, Victoria, Submission #127)

[Y] died … apparently driven to suicide after living with her husband who was diagnosed with bipolar disorder. He was often non-compliant and when not taking his medication, threatened to kill her and [their child] if she tried to leave him. She could not get adequate support from Psych services or obtain emergency housing so that she could be safe to leave.

(Anonymous, Victoria, Submission # 306)

His family, who all work, and his doctor, were effectively excluded. When we asked about making arrangements for supported accommodation, in preparation for his discharge, we were told "There will be another meeting later. There will be plenty of time before it's needed." There was no such meeting. … [X]'s doctor & family ignored. Worse, we were not informed that his bupromorphin had been stopped. It had been prescribed to protect him from heroin. The meeting that we were told would be arranged did not happen. Just a phone call during dinner one night, to say he was being released into the care of the girl who'd been visiting him. No time was allowed to make plans for supported accommodation, of which we'd found three. [X] had already indicated earlier, he was interested in going back to the Arc House. [X] was released just before the Easter break, into the care of the person who he said had "latched" onto him. No urine tests were done to establish his status as an addict, even though on the phone I was told they would do this. I had requested it. He came to me, desperate to get back onto the bupromorphin. He was in withdrawal. I phoned Dr. [Z], who was going on holidays, but said he'd wait for us. He was extremely angry at the hospital! [X] told him he'd been using while in the hospital. He said he'd been set back 8 years. Dealers had got to him in the psych ward. That was the last time I saw my son. … He was found dead ten days later.

(Carer, Mother, Victoria, Submission #353)

6.3 QUEENSLAND

ANALYSIS OF SUBMISSIONS AND CONSULTATIONS FROM QUEENSLAND AGAINST THE NATIONAL STANDARDS FOR MENTAL HEALTH SERVICES

In summary, information presented in this section was gathered from 47 submissions (see Appendix 8.3.3) and presentations made at community forums attended by approximately 110 people (see Appendix 8.1). A draft copy of this report was sent to the Premier and Minister for Health for comment. An analysis of the response from the Queensland Government (reproduced in Appendix 8.4.3) and an overall review of mental health service delivery in Queensland is contained in Part 2.7.3.

6.3.1 STANDARD 1: RIGHTS

The rights of people affected by mental disorders and/or mental health problems are upheld by the MHS.

> *Human rights in regional and especially remote areas, are often infringed upon, because of lack of resources and very poor (if any) government funding. In fact in many areas services are being drastically reduced because of dramatic cuts in both Federal and State funding.*
>
> (Consumer Advocate, Queensland, Submission #16)

Under this Standard, submissions and presentations indicate concerns about:

- people with mental illness not being informed of their rights and advocates not sufficiently trained and resourced to protect their rights;
- lack of respect for patient dignity and the right to the least restrictive form of treatment;
- access to advocates and support people not being actively promoted;
- protocols not being followed to protect the rights of people with mental illness in the criminal justice system; and
- problems with the current complaints process and requests to various organisations to assist with the protection of rights of people with mental illness.

6.3.1.1 People with mental illness not being informed of their rights and advocates not sufficiently trained and resourced to protect their rights

Reports were received that raise many concerns about the protection of rights of people with mental illness. In particular, it appears that some people are not being provided with a written and verbal statement of their rights and responsibilities as soon as possible after entering the Mental Health Service (Standard 1.2) in a manner that is understandable (Standard 1.3). Also, concern was expressed by one consumer advocate that even if people are aware of their right to have an independent advocate at any time during their involvement with the Mental Health Service (Standard 1.6), many advocates are not sufficiently trained or resourced to carry out this function.

> *Here in Queensland there is no booklet, as in other states to inform people of their legal rights and worse still, there are very few advocates or consultants to ensure people are aware of their rights. Also many of the advocates and consultants are under trained and under resourced. Further infringing upon the rights and well being of the mentally ill.*
>
> (Consumer Advocate, Queensland, Submission #16)

*[The following are what I put as necessary] Patients to be provided at the earliest time with a list of their rights and **all** avenues of complaint. (author's emphasis)*

(Carer, Father, Queensland, Submission #141)

6.3.1.2 Lack of respect for patient dignity and the right to the least restrictive form of treatment

Concern was expressed about practices involving degrading treatment during their involvement with the MHS. The practices referred to in the following quote indicate that relevant legislation, regulations and instruments protecting the rights of people with mental illness or mental health problems are not being complied with in all cases (Standard 1.1).

I have a friend in Queensland who has been diagnosed with Borderline Personality Disorder. Recently when she was in hospital she lacerated her vagina. Staff made her publicly take off her clothes and, nude, explain what she had done in a room full of staff at changeover. This sort of treatment is more than disrespectful. It is cruel and barbaric.

(Consumer, Australian Capital Territory, Submission #287)

Concern was also expressed that about occasions when an inability of people with mental illness to access treatment and support services when necessary resulted in their declining health and entry into the criminal justice system. The provision of treatment and support in prison is not in the least restrictive environment or support which imposes the least personal restriction of rights, and is clearly not the optimal environment for mental health care.

Prison is an expensive housing option for the mentally ill: it is also a grave abuse of their human rights.

(Anonymous, Queensland, Submission #67)

6.3.1.3 Protocols not followed to protect rights of people with mental illness in criminal justice system

According to Standard 1.1: 'Staff of the MHS comply with relevant legislation, regulations and instruments protecting the rights of people affected by mental disorders and/or mental health problems'. This includes a variety of legislation and departmental codes of conduct. One carer in particular expressed concern about the way her son was treated and the lack of dignity accorded to him and that protocols were not followed:

My beef is with the police – it was reported that he had a mental illness and the police threw him in the cell with nothing, not a bucket to pee in or anything. He told them he had a mental illness and they didn't follow the protocol.

(Carer, Mother, Queensland, Rockhampton Forum #9)

The police soon phoned and told me of this and that the Government Medical officer would be seeing my son soon. This was now Sunday. Sometime during that day a decision was made not to call in the GMO and that only Blue Care nurses would attend to my son's head injury. My son's case manager was actually on call that day at Mental Health and I phoned her. She said nothing could be done by them to help my son unless the GMO requested that they attend my son. As the GMO was never called in there was no way my son could get help from Mental Health! Basic rights denied! No amount of pleading on my part changed this. No attempt was made by Mental Health at any time he was in the watchhouse to get help for my son. (It is a case of 'who you are and what you are' in this town as to whether 'strings are pulled' on your behalf or not). …I believe that Mental Health, the law and the judiciary all have let my son down when he needs care!

(Carer, Wife and Mother, Queensland, Submission #52)

Corrections staff encourage a culture of violence. Prisoners who ask for protection are sneered at. If they resort to fighting, they are treated with 'respect'. People with damaged brains are being rewarded for solving difficult problems with their fists, so that their integration into community is further compromised. A policy that provides for a parallel justice system for vulnerable people would alleviate much unnecessary suffering…

(Anonymous, Queensland, Submission #67)

6.3.1.4 Access to advocates and support people not promoted

Concerns were also raised that the rules and procedures to ensure a fair hearing of a person with mental illness before the Mental Health Review Tribunal are not being fully implemented. Standard 1.6 states that: 'Independent advocacy services and support persons are actively promoted by the MHS and consumers are made aware of their right to have an independent advocate or support person with them at any time during the their involvement with the MHS'. The fact that people are appearing without an advocate or support person could also imply that they are not receiving written or verbal information about their rights in a way that is understandable to them and their carers (Standard 1.3).

When I sit on the [Mental Health Review] tribunal it distresses me the lack of support that patients have. I leave feeling that natural justice has not been done.

(Consumer, Queensland, Brisbane Forum #12)

6.3.1.5 Complaints process and requests to assist with rights protection – all of no help!

A number of carers also expressed concerns that complaints procedures were not easily accessed, responsive or fair (Standard 1.10). Carers who had followed the procedures felt that justice had not been done and that they were given inadequate responses. Carers felt that many statutory bodies and processes designed to assist with the protection of rights of people with mental illness had also been unable to assist them when necessary.

…daughter-in-law who was seriously mentally ill but had difficulty accessing care. She attempted to jump off a moving ferry, she said the voices told her to jump off. She was finally transported to hospital at 10am and assessed by the mental health assessment team. She was then sent home in a taxi and murdered her nephew. [Y], Acting Director met with the family – no answers. The Queensland Health Minister said she was satisfied that the responses had been adequate. But she had previously murdered her own child first and was hospitalised and then released…Inadequate sets of responses.

(Family Member, Queensland, Rockhampton Forum #2)

The CJC [Criminal Justice Commission] found 'no serious acts of misconduct occurred' but some police officers were reprimanded as a result…

(Carer, Wife and Mother, Queensland, Submission #52)

I also feel Human Rights Commission let me down early in the piece as when I contacted them for help I was told because another Commission was already involved they could not be involved as well. The following year I was told this was not so.

(Carer, Wife and Mother, Queensland, Submission #52)

In mid-2000 I attended a cabinet meeting and presented my son's story at a round-table conference involving the Minister for Police, Police Commissioner and his Deputy. The outcome was that complaints regarding watchhouse matter should be made within (I think) 24 hours! So much for justice…

(Carer, Wife and Mother, Queensland, Submission #52)

My son was in an extremely agitated state and when I spoke to an officer regarding his need to see a doctor he just said 'he'll be right'. The next day he appeared in court still in an agitated state, still in his blood-stained clothes and because he was regarded a danger to himself and others he was remanded to Etna Creek for 6 weeks! In those ensuing 6 weeks I spoke to people from the Criminal Justice Commission, Health Rights Commission, Members of Parliament, the director of Mental Health, Legal Aid and eventually the Human Rights Commission and Anti-Discrimination. No-one it seemed could help my son!

(Carer, Wife and Mother, Queensland, Submission #52)

Most members of our group have experienced similar problems to many I have experienced and included in this submission, but they are reluctant to speak out publicly. Any complaints made via the appropriate channels within the service about the unit have, to date, only been 'turned around' making it seem like the carer / consumer is actually at fault.

(Carer, Wife and Mother, Queensland, Submission #52)

[X] reported to staff 28th September 2002 that unwelcome sexual contact had occurred with a male patient. Staff ignored this report preferring to regard it as delusional behaviour…[Y] and the family tried unsuccessfully on many occasions to arrange family meetings to discuss with staff [X]'s best care…On 16th October 2002, [Y] phoned the hospital asking to be put in contact with an appropriate person to express his concerns about [X]'s welfare. His call was put through to Acting Team Leader, [Z] who took the complaint and promised to investigate and call back. Even though staff had known since 28th September no return call was made to [Y]. At no time has any officer for Queensland Health advised the proper complaints procedures to be followed or indeed that the process followed was incomplete…Our situation is so frustrating that it makes it difficult for me to focus properly. One of the reasons was that we had just received notification from Audit and Operational Review of Queensland Health that there was to be no proper examination of our concerns and we were dismissed as it were. Tends to make it tough. Because nobody tells you how these things work and what the tactics are, the enemy is always several moves ahead. And believe me enemy is the right word. There is no negotiation and the complainant is the problem never anything else.

(Carer, Husband, Queensland, Submission #124)

Six years ago my husband took his own life after being released from Brisbane Hospital when staff knew that the previous evening he had attempted suicide. I could get no support or answers for his four children - even after writing to the Brisbane hospital ombudsman, the Brisbane Police, the coroner's office for an autopsy report. I engaged a lawyer…to no avail. I dropped the search for answers when the lawyer told me it was too hard. For years my children and I have had to carry the weight of their father's suicide with the only answer being that it was sad but too bad, there was nothing anyone could do. Well the Sunday program has raised all my angry again at the indifference of the Medical community of Queensland at the time and I still want answers for my children as to why the system failed their father.

(Carer, Wife, Queensland Submission #85)

Particularly sickening is the patient review / complaints system, where in Queensland "trust me Beattie" and AWU country, the various bodies act to justify and protect the inhuman treatment, creating huge backlogs to justify their continuing existence.

(Carer, Father, Queensland, Submission #141)

The large number of concerns raised about the rights of people with mental illness and mental health problems, as evidenced through the forums and submissions documented here and other advocacy agencies, is sufficient for a worker at the Office of the Public Advocate to support a larger inquiry.

We are charged with providing support to people with psychiatric disability – I would strongly support a much broader inquiry.

(Office of the Public Advocate worker, Queensland, Brisbane Forum #14)

A carer suggested that official visitors should be appointed to carry out random visits to ensure that the rights of people with mental illness are being protected at all times.

> *"Official visitors" to have widespread appointment support, to have access to all facilities at all hours with no notice given and no set routine. To see patients on request as well as inspections.*
>
> (Carer, Father, Queensland, Submission #141)

6.3.2 STANDARD 2: SAFETY

The activities and environment of the MHS are safe for consumers, carers, families, staff and the community.

> *Public safety must be paramount. In this case the assessing clinicians completely and totally ignored the wider public safety concerns to the patient to his family and to the wider public.*
>
> (White Wreath Association Inc, Queensland, Submission #81)

Under this Standard, submissions and presentations indicate concerns about:

- inadequate treatment and support services to ensure the safety of consumers, carers and the community; and
- safety not ensured in hospital environments.

6.3.2.1 Inadequate treatment and support services to ensure the safety of consumers, carers and the community

> *The only way the people I have mentioned will receive help is if they harm themselves severely or someone else which is more than likely and why should carers have to wait for such a result.*
>
> (Carer, Queensland, Submission #109)

As documented elsewhere in this Report, consumers and carers also raised concerns about their inability to access to treatment and support services during times of crisis (particularly when a threat to self or others or immediately after a suicide attempt).

> *[X] was on medication and her father apparently had been going to the [Rockhampton Mental Health] Unit advising them of the changes in [X] but they (M.H.U) ignored her father's concerns. On [date] 2003 [X] went to the mental health unit seeking help as she was hearing voices. They turned her away (this has been confirmed by the Rockhampton Police). Approximately 4pm on [date] 2003 [X] (after returning home) stabbed her nephew [Z] aged 3 yrs 11 months approximately 6 times in the chest (I have since been advised [X] did exactly the same thing to [X] as she did to her own child 5 years ago). [Z] died not long after…1. We are looking for answer as to why the M.H. Unit turned [X] away from help on a public holiday. 2. Ignored [father's] pleas that he knew ([X] was living with him) there was something wrong with [X]…4. Why was [X] discharged from the John Oxley Centre against her father's wishes into the care of the Rockhampton M.H.Unit. Some one has a lot to answer for after [X]'s unnecessary murder.*
>
> (Family Member, Queensland, Submission #43)

Two consumers died at Xmas one who self harmed and took it too far – we referred him to the service as he was very distressed and out of control he was assessed by a case manager as ok but died within the following week; The second went to the service begging to go into the unit as he knew that when he got this depressed he was at risk – this was our experience in the past and he was hospitalised and kept safe; they refused on this occasion – he took his own life a couple of days later.

(Anonymous, Queensland, Submission #113)

I believe if I were to have had counseling from the mental health team at Rockhampton when I required it I would not had had slapped the lady and would not have a criminal record now.

(Consumer, Queensland, Submission #192)

Concern was also expressed about the lack of follow-up and support services to ensure the safety of family members, service providers and the community.

More than half of the time within 48 hours, to a week, of her release we would be back at the emergency room when the medication had worn off and the delusions had returned full force and often she had lashed out at myself or my grandparents. … We do understand that my mother makes it terribly difficult for the mental nurse to give her her medication, but still it happens all too often; when she will go without medication for a period of 2 weeks or longer. We are not only concerned for her, but for others whom she may come across when she is in an agitated state.

(Anonymous, Queensland, Submission #82)

As far as I can assess, community safety has been ignored. There is a high probability of antisocial behaviour and crime. There is no support or buddy system. Personnel at halfway facilities have not training in mental health issues. During their prison stay, offenders are encouraged to undertake rehabilitation courses such as substance abuse and substance abuse relapse programs. However once out of the predictable and structured institutional environment and experiencing high anxiety and with no community support network...if they get the offer of a quick fix from a drug dealer, it is not surprising that they would accept. Moreover, dealers hang around halfway facilities and prey on anyone who looks vulnerable: it is a system designed for failure.

(Anonymous, Queensland, Submission #67)

My brother has had so many hospital experiences where he should have been assessed and put into the mental illness acute care unit to stay. But never was. He has hung himself (survived) got cut down by his girlfriend at the time. He has drinking problem from using it for so long to cope. He has a self mutilation problem. He cuts himself with knives, stanley knives, any sharp instrument really. I have myself even taken him to the hospital and they have sent him home with me saying he's not a harm to himself. He has so many cuts over his body I've lost count. I mean cuts that have needed stitches. His last episode was only 2 weeks ago. He stabbed himself in the chest and ran the knife down to his stomach (20 stitches) on the outside and was lucky to have not hit any heart, bowel, major artery at all. Lost a lot of blood and pushed the knife in so deep is went through his breast bone. It was quite horrific. Once again he was sent home to us. Friday 3am in the morning this accident occurred. He was home Sunday morning with us. I am just so stunned that they think he is safe to be home when he can do such horrific things to himself. As our family we can't tie him down, we have to watch him 24 hours around the clock. If he disappears and goes drinking which he did one day later it is just so frustrating, tiring, and sad that there is no help. I thought he would get assessed by a psychiatrist at least and maybe had to stay in for so many days to be monitored. But no…Sorry to have prattled on. What can I do - to help to fight for more funding - more help - more support.

(Carer, sister, Queensland, Submission #159)

My dearly missed mother struggled with her demons over a period of four to five months. In this time she attempted suicide on four occasions. It seemed that my mother's case was put into the ("too hard") basket and she was thrown on the scrap heap. We the family were left to figure it out in many ways on our own, and been sent back home to be shared among the family to help care for her and keep watch on twenty four (24) hours a day, seven days a week…At this stage of my wonderful mother's sad story, it was having a huge affect on the whole family. The answer to my question to the doctor about how many attempts would be enough. Apparently the answer to that question as found out was five. Because on the fifth occasion, at approximately 1:30pm on the 15th October 2003, my mum decided to douse herself in petrol and set herself alight.

(Carer, Son, Queensland, Submission #184)

6.3.2.2 Safety not ensured in hospital environments

Concern was expressed that policies and procedures are not offering sufficient protection for consumers to feel safe in hospital settings. Standard 2.2 states: 'Treatment and support offered by the MHS ensure that the consumer is protected from abuse and exploitation'. The notes to Standard 2.2 state that safety is 'considered in terms of physical, social, psychological and cultural dimensions'. Standard 2.3 further states: 'Policies, procedures and resources are available to promote the safety of consumers, carers, staff and the community'.

In my last admission (one year ago) to a public hospital I was assaulted and many of my things were stolen and some jewellery was flushed down the toilet. I do not blame the other patient because she was very unwell but I expect to be safe when I get admitted to hospital…

(Consumer, Queensland, Submission #204)

A few years ago a friend suffering from major depression and a high suicide risk was hospitalised in a large public hospital. The environment was appalling – there was no comfortable or safe place to meet and visit with patients and we were forced to sit outside in the car park so she could have a smoke, this was also to escape from the bizarre behaviour of other patients, which was disturbing and frightening to my friend She witnessed patients being assaulted by fellow patients (with no provocation on her part, one woman had a scalding cup of coffee thrown into her face by a male inpatient), had some possessions were stolen, was fearful of other patients and their behaviour and was mostly left unsupervised despite being a high suicide risk. I regularly witnessed patients absconding from the unit and also saw them at the nearby shopping centre, which was accessed by a very busy main road. Patients with quite bizarre behaviour were with patients with less confronting behaviours and this was frightening to those patients and also their relatives and friends. It was certainly no place to being to heal and the whole situation was quite traumatic for her as well as her friends and relatives. Upon her eventual discharge she was forced to wait for up to 6 weeks for a follow up psychiatric appointment. Luckily she had a wonderful GP.

(Clinician, Queensland, Submission #105)

It is likely that aggression to staff and financial risks from adverse events relating to the management of dementia and delirium in hospitals are rising. These issues deserve further attention.

(Clinician, Queensland, Submission #140)

Concern was also expressed by one carer that the consequence of a lack of appropriate safety procedures is increased police intervention:

I don't know how many times I had to get the police because he had absconded from hospital.

(Carer, Mother, Queensland, Submission #168)

6.3.3 STANDARD 3: CONSUMER AND CARER PARTICIPATION

Consumers and carers are involved in the planning, implementation and evaluation of the MHS.

No submissions or comments were received pertaining to this Standard.

6.3.4 STANDARD 4: PROMOTING COMMUNITY ACCEPTANCE

The MHS promotes community acceptance and the reduction of stigma for people affected by mental disorders and/or mental health problems.

> *My son had schizophrenia and he's now dead as well - he committed suicide. The community didn't understand and when people found out he had a mental illness they dropped him like a hot potato.*
>
> (Carer, Mother, Queensland, Rockhampton Forum #9)

Under this Standard, submissions and presentations indicate concerns about:

- high levels of stigma and discrimination;
- social isolation experienced by consumers and members of their family;
- discrimination in employment settings;
- discrimination by real estate agents;
- stigma and stereotypes being perpetuated by the media; and
- the impact of insufficient community education and lack of access to services on stigma.

> *My daughter has bipolar disorder…My daughter has been able to return to teaching. But the point I want to make is that we still need to do a lot to educate the community.*
>
> (Carer, Mother, Queensland, Rockhampton Forum #12)

6.3.4.1 High levels of stigma and discrimination

Standard 4.1 states that activities are to be designed by the MHS which 'promote acceptance of 'people with mental disorders and/or mental health problems by reducing stigma in the community'. According to many reports received from consumers, carers and clinicians the level of stigma and discrimination being experienced across the State and across settings (e.g. in the community, in the workplace, with real estate agents and via the media in general) is still very high. Such discrimination is one of the key barriers to the realisation of the social, economic and political rights of people with mental illness.

> *People with a mental illness are treated like the 'untouchables' in India. …carers are unpaid slaves and carers are also untouchables.*
>
> (Anonymous, Queensland, Rockhampton Forum #8)

> *There is an extraordinary amount of discrimination against people with a mental illness.*
>
> (Clinician, Queensland, Brisbane Forum #7)

For those left behind by these tragedies the hurt is no less traumatic and yet society's response to these surviving families and friends is vastly different from the help offered in other kinds of medical and social tragedies. It seems that no one cares or understands that the families and friends of suicide victims are in as much need of help and support as other members of our Australian society and are just as deserving of our understanding and respect. We have been creating - in the wider community - awareness of the misunderstandings relating to mental illness and providing community education concerning the lack of appropriate treatment.

(White Wreath Association Inc, Queensland, Submission #81)

Community attitudes need to change, to move away from a fear of 'madness' and accept that mental illness is a common and serious condition, which has the capacity to ruin many lives if unacknowledged and untreated.

(Carer, Wife and Mother, Queensland, Submission #157)

Furthermore, the mental health system appears to have failed families and their unwell relatives despite the rhetoric of responsive care and support. It shows little evidence of any commitment to useful change or of meeting the real needs of vulnerable clients and their concerned family members. Public education is imperative in bringing the illness out into the open and in stopping people suffering in silence. Thankfully, out of negative experiences, many positive, personally fulfilling experiences validate families' sacrifices.

(Carer, Wife and Mother, Queensland, Submission #157)

One carer expressed concern about the number of people with mental illness who do not acknowledge that they have an illness and that is probably due to the stigma associated with mental illness.

…the stats show that more than 50% of people with a mental illness don't acknowledge they have an illness. This community is a small community and there are tensions – we need to change but if its going to happen / change then we need to educate and address stigma – get a hold of the National Mental Health Plan. We must call on the community for understanding and action to improve the system.

(Carer, Queensland, Rockhampton Forum #14)

6.3.4.2 Social isolation experienced by consumers and members of their family

Not surprisingly, given the reports of the high levels of stigma and discrimination being experienced by consumers in Queensland, people with mental illness and mental health problems will be unlikely to share their stories or seek support from those in the community, or even close family and friends. Reports were received from carers describing feelings of social isolation and being unable to turn to anyone for assistance or support.

Mental illness is a 'hidden' disability for families who are labelled and marginalised along with their unwell relative. Their predominant theme is loss - of the 'well' relative, a lifestyle, a rightful place in their community and their identity as spouse, parent, child or sibling. They become carers, not by choice, but through love and obligation.

(Carer, Wife and Mother, Queensland, Submission #157)

He somehow got out of the hospital and went home to try and commit suicide. He wrapped wire around his neck and thumbs and then put the wire in the electrical socket in his bedroom. He didn't die. He somehow got a taxi back to the hospital and they had to amputate both thumbs… We are not to tell outsiders of the way in which my uncle lost his thumbs. He didn't want to go out or do anything because people would ask him how this happened. I believe he tells them that he was in an accident. So, you will never get a true record of how many people depression is affecting whilst people won't tell the whole story.

(Consumer and Family Member, Queensland, Submission #94)

Neither my son nor I could turn for help, as no one was interested in helping us. ***I was afraid and afraid for my son.*** *We were* ***alone, inexperienced*** *and* ***left to cope the best way we could*** *with our son's condition. My family and I were treading thin ice constantly as we thought what ever we said or did would aggravate our son's problem. I NOW KNOW BETTER THAT THIS WAS NOT THE CASE. All of this was extremely hard to cope with and the worst part was we* ***had to do this in silence.*** *(author's emphasis)*

(Carer, Mother, Queensland, Submission #81)

[X] finally lost all hope and on the 29th of May 1999 he laid himself on a train track. … Because of the myths and stigma associated with mental illness his condition became worse. He had nobody to turn to about his problem, as mental illness is something that is not discussed in our society. I also did not have anyone to turn to. It was like something very shameful had hit our family.

(Carer, Mother, Queensland, Submission #81)

6.3.4.3 Discrimination in employment settings

Many reports were received describing various barriers for people with mental illness to participating successfully in the workplace. These included problems with application forms, disclosure during the application process, lack of support when employed and termination as a result of mental illness. Many of these problems could be addressed by activities associated with Standard 4.2: 'The MHS provides understandable information to mainstream workers and the defined community about mental disorders and mental health problems'. Employment and support in the workplace by co-workers are seen as critical in the rehabilitation phase and successful reintegration into society at a social and financial level.

I feel lucky that I only have clinical depression. At least I can go to work and lead a relatively "normal" life. I know of a lot of people who can't. I know people who have never been able to go back to work after a major depressive episode and I am sure there are a lot of people in our community who have never been diagnosed with depression.

(Consumer and Family Member, Queensland, Submission #94)

A cousin who worked for the blue nurses in NSW was looking for work. She couldn't get work any more because of her mental illness she ended up killing herself.

(Anonymous, Queensland, Rockhampton Forum #5)

It is very difficult for people with a mental illness to get reemployment – if we have been sick and we have had a period away from work then we end up with a 6-month gap in our resume – how do we explain that when we know that if we mention we have a mental illness then we won't get a job?

(Consumer, Queensland, Brisbane Forum #11)

…issues that are regularly presented to our offices…Job application forms with questions regarding "Have you ever had a mental illness?".

(Office of the Public Advocate worker, Queensland, Brisbane Forum #14)

I can provide examples of people who have been rejected for employment based on the fact that they have a mental illness. I have a friend who was told by her psychiatrist not to mention that she has a mental illness.

(Anonymous, Queensland, Brisbane Forum #15)

I also have a lot of contact with people who have had bad workplace and insurance issues – people who have been working and then need time off work and try to get income support have great difficulty. I also have many clients who have had depression and have lost their jobs because of their illness.

(Clinician, Queensland, Brisbane Forum #20)

Employment discrimination – what to tell interviewing panel about one's mental illness – do you have to disclose?

(Anonymous, Queensland, Submission #49)

…disabled adults received less income that the non-disabled in all the selected countries, but whereas the 16-nation mean was to receive 80% of the non-disabled income, in Australia the figure is only 44%. This puts Australia a long way behind even the second-last place getter the United States (59%), and more than 30 percentage points lower than nearly all the other countries…{from "Inequality And Social Welfare, Ross Gittons (ed), page 153; personal income of disabled persons aged 20-64 as % of that of non-disabled people, late 1990s)]

(Anonymous, Queensland, Submission #49)

A female client hospitalised with major depressive episode and a high suicide risk took sick leave from her job, only to be eventually fired due to her illness. This occurred despite the fact that she was planning on returning to work and was progressing well. She later returned to work with another company (she didn't disclose her history).

(Clinician, Queensland, Submission #105)

I advise clients not to disclose to their employer if they currently have or have had depression or any other mental health condition, as ignorance and stigma remain high in the general community and they are likely to be penalised for their honesty.

(Clinician, Queensland, Submission #105)

I became the target of persistent, malicious rumours about symptoms of my illness. I attempted to address this informally to protect the reputation of some colleagues but was unsuccessful. One day I overheard a senior officer perpetuating this behaviour (some seven months after the allegations began)… What helped me in reclaiming my life - I had an overwhelming desire to regain my pre-illness self (I maintained working with the help of supportive supervisors).

(Consumer, Queensland, Submission #313)

6.3.4.4 Discrimination by real estate agents

One consumer also reported being discriminated against when looking for rental accommodation.

Housing difficulty – if you present to a real estate agency and declare that you are on a disability support pension you aren't assisted – you'll be rejected!

(Consumer, Queensland, Brisbane Forum #11)

6.3.4.5 Stigma and stereotypes perpetuated by the media

How do we get through to the media the need for them to portray fair and true descriptions of people with a mental illness and not contribute to perpetuating stigma?

(Consumer, Queensland, Brisbane Forum #11)

From concerns raised primarily at the consultation forums in Brisbane and Rockhampton, it appears that any activities by the MHS to reduce stigma in the community must also address education of media personnel to modify their portrayal of people with mental illness and comparative references.

There is a lot of discrimination about mental illness in the media and reporting of crime. Data in media is often incorrect.

(Anonymous, Queensland, Brisbane Forum #16)

I'm from the bush and I have bipolar disorder. I agree with the previous speaker that there are many shocking articles in the media that shape the community's attitudes. Stigma is the biggest thing to fight.

(Consumer, Queensland, Brisbane Forum #12)

I head about something on radio national this morning. Someone referred to Mark Latham as needing medication and nurse ratchet. They said the Labor Party has to put him on medication. They were suggesting he had a mental illness and they obviously thought it was okay to make fun of this. That people with a mental illness shouldn't be offended somehow.

(Consumer, Queensland, Brisbane Forum #11)

Politicians and many journalists are contributing to the stigma we experience. It seems to me that rather than improving the use of discriminatory language over the years has gotten worse. It's not as if some politicians don't have real mental illnesses, they do. Some have even attempted to kill themselves.

(Consumer, Queensland, Brisbane Forum #11)

Stigma – how do we get a fair and true description of mental illness in to the media?

(Anonymous, Queensland, Submission #49)

…was seriously mentally ill but had difficulty accessing care. She attempted to jump off a moving ferry, she said the voices told her to jump off. She was finally transported to hospital at 10am and assessed by the mental health assessment team. She was then sent home in a taxi and murdered her nephew…Current Affair did a story on incident – no permission to televise. Media portrayal of these issues.

(Family Member, Queensland, Rockhampton Forum #2)

Depiction of personality disorders (and specifically Borderline Personality Disorder) is rare in the propaganda that is being churned out by government agencies and organisations like SANE. This is despite the growth in community education about mental illness since the original Human Rights and Mental Illness Report was published early in the 1990s. In the few places where people who have been diagnosed with Borderline are included the descriptions are unfair, unflattering, sometimes wrong and judgemental.

(Consumer, Queensland, Submission #204)

6.3.4.6 Impact of insufficient community education and lack of access to services on stigma

Coupled with insufficient community education, the fact that consumers can only access services when they are in crisis reportedly makes it extremely difficult for consumers to be accepted into the community and to overcome the community's stigmatising attitudes and negative perceptions about mental illness. The following quote demonstrates the variability in behaviour according to mental state and the impact this has on behaviour while living in the community:

I don't know how many times I had to get the police because he had absconded from hospital. If these poor patients were kept locked up and treated aggressively when they first get to hospital, it would be better for everyone concerned, most of all the patients. My son is a very nice person and upstanding citizen when well, but does some terrible things when he is ill …

(Carer, Mother, Queensland, Submission #168)

6.3.5 STANDARD 5: PRIVACY AND CONFIDENTIALITY

The MHS ensures the privacy and confidentiality of consumers and carers.

Under this Standard, submissions and presentations indicate concerns regarding confidentiality.

6.3.5.1 Confidentiality

> *But no-one from Mental Health would speak with me on the cop-out of patient confidentiality.*
>
> (Carer, Mother, Queensland, Submission #91)

The complex task of balancing consumers' right to confidentiality and carers' right and need to access information that will assist in their caring duties remains a vexed issue. A number of carers expressed concern and frustration both with current confidentiality policies and procedures and with the perceived failure of some clinicians to engage the family as much as possible. Furthermore, these concerns could also indicate that these policies and procedures are not being made available to consumers and carers in an understandable language and format (Standard 5.2) in order for consumers and carers to understand their rights and responsibilities. Standard 5.3 states: 'The MHS encourages, and provides opportunities for, the consumer to involve others in their care'.

> *Respondent F. spoke of her husband's in-patient psychiatrist as "abrupt, arrogant…I was supposed to defer to his 'expert' knowledge". Due to privacy legislation, most respondents felt they had not been given a full description of their relative's diagnosis. Respondent C. stated, "even my family doctor would not discuss my son's condition with me… how could I continue to care for him if I did not know what to expect?" Confidentiality considerations can be an excuse for lack of family members' inclusion in care planning.*
>
> (Carer, Wife and Mother, Queensland, Submission #157)

> *We as a family were not allowed to be involved with my son's treatment* ***because of the confidentiality law.*** *The law states, that my 19-year-old son - suffering mental illness and living at home - was deemed an adult so we were excluded from his treatment. This was thrown at me –* ***his mother*** *– in every direction and I tried extremely hard trying to contact my son's Doctor's, Psychiatrist and various organisations, but to no avail. (author's emphasis)*
>
> (Carer, Mother, Queensland, Submission #81)

> *The CONFIDENTIALTY LAW needs to be amended. There is no other illness in society that the medical profession do not involve the families or carers. However once a person has been diagnosed with mental illness the confidentiality law is used and abused to the detriment of the family and carers. An example of this abuse is if a person has been diagnosed with cancer, heart attacks, diabetes etc the whole family is involved however if a person who has been diagnosed with some form of mental illness the confidentiality / privacy act comes into play. SO* ***WITH OR WITHOUT THE CONSENT of the person who has been diagnosed with mental illness we the families and carers who are the community care givers and providers MUST*** *be involved, consulted and our opinions respected in determining the health and happiness of our loved ones. Exactly in the same way other illnesses are treated. (author's emphasis)*
>
> (White Wreath Association Inc, Queensland, Submission #81)

The following case scenario was outlined by White Wreath Association to reinforce the point:

> *Phone call from a mother very concerned about her daughter [X] 25 years of age. Her daughter constantly is talking of suicide. Mother does not know what to do. Mother can't handle situation. Daughter has punched and threatened to kill her mother. Mother afraid not only for herself but also for her daughter. Mother feels helpless. Mother can't cope anymore with her daughter's abuse, mood swings and threats. Mother feels ashamed that she wishes it all would end. Mother feels isolated and alone. Mother can't find any help. No service in place to help Daughter or Mother to cope with what is happening. CONFIDENTIALITY LAW EXLUDES MOTHER TO INTERVENE OR USE HER (MOTHER) AS A KNOWLEDGE SCOURCE TO HELP HER DAUGHTER. (author's emphasis)*
> (White Wreath Association Inc, Queensland, Submission #81)

6.3.6 STANDARD 6: PREVENTION AND MENTAL HEALTH PROMOTION

The MHS works with the defined community in prevention, early detection, early intervention and mental health promotion.

Under this Standard, submissions and presentations indicated concerns about:

- the lack of focus on prevention and early intervention;
- the lack of available rehabilitation programs; and
- problems with mainstream social agencies discriminating against people with mental illness.

6.3.6.1 Lack of focus on prevention and early intervention

Concerns was expressed about the lack of a preventive focus in the delivery of mental health services, despite the emphasis of such an approach in Standards 6.4 (capacity to identify and respond to the most vulnerable consumers in the community), 6.5 (capacity to identify and respond as early as possible) and 6.6 (treatment and support to occur in a community setting in preference to an institutional setting). In particular, it was noted that the lack of a preventive focus was resulting in deteriorating illness and increased need for acute care which could not be met by the current number of beds available in inpatient settings.

> *Prevention is obviously better and cheaper than a cure, but this is not happening resulting in a lack of available beds in our psychiatric wards.*
> (Carer, Mother, Queensland, Submission #10)

SANE Australia however, noted that the Queensland Reducing Suicide Action Plan 2003 is being implemented, including projects aimed at identifying and responding to vulnerable consumers and projects which promote mental health and prevent the onset of mental disorders and/or mental health problems (Standard 6.3):

> *The Queensland Reducing Suicide Action Plan 2003 is being implemented, with staff working on education, prevention and intervention projects at a number of sites, including two indigenous projects.*
> (SANE Australia, National, Submission #302)

6.3.6.2 Lack of rehabilitation programs

> *There's a real lack of services to help people get back into society to rehabilitate.*
> (Clinician, Queensland, Brisbane Forum #7)

Rehabilitation programs are acknowledged as a critical step in the reintegration process back into full life after a period of illness and the prevention of relapse for many people with mental illness. Such programs would include living skills programs, respite and social programs.

Access to rehabilitation programs is covered under Standard 6.8: 'The MHS ensures that the consumer has access to rehabilitation programs which aim to minimise psychiatric disability and prevent relapse'. However, both a clinician and a carer expressed concerns about the lack of rehabilitation programs available to help in this regard. These programs are essential to assisting people with disability to promote and protect their social and economic participation rights as evidenced in the following report:

> *We have a son… with a mild intellectual disability…2 years of age and remained in that job for ten years feeling a 'normal' part of the community… Due to all this floundering over the past two years our son now 34 has regressed to a point where he is now in a community care unit seeming as though he has lost all hope of getting anywhere, his hygiene medication and budgeting skills at an all time low. My husband and I both 70 are no experts in mental health but feel had there been positive intervention in the beginning instead of lying about home he would be less reliant on the medical system now, plus the government spending good money into these job agencies which are totally dysfunctional.*
>
> (Carers, Parents, Queensland, Submission #150)

6.3.6.3 Social needs are not being met through the use of mainstream agencies

Standard 6.9 states: 'Wherever possible and appropriate, vocational and social needs are met through the use of mainstream agencies with support from the MHS'. Concern was expressed by Self-help Queensland that some consumers have been turned away from local neighbourhood centres on the basis that these centres can not afford the public liability insurance. Such discrimination only adds to the high levels of stigma experienced by people with mental illness and referred to previously.

> *We get a lot of requests from people who need access to self-help groups for people with a mental illness. They get turned away from neighbourhood centres. They have nowhere to go because they can't afford the public liability insurance.*
>
> (NGO worker, Queensland, Brisbane Forum #18)

One Early Intervention Project Worker in Rockhampton however reported that a large and active and positive community group exists in that area.

> *The Rockhampton community has a large and active network. It meets on a monthly basis – a good network needs to communicate with each other. They very much are working together.*
>
> (Early Intervention Worker, Queensland, Rockhampton Forum #19)

6.3.7 STANDARD 7: CULTURAL AWARENESS

The MHS delivers non-discriminatory treatment and support which are sensitive to the social and cultural values of the consumer and the consumer's family and community.

Under this Standard, a presentation at the Rockhampton forum indicated concerns about:

- social and cultural prejudice from MHS staff towards Indigenous people with mental illness; and
- the delivery of treatment which is seen as insensitive to the social and cultural needs of Indigenous people with mental illness.

6.3.7.1 Social and cultural prejudice by staff towards Indigenous people with mental illness

Concern was also expressed that discriminatory treatment is being delivered to Indigenous people with mental illness due to prejudice by some staff within the MHS. In the report presented, the result of such attitudes was to deny an Indigenous person access to treatment resulting in suicide. It is possible that improved monitoring by the MHS would assist in addressing 'issues associated with social and cultural prejudice in regard to its own staff' (Standard 7.5). This circumstance also indicates the benefit of regular cross cultural training of staff and the need for staff to have 'knowledge of the social and cultural groups represented in the defined community and an understanding of those social and historical factors relevant to their current circumstances' (Standard 7.1).

> *My son committed suicide 2 years ago. There are a lot of deaths here amongst indigenous youth. Before he killed himself my son went to the mental health unit and they told me he was suffering from behaviour problems – the perception was that because he was an indigenous young man that he was 'sloshed out'. We were told that he wasn't suicidal.*
>
> (Carer, Mother, Queensland, Rockhampton Forum #3)

6.3.7.2 Treatment to Indigenous people with mental illness is not delivered in a manner sensitive to their social and cultural needs

Evidence was presented which suggests that some mental health services have not been planned and delivered in a manner which 'considers the needs and unique factors of social and cultural groups represented in the defined community and involves these groups in the planning and implementation of services' (Standard 7.2). The following submission also specifically identified the need for cross cultural training as discussed above.

> *The other thing, I find we have indigenous persons in the mental health unit – it's not okay just to put a black face there – just to have contact with indigenous people. We need our workers to be fully trained and get off their butt and do something.*
>
> (Carer, Mother, Queensland, Rockhampton Forum #3)

> *By far and away the most prominent mental health concern facing the communities to which I travel [remote communities in Central and North West Queensland] are those of accumulated grief and loss and the intergenerational consequences of such losses. The history of colonization and cultural oppression represents over and over as symptoms of trauma, depression, drug and alcohol abuse, relationship breakdown and self harm. Tragically, the current, mental health system seems ill-equipped to deal, in culturally appropriate ways, with the complexities of Indigenous health.*
>
> (Clinician, Queensland, Submission #285)

6.3.8 STANDARD 8: INTEGRATION

6.3.8.1 Service integration

The MHS is integrated and coordinated to provide a balanced mix of services which ensure continuity of care for the consumer.

> *As a GP I have terrible trouble accessing services for people with a mental illness.*
>
> (Clinician, Queensland, Brisbane Forum #7)

Under this Standard, submissions and presentations indicate concerns about:

- components of the MHS which are unwilling to provide integrated and coordinated care;
- high staff turnover resulting in problems with continuity of care;
- the ability of general practitioners to treat people with mental illness or mental health problems; and
- difficulties accessing case managers.

6.3.8.1.1 Difficulties in organising integrated and coordinated care with components of the MHS

Clinicians raised concerns at their frustration with components of the MHS when trying to organise integrated and coordinated care for their consumers. Concerns were expressed that some clinicians were choosing only easy or 'lucrative' consumers, and thus discriminating against consumers with complex cases or who were poor. Additionally, concerns were raised regarding crisis assessment teams not appropriately assessing risk of self harm and discharging their duty of care and delivery of quality treatment.

> *One can usually find a specialist physician or surgeon to follow up difficult cases, offering whatever support they can. As a GP, I find it frustrating when psychiatrists will not do likewise. It appears that psychiatry operates in a comfort zone that conveniently defines the most troublesome and least lucrative cases as outside their concern. I often diagnose a life-threatening personality disorder but can't arrange any specialist support.*
>
> (Clinician, Queensland, Submission #42)

> *4 weeks ago a young man came to see me. He was suicidal, he had several crises in his life he was trying to deal with and he had been self-medicating. I see many people like him – they are not bad people but people who need assistance from society. I managed to get him assessed by a crisis assessment service – that in itself was a really big win! But the crisis service was going to send him home with some phone numbers. Fortunately I had organised to see him and threw a spack attack and asked them how they would feel if this young man was dead in the morning.*
>
> (Clinician, Queensland, Brisbane Forum #7)

> *[With regard to remote communities in Central and North West Queensland] Further inadequacies become evident with the local mental health system insisting that an individual must present with a clinical diagnosis in order to receive any type of service intervention. This policy flies in the face of research and the National Mental Health Strategy which emphasis the need to provide interventions early and to prevent the actual incidence of mental illness. I have personally found it very difficult to make referrals to Queensland Mental Health service due to barriers within the system. Employees within state mental health cite lack of resources and difficulties attracting staff to remote areas for their inability to accept referrals.*
>
> (Clinician, Queensland, Submission #285)

Concern was also expressed about the capacity of the sector to provide services to people with complex needs or people with dual diagnosis.

> *Collaborative service agreements between sectors that respond to the needs of people with dual diagnosis are required.*
>
> (Brain Injury Association of Queensland, Queensland, Submission #60)

These concerns would indicate that Standards 8.1.1 ('an integrated MHS is available to serve each defined community'), 8.1.3 ('There are regular meetings between staff of each of the MHS programs and sites in order to promote integration and continuity'), 8.1.5 (documented polices and procedures are used to promote continuity of care across programs, sites, other services and lifespan) and 8.1.6 (specified procedures to facilitate and review internal and external referral processes within the programs of the MHS) are not being met.

One clinician stated that many people within the health system are trying to provide integrated care to consumers in their community:

> *If someone is dealing with sexual issues they have to link with other service providers - NGOs, Anglicare, St Vincent's, Relationships Australia etc. We do try to respond to the issues in the community.*
>
> (Clinician, Queensland, Rockhampton Forum #7)

6.3.8.1.2 High staff turnover resulting in problems with continuity of care

Concerns were also expressed regarding the high staff turnover in various components of the MHS and that this impacts on the ability of the MHS to deliver continuous and integrated care.

> *…there are major problems in mental health and I would classify these into two particular areas. Firstly the mental health services are basically out-patient based services and appear to have a high turnover of professional staff resulting in poor continuity and frequent early termination of patient treatment programs. Sufferers of mental illness find it more difficult than most to adjust to continually changing professional staff.*
>
> (Dr Bruce Flegg MP, General Practitioner and Liberal Shadow Minister for Health, Queensland, Submission #39)

> *More than once the police local have said that it is not their problem and we should call her mental health worker, who is 100kms away and never able to take our call because she is so busy she is rarely in the office. More often also, the mental health worker who is in charge of my mother's care, changes twice a year, and she is periodically moved between the West End Mental Health Clinic to the one at Ashgrove (I can never remember if it is Ashmore or Ashgrove).*
>
> (Anonymous, Queensland, Submission #82)

6.3.8.1.3 General practitioners lack the skills to treat people with mental illness or mental health problems

One consumer also expressed their concern that in their experience, general practitioners do not possess the skills to treat mental illness.

> *I don't think general practice is skilled up or prepared or ready to deal with mental illness.*
>
> (Consumer, Queensland, Brisbane Forum #11)

6.3.8.1.4 Difficulties accessing case managers

Concern was expressed regarding the difficulties in accessing case managers to ensure continuity of care. Difficulties were associated with apparent changes in policies and procedures and lack of follow up. Standard 8.1.5 states: 'The MHS has documented policies and procedures which are used to promote continuity of care across programs, sites, other services and lifespan' and Standard 8.1.6 ensures that the MHS has specified procedures to facilitate and review internal and external referral processes. Standard 8.1.7 also requires that 'The MHS monitors its performance in regard to the above criteria and utilises data collected to improve performance as part of a quality improvement process'.

> *Last year Central Coast Mental Health Services discontinued the practice of assigning case managers to individual patients which means that unless an ill person calls the Central Intake number asking for help, they will see no-one. This effectively means that a consumer has to decompensate to the stage where friends & family are begging for help. Previously a good case manager, seeing the consumer on a regular basis, would be able to observe a gradual deterioration and arrest it before the consumer required hospitalisation.*
>
> (Carer, Mother, Queensland, Submission #10)

The social worker he seen on Sunday advised that someone would be visiting him. Monday Mum took him to Dr [Z] at the Canbridge Centre. Then no-one came all week. On Friday he did his cognitive therapy on Friday [sic]. He only got a case manager recently, after he [tried to] hang himself. Cognitive Therapy has just started in the last couple of weeks.

(Carer, Sister, Queensland, Submission #159)

The case manager of this person often provides education for carers and community workers around the multiple psychological issues and sometimes physical issues as well and gets a sense of what is normal for that person at their best function in their own home. They facilitate coordinated care across agencies. This integration and awareness often disappears with the withdrawal of case management when the person no longer meets criteria for the psychogeriatric service. The potential consequence is earlier admission to an acute hospital bed or residential care. Theoretically, coordination of care can be achieved by the GP. Unfortunately many older people find visiting and waiting for the GP difficult and home visiting is a vanishing component of practice.

(Clinician, Queensland, Submission #140)

6.3.8.2 Integration within the health system

The MHS develops and maintains links with other health service providers at local, state and national levels to ensure specialised coordinated care and promote community integration for people with mental disorders and / or mental health problems.

Under this Standard, submissions and presentations indicate concerns about:

- the difficulties experienced by consumers in accessing treatment for their physical heath care needs.

6.3.8.2.1 Lack of access to services to meet physical health needs

Consumers and a clinician expressed concerns about the difficulties faced by consumers in having their physical health care needs assessed and treated. Given that this report documents extensively the difficulties consumers face in accessing treatment and support for their mental illness, claims that, due to their mental illness consumers face barriers to accessing treatment and support for their physical illnesses are very concerning. This would also indicate that comprehensive health care is not being promoted for consumers (Standard 8.2.1).

In my experience doctors are very reluctant to accept that people with a mental illness have a physical illness.

(Consumer, Queensland, Brisbane Forum #17)

There's also very poor access to physical health assessments for people with a mental illness.

(Clinician, Queensland, Brisbane Forum #7)

My physical health needs are best attended to by my psychiatrist.

(Consumer, Queensland, Brisbane Forum #11)

On three occasions my son [X] has been admitted with physical problems which either had not been noted on admission or were ignored even when they had been noted. On one occasion he went three days before the symptoms were properly addressed. The end result was an emergency operation for the removal of a salivary gland with embedded calcium stones.

(Carer, Wife and Mother, Queensland, Submission #52)

…he had been assessed / worked with by CCU for 13 months… Another concern is medical attention… For instance his oral care – I doubt [X] has been to a dentist for a decade or more… I also think [X]'s hearing is suspect and if he goes to a doctor occasionally – will he personally raise the issue of hearing? – I doubt it. So things go on unchecked.

(Carers, Parents, Queensland, Submission #150)

6.3.8.3 Integration with other sectors

The MHS develops and maintains links with other sectors at local, state and national levels to ensure specialised coordinated care and promote community integration for people with mental disorders and / or mental health problems.

Under this Standard, submissions and presentations indicate concerns about:

- the lack of a whole-of-government approach to improving the quality of life of people with mental illness;
- the lack of a whole-of-government approach to improving the quality of life of Indigenous people with mental illness and mental health problems;
- children and youth in crisis and the need to integrate youth suicide prevention strategy and strategies for Indigenous youth;
- housing;
- police;
- corrective services and the criminal justice system;
- employment;
- education;
- wards of the state; and
- the lack of coordinated care across sectors for older people with mental illness.

The necessity of a whole-of-government approach to specifically care for children who have become wards of the state was also specifically raised through this consultation process.

6.3.8.3.1 Whole-of-government approach needed to improve the quality of life of people with mental illness

Many submissions and presentations noted a lack of, and expressed the need for, a whole-of-government approach to solve the complex support needs of people with mental illness and their families and carers to live in the community in a dignified manner with the opportunity to participate socially and contribute economically. As described below, problems were reported about housing, employment, education, police and the criminal justice system. Many submissions identified that a broader governmental, societal and community approach was required:

There are questions around quality of life for people.

(Consumer, Queensland, Brisbane Forum #11)

The high levels of unemployment in Rockhampton contribute to the development of mental health problems. These people keep coming back and back but you see the deterioration – no support and no families, living in hostels.

(Anonymous, Queensland, Rockhampton Forum #17)

My concern is with the criminalisation of mental illness. Some people are punished over and over again. There's no housing and support available – so people will continue to get into trouble – so what we end up with is a system where people with mental illness are being socialised in prisons, socialised into criminal activity, criminal ways, they shouldn't be there in the first place.

(NGO worker, Queensland, Brisbane Forum #4)

Our people strike chaos at 21–27 years. I feel the government is trying to dispense with them as their responsibility. There's no accountability between the states and the Federal governments about how the funding is spent or what is achieved with it.

(NGO worker, Queensland, Brisbane Forum #1)

The sector faces further difficulty with the way in which investment is divided between a 'medically focussed' health department and the 'disability focus' of Disability Services Queensland (DSQ)… Moreover, the Alliance is concerned that the types of funding models that are currently available to the non-government mental health sector through DSQ do not meet the needs of people affected by mental illness and psychiatric disability. In fact, the Alliance would argue that the funding framework could at times be detrimental to the wellbeing of this group.

(Queensland Alliance of Mental Illness and Psychiatric Disability Groups, Queensland, Submission #218)

6.3.8.3.2 Whole-of-government approach needed to improve the quality of life of Indigenous people with mental illness and mental health problems

The need for a whole-of-government approach to address the myriad of health and social problems of Indigenous people was particularly identified as critical by one clinician:

In viewing health as Indigenous people do, in holistic terms, it is impossible to overlook the enormous influence social factors have on the mental health of the people of Western Queensland. Poverty, inadequate housing and isolation rank high in the list of challenges to people's general health and well-being… Mental Health services which insist on providing individualized, clinical services cannot hope to be effective without also addressing the collective, environmental influences on mental health. As I write this I am aware that funding approval has been granted for the establishment of a Social Emotional and Well-Being Centre to be based in Mt Isa, for the purpose of providing education and support to Indigenous Health Workers. This is a hugely exciting prospect and will doubtless enhance the capacity of communities to engage early intervention strategies as well as respond to mental health emergencies. This is not a project of the local area Mental Health service, nor state government.

(Clinician, Queensland, Submission #285)

6.3.8.3.3 Children and youth in crisis – need for a whole of government approach

In particular, many submissions and presentations identified serious concerns about the paucity of services and integrated services to assist young people with mental illness or mental health problems. Coordinated services are seen as essential for early intervention to halt spiralling negative life consequences for young people resulting in homelessness, suicide, contact with the criminal justice system, separation from the family and being placed in foster care. Some interagency projects to address these were highlighted by Queensland Health. The need to integrate the youth suicide prevention strategy and initiatives for Indigenous youth is also seen as critical. The need for improved links at the national level and joint responsibility for many of these programs is likewise seen as critical.

The key issues as I see them are the lack of support services available to young people with comorbid mental health and drug and alcohol problems…There is a lot of buck passing that goes on between mental health, justice and welfare departments. Ultimately these young people are primarily dealt with by the justice system. The other departments have failed them and they end up in trouble.

(Youth NGO worker, Queensland, Brisbane Forum #6)

We run a program for young people with dual diagnosis – young people at high risk. We had some funding for 12 months. We had $30,000 from the state and $100,000 from the Feds. We employ 2.5 counsellors. We are now unable to get any further funds so we are focussed on raising funds rather than getting on with the job. It is so difficult to get ongoing support from the State Government.

(NGO Service Provider, Queensland, Rockhampton Forum #18)

We are most concerned about "ping pong therapy". These kids who are diagnosed with difficult behaviour, nobody wants to treat them and they are bounced from one provider to another. We have to ask where are they going? Often they end up being place in foster care.

(Child and Youth NGO worker, Queensland, Brisbane Forum #9)

Too many young people deliberately kill themselves. Over the years, a dozen or more of the statistics have been my patients. Being poor, smelly, irritable or homeless should not be a death sentence. It's time we cut the crap about the tragedy of youth suicide and ensured a service actually gets provided for people who desperately need it.

(Clinician, Queensland, Submission #42)

Also, I have been astounded where child abusing shop keepers sell tobacco and alcohol to kids as young as 14 yet when reported to the authorities nothing happened. What about drug child abusers who provided marijuana to teenagers. I am starting to believe that, where post-pubic people are concerned the worst child abuse is the supply to teenagers of cigarettes, alcohol and marijuana,

(Carer, Mother, Queensland, Submission #91)

Some recent examples of inter-agency coordination include:

- *The Pine Rivers CYMHS [Child and Youth Mental Health Service] established a formal inter-agency forum over six years ago specifically to coordinate care for clients whose needs were not met by normal collaborative processes. Key agencies include CYMHS, the former Department of Families (now communities) and Education Queensland with other services coopted as required for specific cases. A similar interagency forum covers the rest of the Royal Children's Hospital Health Service District.*
- *The Child and Forensic Outreach Service (CYFOS) regularly coordinates and participates in inter-agency meetings and discussions regarding the target group…*
- *Youth Justice Services (YJS) in Morayfield is the lead agency in an inter-agency forum for the Caboolture are that involves CYMHS, Alcohol Tobacco and Other Drugs Services (ATODS), Juvenile Aid Bureau (JAB), Education Queensland and Department of Communities / CYFOS / Indigenous representatives as required. All of these inter-agency processes work on individual case planning.*
- *The CYMHS at Royal Children's Hospital has a number of projects addressing the needs of young people with multiple problems (e.g. a dual diagnosis working party, the Koping project, Future Families etc).*

(Mental Health Unit, Queensland Health, Queensland, Submission #311)

6.3.8.3.4 Housing

Housing difficulties – many people with mental illness living in one public housing block – quality of life in supported care hostels / boarding houses…

(Anonymous, Queensland, Submission #49)

The lack of available housing and accommodation options for people with mental illness was repeatedly raised as a critical gap in the attainment of mental, physical and social well-being. Concerns were expressed (as detailed in Standard 11.4.B Supported Accommodation) that the lack of available supported accommodation or other accommodation options resulted in people remaining in care for longer periods of time than necessary because there were no alternatives or becoming homeless. In particular, access to secure and safe accommodation is seen as essential in the process of reintegration into the community and improved mental health. The lack of available housing and accommodation options and the process of deinstitutionalisation and consequent lack of community services, have resulted in many people with mental illness becoming homeless; placed intolerable strain on families; and contributed to declining health and quality of life.

Where is it? The organisation I work for has tried for the last decade to supply appropriate, affordable ***supported*** *accommodation for people with a mental illness / disability. We are exhausted, frustrated and generally confused by the inflexible poorly coordinated Government Departments that should be providing service to people with a mental illness. It seems to me that no single Department has the ability or inclination to play the lead role in the provision of service to this client group. (author's emphasis)*

(NGO Service Provider, Queensland, Submission #40)

I have seen things which haven't changed at all. For example, the crisis homeless services which are funded under Commonwealth / State Housing Agreement. Initially these were 50 / 50 tied funds between States and the Feds. Queensland put in less than any other State… The Victorian Government on the other hand put in 50 / 50 with the Federal Government and then put in an additional $12 million.

(Supported Accommodation and Assistance Program Service Provider, Queensland, Brisbane Forum #2)

In most cases no account is taken of special needs. One course that appears to provide some hope is to send a letter from a psychiatrist to the Department of Housing. However the housing stock offered may not suit the client and even if it is deemed to be acceptable, much needs to be done to get it set up after the release. There is a need for cooperation between Housing and Corrective Services to allow this transition to work better. Furthermore there needs to be a support team to get it to happen.

(Anonymous, Queensland, Submission #67)

So, when the politicians we approached told us that x many extra dollars were being spent on this and that, I was able to say, "but there is still no long term supported accommodation available." Not that it has made much impact on them. There is some crises accommodation, and some short term accommodation until other long term accommodation becomes available, but none of this latter is supported anyway. We will keep plugging away at this topic for the foreseeable future.

(Carer, Mother, Queensland, Submission #228)

There are 192 SAAP [Supported Accommodation and Assistance Program] Services like mine in Queensland. The Queensland Government did put in some funds to look at people with a mental illness but provided through HACC [Home and Community Care] services. I phoned HACC to seek advice about how funds would be distributed – there was no consultation.

(Supported Accommodation and Assistance Program Service Provider, Queensland, Brisbane Forum #2)

In response to the above claim, after attending the forum Queensland Health provided the following explanation:

> *Whilst the facts of this complaint are not clear, Queensland Health believes this complainant may be referring to the Resident Support Program (RSP), a pilot project in five sites which is actually not targeted at homeless people. The RSP aims to improve the quality of life for people with a disability living in private supported accommodation/hostels (as a priority), boarding houses and aged rental accommodation. Eligible residents receive services such as:*
> - *Community linking:- helping people to develop or rebuild relationships in the community through meaningful activities (e.g. social, educational, recreational and vocational opportunities)*
> - *Disability support:- assistance with personal care (e.g. showering, toileting, dressing / undressing and meals in the place where they live)*
> - *Key support workers:- support for people to get primary health care and / or linking to community based organisations for a range of non-health related services.*
>
> *Disability Services Queensland (DSQ) is the primary finding agency ($1.6 million annually over three years) although Queensland Health also supports the RSP with Home and Community Care funding of $500,000 annually over the same period and $70,000 for project support. Some people living outside the five trail sites (Brisbane, Ipswich, Toowoomba, Townsville and the Gold Coast) understandably may not be aware of these details of the project and may unfortunately have assumed that HACC funding was not being allocated equitably.*
>
> (Mental Health Unit, Queensland Health, Queensland, Submission #311)

6.3.8.3.5 Police

Due to diminishing access to mental health services, police have been increasingly called to respond to assist with people with mental illness, especially in times of crisis. While Memorandums of Understanding and protocols have been drawn up, evidence suggests that further education is required to more clearly protect the rights of people with mental illness who come into contact with the police and the criminal justice system.

> *My beef is with the police – it was reported that he had a mental illness and the police threw him in the cell with nothing, not a bucket to pee in or anything. He told them he had a mental illness and they didn't follow the protocol… The police need education.*
>
> (Carer, Mother, Queensland, Rockhampton Forum #9)

6.3.8.3.6 Corrective services and the criminal justice system

> *Another consumer pleaded guilty to something they didn't do just so they could get into a "better cell" – a 14 week prison sentence was better than being sick and homeless.*
>
> (Carer NGO worker, Queensland, Brisbane Forum #22)

The criminalisation of mental illness was raised by many consumers and consumer advocates as being the inevitable result when services are not available to provide treatment and support, accommodation is not available and levels of stigma are high. Of serious concern were reports that prison (and any subsequent loss of rights) is seen as a positive option as it offers shelter and potential access to treatment. Insufficient treatment and support services were also noted for people with mental illness after release from prison. Again, the need for a whole-of-government approach is seen as essential to redress these problems both to prevent entry and to assist consumers post release. Evidence was presented that sufficient efforts are not being made.

My concern arises from the criminalisation of mental illness. Some people with a mental illness are being punished over and over again. Housing and support for these people has been so neglected that approximately 400 are now housed in mainstream prisons in south-east Queensland.

(Anonymous, Queensland, Submission #67)

Justice system – inappropriate placement of people with mental illness in jails. Buck passing for dual diagnosis.

(Consumer, Queensland, Brisbane Forum #11)

There's a real smokescreen here – Queensland Health has employed a project officer looking at the mental health of women in prison. One project officer! What sort of response is that?

(Prison NGO worker and Consumer Advocate, Queensland, Brisbane Forum #5)

Solicitors may have poor knowledge of mental health issues. A court liaison officer works at the Brisbane courts but mental health clients appearing at other courts have no access to this service.

(Anonymous, Queensland, Submission #67)

The release of prisoners is an area that has been neglected. These people experience high levels of anxiety. Moving home is listed as one of the times of highest anxiety in a person's life: setting up home after being in prison is an impossibly difficult task for some prisoners. Prison becomes the preferred housing option when transition to community is so neglected, even though prison is certainly not safe asylum.

(Anonymous, Queensland, Submission #67)

In my view, a focus on the number of prison days versus community days would be more likely to reveal economic costs of poor policies and practices, and forward the development of changed policies and practices that lead to successful release outcomes.

(Anonymous, Queensland, Submission #67)

In a letter from the minister for Corrective Services dated 15 June 2004, mention is made of a new pre-release program that 'will be introduced in all correctional facilities, with the intention of identifying needs and linking individuals with appropriate agencies'. This sounds all very well in theory, but no commencement date is given, nor any means of follow through to the community. Making vague allusions to some future plan that may or may not come into existence is not enough. Furthermore a joint post-release employment service is offered by Corrective Services and Employment and Training is mentioned. This service may exist, but people without support would not be able to gain access and others would not know about it. It is proposed that dedicated support service teams would provide necessary linkages through a thorough knowledge of this and any other services. It is proposed that the CAP program previously run by Volunteering Queensland and defunded by the incoming Borbidge government be resurrected: this type of access to meaningful activity is much more likely to provide successful outcomes for vulnerable people.

(Anonymous, Queensland, Submission #67)

6.3.8.3.7 Employment

Re-employment is also a critical component in the process of social integration and living a meaningful life with dignity in the community. However, concerns were expressed by one carer who had experiences with many providers that agencies are not providing adequate services.

Enrolling with job agencies who were supposed to deal with clients and their disabilities was a nightmare, only being able to register with one at a time – all keen to take you on their books so they receive government funding but as far as service goes – forget it. One agency failed to return calls, kept telling us nothing on the horizon jobwise, another told me not to worry… the government spending good money into these job agencies which are totally dysfunctional.

(Carers, Parents, Queensland, Submission #150)

6.3.8.3.8 Education

Standard 8.3.2 states: 'The MHS supports staff, consumers and carers in their involvement with other agencies wherever possible and appropriate' and Standard 8.3.3 states 'The MHS has formal processes to develop inter-sectoral links and collaboration.' These Standards apply to the education sector, including schools, TAFE and universities.

Links with the education sector to assist with early identification and early intervention are seen to be critical in any set of strategies targeted at prevention and gaining the necessary skills to attain qualifications necessary for employment and participation in society. One carer reported that despite efforts from the clinician involved, the education sector did not appear to sufficiently accommodate the needs of the consumer and contributed to making matters worse.

> *In 1996 my son [X] was diagnosed with schizophrenia while he was a student at the Central Queensland University in Rockhampton. [X] desperately tried to continue his studies but he received no help or encouragement from the University. Dr [Y], who was [X]'s treating psychiatrist at the Rockhampton Mental Health Unit wrote a letter to the University explaining how Schizophrenia would affect [X]'s abilities. I contacted the Disability Officer at the University to explain [X]'s illness, but she refused to discuss it with me, saying she had to establish a relationship with [X]. [X] had no insight into his illness…[X] changed to studying fewer subjects externally, but there were still problems with administrative tasks. He would enrol in subjects and be unable to carry out administrative tasks. He would fail to withdraw from subjects by the required date. Then he would accrue a HECS debt for that subject. He now has a large HECS debt. I wrote to HECS, enclosing a letter from Dr [Y], explaining the Situation, but HECS would not make any allowances for his illness. I would like Universities and HECS to develop an understanding of mental illness and their effects, so these institutions do not make matters worse. [X] was helped by many people, but not by anyone associated with the Central Queensland University.*
>
> (Carer, Mother, Queensland, Submission #65)

6.3.8.3.9 Wards of the State – need for a whole-of-government approach

> *I was also placed in Wolston Park Mental Hospital, as a child, by the Children's Department and there was nothing wrong with me…we cannot get recognition or help with counselling as our situations are a little different to other state wards that were abused. You have no idea how hard it is to survive and then function after being through a place like that when there is nothing wrong with you and being young. I spent some time locked in with the criminally insane and that is something I will never forget and I cannot, for the life of me work out why children were put in there and then forgotten about.*
>
> (Anonymous, Consumer, Queensland, Submission #304)

Two submissions highlighted the need for the Government to adequately care, through a whole-of-government approach, for those children and adolescents placed in the State's care. These anonymous submissions claimed that they had been placed in adult mental health services when young and that gaps in multiple areas resulted in their deteriorating mental health, resulting in serious life consequences.

They never taught us any life skills at all such as how to manage money or even how to cook or how to have a normal conversation or how to inter-act with normal people. We were never taught how to look for a job or how to present ourselves to a prospective employer or even personal hygiene… I find it very hard to understand why these people messed with children's lives as they did and got to walk away from the damage they had done and the responsibility that they had. How dare they…I challenge any adult, let alone a child, to be drugged, bashed and abused and live in constant fear while living with the criminally insane and see how they come out of it. Then I would like them to try and function normally without any help from anyone or any Government Agencies.

(Anonymous, Consumer, Queensland, Submission #304)

Age 15 I was placed in a security ward with the criminally insane and other dangerous women and eventually men and women some were there under queens pleasure for crimes such as murder, rape, armed robbery etc. Wolston Park Hospital also called Goodna some girls before my time were sent from Karalla House a place for young girls who were terribly abused there and then also suffered at Goodna as young as 12yrs old, there were disabled kids sent there when I was there suffering still brings a tear to my eyes and I'm now 39…

(Anonymous, Consumer, Queensland, Submission #300)

I wonder how a girl who is striped naked by men and women while in a cell then forced to the ground injected with mind blowing drugs left there for days sometimes, what becomes normal behaviour of a child being subjected to this and other abuse.

(Anonymous, Consumer, Queensland, Submission #300)

6.3.8.3.10 Lack of coordinated care across sectors for older people with mental illness

A clinician expressed strong concern with the lack of integration and coordination between mental health and the general health and social service sectors in the provision of treatment and support for older people with mental illness in Queensland:

Relationship between mental health services and the general health and social services sectors. One of the most frustrating aspects of the current system of health care for older people is the lack of integration, continuity and coordination of care between the various agencies that provide assessment, treatment and support for people living in their own homes. Problems include:

- *repetition of assessment*
- *multiple agencies*
- *multiple, unconnected systems of documentation*
- *inter-agency conflict*
- non-overlap of catchment areas

(Clinician, Queensland, Submission #140)

One of the richest sources of expertise, in many districts helping with the recognition of depression and psychosis, the Aged Care Assessment Services, cannot intervene past the point of assessment. They are also poorly integrated with State-funded agencies in many instances.

(Clinician, Queensland, Submission #140)

The development of models of integrated social and health services for older people are highly encouraged e.g. having a common shopfront for community-focussed social, psychogeriatric and geriatric medical services such as ACAS [Aged Care Assessment Services], psychogeriatric community service, community health, all with the same catchment area, with the capacity to:

- *provide assessment and case management and*
- *to deliver specialist geriatric medical or psychiatric expertise as needed*

with the aim of preventing hospital admission and delaying residential care placement, reducing replication of assessment and delays in approval of service packages and perhaps producing economies of scale through rationalisation of documentation, education and training and reception functions.

(Clinician, Queensland, Submission #140)

Policy for older people should reflect the high prevalence of physical and psychological morbidity among carers of older people (eg. Bruce et al. 2002). This "second patient" phenomenon is found more commonly than for carers of younger people. Carers are also more likely to be asked to speak for identified consumers and may have the official position to be able to make health-related decisions for those with impaired capacity. Existing policies around outcome and satisfaction measures may not do justice to this issue. The implementation of programs (e.g. Beyond Blue) arising from the NMHPs [National Mental Health Plans] seems relatively non-inclusive of issues particular to older people.

(Clinician, Queensland, Submission #140)

In conclusion, in an ageing society, omission of psychogeriatric issues in national mental health planning will become increasingly unrepresentative.

(Clinician, Queensland, Submission #140)

6.3.9 STANDARD 9: SERVICE DEVELOPMENT

The MHS is managed effectively and efficiently to facilitate the delivery of coordinated and integrated services.

…issues that are regularly presented to our offices…One of the dilemmas is the culture of the mental health system – "toxic" culture of the mental health system.

(Office of the Public Advocate worker, Queensland, Brisbane Forum #14)

Under this Standard, submissions and presentations indicate concerns about:

- the current state of mental health services in Queensland;
- lack of funding and resources;
- concern about the relocation of community based services back to hospital settings;
- lack of consultation with consumers, carers and service providers;
- planning and accountability;
- need for staff training and development;
- staff attitudes;
- rural and regional issues;
- support for critical services provided by NGOs;
- the cost of care and access to psychiatrists and psychologists;
- low regard for psychogeriatric planning and policy development; and
- research.

6.3.9.1 Concerns about the current state of mental health services in Queensland

While the majority of this Report documents a variety of concerns regarding the current state of mental health services in Queensland, some reports were received indicating that improvements had been witnessed and that not all hope is lost.

Brian Burdekin's 1993 report is just as valid today as it was eleven years ago and in some instances the situation is worse, e.g. with psychiatric clients losing case management support; and the decrease in housing stocks.

(Anonymous, Queensland, Submission #67)

The present policy of incarcerating vulnerable people in mainstream prisons in the first place is questionable. As Sally Satel states, 'Releasing [mentally ill people] from the large state institutions was only a first step. Now we must do what we can to free them from the "cold mercy" that comes from criminalising mental illness.'

(Anonymous, Queensland, Submission #67)

While funding to the State mental health services has increased in recent years, Queenslanders continue to report many problems with access to services – still far too few mental health workers based in the community, difficulty finding in-patient beds when people are acutely ill, and a continuing shortage of supported accommodation.

(SANE Australia, National, Submission #302)

…a larger theme of inequity across the entire health system. That is, Australians acknowledge and have come to demand their right to the best available healthcare in times of need, but the rights of people affected by mental illness have not been as well recognised within the overall system… The Alliance supports the call for an adequately resourced, ethical and effective public mental health system. We believe that there are numerous inadequacies within the current system both in terms of resources and culture. However, the Alliance is concerned that increasing investment in the public mental health system without also investing in the community sector will continue a cycle of dependence on hospital care.

(Queensland Alliance of Mental Illness and Psychiatric Disability Groups, Queensland, Submission #218)

My comments are experience is related primarily to adult services. Not all changes are bad for example integrating and outsourcing and essentially referring people on to be managed in the community. The way in which this was carried out though was appalling (a bit like deinstitutionalisation i.e. no community support when moving people out) and of course this only works if there are the community supports available and they are appropriate…

(Anonymous, Queensland, Submission #113)

Let me say at the outset I consider that in general mental health services are better in Queensland than they were one or two decades ago. I would solely attribute this improvement to adult and children's mental health facilities around the State. Prior to this the advent of these facilities it was often impossible to access mental health for patients in the areas in which I work.

(Dr Bruce Flegg MP, General Practitioner and Liberal Shadow Minister for Health, Queensland, Submission #39)

On a positive note though I believe there is an attempt to work with the standards and have policies in place, which support these. The paperwork looks great. There are as always good case managers and bad and there are some very good ones who care and do have expertise. They are the minority though and the service criteria is shrinking making it harder and harder for people to access and for the good case managers to work effectively.

(Anonymous, Queensland, Submission #113)

There are also very few community and NGO based services. What are available are woefully undermanned, under staffed and under-funded. Surely the right to adequate services is a basic human right?

(Consumer Advocate, Queensland, Submission #16)

Prisoners with a mental illness may become prisoners for life, or revolving door prisoners. The criminalisation of mental illness is a disgrace. There are 400 people with a psychiatric diagnosis in SE Queensland prisons. They may be a released without any notice being given to the IFMH prison liaison officer. There is no mental health service in low security facilities. This is of particular concern in that prisoners are sent to a high security facility if they become unwell: consequently, they may attempt to hide their illness and become even more unwell. Prisoners may be released with less than one-day notice. My son was taken on short notice to a halfway facility where staff had no understanding or training in mental health support. My son arrived but his antipsychotic and antibiotic medications were still at the prison. He phoned me in a highly anxious state. He 'borrowed' medication from another prisoner for that night and the next day he was given leave to go to the allocated hospital (which is not the hospital he was previously assigned to in the community) where he sat for four hours to get a script.

(Anonymous, Queensland, Submission #67)

The Alliance is also concerned by the increasing public call for a return to more "protectionist" responses in the treatment and support of people who experience severe mental illness.

(Queensland Alliance of Mental Illness and Psychiatric Disability Groups, Queensland, Submission #218)

In reference to the "Mental Ill Health System" which has gone backwards since the sell out of mental hospitals, and is now basically "drag em in – drug em up – chuck em out". … The following are what I put are necessary: 1. Total Federal control of the "ill health system"; 2. Restoration of Mental Health hospitals with their various stages… by whatever name; 3. Various types of supervised and unsupervised abodes. 4. Eliminate the "Death Camp mentality".

(Carer, Father, Queensland, Submission #141)

It wasn't until sometime later that I heard that some regulatory bodies refer to (sections of) Queensland Health as consistently displaying a 'toxic culture'.

(Consumer, Queensland, Submission #313)

6.3.9.2 Lack of funding and resources

Many problems were raised related to the current lack of funding and funding distribution across rural and regional areas, which results in lack of staff and resources to deliver quality mental health care. Submissions stressed that their concerns in this regard were not directed at clinicians but at the realisation that insufficient funds and resources were being allocated for clinicians to provide or organise quality care. Lack of funding and resources were also identified as part of a package of problems in recruiting staff to fill vacancies in rural and regional areas.

Only 8% of health budget in Australia goes toward mental health while incomparable countries (N.Z., U.K.) spend 13%.

(Anonymous, Queensland, Submission #49)

There is not enough staff in hospitals.

(Consumer, Queensland, Brisbane Forum #11)

…it's not about the providers but it's the system that's chronically under funded.

(Clinician, Queensland, Brisbane Forum #7)

In January of this year, I spent three days in the psychiatric ward at the Gold Coast Hospital. I found the level of care was very good, but it is hopelessly underfunded.

(Consumer and Family Member, Queensland, Submission #94)

Need for more staff for people with acute condition

(Anonymous, Queensland, Submission #49)

Case managers are burned out and/or distressed by their inability to provide a quality service or simply join the fold and deliver a sub standard service.

(Anonymous, Queensland, Submission #113)

We have not had a full time psychiatrist for approx 3 years while our nearest MHS in the same region has got 2.5 psychiatrists. Issues are inability or lack of recruitment strategies.

(Anonymous, Queensland, Submission #113)

It appears as if there is a significant shortage of bed space in Queensland for people who require sectioned or voluntary admission.

(NGO worker, Queensland, Brisbane Forum #3)

It appears that there are insufficient doctors available at the Rockhampton Mental Health Unit to cope with the patient load. Added to this, as some of my documentation shows, one has to question the quality / ability of some of the doctors that are available. Perhaps their very workload precludes them from being the doctors they would like to be.

(Carer, Wife and Mother, Queensland, Submission #52)

The Queensland government has had a lot of catching up to do, and spending has increased in recent years. As well as a long-term capital works program to create mental health units in general hospitals, the Beattie government is creating an additional 100 positions for mental health clinicians in 2004. These will contribute to staffing the Mobile Support Teams being introduced in some parts of State.

(SANE Australia, National, Submission #302)

The downsizing of the larger psychiatric facilities has been accompanied by an expansion in community mental health services. Overall, mental health staffing numbers have continued to increase since the commencement of the mental health reform process. Queensland employed 2837 staff in 1993/94, rising to 3978 staff in the financial year 2002/03 – an increase of 28%.

(Mental Health Unit, Queensland Health, Queensland, Submission #311)

6.3.9.3 Concern about the relocation of community based services back to hospital settings

Concern was expressed regarding the recent pattern to relocate community based services to hospital sites primarily for financial reasons. It was suggested that this effectively "re-institutionalises" services, works against all the aims of community based service delivery and emphasises the medical model of mental health.

As in NSW, Queensland is drawing back community-based services into hospitals. Some non-government organisations have also been located within hospitals in addition to non-in-patient clinical services. The Association for Mental Health now has to operate out of an old ward at Wolston Park, for example. This institution, established in 1865, was never closed down. Instead it received a $50 million redevelopment to re-open in 2002 as 'The Park' – different name, same place: a brand-new 192-bed institution with extended care, rehabilitation, dual diagnosis, secure, forensic and adolescent programs all together in the same nineteenth century grounds.

(SANE Australia, National, Submission #302)

Rather than calling for a return to hospital and institutional care, the Alliance calls for real investment in the community and in community-governed organisations. People with mental illness want to live in the community – not in hospitals. They have a right to housing, employment and to flexible treatment and support. Queensland has an urgent need to exploit the potential of the non-government sector in providing recovery-focused services, which are cost effective and respect the rights of people affected by mental illness.

(Queensland Alliance of Mental Illness and Psychiatric Disability Groups, Queensland, Submission #218)

6.3.9.4 Rural and regional issues

As mentioned above, planning and resource allocation for services located in rural and regional areas needs to consider a multiplicity of factors that may hinder the operation of such plans or fail to cater appropriately for the differing needs of those communities. For example, the recruitment and retention of staff in rural areas is problematical.

Our community is adversely affected by a lot of really tough issues - issues of drought, transient population, Uni students away from home and little support etc.

(Anonymous, Queensland, Rockhampton Forum #11)

…issues that are regularly presented to our offices… Regional and rural issues – distress in country areas is much worse than in Brisbane.

(Office of the Public Advocate worker, Queensland, Brisbane Forum #14)

6.3.9.5 Lack of consultation with consumers, carers and service providers

Concerns were also expressed that consumers, carers and service providers are not being listened to (and that they have a right to be heard) and are tired of consultations which result in no changes and are not meaningful. Standard 9.8 states: 'The strategic plan is developed and reviewed through a process of consultation with staff, consumers, carers, other appropriate service providers and the defined community' and Standard 9.9 describes the process for such a plan (e.g. consumer and community needs analysis and a service evaluation plan including the measurement of health outcomes for individual consumers). These concerns suggest that even when consumers and carers are involved such processes are not being adhered to in a meaningful way and also indicate that criteria listed under Standard 3 (consumer and carer participation) are also not being met.

I am constantly amazed at how many people in the community have experienced difficulties with the service over the years and it continues unabated, theirs and my constant frustration that nothing changes and that the treatment of consumers and carers remains poor. We have brought many issues up and were tired of our own voices and frustrations; we each have our own stories it just goes on…

(Anonymous, Queensland, Submission #113)

I hope, somehow through enough people contacting organisations such as yours, that we can try and help people. I don't blame the Government for things in life, but I have paid taxes and feel I have a right to be heard about where my money should be going.

(Consumer and Family Member, Queensland, Submission #94)

However, SANE Australia reported steps to strengthen consumer and carer participation

Another positive step has been the appointment of Carer as well as Consumer Consultants in a number of Health Areas, which will hopefully give both a voice in planning and review of services.

(SANE Australia, National, Submission #302)

6.3.9.6 Planning and accountability

Some submissions expressed concerns that planning and accountability mechanisms do not accurately portray the state of service delivery or identify gaps and problems which need to be addressed to meet the needs of consumers and carers who are attempting to access treatment and support services.

> *The manager frequently reports how low their hospitalisation and recidivism rates are. The wards are frequently empty and some staff complain that they are bored and have nothing to do. The district manager supports this because the costs are kept down. The service is lauded as innovative and a model to aspire to but they have these stats because they don't admit people or tell them to go somewhere else.*
>
> (Anonymous, Queensland, Submission #113)

> *Partnerships are proposed, ideas of collaboration are spoken of, meetings are held and boxes are ticked to say that these things are happening but very little changes in how the clinical sector works with the community.*
>
> (Anonymous, Queensland, Submission #113)

> *I not only provide this but make complaint to the HREOC and MHCA regarding the incompetent and inhuman treatment of patients in the system and the self serving "cover up club", which has a vested interest in this continuing.*
>
> *(Carer, Father, Queensland, Submission #141)*

> *…I want someone to see what is happening at the Rockhampton Mental Health Unit and someday changes for the better may be made. I have been dealing continually with the unit for nearly six years now and in spite of seeing four different directors at the helm, in my opinion the inconsistencies, the mismanagement, the unrealistic expectation of 'normal behaviour' from unwell people who are far from 'normal' and indeed a strange lack of understanding of people with a mental illness in general, appear to be deeply ingrained and the only constant.*
>
> (Carer, Wife and Mother, Queensland, Submission #52)

6.3.9.7 Need for staff training and development

Standard 9.17 states: 'The MHS regularly identifies training and development needs of its staff' (for example with reference to industry-validated core competencies for mental health staff) and Standard 9.18 states 'The MHS ensures that staff participate in education and professional development programs'. The White Wreath Association Inc. expressed concern that some clinicians might need to update their skills with regard to treatment and support strategies in order to ensure that any decline in patients mental health or harm to self or others, was not attributable to their skill deficiencies.

> *Personal accountability of Clinicians who refuse to update their skills and thereby cause loss of life. In this case the very practices of the Psychiatric Profession was to push the patient closer towards suicide and murder suicide.*
>
> (White Wreath Association Inc, Queensland, Submission #81)

6.3.9.8 Staff attitudes

Similarly, concerns were expressed about poor staff attitudes towards consumers indicating that staff are in need of training in order to change their attitudes and behaviours (decrease discrimination) and be more supportive when dealing with people with a mental illness.

> *Stigma exists right across our system.*
>
> (Clinician, Queensland, Brisbane Forum #7)

Prosperity and pleasantness are common causalities of severe mental illness. One would hope that psychiatrists, of all people, could accept this but like most doctors, psychiatrists rarely show enthusiasm for, or understanding of, patients who are neither cashed up nor personable.

(Clinician, Queensland, Submission #42)

Also during his last admission to hospital [before completing suicide], staff also told myself and other family members that [X] was becoming too dependent on the hospital system and would not be readmitted to hospital. Myself and my daughter were both also told by hospital staff in another meeting that it was all [X]'s fault, this admission and that he needs to start taking responsibility for himself. How can someone who has a mental illness and lacks insight into their illness take full responsibility for their life. This was the first time my son had ever admitted himself to hospital, [X] knew he was unwell… On previous occasions the police have had to always be involved in getting him there. [X] was finally starting to accept that he had a mental illness.

(Carer, Mother, Queensland Submission #117)

6.3.9.9 Lack of support for critical services provided by NGOs

Concerns were also expressed about the insufficient level of funding provided to the NGO sector and accountability practices to ensure services meet the changing needs of the defined community (Standard 9.15).

I want to speak about a major project implemented by Queensland Health. We regard it as a system attempt to exclude people with a mental illness. When the project was first introduced it was called Project 500, then it was downsized and called Project 300 and then finally it became Project 54. QLD Health used the initial funds to train workers (4 years). But there was no equity in the project – most of the funding was going to those people in the institutions… A lot of others didn't get access to care because of this project.

(NGO worker, Queensland, Brisbane Forum #1)

There is a broader issue which relates to funding the n.g.o sector and how the local managers are involved in this that needs to be part of the review e.g. local MHS mangers have a great deal of input into n.g.o funded services and yet ours for e.g. has never stepped foot in the place…Many consumers who utilise our service have nothing to do with the clinical services – we should be assessed based on our merit and performance: our relationship with the local service is only as good at that which the manager allows.

(Anonymous, Queensland, Submission #113)

The Alliance believes that there needs to be more recognition of the role of the non-Government sector in providing cost effective psycho-social rehabilitation and support services to assist people in their recovery rather than a return to institutional forms of care.

(Queensland Alliance of Mental Illness and Psychiatric Disability Groups, Queensland, Submission #218)

With the exception of a few well-established organisations, the non-government sector is still relatively underdeveloped in Queensland (comparative to states such as Victoria and NSW).

(Queensland Alliance of Mental Illness and Psychiatric Disability Groups, Queensland, Submission #218)

More investment is needed in the non-government sector. Queensland's non-government mental health sector is very poorly resourced and thereby limited in the services that it can offer to people affected by mental illness.

(Queensland Alliance of Mental Illness and Psychiatric Disability Groups, Queensland, Submission #218)

In Queensland we hear about Government and Non-Government services needing to work more collaboratively, which to me means small community organisation providing more support with no help from Government. How can Community organisations be truly expected to work together when Government forces us go through a competitive tending process to provide service?

(NGO Service Provider, Queensland, Submission #40)

However, recent improvement in funding of NGO's was noted by SANE Australia:

> *Funding for non-government organisations providing community support has increased by 50% since two years ago, from 5.2% to 7% of the mental health budget.*
>
> (SANE Australia, National, Submission #302)

6.3.9.10 The cost of care and access to psychiatrists and psychologists

Consumers and clinicians expressed serious concerns that due to the lack of services available though the public mental health sector, consumers were increasingly forced to pay for care (to see psychiatrists and psychologists). Additionally, concerns were expressed that even those prepared to pay had difficulty accessing services due to long waiting lists. Many people though were unable to consider such options for financial reasons.

> *The cost of care is an issue. People can't afford care.*
>
> (Consumer, Queensland, Brisbane Forum #11)

> *Also affordable access to psychologists is on my wish list. The Allied Health EPC Initiative will not satisfy the latter need because minimum criteria for a Care Plan cannot always be met esp for young people, the red tape remains unreasonable and the allied health funds/# of services are limited.*
>
> (Anonymous, Queensland, Submission #260)

> *For those people who need psychological services that sort of care is only available in the private sector. It's expensive and hard to access also.*
>
> (Clinician, Queensland, Rockhampton Forum #7)

> *Earlier this year I discovered a psychiatrist was charging a patient of mine weekly consultation gap fees of up to one quarter of her income. On top of this she was charge non-attendance fees for missed appointments. And naturally, she was missing appointments – because she couldn't afford to pay for them.*
>
> (Clinician, Queensland, Submission #42)

> *I once heard a professor of psychiatry state that chronic mental patients taken against their will to hospital should pay their ambulance bill if they were not covered. His apparent rationale was that anybody in chronic ill-health would be mad not to ensure that they had ambulance cover.*
>
> (Clinician, Queensland, Submission #42)

> *Consumers come to us and tell us that if we don't pay for their prescriptions they'll have mood swings. We call mental health services and ask for their help but the people are back on our doorsteps the next day.*
>
> (NGO worker, Queensland, Rockhampton Forum #6)

> *Another factor in mental health consumers 'missing out' on appropriate services and timely treatment is the users pays system. Many simply cannot afford the cost of luxury 'private' services and many cannot afford the cost of private health insurance. Health insurance is becoming more and more out of reach for the 'average' Australian, let alone for someone who tries to exist on a disability support pension.*
>
> (Clinician, Queensland, Submission #105)

> *I believe that the State Government has to stop out sourcing care like counseling to business like Center care and Life line because people like me are some times required to pay for services that should be free.*
>
> (Consumer, Queensland, Submission #192)

6.3.9.11 Psychogeriatric planning and policy development

The need for psychogeriatric policy development and planning to meet the needs of older people living in Queensland was discussed:

> *But no analysis of mental health issues for older people can omit dementia even if it is not covered currently under the "mental health" policy umbrella. The population of those aged 80 and over is predicted to increase by 500% across the period 1991-2041 as the general population increases by 50% and age is the strongest risk factor for the development of dementia. Its significance lies in:*
> - *Implications for demand on residential care and community services*
> - *High prevalence of psychological sequelae such a depression (30-40% incidence across lifetime with Alzheimer's), behavioural disturbance (~90%) and psychosis (20-30%)*
> - *Reduced availability of acute beds for elective surgery and other indications through delays in placement and acute failure of community based support ("social admissions")*
> - *High rates of morbidity among carers*
> - *Misuse of psychotropics especially in residential settings*
> - *Safety issues for paid and unpaid carers and fellow inpatients or residents*
> - *Special requirements for the assessment of impaired capacity, eg issues around driving*
> - *The fact that older people in mental health assessment and treatment settings often have comorbid cognitive impairment and benefit from environments and trained staff who understand their needs*
> - *Demented people are sometimes inappropriately housed in treatment settings designed for other mental disorders*
>
> (Clinician, Queensland, Submission #140)

> *Comprehensive mental health planning for this age group should consider disorders that are not necessarily dealt with by the public mental health sector as the lead agency. Mental health training is an enormous asset for those dealing with dementia and the potential contribution of mental health professionals is significant. To this extent, dementia must not be forgotten in any global description of older people's mental health. Just as no policy discussion of general adult mental health can avoid mention of substance use disorders, so cognitive disorders such as dementia and delirium must not escape attention in any review of psychogeriatric policy.*
>
> (Clinician, Queensland, Submission #140)

> *Data around the impact of dementia and delirium are needed to plan services.*
>
> (Clinician, Queensland, Submission #140)

6.3.9.12 Research

One submission was received expressing concern that more funding needs to be allocated to research to improve the mental health of the community. According tho Standard 9.31: 'The MHS conducts or participates in appropriate research activities' and Standard 9.30 states 'The MHS routinely monitors health outcomes for individual consumers using a combination of accepted quantitative and qualitative methods'.

> *More money need for research into the social causes / effects – beneficial therapies – biological causes.*
>
> (Anonymous, Queensland, Submission #49)

6.3.10 STANDARD 10: DOCUMENTATION

Clinical activities and service development activities are documented to assist in the delivery of care and in the management of services.

No submissions or comments were received pertaining to this Standard.

6.3.11 STANDARD 11: DELIVERY OF CARE

Principles guiding the delivery of care: The care, treatment and support delivered by the mental health service is guided by: choice; social, cultural and developmental context; continuous and coordinated care; comprehensive care; individual care; least restriction.

Under this global Standard outlining the principles underlying care, submissions and presentations indicate concerns about the right to treatment and care and individual choice.

6.3.11.1 The right to treatment and care and individual choice

A number of submissions by carers were received and presentations made regarding the right to access treatment and care when a consumer fails to acknowledge their illness or comprehend the repercussions of failure to access treatment. Some other submissions expressed their concerns somewhat differently, arguing the problem was not with the emphasis on individual choice, but more a problem about the choice of treatment offered and approach of clinicians.

> *However I have always wondered is there a point where the rights of the individual should be overlooked? Or does there come a time or a point where an individual's rights are not as important as full medical treatment and care. I hate to see a system that not only often cannot help the individuals that rely on it, but one that also fails to recognise the families behind the individuals.*
>
> (Anonymous, Queensland, Submission #82)

> *We are still discussing some issues we discussed through the Burdekin era. The dichotomy between the right to freedom and the right to access care and treatment. At a political level, we want things to change, we need to get political.*
>
> (Carer, Queensland, Rockhampton Forum #14)

> *It seems that the decision of treatment is entirely taken out of the hands of the family or carer and left to the sufferer. In most cases to find their own cure.* **The Public Mental Health System at present - processes people – they do not treat patients individually with the good will and respect that they deserve. The system we have is only too willing to allow this process to continue.** *In my opinion* **no other method of treatment is considered, or recommended** *in the Public Health System.* **The exception being pharmaceutical methods** *where there is limited explanation of how much and how often to take the prescribed medication and their possible side affects. The message to us was that you can't help those who won't help themselves. Yet people suffering mental illness are less able to help themselves. (author's emphasis)*
>
> (Carer, Mother, Queensland, Submission #81)

> *The concerns of the family and the patient must be paramount.*
>
> (White Wreath Association Inc, Queensland, Submission #81)

6.3.11.1 Access

The MHS is accessible to the defined community.

Under this Standard, submissions and presentations indicate concerns about:

- the lack of services in rural areas;
- access not possible even if there is a risk of harm to self or others;
- police are becoming the de facto mental health service;
- inability to access services generally;
- access is limited to those with 'serious mental illness';
- access to psychologists is easier for those who can afford to purchase care in the private sector;
- access denied due to past forensic status;
- lack of services for youth with drug and alcohol problems; and
- carers need to be heard.

> *A lot of my clients I see come to me with bad experiences they have had when trying to access care. It's a sad reflection on the system if it is making people more traumatised!*
>
> (Clinician, Queensland, Brisbane Forum #20)

An inability for consumers to access treatment and support services, within both the community and inpatient care, often results in the infringement of a whole series of rights for consumers, carers and the community. For the consumer, the consequences of these infringements can include increasing disability and hence consequent inability to care for one's self or others, participate socially, or work or study. In some cases, the potential for harm to self or others, incarceration, homelessness and poverty can result.

Increasing disability can also exposed the consumer and their family to discrimination and social exclusion. This often results in the further deterioration of the consumer's mental health. For example, for consumers in rural and smaller regional areas, their ability to access care often required long trips to metropolitan or large regional centres and social dislocation if hospitalisation is required.

> *Early intervention should focus on maintaining life skills and personality – trying to keep family supportive and involved – explaining to the patient exactly what their condition is, what treatments are to be tried and what side effects / benefits can be expected.*
>
> (Anonymous, Queensland, Submission #49)

For children and youth, a failure to gain access to services at this time of their life or for educational bodies to make sufficient accommodations, places their future at risk.

For carers, the burden of care due to a family member's illness is exacerbated when the family member becomes increasingly ill due to lack of treatment and support services in the community. This further disrupts carers' ability to participate socially and to work. Family isolation and increasing instability were also frequently reported due to the lack of community support and acceptance (high levels of stigma and discrimination) and lack of family-centred approaches to treatment and support. For the community, the inability to access care resulted in an infringement of their right to safety and a disruption of their social and economic cohesion.

> *The number of callers into Lifeline regarding mental health problems is going through the roof. It seems that for many people they have no other option other than to phone Lifeline.*
>
> (NGO worker, Queensland, Brisbane Forum #19)

6.3.11.1.1 Lack of services in rural areas

In Queensland, the State's vast geographical area poses serious challenges to the planning and delivery of services to meet Standards 11.1.3 ('mental health services are provided in a convenient and local manner and linked to the consumer's nominated primary care provider') and 11.1.5 ('the MHS ensures effective and equitable access to services for each person in the defined community'). For people living in many areas of Queensland there are no services which were convenient and local. Access to care involves long distances by car, a significant barrier for those who are not so readily mobile or do not have their own transport.

> *My wife got ill when we were living in Emerald – every time she got ill it was a car trip back to Brisbane – that's how we got care, I drove her down here. I don't know how people who couldn't get to Brisbane could get care when they needed it.*
>
> (Carer, Queensland, Brisbane Forum #21)

The statement by a clinician in Rockhampton that the closest option for long term care is in Toowoomba indicates the magnitude of the problem. The social dislocation for both the consumer and carer, if such an option is exercised, is high.

> *The Bailie Henderson Unit in Toowoomba is the only option for long term care. We have a high dependency unit but the vast majority of people are in community based care.*
>
> (Clinician, Queensland, Rockhampton Forum #7)

6.3.11.1.2 Access not possible even if there is risk of harm to self or others

> *…I was once a very depressed, suicidal individual and the gov't hospitals and health care systems did absolutely nothing to help me when I was screaming out for help at the time!*
>
> (Consumer, Queensland, Submission #73)

A constant theme throughout many submissions was not only an inability to access services when needed, but that access was also difficult when consumers were at risk of self harm or harm to others. According to this information it would appear that standards 11.1.4 'The MHS is available on a 24 hours basis, 7 days per week' and 11.1.2 'The community to be served is defined, its needs regularly identified and services are planned and delivered to meet those needs' are not being met.

> *There's a lack of access to services – acutely suicidal and very distressed and they are turned away.*
>
> (Anonymous, Queensland, Brisbane Forum #8)

On the day in question – a Saturday – my son stopped taking his medication (even though the sticker warned 'do not stop taking this medication abruptly'- these guys don't read these things when they are ill). As a result he became extremely psychotic. The first advice from Mental Health Unit was 'bring him in Monday morning'! Next advice was to call police which we did on two occasions. My son was absent for the first call-out. Unfortunately, the second call-out ended disastrously. My son arrived home quietly while the police were still there and 'gave himself up' (putting his hands up). However, for some reason the police officer (young and by his own admission, inexperienced in Mental Health matters) said 'we can't take you, you haven't done anything wrong' which caused my son to produce a small knife (which I later found out he'd been trying to slash his wrists with a short time before) – not in a threatening manner (he had his hands upwards again) but in an effort to get police to shoot him. The situation escalated and just as the police raised their guns to shoot him my husband hit my son from behind (with a heavy stick) wounding him and causing him to stumble thus saving my son's life. The outcome was the police told me they were taking my son to Accident and Emergency at the base Hospital to get the help he needed (and from there he would go to Mental Health). This never happened. On the way they diverted straight to the watchhouse.

(Carer, Wife and Mother, Queensland, Submission #52)

An 18 year old female client with depression rang me after making a suicide attempt by cutting her wrists. She was alone and had scared herself by this action being afraid of what she might do next. I organised an ambulance for her and based on previous experience, warned her that she may not be admitted into hospital. She too was subsequently sent home after having her physical wounds treated. As a student who had relocated from a rural area, she had no family in Brisbane and was quite isolated. It required considerable effort to ensure that she was not left alone in her vulnerable state until her parents could travel to be with her.

(Clinician, Queensland, Submission #105)

An experienced colleague who was concerned about the state of a client personally took the extremely distressed and suicidal client to hospital and waited all day for the client to be seen and assessed – the client was not admitted and was sent home…"

(Clinician, Queensland, Submission #105)

A female client in her early 20's, suffering from depression, was aware that she was becoming suicidal. Being frightened at what she might do, she drove herself to a large public hospital for assistance. She was seen briefly and then sent home. She subsequently required admission into a private psychiatric hospital where she stayed for a number of weeks. As an articulate and intelligent young woman who presented 'well' instead of 'crazy' she was turned away.

(Clinician, Queensland, Submission #105)

6.3.11.1.3 Police are becoming the de facto mental health service

Due to the inability of consumers and carers to access mental health services during times of crisis, police are increasingly being called to assist as they are available 24 hours a day 7 days a week. Standard 11.1.4 states: 'The MHS is available on a 24 hour basis, 7 days per week'. Included in the notes to this Standard are crisis teams, extended hours teams and 'cooperative arrangements with other appropriately skilled service providers and community agencies including General Practitioners, private psychiatrists, general hospitals'.

Another unsatisfactory situation that exists is when someone 'phones the AC Team for advice regarding a psychotic patient, invariable the advice is 'phone the police'.

(Carer, Wife and Mother, Queensland, Submission #52)

Previously it was bad enough when each person had a case manager because the case managers were so overloaded that it often took a few days to get in touch with them. If they weren't on holiday, stressed out, they were away doing some course. Now it is practically impossible to get urgent help without calling the police whom I'm sure do not appreciate being expected to act as health care workers.

(Carer, Mother, Queensland, Submission #10)

More than once the police local have said that it is not their problem and we should call her mental health worker, who is 100kms away and never able to take our call because she is so busy she is rarely in the office.

(Anonymous, Queensland, Submission #82)

First presentation Saturday 20 March – waited in emergency approx 4-5 hours. Finally assessed by Psychiatrist for 30 minutes. Psychiatrist rang father at 11pm and asked him to bring pushbike. Dad refused saying my son is suicidal he needs to remain. The patient said he was suicidal and said he needed to remain. Doctor called taxi to take patient home. Taxi driver dropped patient off 10-15 km away from home. Doctor gave patient Largactil, Valium and other medication, which almost put him to sleep (even though the doctor said there was nothing wrong with the patient). Patient ended up sleeping in a bus shelter. Following Day 21 March patient became angry and agitated presented himself at Jacaranda Police Station (Logan) saying I'm not well I want to kill myself and others. Police took him to Logan Hospital (their response was more appropriate than the hospital response). Patient again waited 4-5 hrs assessed in 10-20 minutes sent to Pindari Salvation Army Hostel, there overnight. Father received a letter from son's GP requesting the patient be fully assessed. Doctor assessed patient as being schizophrenic. Saturday the 3 April parents out – patient took a knife to brother who was 17. Two other brothers ran to next-door neighbours – neighbours called police. Police came. Family arrived home same time police arrived. Police took patient to hospital. Family also tried to get patient admitted to P.A Hospital but told that he was not in their catchment area. What other life threatening condition would a patient be refused hospital admission?…Most importantly this mans concerns were backed up by his entire family yet their concerns were treated with contempt.

(White Wreath Association Inc, Queensland, Submission #81)

6.3.11.1.4 Inability to access services generally

Other concerns were also raised regarding access. These included access being denied due to geographic boundaries, difficulties access inpatient services, and problems accessing services for people with dual diagnosis.

Things said here today resonate with the types of issues that are regularly presented to our offices: Access to inpatient services; Dual diagnosis; Acquired brain injury; People exhibiting self-harming behaviour

(Office of the Public Advocate worker, Queensland, Brisbane Forum #14)

I want to tell you about a couple of cases. The first one is about a young person who tried to seek help and was refused care because of a geographic boundary. Another consumer who pleaded guilty to something they didn't do just so they could get into a "better cell" – a 14 week prison sentence was better than being sick and homeless.

(Carer NGO worker, Queensland, Brisbane Forum #22)

I have personally had clients tell me of their experiences where they have been refused treatment or treated with disdain after presenting themselves at hospital for assistance and treatment for a mental health condition…

(Clinician, Queensland, Submission #105)

Considering the high rate of suicide amongst young people in Australia I find it absolutely appalling that when people do seek treatment and assistance they are refused, given minimal attention or are treated poorly by being labelled as being malingerers

(Clinician, Queensland, Submission #105)

This policy of keeping clients and clinics / hospitals tied causes more problems in the community. A client who was feeling unwell went to the Gold Coast hospital but was told to go to Caboolture, an impossible task for someone in his condition. Just imagine someone with appendicitis being told to get themselves to a different hospital! If a local address is supplied, they may be admitted: that is, psychiatric clients need to remember to tell lies in order to access treatment. In the absence of transition support with assurance of housing and support on release, prisoners also give fictitious release addresses.

(Anonymous, Queensland, Submission #67)

6.3.11.1.5 Equity – access for all – not just 'serious mental illness'

Concerns were also raised that access was being limited to those consumers with 'serious mental illness' and not, as stated in Standard 11.1.5 'equitable access to services for each person in the defined community'.

I have also noticed that the mental health teams in Queensland have narrowed their focus and are shifting the goal posts. What is the definition of serious mental illness? Why don't they define exactly for us who they will and who they won't treat. At least then we would know what we're dealing with.

(Supported Accommodation and Assistance Program Service Provider, Queensland, Brisbane Forum #2)

Someone used the term serious mental illness and talked about the gate-keeping that goes with respect to who gets care and who doesn't. Actually, it really depends on bed availability!

(Clinician, Queensland, Brisbane Forum #7)

In the public mental health system the word 'serious' is taken to be short hand for psychotic illness. For those of us who have exceptionally serious problems which, after a while, don't appear to have an organic base this is disastrous. With all my experiences, awful, awful experiences I now get extremely angry when people use the words Serious Mental Illness and exclude people like me. It feels like a really big kick in the guts when they do this and yet we still see it time after time.

(Consumer, Queensland, Submission #204)

6.3.11.1.6 Equity – access to psychologists easier for those who can afford to purchase care in the private sector

Standard 11.1.1 states: 'The MHS ensures equality in the delivery of treatment and support regardless of consumer's…socio-economic status'. However, one clinician in Rockhampton reported that if consumers required access to psychologists, these services are only available in the private sector, and scarce. This prevents people who can not afford to pay for such services from receiving the treatment they require.

For those people who need psychological services that sort of care is only available in the private sector. It's expensive and hard to access also.

(Clinician, Queensland, Rockhampton Forum #7)

There are also gaps in services for people with less severe disorders. For those people who need psychological services that sort of care is only available in the private sector. It's expensive and hard to access also.

(Clinician, Queensland, Rockhampton Forum #7)

6.3.11.1.7 Discrimination – past forensic status

A report was also received indicating that consumers were discriminated against on the basis of past forensic status. According to Standard 11.1.1 such discrimination is not to occur. Instead, the Standard states that: 'the MHS ensures equality in the delivery of treatment and support regardless of…past forensic status'.

For those who are released their files are tagged to indicate they have been in prison and then the staff of the mental health services don't want to treat them.

(Prison NGO worker and Consumer Advocate, Queensland, Brisbane Forum #5)

6.3.11.1.8 Lack of services for youth with drug and alcohol problems

Given the reports above regarding difficulties in accessing services, it was not surprising to hear that consumers with complex needs found even further barriers.

The key issues as I see them are the lack of support services available to young people with comorbid mental health and drug and alcohol problems. They are shafted between services. It's very difficult to get support services because of the lack of specific diagnoses.

(Youth NGO worker, Queensland, Brisbane Forum #6)

The established system (both in NSW and QLD) attempts to distinguish between mental health problems and drug and / or alcohol problems. I find this distinction to be short-sighted and extremely unhelpful. Many people choose to self-medicate mental health problems, which can result in drug dependency. It is indefensible that such people should be refused a service from Mental Health because they "have a drug problem" or from Alcohol & Other Drug Services because they "have a mental illness". I have been on the receiving end of both arguments at various times, when advocating for individuals seeking treatment.

(Clinician, Queensland, Submission #285)

6.3.11.1.9 Carers need to be heard

Another example supporting claims that a crisis is required before services are provided is that carers may be unable to initiate a response from services or are not heard.

…admitted to hospital, after having to see 5 different people for a decision to be made that he needed to be hospitalised, instead of taking notice of his mother, and 8 hours after arriving at emergency he was admitted to Psychiatric ward.

(Carer, Mother, Queensland, Submission #168)

6.3.11.2 Entry

The process of entry to the MHS meets the needs of the defined community and facilitates timely and ongoing assessment.

Under this Standard, submissions and presentations indicate concerns about:

- problems with entry via Emergency Departments;
- excessive amount of time between time of referral and time of assessment; and
- the amount of time between the assessment being undertaken and a diagnosis being made.

6.3.11.2.1 Problems with entry via Emergency Departments

Concerns were expressed about entry via emergency departments regarding problems with the assessment process and consumers having to repeat their stories many times. According to Standard 11.2.4: 'The entry process to the MHS can be undertaken in a variety of ways which are sensitive to the needs of the consumer, their carers and the defined community'. Notes to this Standard state that this process should be non-traumatic and non-damaging.

People with a mental illness also have to go through the accident and emergency department – they have difficulty in getting assessed.

(Anonymous, Queensland, Rockhampton Forum #13)

Standard 11.2.6 further states: 'An appropriately qualified and experienced mental health professional is available at all times to assist consumers to enter into mental health care'. One clinician reported the following problems with admission procedures.

When clients come through triage the client has to tell their story 5 or 6 times before they get to see a psychiatrist. I can't - as a worker in the community I cannot leave the client. They'll leave if I don't stay with them through the process. They have no other continuity.

(Clinician, Queensland, Rockhampton Forum #15)

Another issue of great concern for consumers and carers is the ongoing policy of having to take unwell Mental Health consumers to A&E [Accident and Emergency] at the Base Hospital for treatment / admission to Mental Health after hours – 'after hours' being between the hours of 4.30pm and 8.30am weekdays and all week-end. Considering these are high-incident times, this practice is totally unsatisfactory. As things stand currently, consumers / carers are required to sit for lengthy periods in the waiting-room at A&E until they are seen be a doctor who then contacts Mental Health. Car accidents and heart attacks take precedence over mental illness. (Earlier this year I had to take my husband to A&E at 11pm as a result of a psychotic reaction to new medication. We ended up leaving at 1.30am without ever having seen a doctor). It does not make any difference if you have a long history of mental illness and this episode is the same as previous episodes, consumers still have to go via A&E before you can access help from Mental Health.

(Carer, Wife and Mother, Queensland, Submission #52)

6.3.11.2.2 Excessive amount of time between time of referral and time of assessment

According to Standard 11.2.12: 'The MHS has a system which ensures that the initial assessment of an urgent referral is commenced within one hour of initial contact and the initial assessment of a non-urgent referral is commenced within 24 hours of contact'. One GP reported that the time between referral and assessments was usually 12 weeks.

As a GP who does a lot of mental health work and knows a lot of people in the system, I can get an assessment in 2 weeks if I pull strings – otherwise it is 12 weeks to get someone assessed.

(Clinician, Queensland, Brisbane Forum #7)

6.3.11.2.3 Amount of time between the assessment being undertaken and a diagnosis being made

The following report from a clinician raises concerns about the length of time between assessment, diagnosis and accessing the appropriate treatment and support services.

There is a single point of entry through the acute care team – they have an initial assessment and then a decision is made within a period of 4-5 weeks.

(Clinician, Queensland, Rockhampton Forum #7)

6.3.11.3 Assessment and review

Consumers and their carers receive a comprehensive, timely and accurate assessment and a regular review of progress.

Under this Standard, submissions and presentations indicate concerns about:

- carers and service providers not being involved or listened to during the assessment process;
- assessments focussing on risk;
- problems with the review process;
- high staff case loads;
- a lack of opportunity to obtain a second opinion; and
- long periods of time between reviews of involuntary orders.

6.3.11.3.1 Carers and service providers not being involved or listened to during the assessment process

According to Standard 11.3.5 the assessment process is 'comprehensive and, with the consumer's informed consent, includes the consumer's carers (including children), other service providers and other people nominated by the consumer'. However, evidence was presented indicating that carers and service providers who hold valuable information are being omitted from this process. These submissions indicated that as a result the patient was then inappropriately assessed and the requisite treatment and support were not arranged.

> *We know of 5-6 cases over the past few months. We don't wish to target Logan but we do wish to ensure that all Psychiatric Services including Logan lift their game to prevent further deaths. We point out that there has been a number of murders, police shootings/deaths in custody as a result of the initial assessment services not listening to the patient, patient's family and the police attempting in good faith to get help for the patient.*
>
> (White Wreath Association Inc, Queensland, Submission #81)

> *Such is the system that young registrars, untrained in psychiatry, are making judgements as to whether a person is mentally ill or not. (Qualified psychiatrists have difficulty doing this at times!) Thus appropriate help for the mentally ill is being denied and once again the carer is given no credence.*
>
> (Carer, Wife and Mother, Queensland, Submission #52)

> *That afternoon [X] was started on Zyprexa medication - appropriate for use in Bipolar Disorder and Schizophrenia. (I had been giving information since January 1999 which indicated [X] had these disorders, but no one would listen.) When is the system going to change and allow carers more input? We are the people who observe the most of our consumers' behaviours - a doctor usually only sees a consumer when he/she has 'pulled themselves together in an effort to appear well'. I am continually hearing this same story from carers.*
>
> (Carer, Wife and Mother, Queensland, Submission #52)

6.3.11.3.2 Assessments not focussing on mental health needs of consumer

Submissions were also received indicating concerns about the focus and purpose of assessments. One submission suggested that assessments appear to be focussing on assessment of risk of self harm or harm to others, rather than focussing on assessment for the purpose of determining treatment and support to halt deteriorating mental health and improve outcomes for the consumer.

The more recent shift though is firstly in the assessment process whether via a justice examination order or a voluntary assessment. I have witnessed and been told by case managers that the assessment in determining case management, hospitalisation or simply providing a service in whatever form, is based on risk, namely serious risk of self or others. This risk assessment though ***does not*** *include risk of deterioration of mental health. There appears to be little concept of early intervention in practice for adult services…or an unwillingness to implement it. For example I have witnessed an assessment of a seriously ill man who was unable to answer all the questions put to him by the registrar (because he couldn't concentrate or comprehend the questions, because he was so ill… The final analysis was "because we cannot determine whether you are a risk to yourself and others, go back on your medication and go home". (author's emphasis)*

(Anonymous, Queensland, Submission #113)

More recently a man with paranoid schizophrenia untreated and becoming increasingly paranoid was assessed via a JEO [Justice Examination Order]. The assessors provided feedback stating that while they agreed he was unwell, because he was not a risk to himself or others and because they could not prove or disprove his delusions of grandeur or beliefs that for e.g. aliens were coming to get him, that there was nothing they could do.

(Anonymous, Queensland, Submission #113)

6.3.11.3.3 Problems with the review process

One carer expressed concern with the management of her son's treatment during the review process which risked worse rather than improved outcomes for her son.

By this time, [X] seemed as if he felt he didn't really need to attend the unit as Dr [Y] had provided him with a script with seven repeats! I didn't even think this was possible. Dr [Y] apparently also increased the dosage. This meant that [X] was not being seen by anyone at Mental Health so his deterioration was going undetected.

(Carer, Wife and Mother, Queensland, Submission #52)

6.3.11.3.4 High staff case loads

As mentioned previously with regards to concerns about the lack of staff and overburdened staff (Standard 9 – Service Development), one clinician specifically raised concerns with regards to caseloads. According to the Standards the MHS is to have a process to monitor such loads. Standard 11.3.19 states: 'The MHS has a system for the routine monitoring of staff case loads in terms of number and mix of cases, frequency of contact and outcomes of care'.

We have case managers who have case loads of 20-30 people.

(Clinician, Queensland, Rockhampton Forum #7)

6.3.11.3.5 Lack of opportunity to obtain a second opinion

Standard 11.4.C.12 states: 'The consumer's right to seek an opinion and/or treatment from another qualified person is acknowledged and facilitated and the MHS promotes continuity of care by working effectively with other service providers'. A report from one carer suggests that either consumers and carers may sometimes be unaware of this right (and not informed of all their rights and responsibilities as soon as possible after entering the MHS – Standard 1.2) or this right to get a second opinion is not being actively promoted due to the scarcity of services and difficulty in accessing those that exist.

[The following are what I put as necessary] Patients right to have another medical opinion by widely supported practitioners or of their own choice.

(Carer, Father, Queensland, Submission #141)

6.3.11.3.6 Long periods of time before involuntary orders are reviewed

One carer expressed concern that reviews of involuntary orders were not occurring with sufficient frequency:

> *[The following are what I put as necessary] Involuntary patients to be taken before magistrate on each occasion with an early review by them.*
>
> (Carer, Father, Queensland, Submission #141)

6.3.11.4 Treatment and support

The defined community has access to a range of high quality mental health treatment and support services.

Under this Standard, submissions and presentations indicate concerns about:

- lack of support services for consumers to live in the community;
- lack of involvement of carers;
- lack of treatment and support services for youth;
- lack of treatment and support services for people with dual diagnosis (drug and alcohol);
- lack of services for people with Acquired Brain Injury;
- lack of services for people with personality disorders;
- lack of services for people with eating disorders;
- lack of appropriate treatment and support services for consumers in the criminal justice system; and
- lack of treatment and support for people with mental illness after release.

6.3.11.4.1 Lack of support services for consumers to live in the community

An underlying theme in many submissions was that treatment and support services are not available for consumers in the community to address their mental illness and assist with recovery, rehabilitation and integration back into the community. Standards 11.4.3 – 11.4.8 state that the MHS will 'ensure' or 'provide' 'access to a comprehensive range of treatment and support services' which are specialised with regard to age, stage in the recovery process, dual diagnosis, cultural factors, and which address 'the physical, social, cultural, emotional, spiritual, gender and lifestyle aspects of the consumer' (11.4.6). Additionally, Standard 11.4.10 states: 'The MHS provides the least restrictive and least intrusive treatment and support possible in the environment and manner most helpful to, and most respectful to, the consumer'. The statements below express concern about the lack of treatment and support received for consumers to recover and remain well in the community.

> *In the last 5 years, my mother has been to hospital approximately 20 times, and this may not seem like a great deal, but it is; especially when she arrives there because she has not had her medication, which her mental nurse is to administer via injection either weekly, fortnightly or monthly. Most recently my mother went without proper medication for 6 weeks! Yet no one felt it was important to inform her family of this, we are never informed of her progress or if there are any problems even though we have asked repeatedly.*
>
> (Anonymous, Queensland, Submission #82)

We have a son… with a mild intellectual disability… 22 years of age and remained in that job for ten years feeling a 'normal' part of the community. In 2001 our circumstances changed, our son was looking for a change of employment also… he applied for hospitality work on Hamilton Island… The move was obviously too much pushing him over the edge causing psychosis – he returned within a week a raving lunatic. We contacted our local hospital where he was admitted for 2/3 day treatment and discharged with no back up service as to rehabilitation, the only place being a 'drop in centre' with no stimulation. We had subsequent visits to a doctor at Queensland Mental Health Clinic together with a psychologist who visited periodically – a complete waste of time and money to pop in asking our son what he had been up to, which our son was not going to divulge honestly anyway through his illness eventually diagnosed as Schizophrenia.

(Carers, Parents, Queensland, Submission #150)

We went through months of absolute trauma because he wasn't kept locked up and given aggressive treatment when he needed it. It wasn't until I started sending emails to people at the top that we got any action.

(Carer, Mother, Queensland, Submission #168)

6.3.11.4.2 Lack of involvement of carers

Despite Standard 11.4.9 acknowledging the involvement of carers ('there is a current individual care plan for each consumer, which is constructed and regularly reviewed with the consumer and, with the consumer's informed consent, their carers and is available to them'), carers repeatedly reported being excluded from assessment and treatment planning. Given the reported problems with access and limited services available in the community, practices which involve carers to assist with the delivery of care and achieve the best possible outcomes for consumers would both help recovery and protect many rights of people with mental illness.

Any intervention on my part was resented by the medical staff and at one stage was told bluntly by my son's doctor to stop diagnosing (I must say this is the diagnosis he has finally been given – but that gives me no joy).

(Carer, Wife and Mother, Queensland, Submission #52)

With all of this confronting us as a family we were still told by the Public Health System that our son was OK. His illness was not taken seriously even though two previous [suicide] attempts were made. Our families concerns and our opinions were never acknowledged or taken into account.

(Carer, Mother, Queensland, Submission #81)

I was his full-time carer and always saw [X] on a regular basis, nearly every day. The hospital was not willing to listen to us… Maybe if the hospital had listened to our family or [X] or kept our son in hospital longer he would have had a chance. The mental health system also needs to start listening to the family members or the mentally ill person when they say they are unwell.

(Carer, Mother, Queensland, Submission #117)

Respondent B [family member]. stated, "I was completely ignored, completely!"… Respondent D. [family member] complained, "Rhetorical offers of help never eventuated!"… Respondents [family members] were made to feel like interlopers and were constantly disempowered and intimidated by 'expert professionals' with a 'cure at all costs' medical model mentality…

(Carer, Wife & Mother, Queensland, Submission #157)

At present the law is formulated to protect the consumer's rights and to ensure that they are not wrongly committed to mental institutions as happened in the past. However, I believe it has gone too far and often the consumers are still disadvantaged because they are now not getting the help they need. Often their very illness causes them to have lack of insight and their carers do not have any legal rights to be able to help them (if they are over 18 years). I believe if a consumers lives under the same roof as their carer, allows them to cook and care for them 24/7, buys and administers their medications, that the consumer is giving unwritten consent to that carer to be involved in every level of that care and this should be recognised by law.

(Carer, Wife and Mother, Queensland, Submission #52)

6.3.11.4.3 Lack of services for youth

As mentioned earlier in this Report (8.3 Integration) a paucity of services exist to provide treatment and support for children and youth in Queensland. Many submissions were received conveying this concern and many indicated that the services for this age group need to be broader in their approach than treatment just for 'mental illness' as other mental health problems and life crises were generally associated with this age group (e.g. behaviour problems, drug and alcohol, homelessness). Standard 11.4.3 ensures access to a 'comprehensive range of treatment and support services which are, wherever possible, specialised in regard to a person's age and stage of development'.

Young people's mental health services are the most difficult to access. Often they are told they are not sick enough and then told they can't get care because they have a comorbid drug and alcohol problem.

(Clinician, Queensland, Brisbane Forum #7)

For a decade, I've provided GP services at a health clinic for homeless young people. Sadly many are no longer alive. Now and then, I get a call to let me know. Last week a death in the park. Last month, a suicide.

(Clinician, Queensland, Submission #42)

My youngest son in 2003 had incredible mood swings, which based on what I know now could have been based on alcohol and marijuana abuse. I asked him to see Mental Health. They prescribed medication which, based on what the internet told me, was a front line treatment for bi-polar disorder. But no-one from Mental Health would speak with me on the cop-out of patient confidentiality. The so-called student counsellor at school was useless, and compounded the problems, whilst again refusing to bring family in on counselling and suggested treatment. It seems the Mental Health doctor invited [X] to bring me in on it, but he refused, so the doctor would not even talk to me.

(Carer, Mother, Queensland, Submission #91)

Finally I would draw your attention to the declining Queensland Government support for accommodation, particularly support for accommodation and inpatient treatment option for under 18s.

(Dr Bruce Flegg MP, General Practitioner and Liberal Shadow Minister for Health, Queensland, Submission #39)

A submission received from Queensland Health recognises the need for youth mental health services and discusses the Queensland Government's response.

The Future Directions for Child and Youth Mental Health Policy Statement (1996) outlines a need for acute treatment services with a 24 hour response capacity. From 1998 – 2001 specialised inpatient units for children and adolescents were commissioned at the Royal Brisbane and Royal Children's, Logan, Mater, Toowoomba, and Robina Hospitals. There are now 61 beds in Queensland providing a range of services to children and young people with serious mental health problems. This includes 10 beds at the Child and Family Therapy Unit at Royal Children's Hospital, which enables mental health professionals to work with families in a safe, specialised environment. In addition to the acute beds there are 15 beds at Barrett Adolescent Unit for adolescents with complex needs requiring longer term treatment and support.

(Mental Health Unit, Queensland Health, Queensland, Submission #311)

It should be noted that hospitalisation is potentially disruptive to a child or adolescent's normal life, including school, family, and social networks. Treatment in an inpatient setting therefore is seen as only part of the spectrum of intervention. Care and treatment of children and adolescents is conducted primarily on an outpatient basis by Child and Youth Mental Health Services (CYMHS).

(Mental Health Unit, Queensland Health, Queensland, Submission #311)

Almost every Health Service District in Queensland has a CYMHS, with approximately 280 staff across the state, working in areas from infant mental health to the mental health needs of young adults.

(Mental Health Unit, Queensland Health, Queensland, Submission #311)

6.3.11.4.4 Lack of services for consumers with dual diagnosis – drug and alcohol

Standard 11.4.7 states: 'The MHS ensures access to a comprehensive range of services which are, wherever possible, specialised in regard to dual diagnosis'. In the notes to this Standard, this includes dual case management with alcohol and other drug services. Concern was expressed that there are an insufficient number of such services to provide treatment and support to consumers with complex needs.

…there is an urgent need for an effective rapid access detox unit to address the increasing drift of young people to illicit drugs and subsequent MH disorders.

(Anonymous, Queensland, Submission #260).

The other "growth" area which is inadequately serviced is the management of substance abuse. It is important in managing substance abuse that treatment facilities are located in proximity to population centres as substance abusers often have reduced motivation and frequently experience transport difficulties.

(Dr Bruce Flegg MP, General Practitioner and Liberal Shadow Minister for Health, Queensland, Submission #39)

Service protocols are required urgently to ensure that both QHealth Mental Health and Alcohol and Drug Services collaborate with services outside their domains.

(Brain Injury Association of Queensland, Queensland, Submission #60)

6.3.11.4.5 Lack of services for consumers with mental illness and Acquired Brain Injury

The lack of mental health services to provide treatment and support for people with Acquired Brain Injury (ABI) was raised by the Brain Injury Association of Queensland. In particular, Brain Injury Association of Queensland noted that as many people with ABI have very complex needs in addition to mental health problems (e.g. drug and alcohol or intellectual disability as a result of the brain injury) many consumers fell through service gaps due to eligibility criteria. Standard 11.4.7 states: 'The MHS ensures access to a comprehensive range of services which are, wherever possible, specialised in regard to dual diagnosis'.

It is with sadness that we report that little has changed for people with acquired brain injury since the "Burdekin Report" in 1993, in particular for those with a dual diagnosis of acquired brain injury and a mental illness or psychiatric disorder. A substantial proportion of people with ABI have a dual disability including mental health, drug and alcohol and intellectual disability (in some cases a mental illness contributed to the individual's brain injury). Service eligibility is commonly denied to these people and they 'fall through the gaps'. The inability for people with ABI to access mental health services compounds and amplifies the complexities of psychiatric and drug related disorders. In extreme cases, individuals with ABI are being inappropriately contained within the criminal justice system.

(Brain Injury Association of Queensland, Queensland, Submission #60)

In the context of this extensive and all-pervasive unmet need, there are certain conditions and circumstances that, individually or in combination, place individuals and carers in a highly vulnerable situation… A number of people with mental illness acquire a brain injury and many people with an ABI develop serious depression or psychiatric disorders, which result in challenging behaviour. These people are denied access to mental health or specialised behavioural services that are vital to successful behavioural interventions. A parallel situation exists in regard to drug and alcohol abuse.

(Brain Injury Association of Queensland, Queensland, Submission #60)

People with ABI should be eligible for Mental Health and Drug and Alcohol services. A diagnosis of ABI and mental health or behaviour disorder should meet eligibility criteria for Mental Health Services. Mental Health Services have historically rationed services and excluded people with ABI. Mental Health Services also do not work well in collaboration with community supports. Mental Health Services require a 'cultural shift', which will likely only be initiated through a Whole of Government strategy.

(Brain Injury Association of Queensland, Queensland, Submission #60)

Alternative accommodation models need to be developed for people with disabilities at risk of inappropriately entering aged care facilities or the criminal justice system.

(Brain Injury Association of Queensland, Queensland, Submission #60)

Increased support is required for ageing parents who support people with a disability at home.

(Brain Injury Association of Queensland, Queensland, Submission #60)

6.3.11.4.6 Lack of services for people with personality disorders

Clinicians and consumers also raised concerns about the lack of services and discriminatory attitudes towards people with personality disorder.

As soon as anyone mentions the words Borderline Personality Disorder after your name you can just about be sure that some sort of punishment, derision, fob off, judgement or disdain is coming your way. Oh! How I hate this diagnosis. It's cruel and I believe does nothing that is the slightest bit helpful because it makes you feel like dirt.

(Consumer, Queensland, Submission #204)

Once you have a personality disorder label in your records it is almost impossible to get rid of it no matter what you do and no matter how much you try and redeem yourself. Whilst records remain in circulation that connects you with Borderline Personality Disorder you are destined to be treated offensively. The wost thing is that the more you try and defend yourself against it the more you seem to convince those observing you that you deserve it.

(Consumer, Queensland, Submission #204)

People with personality disorders and those who self harm are treated with contempt and a lack of understanding particularly by unit staff. There is little or no expertise in working with people with this disorder.

(Anonymous, Queensland, Submission #113)

There are limits on what we can do – impatient care is often contraindicated for people with a personality disorder.

(Clinician, Queensland, Rockhampton Forum #7)

But if you have Borderline Personality Disorder and you have been told that there is no treatment for that well in my view that's discriminatory when people are being told they can't get care.

(Clinician, Queensland, Brisbane Forum #7)

The suicide caused some reflection on my part. The 24-year-old was a troubled woman. I saw her 19 times over a two year period. She strode out of our final consultation, angry that I wouldn't prescribe strong sleeping tablets. She threatened to do something that would shock me. We both knew what she meant. Luckily for my own stress levels this episode took place months before her actual suicide…My patient had rapid severe mood swings and tendency to self-harm. She met the criteria for borderline personality disorder… This already disturbed young woman had problems dealing with the murder of a friend and I sought psychiatric help for her. She told me that community mental health service said she didn't have a mental illness. She was also assessed at a public hospital psychiatric unit and apparently told that she didn't need a psychiatrist. None of this surprised me, and I'm not blaming the clinicians who assessed her. Like most health care problems, the fault does not lie with individuals. They were merely following their training and, of course, to a degree restrained by the resources allocated to the public system. There was certainly nothing unique about the failure to achieve psychiatric support for this woman and I have been down this same path many times with many patients in many locations.

(Clinician, Queensland, Submission #42)

6.3.11.4.7 Lack of services for people with eating disorders

Clinicians, service providers and consumers expressed concerns about the lack of availability and quality of treatment and support services for people with eating disorders.

On a number of occasions I have sought admission for young female patients with life threatening eating disorders only to find that acute private care is almost unattainable. I have been advised by a leading eating disorder specialist that beds are so difficult in units that can handle this type of disorder that patients must be within imminent danger of death within less than seven days to meet their criteria for admission.

(Dr Bruce Flegg MP, General Practitioner and Liberal Shadow Minister for Health, Queensland, Submission #39)

In the public system it is even worse. Essentially patients are taken in to the public system at the point that they require to be admitted to intensive care. Clearly these patients need beds in a general hospital setting with psychiatric capabilities and sadly this is diminishing. The recent closure of the Wesley Hospital's mental health ward has further exacerbated an ongoing shortage of mental health beds in general hospitals and given the nature of eating disorders there is the need for a socialised unit within the public system that has the capability of assisting the mental health issue whilst providing general life saving medical care.

(Dr Bruce Flegg MP, General Practitioner and Liberal Shadow Minister for Health, Queensland, Submission #39)

6.3.11.4.8 Lack of appropriate treatment and support services for consumers in the criminal justice system

Although consumers who are subject to the criminal justice system are ensured access to a comprehensive range of treatment and support services (Standard 11.4.7) concerns were expressed regarding the availability and quality of such services. Problems were also raised regarding the lack of separate facilities for people with mental illness who are subject to the criminal justice system:

The prison psychiatrist was on leave for almost the entire time that my son was in prison so he received almost no psychiatric help during that time.

(Carer, Wife and Mother, Queensland, Submission #52)

I would also like to talk about the criminalisation of women in prison. In Queensland we've lodged a complaint with the Human Rights and Equal Opportunity Commission about the treatment of women in maximum security – it's a 54 placement Unit. The women in this unit are double belted, hand cuffed and left naked – the problem is there is no accountability… We are hoping for a national inquiry about women in prison.

(Prison NGO worker and Consumer Advocate, Queensland, Brisbane Forum #5)

There is minimal medical support – only 1 worker. Psychiatrists recommend drugs and bomb them out. 3 women have been diagnosed with Post Traumatic Stress Disorder from being in that unit.

(Prison NGO worker and Consumer Advocate, Queensland, Brisbane Forum #5)

Women don't have as much access to lower security prisons. Most stay in high security.

(Prison NGO worker and Consumer Advocate, Queensland, Brisbane Forum #5)

My son was in an extremely agitated state and when I spoke to an officer regarding his need to see a doctor he just said 'he'll be right'. The next day he appeared in court still in an agitated state, still in his blood –stained clothes and because he was regarded a danger to himself and others he was remanded to Etna Creek for 6 weeks! In those ensuing 6 weeks I spoke to people from the Criminal Justice Commission, Health Rights Commission, Members of Parliament, the director of Mental Health, Legal Aid and eventually the Human rights Commission and Anti-Discrimination. No-one it seemed could help my son! …It was the same blood-stained clothing he'd left our home in which meant he had been left in them from the early hours of Sunday morning until the Tuesday when he was given prison gear! This was in spite of the fact that he had fresh clothing available. Here was this injured, mentally ill young man trapped in the system for six weeks!…My son was given an eighteen-month probationary period and a conviction was recorded which has given him cause for concern ever since.

(Carer, Wife and Mother, Queensland, Submission #52)

Until housing and support does become available for people with a psychiatric disability, why are those people who do offend not housed in separate facilities, on a farm for example. In mainstream prisons those who are vulnerable and suggestible are suffering abuse and some are learning even more antisocial behaviours.

(Anonymous, Queensland, Submission #67)

Vulnerable persons should not be in mainstream prison, however it would be irresponsible to have no management strategy or community safeguard when a person does offend. It is proposed that a facility such as Westbrook or Boystown be dedicated to house and support approximately 400 people with a psychiatric disability who are presently reinstitutionalised in highly inappropriate facilities; that is, mainstream prisons. It is envisaged that in five years, the population of such a parallel facility would include people would dwindle, as housing and support, including transition support for people leaving a structured institutional environment, is improved. Moreover it is proposed that any vulnerable person who is inappropriately housed in mainstream prisons be afforded asylum in a parallel justice system. This would include people with intellectual impairment; acquired brain injury by physical trauma; acquired brain injury of organic origin (schizophrenia); autistic spectrum disorder; and vulnerable personality. It is expected that psychometric testing and assessment would identify those who are suffering unnecessarily under the present system."

(Anonymous, Queensland, Submission #67)

6.3.11.4.9 Lack of treatment and support for people with mental illness after release from prison

The lack of coordinated treatment and support services for people with mental illness post release was previously mentioned under Standard 8.3 with regard to the need for whole-of-government approaches to circumvent poor release outcomes. In particular, the lack of advocacy and support while in prison and the lack of transition planning were highlighted as critical areas of concern that suggest that the rights of prisoners with mental illness are not being promoted or protected while in prison or immediately post release.

> *The core issue is Housing. Corrective Services assumes, wrongly, that prisoners take up where they left off before incarceration. Many have no family support or any friends. With nowhere to go, prisoners supply an address for release that is not a long-term housing option and may not even be a short-term option. Because his place of living is uncertain, my son has asked to be supplied with a prescription for antipsychotic medication, as no connection can be established with a mental health clinic until a place of residence is given. As far as I know, it is not accepted policy to supply prisoners with scripts, but this request does highlight that, having been through the revolving door, he knows about the problems he will face.*
>
> (Anonymous, Queensland, Submission #67)

> *Compliance with medication and having secure, stable and affordable housing are the fundamentals of mental health management for people with serious disorders. Intensive post-release support is necessary until community links and support networks are established, and anxiety levels are reduced.*
>
> (Anonymous, Queensland, Submission #67)

> *The current release and management practices almost guarantee poor release outcomes. Furthermore my efforts to initiate transition planning are not encouraged by staff working for Health within Corrections. It would appear that the policy of Partnerships – which I see mention of in numerous letters and documents – has no meaning in the working lives of many public servants. Many prisoners have no support or advocacy. A dedicated support team in the prison working with a community support team could provide for better release outcomes.*
>
> (Anonymous, Queensland, Submission #67)

6.3.11.4.A Community living

The MHS provides consumers with access to a range of treatment and support programs which maximise the consumer's quality of community living.

Under this Standard, submissions and presentations indicate concerns about:

- lack of treatment and support services for consumers to live in the community without their health deteriorating;
- the lack of support for carers; and
- lack of family centred-approaches to treatment and support.

6.3.11.4.A.1 Lack of treatment and support services for consumers to live in the community without their health deteriorating

Reports were received describing the incredible strain that has been placed on families due to the lack of adequate treatment and support services for consumers and their families. One account in particular demonstrated the failure to provide consumer with the 'opportunity to strengthen their valued relationships through the treatment and support effected by the MHS'. It would also appear there is a lack of access to family-centred approaches to treatment and support (as stated in Standard 11.4.A.12). A report of the success of Project 300 indicates that positive outcomes can be achieved with adequate treatment and support in the community and integrated and coordinated care between agencies.

> *However since the system in Queensland has been de-institutionalised our family, my mother's parents and I, has born the brunt of having to care for her. She lived with myself and her parents on and off, when her delusions became too strong and she became violent we were left with no course of action but to take her to the hospital, where she would remain for a few months, sometimes only a few days before she would be released into our care again. More than half of the time within 48 hours, to a week, of her release we would be back at the emergency room when the medication had worn off and the delusions had returned full force and often she had lashed out at myself or my grandparents.*
>
> (Anonymous, Queensland, Submission #82)

> *The failure of the health care system in not treating people with mental health problems results in carers giving up on all treatments, programs and the health care system it self.*
>
> (Carer, Queensland, Submission #109)

> *We cannot leave him home by himself more than a couple of days, as he cannot be trusted to remember to take the medication. Mostly he does, but not always. There is also the worry that he will decide as he did earlier this year, that he had been well and out of hospital so long this time, he is obviously cured, and didn't need to take the medication anymore Luckily I managed to convince him to cut it down gradually, and that is what we did, but not anywhere near as far down as he intended. He is more aware, and active on the lower medication, but still not up to doing anything other than basic chores.*
>
> (Carer, Mother, Queensland, Submission #228)

> *The advent of Project 300 (a program that assisted people to move from long-stay psychiatric institutions into the community) provided the foundation for sector development. Despite some inherent problems, Project 300 was an extremely successful de-institutionalisation project. Much of this success was due to the central role of the non-government sector and the provision of public housing. Project 300 demonstrated that people could live high quality lives in the community provided that appropriate supports were in place and that there was a balance between the provision of clinical and psychosocial supports, and housing.*
>
> (Queensland Alliance of Mental Illness and Psychiatric Disability Groups, Queensland, Submission #218)

6.3.11.4.A.2 Lack of support for carers

One clinician also raised concern about the lack of support for carers of people with mental illness and felt this group of carers is discriminated against with regard to the amount and type of support received compared with carers of people with physical illness.

> *Carers of people with a mental illness lack support. There is such a disparity between how the system deals with carers of people with a physical disability and carers of people with a psychiatric disability.*
>
> (Clinician, Queensland, Brisbane Forum #23)

6.3.11.4.A.3 Lack of family centred approaches to treatment and support

As reported throughout this Report, concern was expressed about the incredible strain that has been placed on families as a result of an inability to access treatment and support at the earliest possible stage of onset of illness. For families, this was often further compounded by the lack of housing and accommodation options available for their family members.

Reports received also indicate a lack of family-centred approaches to treatment and support. Standard 11.4.A.12 states: 'the MHS ensures that the consumer and their family have access to a range of family-centred approaches to treatment and support' and Standard 11.4.A.11 states: 'The consumer has the opportunity to strengthen their valued relationships through the treatment and support effected by the MHS'.

The lack of access to other support services (e.g. respite, leisure, recreation, education, training, work, employment, respite, home and community care) also contributed to this strain for consumers and their families. Strain was also seen to emanate from discriminatory remarks made from members in the community towards family members, a general lack of community acceptance and increasing social isolation (family and individual).

> *He lives downstairs, and we live up… But we are getting older, and won't be able to do this for ever. His brothers will be unable to take him into their homes, and it would be nice for us to have a little freedom before we are too old to be able to enjoy it. My husband has just retired, but we will be virtually stuck at home, full time.*
>
> (Carer, Mother, Queensland, Submission #228)

> *Respondent F. cried, "The system sucks!" All nine respondents [family members] reported failed experiences with the Mental Health System. Lack of information about the nature of their relatives' diagnosis, lack of access to clinical and counselling support and community programs and minimal inclusion in care planning and treatment options were identified as major barriers to coping with their relatives' illness…*
>
> (Carer, Wife & Mother, Queensland, Submission #157)

> *To obtain a comprehensive narrative, the author conducted a small research project focusing on the impact on nine family members of persons living with mental illness. The project identified a significant number of traumatic physical, mental and emotional impacts, which had a disabling effect on these relatives. Listening to the stories of spouses, parents, children and siblings it became obvious that all respondents felt the mental health 'system' had failed them and their relative living and/or dying with mental illness.*
>
> (Carer, Wife & Mother, Queensland, Submission #157)

6.3.11.4.B Supported accommodation

Supported accommodation is provided and / or supported in a manner which promotes choice, safety, and maximum possible quality of life for the consumer.

> *My son had schizophrenia… I'm a nurse and I understand why he wasn't kept in hospital – you can't just keep people like him in hospital. What he needed was a halfway house. We need more money spent on after care and pre care – something staged that people can access when they don't necessarily need to be in hospital.*
>
> (Carer, Mother, Queensland, Rockhampton Forum #9)

Under this Standard, submissions and presentations indicate concerns about:

- the lack of available supported accommodation; and
- the lack of support for homeless people with mental illness.

6.3.11.4.B.1 Lack of available supported accommodation

Most people don't expect our loved ones to be wrapped up in cotton wool – what we would like is some sort of place where they could go after hospital and get support.

(Carer, Female, Queensland, Rockhampton Forum #16)

As noted previously in this Report (8.3 Integration), the lack of housing and accommodation options, and supported accommodation options in particular, for people with mental illness is of serious barrier to consumers attaining the 'maximum possible quality of life' and integrating and contributing to the community. Of particular concern was the reported lack of accommodation for youth with mental illness or mental health problems. The scarcity of services for this age group and inability for clinicians to intervene as early as possible, often has serious long term consequences. Not only were concerns raised with regard to lack of available places, but also with regard to lack of resources and staff to adequately provide such services.

There's a real lack of supported accommodation here in this town. We have 23 beds in our intensive unit but a very large geographic area to service – the difficulty is in finding accommodation for these people… We also have a number of hostels in town here

(Clinician, Queensland, Rockhampton Forum #7)

Since early 1996 my mother has been living in privately managed care facilities… somewhat decreasing the burden which has been placed on her parents and myself to care for her. However, this facility is not perfect, and is understaffed and without the resources and trained assistants to fully care for all of its residents. I have been told by the management of this facility that my mother is one of the most mentally ill people living there, and were her condition to worsen, in any way, they would no longer have the resources to care for her and she would have to return to us. I have to ask if these people, who are infinitely more skilled and better trained than either myself or my octogenarian grandparents, cannot care for my mother, then how can we? The only answer people have had for us, is that well, there isn't anyone else.

(Anonymous, Queensland, Submission #82)

Childers backpacker fire has forced closure of beds in hostels. 35% of people in this case have a mental illness but they haven't got access to appropriate medical care and housing.

(Supported Accommodation and Assistance Program Service Provider, Queensland, Brisbane Forum #2)

…issues that are regularly presented to our offices …People being kept in patent care longer than necessary because of lack of housing; Discharge planning – shunted into supported accommodation and hostels; Access to SAAP [Support Accommodation Assistance Program] services.

(Office of the Public Advocate worker, Queensland, Brisbane Forum #14)

Many families, particularly elderly parents / carers, are being placed under a lot of stress because of the severe shortage of suitable assisted accommodation for their mentally ill adult children who are unable to manage on their own. Most of them are worried sick about what will happen to their children when the carer dies. Will the consumer end up on the streets? This is the biggest fear for the parents of these consumers. Many of these consumers COULD manage their own home IF they had the ongoing support of a case manager. And I mean a case manager who visits a minimum of once per week. So the problem of eliminating case managers also affects the ability of consumers to live in society independently of their family. (author's emphasis)

(Carer, Mother, Queensland, Submission #10)

The Report of the National Inquiry concerning the Human Rights of people with a mental illness in 1993 found;

> *People affected by mental illness face a critical shortage of appropriate and affordable housing. The absence of suitable supported accommodation is the single biggest obstacle to recovery and effective rehabilitation.*

This is still the case; in fact I feel the problem has increased.

(NGO Service Provider, Queensland, Submission #40)

Homeless shelters, refuges and boarding houses are now functioning, defacto, as a major component of the accommodation provided by our society for thousands of Australians affected by Mental illness. This is completely unacceptable. It must have been acceptable because it has not changed. Homeless shelters are receiving more referrals from Acute Psychiatric Units to supply accommodation for their patients then ever before.

(NGO Service Provider, Queensland, Submission #40)

It was recommended that Supported accommodation for people with psychiatric disability must be established in all major metropolitan and regional centres. This should include crisis, medium-term and long term accommodation.

(NGO Service Provider, Queensland, Submission #40)

In September 2003, The National Council of Women Queensland took the following resolution to the National Council of Women Australia triennial conference in Perth:

> *Accommodation options for mental health clients. That NCWA requests all Australian governments to increase funding to provide a range of accommodation options for mental health clients, including supervised accommodation, so that wellness is facilitated. Accommodation, together with case management and transition planning, should be addressed as matters of great urgency.*

(Carer, Mother, Queensland, Submission #228)

A couple of years ago I tried to find somewhere he could live, where there would be some support to make sure he took his medication, remind him to have a bath regularly, and have his hair cut etc. Nothing was available, but he was not worried. He is quite happy to stay at home. "You are good for another 20 years yet mum." For the last 3 years I have been suffering from Polymyalgia Rheumatica, and am not sure that I will be. My current symptoms are in my feet, making it very painful to walk.

(Carer, Mother, Queensland, Submission #228)

As he had been assessed / worked with by CCU for 13 months…. I felt he had declined or showed no signs of progress in several areas and there are bound to be others: personal hygiene; financial responsibility; personal motivation; awareness – again I question his hearing ability; level of restlessness / pacing; raised level of smoking – in heath and cost terms needs addressed. From what I understand – he would not be a good candidate for living alone, although I believe an application has been raised with the Housing Dept for a flat? … [Z] expressed concern that they were unable to find ways to stimulate [X] and seemed to be waiting for [X] to "pull himself together". I doubt, having seen [X] that this approach can produce the potential results we all want.

(Carers, Parents, Queensland, Submission #150)

6.3.11.4.B.2 Lack of support for homeless people with mental illness

Concern was also expressed for one of the most marginalised groups in society, the homeless with mental illness. Concerns included the lack of organised treatment and support services for these consumers and the lack of options that can be exercised to protect them from self-harm.

Also, for 10 years I worked as a Welfare Worker in a Hostel for the Homeless, and was astounded that Mackay Mental Health could not institutionalise those who were totally incapable of living in society, not even in a home for the homeless.

(Carer, Mother, Queensland, Submission #91)

I had a lady staying with me and she had a mental illness and I took her home and she had nowhere to go. I went on a holiday and when I came back she had killed herself. Her case worker and I tried to get someone – but no one would take her.

(Anonymous, Queensland, Rockhampton Forum #10)

6.3.11.4.C Medication and other medical technologies

Medication and other medical technologies are provided in a manner which promotes choice, safety and maximum possible quality of life for the consumer.

Under this Standard, submissions and presentations indicate concerns about:

- the emphasis on medication.

6.3.11.4.C.1 Emphasis on medication

Reports were received expressing concern about the major emphasis of treatment for mental illness being a reliance on medication without regard to side-effects, overall well-being or other treatment options.

I'm also concerned that many people are treated for mental illness when the main treatment seems to be to whack them on large doses of medication – there aren't enough reviews of medication.

(Consumer, Queensland, Brisbane Forum #11)

Regulated patients in the community a disguised form of "enforceable" medication. Australia's high rate of medication by injection – forced compliance – "why so different in Europe?"

(Anonymous, Queensland, Submission #49)

Use of medication – most have severe side effects (impotence, constipation, weight gain (diabetes), thyroid damage, facial tichs) – medication given apparently without a regular review unless obvious damage is being done, little or no thought given to reducing doses of medication to see if the patient can function without symptoms on a smaller dose – power of the drug companies undisclosed risks (present scandal on anti-depressants) – respiridone the drug of choice in qld hospitals? "it's the cheapest & we don't know which one is going to work now do we?"

(Anonymous, Queensland, Submission #49)

By this time, [X] seemed as if he felt he didn't really need to attend the unit as Dr [Y] had provided him with a script with seven repeats! I didn't even think this was possible. Dr [Y] apparently also increased the dosage. This meant that [X] was not being seen by anyone at Mental Health so his deterioration was going undetected.

(Carer, Wife and Mother, Queensland, Submission #52)

6.3.11.4.D Therapies

The consumer and consumer's family / carer have access to a range of safe and effective therapies

Under this Standard, submissions indicate concerns about:

- lack of access to a range of accepted therapies.

6.3.11.4.D.1 Lack of access to a range of accepted therapies

According to Standard 11.4.D.2: 'The MHS provides access to a range of accepted therapies according to the needs of the consumer and their carers'. However, concern was expressed that access to such therapies in the public mental health system is difficult. These concerns further support the claims that there is an over reliance on medication as the preferred treatment of choice by clinicians in the public mental health system.

> *What talking therapies are available in the public system to be used instead of or in conjunction with medication?*
>
> (Anonymous, Queensland, Submission #49)

> *It is almost impossible to see a psychologist or psychotherapist in the public mental health sector these days. This is a disaster. Where have they all gone and why? Why do those of us who desperately need counselling and other talking therapies always seem to come last?*
>
> (Consumer, Queensland, Submission #204)

> *During the years I have been involved with the Rockhamptom Mental Health Unit the only option offered to consumers seems to be by way of medication. There is a real need for other options to be available instead of / or in conjunction with the use of medications.*
>
> (Carer, Wife and Mother, Queensland, Submission #52)

However, one consumer reported an ability to access non-medication based therapy:

> *What helped me in reclaiming my life… Starting a course of antidepressants (let me qualify: this helped with bearing the load – they don't cure anything); … Seeing a psychologist and undertaking Cognitive Behaviour Therapy (which is a very effective treatment for depression).*
>
> (Consumer, Queensland, Submission #313)

6.3.11.4.E Inpatient care

The MHS ensures access to high quality, safe and comfortable inpatient care for consumers.

> *I was admitted to hospital one night I had a serious overdose on drugs, trying to commit suicide, I explained this to the nurses in the Logan Hospital, they left me in a room by myself all night and released me at 6am the following morning and told me I was fine.*
>
> (Consumer, Queensland, Submission #73)

Under this Standard, submissions and presentations indicate concerns about:

- the lack of beds; and
- appropriate treatment and support not being provided in inpatient units.

6.3.11.4.E.1 Lack of beds

Treatment is typically brief and often people are released the next day; they are just kept in over night. This type of care is no good – it creates a revolving door – people just get sick again because they have been discharged early so the figures look good and someone else can have their bed. This is not good care.

(NGO worker, Queensland, Brisbane Forum #3)

The lack of available beds for acute care was also cited as a serious concern. Patients requiring admission were generally in desperate need of medical care, often life-saving medical care. It appears that the demand far exceeds the number of beds available which results in a whole series of other decisions which jeopardise the safety and rights of consumers: non-admission and returned 'home', admission and someone else who is still unwell is discharged to vacate a bed, admission to another ward, or, as indicated below, admission to child and adolescent facilities.

On a number of occasions I have sought admission for young female patients with life threatening eating disorders only to find that acute private care is almost unattainable. I have been advised by a leading eating disorder specialist that beds are so difficult in units that can handle this type of disorder that patients must be within imminent danger of death within less than seven days to meet their criteria for admission.

(Dr Bruce Flegg MP, General Practitioner and Liberal Shadow Minister for Health, Queensland, Submission #39)

Perhaps even more acute however is the difficulty in accessing in-patient beds. Let me focus on one particular area where services in Queensland are particularly lacking and that is in the area of eating disorders.

(Dr Bruce Flegg MP, General Practitioner and Liberal Shadow Minister for Health, Queensland, Submission #39)

In the public system it is even worse. Essentially patients are taken in to the public system at the point that they require to be admitted to intensive care. Clearly these patients need beds in a general hospital setting with psychiatric capabilities and sadly this is diminishing. The recent closure of the Wesley Hospital's mental health ward has further exacerbated an ongoing shortage of mental health beds in general hospitals and given the nature of eating disorders there is the need for a socialised unit within the public system that has the capability of assisting the mental health issue whilst providing general life saving medical care.

(Dr Bruce Flegg MP, General Practitioner and Liberal Shadow Minister for Health, Queensland, Submission #39)

We have four units with a total of 60 beds. Eight days is the average length of stay. 10 beds for dual diagnosis at Mater Hospital and we take referrals from across the State. The overflow is dealt with by child and youth mental health services.

(Clinician, Queensland, Brisbane Forum #10)

These admissions are never without drama, and it can take 6-8 hours in the waiting room before he is seen, and a few more hours to find a bed. The worry is that someone else who was not really ready to go home, might have gone to make room for him…

(Carer, Mother, Queensland, Submission #228)

In 2000 he was in Wacol hospital, and went walkabout. The voices told him to swim the river. He had already done that a number of times, and said so. So they said 'OK jump off this bridge'. "Stupid voices, they should have waited until the tide came in". He jumped 6 meters onto rocks under 18inches of water. Smashed both heels and a bone in one leg. He couldn't get out of the creek, and although he spoke to someone, they ignored him. He wasn't found until 28 hours later, during which time he had spent a night in the creek, wet and cold.

(Carer, Mother, Queensland, Submission #228)

> *After years of depression, on and off, Mum was finally Hospitalised in January this year… It was only towards the end of her stay in the Hospital I found out the Doctor there was the Resident Doctor. The whole time Mum was in Hospital she never saw a Psychiatrist once. When I queried this I was told the Doctor was working in consultation with the Specialist, but the Hospital system didn't have the funds to have a Specialist there all the time… She has now been taken off this wonder drug and there is talk of sending her home. I'm confused as to what the future now holds for my Mum as we go along with the Medical people on trust because we have no option. Mum hasn't seen a Psychiatrist since being in Hospital again this time, but what do I do? … I am telling this story because it's just one more person on the merry-go-round of mental health and I don't know where to get off and get more help for Mum.*
>
> (Carer, Daughter, Queensland, Submission #93)

A submission from Queensland Health discusses bed number and distribution. The submission notes that overall bed numbers have not declined since deinstitutionalisation was implemented in 1996.

> *All acute inpatient beds are now mainstreamed within general hospitals. The development of new services and the redistribution of existing services have resulted in improved access and continuity of care for mental health consumers across the state. Queensland Health currently provides facilities across a range of clinical program areas including inpatient services for adults (603); older people (35); children and adolescents (76); and extended treatment services in the areas of Dual-Diagnosis and Extended Treatment and Rehabilitation (348); Acquired Brain Injury (62); Psychogeriatrics (138); and Medium (99) and High Secure (71). Since the commencement of the reform process under the 10 year Mental Health Strategy (1996), Queensland has not reduced the overall number of inpatient beds in the State, which now number 1432. Queensland has, however, decentralised the beds from its large stand-alone mental health facilities at The Park, Baillie Henderson Hospital and Mosman Hall Hospital to other regional sites ensuring extended care services are provided closer to where people live and closer to their natural support networks.*
>
> (Mental Health Unit, Queensland Health, Queensland, Submission #311)

6.3.11.4.E.2 Appropriate treatment and support not being provided in inpatient units

Concern was expressed by carers that appropriate treatment and support was not being provided to their relatives while they were receiving treatment in hospital-based settings. Concerns ranged from short and non-helpful stays, without appropriate planning prior to discharge, and the lack of required aggressive treatment. Standard 11.4.E.1 states: 'The MHS offers less restrictive alternatives to inpatient treatment and support provided that it adds value to the consumer's life and with consideration being given to the consumer's preference, demands on carers, availability of support and safety of those involved'. One carer suggested that interpretation of 'less restrictive alternatives' needs to be considered in the spirit intended 'provided that it adds value to the consumer's life and with consideration being given to the consumer's preference, demand on carers, availability of support and safety of those involved' (Standard 11.4.E.1). In this instance, the family member achieved the best results when admitted to a secure ward and given 'aggressive treatment'.

> *On one of my mother's brief stays, my mum told dad that one doctor said to her what are you doing back here? As if to say, she was wasting his time. The result of this first class care was that in approximately twelve days mum was back there as a result of drinking Weed Killer, for yet another short and non helpful stay, and the Drug Addicts are still there. Yet again mum was sent back to her family's expert care.*
>
> (Carer, Son, Queensland, Submission #184)

> *My son then had to drive him from Logan to PA with a letter of admission. He was registered as an involuntary patient and 5 minutes after going through locked doors he was outside the hospital behind my son who had admitted him. We went through months of absolute trauma because he wasn't kept locked up and given aggressive treatment when he needed it. It wasn't until I started sending emails to people at the top that we got any action.*
>
> (Carer, Mother, Queensland, Submission #168)

6.3.11.5 Planning for exit

Consumers are assisted to plan for their exit from the MHS to ensure that ongoing follow-up is available if required.

Under this Standard, submissions and presentations indicate concerns about:

- inadequate planning prior to discharge
- planning for exit on the basis of need to vacate beds; and
- discharge occurring while consumers are still very ill.

6.3.11.5.1 Inadequate planning prior to discharge

One submission raised serious concerns about the inadequacy of discharge plans, and that sometimes they are not even instigated. Specifically, the allegation suggests that discharge plans have not been developed in collaboration with the consumer (Standard 11.5.2), that understandable information about the range of relevant services and supports have not been provided (Standard 11.5.4) and that consumers have not established contact with the service providers prior to exit (Standard 11.5.6).

> *There are very rarely discharge plans upheld or even instigated. A recent admission reported filling out her name and nothing else on the discharge plan and this was accepted as her plan. She was told she was to be discharged after a two-night stay, with very little contact and no one contacted her for 5 days. This person was drinking or taking excessive medication, cutting, then reportedly blacking out, each night. Their response was 'it's her choice'. Her obsessional thoughts were severe and constant and related to a service provider. She was told she could control them and why doesn't she go and talk to the person she is obsessed with… she had apparently threatened to kill the service provider, knew her phone number and where she lived, wrote poetry about the person and so on.*
>
> (Anonymous, Queensland, Submission #113)

6.3.11.5.2 Planning for exit on the basis of need to vacate beds

Concerns were expressed that discharge was not occurring to an agreed exit plan or health status of the consumer but rather according to the need to vacate beds for new admissions. Such exits could jeopardise the safety of the consumer, especially as entry is almost always on the basis of risk of actual self-harm or harm to others, and frequently results in almost immediate readmission. According to Standard 11.5.2: 'The exit plan is reviewed in collaboration with the consumer, and with the consumer's informed consent, their carer's at each contact and as part of each review of the individual care plan'. Also, according to Standard 11.3.18, a review should be conducted when the consumer is going to exit the MHS, presumably to ensure that exit is occurring at an appropriate stage of the recovery process.

> *Nurses told me when a patient is in emergency needing a bed, they do "eenie, meenie, miny, mo" around the ward and decide who can be discharged – whether or not they are well. On one occasion during the 6 month period my son was ill he was discharged and threatening staff while we were still standing in the ward waiting for his medication.*
>
> (Carer, Mother, Queensland, Submission #168)

6.3.11.5.3 Discharge while still very ill

Concerns were expressed that discharge was occurring without staff reviewing the outcomes of treatment and support (Standard 6.1). One carer reported that her son was discharged while very ill, which indicates that that an individual care plan had not been devised, and an exit plan (Standard 11.5.1) and clinical review of the consumer had not been conducted prior to discharge (Standard 11.3.18).

> *I was amazed on one of my visits to see my mother so distressed that after two days they were sending her home to us the family to give the care she had not received in the Hospital. May I add also that this particular incident occurred after her third attempt on life. She was so frightened because she knew she was not any better.*
>
> (Carer, Son, Queensland, Submission #184)

> *Then he was discharged while still obviously very psychotic, and 14 hours later his brother sat in an emergency room at the hospital for another 5 hours to have him re-admitted.*
>
> (Carer, Mother, Queensland, Submission #168)

6.3.11.6 Exit and re-entry

The MHS assists consumers to exit the service and ensures re-entry according to the consumer's needs.

Under this Standard, submissions and presentations indicate concerns about:

- inadequate or no follow-up; and
- suicide immediately after discharge.

6.3.11.6.1 Inadequate or no follow-up

Concerns were also expressed about the lack of follow-up, even if plans were arranged.

> *…people weren't followed up.*
>
> (Anonymous, Queensland, Rockhampton Forum #8)

> *It is very difficult to be admitted to the facility and in many cases there is no follow up and/or case management is kept to a minimum. But this is not always the case, some people are taken up or case managed long-term that are far less ill than others.*
>
> (Anonymous, Queensland, Submission #113)

> *[X] was in hospital for ten days (a long time by this unit's standards - they are usually sent home after only two or three days treatment almost as unwell as when they were admitted). He was discharged with one week's medication and was to see Dr [Y] in one week for a follow-up and to get scripts. Later in the week when I realised [X] was not given the time of the appointment, I called in at Mental Health to find out the actual time. Typically, no appointment had been made. After much difficulty, the earliest appointment for Dr [Y] was not until Thursday - [X] only had enough medications to do till Monday morning! When I pointed out this fact, I was introduced to a person from the Acute Care Team for advice - which was 'just see how [X] goes and if he has any trouble contact the AC Team'. I couldn't believe I was hearing this! I said 'of course he will have trouble, as soon as he misses a day's medication he will have trouble and what happens if this trouble occurs after 9pm when the AC Team has left?' It was only when I made it clear that I would not leave without the problem being resolved, that a doctor was called and a script was provided.*
>
> (Carer, Wife and Mother, Queensland, Submission #52)

I do believe that there has to be more follow up contact with people to make sure there [sic] on the right track from the acute care team or mental health workers.

(Consumer, Queensland, Submission #192)

6.3.11.6.2 Suicide immediately after discharge

As noted above, concerns have been expressed about the inappropriate discharge of consumers when they are still unwell. Such concerns are reinforced by the report below from a carer whose son died within 48 hours of discharge. When discharged, both the son and family raised concerns that he was still unwell.

My 23 year old son, [X] who suffered from schizophrenia for a period of about 7 years took his own life within 48 hours of being released from an acute psychiatric unit. [X] was released from hospital on the 1st June 2004 and died on 3rd June, 2004. [X] told medical staff at the hospital he was not well enough to leave but they insisted on discharging him. I felt he was not well enough to be discharged and knew there was no way they would keep him in hospital any longer. A nurse told me if patients do not leave the hospital when told, medical staff can have security guards remove them (patients). I believe the mental health system failed my son in a number of ways. They did not care to acknowledge that my son was still psychotic and he was released from hospital too early. Staff at the hospital were not willing to listen to our family about [X] and his illness.

(Carer, Mother, Queensland, Submission #117)

6.3.12 STORIES OF HOMICIDE AND SUICIDE IN QUEENSLAND

[X] was on medication and her father apparently had been going to the [Rockhampton Mental Health] Unit advising them of the changes in [X] but they (M.H.U) ignored her father's concerns. On [date] 2003 [X] went to the mental health unit seeking help as she was hearing voices. They turned her away (this has been confirmed by the Rockhampton Police). Approximately 4pm on [date] 2003 [X] (after returning home) stabbed her nephew [Z] aged 3 yrs 11 months approximately 6 times in the chest (I have since been advised [X] did exactly the same thing to [X] as she did to her own child 5 years ago). [Z] died not long after.

(Family Member, Queensland, Submission #43)

My son committed suicide 2 years ago. There are a lot of deaths here amongst indigenous youth. Before he killed himself my son went to the mental health unit and they told me he was suffering from behaviour problems – the perception was that because he was an indigenous young man that he was 'sloshed out'. We were told that he wasn't suicidal.

(Carer, Mother, Queensland, Rockhampton Forum #3)

I lost my son a few months ago. My son was a drug addict – he was popping pills all the time. Trying to rehabilitate. On the 19th August last year he had an appointment at the mental health service. The doctor changed his medication and gave him 4 prescriptions of methadone 20 tablets (10mg) – putting that prescription in his hand was like putting a loaded gun or a syringe of heroin in his hand – after that he had mood swings, other symptoms came back in a number of days. On the 23rd August, at 6am I found my son dead – he had taken half the box of methadone. I thought Methadone was a controlled substance. Why was my son given this prescription?

(Carer, Mother, Rockhampton Forum #4)

A cousin who worked for the blue nurses in NSW was looking for work. She couldn't get work any more because of her mental illness she ended up killing herself.

(Anonymous, Queensland, Rockhampton Forum #5)

My son had schizophrenia and he's now dead as well - he committed suicide. The community didn't understand and when people found out he had a mental illness they dropped him like a hot potato.

(Carer, Mother, Queensland, Rockhampton Forum #9)

I had a lady staying with me and she had a mental illness and I took her home and she had nowhere to go. I went on a holiday and when I came back she had killed herself. Her case worker and I tried to get someone – but no one would take her.

(Anonymous, Queensland, Rockhampton Forum #10)

Two consumers died at Xmas one who self harmed and took it too far – we referred him to the service as he was very distressed and out of control he was assessed by a case manager as ok but died within the following week; The second went to the service begging to go into the unit as he knew that when he got this depressed he was at risk – this was our experience in the past and he was hospitalised and kept safe; they refused on this occasion– he took his own life a couple of days later.

(Anonymous, Queensland, Submission #113)

Six years ago my husband took his own life after being released from Brisbane Hospital when staff knew that the previous evening he had attempted suicide. I could get no support or answers for his four children - even after writing to the Brisbane hospital ombudsman, the Brisbane Police, the coroner's office for an autopsy report. I engaged a lawyer … to no avail. I dropped the search for answers when the lawyer told me it was too hard. For years my children and I have had to carry the weight of their father's suicide with the only answer being that it was sad but too bad, there was nothing anyone could do. Well the Sunday program has raised all my angry again at the indifference of the Medical community of Queensland at the time and I still want answers for my children as to why the system failed their father.

(Carer, Wife, Queensland Submission #85)

My son [X], aged 19, and 5 and a half months prior to his death was diagnosed with schizophrenia, paranoia and severe depression. During this period we found lack of services, lack of treatment and no understanding by the wider community. During this period [X] tried to kill himself twice in one day. First by connecting the hose to the exhaust pipe of his car, and the second by taking an overdose of prescribed medication. [X] was rushed to the emergency of mental health by an ambulance however he still was not taken seriously by doctors and psychiatrists and allowed to leave after a short few days even though we his family and [X] himself insisted that he was not well enough to leave. [X] finally lost all hope and on the 29th of May 1999 he laid himself on a train track.

(Carer, Mother, Queensland, Submission #81)

The suicide caused some reflection on my part. The 24-year-old was a troubled woman. I saw her 19 times over a two year period. She strode out of our final consultation, angry that I wouldn't prescribe strong sleeping tablets. She threatened to do something that would shock me. We both knew what she meant. Luckily for my own stress levels this episode took place months before her actual suicide. The clinic's nurse was less fortunate, having much more recently experienced a similar interaction over a different issue. My patient had rapid severe mood swings and tendency to self-harm. She met the criteria for borderline personality disorder. There is increasing evidence that, rather than a wicked soul, dysfunction of the brain's limbic system underlies this condition. This dysfunction is often associated with past emotional trauma. Among my female patients, a history of childhood sexual abuse is common. This already disturbed young woman had problems dealing with the murder of a friend and I sought psychiatric help for her. She told me that community mental health service said she didn't have a mental illness. She was also assessed at a public hospital psychiatric unit and apparently told that she didn't need a psychiatrist. None of this surprised me, and I'm not blaming the clinicians who assessed her. Like most health care problems, the fault does not lie with individuals. They were merely following their training and, of course, to a degree restrained by the resources allocated to the public system. There was certainly nothing unique about the failure to achieve psychiatric support for this woman and I have been down this same path many times with many patients in many locations.

(Clinician, Queensland, Submission #42)

At this stage of my wonderful mother's sad story, it was having a huge affect on the whole family. The answer to my question to the doctor about how many attempts would be enough. Apparently the answer to that question as found out was five. Because on the fifth occasion, at approximately 1:30pm on the 15th October 2003, my mum decided to douse herself in petrol and set herself alight.

(Carer, Son, Queensland, Submission #184)

6.3.12.1 Case scenarios outlined by White Wreath Association:

Son 19 years of age attempted suicide. Rushed to hospital. Released after a few days. Threatened to kill himself on several occasions after being released. Family tried to seek help. Discovered no services in place what so ever. Family pleas for help ignored. Found dead 2 months later.

Male aged 33 attempted to kill himself with overdose of Alcohol / medication. Found and rushed to hospital. Released 2 days later. Found dead 1 week later.

Male 42 years of age. Attempted to kill himself and two children. Found in act. Taken to hospital. Released 3 to 4 days later. Found dead 2 weeks later.

Woman rang concerned about her daughter. Daughter has a two-year-old child and is constantly talking of killing herself and her two-year-old. Tried to intervene by seeking help for this woman. 1st Phone call was informed the psychiatrist's only works Monday, Wednesday Morning and Friday. 2nd Phone call there is nothing we can do unless she is assessed. 3rd Phone call because a family member did not ring we can't help you. Ask woman to contact us. 4th Phone call, office hours closed after 5PM please ring this number…. Case history of woman: - Brother suicided, Auntie Suicided, her own mother suffers severe depression and has attempted suicide. NO QUESTIONS EVER ASKED OF HER MENTAL STATE OR FAMILY HISTORY. (author's emphasis)

(White Wreath Association Inc, Queensland, Submission #81)

6.4 SOUTH AUSTRALIA

ANALYSIS OF SUBMISSIONS AND CONSULTATIONS FROM SOUTH AUSTRALIA AGAINST THE NATIONAL STANDARDS FOR MENTAL HEALTH SERVICES

In summary, information presented in this section was gathered from 31 submissions (see Appendix 8.3.4) and presentations made at community forums attended by approximately 120 people (see Appendix 8.1). A draft copy of this report was sent to the Premier and Minister for Health for comment. A partial response was received on 9 May 2005 and a further response on 12 May 2005 – both well after the extended deadline. An analysis of the response from the South Australian Government (reproduced in Appendix 8.4.4) and an overall review of mental health service delivery in South Australia is contained in Part 2.7.4.

6.4.1 STANDARD 1: RIGHTS

The rights of people affected by mental disorders and / or mental health problems are upheld by the MHS.

Under this Standard, a submission indicated concern about:

- the lack of information provided to consumers and their carers;
- the provision of information about rights; and
- the rights of carers.

6.4.1.1 Information not provided

Standard 1.8 states: 'The MHS provides consumers and their carers with information about available mental health services, mental disorders, mental health problems and available treatments and support services'. According to one NGO service provider this is not occurring. This is of concern on many levels with regards to consent, choice, the right of a person to know about their illness and the treatment plan (and any side-effects), and for carers to be informed regarding what is and will be happening and how they best support the consumer or access support for themselves.

> *Very limited written information was provided as "standard consumer information" and access to a more detailed outline of the program was only possible because I was allowed to see a copy and I then shared it with the family.*
>
> (NGO Service Provider, South Australia, Submission #233)

The lack of provision of 'standard consumer information' also implies that this consumer and family were not provided with a written or verbal statement of their rights and responsibilities as required by Standard 1.2 (Consumers and their carers are provided with a written and verbal statement of their rights and responsibilities as soon as possible after entering the MHS).

6.4.1.2 Consumers not informed of their rights

Concern was expressed that some consumers were not being provided with a written and verbal statement of their rights and responsibilities as soon as possible after entering the Mental Health Service (Standard 1.2) in a manner that was understandable (Standard 1.3). This was alleged to be occurring with both voluntary and involuntary patients.

> *Rights are not always explained to voluntary or detained patients.*
>
> (Consumer, South Australia, Submission #77)

6.4.1.3 The rights of carers

The Carers Association of South Australia raised concerns about the rights of carers and the need to develop a comprehensive policy on the role and function of carers to define their rights. They argued this was important as much of the care for people with mental illness is provided in the community by families and therefore they need to have some of their rights formally recognised:

> *The Carers' confusion, stress and tension are exacerbated by failure of the Mental Health system in SA to develop and adopt a comprehensive policy on the role and function of carers in the support of people with a mental illness. This has led to the situation where carers are either ignored by mental health professionals or patronised. At worst, the reaction of the mental health system professionals towards family Carers may be hostile.*
>
> (Carers Association of SA, South Australia, Submission #30)

> *However, it is common for Carers of people with a mental illness to experience a lot of rejection of their caring role, not only from their family member but also from the mental health service system.*
>
> (Carers Association of SA, South Australia, Submission #30)

> *There is a lack of acceptance by the Mental Health System of the Carers legal authority where Enduring Power of Guardianship is held by the Carer. This relates to many of the issues previously highlighted but also relates to:*
> - *The legal authority needing to be triggered by the incapacity of the consumer and this can be hard to define, assess and / or diagnose.*
> - *There is no central registration of legal orders such as Enduring Power of Guardianship / Attorney, so therefore the orders are not viewed as valid by professionals.*
> - *Consumers when unwell can verbally discredit the legal authority held by the Carer, making their legal standing ineffective.*
> - *Although Carers are mentioned in the Mental Health Legislation it is not elaborated upon and they are therefore not afforded rights within in the Mental Health System despite the fact that of much of the care in the community (in the area of mental health) is provided by families.*
>
> (Carers Association of SA, South Australia, Submission #30)

6.4.2 STANDARD 2: SAFETY

The activities and environment of the MHS are safe for consumers, carers, families, staff and the community.

Under this Standard, submissions and presentations indicate concerns about:

- lack of services for children and youth with behaviour problems; and
- requirement for staff to be trained to respond appropriately to aggressive and difficult behaviour.

6.4.2.1 Lack of services for children and youth with behaviour problems

According to the notes for Standard 2.2 'safety' is considered in the broadest terms: physical, social, psychological and cultural dimensions. Specifically, Standard 2.2 states: 'Treatment and support offered by the MHS ensures that the consumer is protected from abuse and exploitation'. According to reports received from both a carer and a teacher, children and youth with mental health issues and behaviour problems are being expelled and excluded from school due to their aggressive behaviour. This has been a result of an inability to access services to treat and support these children and youth. This also led to safety concerns for family members, teaching staff and other students at school.

> *His episodes can be quite abusive and destructive. When I try to help him at this time he threatens me and destroys my property… I am in fear of what [X] is going to do next, to me, to my property, and most of all to himself. This pattern has been our life since [X] was in Primary School.*
>
> (Carer, Mother, South Australia, Submission #195)

> *I have staff using the expulsion / suspension guidelines to exclude these kids. I have staff being attacked by kids who are on drugs. Because of a lack of services there's nothing left but to exclude these kids. Actually they really need care.*
>
> (Teacher, South Australia, Murray Bridge Forum #17)

The additional and unfortunate consequence of failure to access services is the potential to destroy relationships and disruption to education and future employment and life potential for these children and youth.

6.4.2.2 Requirement for staff to be trained to respond appropriately to aggressive and difficult behaviour

Concern was also expressed within treatment settings that nurses are insufficiently trained to 'understand and appropriately and safely respond to aggressive and other difficult behaviours' (Standard 2.4). This results in unnecessary use of force to control situations and jeopardises both the safety of consumers, staff and other consumers in treatment settings.

> *As a nurse academic and educator, I am aware that it seems that nurses often adopt or are directed to adopt a zero tolerance to aggression and violence, creating an often adversarial stance with patients and thus increasing the possibility of an aggressive episode. There is evidence of this in the recent report (2004) entitled 'Aggression and Violence in Health Care' by the Australian Patient Safety Foundation where patients were confronted by nurses for smoking in the wrong place and due to mismanagement, a nurse was assaulted and the patient punished and placed in seclusion. This is avoidable and unacceptable workplace practice. Patients deserve better care, nurses deserve high quality ongoing education and support to provide them with the skills and knowledge to care for people with difficult behaviours.*
>
> (Academic, South Australia, Submission #142)

6.4.3 STANDARD 3: CONSUMER AND CARER PARTICIPATION

Consumers and carers are involved in the planning, implementation and evaluation of the MHS.

Under this Standard, submissions and presentations indicate concerns about:

- the 'tokenistic' approach to consumer and carer involvement;
- lack of funding to support consumer and carer participation; and
- youth participation.

6.4.3.1 Tokenistic approach to consumer and carer involvement

An advocate was so convinced and exasperated with her experiences of consumers and carers not having a voice or role in the 'planning, implementation and evaluation of the MHS' that she stated:

> *We're at no risk of being threatened for speaking out because we're not being heard at all!*
>
> (Advocate, South Australia, Adelaide Forum #15)

This 'lack of involvement' and need was also confirmed by a clinician and another advocate at the same forum.

> *There is a token approach to consumer and carer participation – tokenistic responses. There is no carer and consumer input. No feedback.*
>
> (Clinician, South Australia, Adelaide Forum #11)

According to Standard 3.1 and 3.2 policies and procedures are implemented to 'maximise their roles and involvement' and 'the MHS undertakes and supports a range of activities' that maximise consumer and carer participation.

6.4.3.2 Lack of funding for consumer and carer participation

Related to the lack of meaningful consumer and care participation is the reported lack of funding allocated to support such activities.

> *There's a need for a rural consultation in areas like Port Augusta… There's also a need for consumers, carers etc to be heard and to be supported with funding.*
>
> (Advocate, South Australia, Adelaide Forum #15)

> *I've been involved in the Murray Mallee Consumer Advisory Group for 6-7 years. The first 3 years we funded ourselves. At the moment we are providing a wide service. Responsible for providing education, networking. We do all of this on a budget of $4,000 per year from the Murray Mallee Health Service. Our funding hasn't increased in the last four years.*
>
> (Consumer & Advocate, South Australia, Murray Bridge Forum #8)

> *Consumers and carers continue to be largely denied effective participation in both their personal treatment and in the development of effective service delivery systems.*
>
> (Clinician, South Australia, Submission #56)

6.4.3.3 Youth participation

Youth Affairs Council of South Australia (YACSA) emphasised the importance of participation by youth in reform processes to maximise health outcomes for children and young people. Mental health, drug and alcohol abuse and access to services (especially for young people in rural, regional and outer metropolitan areas) were noted as critical issues for consultation with young people:

YACSA welcomes a health reform process with a human rights perspective that identifies children and young people as a priority population group, and a reform process with a focus on community participation, as determined by the Generational Health Review. In general, health services for young people in South Australia are increasingly inclusive with regard to youth participation in service planning and delivery. YACSA notes that this should be encouraged, and that the need remains for youth health advisory mechanisms such as the now defunct Department of Human Services' Youth Views project. Council contends that such an approach is imperative if youth health issues are to be addressed adequately.

(Youth Affairs Council of South Australia, South Australia, Submission #38)

For a number of years, YACSA has recommended that the State Government establish and resource a youth health advisory mechanism to provide advice to the Department of Human Services on policy and strategic issues aimed at maximising health outcomes. With issues of mental health, sexual health, drug and alcohol abuse and access to services (particularly for young people in rural, regional and outer metropolitan South Australia), there is an urgent need to act on the implementation of an appropriate advisory structure to the Minister for Health. Given the Generational Health Review emphasis on regionalisation and community participation, YACSA recommends that the Department of Human Services establish a number of regional Youth Health Advisory Committees in key, strategic locations as determined through the process of decentralising the existing health system. YACSA envisages that the Committees would comprise relevant departmental officers and non-government stakeholders in the youth, community and mental health sectors, as well as representation from young people / consumers. YACSA further recommends that the structure of the Committees be based on the previously successful Youth Views young consumer participation model, with executive support to be provided by existing staff.

(Youth Affairs Council of South Australia, South Australia, Submission #38)

6.4.4 STANDARD 4: PROMOTING COMMUNITY ACCEPTANCE

The MHS promotes community acceptance and the reduction of stigma for people affected by mental disorders and / or mental health problems.

Under this Standard, submissions and presentations indicate concerns about:

- the high levels of stigma and discrimination still being experienced by people with mental illness;
- feelings of isolation – rejection by family members and the community;
- discrimination directed towards children of parents with mental illness;
- non-acceptance by mental health workers;
- discrimination in employment; and
- stigma and stereotypes perpetuated by the media.

Members of the wider community often have inaccurate perceptions of mental illness, leading to further isolation and exclusion of those who are unwell.

(Health and Community Services Network, Murray Mallee Strategic Task Force, South Australia, Submission #115)

6.4.4.1 High levels of stigma and discrimination

Carers and advocates continue to express concerns about the high level of stigma and ostracism still being experienced by people with mental illness. This would indicate that campaigns and activities to address community acceptance and reduce stigma (Standard 4.1) to date have not been able to turn community attitudes around. As described below, discrimination and lack of community acceptance are key barriers to people with mental illness (and their family members) being able to participate socially, economically and politically in society. Social isolation is often the result.

> *There is a great stigma being attached to having a mental illness.*
>
> (Advocate, South Australia, Adelaide Forum #15)

> *In the early years of my mental illness I felt self conscious and didn't like to bother my doctor over my mental illness. As time went by I became used to seeing my GP every two weeks without feeling bad about taking up his time on a regular basis. Feeling this way is caused by stigma, devaluing myself and my frustration at taking years to get well.*
>
> (Consumer, South Australia, Submission #77)

> *I have 2 sons who have schizophrenia. [X] (eldest son) had a bad breakdown so we decided we would move to a small community to give him a better chance at life but the stigma here was very bad – when our sons went to the pub for a drink the locals would move away from them.*
>
> (Carer, South Australia, Murray Bridge Forum #10)

> *My elder son and myself are [X]'s sole supports.*
>
> (Carer, Mother, South Australia, Submission #279)

> *Finally I have lost some friends because they could not accept or cope with my mental illness. My new friends have their own mental illness and we meet to socialise and support each other but not in an integrated community way.*
>
> (Consumer, South Australia, Submission #77)

In the absence of services to educate the community and services to support integration, family members have reported going to great lengths to assist in this process.

> *On one occasion when my son was ill he frightened some people in the town and when he was in hospital I put an advertisement in the paper to thank the police for their help but also to try to educate the community that he had received treatment and was not a threat to them. It didn't really help.*
>
> (Carer, South Australia, Murray Bridge Forum #10)

> *I have a family member with a mental illness, and I have encouraged my family member to become involved in the community.*
>
> (Carer, Family Member, South Australia, Adelaide Forum #2)

6.4.4.2 Feelings of isolation – rejection by family members and the community

Concern was expressed that stigma and lack of understanding still shape community behaviour and result in the exclusion of people with mental illness in social and workplace settings, and often this behaviour extends to close family members and intimate partners, resulting in relationship breakdown. Standard 4.1 states: 'The MHS works collaboratively with the defined community to initiate and participate in a range of activities designed to promote acceptance of people with mental disorders and / or mental health problems by reducing stigma in the community.' As the following quotes indicate, the need for activities to promote community acceptance not only for the community but for family members as well is critical:

> *Stigma within the family has been great, as well as in the community. These people need more supported housing and employment options, desperately. There also needs to be more community awareness about mental illness.*
>
> (Family member, South Australia, Submission #6)

6.4.4.3 Discrimination directed towards children of parents with mental illness

The extent of the problem with regards to the high level of stigma in South Australia is evidenced by reports of discrimination experienced by children of parents with mental illness:

> *There is still a stigma in the Mallee against people with a mental illness (especially if they were not born and bred in the Mallee). This also leads to discrimination against the children of parents with a mental illness.*
>
> (Health and Community Services Network, Murray Mallee Strategic Task Force, South Australia, Submission #115)

> *Because my kids don't get any support, in fact they get teased about having a father who is mentally ill, they then come home and take it out on me; tell me I'm nuts or I'm a loony.*
>
> (Consumer, South Australia, Murray Bridge Forum #1)

6.4.4.4 Non-Acceptance by mental health workers

Many consumers and carers also expressed concerns about the lack of acceptance and understanding and what they labelled as discriminatory attitudes shown by some service providers. This is of particular concern given that consumers must come directly into contact with mental health service providers and their views impact directly upon them and their carers:

> *South Australia has a mental health care system of quick fixes and is staff orientated. In my opinion, mental health services staff are overwhelmingly repulsed by the symptoms of mental illness. What is required is change to a consumer-oriented system that recognises 'fine minds'.*
>
> (Consumer, South Australia, Submission #41)

6.4.4.5 Discrimination in employment

Employment and a supportive workplace are seen as key factors in preventing the rapid escalation of mental illness and as being essential in the process of rehabilitation and reintegration into society after a period of mental illness. Standard 4.2 states: 'The MHS provides understandable information to mainstream workers and the defined community about mental disorders and mental health problems'. However, acceptance and understanding of mental illness seem to be lacking in the workplace and discrimination and high levels of stigma are still prevalent in workplace settings:

Employment potential is nil as no one would employ someone who has had a mental illness and been out of the workforce for any length of time such as my ten years so far. The stigma and bias against mentally ill people puts paid to reemployment.

(Consumer, South Australia, Submission #77)

In respect to employment a person can have extended sick leave for a physical ailment or condition but if mentally ill it may be impossible to return to work. A period of mental illness is not looked on favourably by an employer. Applying for work knowing one has been mentally ill for ten years as is the case for me is exceedingly difficult because of stigma. It is assumed I cannot cope with daily life but if I had a broken leg or a bad heart no one would judge me in relation to coping with daily life let alone work. I don't have the right of a job or the right to suffer an illness without bias. Although I do voluntary work at school five days a week for a half hour per day I can't work but if it was possible I might be able to work part time in the future.

(Consumer, South Australia, Submission #77)

6.4.4.6 Stigma and stereotypes perpetuated by the media

Concerns were also raised that any activities by the MHS to reduce stigma in the community must also address education of media personnel to modify their portrayal of people with mental illness and comparative references.

In my opinion there is considerable stigma attached to being mentally ill. The media often reports on certain mentally ill people as being dangerous and frightening. My mentally ill friends and myself are nether dangerous or frightening. Our society expects that people get physically sick but if a person becomes mentally ill for a time they are told unkindly to pull their self together. No understanding is entered into.

(Consumer, South Australia, Submission #77)

6.4.5 STANDARD 5: PRIVACY AND CONFIDENTIALITY

The MHS ensures the privacy and confidentiality of consumers and carers.

Under this Standard, submissions indicated concern about policies and procedures to protect privacy and confidentiality.

6.4.5.1 Staff applying privacy and confidentiality rules without authority or ignore or do not request permission from consumer to share information or involve carers

The Carers Association of South Australia expressed concern that misunderstanding or rigid application of policies and procedures to protect the confidentiality and privacy of consumers is impeding communication between consumers, carers and clinicians in the provision of treatment and the sharing of vital information. These concerns indicate that policies and procedures related to privacy and confidentiality may not be made available to consumers and carers in an understandable language and format (Standard 5.2) and that the mental health system is not encouraging and providing opportunities for consumers to involve others in their care (Standard 5.3). The following quote indicates the level of frustration and despair experienced by carers:

> *Doctrines of confidentiality and privacy of adult patient information are often interpreted by some professionals and adhered to so strongly within that Carers are intentionally not provided with information about medication, treatment and progress. Also, they are frequently denied linkages with those treating the consumer, even though Carers are expected to support and manage the care of the consumer in the community. The reality is that care provided in the community by family members frequently occurs without recognition from the mental health system, the professionals, or the general health care and primary health care sectors.*
>
> (Carers Association of SA, South Australia, Submission #30)

While the following report from one carer suggests that the incident occurred some time ago, it nonetheless demonstrates the negative consequences to relationships that can follow from the total exclusion of carers in the treatment process and failure of carers to be informed (Standard 5.2) and clinicians to understand and apply appropriate privacy and confidentiality policies and procedures:

> *I was married to a paranoid schizophrenic and did not know… No Dr. would tell me – ethics, the result was, this "man" totally destroyed my life, and there was not a thing I could do about that legally… I am still trying to "pick myself up off the floor", but sadly never will.*
>
> (Carer, Wife, South Australia, Submission #148)

6.4.6 STANDARD 6: PREVENTION AND MENTAL HEALTH PROMOTION

The MHS works with the defined community in prevention, early detection, early intervention and mental health promotion.

Under this Standard, submissions and presentations indicate concerns about:

- the lack of focus on prevention in mental health services;
- lack of services for children and youth; and
- lack of rehabilitation programs and recovery services.

6.4.6.1 Prevention not a focus of mental health services

The Health and Community Services Network (Murray Mallee Strategic Task Force) made particular mention of the lack of a preventive focus in mental health services in South Australia.

> *The mental health system still has its focus on acute care at the expense of preventative work and community supports. South Australia spends a lower proportion of its mental health budget on community based supports than other mainland states.*
>
> (Health and Community Services Network, Murray Mallee Strategic Task Force, South Australia, Submission #115)

Indeed, Standard 6.1 states: 'The MHS has policy, resources and plans that support mental health promotion, prevention of mental disorders and mental health problems, early detection and intervention.' Evidence presented in other sections of this Report support the above claim of a lack of community services to intervene early and therefore avert the need for acute care. This focus on the provision of acute care and hospital based services, rather than community based care, is also contradictory to Standard 6.6 'Treatment and support offered by the MHS occur in a community setting in preference to an institutional setting unless there is justifiable reason consistent with the best outcome for the consumer.'

Another aspect of prevention is to assist consumers to identify 'early warning signs of relapse and appropriate action' (Standard 6.7). Evidence was also presented that sufficient information with regards to prevention and mental health problems is not being provided at either a community, individual or carer level.

> *There is a general lack of awareness and information about mental illness, so that those affected and their friends and family members may not realise that they are becoming unwell.*
>
> (Health and Community Services Network, Murray Mallee Strategic Task Force, South Australia, Submission #115)

6.4.6.2 Lack of services to provide early intervention for youth is a critical problem

> *…others who unfortunately enter the system from "Boys Homes" because of existing childhood problems seemed trapped in a vicious punishment cycle. They need desperate help for their symptoms, not continual punishment. This 'lockup the too hard basket' attitude makes it almost impossible for people like [X] who have had an abusive childhood combined with mental problems to survive. This is no way to help a person with psychiatric problems who is suicidal. The system seems to be continuing the abuse his father started. He never had any time with out abuse to get his life together.*
>
> (Carer, Mother, South Australia, Submission #195)

The availability of services to provide treatment for children and youth with mental illness or mental health problems is critical in terms of averting serious life repercussions. Standards 6.4 ('The MHS has capacity to identify and appropriately respond to the most vulnerable consumers…') and Standard 6.5 (' .. as early as possible') are clearly not being met according to the concerns expressed in this Report. The concerns expressed here follow concerns previously expressed under Standard 2 (Safety) with reference to protecting the social and psychological wellbeing of children and youth.

> *We just don't have the resources to support these kids so the schools call the police. Yes we have other avenues, other services but how do we access these – the waiting lists are sometimes 18 months. These kids do not complete their education and they end up in a life of trouble – a horrendous situation – we have the mandate to keep the schools safe – but it's too hard.*
>
> (Teacher, South Australia, Murray Bridge Forum #17)

> *This pattern has been our life since [X] was in Primary School. The cycle has to be broken, as we all deserve a better quality of life…*
>
> (Carer, Mother, South Australia, Submission #195)

6.4.6.3 Lack of rehabilitation programs and recovery services

Rehabilitation programs are acknowledged as a critical step in the reintegration process back into full life after a period of illness and the prevention of relapse for many people with mental illness. Such programs would include living skills programs, respite and social programs. Standard 6.8 states: 'The MHS ensures that the consumer has access to rehabilitation programs which aim to minimise psychiatric disability and prevent relapse'. Concern was expressed by one consumer that he has been unable to access any rehabilitation programs in his area:

> *Sadly my mental illness has led to me being ill from 1994 to 2004. I am still ill but despite no available rehabilitation program of any sort I try to do voluntary work and do things at home when I can.*
>
> (Consumer, South Australia, Submission #77)

Information about mental illness for patients and their families is not forth coming and there is not therapy or rehabilitation in the country such as Murray Bridge in SA. I have spent ten years 1994-2004 doing my own rehabilitation. I was a social worker prior to becoming very mentally ill.

(Consumer, South Australia, Submission #77)

6.4.7 STANDARD 7: CULTURAL AWARENESS

The MHS delivers non-discriminatory treatment and support which are sensitive to the social and cultural values of the consumer and the consumer's family and community.

Under this Standard, submissions and presentations indicate concerns about:

- the lack of culturally appropriate practices for Indigenous people;
- lack of culturally appropriate practices for consumers from a non-English speaking background; and
- the need for culturally appropriate mental health programs for newly arrived young people

6.4.7.1 Lack of culturally appropriate practices for Indigenous people

Evidence was presented which suggests that mental health services have not been planned and delivered in a manner which 'considers the needs and unique factors of social and cultural groups represented in the defined community and involves these groups in the planning and implementation of services' (Standard 7.2).

I'm an Aboriginal Mental Health Worker for the region. Gender issues are a real problem. I've got a case-load of roughly 20, plus their families and then I get new referrals, though many indigenous people do not access services anyway. There's a gender problem too which makes it even harder because some Aboriginal males can not approach female psychiatrists and females won't approach male psychiatrists.

(Clinician, South Australia, Murray Bridge Forum #4)

When indigenous people become unwell they are all put in baskets, they either have a mental illness or a drug and alcohol problem. There's no holistic care. There have been 20 close deaths in my family.

(Anonymous, South Australia, Murray Bridge Forum #15)

However, the Medical Specialists Outreach Assistance Program, funded by the Federal Government, has improved Indigenous services to South Australia's rural and remote communities by providing culturally sensitive mental health services to Aboriginal people in their own communities.

…significant progress that has been made in Sth Aust during the last 2 years in the development of outreach psychiatric services to remote communities in SA under the Medical Specialists Outreach Assistance Program funded by the Federal Govt. They describe the efforts of a group of Adelaide based psychiatrists to provide culturally sensitive mental health services to Aboriginal people in their own communities. The practice model used is that of a Consultation / Liaison model which emphasises the support and upskilling of the local mental health workers. This is a new application of the C-L model. It appears to be reasonably successful in delivering sustainable services to rural and especially remote areas.

(Clinician, South Australia, Submission #274)

6.4.7.2 Lack of culturally appropriate practices for consumers from a non-English speaking background (NESB)

Comments were received which suggests that mental health services have not been planned and delivered in a manner which 'considers the needs and unique factors of social and cultural groups represented in the defined community and involves these groups in the planning and implementation of services' (Standard 7.2). Concern was expressed that even though culturally appropriate practices could be enhanced by a variety of strategies, for example, redesigning job descriptions or employing staff from a variety of backgrounds, organisational support and sufficient resources are not available to enable this to occur. Also, concern was expressed that where strategies had been devised by staff to improve service delivery to consumers from a NESB, proposals have been allegedly ignored:

> *A recent such example comes from a clinician concerned with access and equity and appropriateness of assessment and treatment methods for persons of diverse linguistic and cultural backgrounds. When past reform initiatives encouraged staff to critically assess their practice and methods with respect to these issues, this, and other clinicians developed some proposals which responded to the National Standards for Mental Health Services, as well as policies and regulations within the State Public Service and specific health services / regions. These proposals were met with contempt, not deserving of even the acknowledgement of being received, in spite of the promise by the current Minister for Health, when in opposition, that, if elected, she would give it serious consideration. All the way down the hierarchy, resistance to suggestions from the "battlefront" were shoved aside and ignored. The response of management has consistently been to stonewall such proposals, to never respond to them, never to reject them on the basis of rational/objective criticism, but to simply ignore them, in spite of these proposals being re-submitted, adjusted to new circumstances and knowledge etc. Over more than 5 years this particular clinician submitted proposals that were essentially costless, but required a minimal reallocation of existing resources, while providing an important qualitative improvement to access and equity and appropriate assessment and treatment approaches.*
>
> (Clinician, South Australia, Submission #56)

> *The marginalisation / denigration takes different forms. One has been the withholding of an appropriate and relevant Job Description for many years, up to the present time, in spite of regular requests from the concerned clinician, many meetings and vague promises. Another form has been the constant verbal character assassinations of the clinician as racist because of [his / her] focus on non-Anglophone immigrants, to [his / her] face and to others, or on the phone. The team leader felt so confident of being at least passively supported by [his / her] superiors that [he / she] eventually lodged a memo to the Service Director accusing the clinician of being racist in [his / her] patient / client selection. Higher management did not respond to this memo, other than making the verbal comment to the clinician that "well there are people who think you should see more English speakers", ignoring the fact that this clinician was the only practicing multilingual staff member of [his / her] service of about 50 staff, and that no other staff member was being asked to see more non-Anglophone patients / clients, in a region where more than one third of the total population is of non-English speaking background, and the rate of referral of persons of non-English speaking backgrounds is in excess of 40% on average over time. This clinician has sought to have the issue of these accusations addressed, but so far unsuccessfully. This is only one example, but it clearly illustrates an organisational culture paralysed by lack of forward looking principles, lack of any ideas of how to put into practice the existing principles of mental health reform contained in the National Standards for Mental Health Services and the mental health reform agenda in general, and an organisation which resorts to tactics of petty repression, bullying etc to maintain the status quo of bureaucratic politics, in a textbook case of sociological / organisational dysfunction.*
>
> (Clinician, South Australia, Submission #56)

6.4.7.3 The need for culturally appropriate mental health programs for newly arrived young people

The Youth Affairs Council of South Australia (YACSA) raised concerns about the need for culturally appropriate mental health programs for newly arrived young people:

> *YACSA's report Out of the Mist: Young People, Emotional Well Being and Life Choices, prepared in conjunction with the Migrant Health Service and the Adelaide Central Community Health Service, contains several recommendations for increasing the effectiveness of mental health services provided to newly-arrived young people. Given the State Government's commitment to culturally appropriate mental health programs, and its pledge through the Platform for Government to ensure that CLDB [Culturally and Linguistically Diverse Background] young people, particularly those who are newly arrived, have access to the services they need. YACSA proposes that a centralised peer support training program be established. This could possibly be in collaboration with TAFE and Multicultural Youth South Australia, to provide trained youth peer support workers from relevant communities to work with community agencies to support newly-arrived young people, from a mental health perspective. Such a project might be modelled on the Cornerstone project currently being run by the Adelaide Central Mission and the Migrant Health Service. Peer support workers would be appropriately trained to work with the relevant issues and would receive ongoing support in their roles.*
>
> (Youth Affairs Council of South Australia, South Australia, Submission #38)

6.4.8 STANDARD 8: INTEGRATION

6.4.8.1 Service integration

The MHS is integrated and coordinated to provide a balanced mix of services which ensure continuity of care for the consumer.

> *People could be placed in the hospital without any mental health workers.*
>
> (Clinician, South Australia, Murray Bridge Forum #14)

Under this Standard, submissions and presentations indicate concerns about:

- problems with continuity between adolescent and adult mental health services;
- the link between mental health services and general practitioners; and
- integration with NGO services.

6.4.8.1.1 Problems with continuity between adolescent and adult mental health services

> *There is a lack of continuity between Child and Adolescent Mental Health Service (CAMHS) and adult mental health services.*
>
> (Health and Community Services Network, Murray Mallee Strategic Task Force, South Australia, Submission #115)

As mentioned previously, not only were concerns raised at the scarcity of services for children and youth, but concerns have also been raised with regards to the continuity of care between adolescent and adult mental health services. Standard 8.1.5 states: 'The MHS has documented policies and procedures which are used to promote continuity of care across programs, sites, other services and lifespan.'

Young people 16-17 come and see us but we do some transitioning to the adult mental health service also. There is a period when there's nothing for young people during this transition.

(Clinician, South Australia, Murray Bridge Forum #14)

6.4.8.1.2 Link between mental health services and general practitioners

Included in Standard 8.1.5 are arrangements for shared care with general practitioners. Varied reports were received with regards to successful shared care arrangements.

GPs sometimes don't listen and a client didn't get admitted because the GP wouldn't support admissions.

(NGO Worker, South Australia, Adelaide Forum #24)

There are some advantages to working in this type of area. There's a community of professionals with the local GP's. I can phone the local GP's for a social admission.

(Clinician, South Australia, Murray Bridge Forum #14)

Some GPs are concerned about taking action (when a person is in need of being collected by the police it is necessary for a doctor to approve an involuntary admission).

(Advocate, South Australia, Adelaide Forum #15)

Notwithstanding the excellent but limited TELEMED and TRIAGE services from Glenside Hospital Campus local GP's can receive consultation with distant psychiatrists to help them manage their local mentally ill patients. Sadly such a service doesn't serve patient's family by enabling them to understand their family member's mental illness; to see and keep in touch with their loved one because of the distance from home to hospital.

(Consumer, South Australia, Submission #77)

6.4.8.1.3 Problems with integration with NGO services

One NGO service provider expressed concern about not being able to work together with other mental health service providers in a coordinated and integrated manner as stated in Standard 8.1.5.

At that further meeting with the Program Director and other family therapist, and after trying to gain clarification on how we could collaborate, I was clearly told that this could not occur and we could only work in "parallel." I was not allowed to discuss my approach with the young person's regular nursing staff and how their work may contribute to the therapeutic process. Although I appreciated that there may be some sensitivities and caution with collaborating with someone outside of their hospital, like myself, there was no flexibility on this matter – something that stands apart from recommended good practice in interagency or private/public sector collaboration.

(NGO Service Provider, South Australia, Submission #233)

6.4.8.2 Integration within the Health System

The MHS develops and maintains links with other health service providers at local, state and national levels to ensure specialised coordinated care and promote community integration for people with mental disorders and / or mental health problems.

Under this Standard, a presentation indicated concern about:

- the lack of access to health services to meet the physical health needs of people with mental illness.

6.4.8.2.1 Lack of access to services to meet physical health needs

One police officer expressed concern about his / her repeated observation that people with mental illness appear to be having difficulty accessing health services to meet their physical health needs.

> *There are good things happening but my client groups are the difficult ones. Since the closure of the institutions there has been a large influx of people into this community. But these people need access to other health services for their physical and mental health needs – they often get sent on buses and taxis to Adelaide for care.*
>
> (Police Officer, South Australia, Murray Bridge Forum #16)

> *Mentally ill people can suffer other medical problems such as;*
> 1. *arthritis (lithium possibly leaching calcium)*
> 2. *sleep apnea (may have triggered epilepsy*
> 3. *underactive thyroid (lithium for mood side effect)*
> 4. *weight problems (zyprexa major tranquiliser)*
> 5. *epilepsy (imbalance in brain biochemistry)*
>
> *These conditions can require referral to other specialists and in my case only some visit Murray Bridge but others are seen in Adelaide.*
>
> (Consumer, South Australia, Submission #77)

6.4.8.3 Integration with other sectors

The MHS develops and maintains links with other sectors at local, state and national levels to ensure specialised coordinated care and promote community integration for people with mental disorders and/or mental health problems.

Under this Standard, submissions and presentations indicate concerns about integrated service with regards to:

- housing and accommodation;
- home and community care;
- police;
- education;
- youth;
- employment and support from Centrelink;
- youth employment;
- transport;
- carer allowance;
- cost of medication;
- wards of the state;
- health in rural and remote areas; and
- the criminal justice system.

Integration with these, and other sectors, is vital in the whole-of-government approach required to realise the rights of people with mental illness.

The necessity of a whole-of-government approach to specifically care for children who have become wards of the state was also specifically raised through this consultation process.

6.4.8.3.1 Housing

There's a real revolving door syndrome – people get admitted, they get treatment and then they get discharged but because there's no supported accommodation for them they keep coming back into the hospital.

(Clinician, South Australia, Murray Bridge Forum #5)

Lack of available housing and accommodation options for people with mental illness was repeatedly raised as a critical gap in the process of integrating people with mental illness in the community and improved mental health (see Standard 11.4.B Supported Accommodation). The lack of available housing and accommodation options and the process of deinstitutionalisation and consequent lack of increased community services has also seen an increase in the proportion of people who are homeless who have a mental illness. The housing and accommodation needs of young people were highlighted as major areas of concern by Youth Affairs Council of South Australia.

Housing availability is critical here. Once we get people with a mental illness in our service there's nowhere else for them to go and then we are so stretched we can't respond to the needs of our other clients.

(Accommodation Service Provider, South Australia, Adelaide Forum #4)

Disability supported housing is the only option available, but as there is no interaction with mental health services people with mental disability miss out. There are some disability support mechanisms but they're not funded to support those with a psychiatric disability. We can get them in if they have a dual disability. HACC [Health and Community Care] funding means we can not help people with psychiatric disability only.

(NGO Service Provider, South Australia, Murray Bridge Forum #6)

In his father's opinion neither Governments nor Departments or Courts understand the impact of [X]'s continued homelessness upon his current situation.

(Anonymous, South Australia, Submission #183)

Changes to the Commonwealth State Housing Agreement over recent years have in turn necessitated changes in the provision of public housing in South Australia. YACSA contends that the housing needs of young South Australians must take a priority for the State Government through the South Australian Housing Trust. Public housing plays a fundamental role in the reduction of housing-related poverty and broader social and economic inequalities, offering young people non-discriminatory, affordable housing with security of tenure. In consultation regarding the discussion paper for the upcoming Youth Action Plan, young people noted that it is increasingly difficult to access public housing, and that even if a young person is in need, they are often not in 'enough need' to warrant priority housing. As one young participant noted, "You need to be having a baby to get a house."

(Youth Affairs Council of South Australia, South Australia, Submission #38)

YACSA strongly commends the State Government on its initiation of a ten-year State Housing Plan for South Australia. Council reiterates the Minister for Housing's assertion that young people should be a focus of any initiative that aims to improve housing services for South Australians. In light of this, YACSA recommends that a Youth Housing Strategy comprise a core component of the State Housing Plan, to be developed in conjunction with young people and stakeholders in the youth sector. A Strategy would need to take into consider the particular housing needs of a variety of youth populations, including Indigenous young people, young people leaving care, young people with disabilities including mental health issues, newly arrived young people, etc. Also, while the Plan is statewide in scope, YACSA notes that housing needs vary around South Australia, and needs are not homogenous across all metropolitan areas or all regional areas, a feature that needs to be considered in every stage of the Plan. Features of the Youth Housing Strategy should include but not be limited to:

- *A commitment to working across Government to improve housing outcomes for young people. The strategy should draw together the Department of Human Services (including the Office for Youth, the South Australian Housing Trust, the Aboriginal Housing Authority, the South Australian Community Housing Authority and Family and Youth Services), the Department of Education and Children's Services, the Department of Further Education, Employment, Science and Technology, the Office of Consumer and Business Affairs and relevant others to establish a service and support framework cognizant of the vital role stable, appropriate housing plays in young people's ability to participate in education, training and employment and maintain a healthy lifestyle.*

(Youth Affairs Council of South Australia, South Australia, Submission #38)

6.4.8.3.2 Home and Community Care (HACC)

Mental illness isn't recognised as a disability by HACC services.

(Anonymous, South Australia, Adelaide Forum #10)

The ineligibility of people with mental illness to qualify for HACC services was described by one consumer as an example of direct discrimination. An inability to access HACC services makes it difficult if not impossible for some people with mental illness to continue to choose to live independently.

People with a mental illness are discriminated against. People with other health problems who have been in hospital will get Domestic Care but not so for people with a mental illness – surely they should get the same sort of help.

(Consumer, South Australia, Murray Bridge Forum #7)

In the HACC guidelines there's no acknowledgement of mental illness.

(Social Worker, South Australia, Adelaide Forum #20)

We get our funding through HACC and HACC doesn't include psychiatric disability as a disability. It's very hard to link in with the mental health side of it because there's a very limited number of people to work with and the funding is limited. Dual disability is the biggest problem because it's very difficult to network when everyone is so stressed and stretched.

(NGO Service Provider, South Australia, Murray Bridge Forum #6)

6.4.8.3.3 Police

One police officer raised concerns that collaboration was not occurring to the mutual benefit of all professionals involved in the provision of services to people with mental illness. This feeling of frustration stemmed from a desire to work collaboratively with other professionals to achieve the best possible outcome for consumers given the limited resources and overwhelming demand. Standard 8.3.2 states: 'The MHS supports staff, consumers and carers in their involvement with other agencies wherever possible and appropriate' and Standard 8.3.3 states 'The MHS has formal processes to develop intersectoral links and collaboration.'

We are very frustrated at the coal face. I've charged 1,000's of people. I know when someone is mentally ill. As far as I'm concerned there's no collaboration between professionals in this community. The doctors do not listen to what we say, we don't get any acknowledgement. The doctors won't talk to the nurses or the teachers either.

(Police Officer, South Australia, Murray Bridge Forum #16)

6.4.8.3.4 Education

Similarly, Standards 8.3.2 and 8.3.3 apply to the education sector, including schools, TAFE and universities. Links with the education sector to assist with early identification and early intervention are critical in any set of strategies targeted at prevention. Many presentations were made at forums expressing concern at the inability of schools and TAFEs to identify and support children and adolescents with mental illness or mental health problems. As a link with strategies to reduce youth suicide, this area of service delivery and need for integration is vital.

> *Our core business is education – we identify children with intellectual disability but not psychiatric disability. We are not funded to support these kids. We can provide inclusive resources but we can't really do it properly. Generally they are just piece-meal packages. I have staff using the expulsion / suspension guidelines to exclude these kids… Because of a lack of services there's nothing left but to exclude these kids. Actually they really need care.*
>
> (Teacher, South Australia, Murray Bridge Forum #17)

> *There's only 1 FTE [Full-time Equivalent] Disability Coordination Officer for the whole state. We also cover learning difficulties and mental health issues. One of our jobs is to help these kids to get into classes. 1 of our TAFE teachers has 90% of her class with a mental illness.*
>
> (Anonymous, South Australia, Adelaide Forum #23)

> *My position is funded by the Federal Government. I am employed at a 0.5 allocation but my position covers 75% of South Australia.*
>
> (Disability Coordinator, South Australia, Adelaide Forum #17)

> *Alternative education programs have been increasingly recognised by the State Government, schools and the community as an effective way to cater to the needs of young people 'at risk', particularly those excluded or otherwise disconnected from mainstream education. The youth sector has this year begun to report that some young people have been disadvantaged and disengaged as a result of the raised minimum school leaving age, and for this group of young people appropriate alternative education options are imperative. Such alternative education programs are frequently delivered by youth workers, and allow young people to learn at their own pace in supported environments where their educational and personal support needs are met.*
>
> (Youth Affairs Council of South Australia, South Australia, Submission #38)

> *Teachers, students and workers in the public school system report that young people's out-of-school concerns such as mental health and child protection issues are having a broadly negative impact on students' educational outcomes. Further, student populations are diversifying, particularly with an increase of newly-arrived and refugee students who are requiring extra support. Consultation by the Social Inclusion Unit with young people earlier this year regarding school retention issues uncovered a strong recommendation from young people that youth workers be employed in public schools to provide direct support and advocacy to students. The consultation report notes that "young people consulted indicated that they would like to see youth workers in schools. They considered that youth workers were:*
>
> - *Impartial about student difficulties*
> - *Knowledgeable about services*
> - *Good at creating positive connections with young people*
> - *Able to liaise between students, teachers, parents,*
> - *Centrelink, and other relevant parties*
> - *Able to deliver world and life related topics and to speak engagingly about issues such as disability, discrimination and mental health."*
>
> (Youth Affairs Council of South Australia, South Australia, Submission #38)

6.4.8.3.5 Whole-of-government approach for youth

The Youth Affairs Council of South Australia expressed concern about the capacity of services to work with youth with high and complex needs. Coordinated services are seen as essential from an early intervention perspective to halt spiralling negative life consequences which result in homelessness, suicide, entry into the criminal justice system or separation from the family. The need for integration with drug and alcohol initiatives was also seen as critical:

> *There is a consensus across human service agencies working with homeless young people with high and complex needs that the capacity of agencies to retain and work constructively with these clients needs to be developed. There is also a consensus that there is a need for a residential service that can manage and support these young people in extreme circumstances, as an alternative to hospitalisation or worse.*
>
> (Youth Affairs Council of South Australia, South Australia, Submission #38)

> *The highest risk factors to young peoples' health are related to tobacco and alcohol use. YACSA's Policy Platform acknowledges that there are connections between addictive drug use (including alcohol) and wider issues such as suicide, unemployment, homelessness and social alienation. Other interrelated issues include links with poverty, educational outcomes, and living in outer metropolitan, regional, rural and remote areas… Young people's health and the problems they experience are diverse and far-reaching. Inequity, and related issues such as poverty, lack of education, housing and access to basic health services, are broad factors that contribute to the health concerns that many young people face.*
>
> (Youth Affairs Council of South Australia, South Australia, Submission #38)

6.4.8.3.6 Employment and support from Centrelink

Access to welfare, the supported wage and finding suitable employment are all critical components in the process of social inclusion and living a meaningful life with dignity in the community. However, many concerns were raised regarding difficulties with the current welfare and employment systems and Centrelink. One example of a successful program, funded by the Federal Government, was described.

> *I just recently obtained a job cleaning houses. The work became very difficult and I could no longer do it. I was given the option of going off the pension because I was earning too much. The problem was if I then could no longer work I'd have no pension either. Luckily I didn't go off the pension because I couldn't keep working.*
>
> (Consumer, South Australia, Murray Bridge Forum #12)

> *I worked as a Job Network case worker of 80 people at Centrelink in Adelaide. 60% of the people I saw had a mental illness but were not on the Disability Pension as nobody would do the paper work to get them on Disability Support Pension. There's no continuity of process and Centrlink's sole purpose is to mask employment jobless rather than help them.*
>
> (Anonymous, South Australia, Murray Bridge Forum #13)

> *We need more opportunities for people with psychiatric disabilities and need to restructure the supported wage system. The system doesn't take into account the episodic nature of mental illness so currently the appraisal system is unfair.*
>
> (NGO Service Provider, South Australia, Murray Bridge Forum #11)

> *We have supportive people here in Centrelink but they are also very under resourced and so the system only benefits people who the can act on their own behalf, not those who are most disabled.*
>
> (NGO Service Provider, South Australia, Murray Bridge Forum #11)

It's really hard to meet your mutual obligations on the disability support pension. I know someone who is trying (for the third time) to apply for the disability support pension. The questions regarding physical disability are focused and straightforward but not for psychiatric disability. Some people are too unwell to meet their mutual obligations.

(NGO Service Provider, South Australia, Murray Bridge Forum #11)

One positive program, funded by the Federal Government, indicated the positive outcomes that be achieved for a particularly vulnerable group when integration works successfully. The rights to social and economic participation and living a life with dignity are greatly enhanced by initiatives such as this.

My program is federally funded and has been running for three years. It's aimed at supporting those people with a mental illness & acquired brain injury in the indigenous community – it's a pilot project. After 2 years we had 12 people in employment.

(NGO Service Provider, South Australia, Murray Bridge Forum #11*)*

6.4.8.3.7 Employment for young people with mental illness or mental health problems

In addition to the general employment concerns raised above, the Youth Affairs Council of South Australia highlighted that specific strategies and initiatives need to be developed to address the issue of barriers to employment for young people with mental illness or mental health problems:

The social cost of unemployment is well-documented; youth unemployment has enormous repercussions for other aspects of young people's lives and decreases their general social health and wellbeing. Four years ago, the report focusing on metropolitan Adelaide entitled Surviving Unemployment: Health Consequences of Youth Unemployment, noted that "labour market programs for young people focus almost exclusively on job skills targeted to meet the needs of employers whilst the health system has primarily focused on acute symptoms such as youth suicide or depression without tackling their structural determinants. The need for integrated multi-disciplinary approaches to tackle the adverse affects of youth unemployment has never been greater." Such a finding is also consistent with the primary health care approach underpinning the Generational Health Review.

(Youth Affairs Council of South Australia, South Australia, Submission #38)

6.4.8.3.8 Transport

Another related but indirect problem with regard to access to services is transport. This concern was raised at one forum indicating that for many consumers, for a myriad of reasons, reliance on public transport and location of services is critical. Collaboration with local transport providers may also be an essential link to be made to enable access to services without discrimination for all consumers.

Lack of transport impacts considerably on access to services.

(Community Health Service worker, South Australia, Murray Bridge Forum #9)

6.4.8.3.9 Wards of the State – need for a whole-of-government approach

Years of neglect and self abuse have taken their affect. The failures of his parents, the across the board systemic failure of governments, departments and services set up to help, the failure of individuals in positions of authority and support, all form part of the complications that go together to make 'X's future existence problematical in the extreme.

(Anonymous, South Australia, Submission #183)

One submission highlighted the need for the Government to adequately care, through a whole-of-government approach, for those children and adolescents placed in the State's care. This anonymous submission claimed that gaps in multiple areas resulted in the deteriorating mental health of one consumer, resulting in serious life consequences.

> *But whereas for the most part, parents and families don't have the knowledge and resources to take determinative action governments do. Failure to honour the trust which is given it to assist a child in need is a failure of government to maintain the rule of law by which we all in security co-exist.*
>
> (Anonymous, South Australia, Submission #183)

> *With the attention that has now been given in South Australia to inmates of hospitals for the mentally ill and the procedures in place to process them, it is hoped that greater attention will be given to the 'duty of care' responsibilities place upon governments in regard to those given or taken into their care.*
>
> (Anonymous, South Australia, Submission #183)

6.4.8.3.10 Carer allowance

With limited access to mental health services, supported accommodation and access to early intervention treatment and support, the burden on families and carers from providing long-term and crisis support is immense. This often impacts on the financial income of the family due to a reduced ability of carers to work. The shifting of care by governments to carers fails to recognise that carers are providing a significant cost-free service that is not being shouldered by the community. Concern was raised with regard to the financial hardship experienced by carers due to the lack of services in the community to provide appropriate treatment and support to people with mental illness and / or mental health problems:

> *CENTRELINK CARER PAYMENT - The Carer allowance my wife receives for looking after me works out at 70 cents an hour because income [sic] from superannuation and shows how little carers receive. When compared to the average wage Centrelink payments are considerably lower and place real limits on what we can afford. A nurse in hospital looking after me would cost considerably more but hospital admission is need from time to time to give my wife respite.*
>
> (Consumer, South Australia, Submission #77)

> *We need to redefine and reconsider the value we place on caring. What I do know is that carers are not truly valued… They have no real financial value placed on their work – it is not factored fully into the running of our economy.*
>
> (Anonymous, South Australia, Submission #44)

6.4.8.3.11 Cost of medication

With complex issues regarding difficulties in accessing services, especially during the onset of illness and recovery phase, barriers to employment, lack of available supported accommodation or other housing / accommodation options, many consumers experience short and long term financial difficulties. One consumer expressed concern at his inability to afford necessary medication despite holding a pension card:

> *Although I have a pension card cheaper pharmaceuticals [sic] it still costs a lot regularly especially if like me you have other ailments. They only become free in December when I reach the safety net.*
>
> (Consumer, South Australia, Submission #77)

6.4.8.3.12 Health in rural and remote areas - collaboration between State and Federal Governments to improve services in rural and remote areas

As outlined previously in Section 2.8.4, the Medical Specialists Outreach Assistance Program, funded by the Federal Government, is a positive example of how integration and collaboration has worked successfully to enhance mental health services to Indigenous communities living in rural and remote areas of South Australia.

> ***The Medical Specialist Outreach Assistance Programme in South Australia – Improving services to rural and regional areas*** *November 2003 marks the second anniversary of the expansion of visiting psychiatric services to rural South Australia under the Medical Specialist Outreach Assistance Programme (MSOAP)… The MSOAP-funded psychiatrists now visit 20 towns and communities in rural and remote South Australia. They provide consultation-liaison services that emphasise the upskilling of local general practitioners (GPs) and other health-care workers. Although most of the visiting psychiatrists provide adult services, child psychiatrists now visit four regional centres. The child psychiatry services have been an important development for MSOAP because this is an area of special need and clinician numbers are quite limited. Local child mental health services are highly desired. The disruption to family life is substantial when a child is ill and treatment always involves the inclusion of one or both parents and often other family members. If treatment occurs in the capital city, there is inevitably a major disruption to the family routine, with substantial stress arising from the added costs and social dislocation. Furthermore, the provision of child psychiatric services in the local community facilitates the mobilisation of the community resources for the immediate treatment and ongoing management of the child's condition. The new MSOAP services are likely to improve continuity of care and will help prevent future complications and trauma, both for the patient concerned and the local community. Indigenous South Australians are also beginning to benefit from MSOAP initiatives. (author's emphasis)*
>
> (Clinician, South Australia Submission #274)

6.4.8.3.13 Criminal Justice System - collaboration with the Adelaide Magistrates Court to provide services to, and reduce offending by, people with mental illness

As outlined previously in Section 2.8.4, The Magistrates Court Diversion Program is an example of a successful collaborative link to enable the criminal justice system to identify and deal more appropriately with people with mental illness who come before the court and are charged with a summary or minor indictable offence.

> The Magistrates Court Diversion Program – Diverting people with mental illness out of the criminal justice system
>
> *The pilot Magistrates Court Diversion Program (MCDP), which commenced operation in the Adelaide Magistrates Court in August 1999, was the first 'problem solving' court in Australia designed to deal with offenders with mental impairment… The impetus for this court came, in part, from South Australia's then Chief Magistrate who recognised that courts needed to improve their ability to identify and respond to people who had a mental impairment. He noted that people "who did not belong in the criminal justice system" were continually appearing before Magistrates and were "being punished for things which were nothing but a manifestation of their problems" (Alan Moss, 1999).*
>
> *Aims and Objectives of The Magistrates Court Diversion Program… The MCDP was designed to 'better ensure that people with a mental impairment who come before the court have access to appropriate interventions that will assist in addressing their offending behaviour' (Justice Strategy Unit, 2000). Overall then, in line with other courts predicated on a therapeutic jurisprudence model, the aim was to use the defendant's contact with the criminal justice system as a vehicle for providing a treatment and support program designed to effect behavioural change.*

Description of The Program Persons suspected of a mental impairment and who are charged with a summary or minor indictable offence are referred to the program, generally at the time the charges are laid. Upon referral, the individual is assessed to determine his/her suitability for the program. At that time, the defendant's willingness to participate is also ascertained. Those who do not want to participate are referred back to the normal court process. If a defendant is accepted onto the program, his / her case is then adjourned and an individualised intervention plan is developed which outlines appropriate intervention strategies designed to address the individual's mental impairment issues, any associated factors such as homelessness, and drug and alcohol addiction. For many clients who are already in treatment, the program aims to reinforce and support their continued engagement with their treatment or service provider. For others, it may involve referral to new treatment agencies and services. It should be noted that the court itself does not provide treatment. Instead, the client is referred to existing treatment and service providers… At the end of the program (which generally extends for between 4 to 6 months), the charges against some defendants are withdrawn by prosecution. In the majority of cases, though, the defendant is sentenced, with his / her progress while on the program taken into account at that point. The majority of defendants are given a good behaviour bond.

Evaluating The Program… Overall, the results showed a reduction in both the number of participants who were apprehended for offending post-program compared with pre-program, as well as a reduction in the actual number of incidents charged against this group. In particular: There was a significant reduction in the number of participants who offended as well as in the number of incidents detected post-program. Two thirds (66.2%) of program participants did not offend during their post-program year1. At an individual level, just over three quarters (76.4%) of the participants either became non-offenders or were charged with a smaller number of incidents post-program. Although these findings must be treated with caution, they suggest that the program may be having a greater impact on the more serious pre-program offenders… These findings… auger well for its future.

(from Skrzypiec, Wundersitz & Mcrostie (2004) Magistrates court diversion program – An analysis of post-program offending – Evaluation findings [Short report])

(Office of Crime Statistics and Research, Attorney-General's Department, Government of South Australia, South Australia Submission #278)

6.4.9 STANDARD 9: SERVICE DEVELOPMENT

The MHS is managed effectively and efficiently to facilitate the delivery of coordinated and integrated services.

The system doesn't reflect the clients' needs – the system is more interested in reflecting KPI's [Key Performance Indicators] / good outcomes / indicators so they don't deal with the difficult ones. These are the ones that are given the bus tickets from other places and they end up here in our community. I know this happens.

(Police Officer, South Australia, Murray Bridge Forum #16)

Under this Standard, submissions and presentations indicate concerns about:

- the current state of mental health services;
- the lack of resources and services and the impact of this on clinicians;
- the lack of services in rural and regional areas;
- the model of mental health care needs to change as there are insufficient community-based services and there is an inappropriate focus on inpatient and crisis care;
- lack of consultation with consumers, carers and staff;
- lack of mechanisms to improve service delivery and accountability;
- lack of funding;

- affordability of care - public versus private;
- problems with funding arrangements for service providers;
- lack of funding and services for young people; and
- a shortage of mental health professionals.

6.4.9.1 Current state of mental health services

The Rann government's inaction on community mental health services can only be described as contempt for South Australians affected by mental illness.

(SANE Australia, National, Submission #302)

Doctors and mental health people will not give us what is necessary to help my son. There are often throw away comments such as "the mental health system is not working", "there's not enough money", "there's little that can be done", "he has to seek the help".

(Carer, Mother, South Australia, Submission #11)

If you spend more dollars on an inefficient and traumatising system, without reforming and modernising first, it will not only be a waste of time, energy and dollars, but will result in a larger mess than before.

(Consumer, South Australia, Submission #335)

On a personal note, there seems to be this amazing reform occurring in SA (so they say anyway). A great deal of money has been allocated but it seems to be for Capital Works. The future for SA seems to be that we will have lovely new buildings / wings etc but of great concern will be the lack of well educated and supported workforce dealing with clients with very specific needs. The lack of supports etc when the client goes home?? We will see terrific buildings but I am very concerned that the foundations are faulty. The foundations of mental health do not only belong within the hospitals / clinics they need to stretch out further into the communities - reinforcement needs to extend itself. We have seen the problems that have occurred in Western Australia and are aware that it could so easily occur here.

(Anonymous, South Australia, Submission #61)

[N]ot much has changed in the country Post Burdekin… A few years ago (but since Burdekin) my brother in law hung himself - in his shed in a country town. This followed at least 2 prior attempts. Although he presented to the local GP at no time was he detained or in receipt of anything close to resembling reasonable psychiatric care. His poor mental health was long standing… Everyone in town also knew about his alcohol addiction… the treating GP had treated many of [his family] for many years… so he knew who & what he was dealing with… I believe that he left a note which was quite readable and was able to make the necessary arrangements to hang himself in a space some distance from his home. On his 2 previous attempts (and there could well have been more) he was unsuccessful because the methods offended his sense of not wanting to make a mess - and he didn't get any appropriate help. Given that that GP is still the dominant medical officer in town & not much else has changed in terms of service availability, I don't think my brother in law's prognosis would be any different today. Now I fear for his son's life.

(Family Member and Service Provider, South Australia, Submission #34)

6.4.9.2 Lack of resources and services and the impact of this on clinicians

We have some excellent workers but they aren't resourced to be able to provide the sort of care people need.

(Anonymous, South Australia, Adelaide Forum #9)

Many presentations were made at forums indicating the negative impact on staff of lack of resources and lack of other services to assist with the delivery of quality treatment and support to consumers and their carers. Feelings of burnout, 'craziness' and stress were reported and observed by clinicians and consumers.

I am a clinical psychologist and I left the mental health system because of burnout and the feeling that in my previous role I felt like I was perpetuating the abuse because I didn't have the resources I needed to do my job properly.

(Anonymous, South Australia, Adelaide Forum #12)

I work as a clinical psychologist in the mental health service. Some days I feel crazy each day.

(Clinician, South Australia, Adelaide Forum #11)

Staff conditions… day-to-day conditions are so poor we struggle to work.

(Clinician, South Australia, Adelaide Forum #11)

Staff turnover in the mental health services is very high. We're lucky if we get an allied health worker to stay for 3 months.

(NGO Worker, South Australia, Adelaide Forum #24)

6.4.9.3 Distribution of services – lack of services in rural and regional areas

…there has been ongoing debate regarding the mal-distribution of medical services in Australia… The majority of medical services have been concentrated in capital cities and major regional centres and have been quite limited in rural and remote areas. It has become increasingly difficult to recruit and retain general practitioners (GPs) in country areas and there is a long history of difficulties in the provision of specialist services outside large population centres. It is a fact that there are relatively few medical specialists living and working outside major regional centres… For example, in South Australia in 1997, only 1.1% of psychiatrists lived outside Adelaide.

(Clinician, South Australia, Submission #274)

One of the key concerns expressed both directly and by implication, and particularly at the Murray Bridge Forum, was of the lack of services in rural and remote areas of South Australia. Many consumers and carers spoke of the absence of any service to access and their only options were at a great distance away. Due to the scarce number of services, these services are difficult to access (e.g. long waitlists) and involved great disruption on a daily or long-term basis. Additionally, if long term treatment or supported accommodation is required, this involves removal of consumers, and sometimes carers, from social support networks and employment, and often at considerable financial cost.

Historically, specialist services to rural and remote areas have generally been provided on a visiting private practice basis, sometimes with State Government or local area funding support. In more recent years with the development of tele-conferencing facilities, it has become possible to provide a number of services at a distance from a capital city base. Psychiatric services are a good example of this and tele-psychiatry consultations have been performed by the Rural and Remote Mental Health Service of South Australia since 1994.

(Clinician, South Australia, Submission #274)

The hospital facilities for regional South Australians needing inpatient treatment are in the city (Glenside Hospital) which means that hospital patients with a mental illness who come from country areas such as the Murray Mallee are removed from their families and networks. Secure hospital facilities in regional areas are needed.

(Health and Community Services Network, Murray Mallee Strategic Task Force, South Australia, Submission #115)

As mentioned previously, the Medical Specialist Outreach Assistance Programme has improved access in rural and remotes areas.

The new MSOAP services are likely to improve continuity of care and will help prevent future complications and trauma, both for the patient concerned and the local community. Indigenous South Australians are also beginning to benefit from MSOAP initiatives.

(Clinician, South Australia, Submission #274)

What has improved in the South Australian Murray Mallee region:

1. There are more mental health workers in the region than there were 10 years ago, which has given some people with mental illness better access to supports.
2. The Mental Health Line / Rural and Remote Triage has helped to reduce the isolation for those in the region who suffer from mental illness and for those who support them.
3. *Telemedicine and videoconferencing facilities have enabled more people to have access to psychiatrists.*
4. *Recent group programs such as the women's strength-building course have assisted women in the region to enjoy improved mental health and self confidence.*

(Health and Community Services Network, Murray Mallee Strategic Task Force, South Australia, Submission #115)

Despite these improvements, however, the evidence presented suggests that the model of service and resource distribution across South Australia needs to fundamentally change in order to ensure that the rights of consumers and their families are protected. This included access (according to Standard 11.1; equitable access) to treatment and support services for all stages of the recovery process (according to Standard 11.4) as well as access to supported accommodation (Standard 11.4.B) and services to support the consumer's quality of living (Standard 11.4.A).

We don't have enough workers here – our workers are always stressed. We can't expect much off them. One of the things we will do will be to lobby government.

(Consumer & Advocate, South Australia, Murray Bridge Forum #8)

As recommended by the Health and Community Services Network, Murray Mallee Strategic Task Force, access to both community based services and acute care treatment facilities (for example, closer proximity) need to improve.

Recommendation: That funding is allocated to community support services in rural areas (and not just for those living in regional centres) to supplement clinical mental health services. These services should include programs aimed at reducing social isolation, developing confidence and self esteem and promoting integration into the wider community. These programs should also include support for people with a mental health disability to return to study or work.

(Health and Community Services Network, Murray Mallee Strategic Task Force, South Australia, Submission #115)

Recommendation: That secure facilities for mental health patients are provided in regional hospitals with staff trained in psychiatric nursing and associated allied health professions.

(Health and Community Services Network, Murray Mallee Strategic Task Force, South Australia, Submission #115)

Two submissions also highlighted staffing issues. The first argues that any plan to increase services in remote and rural areas needs to address staff recruitment and retention issues which have hindered the filling of vacancies in the past.

There are a number of reasons why it has been so difficult to attract specialists to work and live in country areas… These include the isolation from peer support, the demands of families, including the career needs of the spouse and the educational and other needs of children, as well as likely future difficulties in returning to metropolitan practice. There can also be problems in limiting service demands and the potential for associated 'burnout'. Furthermore, there are the unique stresses associated with living in a small community where there is a lack of anonymity and the likelihood of more intense public scrutiny of one's day-to-day activities. There may be financial disincentives associated with working in country areas. There can be major difficulties for the clinician in providing for his or her emotional and professional needs. For example, it can be hard to establish and maintain support networks locally, particularly for clinicians working in such an emotionally intense area as psychiatry. It is also hard to provide for one's recreational needs, including holidays, because there may be a limited availability of local support and after-hours back up, and the likelihood of having to deal with clinical emergencies after hours would be particularly draining. Finally, there are often major constraints upon the opportunities to engage in regular professional development and ongoing educational activities, such as attending conferences and medical college seminars.

(Clinician, South Australia, Submission #274)

There is [sic] not enough nurses, social workers and psychiatrists in the country where as in the city there are more however even in the city staffing in the mental illness field is less than satisfactory.

(Consumer, South Australia, Submission #77)

6.4.9.4 Model of mental health care needs to change – lack of community-based services and inappropriate focus on inpatient and crisis care

Concerns were expressed about the model of mental health care underlying service delivery and planning in South Australia. Concerns were raised about the emphasis on inpatient and crisis care and the medical model. Concern was also raised regarding 're-institutionalisation' as people with mental illness are now being diverted and 'institutionalised' in prisons. This emphasis needs to change to improve outcomes for people with mental illness.

There have been three mental health plans since the Burdekin Report. There have been great advances in medication – there have been great collaborations with GPs and other reforms with strong evidence bases and new technologies developed. But we remain one of the lowest spending countries in terms of what we spend on mental health care. We spend almost half what other countries spend. We spend very little on supported accommodation where it's really needed and we still spend a lot on inpatient or crisis care. The problem is that we are locked into an old model. The evidence suggests that people do need supported accommodation – but the system has been poorly funded in SA.

(NGO Worker, South Australia, Adelaide Forum #22)

This institutional model extends into the prison system. The Chair of the SA Parole Board has drawn attention to the high number of people with a mental illness in the State's prisons, saying the government was using them as a 'sump' for people who should be cared for by mental health services.

(SANE Australia, National, Submission #302)

I am extremely concerned about the use of restraint and seclusion in SA hospitals. There have been frequent recent stories of psychiatric patients being shackled in the ED [Emergency Department] at central city hospitals, inappropriate use of seclusion (for staff convenience not patient care), the use of outmoded and banned restraint holds by nurses and patients not being treated with the care and respect they deserve.

(Academic, South Australia, Submission #142)

We've got a 19th century hospital system with 21st century demands.

(Anonymous, South Australia, Adelaide Forum #9)

We have medicalised something which is not necessarily medical – there are potentially harmful side-effects. For a start it takes away ownership of the problem/the illness.

(Academic, South Australia, Submission #219)

[Recommendation] Decisive action by the State government to reform South Australia's mental health services in consultation with the Mental Health Coalition of SA – committing political will and resources to close Glenside and implement community-based services, with acute wards mainstreamed into general hospitals and a new forensic facility.

(SANE Australia, National, Submission #302)

We need more emphasis on people's social & spiritual needs.

(Social Worker, South Australia, Adelaide Forum #20)

The mental health system here in South Australia is too weird for me.

(Carer, Family Member, South Australia, Adelaide Forum #2)

6.4.9.5 Lack of consultation with consumers, carers and staff

Concerns were expressed about the lack of consultation with clinicians, consumers and carers in the planning and delivery of mental health services. According to Standard 9.8, a strategic plan is to be 'developed and reviewed through a process of consultation with staff, consumers, carers, other appropriate service providers and the defined community'. Clinicians and consumer advocates spoke of the need for genuine consultation, 'to be heard' about their needs and to contribute innovative ideas to solve service delivery problems.

…there is a tokenistic response to staff who have innovative ideas – great program.

(Clinician, South Australia, Adelaide Forum #11)

There is a token approach to consumer and carer participation – tokenistic responses. There is no carer and consumer input. No feedback.

(Clinician, South Australia, Adelaide Forum #11)

There's a need for a rural consultation in areas like Port Augusta. There are huge workloads for staff and GPs in our area… There's also a need for consumers, carers etc to be heard and to be supported with funding.

(Advocate, South Australia, Adelaide Forum #15)

The following statements from a clinician provide just one example of the tokenistic responses experienced by those staff who seek improvement of the mental health services, and of the repercussions that may be experienced for attempting to do so.

It is evident to clinical staff that contributions to policy formulation or micro-reform suggestions aimed at service improvement are not welcome. In the rare instances where consultation processes exist they are tokenistic, without power and their outcomes are not acted on. When suggestions / proposals are submitted they are ignored as a rule. If the person making suggestions, raising issues insists, s/he will be increasingly ignored, and should s/he persist, s/he will be marginalised, described as having a 'bee in his / her bonnet' or 'a chip on his / her shoulder'. This may gradually degenerate in outright denigration of his / her work or person on the part of managers, team leaders, including character assassination which outside of the Public Service would be subject to slander and libel laws.

(Clinician, South Australia, Submission #56)

Day to day working conditions within the mental health services are often so poor that staff are struggling to contend with the daily issues of accommodation, equipment, safety provisions and aspects of managerial culture. Consequently, staff are less able to address the more complex issues of service reform. A culture of inertia and hopelessness sets in, as staff are forced into a position of simply having to cope with less than adequate working conditions.

(Clinician, South Australia, Submission #56)

As with the tokenistic responses to consumer and carer participation, staff initiatives for service improvement frequently remain unsupported, if not discouraged… Staff advocacy for the development of a hospital at home program was similarly discouraged and a proposal to aid the development of culturally appropriate service has been unsupported. Whilst it is apparent that not all proposals can, or should, be supported, the more fundamental issue that is being raised here is of a culture that does not foster the development and implementation of new ideas, but which actually might be seen to discourage them. Further, questions must be raised as to the commitment to the National Mental Health Strategy.

(Clinician, South Australia, Submission #56)

6.4.9.6 Lack of mechanisms to improve service delivery and accountability

Associated with concerns about an inability to contribute in a positive manner to service improvement are concerns about speaking up and fear of consequent reprisal. Accountability ensures the protection of rights of people with mental illness and practices to ensure delivery of quality care. Standard 9.2 states: 'There is single point accountability for the MHS across all settings, programs and age groups', and Standard 9.29 states 'The MHS has an evaluation strategy which promotes participation by staff, consumers…'.

I have advocated in the past on behalf of a mental health worker who wanted some changes to occur - because they are employed by the system they get into trouble if they speak up, they can't speak up.

(NGO Worker, South Australia, Adelaide Forum #24)

Sheer bullying and harassment of staff who speak out is a problem – we need to strengthen the culture. The Equal Opportunity Act in South Australia still doesn't include mental health – we know it will be on the table in September and we would appreciate your support.

(Clinician, South Australia, Adelaide Forum #11)

6.4.9.7 Lack of funding

Along with reports about the need for increased funding and services for many vulnerable groups described elsewhere in this Report (for example for children and youth with mental health and drug and alcohol problems) one consumer advocate expressed particular concern about the lack of funding for people with co-occurring physical disability and mental illness or mental health problems. The health care needs (both physical and mental) for people with physical disability beyond those directly associated with their specific physical disability are a common problem faced by this group. SANE Australia's *SANE Mental Health Report 2004* also discusses funding concerns.

I am here representing people with physical disabilities who also have a mental health problem… The funding is extremely important, we need adequate funding for appropriate services.

(Consumer and Advocate, Female, South Australia, Adelaide Forum #3)

While other jurisdictions spend around 47% of the mental health budget on hospitals, South Australia spends a massive 60% – in fact, around 45% of the entire mental health budget continues to be swallowed up by Glenside Hospital.

(SANE Australia, National, Submission #302)

As well as limited funding for community-based clinical services, the proportion of the mental health budget allocated to non-government organisations providing community support has shrunk to a minuscule 1.9%. The key area of supported accommodation receives just 0.4% of the mental health budget (compared to 17.9% in better funded States).

(SANE Australia, National, Submission #302)

Some additional funding has been released for mental health services since 2002, primarily for clinical services and often on an ad hoc basis. This includes a welcome $11.4 million for supported residential facilities and extra support for case management. A further $800,000 has been spent to increase security at the Glenside Psychiatric Hospital – mainly, it would seem, in response to local media 'beat-ups' about patients leaving the grounds (whom they misleadingly describe as 'inmates' who 'escape' and have to be 'recaptured').

(SANE Australia, National, Submission #302)

6.4.9.8 Affordability of care: public versus private

In contrast to the many concerns raised by consumers, carers, clinicians and academics about the quality of public mental health service delivery in South Australia, the following report from a carer at the Adelaide forum is potentially an indicator of a growing trend in health care: that only those with the financial resources can access 'marvellous' mental health care.

The Adelaide clinic (private clinic) has been marvellous with our family and the new young shrink has been marvellous.

(Carer, Family Member, South Australia, Adelaide Forum #2)

Also of serious concern, was the following remark made by a consumer who was unable to find a bulk billing psychiatrist and making it difficult to access care if she was struggling to pay the gap required.

But then the problem in Adelaide if you can get up there is that there's very little bulk billing by psychiatrists in Adelaide. Earlier in the year I was told that I needed a psychiatrist but I couldn't find one that was bulk billing that was taking new patients.

(Consumer, South Australia, Murray Bridge Forum #2)

6.4.9.9 Problems with funding arrangements for service providers

Concern was expressed regarding funding arrangements for services, the brevity of the contracts, the competitive tendering process and the negative impact these processes have had on collaborative arrangements between agencies:

I am currently trying to set up [Y] for residents of Supported Residential Facilities in Adelaide under a new funding arrangement. While this all sounds wonderful, I have serious reservations some of which tend to be funding based:

1. *our funding is only for 12 months at a time and there is pressure on us from 'bureaucrats' to provide them with data to prove we're achieving outcomes which are still vague but in the realm of a long term research project & have no relationship to the level of chronic ill-health - mental & physical) & the level of dysfunctionality due to long term institutionalisation. Initially I was led to believe that the funding would be for 4-5 years (1 year of service delivery has been lost while bureaucrats thought about what to do) but it seems we'll only be funded year-by-year for up to 4-5 years. This has implications for planning effective services, recruiting staff etc.*

2. *some of the new services are to be provided by NGOs. Prior to the tendering process for provision of these services, there was significant & positive collaboration between all of the NGOs & govt agencies - this level of collaboration has now diminished to include those agencies receiving specific funding - we've lost a pool of partners because of a competitive tendering process.*

(Family Member and Service Provider, South Australia, Submission #34)

6.4.9.10 Lack of funding and services to meet the needs of young people

The Youth Affairs Council of South Australia expressed concern that the level of funding allocated to youth services and programs was inadequate to meet the mental health needs of young people and called for equitable distribution of mental health funding;

The greatest burden of disease for young people is mental health. In 2000-2001, up to 20% of young people aged 12 to 17 and more than one quarter of 18 to 24 year olds experienced mental health issues, making mental health a strong priority for YACSA in this submission. Funding allocated does not reflect the significant impact mental health issues have on young people, and YACSA contends that a more equitable distribution of mental health funding to young people should be determined…

(Youth Affairs Council of South Australia, South Australia, Submission #38)

Because of concerns that homeless young people with high and complex needs including mental health issues are not being well served by accommodation, support and health services, YACSA has conducted consultations with providers and consumers. The key findings of those consultations are also supported by various recent reviews and research into this area… In summary the findings are that services are characterised by:

- *High and increasing demand associated with the combination of mental health problems and homelessness leading to higher rates of hospitalisation, arrest, misuse of alcohol and drugs etc*
- *Increasing numbers of young people presenting to agencies with an increasingly severe range of problems in relation to:*
  - *Sexuality related issues*
  - *Behavioural problems*
  - *Substance abuse*
  - *Depression / anxiety*
  - *Violence/anger*
  - *Grief / loss*
  - *Homelessness*
  - *Physical and / or sexual abuse*
- *Fragmentation of services, especially given that clients usually present with multiple needs that may require the involvement of multiple agencies across several sectors*
- *A tendency for 'difficult' clients to be 'handballed' to other services – that is, referred without any communication between agencies*
- *A particular shortfall in supported residential services with access to mental health outreach and support*
- *A concentration on highly focused, short term, acute crisis management casework at the cost of continuity of care and a community development capacity*
- *A pressure to meet the funding body numbers – output not outcomes*
- *Restrictive eligibility criteria (age, geographic, diagnostic and behavioural) especially for high need / severe cases, leading to exclusion and consequent exacerbation of mental health issues, homelessness, and associated problems*
- *Poor communication across sectors, characterised by confusion about respective roles and expectations*
- *A lack of flexibility of response from many agencies, failing to address the widely varied immediate needs of young people, and therefore failing to engage with them*

(Youth Affairs Council of South Australia, South Australia, Submission #38)

One major consequence of this situation is that a relatively small number of young people with high and complex needs, whose extreme and repeated behaviours have effectively excluded them from SAAP [Supported Accommodation and Assistance Program] accommodation and other supports, are relying on hospital admissions for accommodation and support and creating a significant demand on police and the criminal justice system. The costs to government incurred by this small group are substantial. This proposal argues that a comparatively small investment in a new capacity–building service could significantly reduce these costs.

(Youth Affairs Council of South Australia, South Australia, Submission #38)

6.4.9.11 Shortage of mental health professionals

Associated with the lack of services are reports of an excessive demand for the services that exist, and reports that these services often had difficulties recruiting and retaining staff. The shortage of qualified mental health professionals was noted as a critical problem:

Firstly, one of the areas we have had difficulty in is finding workers that have training or experience in working with people with mental illnesses. Much training is based around aged care or general disability. We would like to provide more support to carers of people with mental health conditions but we need to ensure that we have appropriate, qualified workers available to assist with the respite care. Secondly, one of our constraints is that we cannot provide respite care if it is an "at risk" situation for the worker. If a person is having an acute episode, we may not be able to provide respite care to allow the carer to have a break- hospital admission may be the only option.

(Service Provider, South Australia, Submission #57)

6.4.10 STANDARD 10: DOCUMENTATION

Clinical activities and service development activities are documented to assist in the delivery of care and in the management of services.

Under this Standard, submissions and presentations indicate concerns about:

- documentation systems not being utilised; and
- carer's plea for access to be corroborated with clinical records ignored.

6.4.10.1 Documentation systems not being utilised

Standard 10.2 states 'Treatment and support provided by the MHS are recorded in an individual clinical record which is accessible throughout the components of the MHS' and Standard 10.4 states 'A system exists by which the MHS uses the individual record to promote continuity of care across settings, programs and time'. According to one NGO worker this is not occurring and consumers are becoming frustrated at having to tell their stories repeatedly. Additionally, if records are not being accessed, this would also imply that clinicians are also not entering data regarding any interventions (Standard 10.5, 'Documentation is a comprehensive, factual and sequential record of the consumers' condition and treatment and the treatment and support offered') and signed and dated (Standard 10.3).

The system is stuffed and so difficult for consumers to navigate. People have to tell the stories over and over again to a range of different people. They should only have to tell their story once.

(NGO Worker, South Australia, Adelaide Forum #24)

6.4.10.2 Carer's plea for access to be corroborated with clinical records ignored

In one submission a mother highlighted a problem with accessing care for her son and hoped that his record could be used to corroborate his need for treatment as he was too ill to request the help himself.

> *I rang ACIS (Assessment and Crisis Intervention Service) on the afternoon of 27/2 [2004] in an attempt to understand how things had gone so wrong. [Y] told me that there had been several phone calls made to [X] by ACIS and that he had not wanted intervention!!! We are referring here to a man who… HE HAS NOT BEEN WITHOUT SOME FORM OF TREATMENT OR DETENTION ORDER SINCE ABOUT 1988 AND HE WAS CONTINUALLY UNDER... DETENTION AND OR COMMUNITY ORDERS IN THE PRECEEDING FIFTEEN MONTHS. There is an ample collection of SA files on [X]… (author's emphasis)*
>
> (Carer, Mother, South Australia, Submission #279)

6.4.11 STANDARD 11: DELIVERY OF CARE

Principles guiding the delivery of care: The care treatment and support delivered by the mental health service is guided by: choice; social, cultural and developmental context; continuous and coordinated care; comprehensive care; individual care; least restriction.

Under this Standard outlining the principles underlying care, submissions and presentations indicate concerns about:

- the lack of choice and individualised and continuous care currently available in mental health services.

Further evidence supporting this is presented under other subsections of this Standard.

6.4.11.1 No choice, no continuous care, no individual care

> *The family is facing another situation of the ultimatum between participating in the complete program with suspension of their preferred treating professionals, or repeating the above process with no guarantee that there will be another premature discharge that places the young person's life at risk, let alone another experience of not being heard, and no willingness for collaboration that works toward shared approaches and negotiated goals wherever possible.*
>
> (NGO Service Provider, South Australia, Submission #233)

This example presented by an NGO service provider raises serious concerns that nearly all the underlying principles governing the delivery of care are not being implemented resulting in the young person's life being placed at risk. Other similar concerns were expressed at the forum held in Adelaide:

> *People need choice – the current system doesn't afford choice – it's falling over.*
>
> (Social Worker, South Australia, Adelaide Forum #20)

> *I'm really disgusted with the situation, I went to a mental illness conference in Canberra last year and heard someone say that people are treated like 'objects' – I believe that because that's what it's like in Adelaide.*
>
> (Carer, Consumer & Advocate, South Australia, Adelaide Forum #5)

> *In the country you don't have a choice of psychiatrist, and there is no alternatives [sic] when it comes to what is available to help you. There is no therapy, little in the way of counseling [sic] and no choice but to do your own rehabilitation.*
>
> (Consumer, South Australia, Submission #77)

An extreme example of the consequence of the inability of one mother to obtain the care, treatment and support she required for her son was that she decided she could no longer care for him and made him a ward of the State.

> *[X] became a ward of the state because I was aware I needed help with his personality changes and respect for himself.*
>
> (Carer, Mother, South Australia, Submission #195)

6.4.11.1 Access

The MHS is accessible to the defined community.

Under this Standard, submissions and presentations indicate concerns about:

- attitudes towards Indigenous people;
- operational policies which limit access (opening hours and mode of contact);
- a crisis is required before services can be accessed;
- carers concerns are being ignored;
- long waitlists or no clinicians available at all;
- lack of services for people with mental illness and complex needs; and
- lack of services for people with personality disorders.

An inability for consumers to access treatment and support services, both within the community and inpatient care, often results in a whole series of rights being infringed for consumers, carers and the community. For the consumer, the consequences of these infringements can include consequences ranging from increasing disability, and hence consequent inability to care for oneself or others, participate socially or work or study, to (in some cases) the potential for harm to self or others, and to becoming poor and ultimately homeless. Increasing disability can also further expose the consumer and their family to discrimination and social exclusion, further compounding their illness.

For children and youth, failure to gain access to services at this time of their life can place their future life course at risk. For example, if they are expelled from school, their problem behaviours can increase, further disrupting their relationships with their peers.

Similarly, increased burdens on carers can disrupt their ability to participate socially and work when their family member became increasingly ill and require increasing care. Family isolation and increasing instability were also frequently reported due to the lack of community support and acceptance (high levels of stigma and discrimination) and lack of family-centred approaches to treatment and support. For the community, rights to safety can be infringed upon and social and economic cohesion disrupted.

6.4.11.1.1 Difficulties being experienced by Indigenous people

> *The main problem for Indigenous people is that people are so judgemental of Indigenous people. Our clients are most often judged as taking drugs or alcohol and not being mentally ill. Because of this, because it's easy to say they've taken something, they receive no mental health care. It's very hard when we go to government services for care.*
>
> (Clinician, South Australia, Adelaide Forum #13)

According to Standard 11.1.1 'The MHS ensures equality in the delivery of treatment and support regardless of consumer's age, gender, culture, sexual orientation, socioeconomic status, religious beliefs, previous psychiatric diagnosis, past forensic status and physical or other disability'. Despite this, concerns were expressed regarding the inability of Indigenous people to access care due to discriminatory attitudes and beliefs. As a result, care has been denied to Indigenous people. As an example of the barriers experienced by Indigenous people, a clinician at the Adelaide forum described the lengths one Indigenous person went to access care:

> *…Indigenous people… I want to tell you about a guy that I saw on the streets. He went to the Royal Adelaide Hospital to seek treatment and they basically told him to piss off. I picked him up off the streets with 2 broken legs and a broken hip. He jumped off the bridge so he could get help.*
>
> (Clinician, South Australia, Adelaide Forum #13)

By contrast, at the Murray Bridge Forum, a more positive picture was described with regards to services for Indigenous people as a result of the involvement of Indigenous workers. Unfortunately, services appear limited due to lack of resources.

> *We have a high population of indigenous people. The indigenous workers are great but they are so stretched. We have data from York Peninsula from programs they have run there that shows that if people with a mental illness are supported to break down their social isolation then they do get better and it aids with their rehabilitation.*
>
> (Community Health Service worker, South Australia, Murray Bridge Forum #9)

6.4.11.1.2 Operational policies are limiting access (opening hours and mode of contact)

Standard 11.1.4 states: 'The MHS is available on a 24 hour basis, 7 days per week' and Standard 11.1.3 further states '…in a convenient and local manner'. One police officer expressed concern that as a result of services only being available during office hours, the police service was the de facto after-hours service. This is of grave concern on many levels, not the least of which is the stigma for the consumer and their carers resulting from contact with the police which is misinterpreted as threats to safety or criminality.

> *I see a real lack of home support for people living with a mental illness. After hours there's no after hours support – that is when they call on us.*
>
> (Police Officer, South Australia, Murray Bridge Forum #16)

Another 'equality of access' concern was raised by an NGO worker for people with mental illness who are poor. In many areas, mental health service providers have tried to ensure 24-hour access by the provision of a phone service. However, focus on a single mode of contact disadvantages consumers who do not have a phone or who can only receive calls. Standard 11.1.3

I work for a consumer / carer organisation. We rely on volunteers and we've been operating since 2001. I want to raise an issue about providing phone support. It is important to be able to provide phone support but we also need to recognise that many of our clients cannot phone out – they can only accept incoming calls because they can't pay their phone bills.

(NGO Worker, South Australia, Adelaide Forum #24)

6.4.11.1.3 Crisis required before access is permitted

As illustrated in the example above with the Indigenous person who jumped off a bridge to access care, another report was received providing further evidence that often care cannot be accessed until a person is either a threat to themselves or others. This further supports other evidence that prevention and early intervention are not a key focus of service delivery in South Australia.

Someone close to me has 'episodes' and nobody wants to know until he's done something wrong and then the police are called.

(Carer, Consumer & Advocate, South Australia, Adelaide Forum #5)

One police officer reported the tragic story of a woman who the police had tried to assist to care, but failed. The women died as a result.

I can tell you about a woman who arrived on a bus from Victoria – we tried to certify her three times one weekend. We couldn't get her certified but then she jumped off the bridge.

(Police Officer, South Australia, Murray Bridge Forum #16)

6.4.11.1.4 Carers not heard

Another example supporting claims that a crisis is required before services are provided is that carers are unable to initiate a response from services. One mother outlined her desperate attempts to access services for her son who was becoming increasing unwell (and who was well known to the mental health service) but her notification and attempts were ignored.

I rang ACIS on the afternoon of 27/2 [2004] in an attempt to understand how things had gone so wrong. [Y] told me that there had been several phone calls made to [X] by ACIS and that he had not wanted intervention!!!

(Carer, Mother, South Australia, Submission #279)

6.4.11.1.5 Long wait lists or no clinicians available

Apart from contact with professional mental health workers there are no ongoing community support programs in the Mallee outside the regional centre of Murray Bridge.

(Health and Community Services Network, Murray Mallee Strategic Task Force, South Australia, Submission #115)

Reports were also received regarding the lack of sufficient staff and services to meet the needs of the community, especially in rural and remote areas. This was evidenced by long wait lists for the staff available, or no staff or services to meet the needs of special groups. Standard 11.1.2 states: 'The community to be serviced is defined, its needs regularly identified and services are planned and delivered to meet those needs'.

I work 7 days a week at the hospital in accident and emergency. This is a shared position with [MH nurse]. Together we cover the 7 days. I have requested for someone to see Dr [Z], the visiting psychiatrist. It can take weeks or even months wait before someone can get in to see a psychiatrist.

(Clinician, South Australia, Murray Bridge Forum #5)

There's only a visiting psychiatrist for this area. They come 1 day a week. We need more access than that. But then the problem in Adelaide if you can get up there is that there's very little bulk billing psychiatrists in Adelaide. Earlier in the year I was told that I needed a psychiatrist but I couldn't find one that was bulk billing that was taking new patients. There's not even a social worker here now, no OT now, no psychologists after several years. It's all left to the mental health nurses who are expected to carry the load.

(Consumer, South Australia, Murray Bridge Forum #2)

In the country there is no resident psychiatrist and I had to travel to Adelaide on a regular monthly basis to see a psychiatrist. This meant petrol money, and travel of an hour duration each way. Other specialists I have seen also consult in Adelaide for the most part. The cost of travel to Adelaide together with an hour drive there and back and an appointment of only ten minutes or so became unsatisfactory and unaffordable. Now we have a visiting psychiatrist once a fortnight but this can't reasonably enable all mentally unwell people to see her. I am none the less thankful she comes to Murray Bridge.

(Consumer, South Australia, Submission #77)

Services such as visiting psychiatrists often offer no choice and long times between visits. If I travel to Adelaide to see a psychiatrist there is an hour trip down and back for a ten minute consultation. The petrol cost and short interview led me to stop seeing a psychiatrist and instead see a GP regularly.

(Consumer, South Australia, Submission #77)

6.4.11.1.6 Lack of services for people with mental illness and complex needs

Given the reports above regarding difficulties in accessing services, it was not surprising to hear that consumers with complex needs found even further barriers. Police describe circumstances of being left to deal with 'the difficult clients no one wants' and concerns were expressed about services for people with eating disorders, behaviour problems and drug and alcohol problems.

People are being given bus tickets to be moved on… we're left dealing with the difficult clients that no one else wants.

(Police Officer, South Australia, Murray Bridge Forum #16)

At the beginning of this year, I began to suffer debilitating depression and eating disorder symptoms. I sought help in the Emergency Department of Flinders Medical Centre three times. The first time I sought help there, I waited well over 3 hours to be seen, then was admitted and left in "Extended Emergency Care Unit" for 3 days, then discharged because there were no beds available in the Psychiatric Ward. The second time I presented, I gave up after a day in the EECU. I was on the waiting list for a bed, and after a number of weeks and another presentation to FMC Emergency, I finally got admitted.

(Consumer, South Australia, Submission #158)

He tried cutting down on his antidepressant tablets when he was living in Salisbury about five years ago. He was bed ridden and physically ill in his attempt. He was crying out for help. He rang Glenside a few times and tried to convey to them by phone his desperate situation. His frustration in being dismissed combined with his lack of verbal and social skills resulted in the opposite from obtaining help. Again [X] faced court and was charged with abusive language. The system that should have protected [X], failed him.

(Carer, Mother, South Australia, Submission #195)

There is a drug and alcohol service in the area but it doesn't work with the mental health service. People get pushed between the services. People with both problems get told to go to the other service for help.

(Consumer & Advocate, South Australia, Murray Bridge Forum #8)

6.4.11.1.7 Lack of services for people with personality disorders

Many reports were received regarding the lack of treatment and support options for people with personality disorders (discussed in section 11.4 Treatment and Support). As a consequence, access issues were for this group were seen as critical.

> *I'm concerned for those people who are seriously mentally ill. They are reluctant to go to mental health services because they are told there is no or minimal help for people who have been labelled as having personality disorders.*
>
> (Consumer, South Australia, Adelaide Forum #16)

6.4.11.2 Entry

The process of entry to the MHS meets the needs of the defined community and facilitates timely and ongoing assessment.

No submissions or comments were received pertaining to this Standard.

6.4.11.3 Assessment and review

Consumers and their carers receive a comprehensive, timely and accurate assessment and a regular review of progress.

Under this Standard, submissions and presentations indicate concerns about:

- the quality of the assessment and review process; and
- assessment concerns for people from a non-English speaking background.

6.4.11.3.1 Concerns about the quality of the assessment and review process

One carer described the apparent failure of services to conduct an adequate assessment and provide treatment to a consumer who openly declared he was suicidal.

> *He went to The Flinders Medical Centre three times and told them he was suicidal and asked for help. He badly needed to be admitted for assessment in Glenside. They kept him overnight a few times and then let him go.*
>
> (Carer, Mother, South Australia Submission #195)

And yet another carer said that she did not believe the 'principles of good practice' had been applied in her son's case:

> *[X] needed a comprehensive assessment of his condition and medication but I believed that he would either find his own way to hospital through his bizarre / anti-social behaviour or would be assessed by ACIS as requiring admission… I have re-read the glossy booklet P8-02 Assessment and Intervention Service and I cannot see how the 9 Principles of good practice have been applied in this case. And in particular, nowhere do I find that it is only the willing consumers who get a service while the remainder become the responsibility of the Police.*
>
> (Carer, Mother, South Australia, Submission #279)

Standard 11.3.3 states "The MHS has a procedure for appropriately following up people who decline to participate in assessment'. Clearly this carer felt that this Standard was not met and that the mental health service had handed over their duty of care for these people to the police.

6.4.11.3.2 Assessment concerns for people from a non-English speaking background

Even though Standard 11.3.9 states: 'There is opportunity for the assessment to be conducted in the preferred language of the consumer and their carers' and Standard 11.3.10 states 'Staff are aware of, and sensitive to, language and cultural issues which may affect the assessment', there were some who did not perceive this be the case. For example, concern was expressed about the potential misdiagnosis of a person from a non-English speaking background, which could indicate problems with the assessment process:

> *A consumer reported that he had been tortured in a military context, in which it is conceivable that such an event might have taken place. The initial interpretation by mental health staff was that he was psychotic. No other possible explanations were entertained. A second interpretation by staff, some weeks later was that the man reported things that were so incredible that he was not to be believed. This was accompanied by the observation that the man in question presented with signs of physical injury. It was at this time that staff refused to refer to Survivors of Torture and Trauma, or to a Clinical Psychologist of the man's own cultural background, for a more comprehensive assessment. The man concerned was of an NESB background and did not possess English in his linguistic repertoire. Hence, the need for informed assessment was doubly important. Some weeks later, staff made the observation that it turned out that the man was right and that he had been tortured. This conclusion was not reached by a methodical process of assessment and, as such, appears to have occurred through good fortune rather than through good management. It was not accompanied by any reflection on the earlier conclusions that had been reached.*
>
> (Clinician, South Australia, Submission #56)

6.4.11.4 Treatment and support

The defined community has access to a range of high quality mental health treatment and support services.

> *I guess I am writing this letter in desperation for help as I continually worry about my son ending up just another suicide victim.*
>
> (Carer, Mother, South Australia, Submission #195)

Under this Standard, submissions and presentations indicate concerns about:

- restrictive and intrusive practices;
- lack of involvement of carers;
- lack of services for refugees and newly arrived immigrants;
- lack of services for people with dual diagnosis (drug and alcohol);
- lack of services for people with physical disability;
- lack of services for the aged;
- lack of services for people with personality disorders; and
- lack of services for people with eating disorders.

6.4.11.4.1 Restrictive and intrusive practices

> While acknowledging the difficulty of service provision to consumers with complex problems and behaviours, it is expected that specialist mental health services will have and use the necessary skills to engage people with such a profile, who are recognised as a priority consumer group. It is proposed that successful engagement with the consumer can improve the chances of good outcomes without resorting to the most restrictive forms of care. (excerpt from a letter from the Director of Mental Health, Mental Health Services and Programs, Department of Human Services, 2004)
>
> (Carer, Mother, South Australia, Submission #195)

Standard 11.4.10 states: 'The MHS provides the least intrusive treatment and support possible in the environment and manner most helpful to, and most respectful to, the consumer.' However, reports were received indicating that this is not the case. One academic alleged that restraint practices were being used across South Australia and another NGO reported coercive approaches to treatment.

> *Restraint practices across the state appear to be often cruel harsh and in many cases, in breach of the WHO [World Health Organisation] guidelines re least restrictive environment.*
>
> (Academic, South Australia, Submission #142)

> *Some of our clients report having been threatened by a mental health worker that they will be admitted if they get upset during a session. This is control through fear, it's not good mental health care.*
>
> (NGO Worker, South Australia, Adelaide Forum #24)

6.4.11.4.2 Lack of involvement of carers

Despite Standard 11.4.9 acknowledging the involvement of carers ('There is a current individual care plan for each consumer, which is constructed and regularly reviewed with the consumer and, with the consumer's informed consent, their carers and is available to them'), carers repeatedly reported being excluded and either feeling disempowered to request involvement or having to 'demand' it. Given the reported problems with access and limited services available in the community, practices which involve carers to assist with the delivery of care and achieve the best possible outcomes for consumers would both help recovery and protect many rights of people with mental illness.

> *As a carer I was invisible to the medical profession. We are a silent workforce. Carers should be recognised as collaborators of care and if we were recognised in this way then everybody would benefit. If I had my caring role again, I would not be so disempowered, I would now know exactly how to speak to that neurologist who disregarded me before. I would say to him that he should speak to me, I am the wife and I know what's going on with my husband.*
>
> (Carer, Wife, South Australia, Adelaide Forum #1)

> *…by last month was agreeing to return to Adelaide on the proviso that he live with me for the time being. He had spent most of 2003 in hospital and had been discharged into the community in January 2004. He had been placing himself at high risk even though he was on a Community Order. I was aware of the difficulties inherent in living with [X] but I readily agreed as he had been out of contact over many months… to my amazement both psychiatrist and worker left without having exchanged a single word with me about my son. Soon after I found him snoring very loudly and saw a bottle labelled Diazepam 5 mg (10 tablets) of which five were missing… There was no discussion of a care or management plan, assessment, follow up visit or the medication which had been left… The visit totally disregarded my role as a carer in extreme circumstances.*
>
> (Carer, Mother, South Australia, Submission #279)

> *…we had to demand to be involved.*
>
> (Carer, Family Member, South Australia, Adelaide Forum #2)

…she now lives with us … and we must admit it is very calm now and working. We have been very lucky as she now has an excellent doctor in Dr [X] whom we think genuinely cares for her welfare and has always involved us in any decision both in her welfare and of her son… So in finalising We would say in the beginning we had an up hill struggle with the services who we believe did not really or fully comprehend our needs and dismissed our phone calls as just whingeing but we were totally ignorant of this problem and needed as much help in dealing with it as our daughter did but in a different way, several times we had the crisis team out only to be told to our faces, yes she is sick and needs treatment, then they went away leaving us to deal with a totally psychotic person and we have had no training on how to deal with this. If this letter is of any help we are pleased but up until we got a doctor who cared we were totally annoyed with all the promises and false information.

(Carers, Parents, South Australia, Submission #72)

6.4.11.4.3 Services for refugees and newly arrived immigrants

Standard 11.4.8 states: 'The MHS ensures access to a comprehensive range of treatment and support services which are, wherever possible, specialised in addressing the particular needs of people of ethnic backgrounds'. With regards to this, additional services for refugees and newly arrived immigrants were mentioned.

Need for additional services for refugees particularly those who have experienced severe traumas.

(Clinician, South Australia, Murray Bridge Forum #14)

It's particularly difficult for newly arrived immigrants in South Australia to access mental health care.

(Anonymous, South Australia, Adelaide Forum #12)

6.4.11.4.4 Lack of services for people with mental illness and drug and alcohol problems

I have previously investigated how our mental health services deal with clients who have drug and / or alcohol dependencies in addition to mental health problems, and I am concerned that this group seems particularly likely to fall through the gaps in the system. I will continue to lobby the Government to improve services in this area, particularly in terms of providing greater resources for institutional and community-based mental health care and support for families dealing with mentally ill family members.

(excerpt from a letter from Kris Hanna MP, Member for Mitchell)
(Carer, Mother, South Australia, Submission #195)

As noted above in this letter from a Member of Parliament and below, from the Health and Community Services Network, Murray Mallee Strategic Task Force, this gap in service provision is well documented. Standard 11.4.7 however states: The MHS ensures access to a comprehensive range of services which are, wherever possible, specialised in regard to dual diagnosis…'. In the notes to this Standard, this includes dual case management with alcohol and other drug services.

It is well documented that substance abuse, including polydrug use, amongst people suffering from mental illness is extremely common. Yet mental health services and drug and alcohol services remain separate. Some residential mental health programs require participants to be drug and alcohol free before they are eligible.

(Health and Community Services Network, Murray Mallee Strategic Task Force, South Australia, Submission #115)

The other thing that concerns me is the substance abuse problem. There is an increasing problem for parents of children with dual drug and alcohol and mental health problems. These problems often start in Glenside when young people are first admitted – they get exposed to illegal drugs there and they start taking them.

(Consumer & Advocate, South Australia, Murray Bridge Forum #8)

The youth health sector has for many years highlighted the need for a dedicated youth detoxification program focusing on young people. Generalised detoxification services such as Warinilla are often reluctant to accept young people as inpatients due to concerns around contamination. In recent years the Women's and Children's Hospital began a small program focusing on youth detoxification in response to demand; however, an expanded and dedicated youth detoxification service is urgently needed. Similar youth specific services already exist in Victoria, Queensland and Western Australia. YACSA envisages that such a service would in the first instance support 11 to 16 year olds (with scope to encompass up to 18 years), comprise six to eight beds with a nursing component, visiting general practitioner and a staff team to manage residential and recreation support and to provide psycho-social support (case manager, youth workers, psychologist). Such a service would ideally be located in a publicly owned house adjacent to a public hospital, such as the Women's and Children's Hospital, in order to enable quick medical response. A service of this kind is also consistent with the Government's strategic directions for future drugs policy, specifically with regard to 'strengthen[ing] support' and 'timely and effective treatment', as outlined in its response to the South Australian Drugs Summit, and would fulfill Labor's promise through its Platform for Government to "review treatment and support services for young people dealing with [drug and alcohol] issues and examine the feasibility of establishing an adolescent residential treatment facility."

(Youth Affairs Council of South Australia, South Australia, Submission #38)

The Health and Community Services Network, Murray Mallee Strategic Task Force, have made the following recommendation with regard to this vulnerable group of consumers:

Recommendation: That programs be developed that will take a holistic approach to people who suffer mental illness and who also depend on drugs and self medicate to cope with life.

(Health and Community Services Network, Murray Mallee Strategic Task Force, South Australia, Submission #115)

6.4.11.4.5 Lack of services for people with physical disability and mental illness

Included in Standard 11.4.7 with regard to the delivery of services to people with dual diagnosis are people with other disability. One consumer advocate expressed concerns that this group of people experience difficulty in accessing services and are being discriminated against. Standard 11 (Access), states that 'The MHS ensures equality in the delivery of treatment and support regardless of… physical or other disability' and Standard 11.1.7 states 'The MHS, wherever possible, is located to promote ease of physical access with special attention being given to those people with physical disabilities…'.

I am here representing people with physical disabilities who also have a mental health problem. Trying to get access to hospital services is problematic. An official complaint has gone in to the Human Rights and Equal Opportunity Commission regarding this matter and it's happening throughout Australia. The Australian Cerebral Palsy Association can testify to this. We are concerned that something be done about this situation. We have a saying… "We're consulted to death but we're still dying!"

(Consumer and Advocate, South Australia, Adelaide Forum #3)

I was recently at a funeral of a friend and a large number of mental health workers came to his funeral. The problem is that they weren't there for him before his funeral when he really needed them and they haven't been back since his funeral! The funding is extremely important, we need adequate funding for appropriate services.

(Consumer and Advocate, South Australia, Adelaide Forum #3)

6.4.11.4.6 Lack of mental health services for the aged

Older people make up about 14% of South Australia's population but more than half of the admissions to hospitals. The frail aged are a special needs group in our community and are frequently found to experience high prevalence mental disorder – this is important in residential care where rates are higher than found in the community. These high-prevalence disorders are the dementias, delirium, depression and behavioural disorder at a level that cannot be addressed by acute psychiatric services, but which lead to significant distress to the person or those providing their care.

(Academic, South Australia, Submission #187)

Concerns were raised with regards to the many difficulties in providing services to this age group. Standard 11.4.3 ensures access to a 'comprehensive range of treatment and support services which are, wherever possible, specialised in regard to a person's age and stage of development'.

In this group–and particularly with the 70+ group –we see a blurring of the boundaries between physical and mental function.

(Academic, South Australia, Submission #187)

Given that the issues arise in community and residential (as well as acute inpatient) settings, the sources of funding ought to include the Commonwealth and State government departments of health, ageing and mental health. The service needs to be developed as a partnership of the acute, aged/community sectors and GPs.

(Academic, South Australia, Submission #187)

Disturbing behaviour was cited as a difficulty both in terms of settings where treatment is provided for other patients and staff (e.g. acute care and mix of consumers, aged residential setting) and discharge planning.

The evidence suggests that people with mental or behavioural disorders are likely to be seen as difficult and complex with the result that they are less likely to receive adequate or appropriate care. Disturbing behaviour is obviously not restricted to the nursing home setting… These behaviours are common and they have a significant impact on both the quality of care and the carer burden / burnout.

(Academic, South Australia, Submission #187)

…behavioural disorder and psychological symptoms associated with dementia are common in acute care settings (with implications for length of stay and discharge planning as well as issues for care provision) and residential care (where they are associated with increased dependency and higher care costs). They are not always well managed. (Brodaty, Draper & Lee-Fay 2003)

(Academic, South Australia, Submission #187)

People in acute hospitals with behavioural and psychological symptoms of dementia are more difficult to discharge because of difficulties in placement (Draper & Luscombe 1998). This is often due – quite reasonably – to the reluctance of residential care facilities to accept people whom they feel they may not be able to manage.

(Academic, South Australia, Submission #187)

Whilst at the Consultation I also noticed that the elderly with mental illness were not mentioned?? I would like to highlight the urgent need for accommodation such as nursing homes / hostels here in SA and the lack of mental illness understanding within the mainstream nursing homes (they do have understanding of dementia and alzheimers though). There is also a lack of psychiatrists that specialise in this arena here in SA.

(Anonymous, South Australia, Submission #61)

6.4.11.4.7 Lack of services for people with personality disorders

I am particularly concerned for those people with personality disorders because they are not getting any help.
(Social Worker, South Australia, Adelaide Forum #20)

Clinicians and service providers also raised concerns about the lack of services for people with personality disorder. Specifically, evidence was presented indicating the positive results that can be achieved both at a personal and societal level from providing treatment to people with this mental illness.

We get referrals from the prison and one of the big problems is that people are not getting access to accommodation and support especially those people with borderline personality disorders.
(NGO Service provider, South Australia, Adelaide Forum #21)

…draw the Committee's attention to research highlighting the cost benefits of implementing best practice strategies in the treatment of Borderline Personality Disorders. Borderline Personality Disorders is a serious mental illness that affects 2% of the general population, resulting in a suicide rate of 10% and a dependency on social security supports extending from 19-years old through to their mid 50's. This group constitutes around 20% of the population admitted to psychiatric inpatient services. The results of a NSW study (1999) indicated that the cost of 12 months treatment for a sample of 30 (involving only inpatient, ambulatory, diagnostic and pharmacotherapy services) was $765,789. If instead, this same sample was provided twice weekly therapy sessions, then a* ***saving of over $500,000*** *was made (this figure includes the cost of therapy)**. (*DSM-IV-TR Diagnostic and Statistical Manual of Mental Disorders. Fourth Edition 2000 pp 707-708; **Hall J, Caleo S and Stevenson J. Economic Analysis of Psychotherapy for Borderline Personality Disorder Patients. CHERE Project Report 9 Discussion Paper, June 1999) (author's emphasis)*
(Anonymous, South Australia, Submission #239)

…preliminary results of long term outcomes would indicate that most return to work. The implication of this would be that a percentage of this population would move from receiving the Disability Pension into the work force/tax paying population. That is, they would be adding to Government funds not drawing on it. …We believe that two ***conclusions*** *can be reached:* ***Evidenced-based programs*** *indicating best practice models in the treatment of Borderline Personality Disorder are available and underutilised. These are available for both the in-patient and community-based setting. If utilised, they can lead to* ***significant cost benefits*** *to local and state government revenue. (author's emphasis)*
(Anonymous, South Australia, Submission #239)

6.4.11.4.8 Lack of services for people with eating disorders

I have personal experience in telephone helpline and lobbying and support for people with Eating Disorders… I can relate to what [Y] said about the lack of services available - often the only service option is to go to Flinders Hospital. We hear stories of girls being told they need to lose more weight before they can get admitted – services are very restricted. We need a holistic approach and I'd love to see that developed further.
(Clinician, South Australia, Adelaide Forum #7)

Clinicians, service providers and consumers expressed concerns about the lack of availability and quality of treatment and support services for people with eating disorders.

The Blackwood program… is under high demand, usually carrying waiting lists of several months.
(Service Provider, South Australia, Submission #233)

Also there is a lack of acknowledgement of young teens (12 years and older) of having a real diagnosis. Other co-morbidities also don't get acknowledged, particularly anxiety. There are lots of health issues for our client group… the response from primary care isn't there and we know that a good response in the early stages of an eating disorder will help improve longer-term outcomes. But the reality is that the response isn't good and there aren't enough psychologists or counsellors.

(Clinician, South Australia, Adelaide Forum #8)

…I am very disappointed by the quantity, quality, variety, specificity and expense of the inpatient and outpatient treatment available to (public) mental health patients, particularly for sufferers of eating disorders. Eating disorders (and depression) are extremely debilitating and can be fatal. It is no way to live. I urge the government to improve public access to quality, specific help for eating disorders and depression.

(Consumer, South Australia, Submission #158)

It just felt like I was bashing my head against a brick wall. After 3 days in the Psychiatric Ward, I was put on the Eating Disorders 2-week assessment program. I experienced the most laughable thing during this time; I was not able to see a doctor or physiotherapist in hospital for four days, even though I was experiencing considerable back pain, because it was Easter! This meant I could not even get painkillers stronger than asprin! During the 2 weeks, I saw nurses, student doctors and student psychiatrists reasonably often, but saw qualified doctors rarely, and the only time I got to see the psychiatrist was for about 8 minutes when I was being discharged! What a joke! I did not even receive any helpful "assessment" or advice out of the program.

(Consumer, South Australia, Submission #158)

South Australian mental health resources are dangerously inadequate - particularly for those people requiring inpatient treatment and intensive care over a longer period of time, for such illnesses as eating disorders. While only in my early 20's, I have been tangled in an unsupportive mental health system for nearly 10 years - during which time little (if any) long term progress has been made. I have no hesitation in saying that a more supportive system could well have seen me in and out in a matter of years, rather than still utilising the seemingly ineffective treatments available to me through sheer desperation… The system may have saved me in the short term, but it has done nothing to improve my quality of life in the longer term. My fear is that I will remain in the system, and never break free of the shackles mental illness has placed on me. Nothing would please me more than to legitimately earn my way out of the system. In order for that to happen though, I need to be provided with viable treatment options.

(Consumer, South Australia, Submission #215*)*

Despite having private health insurance, in the absence of a private facility to effectively treat people who suffer from eating disorders, I have been forced to add to the burden already placed on the public hospital system - where there is an eating disorders treatment program (albeit suspectly effective). Brief inpatient treatments of 2...4...6 weeks are seemingly not successful (as can be seen by the high readmission rate of patients to the Weight Disorder Unit at Flinders Medical Centre).

(Consumer, South Australia, Submission #215)

As you would know, eating problems are a high prevalence disorder among young people and are also the most fatal (~15%), particularly anorexia, even compared with depression and schizophrenia. Of course, eating problems commonly co-occur with depression and anxiety… Although in-patient facilities are not a preferred way of dealing with anorexia, when the person's life is severely compromised they are inevitable, provided there are places/beds available. The major dilemma I am witnessing is the limited capacity in SA (really Adelaide as there are only metro-based programs), to provide an appropriate youth-friendly and family/carer-inclusive service… The only program with a good reputation for offering such a service is the private Blackwood Hospital program, although if people's physical health is so poor as to require nutritional rehabilitation/restoration via medical intervention then the person must go to WCH [Women's and Children's Hospital] or FMC [4G Psychiatric Ward of Flinders Medical Centre].

(Service Provider, South Australia, Submission #233)

By working on 'networking' we have increased access to people who, as a result of personal experience, have skills knowledge and insights which could, accompanied with other work experience they have, provide a very valuable resources which could be of great benefit to people recovering from eating disorders. I would love to see appropriate people make up a new workforce of non clinical community mental health workers; people who, as a result of personal experience and including their work and study qualifications, work to fill the gap in services that exists between GPs diagnoses and hospital admissions.

(Anonymous, South Australia, Submission #44)

I wish to add, that I feel extremely positive about and believe that there are many women (and men) with eating disorders who could recover far more quickly than they presently do. I believe that worked with in the 'correct' light, eating disorder issues could be broken down and worked with in such a way that we see very positive cultural (social) changes as well as health changes in the future. There are many inspired people who wish to support these changes but within the current governing framework (rules and regulations) this process is slowed down or prevented.

(Anonymous, South Australia, Submission #44)

6.4.11.4.A Community living

The MHS provides consumers with access to a range of treatment and support programs which maximise the consumer's quality of community living.

Under this Standard, submissions and presentations indicate concerns about:

- the lack of family-centred approaches and support services;
- lack of self care and living skills programs;
- lack of community support services to maximise opportunities to live independently; and
- lack of support for children of parents with mental illness.

6.4.11.4.A.1 Lack of family-centred approaches and support services

Many reports were received from consumers, clinicians and carers describing the incredible strain that has been placed on families, in particular, on children of parents with mental illness. The lack of access to family-centred approaches and support groups was repeatedly mentioned (as stated in Standard 11.4.A.12). Also, the lack of access to other support services (e.g. leisure, recreation, education, training, work, employment, respite, home and community care) also contributed to this. Strain was also seen to emanate from discriminatory remarks made from members in the community towards family members, a general lack of community acceptance and increasing social isolation (family and individual).

I have been mentally ill for 10 years. There's no support for my children or my wife. Because my kids don't get any support, in fact they get teased about having a father who is mentally ill, they then come home and take it out on me; tell me I'm nuts or I'm a loony. Schools need to provide my family, my children with support. We also need a support group for my wife / carer. Perhaps something like this could be run through the hospital.

(Consumer, South Australia, Murray Bridge Forum #1)

Children who have parents with a mental illness are not having their needs met. Sometimes those kids are removed from the care of their parents, instead of supporting them in their homes.

(Clinician, South Australia, Murray Bridge Forum #14)

The system has continually failed [X] from early childhood. It has failed me as a parent, and I know I must keep fighting while I can. I know there are mothers and sons out there, but I feel very lonely and drained. I only have short bursts of happiness knowing my son is living such a horrendous life with no way out.

(Carer, Mother, South Australia, Submission #195)

I run a monthly support group for 40 or 50 people. Many have sons or daughters with mental illness. These people need long-term supported housing for their children. They cannot continue providing all the care without support and they can't wait for support to occur every 2 weeks.

(Carer, South Australia, Adelaide Forum #18)

Consumers can support other consumers but they also need access to resources to be able to do this.

(Carer, South Australia, Adelaide Forum #18)

There is insufficient respite for carers of people with mental illness.

(Health and Community Services Network, Murray Mallee Strategic Task Force, South Australia, Submission #115)

6.4.11.4.A.2 Lack of self care and living skills programs

As alluded to above by a carer, with the current lack of supported accommodation, many consumers are forced to return to live with their families. In many instances, this placed intolerable strain on families as they waited for places to become available. Additionally, the lack of self care and living skills programs meant that consumers are also not able to gain the necessary skills to live independently and move out.

When people have been severely mentally ill they do forget the basic hygiene and basic survival skills they once had so they need help to relearn these skills and this involves someone coming into their home to help relearn how to make soup and other things and how to clean the house. A lot of people don't have families that can help them in this way.

(Consumer, South Australia, Murray Bridge Forum #7)

As indicated by one consumer, some people have carers who can assist with this, but many do not. An NGO employment service provider who provides cleaning services indicated the living conditions and result for consumers who have been unable to access such programs:

We are now seeing houses that are nothing short of disgusting! These houses are occupied by people who have been discharged from psychiatric institutions and they live like dogs because there's no follow-up care for them, they are not taught any basic living skills and most don't even know how to cook for themselves.

(NGO Employment Service Provider, South Australia, Adelaide Forum #19)

Living skills and self care programs would enable consumers to live with dignity in society and are seen as critical. Standard 11.4.A.13 states: 'The MHS provides a range of treatment and support which maximises opportunities for consumers to live independently in their own accommodation' and 11.4.A.2 states: 'Self care programs or interventions provide sufficient scope and balance so that consumers develop or redevelop the necessary competence to meet their own everyday community living needs'.

6.4.11.4.A.3 Lack of community support services to maximise opportunities to live independently

Coupled with the lack of available programs for consumers to learn the necessary skills to live independently, is the lack of services available to assist with domestic care and general support.

Mental Illness not recognised as a disability by HACC! Funding for service delivery not available.

(Consumer Advocate, South Australia, Submission #136)

People with a mental illness are discriminated against. People with other health problems who have been in hospital will get Domestic Care but not so for people with a mental illness – surely they should get the same sort of help.

(Consumer, South Australia, Murray Bridge Forum #7)

Consumer advisory group in the process of developing a service to provide support services to people with a mental illness / families & carers. On numerous occasions they have encountered animosity from some staff / service providers who are questioning their ability to provide such a service.

(Consumer Advocate, South Australia, Submission #136)

Social support also needs to be extended. These people have suffered at different times from inappropriate drugs or the amount of drugs prescribed; they would like more information about drugs and their side-effects which can cause stigma. A huge focus of their life is their mental illness as they are constantly being defined in relation to it and there are few options of independent living or employment or to socialise with people who do not have a mental illness. It is impossible for them to get a job in the private employment or housing market due to stigma. False friends often rip them off financially or involve them in crimes without their knowledge.

(Family Member, South Australia, Submission #6)

There is a lack of services in country regions and in Murray Bridge South Australia there is local GP's the general hospital, and SWANPORT HOUSE COMMUNITY PROJECT. The latter provides opportunity to do social activities on a regular basis and receive individual support and counseling [sic] as required. The service is struggling to cater for 40 mentally ill adults with limited funding and only one full time worker and one part time worker. There are many people on a waiting list who do not receive any support which is unacceptable. There is no capacity to expand the service is none the less as good as it can be but is insufficient in its present form. There is no choice or alternative services and no specialised services for employment or children of mentally ill adults.

(Consumer, South Australia, Submission #77)

Families are left to fend by themselves with no social workers or mental health workers working outside the hospital. (Kahlyn, Glenside, Murray Bridge Soldiers Memorial Hospital.)

(Consumer, South Australia, Submission #77)

6.4.11.4.A.4 Lack of support for children of parents with mental illness

The lack of programs and services to support children of parents with mental illness were also highlighted. Standard 11.4.A.12 states: 'The MHS ensures that the consumer and their family have access to a range of family-centred approaches to treatment and support'. This support would assist parents with mental illness to continue to live in the community and fulfil their role as a parent and keep the family unit as functional as possible. However, as seen in the comment below, this is not always the case:

We… feel that Human Rights breaches are occurring every day. We highlight the following - When an adult presents unwell and is diagnosed. the question is not necessarily asked "Are you a parent?", "How old are your children / how many do you have?", "What age are they?". The Adult Mental Health Sector has been negligent for many, many years in this arena and there is a lack of consistency. Some adult mental health workers have spoken openly of their concern for their clients children and not followed up??? (usually because of lack of support services in the community). We do not suggest for one moment that a parent with a mental illness is a poor parent but what we do say very clearly is that when a parent is becoming unwell, is unwell and then released from hospital / clinic these times can be very challenging not only for the adult structure of the family but also for the children. A parent may go home to a family of two small children with not support - parenting is difficult at the best time, imagine going home to two small children and having to cope with your mental illness, medication, doctors appointments etc and having no support?? We refer you to Article 16.3 - Universal Declaration of Human Rights to highlight the lack of protection by society and state.

(Anonymous, South Australia, Submission #61)

6.4.11.4.B Supported accommodation

Supported accommodation is provided and / or supported in a manner which promotes choice, safety, and maximum possible quality of life for the consumer.

Under this Standard, submissions and presentations indicate concerns about:

- the general lack of supported accommodation;
- the need for interim (step up and step down) accommodation;
- lack of supported accommodation options for young people; and
- the lack of support for providers of supported accommodation.

6.4.11.4.B.1 Lack of available supported accommodation

The lack of supported accommodation was cited on several occasions as being a reason for 'revolving door admissions' and consumers remaining unwell unnecessarily for extended periods. The lack of supported accommodation in rural and regional areas was particularly noted. The lack of such accommodation options, combined with the lack of community based treatment and support services, places intolerable strains on families.

> *The lack of supported accommodation in Murray Bridge results in people leaving hospital then returning 3 or 4 weeks later as the system is overloaded.*
>
> (Clinician, South Australia, Murray Bridge Forum #5)

> *In my country town there is supported accommodation but not for people with a mental illness.*
>
> (Carer, Consumer & Advocate, South Australia, Adelaide Forum #5)

> *There is a lack of supported accommodation and supported residential facilities for those with chronic mental health problems living in the Murray Mallee. This means extra pressure on carers and / or that those with a mental illness are living in isolation without day to day support.*
>
> (Health and Community Services Network, Murray Mallee Strategic Task Force, South Australia, Submission #115)

> *Our complaints workers are dealing almost entirely with mental health related complaints. We are also very concerned with the lack of appropriate supported accommodation facilities for people in South Australia. There are old boarding houses that are privately run but they are the dumping ground for people with a mental illness and these places get no funding. People are sent there in taxis from hospital when these facilities don't have the capacity to care for these people.*
>
> (Anonymous, South Australia, Adelaide Forum #14)

> *On the 6/8/04 my son rang distressed saying he had to have somewhere permanent to live if he had a C.T.O. [Community Treatment Order]. Apparently it was suggested to him an alternative possibility would be a backpackers hostel. He asked to live with us again… Again whilst discussing suitable accommodation my son suggested he sleep at a friend's on a couch. I told the nurse this was not an option. My son then suggested sleeping in his car, something he did for periods prior to his hospitalisation. Again I expressed the belief that this is not conducive to his mental and medical rehabilitation. I was taken aback at her suggestion that living in the car is an option, it is an alternative lifestyle that some people like. This I believe is not an option for a vulnerable person in Australia in 2004. We have seen no evidence of my son being able to function alone.*
>
> (Carer, Mother, South Australia, Submission #11)

My nephews are living with their father, and have not been able to successfully maintain housing independently, or employment. The recreational club that one of them goes to has been called a 'lifeline', however transport to the centre has been cut entirely, and the service itself has been cut (e.g. from 5 days to 3 days). Most people who attend the centre are over 30, and living with their parents in the community. The boarding house option was tried by one nephew, but it offers absolutely no privacy and due to this one is drawn into conflicts.

(Family member, South Australia, Submission #6)

Recommendation: That governments give priority to providing supported residential facilities as well as supported accommodation in the community for people recovering from mental illness, including those in rural and regional areas.

(Health and Community Services Network, Murray Mallee Strategic Task Force, South Australia, Submission #115)

[Recommendation] Urgent action to redress the lack of supported accommodation, with development of a Statewide plan and an increase in funding from 0.4% to a level sufficient to meet need.

(SANE Australia, National, Submission #302)

6.4.11.4.B.2 Need for interim (step up and step down) accommodation

Many submissions argued that a range of accommodation options were needed and that these needed to be flexible, for example, interim step-up and step-down facilities. Concern was expressed that as discharge often occurs 'far too early', an interim 'step down' facility between hospital and home would assist the recovery process:

It is easier to recover from mental illness in hospital than at home. However, the average is about 3 days, and discharge from mental health care occurs far too early. Consumers have no option but to rely on hostels for accommodation, which cannot provide proper care or suitable environments for recovery.

(Consumer, South Australia, Submission #41)

6.4.11.4.B.3 Lack of supported accommodation options for young people

After 30 years of social work practice I've entered many SRFs [Supported Residential Facilities] - starting in 1970s. I can confidently say that the Burdekin Report made absolutely no difference to the lives of these men & women, most of whom experience mental illness. Their level of physical & mental health is at the same disastrous level as homeless & Aboriginal people. If you haven't seen the SA Research paper "Somewhere to call home - Supported Residential Facilities: the sector, its clientele & its future" then you might find it informative… Going into some of the Facilities today, I feel like they are in worse shape than in the 1970s when many were established at the encouragement of the govt to "empty out" the backwards of the psychiatric hospitals. And talking with the managers, it's clear that they do not feel that they and their residents are receiving anywhere near an adequate service from the mental health services - some do have the ear of an overworked mental health worker but not the system.

(Family Member and Service Provider, South Australia, Submission #34)

Of particular concern was the reported lack of accommodation for youth with mental illness or mental health problems. As mentioned previously in this report, the scarcity of services for this age group and inability for clinicians to intervene as early as possible often has serious long term consequences.

We're dealing with young people with their first episode of mental illness and that's quite a frightening experience. We're also really concerned for those young people with comorbid mental health and drug and alcohol problems. Who picks them up? Nobody really, they get shifted back and forth because nobody wants to deal with them.

(Supported Accommodation and Assistance Program (SAAP) Service Provider, South Australia, Adelaide Forum #4)

I've noticed a marked increase in the number of young people with a mental illness and we're constantly asked to provide accommodation these young people but we're not funded to do that.

(Supported Accommodation and Assistance Program (SAAP) Service Provider, South Australia, Adelaide Forum #4)

We're often getting referrals from mental health services and we often have pressure put on us to take these young people because we're told they can't come out of hospital if they don't have anywhere to go.

(Supported Accommodation and Assistance Program (SAAP) Service Provider, South Australia, Adelaide Forum #4)

I did want to raise the issue of supported accommodation for young people with a mental illness. Our members have been reporting to us that when they have young people with a mental illness they often have behaviours which exclude them from housing. 3 years ago we produced a report. We are also advocating for a youth-specific detoxification service in South Australia – a lot of young people with drug and alcohol problems are not getting the care they need or deserve. We've sent a report on this to Human Services. And we have put a recommendation in every budget cycle and even though there has been some interest from some Ministers for further information, nothing has happened!!!

(Youth Worker, South Australia, Adelaide Forum #6)

In response to increasing concern about a widening gap in available services from the youth sector, YACSA recommends the establishment of an accommodation service specifically for young people between the ages of 12 and 18 years who are experiencing mental illness. The accommodation facility would offer specialist fully supported accommodation for up to six young people (three young women and three young men). In order to provide a comprehensive service, four full-time social workers would be co-located with the accommodation facility. The social workers would provide an outreach service to young people experiencing mental illness and their families in order to support young people to remain living at home.

(Youth Affairs Council of South Australia, South Australia, Submission #38)

6.4.11.4.B.4 Lack of support for providers of supported accommodation

According to Standard11.4.B.6: 'A range of treatment and support services is delivered to the consumers living in the accommodation according to individual need.' Listed in the notes to this Standard are crisis intervention and 24-hour access to the MHS. According to concerns expressed by one Supported Accommodation and Assistance Program service provider, crisis services were not able to be obtained and the police had to be called.

If we ring ACIS, the Assessment & Crisis Intervention Service, the response is poor, I can tell you about an incident where even an acutely unwell person couldn't get a response. I really pushed for assessment and they told me to take them to hospital so I had to call the police. Calling the police is not good for our relationship with our clients. We shouldn't have to do that.

(Supported Accommodation and Assistance Program (SAAP) Service Provider, South Australia, Adelaide Forum #4)

6.4.11.4.C Medication and other medical technologies

Medication and other medical technologies are provided in a manner which promotes choice, safety and maximum possible quality of life for the consumer.

Under this Standard, a presentation indicated concern about:

- the exclusive use of medication as the only treatment option;
- the use of antidepressants for children.
- informed consent and the use of Electro Convulsive Therapy (ECT)

6.4.11.4.C.1 Medication the only treatment option

One social worker expressed concern that there is 'no choice' being offered to consumers and effectively 'no care' being provided, just the dispensing of medication. This would also imply that the 'maximum quality of life' for the consumer could also not be attained by this method.

> *People are being forced to take medication and get no other care – there's often nothing else.*
>
> (Social Worker, South Australia, Adelaide Forum #20)

6.4.11.4.C.2 Concerns about the use of antidepressants for children

According to Standard 11.4.C.10 'The MHS ensures access for the consumer to the safest, most effective and most appropriate medication and/or other technology' and Standard 11.4.C.1 'Medication and other technologies used are evidence-based and reflect internationally accepted standards'. One academic also raised safety and efficacy concerns about the use of antidepressants for children and adolescents.

> *We are concerned that biased reporting and overconfident recommendations in treatment guidelines may mislead doctors, patients, and families. Many will undervalue non-drug treatments that are probably both safer and more effective. (Jureidini et al article also referenced)*
>
> (Academic, South Australia, Submission #219)

6.4.11.4.C.3 Informed consent and the use of Electro Convulsive Therapy (ECT)

Standard 11.4.C.3 states 'The MHS obtains the informed consent of the consumer prior to the administration of medication or use of other medical technologies such as Electro Convulsive Therapy'. One consumer expressed concern that more information about benefits and side-effects needs to be provided and that a support person or advocate should also be required to be involved in the process of obtaining consent:

> *This is a situation that I feel needs attention as there may be other mentally ill patients being given ECT without their informed consent and I believe it devalues me as a person. ECT gave a brief improvement and did not in my opinion solve my depression. My depression was more effectively dealt with by medication. … I am writing this as a follow up of your visit to MURRAY BRIDGE recently. I hope this experience can be noted as I suspect many mentally ill persons may be treated with ECT without their real permission. Had I known of the memory problems which they deny exist I would not have consented to ECT. I really needed my wife or a Government person to act on my behalf in making the decision to undergo ECT. (author's emphasis)*
>
> (Consumer, South Australia, Submission #77)

6.4.11.4.D Therapies

The consumer and consumer's family / carer have access to a range of safe and effective therapies

Under this Standard, a presentation indicated concern about the limited range of therapies offered by the mental health service.

6.4.11.4.D.1 Limited range of therapies offered by the mental health service

One carer expressed concern that group therapy was not available for people with mental illness.

> *I am however, concerned about the lack of group therapy available to people with a mental illness.*
>
> (Carer, Family Member, South Australia, Adelaide Forum #2)

According to Standard 11.4.D.2 the MHS 'provides access to a range of accepted therapies according to the needs of the consumer and their carers'. This includes group methods. According to the notes to this Standard, the MHS should provide the therapy or refer the consumer or carer to another provider.

> *I am very aware of the need to work with people over the long term… and holistically… I am aware that this holistic approach is a considerably 'untapped' approach regarding treating people with eating disorders and mental illnesses generally. When a great percentage of the issue of eating disorders has to do with being 'cut off' from ones body - non ingestive / non invasive body work and psycho-education can play a huge part in encouraging women (and men) to adopt physical (and mental) self care techniques. It is in the communities [sic] interest to integrate these 'other' methods practice to assist people with mental health issues. In particular they need to be accessible constantly – not just financed for short periods of time.*
>
> (Anonymous, South Australia, Submission #44)

> *Professionals are aware that alternative and complimentary (non clinical community) services could be set up privately. However there are two things that work against this pursuit.*
>
> - *This would exclude a large majority of people who suffer from eating disorders. Regardless of the governments push to get individuals to take out private health insurance, most people do not have private health insurance or if they do, then the insurance that will cover the types of treatment needed to recover (often needed over a long term). It is wrong to exclude them from access to treatment (where there is such a great lack of it at any rate).*
> - *Because government does not equally recognise complimentary (and preventative) health practices within the system, it can foster suspicion about the therapeutic method used in the private system.*
>
> (Anonymous, South Australia, Submission #44)

6.4.11.4.E Inpatient care

The MHS ensures access to high quality, safe and comfortable inpatient care for consumers.

Under this Standard, submissions and presentations indicate concerns about:

- excessive use of restraint and seclusion;
- consumers and carers are not being informed or involved in treatment plans; and
- impact of admission not minimised for families of consumers who live in rural and remote areas.

6.4.11.4.E.1 Excessive use of restraint and seclusion

> *There have been frequent recent stories of psychiatric patients being shackled in the ED [Emergency Department] at central city hospitals, inappropriate use of seclusion (for staff convenience not patient care), the use of outmoded and banned restraint holds by nurses and patients not being treated with the care and respect they deserve. In some cases, patients are being subjected to restraints and confinements unnecessarily and without proper care. I have heard one story of a female patient placed in seclusion in a hospital gown, who was menstruating and the female nurses removed her sanitary products on the grounds of safety. This is grossly unacceptable.*
>
> (Academic, South Australia, Submission #142)

Such practices would not be in accordance with Standard 11.4.E.1 which states 'The MHS offers less restrictive alternatives to inpatient treatment and support provided that it adds value to the consumer's life and with consideration being given to the consumer's preference, demands on carers, availability of support and safety of those involved'. Excessive use of restraint and seclusion infringes on many consumer rights, as described below.

> *When I asked patients in a research study about what they thought of seclusion, their answers were largely negative, they feel punished, humiliated, bored and scared when in seclusion. This is not quality nursing care.*
>
> (Academic, South Australia, Submission #142)

Given the scarcity of early intervention and treatment options in the community setting, consumers are often forced to reach crisis point before access to treatment is allowed and then they are 'punished' by the mental health service by the use of restraint and seclusion. The necessity to use restrictive practices would be minimised if treatment and support could be accessed earlier.

> *I have been writing and researching seclusion for ten years in South Australia and perceive that standards have fallen markedly since the Burdekin Report.*
>
> (Academic, South Australia, Submission #142)

6.4.11.4.E.2 Consumers and carers not informed or involved in treatment plan

The following report from an NGO service provider raises serious concerns about the lack of involvement of the consumer in the planning and delivery of treatment, non-involvement of the carer, and assessment and review procedures. Furthermore it would appear that the consumer was not informed of her rights (Standard 11.4.E.6) and many of the criteria as outlined under Standard 11.4 (Treatment and Support) were not met (e.g. Standard 11.4.9 'There is a current individual care plan for each consumer, which is constructed and regularly reviewed with the consumer and, with the consumer's informed consent, their carers and is available to them').

> *Upon entering the WCH (the Adolescent Ward of the Women's and Children's Hospital) Eating Disorders Program on a Friday lunchtime, having been admitted by the treating private gastroenterologist that works with the Program Team, there was no contact with the young person or her mother by the Program Director to explain the program focus and stages for 5 days (the following Wed afternoon), and only then after a direct request for this to occur by myself during a conversation on the Tuesday afternoon… Five days is a very long period of time for a 14 year old, particularly in a hospital environment where there is no clear information on what is going to happen… There was no proactive effort on the part of the Program staff to gain the background and context of the eating problem, or to discuss it with the family or the treating professionals.*
>
> (NGO Service Provider, South Australia, Submission #233)

At no point in this process did anyone from the Eating Disorders Team have direct personal contact with the young person and family to talk about their experiences, needs and progress, apart from the gastroenterologist. Any feedback received and used at team meeting decisions (which occurred twice / week) came from the gastroenterologist and presumably the nursing staff. Neither the mother or I were invited to any further team meetings; the main link into the team was the gastroenterologist.

(NGO Service Provider, South Australia, Submission #233)

6.4.11.4.E.3 Impact of admission not minimised for families of consumers living in rural and remote areas

Standard 11.4.E.7 states: 'The MHS assists in minimising the impact of admission on the consumer's family and significant others'. The notes to this Standard include 'support for extended family'. According to one submission, no communication or assistance was received by the family to help them understand what was happening as they could not visit personally:

When admitted to an Adelaide hospital you become distant from your family and visiting is less affordable. Again no communication from the hospital to help families adjust and understand what is happening occurs.

(Consumer, South Australia, Submission #77)

6.4.11.5 Planning for exit

Consumers are assisted to plan for their exit from the MHS to ensure that ongoing follow-up is available if required.

Under this Standard, submissions and presentations indicate concerns about:

- inadequate planning prior to exit; and
- discharge being used as a threat with the consumer.

6.4.11.5.1 Inadequate planning

When the inpatients return to the Mallee from a period in Glenside discharge planning is often inadequate.

(Health and Community Services Network, Murray Mallee Strategic Task Force, South Australia, Submission #115)

This concern raised by the Health and Community Services Network, Murray Mallee Strategic Task Force, raises concern about both the adequacy of the planning that should have occurred prior to discharge and the limited access to treatment and support services in rural and regional areas (discussed previously) which could hinder the development of such a plan. Specifically, the submission suggests that discharge plans have possibly not been developed in collaboration with the consumer (Standard 11.5.2), that understandable information about the range of relevant services and supports have not been provided (Standard 11.5.4) and that the service has failed to ensure consumers have established contact with relevant external service providers prior to exit (Standard 11.5.6).

6.4.11.5.2 Discharge used as a threat

A report was also received suggesting that discharge was being used as a threat to comply with treatment and not as part of a care and treatment plan with and agreed stage of recovery where discharge is appropriate with follow-up.

The suicidal behaviour resulted in a request for a risk assessment by the psychiatrist. Immediately after this occurred the young person was highly distressed and self-harming again. Soon after she was calmed, she then absconded from the hospital – upon recovery and return she was, understandably placed on a detention order. The psychiatrist lifted this the following day, but recommended that either the young person engaged in the complete program, or she was moved toward discharge ASAP. The mother and young person experienced this as an ultimatum.

(NGO Service Provider, South Australia, Submission #233)

6.4.11.6 Exit and re-entry

The MHS assists consumers to exit the service and ensures re-entry according to the consumer's needs.

Under this Standard, submissions and presentations indicate concerns about:

- inappropriate discharge; and
- lack of follow-up.

6.4.11.6.1 Inappropriate discharge

Concerns were expressed that discharge was occurring without appropriate planning and notification to either the consumer or carer, and in this instance, jeopardising the safety of the consumer. According to Standard 11.6.1, 'Staff review the outcomes of treatment and support as well as ongoing follow-up arrangements for each consumer prior to their exit from the MHS'. Standard 11.6.2 implies that both consumers and carers are notified about discharge so that they can be provided with information and are aware of 'how to gain entry to the MHS at a later date'.

Five days after this letter was written [March 2004] my son was unexpectedly and inappropriately discharged from the Royal Adelaide Hospital. I was not notified, no discharge planning was done, and a Guardianship Board Order was not sought. When I spoke to the Registrar on this last point I was told that the waiting time for a Guardianship Board Order was such that the decision was made not to apply for an order. This in relation to a man who has not been without some kind of Order since 1988… My son headed to the parklands and could not be found for five days. He then appeared at RAH emergency seeking admission where he claimed he had been threatened and assaulted and was being followed.

(Carer, Mother, South Australia, Submission #279)

6.4.11.6.2 Lack of follow-up

Concerns were also expressed about the lack of follow up following discharge from the mental health service. Consumers and carers reported occasions when they were left with no support or follow up care, even when such plans were referred to in the discharge summary.

Carers also reported that they had been given insufficient information to understand the nature of the mental illness and the treatment support necessary. This left carers with feelings of extreme stress and fear for the safety of their family member with mental illness and their own safety. Another carer commented that despite adequate planning for follow-up, this had not occurred and that the mental health service needs to be more vigilant. Standard 11.6.4 states 'The MHS attempts to re-engage with consumers who do not keep the planned follow-up arrangements'.

It is also apparent and of concern that follow-up had not occurred following Mr [X]'s departure from inpatient care, despite concerns in the discharge summary that future treatment may have to be provided in an intensive care setting. (excerpt from a letter from the Director of Mental health, Mental Health Services and Programs, Department of Human Services, 2004)

(Carer, Mother, South Australia, Submission #195)

After exhibiting psychotic behaviour my son spent 21 days (detained) in Glenside Hospital in March 2002. He was counselled and medicated then turned out into the community with some medication but no follow up care. Shortly afterwards he stopped his medication, reverted to his anti-social, aggressive and irrational behaviour, a state he has been in unchecked for two years.

(Carer, Mother, South Australia, Submission #11)

On discharge there is no discharge plan and the support received by the patient from the hospital ends with not even a phone call to see how you are.

(Consumer, South Australia, Submission #77)

We fear for my son's life and that of others. Currently he tells us he hears his dead father talking to him saying I, (his mother), is Satan and evil and must be killed. I believe after my son's release from Glenside in 2002 some sort of compulsory care and medication should have ensued. He should have been allocated a case worker who could assist him in decision making and support for us. We do not have the necessary skills and understanding of his problems and with the mental health system as it stands his and our prospects of positive outcomes are negligible.

(Carer, Mother, South Australia, Submission #11)

6.4.12 STORIES OF HOMICIDE AND SUICIDE IN SOUTH AUSTRALIA

I can tell you about a woman who arrived on a bus from Victoria – we tried to certify her three times one weekend. We couldn't get her certified but then she jumped off the bridge.

(Police Officer, South Australia, Murray Bridge Forum #16*)*

[N]ot much has changed in the country Post Burdekin… A few years ago (but since Burdekin) my brother in law hung himself - in his shed in a country town. This followed at least 2 prior attempts. Although he presented to the local GP at no time was he detained or in receipt of anything close to resembling reasonable psychiatric care. His poor mental health was long standing… Everyone in town also knew about his alcohol addiction… the treating GP had treated many of [his family] for many years… so he knew who & what he was dealing with… I believe that he left a note which was quite readable and was able to make the necessary arrangements to hang himself in a space some distance from his home. On his 2 previous attempts (and there could well have been more) he was unsuccessful because the methods offended his sense of not wanting to make a mess - and he didn't get any appropriate help. Given that that GP is still the dominant medical officer in town & not much else has changed in terms of service availability, I don't think my brother in law's prognosis would be any different today. Now I fear for his son's life.

(Family Member and Service Provider, South Australia, Submission #34)

6.5 WESTERN AUSTRALIA

ANALYSIS OF SUBMISSIONS AND CONSULTATIONS FROM WESTERN AUSTRALIA AGAINST THE NATIONAL STANDARDS FOR MENTAL HEALTH SERVICES

In summary, information presented in this section was gathered from 46 submissions (see Appendix 8.3.5) and presentations made at community forums attended by approximately 280 people (see Appendix 8.1). A draft copy of this report was sent to the Premier and Minister for Health for comment. An initial response from the Western Australian Government was received by MHCA but then later withdrawn. A further response from the Minister was received on 10 June 2005, too late to be incorporated into the analysis below. The response is at Part 8.4.5. An overall review of mental health service delivery in Western Australia is contained in Part 2.7.5 and is in-part informed by discussions with the WA Department of Health.

6.5.1 STANDARD 1: RIGHTS

The rights of people affected by mental disorders and / or mental health problems are upheld by the MHS.

Under this Standard, submissions and presentations indicate concerns about:

- consumers not informed of their rights;
- lack of access to interpreters;
- problems with complaints procedures;
- right to have others involved denied;
- consumers' rights are not being protected; and
- consumers not being treated with dignity and respect.

6.5.1.1 Consumers not informed of their rights

Concern was expressed that not only were consumers not being informed of their rights (Standards 1.2 and 1.3) or provided with information (Standard 1.8), many were not informed specifically that they had been made an 'Involuntary Patient' and what this meant. One academic also indicated that policies and procedures designed to ensure that consumers are provided with necessary information in verbal and written form are not being adhered to:

> *[X] was not informed of his rights as a Voluntary Patient and was not made aware that he had been made an 'Involuntary Patient'. This had been done without notification, oral or written. This was witnessed by us prior to [X] being placed in a drug induced sleep. He has not obtained or received copies of associated Forms relevant to this admission… Management of [X]'s case, have violated his rights as a person with a mental illness.*
>
> (Carers, Western Australia, Submission #177)

> *The audit indicated that many of the nursing programmes were not running and procedures relating to other activities were not being adhered to. Events such as staff meetings, patient meetings, seclusion meetings, primary nurse meetings were erratically held if at all. Hand-over sheets, information sheets to patients, allocation files, medication sheets, information boards were rarely used and not fully replenished or when used were not completed systematically or consistently.*(Excerpt from: Shanley (2001), Management of change in a psychiatric hospital using a 'bottom up' approach)
>
> (Eamon Shanley, Professor of Mental Health Nursing, Australia, Submission #33)

Failure to inform consumers of their rights. The recent review of the Mental Health Act 1996 revealed continued resistance amongst mental health workers to the philosophy and practice of informing mental health consumers of their rights, including review of orders, involuntary treatment second opinions, use of advocates. The provision of pamphlets listing consumers' rights is the most routine means of meeting the duty to inform. This is a minimum standard and considerable pressure needs to be applied to encourage verbal communication by staff about rights, at levels appropriate to consumer needs, at various times during hospitalisation or care in the community.

(Health Consumers' Council WA, Western Australia, Submission #29)

6.5.1.2 Lack of access to interpreters

For people who speak a language other than English, access to mental health care is further compounded by language and cultural barriers. These barriers compound understandings of mental health services, mental disorders, mental health problems and available treatment and support services and how to navigate the system. In many cases, a person may be socially isolated or reluctant to have family or friends involved as carers or act as interpreters for reasons of confidentiality or perceived stigma.

Evidence presented at forums and submissions indicate that many consumers from a non-English speaking background (NESB) are not made aware of their rights and responsibilities in either a written or verbal manner as required by Standard 1.3 (e.g. written material in their language or via an interpreter). This failure to inform people of their overall rights meant that consumers were specifically unaware of their right to have access to an accredited interpreter. This problem was compounded if the information regarding the availability of interpreters was not available in the consumer's first language (Standard 1.7).

Additionally, in some cases it appears that health professionals are also not aware of the right of consumers and carers to have access to accredited interpreters or alternatively they are specifically denying consumers and carers this right. This was highlighted by a service provider attending the West Perth Forum with regard to refugees:

The lack of interpreters is a real issue. Many of our people don't have carers, they are socially isolated and they have problems with the language. But they are told by many practitioners that they don't work with interpreters so they can't access adequate care.

(Service Provider, Western Australia, West Perth Forum #36)

Interpreter use of people with limited English. The Health Consumers' Council has assisted a Macedonian mental health consumer who was challenging the actions of mental health services to require him to submit to medication and involuntary hospitalisation. The clinical consultation during which the decision was made to place the consumer on an involuntary order occurred without an interpreter. We include an Advocacy report produced at the time of this consultation that highlights our concerns about the failure of mental health service clinicians to engage interpreters. Specific comment: The engagement of an interpreter should not be optional where action under the Mental Health Act is likely or possible.

(Health Consumers' Council WA, Western Australia, Submission #29)

This also suggests a failure of service providers to understand the repercussions of the refusal to engage interpreters to treat refugees (Standard 7 – Cultural Awareness). As mentioned, many refugees are socially isolated and lack the necessary family and social supports to assist them through their illness. Also, language barriers and cultural barriers may also impede help seeking behaviour. For this particularly vulnerable group of consumers, to have overcome all these issues and then be turned away could result in no further attempts being made to access alternate service providers or receiving inadequate care.

6.5.1.3 Problems with complaints procedures

Carers who had used the complaints procedure reported feelings of anger with the process, of being ignored or their concerns trivialised. As the following quotes highlight, carers described experiences that were generally unsatisfactory, and none described the complaints procedure they dealt with as 'easily accessed, responsive and fair' (Standard 1.10):

> *Three months later he succeeded in killing himself. I was so angry at having been so consistently 'fobbed off' that I went to the mental health place in Bunbury and complained and the lady I spoke to said. "These things happen". As if it simply wasn't important.*
>
> (Carer, Wife, Western Australia, Submission #96)

> *…even numerous complaints to the WA Medical Board have been dismissed with such statements as 'time lessens the memory'… sure, after they kept fobbing off meetings with them and letting time lapse. I went to every viable person in Perth only to crash into brick wall after brick wall. [Y], Head Pysch for the state, told me I was just an emotive mother...too right I am! [Z], the shadow Health Minister at the time did what she could and in the Hansard Report this shows her attempt. At least she tried. [W], the Premier wrote me letters with pretty headings and passed the buck and did nothing.*
>
> (Carer, Mother, Western Australia, Submission #103)

> *…son who was sedated for 20 hours awaiting a psych review and transfer to hospital…I supported this family in the process of making a complaint about the whole issue…They made written complaint to [Y] at the Office of the Chief Psychiatrist. They then travelled to Perth for a meeting with [Y] with written permission from their son to discuss the issues. They also sent the letter of complaint to various other organisations and the local member. Within a few weeks they received an invitation to [Z]'s office (local MLA) with representatives from SWAHS [South West Area Health Service]. They attended this meeting but once again they were not offered any acknowledgement of their son's breach of rights or an apology. They have now received a letter from the Office of Health Review thanking them for their concerns and requesting authorisation forms to be completed. This family, after 3 months and no signs of resolution, to be now asked to initiate further engagement with another, are understandably angry.*
>
> (Family Support Worker, Western Australia, Submission #177)

> *Whilst this husband wrote to the person in charge of the service on 18 May and I lodged a formal complaint on his behalf through the appropriate channels on 24 May he has still not received any response [as at 6 July 2004].*
>
> (Carer Advocate, Western Australia, Submission #339)

Failure to have in place a system which enables consumers, their families and carers to make complaints confidentially and ensure that complaints procedures are adhered and responded to, weakens this right and fails to provide a mechanism by which to 'improve performance as a part of a quality improvement process' (Standard 1.12). These concerns indicate that the complaints procedure is obstructive. It is apparent that in some instances the process does not allow for the identification of single or systemic failures, and thereby is failing to allow for personal redress or systemic improvement. For consumers and carers, information about the complaints process also needs to contain clear references to the fact that advocates or other support people are available to assist them to voice their concerns:

> *…I respectfully request you to make representations to the Area Director of Mental Health and the Area Chief Executive Officer such that the chronic bed shortage problem and the absence of readily available emergency beds are both satisfactorily addressed in the interests of our patients and their carers – people who are often unable to advocate for themselves. (Extracts from letter to Director of Community Mental Health Programme)*
>
> (Clinician, Western Australia, Submission #24)

6.5.1.4 Right to have others involved denied

Concern was expressed that consumers are not being made aware that they have a right to have 'an independent advocate or support person with them at any time during their involvement with the MHS' (Standard 1.6). This has resulted in support people, including requested service providers, explicitly being refused involvement when consumers have specifically requested their co-attendance:

> *I made an appointment to see the psychiatrist outside of school hours so that my wife could attend too. I was told 'you are the patient' and they did not approve of my wife being at the appointment. I need the support of my wife as I always have to discuss the appointment with her afterwards as I am unable to remember it all and it helps me to understand things better. I was disturbed by the attitude of this person. I was asked 'do you want the appointment or don't you?'… I said 'No'.*
>
> (Consumer, Western Australia, Geraldton Forum #72)

> *My brother also has an intellectual disability as well as bipolar disorder… DSC want to handball him to Mental Health Services and visa versa. I have had to apply for guardianship of my brother in order for the mental health professionals to hold any sort of discussions with me… the person (Me) who supports and follows his medical care and history, has been until now unable to speak with doctors to share valuable, timesaving, costsaving information that would support my brother more effectively with his care.*
>
> (Carer, Sister, Western Australia, Submission #101)

6.5.1.5 Consumers' rights are not being protected

Overall, many consumers, carers and advocates expressed concern that during their involvement with the mental health service their rights were being ignored. In particular, concern was expressed that the Mental Health Review Board is failing to protect the rights of people with mental illness and processes to support the proper functioning of the Board are also being curtailed. Problems were also highlighted with regards to the rights of people with mental illness and guardianship and administration orders:

> *I heard you say that Australia does not have a bill of rights but surely there is legislation (or needs to be) for basic support for long term survival of any person in our society.*
>
> (Carer, Western Australia, Submission #163)

> *The Review Board has failed mental health consumers to a huge degree. There is a culture of custody and control which is prevalent in WA. What we have at the moment is a mental health system that's taking money away from non-secure beds to secure beds. Part of the culture of control is the resistance to addressing a person – civil liberties. The Mental Health Review Board as a mechanism has failed us in WA. It does not use the powers.*
>
> (Consumer Advocate, Western Australia, West Perth Forum #36B)

> *The hospital has reduced the Ward Clerk hours, which leaves her unable to provide the time needed to do the paperwork to comply with the Mental Health Act. Often when a patient is to have a review by the Mental Health Review Board, there is no paperwork ready, no psychiatrist in attendance and no report by the treating psychiatrist.*
>
> (Nurse, Western Australia, Submission #55)

Mental Health Review Board (MHRB) fails to uphold human rights of mental health consumers. The MHRB has consistently failed to work to the reasonable extent of the scope of its powers, by testing the attitudes and practices that lead to detention and forced treatment of consumers. The MHRB is widely regarded by mental health consumers with experience of the system as not being worth the effort of contacting. Reviews are routinely limited to 20 minutes, psychiatrists' reports are taken on face value and rarely challenged, procedural fairness is seen by most consumers and advocates as completely absent.

(Health Consumers' Council WA, Western Australia, Submission #29)

Guardianship and Administration orders to readily applied to mental health consumers. … Once an administration order has been made, it is extremely difficult to have it set aside and there is no agency or body that is able to assist consumers to approach the GAB on this matter.

(Health Consumers' Council WA, Western Australia, Submission #29)

6.5.1.6 Consumers not being treated with dignity and respect

Concern was expressed that consumers are often not being treated with dignity and respect:

All we want is our human rights, to be treated with dignity and respect - we all want that - to be respected. I can't help speaking in this passionate way.

(Consumer, Western Australia, West Perth Forum #37)

We are often required to transport these people but they are not criminals, they are ill.

(Police officer, Western Australia, Bunbury Forum #9)

Our son had done no wrong and as a mentally ill person deserved to be treated with dignity, care and understanding not to be confronted by police.

(Carer, Western Australia, Submission #175)

Police are routinely used by mental health services staff to accompany them on home visits and transport consumers to authorised hospitals for assessment. The attendance of police indicates a foregone conclusion by mental health staff that an order will be written out for the person to go against their will for assessment. Use of police shows the consumer and their neighbours that mental health staff presume the person to be dangerous and unpredictable… Use of police in company with mental health service staff almost always leaves consumers feeling invaded in their own home and neighbourhood, treated like a criminal, presumed to be dangerous and with no regard given for anything that they may say on their own behalf..

(Health Consumers' Council WA, Western Australia, Submission #29)

Failure to inform consumers routinely of the designation of a practitioner as Psychiatrist, Registrar, Medical Officer, and leaving the consumer in the dark about what to reasonably expect from the person before them.

(Health Consumers' Council WA, Western Australia, Submission #29)

6.5.2 STANDARD 2: SAFETY

The activities and environment of the MHS are safe for consumers, carers, families, staff and the community.

Under this standard, submissions and presentations indicate concerns about:

- excessive use of physical restraint;
- lack of response to family concerns of danger;
- problems with use of security guards with inpatients;

- unsafe hospital and supported accommodation environments;
- safety concerns for children and youth with mental illness;
- lack of trust in MHS to ensure safety for consumers and the community; and
- occupational health and safety issues.

6.5.2.1 Excessive use of physical restraint, sedation and armed escort

Despite continued assurances by the WA Government that there are sufficient services to ensure the safety of people with mental illness and the community, submissions suggest the Government's current focus on containment and control has failed to deliver 'safety' for people with mental illness, families, carers or the community. Instead, submissions documented excessive use of physical restraint and sedation, unnecessary involvement of the police, failure by services to respond to requests of assistance by both consumers and carers, lack of access to services when crises arose and unsafe environments within treatment settings. These concerns were raised equally by consumers, carers, clinicians and service providers:

> *In Esperance…If consumers need acute care they have to be taken to a GP and then tranquilised and strapped to stretcher to be transported to Perth. I was told when I was suicidal to drive myself to the city.*
>
> (Consumer, Western Australia, West Perth Forum #45)

> *Consumers are driven in the back of paddy wagons – three day trips – from Kununurra to Perth. The artificial geographic boundaries create huge problems for people needing care.*
>
> (Carer, Carer, Western Australia, West Perth Forum #43))

> *I had an incident a while ago when I went to hospital in Bunbury, I was put aside (waited) a couple of hours – I wanted to go home but the hospital wouldn't let me go. I finally went home and a few hours later the police came to take me back to the hospital. I went willingly and saw the doctor who said I needed an injection. I was threatened that the police would hold me down while I had the injection so I agreed to have it. After they injected me I was taken to Graylands Hospital in Perth but nobody informed my family of my admission to Graylands.*
>
> (Consumer, Western Australia, Bunbury Forum #1)

> *Dr [Y] telephoned later that day to say that he was coming to see our son. He was advised this was not possible because our son was asleep and we did not want him disturbed. Sometime before 4pm that same afternoon Dr [Y] together with an assistant and a police vehicle carrying three police officers arrived at our son's house and forced our son, who was ill and asleep at the time, to open his door. Needless to say our son was traumatised by the event. Fortunately my wife noticed the vehicles outside our son's house and we went to investigate. By this time the vehicles were moving off but we were able to speak to the police officers who were less than co-operative and the medical staff, who did not have the common decency to inform us of the visit, told us they were within their rights and that we had no reason to be upset. My contention is that Dr [Y] was not within his rights and by his actions he has caused a mentally ill patient additional needless trauma. My wife spent several hours with my son after the visit trying to calm him down...In my opinion the actions taken by Dr [Y] were completely inappropriate, unprofessional and unethical and have caused damage to a mentally ill patient and destroyed his faith in the Mental Health Service.*
>
> (Carer, Father, Western Australia, Submission #175).

There is an agreement between the police and the local mental health service. If patients are sectioned under the Mental Health Act the police are not allowed to transport more than 250 kilometres. Therefore the only option here is to take patients to Perth by the Royal Flying Doctor Service, the result being that the patient has to be extremely sedated. There is a need for them to be sedated to stop them from doing harm to themselves or others. I don't have a problem with that – but what I can't cope with is when I am asked to give a higher level of medication in order to transport this patient by air. Ethically I feel it is wrong to over sedate a patients in order to be transported by Royal Flying Doctor Service. This can lead to them being a vegetable for three or four days when they get to Graylands before they wake up. More than one I know of people having aspiration pneumonia and sometimes requiring intubation. I have to be able to live with myself having to do this. The potential is for a serious outcome of death – I don't want to take this risk. Why are we in a position of giving people enormous quantities of medication for the convenience of transport? Personally I have had people who were disturbed with whom I have had a good rapport and did not want to have to excessively sedate, but I had to do it. We're giving enormous quantities of psychotropic medication for this reason and whilst it has not happened yet there is a possibility I fear, of death. I know of patients who are also taking illicit drugs – we have no idea what is in their system. Why should I or other doctors – contractually obligated to give people this medication – be required to over sedate patients just for convenience of transport?

(GP, Western Australia, Geraldton Forum #53)

There are conflicting reports about whether or not the Royal Flying Doctor Service wants to transport mentally ill clients. Sometimes consumers have to wait another day to be sedated and possibly have a police escort to take them to Graylands. Sometimes they need armed escort.

(Anonymous, Western Australia, Geraldton Forum #52)

6.5.2.2 Lack of response to family concerns of danger

In an oral presentation at the forum in Geraldton, one father spoke of the failure of both mental health services and police to respond to calls for assistance for his son who was delusional and in crisis. Failure of mental health services to respond and provide treatment and support resulted in the community's right to safety being infringed (a homicide) and incarceration of a person with mental illness.

My son has been diagnosed as paranoid schizophrenic since 1996. My wife and I looked after him for two years. He was charged with wilful murder in November 2000. He is now in prison facing a 20 year prison sentence. In 1999 he received threatening letters…He rang me from Maylands. I was unable to leave my wife. I was on call 24 hours a day because she was ill and my son was in Perth. He was delusional and needed help. Over four days I rang the crisis centre in Maylands Mental Health (PET) regularly and each time had to tell the full story - they wouldn't listen to me and wouldn't do anything. I rang the police nothing was done. They wouldn't do anything. After three and a half years in Graylands he is now better than he has ever been. He is now in Hakea prison. The help I got was none. For a dangerous situation there was no help available for me or my son.

(Carer, Father, Western Australia, Geraldton Forum #49)

6.5.2.3 Problems with use of security guards with inpatients

As a result of a shortage of secure beds, an unfortunate consequence has been the increased use of security guards in hospital settings. This has had the result of not only focussing the issue on containment rather than care, but also compromising the safety of both the consumer and security guards who are not trained for such situations:

One of the most disturbing practices for me is the use of security guards from a private security firm to facilitate the care of inpatients, due to lack of proper facilities and staffing levels in Bunbury. The hospital regularly employs guards to "special" patients who are considered at risk of either self-harm or absconding. They often use the guards to boost the staffing levels in the unit to try and make the environment safe. This can often mean an untrained person, usually male, following around a very ill or deeply disturbed person in the medical ward of the hospital as well as the psychiatric unit, or is sitting around in full uniform in the psychiatric unit. This has a couple of very major concerns. Firstly, the patient often self discloses to the security guard their personal history, which may often include a history of sexual abuse. Secondly, it also gives the patient, visitors and other patients, the impression that the person with the guard is "trouble", i.e. violent, bad, etc.

(Nurse, Western Australia, Submission #55)

I have witnessed young male security guards following around young female patients, watching them in their bedrooms. I have seen the situation escalate whereby a young male security guard, who had a history of depression, suicidal ideation in the past, have to try and restrain a female who was absconding from the Unit (as it is open and not a secure environment). He failed to restrain her, she absconded and placed herself on a tower in Bunbury threatening to jump off. The security guard was so distraught from the incident, feeling that he was responsible for anything that happened to her, that he began crying and had to be consoled by staff.

(Nurse, Western Australia, Submission #55)

6.5.2.4 Unsafe hospital and supported accommodation environments

Lack of adequate staffing and resources have also resulted in consumers feeling unsafe in a setting that provides little beyond a place to sleep and shower. Identification of safety risks by clinicians and release of Task Force Reports highlighting areas of clinical safety concerns appear not to have resulted in safety improvements:

I'm a patient in the hospital at the moment under an involuntary order and it was very difficult for me to get here to this forum today…It's a place where you can get away from the world but there's not much else. The situation is terrible and I can't even have a shower in private. I'm scared and I have no privacy.

(Consumer, Western Australia, Bunbury Forum #17)

There are ethical, forensic, and practical problems. The nursing staff were put under an intolerable situation when there were people highly disturbed. There is no secure ward nor are there any plans for one, therefore there are no means to prevent people harming themselves.

(GP, Western Australia, Geraldton Forum #53)

Hostels like St. Bartholomew's House can no longer afford the risk of injury to staff and/or other residents from people who are not having adequate treatment and support from mental health services.

(St Bartholomew's House Inc, Western Australia, Submission #37)

A friend recently witnessed an extremely agitated young man who claimed he needed to see a doctor urgently at Avro Clinic and was told this was impossible and was turned away by the staff – an extremely dangerous situation!

(Carers, Parents, Western Australia, Submission #76)

Evidently, yet another report in October 2003 has confirmed the urgent need to address a range of issues pertaining to clinical safety on the inpatient psychiatric unit. It appears that someone has to sustain serious injury or to die before senior management (who hold budgetary control) can be encouraged to address the systemic problems that have been clearly evident for a long time. I can assure you that, as an humble clinician and with no ability to influence budgetary issues, I have found it extraordinarily frustrating to have been so powerless to influence clinical service delivery over the last few years of my employment with South West Area Health….(extract from a letter to the Chair of Mental Health Council of Australia)

(Clinician, Western Australia, Submission #24)

I am writing to you in order to express how appalled I am to hear that, eighteen months after the release of the Bunbury Health Task Force Report major problems with clinical safety at the Bunbury Hospital Psychiatric Inpatient Unit still continue…I can only hope that now, with the release of yet another report, your Office and that of the State Wide Office of Mental Health will be able to insist upon change – before someone is seriously injured, killed or otherwise jeopardised… (extract from a letter to the Office of the Chief Psychiatrist)

(Clinician, Western Australia, Submission #24)

The absence of readily available psychiatric beds for emergency situations compromises clinical care and increase risk to the individual – and possibly to others. (extract from a letter to the Director of Community Mental Health Programme)

(Clinician, Western Australia, Submission #24)

(i) –patients are being managed over long periods on emergency departments, the environment is unsafe clinically inappropriate, already struggling to meet demand and by no means secure. The re-sedation of patients is poor practice, traumatic and likely to lead to significant secondary trauma. It also gives a message that the patient is unwanted, by the ED [Emergency Department] or the Mental Health sector.

(Consumer Advocate, Western Australia, Submission #338)

(ii) – patients who require secure accommodation managed on open wards with a 1:1 or 2:1 nursing special. This is obviously poor practice, the nurse is at risk the patient is placed at risk as are other staff on the unit, and these are Mental Health patients, the messages given by inappropriate management are themselves highly relevant to the therapeutic outcome. The cost is phenomenal…

(Consumer Advocate, Western Australia, Submission #338)

In Western Australia we have mental health services now that are provided in an unsafe and clinically unacceptable manner.

(Consumer Advocate, Western Australia, Submission #338)

6.5.2.5 Safety concerns for children with mental illness

A paucity of services for children and youth with mental illness was noted in many submissions. Not only does this jeopardise the safety of children and youth who are in need of care but another consequence is that if treatment is urgently needed children have been treated in inappropriate adult settings compromising their safety:

There's a 9-10 month waiting list for mentally ill children to get into care. Children as young as 13 years old are being put into Graylands Adult Units and they are exposed to adults who are dangerous.

(Consumer, Western Australia, West Perth Forum #41)

6.5.2.6 Lack of trust in MHS to ensure safety for consumers and the community

Submissions describe a system in Western Australia characterised by a lack of resources and services, high levels of stigma still present in the community and a failure of the MHS to provide the public with assurances that post-deinstitutionalisation, treatment and support is available and accessible to people with mental illness. As a result, families and the community report feeling unsafe and that their right to safety and the right of people with mental illness to feel safe have been compromised.

> *For quite some time now clinicians at the coal face have been struggling more and more in their attempts to provide safe, quality services to consumers and their families. Unfortunately, things seem to be getting worse rather than better. One of the major difficulties for those who provide services in the community is in accessing inpatient beds at times of emergency. There is no doubt that resultant delays expose seriously unwell patients, carers, staff and members of the community generally to increased risk of harm.* (extract from a letter to a Member of Legislative Assembly)
>
> (Clinician, Western Australia, Submission #24)

> *It is all very well to expect the community to deal with mental health patients if they are medicated and stable, but what about those patients who are resistant to medication. How is this safe for the community?*
>
> (Anonymous, Western Australia, Submission #145)

> *It is, however, of enormous concern that the management of a challenging clinical situation in the community (the patient's home) was extended by about another hour simply on the basis of bed availability. It is undoubtedly the case that embarrassment and distress for the patient and family members would have been much more limited had an earlier departure for the hospital being possible. There would have been less concern and distress for other residents in the street some of whom were moving about to collect children from school. The time of 4 Police Officers and 2 Police vehicles was extended unnecessarily, by a further hour. Equally, resources of the Mirrabooka Clinic and a local general practice were also tied up for longer than was necessary on a clinical basis… This clinical situation demonstrates, once again, the additional cost to the community as a whole that results from an insufficiency of beds for emergency admissions under the Mental Health Act. There is not only the emotional and psychological cost to the patient, family and neighbourhood community members but also the actual cost in monetary terms to the Police service, community clinic and general practice.* (extract from a letter to the Clinical Director of the North Metro Health Service)
>
> (Clinician, Western Australia, Submission #24)

6.5.2.7 Occupational health and safety issues

Scarcity of resources, diminishing funding and an increase in demand for those providing services has also resulted in unsafe work practices, jeopardising the safety of both consumers and staff:

> *A number of workplace incidents occurred at St Bartholomew's House, which resulted in a $350,000 payout for one staff member and another claim still pending at the time of writing this submission. WorkSafe attended and put a number of work improvement orders on the property. The outcome of those orders and the increased workers compensation claims only exacerbated the viability issues already being experienced by the SAAP [Supported Accommodation and Assistance] program.*
>
> (St Bartholomew's House Inc, Western Australia, Submission #37*)*

> *…despite clinician concerns, the SWAH [South West Area Health] did nothing to act on the deteriorating situation at the Molly St clinic. It was, I understand, only because the landlord chose to terminate the lease that the SWAH actually started to act. Lamentable given that…actual harm to…clients [was identified] by the situation as it existed in the Molloy St clinic.*
>
> (Anonymous, Western Australia, Submission #1)

6.5.3 STANDARD 3: CONSUMER AND CARER PARTICIPATION

Consumers and carers are involved in the planning, implementation and evaluation of the MHS.

Under this Standard, submissions and presentations indicate concerns about participation by consumers and carers in planning, implementation and evaluation processes by the MHS.

> *We have given up trying because there is no where to go, we have run out of steam.*
>
> (Consumer advocate, Western Australia, Submission #35)

6.5.3.1 Participation by consumers and carers

Significant concerns were expressed via submissions and at forums about the state consumer and carer participation in Western Australia. Some reports indicated the belief that the WA Government and health administrators made a decision to diminish the involvement of consumers and carers in the planning, implementation and evaluation of the MHS. There were also claims of not being consulted prior to critical service delivery decisions being made and the de-funding of programs which trained and supported consumers and carers to participate in such activities:

> *The Health Consumers' Council operated a Mental Health Consumer Advocacy Program for six years until this was de-funded in late 2003. This program supported consumer participation in service decision-making, trained consumers as public speakers on service standards and provided a Participation Payment scheme to assist consumer participation. The most promising feature of this program was the employment of mental health consumers as advocates for service reform. Consumers worked on a part-time basis in a team supporting a wide network of peers involved in service reform work. The cost to the state of this program was in the order of $130K per year – 4 workers, 200 consumer reps, 100 committees. The loss of this program was catastrophic for the emerging mental health consumer movement. Almost all progress against the National Mental Health Plan in respect to consumer participation in mental health services has stopped in Western Australia.*
>
> (Health Consumers' Council WA, Western Australia, Submission #29)

> *Mental health consumers are the great hope for the reform of mental health services in this state and no double elsewhere. … [U]ntil the users of mental health services are brought into the centre of the service delivery culture, there will be no change for the better. Consumer participation in meaningful and robust ways, will be the singlemost important accountability mechanism that will improve the safety and quality of mental health services in this state…*
>
> (Health Consumers' Council WA, Western Australia, Submission #29)

> *Only recently in July, Carers at a Carer Advocacy & Issues Forum in Bunbury met and expressed their frustration regarding the sudden closure of mental health services in their community. Specific concerns regarding the closure of services include: …The complete lack of consultation with carers, consumers and health professionals regarding the closure.*
>
> (Carers WA, Western Australia, Submission #277)

> *Can you please tell me what specifically Mirrabooka MHS is doing to enable carers to "shape reform" and "to meaningfully participate at all levels"?*
>
> (Carer, Husband, Western Australia, Submission #146)

There are many consumer advocates employed here in WA but the attitude is one of extreme paternalism by the Office for Mental Health - when consumer advocates speak up and their position is in any way critical of the Government or the system, they are classed as being unwell.

(Consumer advocate, Western Australia, West Perth Forum #28)

...our deep concern over the ever dwindling services available to people and families, living with mental illness. This is accompanied by an apparent lack of responses to efforts to raise these concerns. The points of concern are:

1. *Closure of clinic patient access, and cancellation of appointments and therapy program.*
2. *Lack of information*
3. *Lack of consultation*
4. *Lack of apparent plan / direction*
5. *Suspension of living skills program*
6. *Discontinuation of consumer / carer reference group*
7. *Limited therapy program at the inpatient unit, including outpatients' access*
8. *Repeated failure to employ staff to fill vacated positions*
9. *Southwest 24 being "one point of access"*

It would appear that these decisions have been enacted with very little consideration being given to the consequential impact. It is without question that consumers and their families are experiencing a huge increase in their anxiety levels and a similarly huge decrease in their confidence in South West Area Health Services.

(Anonymous, Western Australia, Submission #22)

[Supporting mothers with mental illness] Recommendations: Increase the use of consumer groups including adult children to train mental health clinicians on the effects of parental mental illness

(Health Consumers' Council WA, Western Australia, Submission #29)

Mental health consumers are the great hope for the reform of mental health services in this state and no double elsewhere… [U]ntil the users of mental health services are brought into the centre of the service delivery culture, there will be no change for the better. Consumer participation in meaningful and robust ways, will be the singlemost important accountability mechanism that will improve the safety and quality of mental health services in this state…

(Health Consumers' Council WA, Western Australia, Submission #29)

The Health Consumers' Council operated a Mental Health Consumer Advocacy Program for six years until this was de-funded in late 2003. This program supported consumer participation in service decision-making, trained consumers as public speakers on service standards and provided a Participation Payment scheme to assist consumer participation. The most promising feature of this program was the employment of mental health consumers as advocates for service reform. Consumers worked on a part-time basis in a team supporting a wide network of peers involved in service reform work. The cost to the state of this program was in the order of $130K per year – 4 workers, 200 consumer reps, 100 committees. The loss of this program was catastrophic for the emerging mental health consumer movement. Almost all progress against the National Mental Health Plan in respect to consumer participation in mental health services has stopped in Western Australia."

(Health Consumers' Council WA, Western Australia, Submission #29)

A submission by a Professor of Mental Health Nursing, detailing how positive change was recently brought about in a psychiatric hospital, emphasised that the key to improving the protection of the rights of people with mental illness was the involvement of consumers:

By empowering patients, consumer representatives and the clinical nurses, major changes have been brought about in the NPDU [Nursing Practice Development Unit]. Most of the alterations reflected improvements in human rights that most people in the wider community would have assumed were already been in place. (Excerpt from: Shanley (2001), Management of change in a psychiatric hospital using a 'bottom up' approach)

(Eamon Shanley, Professor of Mental Health Nursing, Australia, Submission #33)

The prime movers in initiating and maintaining the changes have been a minority of nursing staff on the ward and the consumer representatives. They effected major improvements on the ward despite a social and organisational environment that was at times sceptical and at other times obstructive to their efforts. It was mainly through the drive of these committed people that the changes mentioned in this report were possible. (Excerpt from: Shanley (2001), Management of change in a psychiatric hospital using a 'bottom up' approach)

(Eamon Shanley, Professor of Mental Health Nursing, Australia, Submission #33)

It can be seen that the introduction of a 'bottom up' system of management not only impacted on the quality of living conditions and the environment of the ward but it also positively affected the perceptions and feelings of patients and nurses about the services offered. There was an increase in patients' satisfaction in the NPDU. There was also a reduction in burnout scores and a drop in the seclusion rates in the NPDU despite the increase and the maintenance of the high levels of bed occupancy within the ward during the evaluation period. (Excerpt from: Shanley (2001), Management of change in a psychiatric hospital using a 'bottom up' approach)

(Eamon Shanley, Professor of Mental Health Nursing, Australia, Submission #33)

6.5.4 STANDARD 4: PROMOTING COMMUNITY ACCEPTANCE

The MHS promotes community acceptance and the reduction of stigma for people affected by mental disorders and / or mental health problems.

Under this Standard, submissions and presentations indicate concerns about:

- discrimination in the workplace and the need to educate employers;
- lack of community acceptance and support; and
- the need for community education.

6.5.4.1 Discrimination in the workplace – need to educate employers

Employment and a supportive workplace are seen as key factors in preventing the rapid deterioration of mental illness and essential in the process of rehabilitation and reintegration into society after a period of illness. However, acceptance and understanding of mental illness seem to be lacking in the workplace and, according to submissions received, discrimination and high levels of stigma are still prevalent. The need for employer education and additional anti-discrimination campaigns were expressed by consumers, carers and government employees:

I am a nurse but I have been told that I will never get a job in this area because of my previous mental health condition.

(Consumer, Nurse, Western Australia, Bunbury Forum #2)

Basically we have to deal with the stigma and discrimination that is entrenched. For example, take a police officer with a mental health problem – a possibility with all government agencies. If a police officer has a broken leg it is acceptable, but if they need medication or time off for mental health reasons they are discriminated against. There is an entrenched stigma and no one is looking after them. It's a culture – police officers are too proud and don't feel free to talk about it. There is a need for publicity saying that you can't discriminate against it…

(Police Officer, Western Australia, Geraldton Forum #90)

I have three family members with mental health problems. Personal experiences have been traumatic. There is a need for more facilities and need more education of employers. Most employers feel that if a person doesn't turn up for work, they won't have a job. Mental health clients may have difficulty sleeping and therefore are not fit to turn up for work the next day. There are difficulties with the control of medications. There is a need for more emphasis on rehabilitation and part-time work.

(Carer, Western Australia, Geraldton Forum #50)

6.5.4.2 Lack of community acceptance and support

Carers and community members spoke of the continued discrimination and isolation experienced by people with mental illness and their families. Of particular importance was a claim made by one carer that discriminatory practices are also being perpetuated by health providers and the government, indicating that community education programs need to encompass the community, the government and workplace training. Increasing community understanding of mental illness, acceptance of people with mental illness and information about how to support people with mental illness and their families and carers is critical to destigmatise mental illness and realise the social, economic and political participation rights of people with mental illness. The ongoing failure of governments to achieve this has devastating consequences:

I can understand how there are so many suicides in our community. Any hope for a normal life is minimal. Not only is the welfare of these people ignored there is positive discrimination against any progress they might want to make. More understanding and education is needed. The last government (and only) education campaign fell far below the mark required. Mental health sufferers need long term care and understanding. Not only by the general population but also (and more so) by the health industry and government.

(Carer, Western Australia, Submission #163)

I also want to talk about an incident that happened recently in my street. My neighbour took a turn 7 months ago and as a community member I was frightened by what was happening. I was seeing a situation worsen. I tried to support the mum by going in and talking with her. She told me that the neighbours would just have to put up with it. I think if the system was working then that person would have had some community support.

(Anonymous, Western Australia, Bunbury Forum #18)

…[my] son who was diagnosed with schizophrenia when he was 18… [X] has been unable to hold down a job and has lost his friends along the way… His father will not allow him back home... [X] is a young man who is very lonely, spending so much time on his own – which does not help his condition. It is so sad so sad to see. He was a champion runner, but that has all gone now.

(Carer, Mother, Western Australia, Submission #99)

6.5.4.3 Need for community education

Without community education, not only will community acceptance and understanding not be forthcoming, but fears based on myths, stereotypes and inaccurate information will continue. This will further perpetuate stigma and discrimination and support an unwarranted call for seclusion and restraint and the curtailment of rights of people with mental illness:

It is all very well to expect the community to deal with mental health patients if they are medicated and stable, but what about those patients who are resistant to medication. How is this safe for the community?

(Anonymous, Western Australia, Submission #145)

In Western Australia mental health problems are shrouded in ignorance. Few people ever think about the mental health needs of our communities and even less people think about the needs of mothers with mental illness and their children. The cost to our community is only counted in fiscal terms for the Health Department… Systemic prevention education will complement systemic cross sector collaboration and build a recognition and understanding of the difficulties encountered by mothers with mental illness and their children. Recommendations: Develop comprehensive and sustained education programs to implement a systemic approach to mental health.

(Health Consumers' Council WA, Western Australia, Submission #29)

[Supporting mothers with mental illness] Recommendations: develop policies to change the belief that a problem within the family is the family's problem to recognising that a problem within a family is also a problem for the society.

(Health Consumers' Council WA, Western Australia, Submission #29)

6.5.5 STANDARD 5: PRIVACY AND CONFIDENTIALITY

The MHS ensures the privacy and confidentiality of consumers and carers.

Under this Standard, submissions and presentations indicate concerns about:

- lack of privacy and control over personal space;
- the Privacy Act and policies related to confidentiality; and
- the MHS denying consumers their right to have others involved in their care.

6.5.5.1 Lack of privacy and control over personal space

Lack of privacy and personal space available at mental health services is still of major concern to consumers and carers:

Many people fear that ultimately Graylands Hospital will be closed down, as was Heathcote Hospital. It should always be born in mind that to replace beds in a facility like Graylands Hospital with its peaceful surrounds with extra beds in a general hospital like Royal Perth or SCGH [Sir Charles Gairdner Hospital] with their locked wards and lack of personal space is absolutely a huge step backward!

(Carers, Parents, Western Australia, Submission #76)

The patients have lost their group room, which now houses community staff, desks and computers. The whole APU [Acute Psychiatric Unit] is an overcrowded situation with the community staff moving into the small premises.

(Nurse, Western Australia, Submission #55)

Issues of Bunbury Mental Health Services:

- *The interim arrangements for the community staff currently is that offices within the therapy areas of the inpatient unit are being utilised. These staff do not have facilities that are deemed to be suitable for seeing patients. Plans are now in process for renovations to take place to extend the offices and make them suitable for patient contact. It is said that these arrangements will be in place for 8 to 12 months. The decisions for these arrangements have again been behind closed doors by unidentified managers. The implications for consumers are many:*
    - *The inappropriateness of having appointments with community staff within the inpatient unit of the hospital, is not an acceptable to many people*
    - *This creates a huge impost on the workings of the inpatient unit, which is already operating under duress. It directly limits the opportunity for therapy and comfort of inpatients.*
    - *It again fails to recognise the need to involve consumer in decisions in which the consequences are borne by the consumer group.*

(Advocate, Western Australia, Submission #2)

6.5.5.2 Privacy Act and policies related to confidentiality

Both clinicians and carers expressed concerns that a misunderstanding of the Privacy Act and policies and procedures to protect the confidentiality and privacy of consumers is hampering communication between consumers, carers and clinicians in the provision of treatment. Furthermore, these concerns would indicate that these policies and procedures are not being made available to consumers and carers in an understandable language and format (Standard 5.2) and that the MHS is not encouraging and providing opportunities for consumers to involve others in their care (Standard 5.3):

Carers continue to report that they feel there is minimal recognition of them by mental health services and minimal efforts to consider their views and/or involve them. Whilst Carers respect the need for confidentiality the lack of possible involvement of carers is a significant barrier to carers in providing care and support for their family members/friends with mental illness.

(Carers WA, Western Australia, Submission #277)

I would also like to say that there is a lack of communication because of the Privacy Act.

(GP, Western Australia, Geraldton Forum #62)

She was over 18, depressed and when I informed her doctors of paternal depression they didn't want to know. Surely if a person is in crisis doctors should listen to family members who may be able to throw some light on a situation. The Privacy Act has gone too far.

(Carer, Mother, Western Australia, Submission #103)

6.5.5.3 MHS denying consumers their right to have others involved in their care

Despite Standard 5.3 stating that the 'MHS encourages, and provides opportunities for, the consumer to involve others in their care' submissions were received indicating that some services actively discourage the involvement of others (carers and other mental health workers) in treatment and care plans. This denial, especially when involvement was specifically requested by the consumer, angered both consumers and carers alike. The exclusion of carers was seen to be detrimental to the planning and delivery of treatment and support:

Some months ago I had a client ask me to accompany him to see his psychiatrist for a 2 pm appointment. The client requested I went in with him, I agreed. The mental health person said that they wanted a few minutes with the client by himself first. I waited the hour and when the gentlemen returned I was just not acknowledged or communicated with. At least I would have liked some acknowledgement and some courtesy.

(Clinician, Western Australia, Geraldton Forum #71)

I made an appointment to see the psychiatrist outside of school hours so that my wife could to attend too. I was told you are the patient and they did not approve of my wife being at the appointment. I need the support of my wife as I always have to discuss the appointment with her afterwards as I am unable to remember it all and it helps me to understand things better. I was disturbed by the attitude of this person. I was asked do you want the appointment or don't you? I said No.

(Consumer, Western Australia, Geraldton Forum #72)

6.5.6 STANDARD 6: PREVENTION AND MENTAL HEALTH PROMOTION

The MHS works with the defined community in prevention, early detection, early intervention and mental health promotion.

Under this Standard, submissions and presentations indicate concerns about:

- no prevention and early intervention is happening due to the lack of access to services; and
- lack of services for youth, no early intervention or mental health promotion possible.

6.5.6.1 No prevention and early intervention is happening due to lack of access to services

Concern was expressed about the inability of consumers and carers to access services at the earliest possible moment or to have services respond appropriately when contact was made. Reports were received of occasions when serious consequences occurred such as escalating illness, suicide, or incarceration:

I would like to comment on the fact that people with a mental illness are being arrested because often it's the only way they can get any help. They have a right to get care, not be arrested. We've got to get access to early intervention programs but it doesn't happen – now my brother is in the court system, not because he's bad but because he's got a mental illness.

(Carer, Sister, Western Australia, Bunbury Forum #24)

My eldest child gassed himself in his car. After that when we really needed support there was hardly anything for us. It was the lack of support that led to my husband walking out – our family broke up because we had nowhere to turn for help. Then my 12 year old son tried to hang himself on the washing line. I got him down and we got treatment from a private psychologist but he later hung himself in his flat. I have lobbied through Lifeline and Parliament and I have got nowhere – I am not a judgmental person but I find [the Minister for Health] is aloof and doesn't care. We need to educate our young people about mental illness and about how to ask for help. Where's the money to educate our young people to ask for help?

(Carer, Mother, Western Australia, West Perth Forum #35)

National Mental Health Plan 2003-2008…Page 20 – "Outcome 9: Improved access to early intervention services."...the reality is 'the system' does nothing unless the consumer is either psychotic, suicidal, or in some other emergency.

(Carer Advocate, Western Australia, Submission #339)

Consumer relapse knowledge ignored. Consumers who feel themselves to be becoming unwell have little or no access to assistance from their treating team. It is not uncommon to contact a clinic on behalf of a consumer who feels the need for immediate intervention and be told that the referral will be placed on a list to be discussed at an 'intake' meeting at a later date…It is the experience of mental health consumers with early signs of relapse or episodes of need that the inability of services to respond to their needs pushes them towards crisis, disruption of their life and greater need to call on those same mental health services.

(Health Consumers' Council WA, Western Australia, Submission #29)

6.5.6.2 Lack of services for youth – no early intervention or mental health promotion possible

Numerous submissions were received that commented on the lack of mental health services for youth. This was seen as a significant failure by the mental heath service in their ability to identify and respond as early as possible to this vulnerable group with mental health problems and prevent deterioration and negative life consequences:

Youth mental heath services…At the moment there's no access to services at all – previously there was a 6-months waiting list – so the notion of early intervention or prevention doesn't exist for this community.

(School counsellor, Western Australia, Bunbury Forum #8)

I have noted the following issues with the Mental Health Services in both Carnarvon and Geraldton; The Child and Adolescent Mental Health service in both Geraldton and Carnarvon has not been running for substantial periods of time over the past three years. This has left many children and adolescents at high risk of suicide. In Carnarvon a number of Aboriginal adolescents have committed suicide.

(Clinician, Western Australia, Submission #333)

[I]n Meekatharra the CAMHS [Child and Adolescent Mental Health Service] worker who visited once every two months was always booked out with appointments. Therefore, it would appear that the need indicated that the amount of times she visited should have been increased. Instead these visits are no longer taking place.

(Clinician, Western Australia, Submission #333)

"To invest in the effective treatment of young people where mental health issues are a concern is of paramount importance. It can and does change the entire trajectory of an illness over a lifetime as so many studies have indicated. I'm sure this needs no debate." (Consumer contribution to Mental Health Coalition Council On-line forum).

(Consumer Advocate, Western Australia, Submission #338)

6.5.7 STANDARD 7: CULTURAL AWARENESS

The MHS delivers non-discriminatory treatment and support which are sensitive to the social and cultural values of the consumer and the consumer's family and community.

Under this Standard, submissions and presentations indicate concerns about:

- staff imposing their own religious and cultural attitudes on consumers; and
- the cultural background of consumers and carers is not being respected and considered in the delivery of treatment and support.

6.5.7.1 Staff imposing their own religious and cultural attitudes on consumers

Cultural awareness includes awareness by staff of their own cultural and religious values and an understanding that it is not appropriate to impose their values and beliefs on consumers. As the following statement shows, this is not always the case:

> *[I] attended the hospital with a friend who had attempted suicide. This was after hours. When I took her to the A and E she was initially checked over for any physical effects of the overdose she had taken. She also reported that she had been abused as a child. The consulting doctor then talked to her at length about religion indicating to her that people who commit suicide "go to hell". This greatly upset my friend who was already very upset. She said later it made her feel guilty about what she had done…An understanding and non-judgemental attitude would also have helped.*
>
> (Clinician, Western Australia, Submission #333)

6.5.7.2 Cultural background needs to be respected and considered in the delivery of treatment and support

Concern was expressed by carers that the cultural background of consumers and carers needs to be understood and respected more. In a special focus group with carers from culturally diverse backgrounds, this was identified as an important issue to be addressed so that treatment and support was sensitive to social and cultural beliefs, values and cultural practices of the consumers and their carers (Standard 7.3). The following comment indicates that staff may need to receive cross cultural training (Standard 7.5) or have more specific knowledge of social and cultural groups of communities represented in their area (Standard 7.1):

> *The focus group was held with carers from culturally and linguistically diverse backgrounds. Again the findings from the focus group were consistent with the written surveys with the following addition. To the question "What three things would you change about mental health services?" carers would like to receive more respect for their different cultural backgrounds and that mental health service staff understood their particular cultural and family background better so that carers' own situations would be respected. (McKeague B, 2003. Worried, Tired & Alone – A report of Mental Health Carers' Issues in WA. Briefing Paper)*
>
> (Carers WA, Western Australia, Submission #277)

6.5.8 STANDARD 8: INTEGRATION

6.5.8.1 Service integration

The MHS is integrated and coordinated to provide a balanced mix of services which ensure continuity of care for the consumer.

Under this Standard, submissions and presentations indicate concerns about:

- more staff and resources required for integrated service to respond effectively to crises;
- lack of cooperation within MHS – poor attitudes towards patients and providers from rural and regional areas;
- lack of any youth mental health services; and
- MHS not providing continuity of care for consumers.

6.5.8.1.1 More staff and resources required for integrated service to respond effectively to crises

Concern was expressed that an insufficient number of staff and lack of resources were factors which were seen to inhibit the provision of integrated and continuous care to consumers in crisis (Standard 8.1).

> *I have a friend who had a mental breakdown…I rang the mental health team and they couldn't see her for 5 days, there was no appointment for three to four weeks. The GP tried to cope. Good clinicians took her details but three, four weeks later she was asked the same questions again. There is a lack of staff – the team in community and lack of coordinated services. For example, home help etc.*
>
> (Friend, Western Australia, Geraldton Forum #65)

> *…my wife was suicidal and the psychiatric nurse on-call…refused to come and see her. She ended up in hospital that night, spending the night in [Z] Emergency Department because there were no beds…my wife was suicidal again…I immediately wrote a letter to Dr [psychiatrist] on her behalf, expressing my grave concern at her current mental health status, her risk for suicide, and her need for urgent treatment and assessment. My letter was not even acknowledged! [Z] MHS couldn't be bothered seeing my wife until the following week. I was forced to call PET [Psychiatric Emergency Team] in order to get my wife assessed. I find this totally unacceptable. (author's emphasis)*
>
> (Carer, Husband, Western Australia, Submission #146)

> *It is intended to fill the position with a person qualified in mental health. But one person doesn't make a team.*
>
> (Anonymous, Western Australia, Geraldton Forum #105)

> *GRAMS [Geraldton Regional Aboriginal Medical Service] see the patient straight away will see the client anywhere - at home or the clinic night or day. The psychiatric nurse is currently on leave but there is a query regarding him coming back. We may loose his expert skills, compassion and local knowledge. Retention is a big problem – building relationships. If we loose them we have a big problem supporting the workers.*
>
> (Anonymous, Western Australia, Geraldton Forum #93)

6.5.8.1.2 Lack of cooperation within MHS – poor attitudes towards rural and regional patients and providers

Given the vast geographical area of Western Australia and the rationalisation of services and resources to principally metropolitan areas, poor staff attitudes, which lower the standard of care delivered to consumers from rural and regional areas, is of serious concern for many reasons. Consumers from rural and regional areas have no alternative avenues of care to pursue; metropolitan services are aware in their service plans that consumers from rural and regional areas will access their services; practices of early discharge and lack of follow up plans for consumers who cannot readily return or rely on other support services are unsafe for the consumer. For consumers in rural and regional areas continuity of care is problematical due to the scarcity of services outside metropolitan areas:

> *Of great concern is the attitude of Perth Metro area hospitals regarding the patients from the South West. Often the statements are we have "one of yours", our hospital is full of "your" patients and I was even told by a senior clinician that our patients were using up the beds in Perth funded by her tax money! There is a perception in the community and by the community mental health team that patients from the South West are discharged prematurely and without follow-up being arranged.*
>
> (Clinician, Western Australia, Submission #55)

6.5.8.1.3 Lack of youth mental health services

The lack of mental health services for youth makes the realisation of Standard 8.1.5: 'The MHS has documented policies and procedures which are used to promote continuity of care across programs, sites, other services and lifespan' problematic.

The lack of youth mental health services means that services for youth are not integrated, coordinated and balanced, and from evidence presented, it would appear that services are either non-existent or inappropriate for this age group:

> *Youth mental health services are disconnected and often staffed by people with limited or no experience in working with these client groups. At the moment there's no access to services at all…We can't get staff with the right skills to this area. The situation is very poor and we rarely receive information about what's happening with services.*
>
> (School counsellor, Western Australia, Bunbury Forum #8)

> *I've been on a few committees and it's not the service providers who are the problems; they are on our side. It's the politicians and our government that are negligent – can the Human Rights and Equal Opportunity Commission help us? There's a 9-10 month waiting list for mentally ill children to get into care.*
>
> (Consumer, Western Australia, West Perth Forum #41)

> *The psychiatrist that was here before was great with feedback to other services and families - now the situation is hopeless. There are 2 of us (school counsellors) covering 8,000 people in this area.*
>
> (School counsellor, Western Australia, Bunbury Forum #8)

> *When a young person visits the mental health service or GP and has a bad experience they loose confidence with the organisation as they feel let down and are reluctant to revisit and therefore have no where else to go. It becomes a problem.*
>
> (Anonymous, Western Australia, Geraldton Forum #93)

6.5.8.1.4 MHS not providing continuity of care for consumers

Concern was expressed about the ability of the MHS to provide a balanced mix of services to ensure continuity of care for consumers (Standard 8.1.5). Problems ranged from lack of services to deliver treatment and support after being discharged from hospital, lack of coordinated services in the community to provide sufficient support for consumers and their children to live independently in the community, long wait lists for services and a failure of the MHS to integrate with NGO service providers:

> *There is no continuity of care. If you can't get better in a short period of time – tough. I needed to see someone sooner.*
>
> (Consumer, Western Australia, Geraldton Forum #66A)

> *My son is 19 and he has chronic schizophrenia and a drug abuse problem. He's been in the locked ward at Graylands for quite a while and I'm glad he's been locked up for that long because he can't cope outside the hospital. He lives with me and I worry about what will happen to him if he is released. He can't be accommodated anywhere and this is a human rights issue. There's unreasonable pressure on the family to provide care for really sick people like my son.*
>
> (Carer, mother, Western Australia, West Perth Forum #31)

I have schizophrenia and over the past 6 weeks I have had problems, as I have been given a new medication which has made it difficult for me to do my housework and to look after my 6 yr old daughter. My psychiatrist comes from Perth fortnightly and I have to make an appointment a month ahead. I have been unable to get help from CWMH [Central West Mental Health] to enable me to look after my daughter and do my housework; I have taken myself off the medication for two days at a time. My caseworker has not been available and no one else has been available to make a decision for me.

(Consumer, Western Australia, Geraldton Forum #41)

I also suffer from depression. The changes 9 months ago to the structure of the care of hospitalised patients have reduced the ability for GPs to look after their own patients as they did in the past. GPs no longer work with their patients when they are in hospital.

(GP, Western Australia, Geraldton Forum #53)

There were a number of GP's in Bunbury who wanted to be involved with the mental health unit but only if there was adequate support. We don't have that support anymore.

(GP, Western Australia, Bunbury Forum #19)

My daughter was waiting for treatment and she had to wait 7 months to see a psychologist. It got to the point where she started using drugs to help her symptoms. Basically it got to the point where the psychologists would say they wouldn't treat her because of her drug use but the drug and alcohol service wouldn't treat her because she was severely depressed!

(Consumer and Carer, Western Australia, West Perth Forum #34)

Issues of Bunbury Mental Health Services:
The current interim arrangements provide limited opportunity for appointments with psychiatrists, psychologists or social workers. This is having an impact on individuals who previously were seeing one of these clinicians regularly. In some case this has resulted in hospitalisation, pressure on GPs and other support services.

(Advocate, Western Australia, Submission #2)

We were very satisfied with the therapeutic relationship he had developed with the doctors at RPH [Royal Perth Hospital] over that period. However, when ever he suffered a psychotic episode or required any other external support, RPH were unable to provide this as our son resides outside their catchment area, the PET team were unwilling to become involved and they required us to call the police to render assistance. We and Dr [Y] have attempted to have this rectified by enjoining with Armadale clinic, they in turn refused to attend or become involved unless he became one of their patients. Finally in desperation his files were transferred to Armadale and we set about trying to arrange an appointment. Whilst we waited for the appointment (some three months later) he experienced several more episodes which were reported to the Mead clinic who in turn were unable to assist because he had not yet seen one of their doctors. The classic catch 22. Finally the day for the appointment dawned but when we arrived, we were told it had been cancelled and rescheduled for the following week.

(Carer, Mother, Western Australia, Submission #13)

I do not refer to Mental Health Services because of past experiences, particularly as they will not see people who have a drug problem. I use GRAMS [Geraldton Regional Aboriginal Medical Service] where possible.

(Anonymous, Western Australia, Geraldton Forum #94)

If the client is using drugs then they are not a mental health patient there is a gap in this situation.

(Anonymous, Western Australia, Geraldton Forum #94)

Mental Health Services' response there has been poor. Appointments are 2 weeks into the future – On one occasion a client went there and was told he was fine. Therefore I sent him to GRAMS [Geraldton Regional Aboriginal Medical Service]. They see everyone there, not just Aboriginal people.

(Anonymous, Western Australia, Geraldton Forum #94)

Concern was also expressed that the MHS is not integrated with NGO service providers to provide continuity of care:

> *At the Department of Community Development, for many years field workers have commented that there are no links or feedback with mental health services. When they take people along with personality disorders and they say no they don't deal with them as they don't fit and we have had problems in that area, they are sent back to our workers. Sometimes we do have a working relationship but I do have to say that there is not a good networking relationship with the mental health service. We have a counselling service where we see quite a number of mental health people who do not have access to the mental health service. Also our NGO counselling services have a number of people with mental health problems and therefore their services are overloaded. The mental health gatekeepers keep them away. We have family counsellors and a lot of our other services and some NGOs funded by DCD.*
>
> (Department of Community Development worker, Western Australia, Geraldton Forum #85)

> *…organisation through its contractual agreement with the Health Department of WA is directed to only take referrals from the SMHS [South West Mental Health Service]. However if clients are to be referred to their GPs for treatment then they will have no means of access to the Community Support Services in their area. This loop hole in the referral process can for many mean they will have no daily support networks and will be totally reliant on GP visits or repeat calls to South West 24 Services for any contacts or support. Again this tends to demonstrate the lack of communication or recognition of the NGO services providers.*
>
> (NGO Service Provider, Western Australia, Submission #45)

> *The MHS doesn't help - the only ones who help are Baptist Care and GPs are left to pick up the pieces. Government does nothing.*
>
> (Former consumer, Western Australia, Geraldton Forum #60)

As the following examples show, for some people, their experiences of accessing care or providing other services were extremely positive. Unfortunately, the relating of positive experiences was not a common phenomenon but the reviewers acknowledge it is more likely that people who have had negative experiences come forward to give evidence.

> *I had a very positive experience with the Molloy Street Clinic. I got the right sort of care when I needed it. My child was born recently and I had anxiety but because I got care I'm okay. My concern is that I'm a really good example of a person who might not be here in the future now that the clinic is closed.*
>
> (Consumer, Mother, Western Australia, Bunbury Forum #21))

> *I would like to speak in defence of the mental health service and in the region. Carelink is a federally funded government service. In defence of mental health staff they do contact me to get help they are quite happy to call me to access services – I get a lot of phone calls from mental health services for people who have been unable to contact my service.*
>
> (Anonymous, Western Australia, Geraldton Forum #88)

6.5.8.2 Integration within the health system

The MHS develops and maintains links with other health service providers at local, state and national levels to ensure specialised coordinated care and promote community integration for people with mental disorders and / or mental health problems.

Under this Standard, submissions and presentations indicate concerns about:

- problems with integrated and continuous care when consumers are admitted to hospital for physical illnesses; and
- difficulties encountered by consumers in accessing General Practice.

6.5.8.2.1 Problems with integrated and continuous care when consumers are admitted to hospital for physical illnesses

One consumer expressed concern that she was unable to continue seeing her caseworker while she was in hospital for a physical condition. This suggests that links had not been established, that the MHS was not part of the general heath care system or that polices and procedures were not adhered to:

> *I've recently been to hospital for a physical condition. I asked to see my caseworker whilst in hospital. I was informed that I could only talk to my case manager on the phone or she could visit as a friend not as a professional. I would like to know why?*
>
> (Consumer, Western Australia, Geraldton Forum #2)

6.5.8.2.2 Consumers and problems with accessing General Practice

One general practitioner noted as a concern that, from his experiences, people with mental illness have difficulty accessing general practice. This has implications for consumers in their ability to seek treatment for either mental or physical illnesses:

> *I suppose the thing to say is that people have difficulty accessing general practice particularly if they have a mental illness.*
>
> (GP, Western Australia, Bunbury Forum #19)

6.5.8.3 Integration with other sectors

The MHS develops and maintains links with other sectors at local, state and national levels to ensure specialised coordinated care and promote community integration for people with mental disorders and/or mental health problems.

Under this Standard, submissions and presentations indicate concerns about:

- the need for a whole of government approach;
- lack of support from Centrelink;
- lack of support for families;
- police; and
- the lack of housing and accommodation options.

6.5.8.3.1 Whole-of-government approach needed to improve outcomes for people with mental illness and their families and carers

Overall, many submissions indicated a lack of integrated service delivery or of a whole-of-government approach to solve the complex support needs required for people with mental illness and their families and carers to live in the community in a dignified manner. These problems were reported with welfare, criminal justice, community service, legal, housing and disability services. Many submissions identified that a broader governmental, societal and community approach is required:

Come and walk in our shoes for a day – we're damned no matter how hard we work we can't win. There's a lack of resources but also a societal problem. It's a whole of government approach that's required.

(Clinician, Western Australia, West Perth Forum #40)

I am a solicitor recently come to Geraldton and I find there is a poor nexus with mental health services. Local mental health services will not supply letters to the legal system therefore people are being charged instead of treated. There was one instance where a person was heard by 2 JPs [Justice of the Peace] who could not order an assessment, this was referred to a Magistrate in Carnarvon. I am not aware of any assessments being brought on in Geraldton. I am concerned because it then goes through to what? This is a concern to me. There needs to be improvements in communications.

(Solicitor, Western Australia, Geraldton Forum #57)

In 2001 I was caring for a foster child who had a mental and a physical disability. When I took him in for care I was told he didn't have a mental illness and he was discharged by the hospital on the Friday but was then admitted to Graylands and I was told he has schizophrenia.

(Friend, Western Australia, Bunbury Forum #3)

[Supporting mothers with mental illness] Recommendations: Use the education system as the primary system for referral forums to develop greater cooperation between education, child development, child protection, family support and child and adolescent mental health systems. All systems use the same tax dollar.

(Health Consumers' Council WA, Western Australia, Submission #29)

Lack of integration and coordination with Disability Services was also reported:

My brother is both Bipolar and has an intellectual disability. I believe his convictions are a direct result of the lack of available services to him whilst he tries to live independently in the community. Up until now we have always had to jump hurdles in order that the Mental Health Services and Disability Services work together as a team

(Carer, Sister, Western Australia, Submission #101)

6.5.8.3.2 Lack of support from Centrelink

With declining access to mental health services, supported accommodation and the implementation of early intervention strategies, the burden on families and carers to provide long-term and crisis support is immense. This often impacts on the financial income of the family due to a reduced ability of carers to work. The shifting of care by governments to carers fails to recognise that carers are providing a significant cost-free service that is not being shouldered by the community:

My husband has drug resistant schizophrenia. My son is deeply affected by my husband's illness but we get no support from Centrelink for the effect on our kids. To give you an idea how bad Centrelink treats us I got a computer generated letter indicating that our pension had been cut off.

(Carer, Wife and mother, Western Australia, West Perth Forum #26)

6.5.8.3.3 Lack of support for families

When people with mental illness are living in the community, many other supports may be required beyond direct treatment and support for their mental illness as well as assistance with rehabilitation and integration into the community. These additional supports may be financial as discussed above, or more frequently, are required in the form of assistance for the family as a unit, e.g. care for children if a parent with mental illness requires hospitalisation, support for families after the suicide of a family member with mental illness, or community support services for the family to cope on a day to day basis. The following quotes highlight the support services required, their lack of availability and the impact on families:

> *I am an NGO provider. Our surplus of funding from last year was taken from us by the Government without notice. The Government just doesn't think about the implications of taking away funding from NGOs. We already have long waiting lists and taking away funding makes them even longer. One of the young consumers who was on one of our waiting lists for four months was also caring for her Mum – she killed herself because she felt she couldn't cope looking after her mum anymore without some support. Waiting lists for support from us have gone up from three weeks to four months.*
>
> (Service Provider, Western Australia, West Perth Forum #29)

> *There is no available respite for families/carers of those people with mental health issues. However, for a carer of someone with an intellectual disability resources are available for respite. This raises another concern which is for that of the mental and physical health of the carer. (I have seen the health of carers and their families – including young children – deteriorate as they struggle to cope with their loved one).*
>
> (Anonymous, Western Australia, Submission #145)

> *Despite the fact that in Busselton there is LAMP (a support for carers and some limited activities are organised for mental health patients) and Pathways (a four bedroom house for limited respite which covers the whole of the South West) in Bunbury, if a patient is considered disruptive then he/she is not referred to these places and the burden continues to rest with the family with no respite at all.*
>
> (Anonymous, Western Australia, Submission #145)

> *The profound impact on the families of the mentally ill needs to be given due consideration and care.*
>
> (Carer, Sister, Western Australia, Submission #101)

> *Carers WA and the Mental Health Carers Issues Network recently conducted research into the needs and issues of carers of people with mental illness. 1. What Is The Most Difficult Part Of Your Role As Carer? Emotional strain was identified by 52% of carers as being the most difficult part of their role as a carer. This resulted from feelings of uncertainty and fear about the future; the unpredictability and uncertainty of the consumers' behaviour; abusive, angry and intolerant behaviours; feelings of helplessness; the carer's own deteriorating personal health; the difficulty of letting go of the responsibility; and sense of isolation and loneliness. (McKeague B, 2003. Worried, Tired & Alone – A report of Mental Health Carers' Issues in WA. Briefing Paper)*
>
> (Carers WA, Western Australia, Submission #277)

> *Carers WA and the Mental Health Carers Issues Network recently conducted research into the needs and issues of carers of people with mental illness…What impact has being a carer had on your life? The majority of carers (88%) reported a negative impact that being a carer has had on their life. Loss of personal, physical and emotional freedom, and restricted social and work opportunities was identified by 30% of carers. Impact on family dynamics was the second most frequent response to how caring had impacted their life (25%). There were effects on children and siblings, disturbing family emotions, difficult relationships with partners, and marriage breakdown. Other negative impacts included personal illness, tiredness and sadness (22%). (McKeague B, 2003. Worried, Tired & Alone – A report of Mental Health Carers' Issues in WA. Briefing Paper)*
>
> (Carers WA, Western Australia, Submission #277)

6.5.8.3.4 Police

Due to diminishing access to mental health services, police have been increasingly called to assist with people with mental illness, especially in times of crisis. In some places, Memorandums of Understanding (MoUs) have been drawn up between police and mental health services and training has also occurred, but evidence suggests that further consultation is required to more clearly define police involvement with people with mental illness and acknowledge the limitations of their involvement. Additionally, involvement of police to assist with people with mental illness increases the stigma that ensues from police contact and heightens community fears, in what should be a mental health response:

> *The police have a MoU with SW [South West] Health and we are working on positive steps to address the issue.*
>
> (Police officer, Western Australia, Bunbury Forum #11)

> *The last thing we want to do is get involved with mental health issues but we have a legislative requirement to get involved. One thing that concerns me personally is the transport of people with a mental illness. We are often required to transport these people but they are not criminals, they are ill.*
>
> (Police officer, Western Australia, Bunbury Forum #9)

> *(In response to question How do the Police behave? Are they adequately trained? Do they know what they are doing?) Yes but they don't always give it a high priority therefore things can get out of hand in the time it takes for them to respond. They are sometimes short staffed. We need to have more trained people on the ground.*
>
> (Carer, Family member, Western Australia, Geraldton Forum #51)

6.5.8.3.5 Lack of housing and accommodation options

The lack of accommodation, and in particular supported accommodation, options was repeatedly raised in submissions and at forums. The increasing demand on current services and their increasing inability to deal with clients with complex needs (e.g. mental illness) due to lack of resources is resulting in increased homelessness, increased pressure on families with little or no available community support, and additional barriers for the successful rehabilitation and reintegration of the person with mental illness into the community. As evidenced in the following quotes, coordination with the Department of Housing is urgently needed to address this critical issue to provide both sufficient accommodation in conjunction with the Department of Health and also to provide mental health treatment and support for people using supported and crisis accommodation services to ensure specialised and coordinated care:

> *We have 12 houses and a boarding house for single men so we can take in 18 men. I have worked in human services for the last 16 years and I can tell you that we are now on a path to disaster – people are being 'dumped' on our service and on the streets because other people don't know what to do with them. They are sent here by the service or the hospital with no consultation with us – they are just told where to go, how to find us.*
>
> (Service Provider, Western Australia, Bunbury Forum #12)

> *We had a client who was suicidal a few months ago. When contacting the mental health service during the day time – because the worker would not give a surname, (our workers do not give out their surnames) they hung up on her. We managed to get her to Perth for help. About six weeks later I contacted them and gave my full name and she laughed at me, because she didn't believe it was my real name – my surname is [Y] – She laughed at me and said that that was not my real name and hung up on me. I was told that it was Domestic Violence and it was not mental health.*
>
> (Service Provider, Western Australia, Geraldton Forum #89)

…advised of the availability of two units for consumers…the units are much needed as at the moment most local consumer have to remain living at home in what for some is less than favourable circumstances, the alternative is for them to move to Bunbury or at least Busselton which means leaving support networks of family and/or friends…approached the Health Department seeking funding for an appropriate support worker to service these units we were advised, after the 2004 review of NGO funding the Minister had withdrawn and further funding application and therefore we were not able to provide a support service to the units and they were turned in.

(NGO Service Provider, Western Australia, Submission #45)

Further for three consecutive years [Y] did not even receive CPI [Consumer Price Index] increments to assist in provision of services…the health department their response was to suggest [Y] do what other organisations have done and reduce service. To this agency this makes no sense…therefore to continue offering quality service I have staff members in their own time fundraising for…much needed items.

(NGO Service Provider, Western Australia, Submission #45)

We are also now in the position where we are housing people when properties become available, without the capacity to support them in their housing. In 2002, NGO's were invited by the Office of Mental Health to tender for disability support services. Many I know worked extremely hard to put in their submissions, only to be advised in writing the following year, that no funding would be forthcoming…This organisation has recently approached The Gaming Community Trust Grants Program to request funding for the growing number of children in the Program, which now totals 40. So much work has been completed through the COPMI [Children of Parents with Mental Illness] Project in WA, yet the children remain unsupported. Unfortunately, the application was not successful and we have been referred to DCD and Lotterywest to pursue the Project, a Project I believe that Mental Health should be funding as part of an early intervention and prevention strategy. I do not think that the Office of Mental Health appreciate the lengths to which many NGOs go to try and come up with innovative ways to support this group of people and many of the workers in mental health in WA are extremely united and dedicated.

(NGO Service Provider, Western Australia, Submission #18)

In November 2001, St Bartholomew's House wrote to the Premier of WA, Dr Geoff Gallop, to highlight some of the difficulties they were experiencing in caring for people with mental illnesses. At that time the Supported Accommodation Assistance Program (SAAP) service had over 60% of the 54 residents with a known mental illness…Dr Gallop asked that a number of government officers from both mental health and SAAP services meet with St Bartholomew's House to discuss possible solutions. After 14 months of deliberation a report was written and St Bartholomew's House was provided with an additional $30,000 of SAAP funds but there was no money from mental health.

(St Bartholomew's House Inc, Western Australia, Submission #37)

6.5.9 STANDARD 9: SERVICE DEVELOPMENT

The MHS is managed effectively and efficiently to facilitate the delivery of coordinated and integrated services.

Until we erase the current culture of poor Health governance in W.A., unfortunately we will not move forward. For example, local doctors were excluded from participating on the local Hospital Board from the mid 1990's, and the Hospital and Health Department have ignored, or been unwilling to accept our advice on all matters medical, for many years…Government cannot continue to blame lack of staff for our current Mental Health care problems. Any money thrown at the current system without a fundamental change, as outlined, will not work.

(GP, Western Australia, Submission #326)

Under this Standard, submissions and presentations indicate concerns about:

- the current state of service delivery in Western Australia;
- consumers, carers, staff and service providers not involved in planning and delivery of services;
- lack of planning to provide continuous care;
- lack of resources to deliver quality mental health care;
- services ever diminishing in rural and regional areas;
- problem with 'custody and control' model of care;
- funding model needs to change;
- lack of funding to NGOs;
- Impact of lack of resources on staff and recruitment and retention;
- staff training and development needed;
- need for more graduate programs and supervision for mental health nurses;
- problems with accountability; and
- private vs public mental health services.

6.5.9.1 Current state of service delivery in Western Australia

Many submissions and presentations at forums conveyed feelings of despair that since the Burdekin Report and the closure of institutions and promise of community care, services have been declining and deteriorating rather than improving:

> *The only people we can rely on are the police who always respond but then they are left with nowhere to take him due to the appalling state of the mental health services and lack of facilities.*
>
> (Carer, Mother, Western Australia, Submission #13)

> *National Mental Health Plan 2003-2008…Page 16…Increasing service responsiveness?! 'The system' couldn't be any less unresponsive if it tried.*
>
> (Carer Advocate, Western Australia, Submission #339)

> *What have we got for a mental health system? Nothing, absolutely nothing! My support group helps me but not the mental health system.*
>
> (Consumer, Western Australia, Bunbury Forum #1)

> *Unfortunately, in more recent years positive change does not seem to have continued, and if anything, deterioration has taken place. Now, at least in Western Australia, there is a crisis in regard to provision of Mental Health Care within the community.* (extract from a letter to Communications Manager, Mental Health Council of Australia)
>
> (Clinician, Western Australia, Submission #24)

> *I am a consumer of mental health care and I would like to say that since the new Mental Health Act has been introduced things have gotten much worse. I was better off before. When I get sick I will be looked after for a month and then there's nothing else for me – no care. The local government providers say I should go to the GP for care because I don't have a mental illness – I have temporal lobe epilepsy.*
>
> (Consumer, Western Australia, West Perth Forum #27)

> *…consultations into mental health care in Australia…is particularly important and necessary in Western Australia due to the dire state of mental health care from years of neglect and under funding of mental health services.*
>
> (Carers WA, Western Australia, Submission #277)

On a personal level, working in the APU [Acute Psychiatric Unit] provides a lot of anxiety for me at times. I feel there is no commitment by the hospital to provide a high standard of care for the mentally ill, funding is lacking, and the issue of safety, being an expensive one, does not hold high priority for the hospital or the current government.

(Clinician, Western Australia, Submission #55)

During the last 28 years I have practised as a GP in Geraldton. The provision of mental health has at best been poor to fair, and at the worst been atrocious.

(Clinician, Western Australia, Submission #326)

…the terrible shambles that SW MHS [South West Mental Health Services] has become.

(Clinician, Western Australia, Submission #19)

Carers fill the gaps in the system, providing the care and support for their family members and friends with mental illness who are unable to access the services they need. Without Carers, the system would collapse.

(Carers WA, Western Australia, Submission #277)

I suspect the increasing rates of imprisonment may be linked to the deinstitutionalisation of men and women from mental health facilities. As well as the inability of existing services to provide holistic health care arrangements that see drug use as a symptom of mental health issues and not always the cause.

(Service provider, Western Australia, Submission #14)

The good news from the same committee [Standing Committee], which I happen to chair, is we have decided to conduct an inquiry into the adequacy of Mental Health Funding in Western Australia. The terms of reference will be to enquire and report on the level of need and adequacy of funding for Mental Health Services in Western Australia.

(Dr Christine Sharp, MLC, Western Australia, Submission #3)

Mental Health Care in WA is a disgrace. The system is chronically under-funded and under-resourced. There is a chronic shortage of psychiatric beds. Community Clinics are overworked and under-resourced. Supported accommodation options for mental health clients are severely lacking. The Psychiatric Emergency Service is viewed as a joke by clinicians and clients alike and function as little more than a telephone advisory service.

(Clinician, Western Australia, Submission #4)

It is an unhealthy system that allows even a minority of its parts to operate in ways that are so hostile to its service users and against its own mandate.

(Health Consumers' Council WA, Western Australia, Submission #29)

I do not want what I have to say as being service bashing because I believe that a lot of service providers are endeavouring to do their best with limited resources and are often hampered by what I see as bureaucratic processes which can no doubt be justified by bureaucrats. I see it very much as a political issue with inadequate funding being a substantial cause of the ongoing problems.

(Carer Advocate, Western Australia, Submission #339)

I have pulled my wife out of the Public Mental Health system – I feel the Public Mental Health system should only be used in emergencies as a last resort.

(Carer Advocate, Western Australia, Submission #339)

The Gallop government drew appalled criticism from all around Australia when it actually cut funding to mental health services in 2003. There is no indication it acknowledges the scale of the severe crisis in mental health services in WA or the need to commit sufficient resources to address it. Yet as the Department of Health admits in its 2004 discussion paper, 'clinical community support for people with mental illness is inadequate to provide effective case management and discharge planning…services they require either do not exist or are insufficient'.

(SANE Australia, National, Submission #302)

The WA Office of Mental Health has established a Branch solely to examine reform and redesign issues, based on WA's Mental Health Strategic Plan 2004-08. Any action, however, will depend on the Gallop government which has been defensive and reluctant to commit itself seriously in this area.

(SANE Australia, National, Submission #302)

A 2004 discussion paper, Enhancing the Capacity of Mental Health Services, suggests improved support for psychiatric services in hospital Emergency Departments and some other measures – but seems a despairing, hastily-composed document listing more problems than solutions.

(SANE Australia, National, Submission #302)

There are continuing problems in regard to the integration of the APU [Acute Psychiatric Unit] into the management structure of the Bunbury Regional Hospital. It is by no means clear that senior management staff have a good grasp of issues to do with mental health and psychiatric clinical service delivery. Despite principles of integration and mainstreaming there still is a tendency for psychiatry to be treated differently to other medical specialities…

(extract from a letter to the Office of the Chief Psychiatrist) (Clinician, Western Australia, Submission #24)

6.5.9.2 Consumers, carers, staff and service providers not involved in planning and delivery of services

Failure of the hospital to maintain the progress apparent in other states, to involve consumers not just in representation on committees but at a clinical level. This inaction has ensured that a philosophy of consumer focused care (as recommended by the Mental Health Strategy) has not taken root and that the culture of stigmatisation (devaluing and dismissive attitudes and behaviours) of consumers has prevailed. (Excerpt from: Shanley (2001), Management of change in a psychiatric hospital using a 'bottom up' approach)

(Eamon Shanley, Professor of Mental Health Nursing, Australia, Submission #33)

Another overriding theme in many submissions was the widespread decline or cessation of consultation with consumers, carers, clinicians and service providers in the planning, implementation and evaluation of MHS (Standards 9.8 and 9.9). Service providers in particular expressed feelings of complete frustration and helplessness and reported further reduced ability to deliver treatment and support services to people with mental illness:

Senior clinicians have lobbied the Office of Mental Health and the Health Minister but their concerns fall on deaf ears.

(Clinician, Western Australia, Submission #4)

Over the years I, and many colleagues, have attempted to resolve identified problems of clinical service delivery through traditional channels of communications within the Health Department. I have to confess that I have been singularly unsuccessful in achieving much change. (extract from a letter to a Member of Legislative Assembly)

(Clinician, Western Australia, Submission #24)

The part-time role of clinical director is being marginalised. This, in my opinion, is quite unfortunate as such a role can play an extremely important part in relationship to matters of clinical governance and to the integration (rather than separation) of administrative and clinical matters…(extract from a letter to the Office of the Chief Psychiatrist)

(Clinician, Western Australia, Submission #24)

It was on the 1st of April that SouthWest 24 became the main point of contact for Bunbury people needing mental health care. There was no consultation with the community before the service was closed. We simply received a letter advising us of the changes!

(Clinician, Western Australia, Bunbury Forum #6)

I'm a service provider and we didn't even receive a letter!

(Service Provider, Western Australia, Bunbury Forum #7)

We received a letter informing us that there were no longer any mental health services in Bunbury and that we would have to use SouthWest 24. We were told there would be a response if there was an emergency.

(School counsellor, Western Australia, Bunbury Forum #8)

…[Bunbury clinic] was recently allowed to close…I hope that the MHCA was aware that there was no consumer representation on any body that allowed such a tragic act to occur in our town. I can certainly say that the clinicians working in this area are totally frustrated and saddened by the inattention to community mental health issues by SW Area Health. In my view this reflects a serious disconnection between the health service management, clinicians and consumers that I fear may never recover under the current administrative structure.

(Clinician, Western Australia, Submission #19)

Youth mental health services…The situation is very poor and we rarely receive information about what's happening with services.

(School counsellor, Western Australia, Bunbury Forum #8)

There's disconnection between GP's and us. These findings have been identified and re-identified but nothing is being done. Perhaps the greatest disconnection has occurred between the consumers, the providers and the decision makers. Consumers are no longer being consulted about their needs here. It was 12 months ago that we clinicians wrote to the District Director advising of problems with the mental health clinic. Nothing was done!...The clinicians don't want to work like this but we are forced to work in crisis-mode.

(Psychiatrist, Western Australia, Bunbury Forum #15)

SouthWest 24 has been around for quite a while as a private company – it used to work reasonably well but the problems occurred earlier this year when it became the single point of entry into the system! One of the biggest problems was in how the information was communicated. Our organisation had a MoU [Memorandum of Understanding] with the local mental health service about how we would work together to better deliver mental health care. That was changed unilaterally by the mental health service – so that's left us (general practice) feeling pretty bad and pessimistic about trying again.

(GP, Western Australia, Bunbury Forum #19)

There is a plan for Diabetics, Asthmatics for their drug use etcetera. But we have systemic problems with mental health since I came to Geraldton in 1997. The Division [Mid Western Division of General Practice] funded another health worker. The box was ticked – your concern has been heard – but no change. Lots of meeting where we are told why they can't do things. Nothing happens. As for GPs' referrals, a large proportion of my patients have mental health problems.

(GP, Western Australia, Geraldton Forum #62)

Issues of Bunbury Mental Health Services:

- *Clinic ceased functioning at Molloy Street 29/04/04, 9 weeks ago at 1/7/04*
- *No notification was forthcoming to consumers until 10/06/04, when a mail out was done after the consumer carer group insisted on this.*
- *There has been no consumer consultation of any kind in respect to the plans, location and functioning of the new clinic. It has been acknowledged that this should happen but nothing has been forth coming. Costing for renovations are currently before the director general for approval. At what point will consumers be involved in the planning process?*
- *It has been suggested that the rehabilitation program (living skills) will be co-located with the new clinic. Consumers have not been given an opportunity to discuss the appropriateness of this.*

(Advocate, Western Australia, Submission #2)

Issues of Bunbury Mental Health Services:

- *Basically decisions are being made behind closed doors, top down management with no consultation on anything. Consumers are getting angry at placating comments, and lack of real response to concerns over lack of service. Needs are not being met in anything but the most reactive way. There is a general perception that moral is universally declining along with confidence. The analogy of the titanic describes the emotion of most people involved.*

(Advocate, Western Australia, Submission #2)

Unfortunately, no matter what clinicians say or do, it is managers within the various systems that control budgets and therefore the important resource requirements. The system in Western Australia now is such that it is as though a divide exists between managers on the one hand and clinicians on the other.(extract from a letter to Communications Manager, Mental Health Council of Australia)

(Clinician, Western Australia, Submission #24)

6.5.9.3 Lack of planning to provide continuous care

Standard 9.4 states: 'The organisational structure of the MHS ensures continuity of care for consumers across all settings, programs and age groups'. However, evidence indicates that the MHS is not providing and supporting continuity of care in multiple ways; e.g. by declining to fill key critical positions even when ample advance warning of departure was known and the implementation of restrictive policies. One accommodation service provider reported that when the service had approached the WA government for assistance to provide services for people who are homeless and have a mental illness. However, not only was their request denied, but they were also told to "just move these people on".

There is no child psychiatrist in the area and the service knew for about 12 months that he was leaving. Nothing has been done that I can see to replace him.

(School counsellor, Western Australia, Bunbury Forum #8)

I would like to talk about two main things. In August 2003 at the Mental Health Forum in Dongara the question was put regarding the money designated for a second psychiatrist for Geraldton had been taken out of the mental health service and put elsewhere. We were assured that we would still get another psychiatrist next year. However, a short time later I was informed that that was no longer going to happen.

(Mental health worker, Western Australia, Geraldton Forum #56)

We run a 20 bed aged care and crisis service for people with a mental illness. 18 months ago we had to restrict the number of people with a mental illness coming into our service. I'm not proud of that but we were having too many problems and incidents with those people we identify as the "hard homeless" – they are difficult to care for, they don't pay but where do they go? If you are homeless, with a mental illness you don't get help from anywhere, you don't have a pension because you can't comply with the rules and regulations and most often there's nobody advocating for you. These are the forgotten people! When we've asked government for additional support for these people we've been told we should just move these people on.

(Accommodation Service Provider, Western Australia, West Perth Forum #33)

This loop hole in the referral process can for many mean they will have no daily support networks and will be totally reliant on GP visits or repeat calls to South West 24 Services for any contacts or support.

(NGO Service Provider, Western Australia, Submission #45)

6.5.9.4 Lack of resources to deliver quality mental health care

We now have access to the lowest cost health service! Not only do we have to tolerate the closure of our mental health service but ever diminishing resources. My experience is that we have extremely diligent staff and GP's but there simply isn't enough money or resources to support them in delivering quality mental health care.

(Carer, Western Australia, Bunbury Forum #14)

The lack of resources to deliver treatment and support services to people with mental illness and intervene at the earliest possible moment was a theme expressed repeatedly throughout many submissions and at all the three Western Australia community forums. Claims were made that the MHS was focusing on beds (end crisis point) and not community services (early intervention) and resources were not being allocated to reflect national mental health policies (Standard 9.14) or in a manner which allows the MHS to respond promptly to the changing needs of the defined community (Standard 9.15). Comments indicated that services are barely able to deliver basic services or treatment which requires minimal support (e.g. medication was the only treatment option).

I feel that the public system is over worked, psychiatrists aren't well trained and they don't have the resources they need to be able to respond properly.

(Consumer and Carer, Western Australia, West Perth Forum #34)

A pathetic 12 extra beds won't solve anything.

(Carer, Husband, Western Australia, Submission #146)

…services in the lower south west there is a mental health clinic located at Bridgetown which often only opens one or two days per week. This clinic is up to one hundred and twenty kilometres away from some of the towns it services and often further for those living on remote properties. There are two mental health nurses who service this region and they are greatly stretched, making quality contact time impossible.

(NGO Service Provider, Western Australia, Submission #45)

If I was a client and needed help I'd now be forced to phone SouthWest 24 for help. I would then be referred to triage services and my situation/problem would be discussed at an intake meeting. I went to an intake meeting recently and it was a scary process in the way that decisions were being made that would result in clients being excluded from care– not because they didn't need care but because of a lack of resources.

(Mental health worker, Western Australia, Bunbury Forum #16)

I think it needs to be recognised that a lot of the people who provide care are family members – the carers – when my sister needs care she doesn't contact SouthWest24, she comes to us. The service providers are good people they just don't have the resources they need. It's very hard, very difficult.

(Sister, Western Australia, Bunbury Forum #25)

Carers consistently report that mental health services are inadequate and their family members can't get access to services when needed. On these occasions the responsibility for care and management is transferred onto the family carer who tries their best to manage and provide the care and support that is not available through mental health and community services. Without this sustained contribution from carers, the mental health system which is already under extreme pressure would be placed in greater jeopardy.

(Carers WA, Western Australia, Submission #277)

Carers report that the current funding and provision of mental health care in WA is clearly inadequate to meet the level of need. This is demonstrated by: People unable to access community mental health services unless they are in crisis and are a threat to themselves or others; People presenting at hospital emergency departments requiring treatment for mental illness waiting in corridors as beds are not available in psychiatric hospitals; The lack of independent accommodation options for people with mental illness. There should be a range of options available and flexible to the individual needs of people with mental illness.

(Carers WA, Western Australia, Submission #277)

As a result of our enquiries into this area, we were made increasingly aware of the incredible reduction in the amount of care in almost every area which affects mental health treatment. Doctors and nursing staff are struggling with ever mounting burdens of care, while working with continually decreasing resources in Graylands Hospital and the mental health clinics. When our son was first admitted to Graylands Hospital in 1990, there were approximately 300 beds available. Now, after several wards have been closed, there are only 197 beds, of which 30 are in a separate locked forensic ward (built in about 1995), and hence are not available to the general public!! As Perth has grown in leaps and bounds with an ever increasing population, and therefore by extension, ever increasing numbers of mentally ill people of all ages, the amount of available care has been significantly reduced by successive governments, and particularly so in the past few years.

(Carers, Parents, Western Australia, Submission #76)

The third area of neglect is the overburdening of the mental health clinics themselves whose staff, despite the best of intentions are virtually unable to offer more than just basic supply of medication and an occasional doctor's appointment (usually in over a month's time – hardly ideal for fragile patients). Patients will occasionally get a home visit from a nurse, but as there is no interim accommodation as detailed above, this is completely inadequate in most cases.

(Carers, Parents, Western Australia, Submission #76)

I feel the inpatient unit in Bunbury provides a second-rate service to the mentally ill in the region as it does not provide a multi-disciplinary team.

(Nurse, Western Australia, Submission #55)

Although St Bartholomew's House continues to try and provide a quality service in supported accommodation (SAAP), the lack of resources, a staff ratio of 1:54, poor education of staff and the numbers of people requiring care limits the capacity to delivering safe quality care.

(St Bartholomew's House, Western Australia, Submission #37)

The WA State Mental Health Strategic Plan 2004-2008 highlights that 371 staff are currently needed to meet accepted benchmarks and 233 beds are currently required to meet benchmarks. By 2008 we will need an additional 559 staff and an additional 368 beds. (author's emphasis)

(Clinician, Western Australia, Submission #4)

Resourcing has now become critical. This is well exemplified in Western Australia by the absence of sufficient emergency beds for those who are acutely unwell with serious psychiatric conditions. (extract from a letter to Communications Manager, Mental Health Council of Australia)

(Clinician, Western Australia, Submission #24)

6.5.9.5 Services ever diminishing in rural and regional areas

Concern was expressed regarding the continued reduction of treatment and support services in rural and regional areas rather than strategies to enhance and improve service delivery. Consumers, carers and the few service providers operating in these areas with minimal support reported negative impacts of the result of such planning:

…the Midwest Mental Health Department was established. The aim of this organisation was OK, but its implementation and structure was flawed from the onset.

(GP, Western Australia, Submission #326)

…the supportive caseworkers withdrew their after hour's services completely, leaving effectively, no after hours psychiatric service in Geraldton…The problems have therefore been:

(1) An ineffective resident psychiatric service, both acute and non acute.
(2) Management (local and Perth) with questionable skills.
(3) Poor methods of case handing.
(4) Poor communication with local GPs.

The solutions are:

(1) A totally new Psychiatry system, involving a board consisting of GPs and a well trained autonomous psychiatrist.
(2) The psychiatrist should be highly paid with a right of private practice, and form his or her own team, and "run the show".
(3) The psychiatrist will report to the Board of Management at regular meetings, to assist in management decisions.
(4) Government should fund this initiative adequately, and heed the advice of the board.

(GP, Western Australia, Submission #326)

…I am constantly reminded of the additional problems for those families living in the more remote rural areas of the State…how regionalising a service to a central area will have little or no benefit too them.

(NGO Service Provider, Western Australia, Submission #45)

…the decision to cancel the locum at the eleventh hour as an apparent gross error of judgement at best and, at worst, the demonstration of a callous disregard for the psychiatrically unwell who happen to suffer the additional disadvantage of living in a rural area…the rural community served by it continues to suffer considerable disadvantage in comparison with residents of the Perth metropolitan area. Your recent intervention provides no comfort for a rural service that hopes to gain equity of access for its consumer base… (extract from a letter to the Director General, Health Department of WA)

(Clinician, Western Australia, Submission #24)

Changes to policies and procedures were reported as further complicating access to sparse resources in rural and regional areas:

…recently informed of the changes to the…South West Mental Health Services procedure for referral of a consumer presenting unwell…staff are to advise the person for whom they are concerned to either seek consultation with their GP or go direct to the local hospital where their details will be passed on to the SWMHS who in turn will forward these details to the South West 24 telephone service which is now the single point of entry for all consumers and Carers. Once these details have been received by the South West 24 worker they will contact the consumer by telephone and then they will triage them at this time. One concern is the probability of the client not having a contact number or home phone or even a home. If contact can be made the South West 24 worker will decide who the person should be referred to this may well be their GP who referred them in the first place or the South West Mental Health Services in their area. After this referral has taken place a referral an appointment will be made with the nominated service…this process appears to be lengthy and could take several days for a potentially unwell client to be "seen" by a clinician. A concern for this organisation is the welfare of the client and the possible difficulties they experience during this referral period.

(NGO Service Provider, Western Australia, Submission #45)

…organisation through its contractual agreement with the Health Department of WA is directed to only take referrals from the SWMHS. However if clients are to be referred to their GPs for treatment then they will have no means of access to the Community Support Services in their area. This loop hole in the referral process can for many mean they will have no daily support networks and will be totally reliant on GP visits or repeat calls to South West 24 Services for any contacts or support. Again this tends to demonstrate the lack of communication or recognition of the NGO services providers.

(NGO Service Provider, Western Australia, Submission #45)

6.5.9.6 Problem with 'custody and control' model of care

As alluded to above, there is a belief by some that a shift has occurred to the model of care ('custody and control') underpinning resource distribution and the planning of service delivery. A focus on this model emphasises containment rather than treatment at the earliest possible time to prevent people requiring hospitalisation or entering the criminal justice system:

However any change being brought about, without a fundamental change in the value system of the culture of the hospital towards a more humanistic attitude to patients, is likely to be little more than tokenistic. (Excerpt from: Shanley (2001), Management of change in a psychiatric hospital using a 'bottom up' approach)

(Eamon Shanley, Professor of Mental Health Nursing, Australia, Submission #33)

I have been a consumer advocate in WA for many years. What I've noticed in WA is an emphasis on control rather than mental health care. The Government's response is a lock and key response rather than good mental health care. We need to emphasise the care as important and not building monuments to misery!

(Consumer advocate, Western Australia, West Perth Forum #28)

Culture of control, not therapeutic engagement. The WA mental health system has evolved within the treatment model, excessive use of medication and routine use of police in dealing with patients. There is room for debate on the attitudes and practices of mental health service workers and whether these social norms support punitive handling of mental health consumers.

(Health Consumers' Council WA, Western Australia, Submission #29)

6.5.9.7 Funding model needs to change

Associated with the complaints of lack of available resources to deliver quality mental health services, are requests and demands that the funding model needs to change in order that appropriate services are delivered and the rights of people with mental illness protected. Funding issues were raised both within the health budget and also as a whole of government package in the provision of support services for people with mental illness and their families.

> *"Western Australia spends about 7.5% of its health budget on mental health, although mental illness is thought to account for at least 20% of the economic costs of and premature deaths. Other first world countries invest 10-14% of their total health expenditure on mental health services." (WA Association for Mental Health, 2003). The Mental Health Carers Issues Network has concerns that ad-hoc funding commitments only address specific unmet needs areas in the short term and don't address systemic problems in mental health services and areas of unmet need in the long term.*
>
> (Carers WA, Western Australia, Submission #277)

> *While the immediate crisis may be alleviated by an injection of funds, a long term vision is required for mental health care in WA supported by a commitment and funding by government for future mental health care of Western Australians. In addition, clear accountability processes need to be put in place to ensure funding provided by the Commonwealth Government to the State Government for mental health programs is not redirected towards other general health areas and hospitals.*
>
> (Carers WA, Western Australia, Submission #277)

> *More money into mental health services will not make the difference without some changes to the fundamental assumptions that direct the current treatment paradigm.*
>
> (Health Consumers' Council WA, Western Australia, Submission #29)

> *If the metro is $118 and Geraldton is $70 per capita, I would think that Dongara would be about $1.50 per capita…There is a lack of support for carers and acute clients.*
>
> (Anonymous, Western Australia, Geraldton Forum #108)

6.5.9.8 Lack of funding to NGOs

Concerns were also expressed about the insufficient level of funding diverted to the NGO sector and the manner in which funding is determined. Standard 9.15 states: 'Resources are allocated in a manner which follow the consumer and allows the MHS to respond promptly to the changing needs of the defined community'.

> *Non-government organisations which provide essential day-to-day community support to consumers and carers are not funded in any coherent manner, and were especially hard hit by the 2003 cuts.*
>
> (SANE Australia, National, Submission #302)

6.5.9.9 Impact of lack of resources on staff and recruitment and retention

Lack of resources, high demand and overstretched staff is also seen to be contributing to high staff turnover, recruitment problems, low morale and impacting on attitudes and behaviour of staff. All of these factors impact on the ability of the MHS to deliver 'a range of high quality mental health treatment and support services (Standard 11.4) and protect the rights of people with mental illness and mental health problems'.

> *Junior nurses and doctors are discouraged from pursuing careers in mental health due to the disgraceful working conditions that staff are forced to endure. This only compounds the problems of staff shortages.*
>
> (Clinician, Western Australia, Submission #4)

I confirm that there are continuing difficulties with the medical staffing of the Acute Psychiatric Unit (APU) at the Bunbury Regional Hospital...(extract from a letter to the Office of the Chief Psychiatrist)

(Clinician, Western Australia, Submission #24)

[Z], the other psychiatrist also contributing to the current roster, is reluctant to continue feeling that the role is not well supported and lacks parity with metropolitan arrangements. (extract from a letter to the Office of the Chief Psychiatrist)

(Clinician, Western Australia, Submission #24)

The South West Area Mental Health Service is also struggling with a number of other issues that relate rather more to resource allocation. Considerable population growth…Staffing levels, however, have not changed a great deal over the last two or three years. In addition, there appears to be substantial change in regard to both the numbers of presentations and level of acuity of same...It is also probable that there are changes in morbidity patterns as well – for example, drug related disorders. (extract from a letter to the Office of the Chief Psychiatrist)

(Clinician, Western Australia, Submission #24)

Junior medical staff are voting with their feet, we've seen a dramatic reduction in the number of applicants psychiatry training. Also an increased drop-out rate once in and a massive shift towards immediate private practice post Fellowship…

(Consumer Advocate, Western Australia, Submission #338)

6.5.9.10 Staff training and development needed

Standard 9.17 states that the MHS 'regularly identifies training and development needs of its staff' and Standard 9.18 states that the 'MHS ensures that staff participate in education and professional development programs'.

Concerns were expressed indicating a need for training and development to inform clinicians about the rights of patients and support services to assist consumers. Evidence was also presented that staff are in need of disability awareness and cultural competency training in order to change their attitudes and behaviours (decrease discrimination) when dealing with people with a mental illness and people with a mental illness from a non-English speaking background:

In Dongara the health service has just one nurse on at night. The question was asked if the nurses could have more training in mental health. It has been suggested but nothing is happening. If they have a problem with a mental health patient they are lucky to be able to call on an aged carer to help. My understanding is that there are people willing to undertake this training but nothing is happening.

(Mental health worker, Western Australia, Geraldton Forum #56)

Attitudes and work practices of managers and clinical nursing staff that perpetuate the culture of stigmatisation towards innovative staff within the NPDU [Nursing Practice Development Unit] by: Other staff, not involved in the changes, making devaluing and degrading comments both verbal and written to staff who were attempting to make changes in the NPDU. (Excerpt from: Shanley (2001), Management of change in a psychiatric hospital using a 'bottom up' approach)

(Eamon Shanley, Professor of Mental Health Nursing, Australia, Submission #33)

But we are told by many practitioners that they don't work with interpreters so they can't access adequate care.

(Manager of mental health access service for refugees, Western Australia, West Perth Forum #36)

6.5.9.11 Need for more graduate programs and supervision for mental health nurses

Concern was expressed that many mental health nurses are not receiving supervision and that this could also be contributing to the difficulty in recruiting and retaining staff in mental health services. An inability to attract and retain staff contributes to problems of continuity of care with clients. Standard 9.20 states 'The MHS ensures that staff have access to formal and informal supervision' and 'the MHS has a system for supporting staff during and after critical incidents' (Standard 9.21). However, the evidence paints a different picture:

> *Despite the fact that mental health nurses are involved in a high level of intensive interaction with disturbed patients over prolonged periods of time no formal clinical supervision system is in place in WA. Clinical supervision would support them in coping with the demands placed on them and minimise the risk of burnout. Other groups such as psychologists, social workers and psychiatrists consider supervision as a crucial aspect in their professional development and support. (Excerpt from: Shanley (2001), Management of change in a psychiatric hospital using a 'bottom up' approach*
>
> *(Eamon Shanley, Professor of Mental Health Nursing, Australia, Submission #33)*

> *The difficulty with the recruitment and retention of nurses working in the mental health field lies not with nurse education but with the inadequacy of support that is able to be provided for beginning practitioners after their graduation. The Health Department needs to provide funding for the inclusion of mental health nursing in graduate programs so that experienced nurses have the time to mentor the beginning practitioner. At present there is not program available in community mental health to nurture new graduates so that they have the opportunity to become experienced mental health nurses. In Geraldton, where both enrolled and registered nursing education takes place, some students from every enrolled nursing and registered nursing courses want to work in mental health but do not get the opportunity to join the mental health workforce because no graduate program in this area is funded. If Geraldton graduates want to work in mental health, they have to move to Perth to take part in the graduate program at Graylands Hospital. In addition, there are no positions for enrolled nurses in community mental health.*
>
> *(Nursing Lecturer, Central West TAFE, Geraldton, Western Australia, Submission #222)*

> *I work at TAFE. There is a shortage of mental health nurses. In every class that I have, some want to do mental health but are unable to get jobs in Geraldton. The time taken for training means mental health nurses are unable to get support because of pressure of work. They need support.*
>
> *(TAFE Worker, Western Australia, Geraldton Forum #68)*

6.5.9.12 Problems with accountability

Failure to ensure accountability jeopardises the protection of rights of people with mental illness and practices to ensure delivery of quality care. Standard 9.2 states: 'There is single point accountability for the MHS across all settings, programs and age groups'. Problems with accountability also impede the resolution of complaints (as discussed in Standard 1) and inhibit processes which allow for continuous quality improvement:

> *A serious concern is the failure of the hospital to provide a means of holding people accountable and responsible for the performance of others by: (a) Managers and the CNS failing to monitor and exercise control in maintaining the operation of initiatives agreed upon, on the ward…(b) Senior nurses not being held accountable for decisions they had agreed to implement…Concern – Managers and the senior nurses in the NPDU [Nursing Practice Development Unit] showed poor management skills in the areas of accountability, responsibility and leadership.*(Excerpt from: Shanley (2001), Management of change in a psychiatric hospital using a 'bottom up' approach)
>
> (Eamon Shanley, Professor of Mental Health Nursing, Australia, Submission #33)

The prevailing culture of the hospital meant that staff, who reported unacceptable behaviours displayed by other staff on the NPDU, were unsupported and frequently ostracised…One nurse was told by another nurse that she was wrong to report a staff member found to be abusive to a patient. The way of the hospital was to stick together (mateship) and not to "rock the boat"…The current system of complaints procedure should be changed to allow greater flexibility in reporting. (In some incidents members of staff feared repercussions in approaching the direct line manager). The system should also ensure a greater degree of confidentiality that would minimise the practice of junior nurse managers discussing with ward staff the subject of the complaints. The process and outcome of each complaint should be reviewed using an independent system within a specified timeframe. (Excerpt from: Shanley (2001), Management of change in a psychiatric hospital using a 'bottom up' approach)

(Eamon Shanley, Professor of Mental Health Nursing, Australia, Submission #33)

6.5.9.13 Private versus public mental health services

The following presentation made at the forum held in Geraldton is an alarming reflection of a consumers' experience of both public and private care today in WA suggesting that the only way to access quality care is to have the resources to purchase it in the private sector.

I attempted suicide – I owe my life to the clinical psychologist that attended to me. I pleaded with my wife not to send me to Graylands where they wanted to send me. I was fortunate I had health cover, I was diagnosed with Bipolar. The last five months I spent two lots of one month in the Perth Clinic. I was lucky enough to be able to afford to do this…The clinic here saved my life.

(Consumer, Western Australia, Geraldton Forum #61)

6.5.10 STANDARD 10: DOCUMENTATION

Clinical activities and service development activities are documented to assist in the delivery of care and in the management of services.

Under this Standard, submissions and presentations indicate concerns about:

- the lack of coordinated, comprehensive and accessible documentation systems; and
- the system does not allow continuity of care across settings.

6.5.10.1 Lack of coordinated, comprehensive and accessible documentation system

Standard 10.5 states: 'Documentation is a comprehensive, factual and sequential record of the consumer's condition and the treatment and support offered'. Varied problems however were reported with documentation systems ranging from problems with the amount of time required to complete paperwork, incomplete record keeping, failure of systems to retrieve records quickly enough and lack of continuity of care across settings. Reports received through the forums and submissions indicate that these problems complicated the delivery of appropriate and timely treatment and support and potentially compromised the safety of consumers:

There are now so many extra forms that the clinical have to spend most of their time with administration instead of their counselling job.

(Consumer, Western Australia, Geraldton Forum #61)

Several months following the creation of the Coordination Committee there was an audit of the activities of the ward by a senior nurse manager and the professor of mental health nursing. It found that although some of the changes introduced have been maintained a number had been modified or abandoned… Hand-over sheets, information sheets to patients, allocation files, medication sheets, information boards were rarely used and not fully replenished or when used were not completed systematically or consistently. (Excerpt from: Shanley (2001), Management of change in a psychiatric hospital using a 'bottom up' approach)

(Eamon Shanley, Professor of Mental Health Nursing, Australia, Submission #33)

The Community Mental Health Team from the Perth Hospital provides support to the Hostel with clinical services but each nurse's workload is considerable and if a person is unwell they are often not able to get them an inpatient bed. Nurses refill dossett boxes and mange medications but are reluctant to write in residents files when they visit or medicate residents. This puts residents at risk because St Bartholomew's House staff do not know what is going on if a resident has an adverse reaction to a treatment or whether he has had his regularly injection. All care plans are kept in the hospital.

(St Bartholomew's House Inc, Western Australia, Submission #37)

There may be a problem with the fund shifting from State to Commonwealth governments and the way prescriptions are handled. A couple of weeks ago I went to the hospital for medication. I was put on a chair and I had to spend 1½ hrs lying on the floor as I fell off the chair because I felt very dizzy.

(Consumer, Western Australia, Geraldton Forum #79)

I have a friend in trouble who threatened to kill her daughter. I phoned SouthWest 24 and they told me to phone the police… she was taken away. The following day a nurse from the service phoned me and asked me where the woman was – she was in hospital! The nurse didn't even know she was in hospital – there's no coordination! My friend wasn't under a section but she was in hospital…

(Friend, Western Australia, Bunbury Forum #3)

6.5.10.2 System does not allow continuity of care across settings

Reports that systems were not allowing for documentation to be accessed across settings indicate a serious impediment to accessing urgently required care. Standard 10.4 states 'A system exists by which the MHS uses the individual clinical record to promote continuity of care across settings, programs and time'. In many instances, consumers and carers spoke of documentation systems which had been working to provide care across settings, programs and time, suddenly being changed or stopped without adequate explanation or alternative arrangements being implemented:

My brother has done the hospital shopping in Perth looking for help. What this means is that his current case notes are not available, the person (Me) who supports and follows his medical care and history, has been until now unable to speak with doctors to share valuable, timesaving, costsaving information that would support my brother more effectively with his care.

(Carer, Sister, Western Australia, Submission #101)

There have been problems with the hospital since the changes six months ago. Before my doctor had a chart with my details at the hospital and I could obtain the medication when I needed it without waiting, it was OK. Now that has been abolished and because there are different doctors each time, it takes five or six hours for me to tell everything again before I can get my medication. In this time my condition is getting worse.

(Consumer, Western Australia, Geraldton Forum #79)

Also my doctor writes a letter for me when I go on holidays to Port Hedland I present the letter to the hospitals along the way if I am in need of medication and they supply it. I asked my doctor to do the same for me for here – when I presented the letter it was just ripped up. They just don't want to know.

(Consumer, Western Australia, Geraldton Forum #79)

My son who is 42 suffers from a mental disorder and has had several episodes over the past 25 years. He is presently living in his own house, on my property and has done so for several years. For some time now he has been treated for his condition by injection at home. On Thursday, August 19, 2004 he commented that he thought he felt another episode coming on. My wife then contacted the local mental health office and was advised that it was no longer possible to treat our son as in the past and that we would have to see Dr [Y]. An appointment was made for August 27 2004. We attended this appointment and were told no treatment would be administered until our son was assessed. This we were told might result in our son being placed on community order and admitted to hospital - presumably Graylands.

(Carer, Father, Western Australia, Submission #175)

6.5.11 STANDARD 11: DELIVERY OF CARE

Principles guiding the delivery of care: The care, treatment and support delivered by the mental health service is guided by: choice; social, cultural and developmental context; continuous and coordinated care; comprehensive care; individual care; least restriction.

In summary I have no confidence in Mirrabooka MHS to deliver a timely, quality and responsive service. It's service is simply substandard – patients are treated like 'just another problem' to be solved and got rid of as soon as possible.

(Carer, Husband, Western Australia, Submission #146)

Evidence presented indicates that the mental health system in WA is failing to deliver care according to the six principles of care: (1) choice; (2) social, cultural and developmental context; (3) continuous and coordinated care; (4) comprehensive care; (5) individual care; and (6) least restriction. This is supported by reports of lack of access to any care (and therefore no choice), lack of service for youth, the elderly, people from a NESB and Indigenous people; lack of continuous and coordinated care (again, due to problems of services, limited resources and crisis response-driven access); lack of comprehensive care (due to an inability for consumers to access services during the onset phase, lack of access to rehabilitation services, and an overall inability to access mental health services); lack of individual care (for the reasons just mentioned); and as there are reports of a focus on containment and control, this indicates that treatment and support is not the least restrictive:

Trying to help people seek help - what will they get?

(GP, Western Australia, Geraldton Forum #62)

Closure of South West Community Mental Health facilities to the public due to the unsafe condition of the building. This closure has prevented [X] from obtaining adequate and confidential assistance and treatment locally.

(Carers, Western Australia, Submission #177)

Culture of custody and control which is prevalent in WA. Part of the culture of control is the resistance to addressing a person – civil liberties.

(Consumer Advocate, Western Australia, West Perth Forum #36B)

I had an incident a while ago when I went to hospital in Bunbury, I was put aside (waited) a couple of hours – I wanted to go home but the hospital wouldn't let me go. I finally went home and a few hours later the police came to take me back to the hospital. I went willingly and saw the doctor who said I needed an injection. I was threatened that the police would hold me down while I had the injection so I agreed to have it. After they injected me I was taken to Graylands Hospital in Perth but nobody informed my family of my admission to Graylands.

(Consumer, Western Australia, Bunbury Forum #1)

6.5.11.1 Access

The MHS is accessible to the defined community.

Under this Standard, submissions and presentations indicate concerns about:

- an inability to access services when needed;
- police response is the only response – police are the de facto mental health service;
- lack of access to care - "right to get care, not be arrested";
- access denied due to past forensic status;
- access denied due to history of sexual abuse;
- no access to any MHS - regional location;
- lack of access to care – regional area – transportation issues;
- phone service is the only contact with MHS service;
- access denied for consumers with intellectual disability;
- lack of access to treatment and support services for people with Personality Disorders; and
- difficulty accessing psychiatrists and psychologists.

Concerns were expressed across Western Australia that mental health services are not available on a 24 hour basis, seven days per week (Standard 11.1.4). Consumers and carers repeatedly reported examples of failure to gain access throughout the course of their illness or even when in extreme crisis.

An inability to access services was the catalyst for potentially infringing a whole series of other rights for consumers, carers and the community. For the consumer, the infringement of these rights resulted in increasing disability and hence consequent inability to participate socially or work and study, and in some cases, the potential for harm to self or others, or becoming homeless or poor. For children and youth, failure to gain access at this time of their life placed their future life course at risk.

Similarly, increased burdens on carers as the mental health of consumers deteriorated resulted in carers being unable to participate socially and work. Family isolation and increasing instability were also frequently reported due to lack of community support and acceptance (high levels of stigma and discrimination). For the community, rights to safety were potentially infringed upon and social and economic cohesion disrupted.

6.5.11.1.1 Can't access services when needed

> *I ask the following questions: If a patient develops an acute abdomen and possibly has appendicitis the patient can be transported to an [sic] hospital emergency department. There is no requirement to establish that a bed is available. If a patient develops severe chest pain and may be experiencing a heart attack, again, the patient is transported to an [sic] hospital emergency department for further assessment and treatment. It is not necessary to establish the availability of a bed. Why is it that acutely unwell psychiatric patients in emergency situations are treated differently? How does this reflect equity of access to high standard clinical care? (extract from a letter to the Director of Community Mental Health Programme)*
>
> (Clinician, Western Australia, Submission #24)

A constant theme throughout many submissions was not only an inability to access services when needed, but that access was also difficult even when consumers are at risk of self harm or harm to others:

National Mental Health Plan 2003-2008…Page 20 – "Outcome 8: Improved access to acute care". Well, it couldn't get any worse from here if treating psychiatrists are 'too busy' to see suicidal patients!

(Carer Advocate, Western Australia, Submission #339)

I make the following observations: Had an emergency bed been readily available then the Mental Health Act could have been rapidly implemented with the support of the Police, this would have prevented the escalation of a difficult clinical situation. It would have minimised risk to all concerned. A much better quality of clinical care would have been provided to the patient in line with psychiatric best practice…(extract from a letter to the Director of Community Mental Health Programme)

(Clinician, Western Australia, Submission #24)

Why on earth are consumers who are exhibiting signs of a relapse not taken seriously? Why is it that the consumer needs to be either psychotic, suicidal, or in some other emergency before they are seen and treated? (author's emphasis)

(Carer, Husband, Western Australia, Submission #146)

They must be [an] emergency to be admitted, if not the already overburdened and underfunded/resourced community teams have to try and maintain them, but in reality it is more likely to be the family / carer and the GP. There is no room for innovation, just relentless grind: the culture of therapeutic nihilism is now deeply ingrained. Staff fight with staff, barriers to service access are getting higher and higher.

(Consumer Advocate, Western Australia, Submission #338)

The psychiatric nurse agreed with my wife that she required urgent treatment and assessment – the psychiatric nurse went in to personally ask Dr [psychiatrist] if he could see her. He refused to do so! I find this outrageous. We ended up in [Z] ED [Emergency Department] yet again…

(Carer, Husband, Western Australia, Submission #146)

Carers report that the current funding and provision of mental health care in WA is clearly inadequate to meet the level of need. This is demonstrated by: People unable to access community mental health services unless they are in crisis and are a threat to themselves or others.

(Carers WA, Western Australia, Submission #277)

This leaves us as carers and in the worse case scenario, the general public at large, in a very vulnerable position. We no longer have any faith that the PET team will respond as we have rung many times, over the years but they cannot attend so we don't bother to ring them anymore.

(Carer, Mother, Western Australia, Submission #13)

…recently informed of the changes to the…South West Mental Health Services procedure for referral of a consumer presenting unwell…staff are to advise the person for whom they are concerned to either seek consultation with their GP or go direct to the local hospital where their details will be passed on to the SWMHS who in turn will forward these details to the South West 24 telephone service which is now the single point of entry for all consumers and Carers. Once these details have been received by the South West 24 worker they will contact the consumer by telephone and then they will triage them at this time. One concern is the probability of the client not having a contact number or home phone or even a home. If contact can be made the South West 24 worker will decide who the person should be referred to this may well be their GP who referred them in the first place or the South West Mental Health Services in their area. After this referral has taken place an appointment will be made with the nominated service…this process appears to be lengthy and could take several days for a potentially unwell client to be "seen" by a clinician. A concern for this organisation is the welfare of the client and the possible difficulties they experience during this referral period.

(NGO Service Provider, Western Australia, Submission #45)

Women who are deemed to be an extremely high risk are referred to the Forensic Community Mental Health Service. One case I can cite will demonstrate the extreme difficulties and deficiencies in service delivery in this area. The woman I am referring to has been assessed as an extremely high risk of suicide, and of re-offending. Her offending behaviour is of a nature that constitutes an extremely high risk of harm to others. The Forensic Mental Health Service repeatedly warned me what a high risk this woman is. However, every time I called them in a crisis, there seemed to be some reason (usually lack of available staff) why they could not respond. The case manager actually said to me on several occasions that they just do not have the resources to respond to crises, and that they are not an emergency service. I would be left to negotiate with an extremely unwell and potentially dangerous person, to accompany me to A&E [Accident and Emergency] (and wait 5-6 hours) to undergo an emergency psychiatric assessment. With no statutory power, there was nothing I could do if she refused to come. The Forensic Team eventually transferred this client to a different team, on the basis that they were not adequately resourced to respond to this client's level of need. I have grave doubts about any community forensic mental health team (or any community mental health team for that matter!) that says they are not a crisis service.

(Social Worker, Western Australia, Submission #15)

Issues of Bunbury Mental Health Services:

- *It is reported that there is no clear policy on how to prioritise who is seen and who is not seen, currently emergency referrals are the only ones being responded to. Individuals and other agencies are describing extreme difficulty in successfully referring new patients.*

(Advocate, Western Australia, Submission #2)

…shortage of beds. When a patient is on a Community Treatment Order which has to be revoked because the patient has become unwell and in the absence of any intermediary facility requires hospitalisation. There is again often no bed available for them…

(Carer Advocate, Western Australia, Submission #339)

Involuntary patients continue to be transferred to Perth, sometimes despite attending as a voluntary patient. There is some suggestion of a black list of people who will always be refused entry to Bunbury Hospital. If this is case, should there not be a process of appeal against what may in fact be nothing more than a punitive measure.

(Advocate, Western Australia, Submission #2)

6.5.11.1.2 Police response is the only response – police are the de facto mental health service

Due to the inability of consumers and carers to access mental health services during times of crisis, police were called as a last resort as they were available to respond 24 hours a day 7 days a week. However, the mental health service is also meant to be available and provide crisis intervention services on a 24 hour basis, 7 days per week (Standard 11.1.4). Included in the notes to this Standard are crisis teams, extended hours teams and 'cooperative arrangements with other appropriately skilled service providers and community agencies including General Practitioners, private psychiatrists, general hospitals'. The following comments indicate that this level of support is not currently available as the mental health service is directing people to call the police:

As a carer of a daughter with a mental illness my husband and I were forced to call police for help because we couldn't get any other response. The police were wonderful but after an 8 hour wait to be assessed the local hospital said they couldn't deal with her and she was sent to Perth to a secure ward. She was very quickly discharged and now we are dealing with the same situation again. Where do we go for help when there is no help?

(Carer, Western Australia, Bunbury Forum #10)

I have a friend in trouble who threatened to kill her daughter. I phoned SouthWest 24 and they told me to phone the police. The police were fantastic…

(Friend, Western Australia, Bunbury Forum #3)

(In response to the questions, "How do the Police behave? Are they adequately trained? Do they know what they are doing?") …Yes but they don't always give it a high priority therefore things can get out of hand in the time it takes for them to respond. They are sometime short staffed. We need to have more trained people on the ground.

(Carer, Family member, Western Australia, Geraldton Forum #51)

Carers in some of these remote rural areas have reported having a crisis at midnight on a Friday. When attempting to contact SW24 they have told me the service has advised them that their problem will be forwarded to the clinicians who they know will not be in the office until the following Tuesday. When they explain this they are often asked to take the person they are concerned about to the nearest health facility which will handle psychiatric emergencies…Should this not be possible their alternative is to contact the local police, who are for most at least fifty kilometres away and usually only have one officer on duty, who then has to choose between leaving a town with out a service for what may turn out to be a ten hour round trip to Perth or advise the family they can not attend and this leaves them to fend for themselves.

(NGO Service Provider, Western Australia, Submission #45)

6.5.11.1.3 Lack of access to care - "right to get care, not be arrested"

An inability to access services when needed in some instances resulted in consumers entering the criminal justice system as a result of their deteriorating and untreated mental illness. The failure of services to respond and intervene in these instances also had the regrettable outcome of the right to safety of the community being infringed and in the extreme case, death of a person:

My brother suffers from bipolar disorder and my mother and I came here for him for 23 years. But I would like to comment on the fact that people with a mental illness are being arrested because often it's the only way they can get any help. They have a right to get care, not be arrested. We've got to get access to early intervention programs but it doesn't happen – now my brother is in the court system, not because he's bad but because he's got a mental illness.

(Carer, Sister, Western Australia, Bunbury Forum #24)

My brother also has an intellectual disability as well as bipolar disorder… Yes my brother has been convicted of crimes. I have had to represent him in court. He would never have ended up in those terrible predicaments if he had adequate facilities and care to live independently within the community.

(Carer, Sister, Western Australia, Submission #101)

He was charged with wilful murder in Nov 2000. He is now in prison facing a 20 year prison sentence. In 1999…[h]e was delusional and needed help. I spent four days ringing the crisis centre in Maylands Mental Health (PET) regularly and each time had to tell the full story - they wouldn't listen to me and wouldn't do anything. I rang the police nothing was done. They wouldn't do anything. After three and a half years in Graylands he is now better than he has ever been. He is now in Hakea prison. The help I got was none. For a dangerous situation there was no help available for me or my son.

(Carer, Father, Western Australia, Geraldton Forum #49)

6.5.11.1.4 Access denied due to past forensic status

Reports were also received that consumers were discriminated against on the basis of past forensic status. According to Standard 11.1.1 such discrimination by the MHS is not to occur and such consumers are not to be diverted to other services. The Standard states that the MHS ensures equality in the delivery of treatment and support regardless of past forensic status. However, this was not the case for some people:

> *I understand that an application of referral to the South Guilford Centre for rehabilitation has been declined due to his conviction…My brother is both Bipolar and has an intellectual disability. I believe his convictions are a direct result of the lack of available services to him whilst he tries to live independently in the community. Up until now we have always had to jump hurdles in order that the Mental Health Services and Disability Services work together as a team…The very idea that my brother has been refused admission to attend the South Guilford Centre for rehabilitation is discriminatory to say the least. What is the purpose of rehabilitation I believe that my brother presents a low risk to this group and deserves the chance to be considered on his merits not on what he has been convicted of…I believe there is a forensic rehabilitation centre that my brother is considered to be "not criminal enough" to be referred there. It seems to me that once again no-one wants to help my brother as he does not fit the criteria for either centres? Surely he deserves the chance to have some rehabilitation? Or should he be left in limbo with out the resources to rehabilitate himself? I believe in timely intervention and prevention, rather than addressing the situation when things have gone horribly wrong… This group would surely be able to help him live it a little better by developing his skills through a well thought our rehabilitation programme that is ongoing.*
>
> (Carer, Sister, Western Australia, Submission #101)

6.5.11.1.5 Access denied due to history of sexual abuse

One submission detailed discrimination on basis of past sexual abuse and was denied 'equality in the delivery of treatment and support' (Standard 11.1.1):

> *…accessed the Mental Health Services for about three sessions. This was long enough for her to engage with the worker and to feel as though she would be getting a service. However, as soon as she mentioned a past history of sexual abuse she was referred to SARC [Sexual Assault Resource Centre]...I also feel that Mental Health issues and sexual abuse issues often overlap and that the clients should be told they have a choice about which service they access. In this case she was denied further access to Mental Health services.*
>
> (Clinician, Western Australia, Submission #333)

6.5.11.1.6 No access to any MHS - regional location

> *In Esperance we have had no psychiatrist for five months. If consumers need acute care they have to be taken to a GP and then tranquilised and strapped to stretcher to be transported to Perth.*
>
> (Consumer, Western Australia, West Perth Forum #45)

For Western Australia, the vast geographical area poses serious challenges to the planning and delivery of services that are convenient and local and linked to the consumer's nominated primary care provider (Standards 11.1.3) and where effective and equitable access to services is ensured for each person in the defined community (Standard 11.1.5). However, submissions repeatedly reported cuts to services which were already operating at minimal levels in various areas rather than service enhancement.

Lack of access to services appears to leave consumers and carers with no choices but to allow the illness to deteriorate, or for the consumer to be transported while sedated or with armed escort to an appropriate service. Such options placed great burdens on both consumers and carers as often, services are a great distance from the consumer's home.

This generally means that a crisis has to eventuate before services can be accessed and the consumer requires hospitalisation, due to the shortage of acute care beds in WA. The bed shortage also generally results in the consumer being discharged early. For consumers in rural and regional areas in particular, problems with follow-up and support then ensue. In the event of a need for readmission, this is at enormous cost to both consumers and carers, and ultimately on health resources:

> *Consumers are driven in the back of paddy wagons – three day trips – from Kununurra to Perth. The artificial geographic boundaries create huge problems for people needing care.*
>
> (Carer, Western Australia, West Perth Forum #43)

> *How much does it cost to transport a patient by Ambulance to Perth? There are no doctors available here in Bunbury on nights or weekends so they send us to Perth! What have we got for a mental health system? Nothing, absolutely nothing!*
>
> (Consumer, Western Australia, Bunbury Forum #1)

> *There is a perception in the community and by the community mental health team that patients from the South West are discharged prematurely and without follow-up being arranged.*
>
> (Nurse, Western Australia, Submission #55)

> *Only recently in July, Carers at a Carer Advocacy & Issues Forum in Bunbury met and expressed their frustration regarding the sudden closure of mental health services in their community. Specific concerns regarding the closure of services include: Issues surrounding the transfer of patients to Perth including financial costs to carers for transport, accommodation and lost income.*
>
> (Carers WA, Western Australia, Submission #277)

> *There is a concern that many parents in the South West of WA are placed under more pressure (financial and logistical) because there are no specialists in this area to assist children who are diagnosed with ADD/ADHD and they need to travel to Perth.*
>
> (Anonymous, Western Australia, Submission #145)

> *National Mental Health Plan 2003-2008… Page 10 – "All people in need of mental health care should have access to timely and effective services, irrespective of where they live". This is not even a reality for people living in Perth – god knows what it is like in rural areas…*
>
> (Carer Advocate, Western Australia, Submission #339)

> *Surely it would be better to keep mental health people here in this town where they are close to their family and support. This doesn't happen because there is not the facility for their care therefore they are sectioned and sent off.*
>
> (Anonymous, Western Australia, Geraldton Forum #96)

6.5.11.1.7 Lack of access to care – regional area – transportation issues

As mentioned above, when there are no services in an area to access, consumers either have to organise their own care, or in the event of a crisis or large distances, they must be transported. Often this required the involvement of police or the Royal Flying Doctor Service and the requirement for chemical and/or mechanical restraint. Such restraint was in particular seen as excessive by one general practitioner and both potentially a health risk for consumers, and a violation of a person's dignity and right to freedom.

There are many ways in which the consumer's rights were violated when care was not readily available. Problems with the current telephone access plan, common across Western Australia, are illustrated in the following quotes:

There is an agreement between the police and the local mental health service. If patients are sectioned under the Mental Health Act the police are not allowed to transport more than 250 kilometres. Therefore the only option here is to take patients to Perth by the Royal Flying Doctor Service, the result being that the patient has to be extremely sedated. There is a need for them to be sedated to stop them from doing harm to themselves or others. I don't have a problem with that – but what I can't cope with is when I am asked to give a higher level of medication in order to transport this patient by air…Why should I or other doctors – contractually obligated to give people this medication – be required to over sedate patients just for convenience of transport?

(GP, Western Australia, Geraldton Forum #53)

I can support what the police office said earlier about people who have been transported by the police to Graylands hospital often beating the police back to Bunbury!

(Carer, Mother, Western Australia, Bunbury Forum #22)

…We were then told our son wasn't welcome to stay here in Bunbury hospital because of a previous experience they had with him. I told them I would take him to Graylands in my own car but I just needed to go home and get some things first. But then they sedated him even though I told them I would transport him to Graylands…20 hours later after being in a drug induced state in Graylands he was discharged, the next morning, without any explanation to him or to us.

(Carer, Mother, Western Australia, Bunbury Forum #22)

6.5.11.1.8 Phone service is the only contact with MHS service

Many problems have been encountered with this service. The absence of other supporting services left consumers and carers feeling helpless and without any access to any real mental health service.

When we talk about the South West 24 emergency telephone services and how it has now become the single point of entry for those seeking clinical assistance by the South West Mental Health Services I would like to point out for those living in rural areas there is often no landline telephone connections and mobile phones simply will not work. Further this service is for those in the South West and does not cover carers or consumers living in the Lower Great Southern, therefore for many there is no access to this service or anything similar.

(NGO Service Provider, Western Australia, Submission #45)

Carers in some of these remote rural areas have reported having a crisis at midnight on a Friday. When attempting to contact SW24 they have told me the service has advised them that their problem will be forwarded to the clinicians who they know will not be in the office until the following Tuesday. When they explain this they are often asked to take the person they are concerned about to the nearest health facility which will handle psychiatric emergencies. Again for many this may be Bunbury which is located over two hundred kilometres away, further should they be able to get to Bunbury they are often told they can not be seen and are sent onto Perth a further two hundred and forty kilometres. Should this not be possible their alternative is to contact the local police, who are for most at least fifty kilometres away and usually only have one officer on duty, who then has to choose between leaving a town with out a service for what may turn out to be a ten hour round trip to Perth or advise the family they can not attend and this leaves them to fend for themselves. Although on the surface a 24 hour call services appears to be an effective means of offering support to people it is in fact only able to offer information which in most cases the person is already aware of, but it has very limited if not non existent ability to offer "hands on" or "face to face" practical assistance.

(NGO Service Provider, Western Australia, Submission #45)

I want to comment on SouthWest 24 (helpline) – I am a parent carer of a child with a mental illness. For people like me in Bunbury, SouthWest 24 is now our only form of contact with a mental health service unless we take our kids to the emergency department. SouthWest24 is now acting as a triage. We need to be able to access direct mental health care in our community.

(Carer, Parent, Western Australia, Bunbury Forum #5)

South West 24 was often mentioned at the conference. In my opinion this could be a valuable service if it was being used to facilitate an already functional service. This service is attracting a lot of funding approx. $450,000 in the first 8 months, and the core services of mental health providing face-to-face service is being neglected. It further over-burdens the emergency department as it often refers clients to that department and there are little or no mental health services provided there.

(Nurse, Western Australia, Submission #55)

I have also used the Rural link number a number of times after hours and have found the immediate follow up op be excellent. I have also found, however, that the Child and Adolescent Mental Health Service in Geraldton has not been in a position to provide the appropriate follow up and support.

(Clinician, Western Australia, Submission #333)

Issues of Bunbury Mental Health Services:

- *Clinicians who are not currently engaging with their patients are in some cases telling patients to phone if they require support. This is clearly not acceptable, one patient described this a being "effectively told to piss off", there is also the issue that clinicians can only be reached on one phone number and assuming that one is well enough to phone one soon would have one's staying power tested when trying to make contact using the single line that is available. This line is often diverted to South West 24 call centre.*
- *South West 24 continues to be an issue from various points including the inappropriateness of response, being unavailable and having calls queued up, on one occasion a consumer was told that the answering service was off-shore and they could not help.*
- *Another problem is there is no external review process of the service provided by SW24. This seems strange for an allegedly pilot program.*

(Advocate, Western Australia, Submission #2)

…Southwest 24 is a service contracted to [Z] and the call centre is in Perth. I have been told that the overflow calls go to Sydney. Some people report good experiences with this service, and some report being unable to access it. The 1800 number is not free to many consumers and this also causes problems.

(Anonymous, Western Australia, Submission #22)

6.5.11.1.9 Access denied for people with dual diagnosis – mental illness and intellectual disability

Standard 11.1.1 states: 'The MHS ensures equality in the delivery of treatment and support regardless of consumer's age…physical or other disability' and Standard 1.1.5 states 'the MHS ensures effective equitable access to services for each person in the defined community'. Included in the notes to Standard 11.1.5 is 'attention is paid to the needs of Aboriginal and Torres Strait Islander and non-English speaking backgrounds as well as…disability'. However, reports made at the Bunbury forum indicate that access to mental health services is being denied on the basis of intellectual disability:

I'm a paid carer for people with an intellectual disability. These people are denied access to the mental health ward. Is there a policy? No, we've just been told that they should go to disability services.

(Paid Carer, Western Australia, Bunbury Forum # 2)

I just want to say that there seems to be a real gap in services for people with both mental health and intellectual disabilities.

(Anonymous, Western Australia, Bunbury Forum #4)

6.5.11.1.10 Lack of access to treatment and support services for people diagnosed with personality disorders

Concerns were raised about the lack of treatment and support services for people diagnosed with personality disorder and that problems associated with the disorder are not being recognised or acknowledged by some clinicians and services. Evidence was presented indicating that treatment programs are available in other States but not in Western Australia and that lobbying for these has not resulted in these therapies being made available. The devastating consequences of services failing to provide adequate treatment and support for people with Borderline Personality Disorders were recounted by one consumer:

Currently if a client in Parent Link presents with a personality disorder, where do you go??

(Anonymous, Western Australia, Geraldton Forum #82)

At the Department of Community Development, for many years field workers have commented that there are no links or feedback with mental health services. When they take people along with personality disorders and they say no they don't deal with them as they don't fit and we have had problems in that area, they are sent back to our workers.

(Department of Community Development worker, Western Australia, Geraldton Forum #85)

My primary concerns in relation to mental health, are the extremely high rates of incarcerated women (and men) with both diagnosed and undiagnosed mental illness, and furthermore the treatment they receive from health services whilst in prison. There are also serious issues relating to treatment post release from community mental health services… I know I do not have to outline the issues related to dual diagnosis, which this client group exemplify. Particular problems also arise for this client group when a Borderline Personality diagnosis is given, which is very often.

(Service provider, Western Australia, Submission #14)

…a woman I was trying to link into mental health services after she was released from prison. Due to her primary diagnosis of personality disorder, it was impossible to get any mental health service to accept her care, even though it was a condition of her parole that she receive psychiatric treatment. When we tried to get prison medical staff to refer her to appropriate services, and argued that she was prescribed anti- psychotic medication in prison, we received the above quoted response, that so are 95% of the women there. It is an ongoing problem that women leaving prison are not eligible for mental health services, due to a primary diagnosis of PD.

(Social Worker, Western Australia Submission #15)

6.5.11.1.11 Difficulty accessing psychiatrists and psychologists

A report was also received regarding the lack of psychiatrists and psychologists to meet the needs of consumers in rural and remote areas. Concern was expressed about the infrequency of visits by specialists and long waiting lists for appointments:

Availability of psychiatrists is a problem. I suffered from depression in February / March this year. I rang my psychiatrist's office in Perth and he wasn't coming to Geraldton before October – there would be a 3 month wait to see someone in Geraldton. I could get PATS [Patient Assisted Travel Scheme] – I was given the yellow form. I took the form to my GP who wouldn't sign the form because she said I didn't need to see the psychiatrist. So I went anyway and paid for it myself. In the mean time I was asked to have an appointment with the local psychologist in town and I am still waiting for the appointment. This happens all the time.

(Consumer, Western Australia, Geraldton Forum #66)

From time to time difficulty is experienced across the region in gaining access to tertiary level support facilities in Perth. It is appreciated that the metropolitan area is struggling with its own difficulties. However, the flow-on effects of this can be quite challenging in rural areas where resource is even more limited…

(extract from a letter to the Office of the Chief Psychiatrist) (Clinician, Western Australia, Submission #24)

6.5.11.2 Entry

The process of entry to the MHS meets the needs of the defined community and facilitates timely and ongoing assessment.

Under this Standard, submissions and presentations indicate concerns about:

- qualified mental health professionals not available to assist with entry;
- problems when phone is the only entry point to the system; and
- problems with entry via emergency departments.

6.5.11.2.1 Qualified mental health professionals not available to assist with entry

As acknowledged, the vast geographical area of Western Australia does pose challenges to the delivery of services. However, problems with access and entry when at a crisis point are further compounded when an appropriately qualified and experienced mental health professional is not 'available at all times to assist consumers to enter into mental health care' (Standard 11.2.6):

One day my son came to us for help. He said he wasn't feeling well and we tried all day to get a bed for him in the hospital here. As a last resort my lad presented himself to a GP and he was later interviewed by a person who we thought was a mental health professional and we later realised it wasn't. Then a security guard came and informed us he would be sent to Graylands Hospital in Perth. We were then told our son wasn't welcome to stay here in Bunbury hospital because of a previous experience they had with him. I told them I would take him to Graylands in my own car but I just needed to go home and get some things first. But then they sedated him even though I told them I would transport him to Graylands…20 hours later after being in a drug induced state in Graylands he was discharged (the next morning) without any explanation to him or to us.

(Carer, Mother, Western Australia, Bunbury Forum #22)

6.5.11.2.2 Problems when phone is the only entry point to the system

As indicated by one GP, when phone access became the only method to access services in regional areas, problems experienced by consumers and carers were exacerbated:

SouthWest 24 has been around for quite a while as a private company – it used to work reasonably well but the problems occurred earlier this year when it became the single point of entry into the system!

(GP, Western Australia, Bunbury Forum #19)

It appears here that Standard 11.2.3 has been misinterpreted. The Standard states that: 'The MHS can be entered at multiple sites' (e.g. on-call, intake, assessment and triage in emergency department, psychiatric unit, police service, private psychiatrist, school etc.)... 'coordinated through a single entry process'.

6.5.11.2.3 Problem with entry via emergency departments

Problems were also reported with access and entry via emergency departments described as being inappropriate due to long wait times and these areas being crowded and generally inappropriate environments for people with a mental illness:

> *I am speaking on behalf of a man who took his suicidal wife to a mental health service for care. Her assessment by the service was very poor. He felt there was a resistance from the service to treat her but I don't know why – the woman became increasingly unwell and was eventually admitted through the emergency department process, not through the mental health service. This access through emergency departments means that people are being held in situations which are completely inappropriate.*
>
> (Carer and Advocate, Western Australia, West Perth Forum #32)

> *Carers report that the current funding and provision of mental health care in WA is clearly inadequate to meet the level of need. This is demonstrated by: people presenting at hospital emergency departments requiring treatment for mental illness waiting in corridors as beds are not available in psychiatric hospitals…*
>
> (Carers WA, Western Australia, Submission #277)

6.5.11.3 Assessment and review

Consumers and their carers receive a comprehensive, timely and accurate assessment and a regular review of progress.

Under this Standard, submissions and presentations indicate concerns about:

- no notification of arrival for assessment and use of force;
- problems with staff workload and management of work; and
- concerns about the quality of the assessment and review process.

Linked with problems of access and entry and limited services are reported problems with assessment and review. Submissions detailed difficulty organising assessments, poor assessments and problems with assessment and review resulting in early discharge. The problem of early discharge from metropolitan hospitals for consumers living in rural and regional areas where follow up services and support are limited or non existent left carers feeling helpless, as described above. Further problems with regional services are reported below:

> *I am a solicitor recently come to Geraldton and I find there is a poor nexus with mental health services. Local mental health services will not supply letters to the legal system therefore people are being charged instead of treated. There was one instance where a person was heard by two JPs [Justice of the Peace] who could not order an assessment. This was referred to a Magistrate in Carnarvon. I am not aware of any assessments being brought on in Geraldton. I am concerned because it then goes through to what?*
>
> (Solicitor, Western Australia, Geraldton Forum #57)

> *Recently one of these longer-term residents became unwell. He is a very high maintenance resident who needs considerable staff time to assist him to live in the Hostel. The Hostel requested and immediate assessment of this gentleman by clinical services. He was assessed by a doctor and the Hostel was told it did*

such a good job in managing this gentleman's mental health, that there was no need for hospitalisation, just an increase in medication. At that time there were no acute beds available in any case. The man's condition deteriorated and he was threatening both staff and residents and it was finally decided, after much convincing on the part of a number of staff it would be appropriate to admit him to hospital.

(St Bartholomew's House Inc, Western Australia, Submission #37)

6.5.11.3.1 No notification of arrival for assessment and use of force

Of particular concern was a reported incident of an assessment with no notification at a consumer's place of residence with police accompaniment. From this report, it appears that many of the consumer's and his carers' rights were violated. These situations clearly perpetuate problems of stigma and discrimination based on mental illness.

…For some time now he has been treated for his condition by injection at home. On Thursday, August 19, 2004 he commented that he thought he felt another episode coming on. My wife then contacted the local mental health office and was advised that it was no longer possible to treat our son as in the past and that we would have to see Dr [Y]. An appointment was made for August 27 2004. We attended this appointment and were told no treatment would be administered until our son was assessed. This we were told might result in our son being placed on community order and admitted to hospital - presumably Graylands. Because of past experiences with Graylands our son has no intention of voluntarily returning there. My wife and I therefore felt that it would be a betrayal of his trust in us, his parents, to agree to this so we decided to seek other medical advice. Dr [Y] telephoned later that day to say that he was coming to see our son. He was advised this was not possible because our son was asleep and we did not want him disturbed. Sometime before 4pm that same afternoon Dr [Y] together with an assistant and a police vehicle carrying three police officers arrived at our son's house and forced our son, who was ill and asleep at the time, to open his door. Needless to say our son was traumatised by the event. Fortunately my wife noticed the vehicles outside our son's house and we went to investigate. By this time the vehicles were moving off but we were able to speak to the police officers who were less than co-operative and the medical staff, who did not have the common decency to inform us of the visit, told us they were within their rights and that we had no reason to be upset. My contention is that Dr [Y] was not within his rights and by his actions he has caused a mentally ill patient additional needless trauma. My wife spent several hours with my son after the visit trying to calm him down. How could we be expected to show any trust to this doctor again? Any faith in the mental health profession built slowly over the past few years has been destroyed. The actions of Dr [Y] have caused undue stress to my wife and myself.

(Carer, Father, Western Australia, Submission #175)

6.5.11.3.2 Problems with staff workload and management of work

Many submissions wished to acknowledge that failure to deliver quality treatment and support services was not a reflection on the work of individual staff but systemic issues related to workload (Standard 11.3.19), management of work and overall lack of resources that restricted the clinician's ability to deliver quality care. The following quotes highlight this issue:

What I would like to say is that actually we have extremely good mental health people who do the best they possibly can. However, they are over-managed. You ask what happens with mental psychologists however, they are over worked. [Regional Director] says that all is OK.

(GP, Western Australia, Geraldton Forum #62)

CWMH individuals do well and we have a very good psychologist but they are overwhelmed and over managed. As GPs we cannot refer to anyone but "the team" – they decide. They have one day deciding who will take which patient - i.e. they use 1/5 of their working time – it is not an efficient use of their time. I'm trying to help people seek help – what will they get?

(GP, Western Australia, Geraldton Forum #62)

…Nursing and Security Staff at the Bunbury Regional Hospital were extremely supportive and helpful during this most distressful time. These staff members should be commended for their moral and compassionate support to us, when they were clearly under a lot of strain. This, we believe, is mainly contributable by the high work loads that exist for these staff. This is yet another issue which needs to be addressed.

(Carers, Western Australia, Submission #177)

Doctors and nursing staff are struggling with ever mounting burdens of care, while working with continually decreasing resources in Graylands Hospital and the mental health clinics… Every time we speak to nursing staff when visiting our son in Graylands Hospital, the staff speak of their exhaustion and stress.

(Carers, Parents, Western Australia, Submission #76)

The medical on call roster is often left with blanks for the Consultant Psychiatrist, which is unacceptable in an authorised unit. At one time, a Consultant Psychiatrist was on the on-call roster from Perth and when required to attend the Unit for patients received on a Form 1, did not attend. The form often lapsed, the patient wasn't seen, and at times Form 1 is written over again to extend the time.

(Clinician, Western Australia, Submission #55)

6.5.11.3.3 Concerns about the quality of the assessment and review process

Concern was expressed regarding the quality of assessment procedures. Standard 11.3.1 states: 'Assessments are conducted by appropriately qualified and experienced mental health professionals' and Standard 11.3.5 states: 'The assessment process is comprehensive and, with the consumer's informed consent, includes the consumer's carers (including children), other service providers and other people nominated by the consumer'. Standard 11.3.6 further states: 'The assessment is conducted using accepted methods and tools'. Concerns were raised regarding delays in reviews required with certain medications, delays in reviews of Community Treatment Orders, non-comprehensive assessment and diagnosis procedures, concerns about the qualifications of staff conducting assessments, and consumers not being heard:

Issues of Bunbury Mental Health Services:

- *Access to psychiatrist as noted previously is limited due to limitations on rooms that can be used. It is coming to light that Clozapine reviews by psychiatrist are not happening, which according to protocol should be three monthly. The monthly medical officer reviews are continuing at this point, but the office utilised for this is under threat by the expansion of the community staff in the inpatient unit. Also monthly CTO [Community Treatment Order] reviews are not happening. This is the state of play just now however one of the psychiatrists has resigned and will leave in 3 / 4 weeks, what happens then to access to a psychiatrist?*

(Advocate, Western Australia, Submission #2)

When our son did finally get to see Dr [Z], within one hour of entering the clinic he was pronounced miraculously cured, his diagnosis was changed to a behavioural disorder, he was given a three month supply of anti psychotic medication, told to go for a C.T. [Computed Tomography] scan and advised that he would be managed by his local GP from there. This despite the fact his local GP had absolutely no experience with him. However after spending seven years dragging our son to a clinic and dealing with his frequent episodes unassisted, to be told he has no condition other than a behavioural problem, lowers the science of psychiatry into the realm of the black arts… At the time of writing this letter we have still not been able to get our son to the C.T. scan clinic he is so agitated and not well. I rang Armadale Hospital and asked them what to do (they said they would speak to Dr [Z]) this was four weeks ago no one rang back.

(Carer, Mother, Western Australia, Submission #13)

Some Emergency Department medical practitioners rely on Level 2 nursing staff for mental health and psychiatric assessments. To the best of my knowledge this is not the case for medical or surgical emergency presentations. In my opinion, credentialing may need to be reviewed in the case of any medical practitioner unable to undertake a bio-psycho-social assessment including mental state examination, risk assessment and management plan development. All of these issues, really, raise important questions in regard to strong clinical governance…

(extract from a letter to the Office of the Chief Psychiatrist) (Clinician, Western Australia, Submission #24)

Problems consumers have with the referral process to mental health services for assessment by and Authorised Mental Health Practitioner.

- *Many consumers report the experience of not being given any credibility to speak on their own behalf, having previous history given too much weight against what they may have to say on their own behalf, and inordinate weight is placed on the information provided by others relating to their situation.*
- *Another significant complaint from consumers is that of being medicated forcibly before being given an opportunity to speak on their own behalf. The agitated presentation of a person brought in for assessment can be a product of the traumatising experience of police transportation and not exclusively the manifestations of illness…*

(Health Consumers' Council WA, Western Australia, Submission #29)

[Supporting mothers with mental illness] Recommendations: use simple and non-threatening assessment tools to assist in identifying mother's parenting concerns at initial contact. Early assistance will prevent crises.

(Health Consumers' Council WA, Western Australia, Submission #29)

6.5.11.4 Treatment and support

The defined community has access to a range of high quality mental health treatment and support services.

Under this Standard, submissions and presentations indicate concerns about:

- resistance to involve consumers and carers in the planning of treatment and care;
- lack of services for people with dual diagnosis - intellectual disability;
- lack of services for consumers with dual diagnosis - drug and alcohol;
- lack of services for consumers with hearing impairment;
- no child and adolescent service to access;
- lack of treatment and support services for consumers who are elderly and homeless;
- lack of treatment and support services for consumers who are homeless;
- lack of treatment and support services for people with eating disorders;
- lack of services in rural areas;
- lack of treatment and support services for Indigenous consumers and their families living in remote communities; and
- lack of appropriate treatment and support services for consumers in the criminal justice system.

Despite the successes in making the changes outlined in the chapter on 'Changes Made' there are still unacceptable practices to be addressed. The outcomes though commendable do not represent 'best practice' or indeed in many cases even 'good practice'. (Excerpt from: Shanley (2001), Management of change in a psychiatric hospital using a 'bottom up' approach)

(Eamon Shanley, Professor of Mental Health Nursing, Australia, Submission #33)

The above statement captures the essence expressed in many submissions about the quality of treatment offered by mental health services. Indeed, the above indicates that treatment and support offered did not 'reflect best available evidence and emphasise positive outcomes for consumers' (Standard 11.4.1). The inability of consumers to access services particularly at onset of illness and during the recovery phase (Standard 11.4.4) indicates that a 'focus on positive outcomes' is not a serious aim of the WA Government:

> *There has been a reduction in inpatient beds and an increase in people living with mental illnesses being expected to live in the community with little or no support.*
>
> (St Bartholomew's House Inc, Western Australia, Submission #37)

Additionally, a lack of resources and community services often results in the requirement for hospitalisation, but a lack of hospital beds complicates access to services even at this point:

> *Another big problem is around the number of involuntary beds we have in Bunbury Hospital. Once before we had these beds, then they were "taken away", now we have them again but the number is completely inadequate to our needs in this community.*
>
> (GP, Western Australia, Bunbury Forum #19)

6.5.11.4.1 Resistance to involve consumers and carers in the planning of treatment and care

Standard 11.4.9 states: 'There is a current individual care plan for each consumer, which is constructed and regularly reviewed with the consumer and, with the consumer's informed consent, their carers and is available to them.' As the following quote suggests, with respect to the development of individual care plans, there is a significant mismatch between the rhetoric and the reality:

> *The survey showed that nursing care plans were not formulated with the patients or carers, hardly ever consulted by nurses in delivering care, seldom used in shift to shift hand over and rarely, if ever, consulted by medical staff or other disciplines (p. 16). The system is inconsistent with the National Mental Health Policy (1992) which states that consumers have a right to participate in decisions regarding their treatment, care and rehabilitation.* (Excerpt from: Shanley (2001), Management of change in a psychiatric hospital using a 'bottom up' approach)
>
> (Eamon Shanley, Professor of Mental Health Nursing, Australia, Submission #33)

Concern was also expressed that consumers, and their carers, are not involved in decisions about their treatment and care implies that some consumers are denied their right to have information provided about their illness, progress or to be involved in any treatment choices available to them:

> *Patient meetings were originally planned for and held on a weekly basis. However the schedules of the meetings became increasingly erratic. As a result of failure to hold meetings, patients were not given the opportunity to discuss issues and present their concerns to staff. Consumer representatives were also denied the opportunity of speaking directly to patients.*(Excerpt from: Shanley (2001), Management of change in a psychiatric hospital using a 'bottom up' approach)
>
> (Eamon Shanley, Professor of Mental Health Nursing, Australia, Submission #33)

Similarly for carers, involvement at this stage is critical if the best possible outcome is to be achieved for the consumer and the carer is to be empowered with knowledge to assist with the delivery of care:

My other concern is for the carers they are told not to get involved but there's no one else to get involved. If the service doesn't want to involve carers then who do they think will provide the care once someone is discharged from a hospital? Who else is there?

(GP, Western Australia, Bunbury Forum #19)

Carers WA and the Mental Health Carers Issues Network recently conducted research into the needs and issues of carers of people with mental illness… What three things would you change about mental health services? This question received the greatest response. The most important change that carers want from mental health services is respect for and involvement of carers (21%). They want more recognition of and respect for carer knowledge and their role; to be heard and be believed; psychiatrists to take more notice of their knowledge and experiences; to be involved in their family member's/friend's treatment program; a team approach to treatment; a holistic treatment program; greater respect for people with mental illness; and greater monitoring of people with mental illness. (author's emphasis) (McKeague B, 2003. Worried, Tired & Alone – A report of Mental Health Carers' Issues in WA. Briefing Paper)

(Carers WA, Western Australia, Submission #277)

6.5.11.4.2 Lack of services for people with dual diagnosis - Intellectual disability

Standard 11.4.7 states: 'The MHS ensures access to a comprehensive range of services which are, wherever possible, specialised in regard to dual diagnosis, other disability'. In the notes to this Standard is 'collaborative treatment with…disability services'. One carer detailed the problems she had in organising treatment and support for her brother with Bipolar Disorder and intellectual disability, even after suicide attempts. She believes the inability to access appropriate treatment and support services for her brother resulted in his deteriorating mental health and eventual entry into the criminal justice system:

My brother is both Bipolar and has an intellectual disability. I believe his convictions are a direct result of the lack of available services to him whilst he tries to live independently in the community. Up until now we have always had to jump hurdles in order that the Mental Health Services and Disability Services work together as a team.

(Carer, Sister, Western Australia, Submission #101)

There seems to be no where to go if you are at suicidal risk. My brother's wounds are often treated and he is discharged from hospital with little or no regard to his mental health. My brother also has an intellectual disability as well as bipolar disorder. His suicidal attempts are labelled behavioural related to his IQ and not his mental health. DSC [Disability Services Commission] want to handball him to Mental Health Services and visa versa.

(Carer, Sister, Western Australia, Submission #101)

6.5.11.4.3 Lack of services for consumers with dual diagnosis - drug and alcohol

Standard 11.4.7 states: 'The MHS ensures access to a comprehensive range of services which are, wherever possible, specialised in regard to dual diagnosis'. The notes to this Standard include 'dual case management with alcohol and other drug services'. Concern was expressed that there is an insufficient number of services to provide the appropriate treatment and support for consumers with complex needs and hence these consumers are either kept in a locked ward or discharged and become homeless or enter the criminal justice system:

My son is 19 and he has chronic schizophrenia and a drug abuse problem – he's been in the locked ward at Graylands for quite a while and I'm glad he's been locked up for that long because he can't cope outside the hospital. He lives with me and I worry about what will happen to him if he is released – he can't be accommodated anywhere and this is a human rights issue – there's unreasonable pressure on the family to provide care for really sick people like my son…My son can't even get supported accommodation. He was assessed and because he said he wouldn't give up his cannabis – he can't lie - they won't accept him.

(Carer, Mother, Western Australia, Perth Forum #31)

Often the best way to deal with drug and alcohol problems is through a team approach. Sometimes we get very good support from individuals in the mental health teams but now that's become increasingly difficult – almost impossible.

(Manager of drug service, Western Australia, Bunbury Forum #23)

Drug and Alcohol is like a draw bridge, you only let in the ones you want to let in and only let out what you want to let out. They're keeping out those with drug and alcohol problems, which most of them have.

(GP, Western Australia, Geraldton Forum #62)

Where are the services for people suffering form a dual diagnosis (mental patients who use drugs / alcohol)? The drug services want mental health to assist these people. Mental health want the courts and prison system to deal with these people. And the Courts consider the issue to rest with Mental Health. Inevitably these people end up in Prison, which seems to be the dumping ground for anyone with mental health issues and obviously this is not an appropriate place for them. There are not enough beds for mental health patients which means that the few beds available go to the "deserving few" – whatever that means, presumably it means those people who do not have a drug/alcohol problem.

(Anonymous, Western Australia, Submission #145)

I recommend the Western Australian Police Service, Department of Health and Department of Community Development ensure there are appropriate facilities to care for intoxicated persons in need of protection from themselves which need to be adequately: (a) provided for, and (b) funded if the Protective Custody Act 2000 is to achieve in practice the objectives set out in theory. (excerpt from Coroners Report, 2004)

(St Bartholomew's House Inc, Western Australia, Submission #37)

6.5.11.4.4 Lack of services for consumers with hearing impairment

Standard 11.4.7 ensures access to a comprehensive range of treatment and support services which are, wherever possible, specialised in regard to dual diagnosis and other disability. Concern was expressed that consumers who have a hearing impairment were experiencing excessive difficulty in accessing treatment and support services to meet their needs. Also, Standard 11 (Access) states that 'The MHS ensures equality in the delivery of treatment and support regardless of…physical or other disability'.

The needs of people in mental health who are hard of hearing are often not met. If you already have one disability and then have a mental illness on top of that it's doubly hard to get help.

(Consumer, Western Australia, Perth Forum #37)

6.5.11.4.5 No child and adolescent service to access

Consumers, carers and clinicians expressed concern at the paucity of services for children and adolescents. Standard 11.4.3 ensures access to a 'comprehensive range of treatment and support services which are, wherever possible, specialised in regard to a person's age and stage of development'. In particular, concern was expressed that the few services that did exist are rapidly diminishing, waiting lists are becoming longer and children are being inappropriately admitted to adult inpatients units.

The psychiatrist that was here before was great with feedback to other services and families – now the situation is hopeless. There are 2 of us (school counsellors) covering 8,000 people in this area. There is no child psychiatrist in the area and the service knew for about 12 months that he was leaving. Nothing has been done that I can see to replace him.

(School counsellor, Western Australia, Bunbury Forum #8)

I want to talk about the problems in getting services to children and youth – I can't understand why it's such a problem…perhaps there is no staff.

(Anonymous, Western Australia, Bunbury Forum #18)

There's absolutely no service at all for child and youth mental health except through private paediatricians.

(GP, Western Australia, Bunbury Forum #19)

[I]n Meekatharra the CAMHS [Child and Adolescent Mental Health Service] worker who visited once every two months was always booked out with appointments. Therefore, it would appear that the need indicated that the amount of times she visited should have been increased. Instead these visits are no longer taking place.

(Clinician, Western Australia, Submission #333)

…I have noted the following issues with the Mental Health Services in both Carnarvon and Geraldton; The Child and Adolescent Mental Health service in both Geraldton and Carnarvon has not been running for substantial periods of time over the past three years. This has left many children and adolescents at high risk of suicide. In Carnarvon a number of aboriginal adolescents have committed suicide.

(Clinician, Western Australia, Submission #333)

Most recently I have made referrals to the CAMHS [Child and Adolescent Mental Health Service] service in Geraldton…I feel frustrated that we would leave a suicidal 7 year old without the support of a counselling service.

(Clinician, Western Australia, Submission #333)

There is a lack of services for students – for example, no doctor on campus and limited counselling opportunities. We've been allocated a disability officer from Perth who attends the campus twice a year but students are not advised. I raised concerns with the Dean, who said service available to high need students only.

(Consumer, Student, Western Australia, Perth Forum #44)

There is a mental health clinician who spoke at the committee about 13 yeat olds in Graylands and the chair of the committee said we are not to release or discuss any of these statistics. But we will not hide this information any longer.

(Consumer, Western Australia, Perth Forum #42)

I have also found, however, that the CAMHS service in Geraldton has not been in a position to provide the appropriate follow up and support.

(Clinician, Western Australia, Submission #333)

6.5.11.4.6 Lack of treatment and support services for consumers who are elderly and homeless

Standard 11.4.3 ensures access to a 'comprehensive range of treatment and support services which are, wherever possible, specialised in regard to a person's age and stage of development'. Standard 11.4.6 ensures services which address lifestyle aspects of consumers and the notes to Standard 11.4.7 refer to collaborative treatment with service providers such as aged care. However, concerns were raised with regards to the many difficulties in providing services to consumers who are elderly and homeless and services reported failed attempts in requesting additional support from government to meet the needs of these consumers.

We run a 20 bed aged care and crisis service for people with a mental illness. 18 months ago we had to restrict the number of people with a mental illness coming into our service. I'm not proud of that but we were having too many problems and incidents with those people we identify as the "hard homeless" – they are difficult to care for, they don't pay but where do they go? If you are homeless, with a mental illness you don't get help from anywhere, you don't have a pension because you can't comply with the rules and regulations and most often there's nobody advocating for you. These are the forgotten people! When we've asked government for additional support for these people we've been told we should just move these people on.

(Supported Accommodation and Assistance Program (SAAP) Service Provider, Western Australia, Perth Forum #33)

6.5.11.4.7 Lack of treatment and support services for consumers who are homeless

Concerns were expressed regarding the lack of treatment and support services for consumers who are homeless. The increasing number of people who are homeless and who have a mental illness and/or mental health problems has also risen with deinstitutionalisation and the subsequent lack of community based treatment and support services to meet the community's needs. Standard 11.4.6 states: 'the MHS ensure access to a comprehensive range of treatment and support services which address physical, social, cultural, emotional, spiritual, gender and lifestyle aspects of the consumer'.

St Bartholomew's House has been providing accommodation and support for people experiencing homelessness for 40 years. Over that time the profile of the people accessing the service has changed. Previously, men were older and most had an alcohol issue. Today the average age for admission in the supported accommodation area is 28 years and men are presenting with complex needs. Many have alcohol and drug issues and/or mental illnesses.

(St Bartholomew's House, Western Australia, Submission #37)

Although St Bartholomew's House continues to try and provide a quality service in supported accommodation (SAAP), the lack of resources, a staff ratio of 1:54, poor education of staff and the numbers of people requiring care limits the capacity to delivering safe quality care.

(St Bartholomew's House, Western Australia, Submission #37)

The SAAP representatives on the committee advised St Bartholomew's House to exclude numbers of mental health clients if they did not meet the new admission criteria developed with a referral process to indicate resident requirements for support and care. St Bartholomew's House elected to have a nominal figure of 10 residents with mental illness accommodated at one time. Unfortunately the House had 10 long-term residents who are unable to live independently so theoretically no more can be admitted. There was a commitment by the mental health clinical services to work with these long term residents to find them more suitable accommodation. 2½ years later nothing has been done.

(St Bartholomew's House Inc, Western Australia Submission #37)

6.5.11.4.8 Lack of treatment and support services for people with eating disorders

Carers WA expressed concern about the lack of treatment and support services for people with eating disorders:

One specific area of unmet need that has recently been identified by carers/families is the lack of an information and support network for carers and the lack of treatment and support services for people with eating disorders…The parents highlighted a number of issues relating to eating disorders including:

1) *The lack of an information and support network for the carers, parents and families of people with eating disorders;*
2) *The lack of treatment and support services for people with eating disorders;*
3) *The lack of any formal referral pathways for GPs and other health professionals dealing with people with eating disorders;*

4) *The lack of current information on support services for carers, and treatment and support services for people with eating disorders.*

In addition, anecdotal reports from education and health professionals such as school psychologists and school nurses suggest this is a large problem among school students. From a brief investigation of the issues, Carers WA and the Mental Health Carers Issues Network believe this is a serious emerging health and community issue that requires investigation and needs to be addressed.

(Carers WA, Western Australia, Submission #277)

6.5.11.4.9 Lack of services in rural areas

In Western Australia, the vast geographical area poses serious challenges to the planning and delivery of services to meet Standards 11.1.3 ('mental health services are provided in a convenient and local manner and linked to the consumer's nominated primary care provider') and 11.1.5 ('the MHS ensures effective and equitable access to services for each person in the defined community'). For people living in many areas of WA there are no services which are convenient and local. Access to care involves long distances by car, a significant barrier for those who are not so readily mobile or have their own transport.

Carers WA and the Mental Health Carers Issues Network recently conducted research into the needs and issues of carers of people with mental illness…To the question "What three things would you like to change about mental health services?" carers emphasised that there needs to be greater resources for mental health services especially in rural areas. This included more hospital staff and facilities; additional community nursing; and access to private health care. "In the rural area, the counsellor only comes around once per fortnight. So even if the consumer recognises and accepts the need for help, there's not very much available." (McKeague B, 2003. Worried, Tired & Alone – A report of Mental Health Carers' Issues in WA. Briefing Paper)

(Carers WA, Western Australia, Submission #277)

…services in the lower south west there is a mental health clinic located at Bridgetown which often only opens one or two days per week. This clinic is up to one hundred and twenty kilometres away from some of the towns it services and often further for those living on remote properties. There are two mental health nurses who service this region and they are greatly stretched, making quality contact time impossible.

(NGO Service Provider, Western Australia, Submission #45)

There are no doctors available here in Bunbury on nights or weekends so they send us to Perth!

(Consumer, Western Australia, Bunbury Forum #1)

In Esperance we have had no psychiatrist for 5 months. If consumers need acute care they have to be taken to a GP and then tranquilised and strapped to stretcher to be transported to Perth. I was told when I was suicidal, to drive myself to the city.

(Consumer, Western Australia, Perth Forum #45)

...the general feeling is that we [Esperance] are in a worse position than other cities you visited in this State.

(Consumer Advocate, Western Australia, Submission #35)

All rural and remote regions of WA have the same problems as you found in Bunbury and Busselton to varying degrees. Here in Esperance we do not have the luxury of a Mental Health Hospital wing dedicated for specialised treatment. Some years ago such a unit was built but was used for two or three years only, the difficult of providing 24 hour nursing cover was a problem. This unit is not operational now, due to operational costs and the lack of nurses. I believe these problems could be over come if a business plan was put into place. The alternative is flying people to Perth 750 kms away, very costly and so far from friends or family.

(Consumer Advocate, Western Australia, Submission #35)

6.5.11.4.10 Lack of treatment and support services for Indigenous consumers and their families living in remote communities

Concerns were expressed regarding the paucity of treatment and support services for Indigenous consumers and their families living in remote communities across WA. In particular, the lack of services and vast distances to reach care, lack of follow-up and support, reliance on medication and negative life consequences as a result of lack of access to services were mentioned:

> *GPs medicate, if the case is too hard they are dealt with by the hospital. We try to keep them within the service and deal with their housing needs work and education.*
>
> (Geraldton Regional Aboriginal Medical Service Social Worker, Western Australia, Geraldton Forum #74)

> *The mental health nurse is on leave at the moment, but we have a child psychologist who is permanent.*
>
> (Geraldton Regional Aboriginal Medical Service Social Worker, Western Australia, Geraldton Forum #74)

> *GRAMS is OK. I tried out the mental health services but it didn't work out for me but Mental Health is not good. I referred a seven year old sexual assault client who was suicidal to Mental Health. There was no response. I then went to Centacare. Mental Health cannot provide the services. Rurallink was positive outcome with that number. Aboriginal Teenagers, however, the only problem with that is they are referred to the Mental Health Service the next day and they just don't like going there.*
>
> (Anonymous, Western Australia, Geraldton Forum #78)

> *I am concerned especially about the long-term effects on the Aboriginal community of the Mental Health Services in town being inadequate. Many reports have shown that Aboriginal males have the highest suicide rate per capita. Surely more need to be done at a local level to stop this epidemic.*
>
> (Clinician, Western Australia, Submission #333)

> *Currently there is no state mental health services 'on site' in the Ngaanyatjarra Lands. These are provided through the mental health service at Kalgoorlie Base Hospital or people are evacuated by air to Perth to inpatient services at Graylands Hospital.*
>
> (Anonymous, Northern Territory Submission #271)

> *As with the Northern Territory and South Australia, clinic staff make referrals to mental health services. Again, due to the distances involved, generally people are chemically restrained and sent via plane. The closest community to Kalgoorlie on the Ngaanyatjarra lands is 750km km by road. The furthest, Tjukurla), is 1062.kms by road in comparison to 810km by road from Alice Springs. Perth is an additional 595km from Kalgoorlie. As Alice Springs is generally the regional centre used by Anangu, if someone is evacuated to Perth it quite common for this to be his or her first trip to that city.*
>
> (Anonymous, Northern Territory Submission #271)

> *Generally when people are assessed by the mental health team, they are transported back to their community with a referral and information passed on to the clinic nurse re: medication. It is important to note that this is the best possible discharge plan available when the system works effectively. There are many examples of even this level of support not being provided. For example: people being sent back to community without clinic staff being aware of the discharge plan or given any information.*
>
> (Anonymous, Northern Territory Submission #271)

There is then no follow up mechanism in place, except at the initiation of clinic staff. As there are no visiting mental health staff on the Ngaanyatjarra lands, for medication to be reviewed people have to travel to Kalgoorlie. Again it is clinic staff who are responsible for administering medications. It is important to place this in the context of an extremely busy workload, at times in a single nurse clinic. As primary health providers, Ngaanyatjarra Health is under resourced to provide basic primary health. There is extreme difficulty in recruiting and retaining experienced medical staff in remote areas.

(Anonymous, Northern Territory Submission #271)

Ngaanyatjarra Health receives a small amount of funding through the Bringing Them Home program. One worker is employed to provide services in the 159,948 km area. The focus of the funding is to provide grief and loss support in relation to issues of cultural dislocation and policies of forced removal.

(Anonymous, Northern Territory Submission #271)

Anangu living on Ngaanyatjarra Lands have no access to other types of mental health services except for the services described above. Even if the health system works at its' optimum level there are critical and serious service provision gaps.

(Anonymous, Northern Territory Submission #271)

6.5.11.4.11 Lack of appropriate treatment and support services for consumers in the criminal justice system

Although consumers who are subject to the criminal justice system are ensured access to a comprehensive range of treatment and support services (Standard 11.4.7) concerns were expressed regarding the availability and quality of such services. In particular, access to treatment for Borderline Personality Disorder was raised. Problems with forensic committees and the absence of a Chair of Forensic Medicine were also raised as problems impeding the planning and delivery of services to consumers in the criminal justice system:

My primary concerns in relation to mental health, are the extremely high rates of incarcerated women (and men) with both diagnosed and undiagnosed mental illness, and furthermore the treatment they receive from health services whilst in prison. There are also serious issues relating to treatment post release from community mental health services…

(Service provider, Western Australia, Submission #14)

I know I do not have to outline the issues related to dual diagnosis, which this client group exemplify. Particular problems also arise for this client group when a Borderline Personality diagnosis is given, which is very often.

(Service provider, Western Australia, Submission #14)

I like others sit on various committees including forensic committees. These consumers are probably the most disenfranchised of the lot! There is no Chair of Forensic Medicine in WA…

(Carer, Western Australia, West Perth Forum #43)

6.5.11.4.A Community living

The MHS provides consumers with access to a range of treatment and support programs which maximise the consumer's quality of community living.

I see a mistake that was made many years ago, and that was closing down the institutions without putting another better and cheaper way of allowing clients to live with some dignity.

(Consumer Advocate, Western Australia, Submission #35)

Under this Standard, submissions and presentations indicate concerns about:

- difficulties accessing community based services;
- lack of support for children of parents with mental illness;
- need for living skills programs;
- access to leisure and recreation programs is being reduced;
- more support needed to strengthen valued relationships; and
- lack of access to family centred approaches.

6.5.11.4.A.1 Difficulty accessing community based services

> *There need to be more community based treatments available for mental health consumers (especially job placements), voluntary work, educational achievements (at TAFEs) (anything to keep the self-esteem of a mental health consumer as this will develop positive outcomes).*
>
> (Anonymous, Western Australia, Submission #243)

The aim of deinstutionalisation was to provide treatment and support in the least restrictive setting, which for most people means living in the community. However, as discussed above, the necessary treatment, support services and systems have not been sufficiently developed. This is true for people with serious mental illness living in the community and for people who, as a consequence of failure to access treatment and support services at the onset of illness, develop significant disability and require additional community support services to live independently or with their family:

> *We provide a comprehensive service. It is difficult to link mental health clients to get community based services…It seems to be a big problem with links to mental health clinicians linking in with the discharge planning. Mental health patients are not linked in to home help.*
>
> (Social worker at Regional Hospital, Western Australia, Geraldton Forum #84)

> *HACC [Home and Community Care] services, meals on wheels two years ago went under the hospital banner and we had numerous problems. At the moment the waiting list is long for these services…Everywhere else in the state it is run by the community and Local Governments.*
>
> (Anonymous, Western Australia, Geraldton Forum #69)

St Bartholomew's House provided a description of their program to support consumers with severe mental illness to live independently in the community with dignity and respect:

> *St Bartholomew's House…also has a very successful Independent Living Program, which provides benevolent landlord support for 60 people with severe and persistent mental illnesses to live in the community. The three crisis units receive clinical support from their respective local mental health service as does the Independent Living Program. In these programs, people who are living with mental illnesses can expect and receive the dignity and respect any person should be shown. In most cases the clinical support is appropriate and there have been good partnerships established to continue to ensure each individual receives quality care.*
>
> (St Bartholomew's House Inc, Western Australia, Submission #37)

6.5.11.4.A.2 Lack of support for children of parents with mental illness

The lack of programs and services to support children of parents with mental illness was also highlighted. Standard 11.4.A.12 states: 'The MHS ensures that the consumer and their family have access to a range of family-centred approaches to treatment and support'. This support would assist parents with mental illness to continue to live in the community and fulfil their role as a parent and keep the family unit as functional as possible. However, as seen in the comment below, this is not the case:

> *…to request funding for the growing number of children in the Program, which now totals 40. So much work has been completed through the COPMI Project in WA, yet the children remain unsupported. Unfortunately, the application was not successful and we have been referred to DCD and Lotterywest to pursue the Project, a Project I believe that Mental Health should be funding as part of an early intervention and prevention strategy. I do not think that the Office of Mental Health appreciate the lengths to which many NGO's go to try and come up with innovative ways to support this group of people and many of the workers in mental health in WA are extremely united and dedicated.*
>
> (NGO Service Provider, Western Australia, Submission #18)

6.5.11.4.A.3 Need for living skills programs

With the current crisis in lack of availability of supported accommodation, reports indicate that in many cases consumers either became homeless or return to live with their family. In many instances, this places intolerable strain on families as they wait for places to become available, as consumers lacked the skills to live independently and other support services are not available.

Treatment and support which maximises opportunities for consumers to live independently in their own accommodation (Standard 11.4.A.13), or provides sufficient scope and balance so that consumers develop or redevelop the necessary competence to meet their own everyday community living needs (Standard 11.4.A.2), is required. Such programs would enable consumers to live with dignity in society and are seen as critical. As with the decline in other services, living skills programs appear to have also been cut:

> *We need a service here in Bunbury that teaches living skills. It is my understanding that there was someone here doing that once but not anymore. It seems that living skills are the last thing on the agenda for mental health services.*
>
> (Support worker, Western Australia, Bunbury Forum #13)

> *We have 12 houses and a boarding house for single men so we can take in 18 men…A lot of people with mental illness don't have independent living skills but people are regularly dumped on our doorstep – there's now at least one person a week "referred" by department officials to us. These "referrals" are occurring irrespective of the appropriateness of the referral. I have heard of stories where people end up in jail because there is nowhere else to take them.*
>
> (Community housing provider, Western Australia, Bunbury Forum #12)

…the need for Bunbury to have a Living Skills Centre for people to attend on a regular basis. Again I would like to point out this will have little or no real value to those living in isolated rural districts who have neither the means or the time frame to attend...has suggested the provision of a mobile unit which could services several communities. This of course would require ongoing funding, which in itself has always been a problem to the regions. The response to this suggestion from the Health Department has centred on the Department's policy of people with psychiatric illnesses partaking in existing community based activity rather than creating needs-specific services. The problem for many is two fold, being 1) there are no appropriate community based services in many of the rural areas. 2) Living in small community's people
are often reluctant to join any social or training activities or feel ill at ease for a myriad of reasons.

(NGO Service Provider, Western Australia, Submission #45)

Issues of Bunbury Mental Health Services:

- *The living skills program has not been functioning since December 2003, when after the resignation of a staff member the position has not been advertised or filled. This has had a huge impact on people living in the community in that there is no rehabilitation activities taking place. This is further exacerbated by very limited rehabilitation program therapy taking place at the in patient unit again this is associated with staff positions not being filled.*

(Advocate, Western Australia, Submission #2)

6.5.11.4.A.4 Access to leisure and recreation programs is being reduced

Access to day programs to meet the needs for leisure and recreation (Standard 11.4.A.4) were also reported to be declining even though access to such programs is seen as critical for consumers to live in the community:

We were informed a couple of months ago that the facility which allowed [X] to attend the Creative Expression sessions which he has enjoyed up to now would shortly be denied to him. This was because the facility would in future cater only for patients who were either in Graylands Hospital or recently released from the hospital. The aim would be for patients to reach a 'goal' which would enable them to be trained sufficiently to be teachers or presumably fully fledged artists. This should occur over a 3 to 4 month period, and then they would be discharged from the facility and not allowed back. This appears to be a typical consultant "bean-counter's" solution to cut costs. Anyone who has had any experience in dealing with schizophrenia and many other mental illnesses will know that for patients to achieve goals in a certain time frame is nigh on impossible. Art and music therapy is well known to have a calming and therapeutic effect on the mentally ill, and will help to act as a preventative to further breakdown, which in turn would require further medication and possibly repeat hospitalisation. Thus it almost certainly helps in fact to reduce overall costs of treating the mentally ill, as the costs are minimal compared to the costs of hospitalisation, with its requirement of beds, accommodation, staffing etc.

(Carers, Parents, Western Australia, Submission #76)

6.5.11.4.A.5 More support needed to strengthen valued relationships

Many reports were received from carers, NGO and family workers describing the incredible strain that has been placed on families. In particular, the strain placed on family relationships due to an inability for consumers and carers to access services was noted. The importance however of such relationships and the need for mental health services to strengthen them through the provision of treatment and support is recognised by Standard 11.4.A.11 which states: 'The consumer has the opportunity to strengthen their valued relationships through the treatment and support effected by the MHS'.

Carers WA and the Mental Health Carers Issues Network recently conducted research into the needs and issues of carers of people with mental illness…What is the best part of being a carer? For many carers the best part of being a carer related to personal growth and the opportunities provided to develop stronger family relationships. Providing care within the family was identified by 29% of carers who reported that caring for their family member with mental illness had enhanced the bonding within their family and maintained and strengthened family relationships…Of significant note is that 19% of carers reported that there was nothing good about their role or experience as a carer. (author's emphasis) (McKeague B, 2003. Worried, Tired & Alone – A report of Mental Health Carers' Issues in WA. Briefing Paper)

(Carers WA, Western Australia, Submission #277)

6.5.11.4.A.6 Lack of access to family centred approaches

Carers expressed concern that their role in the treatment and support process was overlooked, resulting in their contribution not being acknowledged and their needs not being considered. In particular, the lack of access to family-centred approaches support groups was mentioned. Standard 11.4.A.12 states 'The MHS ensures that the consumer and their family have access to a range of family-centred approaches to treatment and support'.

Carers also have their own needs which are completely overlooked as their role is not even acknowledged. Carers want mental health services to adopt a Family Inclusive Approach to mental health care which acknowledges and assesses both the needs of people with mental illness and their carers.

(Carers WA, Western Australia, Submission #277)

Carers WA and the Mental Health Carers Issues Network recently conducted research into the needs and issues of carers of people with mental illness…What would make your role as a carer easier? Support from mental health service providers was identified by 25% of carers. This included an increase in the level of mental health services available; visits from nurses and other staff at home; better access to information; more support from carer support groups and organisations; and more support services and activities for their family members/friends with mental illness. (author's emphasis) (McKeague B, 2003. Worried, Tired & Alone – A report of Mental Health Carers' Issues in WA. Briefing Paper)

(Carers WA, Western Australia, Submission #277)

6.5.11.4.B Supported accommodation

Supported accommodation is provided and / or supported in a manner which promotes choice, safety, and maximum possible quality of life for the consumer.

Supported accommodation is in extremely short supply – at 80% below the national per capita average.

(SANE Australia, National, Submission #302)

Under this Standard, submissions and presentations indicate concerns about:

- lack of funding for services and support;
- lack of supported accommodation options for people in rural and regional areas;
- a range of accommodation options is needed;
- lack of supported accommodation for people with complex needs (mental illness, drug and alcohol, homeless, aged); and
- lack of resources and support services for NGO supported accommodation providers.

6.5.11.4.B.1 Lack of funding for services and support

Lack of access to supported accommodation was noted as a critical problem by consumers, carers, clinicians and service providers. The result of there being no accommodation available meant that either consumers became homeless, accommodation services took on consumers that they could not adequately support (and therefore placed that consumer and other staff and residents at risk), or families were faced with a dilemma to take on the caring role and place substantial strain on the family unit. A critical lack of funding was noted in many submissions:

> *…is a non government organisation which provides housing and support to people with psychiatric disabilities in the Swan Region of Perth. We have been providing these services for 8 years now and have a waitlist for housing of between 40 and 50 people. It is almost an embarrassment to do an assessment for housing and then have to inform applicants that the waitlist is 3 to 4 years long… We are also now in the position where we are housing people when properties become available, without the capacity to support them in their housing.*
>
> (NGO Service Provider, Western Australia, Submission #18)

> *In 2002, NGO's were invited by the Office of Mental Health to tender for disability support services. Many I know worked extremely hard to put in their submissions, only to be advised in writing the following year, that no funding would be forthcoming. Last year, as you may already know, all NGO's in WA were under scrutiny and fortunately, the sector united and lobbied and the cuts were halted. It reminded me of a statement I read in 'Out of Hospital, Out of Mind' that said something like 'If you are up to your arse fighting the crocodiles, then you forget that your real job was to go in there and drain the swamp'. That is certainly the case for NGO's in WA in 2002… NGO's should not be expected to house people with mental illness and not have the capacity to support them towards recovery and community living.*
>
> (NGO Service Provider, Western Australia, Submission #18)

> *It is obvious that the basic needs of mental health clients are not being met and that without additional resources SAAP services cannot accommodate people with complex needs.*
>
> (St Bartholomew's House Inc, Western Australia, Submission #37)

> *Hostels like St. Bartholomew's House can no longer afford the risk of injury to staff and/or other residents from people who are not having adequate treatment and support from mental health services.*
>
> (St Bartholomew's House Inc, Western Australia, Submission #37)

6.5.11.4.B.2 Lack of supported accommodation options for people in rural and regional areas

The problem of the lack of supported accommodation options was most keenly felt in rural and regional areas:

> *…However, there needs to be noted the greater lack of suitable accommodation for those living in rural areas…at the moment most local consumer have to remain living at home in what for some is less than favourable circumstances, the alternative is for them to move to Bunbury or at least Busselton which means leaving support networks of family and / or friends.*
>
> (NGO Service Provider, Western Australia, Submission #45)

6.5.11.4.B.3 Range of accommodation options needed

Most notably, many submissions argued that a range of accommodation options were needed and that these needed to be flexible:

> *Carers report that the current funding and provision of mental health care in WA is clearly inadequate to meet the level of need. This is demonstrated by: The lack of independent accommodation options for people with mental illness. There should be a range of options available and flexible to the individual needs of people with mental illness.*
>
> (Carers WA, Western Australia, Submission #277)

A huge area lacking in the mental health system overall is the lack of some form of interim accommodation like houses or hostels for patients who have recovered to the extent that they no longer require hospitalisation, but still require some overall supervision in a secure environment to give them their medication regularly and help to prepare them for release into the community. We have come across patients in Graylands hospital who have been there for many months, and have really nowhere to go where they can still be supervised and helped to rehabilitate.

(Carers, Parents, Western Australia, Submission #76)

Apparently all of the psychiatric hostels are privately run and they can then pick & choose who they will allow to reside at the hostels. This means that for difficult or disruptive patients, there is nowhere for them to go.

(Anonymous, Western Australia, Submission #145).

It is our contention that hostel type units should be built or allocated for the use of high care clients, funded to include a high care worker, a type of half-way house. This would also act as a Transitional House where young people (20-40 yrs) can learn life skills, work skills, to enhance life long Self Care.

(Consumer Advocate, Western Australia, Submission #35)

We have trying for many years to get some recognition that there is a real need. The answer that is always the same that it is considered to be more affective for all clients to live in an open environment. I know that is true in most cases but there are many who do not fit that category. Some may grow into a different lifestyle, others never will…Last week a long term client had an altercation with a man living in the same street this is an example of what often happens in this situation.

(Consumer Advocate, Western Australia, Submission #35)

This young man now has two fines which he will not pay. He needs a 'sheltered living hostel', a mentor, some work under supervision, like the Work for the Dole project. It is my contention that a program such as this is not more expensive than the present cost to the community and it may be good for him. He is a walking advertisement for the failure of Mental Health Services to support vulnerable people like him.

(Consumer Advocate, Western Australia, Submission #35

The need for respite services was also noted for the consumer. The need for such services is also seen as essential for the carer and the family when consumers are living with family members:

…I do think some intensive respite care can go long way to saving lives of the mentally ill when they are in crisis.

(Carer, Sister, Western Australia, Submission #101)

Respite for carers, time away from the caring role, is essential to maintaining the care relationship and improving the quality of life of carers and their family members / friends with mental illness. Without it there is the danger of relationship stress and breakdown and social isolation. Carers continually report their need for respite and their difficulty in accessing it. A specific respite program for carers of people with mental illness is required in WA as they aren't a recognised target group for other Commonwealth and State funded programs.

(Carers WA, Western Australia, Submission #277)

There is no available respite for families / carers of those people with mental health issues. However, for a carer of someone with an intellectual disability resources are available for respite. This raises another concern which is for that of the mental and physical health of the carer. (I have seen the health of carers and their families – including young children – deteriorate as they struggle to cope with their loved one).

(Anonymous, Western Australia, Submission #145)

6.5.11.4.B.4 Lack of supported accommodation for people with complex needs (mental illness, drug and alcohol, homeless, aged)

Of the small number of accommodation services operating, most dealt with one particular 'group' (e.g. mental illness, homelessness, elderly, youth, drug and alcohol etc.). These accommodation services were generally overstretched, operating at capacity with waiting lists and under-resourced. Most are not capable of dealing with clients with complex needs. Some services have attempted to take on people with complex needs even though they did not have the capacity to do so. Sometimes this decision results in serious risks for the consumers, staff and other residents. From the nature of the submissions received, it appears that there is a growing number of people with complex needs with nowhere to go:

> *St Bartholomew's House has been providing accommodation and support for people experiencing homelessness for 40 years. Over that time the profile of the people accessing the service has changed. Previously, men were older and most had an alcohol issue. Today the average age for admission in the supported accommodation area is 28 years and men are presenting with complex needs. Many have alcohol and drug issues and/or mental illnesses.*
>
> (St Bartholomew's House, Western Australia, Submission #37)

> *St Bartholomew's had found in 2001 a situation where over 60% of its clients were potentially involved with mental health issues. It was utilised as a quasi-psychiatric service without any resources with respect to this aspect of care. Mental Health Services all over the area were discharging clients directly to St Bartholomew's…* (excerpt from Coroners Report, 2004)
>
> (St Bartholomew's House Inc, Western Australia, Submission #37)

> *…A large number of people with mental health issues fluctuate in the severity of their symptoms and those which are chronic as opposed to acute are frequently discharged from appropriate facilities with no where to go.* (excerpt from Coroners Report, 2004)
>
> (St Bartholomew's House Inc, Western Australia, Submission #37)

> *My son is 19 and he has chronic schizophrenia and a drug abuse problem – he's been in the locked ward at Graylands for quite a while and I'm glad he's been locked up for that long because he can't cope outside the hospital. He lives with me and I worry about what will happen to him if he is released – he can't be accommodated anywhere and this is a human rights issue – there's unreasonable pressure on the family to provide care for really sick people like my son. But one of the big problems is how much people are charged to be in supported accommodation - 80% of a person's income for supported accommodation is too much because it just leaves enough for cigarettes. My son can't even get supported accommodation. He was assessed and because he said he wouldn't give up his cannabis – (he can't lie) they won't accept him. So it's really hard, because my son doesn't have the cognitive skills to give them the answers they want he gets punished. I wish I could teach him how to lie. These kids with co morbid problems like my son are becoming the new generation of homeless people. I have been contacted by a lady who has a daughter on benzo's and if she didn't provide care and accommodation for her daughter she'd be under the bridge.*
>
> (Carer, Mother, Western Australia, West Perth Forum #31)

> *Due to a lack of appropriate facilities for persons with mental health issues and substance abuse issues, many emergency accommodation hostels find themselves in the position of having to accommodate people with disabilities they are not resourced to care for appropriately. A large percentage of homeless persons have nowhere to go if not accommodated by hostels such as St. Bartholomew's.* (excerpt from CORONERS REPORT, 2004)
>
> (St Bartholomew's House Inc, Western Australia, Submission #37)

6.5.11.4.B.5 Lack of resources and support services for NGO supported accommodation providers

The combination of a lack of community services, overstretched community services, lack of funding for supported accommodation and the growing number of people with complex needs has resulted in consumers being placed at risk:

> *The Community Mental Health Team from the Perth Hospital provides support to the Hostel with clinical services but each nurse's workload is considerable and if a person is unwell they are often not able to get them an inpatient bed. Nurses refill dossett boxes and mange medications but are reluctant to write in residents files when they visit or medicate residents. This puts residents at risk because St Bartholomew's House staff do not know what is going on if a resident has an adverse reaction to a treatment or whether he has had his regularly injection. All care plans are kept in the hospital.*
>
> (St Bartholomew's House Inc, Western Australia, Submission #37)

> *In November 2002 a resident died from an overdose of Quetapine. The gentlemen had been a resident at St Bartholomew's House for 6 months. He had a long psychiatric history. The Coroner was supportive of St Bartholomew's House and the care provided, but was very concerned about the number of people with mental illnesses whose cases come before the Coroner's court (see attached Coroner's Finding).*
>
> (St Bartholomew's House Inc, Western Australia, Submission #37)

6.5.11.4.C Medication and other medical technologies

Medication and other medical technologies are provided in a manner which promotes choice, safety and maximum possible quality of life for the consumer.

Under this Standard, submissions and presentations indicate concerns about:

- the over reliance on medication; and
- increasing use of Electro Convulsive Therapy (ECT).

6.5.11.4.C.1 Over reliance on medication

Reports were received indicating that, in hospital settings, there was an over reliance on medication and very little emphasis or choice from a range of accepted therapies.

> *The other patients left back in the hospital would like me to tell you that the Bunbury Hospital is a place where you get medicated first and counselling second. It's a place where you can get away from the world but there's not much else.*
>
> (Consumer, Western Australia, Bunbury Forum #17)

> *Medication as the only treatment modality. Consumers of public mental health services, as in patients or in the community, rarely have an opportunity to 'talk through' the contents of their thoughts, their ideas about the causation of their illness, or the progressive processing or understanding they are developing about their condition. The structure of mental health services means that frequent turnover of staff leads to discontinuous relationships between consumers and doctors. Medication has become the primary treatment modality. Most consultations centre around negotiations on dose, medication type, combinations, side-effects, and consumer concerns about being on chemical treatments…*
>
> (Health Consumers' Council WA, Western Australia, Submission #29)

The failure to engage with these consumers through any other form of treatment, including talking therapy, leaves no options but to continue on medication. When consumers succeed in having their dosage significantly reduced, any behaviour that results from the freedom from sedative effects and disabling side effects are readily considered to be manifestations of illness. Family and others who have felt comforted by mental health services' reliance on medication are easily threatened by medication reductions and are not inhibited about reporting changes in behaviour to mental health services. The tendency to rely upon third party information can lead to pressure from clinicians to increase medication levels…

(Health Consumers' Council WA, Western Australia, Submission #29)

6.5.11.4.C.2 Increasing use of Electro Convulsive Therapy (ECT)

Concern was also raised about the increasing use of Electro Convulsive Therapy in Western Australia:

ECT [Electro-Convulsive Therapy] use is increasing in WA, in both public and private hospitals. There was a marked 25% increase in ECT hospitalisations in the financial year 2000/01 (618), compared with the previous year 1999/00 (495). 63% of these hospitalisations were in private hospitals. Why is this the case?…The majority of hospitalisations for ECT treatment in 2001were female (70%)…There is no standard protocol for the administering of ECT over all hospitals. Individual hospitals have their own clinical protocols, including voltage, area of administration and number of treatments. While a standard protocol for public hospitals is being addressed, the private hospitals adhere to their own individual policies. Elderly patients (24% of ECT patients were over 65 years) are being given "maintenance ECT" with no other treatment, and no treatment plan. Patients are not fully informed of the multitude of side effects associated with ECT. There has been a move away from unilateral ECT (which was thought to minimise side effects) to bilateral ECT. A review of the literature indicates there is little agreement amongst ECT "Experts" about ECT procedures. Issues such as current, electrode placement, and number of treatments remain controversial. I do not believe the public are aware of the extent of ECT use. In my opinion, ECT is an unacceptable treatment. If it is used at all, ECT should be given as an absolute last resort, under the most stringent guidelines. Currently ECT is being given in an ad hoc manner.

(Giz Watson MLC, Western Australia, Submission #171)

6.5.11.4.D Therapies

The consumer and consumer's family / carer have access to a range of safe and effective therapies.

Under this Standard, submissions and presentations indicate concerns about:

- the lack of access to a range of therapies – emphasis on medication.

6.5.11.4.D.1 Lack of access to a range of therapies – emphasis on medication

Following on from the emphasis on medication noted above, was another report that the main emphasis of mental health treatment was on medication with little or no access to a range of safe and effective therapies and rehabilitation approaches:

Mum overdosed on the anti-depressants she had been prescribed, taking 96 of them in one sitting. She had so many anti-depressant pills to take that she had a plastic box labelled with the day, each one containing 4 or 5 tablets. As I recollect, over the twenty year period, she was not offered counselling outside of her GP and all treatment seemed to be purely pharmaceutical.

(Son, Western Australia, Submission #87)

I feel the inpatient unit in Bunbury provides a second-rate service to the mentally ill in the region as it does not provide a multi-disciplinary team. The Therapy Department went from 4 Full Time Employees, providing a day-service to clients for six-weeks intensive therapy to prevent hospital admissions, to now only 1.5 FTE, providing only an abbreviated day program to the current inpatients. The therapy department is now housed in the nursing station of the High Dependency Unit, due to the Community Staff moving into their space when they lost their premises. The patients have lost their group room, which now houses community staff, desks and computers. The whole APU [Acute Psychiatric Unit] is an overcrowded situation with the community staff moving into the small premises.

(Nurse, Western Australia, Submission #55)

Only recently in July, Carers at a Carer Advocacy & Issues Forum in Bunbury met and expressed their frustration regarding the sudden closure of mental health services in their community. Specific concerns regarding the closure of services include: The community service has been relocated to the already limited space at the inpatient facility. This has resulted in further restrictions to the declining availability of therapy for inpatients; The lack of living skills, acute therapy and rehabilitation services…

(Carers WA, Western Australia, Submission #277)

Reluctance to recognise consumer experience of past trauma that contributes to mental illness and distress. This deafness to the consumer narrative reflects a wholesale abandonment of talking and listening therapy in state mental health services…

(Health Consumers' Council WA, Western Australia, Submission #29)

6.5.11.4.E Inpatient care

The MHS ensures access to high quality, safe and comfortable inpatient care for consumers.

Under this Standard, submissions and presentations indicate concerns about:

- care not being provided in the least restrictive environment;
- deaths while an inpatient;
- lack of beds;
- lack of access to clinical MH staff;
- impact of admission on consumers family not minimised;
- voluntary admission not supported;
- transport not most respectful;
- problems with increasing use of security guards in hospital settings due to a shortage of secure beds; and
- lack of supervision and adherence to protocols.

6.5.11.4.E.1 Care not being provided in the least restrictive environment

Serious concerns were expressed through submissions and personal accounts told at the forums that care was generally not provided in the least restrictive environment. The following comments are a sample of this evidence:

It is hospital policy to sedate them and shackle them.

(GP, Western Australia, Geraldton Forum #54)

…higher levels of 'anger and aggression' and 'control' and lower levels of 'autonomy'. While ideally it would be useful to compare Grayland's wards with similar clinical areas within Australia these findings of negative characteristics are a cause for concern though not surprising given the custodial culture that prevails in the hospital.(Excerpt from: Shanley (2001), Management of change in a psychiatric hospital using a 'bottom up' approach)

(Eamon Shanley, Professor of Mental Health Nursing, Australia, Submission #33)

I'm a patient in the hospital at the moment under an involuntary order and it was very difficult for me to get here to this forum today. The other patients left back in the hospital would like me to tell you that the Bunbury Hospital is a place where you get medicated first and counselling second. It's a place where you can get away from the world but there's not much else. The situation is terrible and I can't even have a shower in private. I'm scared and I have no privacy.

(Consumer, Western Australia, Bunbury Forum #17)

…Culture of custody and control which is prevalent in WA. What we have at the moment is a mental health system that's taking money away from non-secure beds to secure beds. Part of the culture of control is the resistance to addressing a person – civil liberties.

(Consumer Advocate, Western Australia, West Perth Forum #36B)

6.5.11.4.E.2 Deaths while an inpatient

Of most serious concern were reports of deaths of consumers while an inpatient and that hospitals did not provide safe settings:

…Graylands Hospital…The place is a nightmare of mammoth proportions and at the moment I am writing a book showing such facts along with the death of my daughter there, along with other young adults. It is usual to go to a hospital to improve one's health...these young people are dying through neglect by hospital staff and not being listened to. Certainly no fault of their own. I have searched long and hard and if I honestly believed that my daughter and the others I know of had died through their own doing and with compassion behind them I would leave well alone. They didn't - they died in strange circumstances.

(Carer, Mother, Western Australia, Submission #103)

Attempts were made to locate a facility to meet the needs of my sister. It is my understanding that of all the hospitals with closed wards, there were no beds available that evening. Eventually after a long delay, she was transferred to the psychiatric unit at Royal Perth Hospital in the Perth CBD. She stayed there the night but was not in a locked ward. In the morning she walked out of the hospital. She walked less than 500m to a multilevel carpark on the corner of Wellington and Pier Streets. She went to the top floor and jumped to her death...It was unnecessary tragedy that could and should have been averted. There are many questions unanswered for my family: How can this happen? Who is accountable? Why are there insufficient resources when the problem is so evident?...the system failed my sister and her family. It is unacceptable and these issues need to be voiced and addressed...I was unable to return to this job after my loss.

(Brother, Western Australia, Submission #89)

Concern around the circumstances of an alleged suicide while an inpatient.

(Carer, Western Australia, Submission #196)

6.5.11.4.E.3 Lack of beds

The lack of beds was a vexed issue for many people. Some considered the Government's focus on increasing bed numbers as problematic because it failed to take into account the need to invest in effective systems of community-based care that would ultimately reduce reliance on hospital beds. For others, the lack of available

beds for people with acute mental illness presented significant distress and a failure of Government to respond to the acute needs of people with a mental illness:

> *Another big problem is around the number of involuntary beds we have in Bunbury Hospital. Once before we had these beds, then they were "taken away", now we have them again but the number is completely inadequate to our needs in this community.*
>
> (GP, Western Australia, Bunbury Forum #19)

> *As the APU [Acute Psychiatric Unit] is not a secure unit and cannot manage high risk patients, there often becomes a need to transfer patients to the more acute units in Perth. The process of transferring a patient to Perth is a lengthy process due to shortages of beds. The result of this is that patients are kept in the APU, the Medical Ward, the Intensive Care Unit and the Emergency Department of the hospital under 'guard', with IV sedation for an extraordinary number of hours or even days. The over-use of the seclusion room in APU on a couple of occasions to detain patients also comes to mind. There was in an occasion where a patient was detained in the medical ward with a guard for five days before a bed became available.*
>
> (Nurse, Western Australia, Submission #55)

> *There are not enough beds for mental health patients which means that the few beds available go to the "deserving few" – whatever that means, presumably it means those people who do not have a drug/alcohol problem.*
>
> (Anonymous, Western Australia, Submission #145)

> *…it is also worth noting that the Consultant Psychiatrist who admitted her had to almost beg for the last bed on the ward, otherwise the client, who was suicidal, would have been sent home with no support. The doctor informed me that on the previous day, he had wasted 3 hours of his clinic time chasing a bed for an extremely unwell patient. His other patients could not be seen due to this.*
>
> (Social Worker, Western Australia, Submission #15)

> *(iii) patients placed "on leave" to make way for new admissions. If a patient is ready to leave hospital the team would have discharged them, obviously these patients are not ready! The strain is then transferred to the family/carers/community teams. The risks of this practice are patently obvious; once again I was forced to agree to this occurring in North metro over the weekend, the only other option would be to refuse admission.*
>
> (Consumer Advocate, Western Australia, Submission #338)

> *(iv) "civil" patients being admitted to the Frankland Center [sic]. This is a forensic mental health facility, the practice exposes the acutely unwell patients to an highly traumatic experience…*
>
> (Consumer Advocate, Western Australia, Submission #338)

> *…ongoing problems that I personally know exist at one hospital emergency department… Frequently there are no beds of either sort available. In the case of involuntary patients they have to be held on forms in cubicles or other appropriate places until a bed can be found which can take a considerable amount of time. This type of situation places not only the patient but also their family / carer under additional distress and is a denial of the human right to the best available health care…*
>
> (Carer Advocate, Western Australia, Submission #339)

6.5.11.4.E.4 Lack of access to clinincal MH staff

In addition to lack of access to hospital beds, the lack of access to suitably qualified staff was also raised as a problem:

> *My friend wasn't under a section but she was in hospital and didn't see a psychiatrist for three days.*
>
> (Consumer, Western Australia, Bunbury Forum #3)

6.5.11.4.E.5 Impact of admission on consumers family not minimised

Standard 11.4.E.7 states: 'The MHS assists in minimising the impact of admission on the consumer's family and significant others'. The notes to this Standard include 'care of dependant children'. According to one presentation at the forum held in Bunbury, no arrangements were made for the care of dependant children when their mother was admitted to hospital.

> *The police were fantastic with that woman but there was nothing done for her children when she was taken away.*
>
> (Friend, Western Australia, Bunbury Forum #3)

6.5.11.4.E.6 Voluntary admission not supported

One carer reported the excessive use of chemical restraint for a consumer who was seeking voluntary admission. According to Standard 11.4.E.2: 'Where admission to an inpatient psychiatric facility is required, the MHS makes every attempt to promote voluntary admission for the consumer'.

> *[X] was kept heavily sedated: [X] was in and out of drug induced sleep for approximately 18 hours until admission at Graylands Hospital. Surely this is way too long and unnecessary considering the fact that [X] was voluntarily seeking treatment! During the assessment stage at the Emergency Department of Bunbury Regional Hospital, [X] had been calm and fully compliant. No grounds were shown for involuntary admission witnessed by parents, security and nursing staff.*
>
> (Carers, Western Australia, Submission #177)

> *Coercive use of involuntary status to secure compliance with treatment – you're only voluntary if you do what we say, including taking the treatment we propose and staying within the walls of the inpatient unit*
>
> (Health Consumers' Council WA, Western Australia, Submission #29)

6.5.11.4.E.7 Transport not most respectful

Standard 11.4.3.E states: 'The MHS ensures that a consumer who requires involuntary admission is conveyed to hospital in the safest and most respectful manner possible'. The following account raises serious concerns on a number of levels, not the least of which is the mode of transportation not being the most respectful (sedation with police escort) when the consumer's father was prepared to drive the consumer as the consumer was not in an agitated state. The reason for escort (the consumer had been made an involuntary patient) had not been discussed with either the consumer of his carers.

> *Parents transported [X] to the Bunbury Regional Hospital (Emergency Department), at his request. [X] requested ED staff to have him admitted on to a psychiatric unit. [X] was willing and cooperative…Dr [Y] entered the interview room and advised that [X] was going to Graylands Hospital. Dr [Y] quickly left the room. Shortly thereafter, a security guard entered the room and explained to the patient that he would be sedated and transported at 0800 the next morning. At this point [X]'s parents spoke to Dr [Y] and asked why [X] required to be sedated? Dr [Y] responded with "we do it this way". [X]'s Father once again stated that he was willing to transport the patient to Graylands and that "if it was a matter of legalities, he was willing to take full responsibility and sign any documents whatsoever for this to happen"…Father spoke with nursing staff at the Emergency Department to determine why transportation had not taken place as scheduled at 0800 hours...Ambulance staff had refused to take charge of the patient because he was sedated. A Form 3 had to be raised and police escort arranged…At no stage whatsoever, up until [X] had been placed into an induced sleep, had medical staff at the Bunbury Regional Hospital, notified [X] or us, that he would be made an 'Involuntary Patient'.*
>
> (Carers, Western Australia, Submission #177)

One thing that concerns me personally is the transport of people with a mental illness. We are often required to transport these people but they are not criminals, they are ill.

(Police officer, Western Australia, Bunbury Forum #9)

Consumers are driven in the back of paddy wagons – three day trips – from Kununurra to Perth.

(Carers, Western Australia, West Perth Forum #43)

There are conflicting reports that the Royal Flying Doctor Service may not want to take the clients. Sometimes consumers have to wait another day to be sedated and possibly have a police escort to take them to Graylands. Sometimes they need armed escort.

(GP, Western Australia, Geraldton Forum #52)

6.5.11.4.E.8 Problems with increasing use of security guards in hospital settings due to a shortage of secure beds

As stated previously (Standard 2 – Safety), the shortage of secure beds has resulted in the increased use of security guards to monitor patients in hospital settings. This has had the result of not only focussing the issue on containment rather than care, but also compromising the safety of both the consumer and security guards who are not trained for such situations as demonstrated by the following reports:

One of the most disturbing practices for me is the use of security guards from a private security firm to facilitate the care of inpatients, due to lack of proper facilities and staffing levels in Bunbury. The hospital regularly employs guards to "special" patients who are considered at risk of either self-harm or absconding. They often use the guards to boost the staffing levels in the unit to try and make the environment safe. This can often mean an untrained person, usually male, following around a very ill or deeply disturbed person in the medical ward of the hospital as well as the psychiatric unit, or is sitting around in full uniform in the psychiatric unit. This has a couple of very major concerns. Firstly, the patient often self discloses to the security guard their personal history, which may often include a history of sexual abuse. Secondly, it also gives the patient, visitors and other patients, the impression that the person with the guard is "trouble", i.e. violent, bad, etc.

(Nurse, Western Australia Submission #55)

I have witnessed young male security guards following around young female patients, watching them in their bedrooms. I have seen the situation escalate whereby a young male security guard, who had a history of depression, suicidal ideation in the past, have to try and restrain a female who was absconding from the Unit (as it is open and not a secure environment). He failed to restrain her, she absconded and placed herself on a tower in Bunbury threatening to jump off. The security guard was so distraught from the incident, feeling that he was responsible for anything that happened to her, that he began crying and had to be consoled by staff.

(Nurse, Western Australia Submission #55)

6.5.11.4.E.9 Lack of supervision and adherence to protocols

Concern was expressed that policies and procedures are not in place to ensure that practices agreed to by clinical staff are being adhered to. Standard 11.4.E.15 states: 'Documented policies and procedures exist and are used to achieve the above criteria' and Standard 11.4.E.6 states 'The MHS monitors its performance in regard to the above criteria and utilises data collected to improve performance as part of a quality improvement process'. The following account also suggests problems with management and accountability to ensure the implementation of decisions made:

Lapses in practice unchecked by senior clinical nurses and nurse managers - Despite the involvement of all nursing staff in the decision making on changes made in the NPDU [Nursing Practice Development Unit], lapses by individual nurses were allowed to occur unchecked by senior clinical nurses and nurse managers. (Excerpt from: Shanley (2001), Management of change in a psychiatric hospital using a 'bottom up' approach)

(Eamon Shanley, Professor of Mental Health Nursing, Australia, Submission #33)

6.5.11.5 Planning for exit

Consumers are assisted to plan for their exit from the MHS to ensure that ongoing follow-up is available if required.

Under this Standard, submissions and presentations indicate concerns about:

- discharge without proper assessment;
- inadequate discharge plans;
- difficulty in coordinating community based services when exiting MHS; and
- other service providers nominated on exit plan not informed prior to exit.

6.5.11.5.1 Discharge without proper assessment

Concerns were expressed that discharge was not based on an agreed exit plan or health status of the consumer and without a proper assessment. Such exits could jeopardise the safety of the consumer, especially as entry is almost always on the basis of risk or actual self-harm, or harm to others. According to Standard 11.5.2: 'The exit plan is reviewed in collaboration with the consumer, and with the consumer's informed consent, their carer's at each contact and as part of each review of the individual care plan'. Also, according to Standard 11.3.18, a review should be conducted when the consumer is going to exit the MHS, presumably to ensure that exit is occurring at an appropriate stage of the recovery process. The following account raises serious concerns regarding the review process and level of planning prior to discharge:

Discharged from Graylands Hospital…after only some 15½ hours after admission into a locked facility. Considering that for the majority of this time, [X] was either heavily sedated or asleep during the night, surely this was insufficient time for a full assessment to be given and for the decision to be made that he was well enough to return to Bunbury.

(Carers, Western Australia, Submission #177)

6.5.11.5.2 Inadequate discharge plans

Concerns were expressed that discharge was occurring without appropriate planning and notification to either the consumer or carer. According to Standard 11.6.1: 'Staff review the outcomes of treatment and support as well as ongoing follow-up arrangements for each consumer prior to their exit from the MHS'. Standard 11.6.2 implies that both consumers and cares are notified about discharge so that they can be provided with information and are aware of 'how to gain entry to the MHS at a later date'. This would also suggest that discharge plans had not been developed in collaboration with the consumer and, with their consent, their carer (Standard 11.5.2), that understandable information about the range of relevant services and supports had not been provided (Standard 11.5.4), and that consumers have not established contact with the service providers prior to exit (Standard 11.5.6). These plans are vital in order to ensure ongoing recovery, prevent relapse and ensure reintegration into society as fully as possible:

But then they sedated him even though I told them I would transport him to Graylands. 20 hours later after being in a drug induced state in Graylands he was discharged (the next morning) without any explanation to him or to us.

(Carer, Mother, Western Australia, Bunbury Forum #22)

6.5.11.5.3 Difficulty in coordinating community based services when exiting MHS

A presentation was also made at the Geraldton Forum suggesting that it is difficult to get clinicians involved with planning prior to discharge and that it was difficult to organise community-based services for consumers once they arrived home. This further supports the evidence presented regarding the lack of planning occurring prior to discharge and the lack of support services in the community which therefore necessitates engagement with carers in order to ensure support:

We provide a comprehensive service. It is difficult to link mental health clients to get community based services. There is difficulty getting mental health staff to work in with discharge of patients. It seems to be a big problem with mental health clinicians linking in with the discharge planning. Mental health patients are not linked in to home help.

(Social worker at Regional Hospital, Western Australia, Geraldton Forum #84)

6.5.11.5.4 Other service providers nominated on exit plan not informed prior to exit

Standard 11.5.6 states: 'The MHS ensures that consumers referred to other service providers have established contact and that the arrangements made for ongoing follow-up are satisfactory to the consumer, their carers and other service provider prior to exiting the MHS'. According to one carer, while staff had assured her that procedures had been followed and notifications made, the service provider was unaware of any plans prior to their arrival:

Mother was contacted by [X] advising that he was to be discharged and could she come and collect him from Fremantle. Before proceeding to Fremantle, mother contacted the Alma Street Centre staff to ensure allocation of case manager and accommodation were organised. Mother advised that these needs had been met. She also questioned staff as to whether the doctor believed he was well enough to leave as she did not believe this to be the case... The South West Community Mental Health team only became aware of [X]'s discharge when he arrived on their doorstep.

(Carers, Western Australia, Submission #177)

6.5.11.6 Exit and re-entry

The MHS assists consumers to exit the service and ensures re-entry according to the consumer's needs.

Under this Standard, submissions and presentations indicate concerns about:

- discharge without involvement of carers prior to exit;
- lack of follow-up;
- individual care plans not being reviewed properly prior to exit; and
- discharge while unwell due to lack of resources.

6.5.11.6.1 Discharge without involvement of carers prior to exit

Carers expressed frustration that they were not notified of the consumer's discharge from the MHS, especially as they were expected to assume responsibility of care upon exit from the MHS. This left carers with feelings of extreme stress and fear for the safety of their family member with mental illness. A clinician also expressed concern about the practice of excluding carers in the treatment and discharge process. The clinician acknowledged that as treatment and support services are not available to provide integrated and coordinated care after discharge then, in their absence, carers must be equipped to assume this role in order to ensure the best possible outcomes for the consumer:

> *My other concern is for the carers. They are told not to get involved but there's no one else to get involved. If the service doesn't want to involve carers then who do they think will provide the care once someone is discharged from a hospital? Who else is there?*
>
> (GP, Western Australia, Bunbury Forum #19)

> *My son was discharged from hospital and we didn't even know he had been discharged until he turned up on our doorstep. No one tried to inform us even though they knew he would come back to us because we are his carers.*
>
> (Carer, Mother, Western Australia, Bunbury Forum #22)

6.5.11.6.2 Lack of follow-up

One carer commented that although an arrangement had been made for the dispensing of medication, there was no other contact from the mental health service after discharge from an acute admission to ensure the health and safety of the consumer:

> *After his discharge from hospital [X] had a couple of appointments with the psychiatrist at Swan Valley Centre, then was discharged from there and told to go his GP for his medication. So far [X] has gone twice to be issued with 6 month repeat prescriptions. There has been no other contact – not even a phone call to ask how he is doing.*
>
> (Carer, Mother, Western Australia Submission #99)

6.5.11.6.3 Individual care plans not being reviewed properly prior to exit

Standard 11.6.1 states: 'Staff review the outcomes of treatment and support as well as on-going follow up arrangements for each consumer prior to their exit from the MHS'. Included in the notes to this Standard are 'perception of quality of life' and 'review of goals individual care plan'. One carer expressed concern that insufficient attention was paid to planning rehabilitation and follow-up prior to her son's discharge:

> *I feel my main concerns are that there is: NO FOLLOW UP ON DISCHARGE, NO REHABILITATION ON DISCHARGE. [X] said to me when he came out of hospital 'Mum what am I going to do with my life? I didn't know what to say. (author's emphasis)*
>
> (Carer, Mother, Western Australia Submission #99)

6.5.11.6.4 Discharged suddenly while still unwell due to lack of resources

Concern was expressed in one submission that a decision to discharge a patient was allegedly made on the basis of insufficient staff resources to enable a staff member to accompany a patient to attend court. As no-one was available and the patient needed to attend court, it is alleged that a decision was made to discharge the patient so they could attend, not on the basis that the patient had been assessed to be well enough to be discharged:

> *One particular patient was discharged from hospital in order to attend court and although the hospital wanted someone to accompany him and escort him to Court, there were no available resources to do this. The patient was discharged and never made it to court at all. The question stands: if he was well enough to be discharged, why was an escort sought?*
>
> (Anonymous, Western Australia, Submission #145)

6.5.12 STORIES OF HOMICIDE AND SUICIDE IN WESTERN AUSTRALIA

[X] was a devoted wife and mother of two. She was caring, giving, creative and ill. She was diagnosed with Bi-Polar Affective Disorder in her early 20's. She had a degree in Education, did not take drugs and would always cry out for help when it was often needed. She was not well, this is no secret. Her illness had led her to attempt to take her own life on several occasions. She however conformed to taking her medication and was, what I would consider to be, a person who wanted to live and was willing to do what ever it took for this to happen. On the night of the 29th July 2003 she admitted herself to Sir Charles Gardener Hospital in WA with the support of her husband. She recognised that she was having delusions and was contemplating suicide. This was made clear to the hospital in the admission. I would like to think that her previous history of illness and attempted suicides would have been familiar to the hospital given that she had been a patient in the closed ward of that hospital on a number of occasion - the last being within a few months of her most recent admission. Attempts were made to locate a facility to meet the needs of my sister. It is my understanding that of all the hospitals with closed wards, there were no beds available that evening. Eventually after a long delay, she was transferred to the psychiatric unit at Royal Perth Hospital in the Perth CBD. She stayed there the night but was not in a locked ward. In the morning she walked out of the hospital. She walked less than 500m to a multilevel carpark on the corner of Wellington and Pier Streets. She went to the top floor and jumped to her death.

(Brother, Western Australia, Submission #89)

I am an NGO provider – our surplus of funding from last year was taken from us by the Government without notice. The Government just doesn't think about the implications of taking away funding from NGOs. We already have long waiting lists and taking away funding makes them even longer. One of the young consumers who was on one of our waiting lists for 4 months was also caring for her Mum – she killed herself because she felt she couldn't cope looking after her mum anymore without some support. Waiting lists for support from us have gone up from 3 weeks to 4 months.

(NGO Provider, Western Australia, West Perth Forum #29)

My eldest child gassed himself in his car – after that when we really needed support there was hardly anything for us. It was the lack of support that led to my husband walking out – our family broke up because we had nowhere to turn for help. Then my 12 year old son tried to hang himself on the washing line – I got him down and we got treatment from a private psychologist but he later hung himself in his flat. I have lobbied through lifeline and parliament and I have got nowhere – I am not a judgmental person but I find Jim McGinty is aloof and doesn't care. We need to educate our young people about mental illness and about how to ask for help. Where's the money to educate our young people to ask for help?

(Carer, Mother, Western Australia, West Perth Forum #35)

My son has been diagnosed as paranoid schizophrenic since 1996. My wife and I looked after him for two years. He was charged with wilful murder in November 2000. He is now in prison facing a 20 year prison sentence. In 1999 he received threatening letters from his landlord. He rang me from Maylands. I was unable to leave my wife I was on call 24 hrs a day because she was ill and my son was in Perth. He was delusional and needed help. I spent 4 days I rang the crisis centre in Maylands Mental Health (PET) regularly and each time had to tell the full story - they wouldn't listen to me and wouldn't do anything. I rang the police nothing was done. They wouldn't do anything. After 3 ½ yrs in Graylands he is now better than he has ever been. He is now in Hakea prison. The help I got was none. For a dangerous situation there was no help available for me or my son.

(Carer, Father, Western Australia, Geraldton Forum #49)

My daughter's hanging was needless as were the high doses of medication and at her coronial enquiry many flaws were unearthed. An uncaring hospital who said they didn't believe she was suicidal even though she had driven herself there and one staff member said 'we didn't believe her as she was well mannered, articulate and attractive!' Her post mortem showed her to be a male of 44 when, obviously, she was female and 24.

(Carer, Mother, Western Australia, Submission #103)

My husband was suffering from Post Traumatic Stress Syndrome (undiagnosed) and spent all his waking hours thinking and talking about suicide. I had no idea where to get help and I think a local GP got me in touch with (probably) South West Mental Health. A male nurse came and visited us at home and we each in turn and in private talked to him. I explained that I felt sure that [X] would try to convince the nurse he was fine and it was in my imagination, which he successfully did. I explained to the nurse how desperate the situation was and that we needed help immediately because [X]'s hyper anxiety and my helplessness was driving me to also consider suicide as the only way out. The nurse said nothing can be done until my cases are reviewed by a psychiatrist who comes down from Perth in two weeks. I stressed how desperately we needed help now, and wasn't there any other avenue. He was adamant it was the only thing that could be done. I rang in two weeks and was told something to the effect that: It is not a high priority. After my crying and carrying on he said I could go to the local GP and get a referral which I did but there was a great waiting period. A couple of weeks later I found my husband in a farm shed covered in blood from cutting his face and wrists. He had caused no great danger to himself and after a couple of days in Harvey Hospital he was transferred to Hollywood Hospital. Three months later he succeeded in killing himself. I was so angry at having been so consistently 'fobbed off' that I went to the Mental health place in Bunbury and complained and the lady I spoke to said. "These things happen". As if it simply wasn't important.

(Carer, Wife, Western Australia, Submission #96)

My mother committed suicide on the 14th May 2002, 4 months after the birth of my eldest daughter. Mum had suffered with depression of what we think was a twenty year period, having made two previous attempts to commit suicide prior to her death. For the 4 years prior to her death we saw a consistent and notable decline in her outlook and demeanour, while receiving occasional treatment from her GP. Myself and my siblings tried so hard to help, but were always out of our depth, and growing up with a depressed mother I think made it hard for us to have a clear perspective. Mum overdosed on the anti-depressants she had been prescribed, taking 96 of them in one sitting. She had so many anti-depressant pills to take that she had a plastic box labelled with the day, each one containing 4 or 5 tablets. As I recollect, over the twenty year period, she was not offered counselling outside of her GP and all treatment seemed to be purely pharmaceutical. … All I know is that I have a strong feeling that my mother's case was poorly managed, and the goal was always to get her through the system as quickly as possible, not to prevent her from dying.

(Son, Western Australia, Submission #87)

6.6 AUSTRALIAN CAPITAL TERRITORY

ANALYSIS OF SUBMISSIONS AND CONSULTATIONS FROM THE AUSTRALIAN CAPITAL TERRITORY AGAINST THE NATIONAL STANDARDS FOR MENTAL HEALTH SERVICES

In summary, information presented in this section was gathered from 14 submissions (see Appendix 8.3.6) and presentations made at a community forum attended by approximately 100 people (see Appendix 8.1). A draft copy of this report was sent to the Chief Minister and Minister for Health for comment. An analysis of the response from the ACT Government (reproduced in Appendix 8.4.6) and an overall review of mental health service delivery in the Australian Capital Territory is contained in Part 2.7.6.

6.6.1 STANDARD 1: RIGHTS

The rights of people affected by mental disorders and or mental health problems are upheld by the MHS.

> *Because intervention comes so late, consumers and families report that once the police are involved and no matter how the police are, there is still a sense of not being treated with dignity. One consumer explained the situation: 'I know when I get sick that I quickly lose insight and will resist treatment but I am sick and there I am being handcuffed by police. No other groups of people with an illness are treated like this. Why are we? Surely there can be a better way. I think it starts with me being able to say, I'm becoming unwell and clinicians taking me seriously.*
>
> (Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

Under this Standard, submissions and presentations indicate concerns about:

- problems with complaints procedures;
- consumers not being treated with dignity and respect; and
- carers not being provided with information.

6.6.1.1 Problems with complaints procedures

Consumers and carers who had used the complaints procedure reported feelings of anger with the amount of time the process had taken. None would have described the complaints procedure they dealt with as 'easily accessed, responsive and fair' (Standard 1.10).

Failure to have in place a system which allows patients, families and carers to effectively and confidentially make complaints weakens this right and fails to provide a mechanism by which to 'improve performance as a part of a quality improvement process' (Standard 1.12). One clinician also expressed concern regarding the delays in dealing with complaints and that many people are fearful of lodging a complaint as it may impact on treatment and service provision in the future. Evidence presented suggests that the process does not allow for the identification of single or systemic failures and thereby does not allow for personal redress or systemic improvement.

The length of time in responding to the coronial inquiry is too long. There has been a very slow response to [X]'s death. A report has been commissioned but won't be released until May. There has been a lack of follow up to [X]'s death. I am still waiting three and a half years later for the coronial inquiry – my human rights are being violated.

(Carer, Partner, Australian Capital Territory, Canberra Forum #17)

We need to look at improving management of complaints to increase turn around time. People are fearful of making a complaint on services they are going to need to use in the future. We need to support registration of complaints.

(Service Provider, Australian Capital Territory, Canberra Forum #22)

We need to face the truth about the abuses that are still happening far too commonly in mental health services – particularly in acute services. The mental health system in still doing a lot of damage to a lot of people and we do, really, need to expose this and creatively find ways to make it better.

(Consumer, Australian Capital Territory, Submission #287)

Other things that have occurred and to make it relevant I will talk about my last admission. Don't get me wrong I have tried to complain and the complaint is ignored or they say I am imagining it or making it up for attention.

(Consumer, Australian Capital Territory, Submission #287)

Because of the publicity we obtained it forced [Y[, the Minister for Health, to order an independent enquiry into the treatment of [our son] and also to look at the Mental Health Act. This was only ordered after we had not heard from [Y] and wrote to the Opposition Leader, [W] who replied to us immediately. [Y] arranged for [Z], Director of Psychiatry at the Alfred Hospital Victoria to prepare an independent inquiry. We have finally received and we are pleased to see that some things have been put in place to protect the patient more and that they would not have as much freedom as [our son] had. As [Dr Z] said our family was taking the place of the staff who should have been doing their job. They are the "the experts" not us.

(Carers, Parents, Australian Capital Territory, Submission #354)

A protocol needs to be developed for the dealing with complaints on a prompt basis whether it be from official agencies such as OCA or others including family, friends and carers. A responsible accountable system for dealing with complaints may well assist morale and confidence in the safe care provided by PSU. (Excerpt from Report of findings by the Chief Coroner)

(Carer, Partner, Australian Capital Territory, Submission #305)

The availability of an accountable complaints system may well alert those responsible to issues that may otherwise be overlooked. (Excerpt from Report of findings by the Chief Coroner)

(Carer, Partner, Australian Capital Territory, Submission #305)

6.6.1.2 Consumers not being treated with dignity and respect

The Mental Health Community Coalition Consumer and Carer Caucus reported that many consumers during their involvement with the MHS felt that they were not treated with dignity and respect. Similar sentiments were expressed by a consumer with regard to treatment in hospital settings and, as noted, above, due to involvement with the police.

A lack of dignity and respect in care received from mental health services are reported generally but in particular, forensic patients, young people and Aboriginal patients are reported to be treated poorly.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

Acute services are mostly horrible places to be. Some of this is because you are sick but I don't believe they have to be as bad as I have experienced them. I do not like being treated like a five year old. I do not like being patronised. I do not like being ignored and having to plead for attention.

(Consumer, Australian Capital Territory, Submission #287)

Consumers and carers both reported that to get help in a crisis generally means getting the police involved. Carers told of the consequences of police involvement and its impact on relationships. 'Once this occurs the person is carted off in handcuffs by police and we are never forgiven'. And 'We don't want to be seen as the enemy but we are put in this position all because we try to get help before something bad happens.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

The thing that happened was spilling hot tea from a cup above [my] lap 4 times and that was not an accident, refusing me laxatives till I had not passed anything for 10 days and stomach swelled, accusation while [I'm in] the toilet or shower that I am cutting or sniffing, bitching about me to other nurses from the nurses station which is in hearing of other patients and myself. Mocking and kicking me while [I'm] in with the psychiatrist and rolling their eyes at me. I know that these are pretty petty to what happens to others but I would be glad for you to use them.

(Consumer, Australian Capital Territory, Submission #287)

6.6.1.3 Information not provided to carers

Carers expressed concern that they were often not given information about a range of services and supports available. Standard 1.8 states: 'The MHS provides consumers and their carers with information about available mental health services, mental disorders, mental health problems and available treatments and support services'. For many carers, this included failure to be notified that they could receive financial assistance from Centrelink. For many families, the inability to access treatment and support services and the lack of available supported accommodation results in disruption to employment for carers and places other considerable strain on families. This information is therefore vital. Concern was also raised that young members of the family are not always acknowledged as 'carers' and being provided with information about how to access support services for themselves.

Service providers present reported that it is not uncommon for families to be unaware of the carer payment available through Centrelink.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

[Y] noted, in considering what services are available to young carers, there are so many kids who don't know, so don't ask.

(17 year old Carer, Sister, Australian Capital Territory, CYCLOPS ACT Young Carers Consultation #1)

As a carer I would ask where can I go to get professional help, rather than pay an arm and a leg for help? I don't have any support.

(Carer, Wife, Australian Capital Territory, Canberra Forum #4)

In response to a discussion on mental health services available for young carers, [Y] said he had been given a phone card which he uses to keep in contact.

(13 year old Carer, Son, Australian Capital Territory, CYCLOPS ACT Young Carers Consultation #3)

The failure to provide information in the above examples also implies that these consumers and carers may not have been provided with a written or verbal statement of their rights and responsibilities as required by Standard 1.2 (consumers and their carers are provided with a written and verbal statement of their rights and responsibilities as soon as possible after entering the MHS) in a way that is understandable to them (Standard 1.3).

6.6.2 STANDARD 2: SAFETY

The activities and environment of the MHS are safe for consumers, carers, families, staff and the community.

Under this Standard, submissions and presentations indicate concerns about:

- inadequate treatment and support services to ensure the safety of consumers, carers and the community;
- safety not ensured in hospital environments; and
- concern over the handling of critical incidents in hospital settings and safety reviews.

6.6.2.1 Inadequate treatment and support services to ensure the safety of consumers, carers and the community

As documented elsewhere in this Report, consumers, carers and staff also raised concerns about their inability to access treatment and support services during times of crisis even when there was an imminent risk of self harm or harm to others. Standard 2.3 states 'Policies, procedures and resources are available to promote the safety of consumers, carers, staff and the community'. Consumers and carers reported that in order to receive treatment, consumers in crisis felt they had to attempt suicide or cause sufficient damage to warrant a response beyond incarceration.

> *My son deteriorates, he is then in and out of gaol, only ends up in hospital after he has harmed himself.*
>
> (Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

> *The CATT [Crisis Assessment and Treatment Team] said my relative was too dangerous and that we were to call the police. We then spent several weeks trying to get our relative mental health treatment. Our relative became sicker, hungrier, more mal nourished and more dangerous to himself. In the end he got help after seriously harming himself. He could have died from self inflicted injuries but a member of the family found him.*
>
> (Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

> *What is wrong with the CATT and the emergency processes? It's getting worse. They tell us they are short staffed. They tell us they can't talk to us that it's a matter of privacy and confidentiality, but surely when our lives and our safety are at risk, they must listen to us.*
>
> (Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

I ended up causing $100,000 damage from smashing windows at the ACT Legislative Assembly. I did this because I had the wrong diagnosis and had received the wrong treatment…I went to ACT mental health services the day before I smashed the windows [at the ACT Legislative Assembly]. I was given an appointment to see them in three days. This was of no help.

(Consumer, Australian Capital Territory, Canberra Forum #14)

"…we're the only ones who cop all his crap." When asked what this is like, [Y] replied: "Bad, it should be the mental health crisis team or whatever, but it's us.

(17 year old Carer, Sister, Australian Capital Territory, CYCLOPS ACT Young Carers Consultation #1)

My biggest concern is, that because he has often had a tendency towards violence, his delusional state while it continues to go untreated, will escalate and one day he will really lash out and someone will be hurt.

(Carer, Father, Australian Capital Territory, Submission #208)

6.6.2.2 Safety not ensured in hospital environments

Concern was expressed that policies and procedures are not offering sufficient protection for consumers to feel safe in hospital settings. Standard 2.2 states: 'Treatment and support offered by the MHS ensure that the consumer is protected from abuse and exploitation'. The notes to Standard 2.2 state that safety is 'considered in terms of physical, social, psychological and cultural dimensions'. Standard 2.3 further states: 'Policies, procedures and resources are available to promote the safety of consumers, carers, staff and the community'.

With regard to his clinical management, it is surprising, however, that the level of potential overwhelming despair and despondency that the patient intermittently suffered and the accompanying suicidality was not managed by a more restrictive approach to the granting of leave. Evidence of this is that he was given accompanied leave on the day of admission within 24 hours of taking himself to Telstra Tower… The family was very much involved in the patient's care and were obviously present on a daily basis. The handing over of the care of the patient, when on leave from the ward, to a family naïve about the management of a seriously ill patient carried some risks… Two problems arise when reviewing the leave arrangements. Firstly, the family members and the girlfriend are not skilled in mental health care and are not expert in the area. They did not know what to expect, what were the potential vulnerabilities, what risks were inherent in the illness of depression and what to look out for. The frequency of handing over the care, during times of leave, of the patient into the family's care, was more than I have expected. Clearly there is a balance that needs to be struck between the wishes of the patient to be in the company of family, and the need to monitor the patient and engage the patient in the ward therapeutic activities program. In retrospect the frequency of leave in the context of a fluctuating mental state and patchy clinical progress appears to go beyond usual practice. The family and the girlfriend have put trust in the directions and instructions of the treating staff. The tragic eventual result of this level of practice was that the girlfriend was present and witnessed his death. (excerpt from a report prepared by an independent external reviewer)

(Carers, Parents, Australian Capital Territory, Submission #354)

Dr. [V]'s comments that the family could be used to "special" (that is, provided one to one care and safety for the patient) in Hyson Green suggests to me a potential conflict of the role of concerned family members. They may well be a support and an adjunctive to care, but should not replace nursing care, whether it is specialling (as in P.S.U. [Psychiatric Support Unit] overnight of the [dates 2003]), or escorting patients on walks and other activities. The obvious reason is that families are not trained in mental health care. (excerpt from a report prepared by an independent external reviewer)

(Carers, Parents, Australian Capital Territory, Submission #354)

Violent and difficult patients: The lack of specified facilities within the ACT mental health system has been identified for coping with violent and difficult patients, in particular with forensic patients in this class…The arrangements with patient [Y] at the time of the incident was fraught with danger and a disaster waiting to occur (Excerpt from Report of findings by the Chief Coroner)

(Carer, Partner, Australian Capital Territory, Submission #305)

Insufficient staff and supervision of the deceased in the HDU [High Dependency Unit] at the time of the incident causing death… The lack of sufficiently detailed protocols and practices to involve valuable clinical information from family, friends and carers resulted in a situation where the fullness of the risk for the deceased may not have been appreciated…(Excerpt from Report of findings by the Chief Coroner)

(Carer, Partner, Australian Capital Territory, Submission #305)

For those of us who have experienced childhood trauma of any kind being locked up and searched and detained in any way can cause even further trauma. I know that I have met many, many people in acute settings who come from such backgrounds. These people are very fragile and need protection, which is often not forthcoming.

(Consumer, Australian Capital Territory, Submission #287)

6.6.2.3 Concern over the handling of critical incidents in hospital settings and safety reviews

Serious concerns were expressed about the handling of clinical reviews following the deaths of people with mental illness while in care. Specifically, an independent external reviewer highlighted as a significant concern the fact that no medical personnel were involved in a coronial inquest of a patient who died while in hospital care, and that a thorough investigation and review had not occurred. In particular, it was noted that such processes could reassure staff and the public that lessons had been learnt and future risks minimised. The lack of adherence to policies and procedures to review such critical events and the need to revise policies and procedures were noted as essential to ensure safety for consumers.

In the medical record I reviewed I could find no evidence of significant clinical review post death either at Calvary Private Hospital or The Canberra Hospital. I would have expected that the management of those hospitals and Mental Health A.C.T. would have required that clinical reports be generated as a death by suicide of an inpatient is a sentinel event which requires thorough investigation and review. This has been undertaken. In such a review I would have expected to find, possibly in the format of a root cause analysis, recommendations and actions. (excerpt from a report prepared by an independent external reviewer)

(Carers, Parents, Australian Capital Territory, Submission #354)

On [date] 2003, the Coroner held an inquest into the death of [X]…The lack of medical witnesses, summonsed or otherwise to the court, is surprising. The patient had died whilst in the care of an inpatient ward and was recently detained under the Act in another. Although the deceased did not meet the criteria under the Coroner's Act for an inquest into the death of a person in custody, the death of an inpatient under treatment by suicide should have, in my opinion, led to a more thorough coronial investigation. The opportunity for the family, through its legal counsel, to ask questions of the medical staff so as to assist the Coroner in the discharge of his responsibilities under the Act did not occur. The Coroner in his findings made no comment about the care and treatment provided in The Canberra Hospital or Calvary Private Hospital as the Coroner did not investigate such…The lack of involvement of medical personnel in the Coronial Inquest is of significant concern. There has been a strong incident reporting and sentinel event review process at both hospitals. I believe that the public and staff can be reassured that lessons are learnt from adverse outcomes and future risks minimised… A sentinel event / serious incident review process policy should be evaluated. There should be at least a root cause analysis of each sentinel event, and it should include recommendations and actions. (excerpt from a report prepared by an independent external reviewer)

(Carers, Parents, Australian Capital Territory, Submission #354)

> *Procedures concerning the response and reaction of the emergency team upon an alarm being raised in PSU should be assessed and appropriate systems be put in place and be subject to continuous audit to ensure proper and prompt operation. (Excerpt from Report of findings by the Chief Coroner)*
>
> (Carer, Partner, Australian Capital Territory, Submission #305)

6.6.3 STANDARD 3: CONSUMER AND CARER PARTICIPATION

Consumers and carers are involved in the planning, implementation and evaluation of the MHS.

No submissions or comments were received pertaining to this Standard.

6.6.4 STANDARD 4: PROMOTING COMMUNITY ACCEPTANCE

The MHS promotes community acceptance and the reduction of stigma for people affected by mental disorders and/or mental health problems.

> *The belief exists that people with mental illness are inferior citizens who are best confined to certain areas, if not buildings, because they "would be happier there" and other citizens have a right not to be even mildly bothered by them. In fact people want them out of sight so that they do not have to deal with the reality of their existence.*
>
> (Carer, Australian Capital Territory, Submission #173)

Under this Standard, submissions and presentations indicate concerns about:

- discrimination in employment settings;
- need for community education;
- non-acceptance by family;
- lack of community support, especially in schools; and
- stigma and stereotypes perpetuated by the media.

6.6.4.1 Discrimination in employment settings

Concerns were expressed about discriminatory practices in employment settings which preclude people with mental illness from participating successfully in the workplace. These included problems with application forms, disclosure during the application process, lack of support when employed and termination as a result of mental illness.

Many of these problems could be addressed by activities associated with Standard 4.2 'The MHS provides understandable information to mainstream workers and the defined community about mental disorders and mental health problems'. Employment and support in the workplace by managers and other employees are seen as critical in the rehabilitation phase, reducing the impact of illness in the long-term and successful reintegration into society at a social and financial level.

> *I suffer from reactive depression. I've been suicidal. I have not attempted suicide, but the issue never goes away. I'd like to talk about the issue of declaring mental illness to employers. I don't declare my illness when I apply for a job, but I had to on joining the [Commonwealth] Public Service. I had to declare my illness on a superannuation form. Then a black mark is put against my name.*
>
> (Consumer, Australian Capital Territory, Canberra Forum #19)

I took 3 months off from work on personal leave to recover from suicidal thoughts. When I came back, I had to deal with new management and new thinking. Previously, I had a supportive supervisor. I asked for a transfer to another section. The new management sought a psychiatric assessment of my illness. Their solution to the problem was to pension me off rather than look to work with me around the illness.

(Consumer, Australian Capital Territory, Canberra Forum #19)

The workforce is in a crisis as there is still a lot of stigma in society.

(Consumer Consultant, Australian Capital Territory, Canberra Forum #23)

The program plays a very important role in supporting the mental health for the people participating. For example, one client of the program who moved on to another job at a café which was going really well, he was managing people and doing well. But he was stressed by the pressures of the job and of hiding his illness. He had no support as he was hiding his illness. He got sick again and this time gotten worse than before. This example demonstrates the dilemma for people with mental illness seeking employment. Should people declare their illness or not? This example shows it is better to reveal mental illness to employers up front.

(Carer, Father and volunteer service provider, Australian Capital Territory, Canberra Forum #16)

6.6.4.2 Need for community education

Carers expressed concern about the stigma that still surrounds mental illness and how this resulted in friends and other members in the community distancing themselves from the consumer and the family. A young carer expressed concern regarding the need for additional community awareness campaigns and that simple provision of information is not enough to change the community's level of understanding and reduce stigma. This would indicate that further work such as campaigns and activities by the MHS to address community acceptance and reduce stigma (Standard 4.1) are required.

Discrimination and lack of community acceptance are key barriers to people with mental illness (and their family members) being able to participate socially, economically and politically in society. Carers reported their family members feeling "like outcasts of society".

It seems as soon as one had an experience and is labelled by the system people just don't listen or think they are important or have anything worthwhile to say. Such is the attitude of some people who make them feel like outcasts of society.

(Carer, Sister, and Consumer, Australian Capital Territory, Submission #172)

[Y] added there needs to be more awareness about mental illness. There is still a lot of stigma. People have misconceptions about mental illness. "Sometimes you see people walking around the streets who obviously have something wrong with them, and there needs to be more awareness so people are more accepting." [Y] said in a PD / CD (personal development / Christian development) class there was a session on mental illness but the teachers had no idea. A student commented to [Y] afterwards they wanted to have schizophrenia so they could hear voices in their head. [Y] said even when provided with information, the message doesn't seem to get through. People just don't want to acknowledge it.

(17 year old Carer, Sister, Australian Capital Territory, CYCLOPS ACT Young Carers Consultation #1)

There is a complete lack of understanding in the community that people may be able to function in some parts of their lives and not in others, or they may well for some part of the day/week/year and not others. This lack of understanding leads to unjustified criticism and discrimination.

(Carer, ACT, Submission #173)

6.6.4.3 Non-acceptance by family

As the following quote indicates, the need for activities to promote community acceptance not only for the community but for family members is critical.

> *The family never rings, or visit even though he has asked them to do so. Their excuse is that they are frightened.*
>
> (Carer, Father, Australian Capital Territory, Submission #208)

6.6.4.4 Lack of community support, especially in schools

Concern was also expressed about the lack of support and understanding for young carers in the school setting. This was particularly expressed with regard to teachers and the lack of school support offered to accommodate this student's needs.

> *[Y] said he had got crap from bullies about his Mum and learnt not to tell anyone. "Most people find it confusing."*
>
> (14 year old Consumer and Carer, Son, Australian Capital Territory, CYCLOPS ACT Young Carers Consultation #2)

6.6.4.5 Stigma and stereotypes perpetuated by the media

Concern was expressed with regard to the manner in which the media reports suicides and method of suicide. Media coverage and reporting influences community attitudes and understanding of mental illness and activities by the MHS to reduce stigma in the community must also address educating the media.

> *…partner also criticised the response of the media in reporting suicide, and in particular that the media often reports the method of suicide.*
>
> (Carer, Partner, Australian Capital Territory, Canberra Forum #17)

> *Each time I contact the media, I point out that there are guidelines published by the Federal Government. They obviously sit on a shelf unopened and nobody except SANE does anything about it.*
>
> (Carer, Australian Capital Territory, Submission #173)

> *Another matter that is misrepresented in the press is the association between schizophrenia and violence. Violent behaviour can occur when a person has schizophrenia, but it is usually associated with drug or alcohol abuse and sometimes with untreated illness. When it does occur, however, it is treated in the media as the norm for such illness. There is never a balancing statement about the large number of people with schizophrenia who have not been violent. Invariably a diagnosis of schizophrenia is highlighted in court reporting when a crime has been committed, yet it is never mentioned when a person charged with a crime has diabetes or some other illness. Does this not amount to discrimination against people with schizophrenia?*
>
> (Carer, Australian Capital Territory, Submission #173)

> *I am appalled with the number of times media articles or TV dramas use words like nutters, loonies etc. to refer to people with mental illness. There was a particularly bad example in the Canberra Times some months ago in an article on arson. It talked about the twenty percent of the population with mental illness and then concluded that those ... loonies (I cannot remember the exact words) could not possibly account for all the examples of arson. Secretarial staff at the paper were appalled when I pointed the words out to them, but editorial staff cared so little that there was no apology nor any attempt to speak to me about the matter. I was given the email address of the writer, a freelance journalist. I wrote to him, but received no reply.*
>
> (Carer, Australian Capital Territory, Submission #173)

6.6.5 STANDARD 5: PRIVACY AND CONFIDENTIALITY

The MHS ensures the privacy and confidentiality of consumers and carers.

> *Those in attendance discussed the National Statement of Rights and Responsibilities that states: There may be circumstances where the consumer is unable to give consent or may refuse consent because of their disturbed mental state. In such cases it may be appropriate for service providers, carers and/or advocates to initiate contact and involve those who may be able to assist with the contact and involve those who may be able to assist with the consumer's diagnosis and care.*
>
> (Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

Under this Standard, submissions and presentations indicate concerns about policies and procedures to protect confidentiality.

6.6.5.1 Problems with policies and procedures to protect confidentiality

Carers expressed concerns that a misunderstanding of policies and procedures to protect the confidentiality and privacy of consumers is hampering communication between consumers, carers and clinicians in the provision of treatment and vital information. Carers continue to express frustration in being expected to provide support but are not informed of the treatment process and can not contribute information about what is occurring. One mother stated: "How are we supposed to help him if we don't know what's going on with him?" Furthermore, these concerns would indicate that these policies and procedures are not being made available to consumers and carers in an understandable language and format (Standard 5.2) and that the MHS is not encouraging and providing opportunities for consumers to involve others in their care (Standard 5.3).

> *There is an issue with confidentiality. I wish I had taken out a Guardianship Order when my daughter first became ill. I would have overcome some of the problems we are now experiencing. I am her support not an interfering mother as I am labelled.*
>
> (Carer, Mother, Australian Capital Territory, Canberra Forum #1)

> *What is wrong with the CATT and the emergency processes? It's getting worse. They tell us they are short staffed. They tell us they can't talk to us that it's a matter of privacy and confidentiality, but surely when our lives and our safety are at risk, they must listen to us.*
>
> (Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

> *Family members reported that confidentiality is often used as reason as to why they cannot told anything by mental health clinicians. Family members argued: 'Surely when my safety is at risk, I have a right to know certain, if not prescribed, information.'*
>
> (Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

> *Carers and advocates have the right to put information concerning family relationships and any matters relating to the mental state of the consumer to health service providers.*
>
> (Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

[Y] provided an example when her mother took time off work to visit her son's GP, as [Y]'s brother was going through a particularly bad time. [Y] said her brother would come over to the house and her mother wanted to ask his GP what was going on from a medical point of view. The GP told [Y]'s mother he could not tell her anything about her son's illness as medical history was private information. [Y]'s mother explained she just wanted a medical point of view on whether her son was OK or not, and explained she had taken time off work to visit with the GP and that she was his mother. The GP asked [Y]'s mother would she like to see a counsellor. [Y] noted her mother said to the GP "How are we supposed to help him if we don't know what's going on with him?"

(17 year old Carer, Sister, Australian Capital Territory, CYCLOPS ACT Young Carers Consultation #1)

The mental health system failed [X] in so many ways. In summary the key failings were: … the role of family members as carers was ignored: they would not listen to our input and apparently valued privacy requirements above everything else, including [X]'s welfare and even his life.

(Carer, Sister, Australian Capital Territory, Canberra Forum #9)

Family, friends and carers could provide information valuable for such a plan and they need to be involved on discharge of patients to be treated within the community. Information from family, friends and carers is important for treatment planning and risk assessment and for the continuation of treatment upon discharge. The problem of patient resistance to the involvement of family, friends and carers and privacy issues needs to be contended with. Best practice does involve this question. It did not happen here at an appropriate level… (Excerpt from Report of findings by the Chief Coroner)

(Carer, Partner, Australian Capital Territory, Submission #305)

6.6.6 STANDARD 6: PREVENTION AND MENTAL HEALTH PROMOTION

The MHS works with the defined community in prevention, early detection, early intervention and mental health promotion.

Under this Standard, submissions and presentations indicated concerns about:

- inability to access treatment and support services for early intervention – need to wait for a crisis;
- need for education campaigns in schools;
- lack of support for children of parents with mental illness; and
- lack of rehabilitation programs.

6.6.6.1 Cannot access services for early intervention – need to wait for a crisis

Whether due to lack of resources, or other reasons, ACT MHS operates under a risk management approach. Thus only people who are in crisis receive attention from MHS. As a result, those people who are not in crisis receive very little support, eg case management. In fact we understand ACT MHS does not provide case management now, but "clinical management".

(ACT Disability, Aged and Carer Advocacy Service (ADACAS), Australian Capital Territory, Submission #139)

Carers and consumers expressed serious concerns about the lack of a preventive focus in the delivery of mental health services, despite the emphasis of such an approach in Standards 6.4 (capacity to identify and respond to the most vulnerable consumers in the community), 6.5 (capacity to identify and respond as early as possible) and 6.6 (treatment and support to occur in a community setting in preference to an institutional setting).

In particular, all mentioned how unacceptable it was, on many levels, for treatment and support services not to be provided at the earliest possible moment to prevent deteriorating illness. As a result, the consumer was at risk of harming themselves or others, and the rest of their life had also deteriorated (e.g. employment, social withdrawal, prison) and required acute care, often in restrictive settings with rigorous treatment regimes.

> *Both consumers and carers reported that in the ACT it is almost impossible to get intervention or be listened to at an early stage when warning signs are initially beginning to appear.*
>
> (Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

> *I come from Toronto in Canada, where I was able to get same-day access to psychiatrists when I need mental health care. In Canberra, I tried to get access to mental health care when I was becoming unwell. The doctor estimated that I wasn't psychotic enough. The doctor told me they couldn't help as they didn't have the resources, but if I was becoming more unwell and reached a point where I couldn't leave my apartment then I should "give him a call". If people are that unwell these things are beyond them!*
>
> (Consumer, Australian Capital Territory, Canberra Forum #21)

> *Families report that mental health services often do not listen to them when they try to get help in a crisis: 'people are just fobbed off in a crisis no matter how well our relative's case is known. The CATT tells us to phone the police.'*
>
> (Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

6.6.6.2 Need for education campaigns in schools

Concern was expressed by a young carer that information about mental illness and mental health problems and promotion of mental health were lacking in schools. Standard 6.3 states: 'The MHS provide information to mainstream workers and the defined community about mental disorders and mental health problems as well as information about factors that prevent mental disorders and/or mental health problems'. Such programs could also address stigma associated with mental illness and community acceptance and acceptance of children of parents with mental illness (discussed below).

> *[Y] added there needs to be more education about mental and physical illness and disabilities in schools. They have sex education and drug awareness and healthy eating education at his school but he hasn't been to a school that talks about mental illness.*
>
> (14 year old Consumer and Carer, Son, Australian Capital Territory, CYCLOPS ACT Young Carers Consultation #2)

6.6.6.3 Lack of support for children of parents with mental illness

Concern was also expressed by a young carer about the lack of support that was provided to him while he cared for his mother and how this resulted in his mental health deteriorating to the point of feeling suicidal. Standard 6.4 states: 'The MHS has the capacity to identify and appropriately respond to the most vulnerable consumers and carers in the defined community'. In the notes and examples to this Standard are: 'services for the children of parents with a mental disorder…and liaison with school counsellors'.

[Y] said his mother has schizophrenia. [Y] said when he was 7yrs old his Mum used to lay in bed until 3pm and then get up and watch television before going back to bed. [Y] said his teachers didn't understand and he was insulted by other kids because his family didn't have any money. [Y] said he felt very suicidal between 12-13 yrs and started seeing a counsellor and was put on medication. He said he thought some of the teachers were bullies. He had difficulty doing home work, was often on detention and found it difficult to make friends.

(14 year old Consumer and Carer, Son, Australian Capital Territory, CYCLOPS ACT Young Carers Consultation #2)

6.6.6.4 Lack of rehabilitation programs

Rehabilitation programs are a critical step for both reintegrating back into full life after a period of illness and preventing relapse for many people with mental illness. Such programs would include living skills programs, respite and social programs. Access to rehabilitation programs is covered under Standard 6.8 'The MHS ensures that the consumer has access to rehabilitation programs which aim to minimise psychiatric disability and prevent relapse'.

Concern was expressed however that ACT mental health services place little emphasis on rehabilitation programs or other programs to prevent relapse or promote recovery as no rehabilitation programs are available for consumers to access. These programs are essential to promote and protect the social and economic participation rights of consumers.

There is no rehabilitation available as follow up.

(GP, Australian Capital Territory, Canberra Forum #5)

6.6.7 STANDARD 7: CULTURAL AWARENESS

The MHS delivers non-discriminatory treatment and support which are sensitive to the social and cultural values of the consumer and the consumer's family and community.

No submissions or comments were received pertaining to this Standard.

6.6.8 STANDARD 8: INTEGRATION

6.6.8.1 Service integration

The MHS is integrated and coordinated to provide a balanced mix of services which ensure continuity of care for the consumer.

Under this Standard, submissions and presentations indicate concerns about:

- service not integrated to provide a mix of services to respond to consumer needs, not even in a crisis; and
- high staff turnover resulting in problems with continuity of care.

6.6.8.1.1 Service not integrated to provide a mix of services to respond to consumer needs, not even in a crisis

A major concern highlighted in many submissions and presentations was the inability for consumers to access services at various stages of the illness cycle. Concern was also expressed that services were not integrated to ensure continuity of care and prevent deteriorating health. The reports indicate that consumers, carers and clinicians had attempted on many occasions to contact the MHS but received an inadequate reply and that separate programs of the MHS were not working in an integrated and supported manner. Standard 8.1.1 states: 'There is an integrated MHS available to serve each defined community'. Included in the notes to this Standard are inpatient care, crisis intervention, case management and rehabilitation.

> *The mental health system failed [X] in so many ways. In summary the key failings were: Third, was lack of integration across the various mental health areas, such as the hospitals and the mental health crisis team, and related areas such as Drug and Alcohol services and accommodation facilities: we are a very "bureaucracy-literate" family and we had immense difficulty navigating the system.*
>
> (Carer, Sister, Australian Capital Territory, Canberra Forum #9)

> *2 weeks ago I received a call from a person who was suicidal. I took her to see her case manager, who assessed her. He told her "you are depressed but there are no beds available". I got the call the morning she was admitted. She said "I am going to kill myself". I spoke to Crisis. They said they would speak to her. 2 hours later they still hadn't called her. I called around and eventually organised a bed.*
>
> (GP, Australian Capital Territory, Canberra Forum #5)

> *The mental health emergency and crisis processes are simply not working and are frequently failing.*
>
> (Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

6.6.8.1.2 High staff turnover and rotations resulting in problems with continuity of care

Concerns were also expressed regarding the high staff turnover in various components of the MHS, which impacts on the ability of the MHS to deliver continuous and integrated care. The impact for one consumer of having to continuously restart the familiarisation process with each new staff member resulted in the consumer choosing an alternative which is less than ideal and jeopardises educational achievement and disrupts his school social system. Standard 8.1.4 states: 'Opportunity exists for the rotation of staff between settings and programs within the MHS, and which maintains continuity of care for the consumer'.

> *He has a different social worker every three months and suffers from psychotic episodes. He finds it difficult to trust people and the constant changes to the social worker assigned to his case are not helpful.*
>
> (17 year old Carer, Sister, Australian Capital Territory, CYCLOPS ACT Young Carers Consultation #1)

> *[Y] has depression and no longer accesses counsellors through ACT government services. [Y] explained the counsellors in the government system change a lot so he had to keep starting from the beginning and moving to a point in his story, when the counsellor would be replaced with another, and he would have to start again. [Y] said he found this really frustrating. [Y] said the counsellors in the government services didn't know why they were swapped around.*
>
> (14 year old Consumer and Carer, Son, Australian Capital Territory, CYCLOPS ACT Young Carers Consultation #2)

[Y] prefers to use the school counsellor or talk to his friends. He noted it is sometimes hard using the school counsellor as he can only see the school counsellor during lunchtimes so he doesn't really get a lunchbreak. [Y] also explained it is difficult using a school counsellor as he often feels down after a counselling session and finds it difficult to concentrate on school work afterwards. [Y] has been seeing a social worker for about two years and has a Doctor.

(14 year old Consumer and Carer, Son, Australian Capital Territory, CYCLOPS ACT Young Carers Consultation #2)

A succession of doctors and caseworkers mean instability and an unwillingness on [X]'s part to do anything.
(Carer, Father, Australian Capital Territory, Submission #208)

6.6.8.2 Integration within the health system

The MHS develops and maintains links with other health service providers at local, state and national levels to ensure specialised coordinated care and promote community integration for people with mental disorders and / or mental health problems.

Under this Standard, submissions and presentations indicate concerns about

- comprehensive health care not being promoted by the MHS; and
- inability of consumers to afford basic health care.

6.6.8.2.1 Comprehensive health care not promoted

The Mental Health Community Coalition Consumer and Carer Caucus expressed concern that physical health care needs of consumers are not recognised and treatment not organised. Standard 8.2.1 states: 'The MHS is part of the general health care system and promotes comprehensive health care for consumers, including access to specialist medical resources'.

There is little recognition of the need for special programs to take care of other medical problems which occur for people experiencing mental illness, often, at least partially the result of side effects of medication. Diabetes, other metabolic problems and cardiovascular conditions affect people with schizophrenia particularly, leading to a life expectancy variously estimated at between 12 and 20 years less than the average of a given population.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

6.6.8.2.2 Inability to afford basic heath care

Concern was expressed that, due to the lack of bulk billing general practitioners and specialist providers, many consumers were unable to access basic health care for many physical health complaints. This may also be the result of mental health staff not knowing about the range of other resources available and how to access them (Standard 8.2.2).

Consumers and carers reported that the most basic of health care is often out of the reach of people experiencing mental illness and sometimes also out of the reach of members of their families. In particular, greater and free access to the following services and professionals is required: GPs; Specialists; Non-urgent, non-life threatening or elective procedures; Dental care; Foot care; Skin care; Optometrists, physiotherapists and psychologists etc.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

There is little access to bulk-billing GPs in the ACT. People with mental illness quickly acquire a backlog of health complaints that remain largely undiagnosed and/or untreated. Dental care is beyond the reach of most people with mental illness as well as their families unless they are able to afford private health insurance.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

You don't have to be mentally ill for long, before you can't afford basic health care. Add in becoming homeless and you soon gather a number of health complaints.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

6.6.8.3 Integration with other sectors

The MHS develops and maintains links with other sectors at local, state and national levels to ensure specialised coordinated care and promote community integration for people with mental disorders and / or mental health problems.

Under this Standard, submissions and presentations indicate concerns about:

- the need for whole-of-government approaches;
- lack of services for youth;
- police and the criminal justice system;
- lack of recognition of cross-border agreements;
- housing;
- Centrelink;
- employment; and
- the need to integrate mental health strategy with drug strategy.

6.6.8.3.1 The need for whole-of-government approaches

Overall, many submissions indicated a lack of integrated service delivery or whole-of-government approach to solve the complex support needs required for people with mental illness and their families and carers to live in the community in a dignified manner. These problems were reported with education, health, welfare, the police, corrective services, community services, disability services and housing. Many submissions identified that a broader governmental, societal and community approach was urgently required:

One respondent wrote: 'We just become poorer and poorer. I cannot get dental care, I'm on the waiting list for that. You name it, I'm on the waiting list for a number of things ranging from health care through to accommodation. I probably won't be able to keep the car going after this year. The payment I get is just not enough to live on. I can't remember our last holiday. I shop at St Vinnies, haven't had new clothes for ages. It is just so tiring trying to make ends meet. It can come down to, do I buy milk and food or go to the doctors.'

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

6.6.8.3.2 Lack of services for youth

Concern was expressed regarding the paucity of services and integrated services to assist young people with mental illness or mental health problems. Such services are seen as essential from an early intervention perspective to halt spiralling negative life consequences which result in homelessness, suicide, and entry into the criminal justice system.

We are letting young people down by not dealing with them properly. We need to provide services in the prison system if that is where they are going to end up.

(Service Provider, Australian Capital Territory, Canberra Forum #20)

I work with young people aged 13-18 years, but this is getting pushed out to work with people as old as 25. I provided 24 hour support to a 21 year old recently who couldn't get care anywhere.

(Service Provider, Australian Capital Territory, Canberra Forum #20)

Services required for adults are different to those for young people. Many young people are presenting to mental health services for the first time.

(Service Provider, Australian Capital Territory, Canberra Forum #20)

6.6.8.3.3 Police and the criminal justice system

Due to diminishing access to mental health services for consumers throughout their illness cycle, police have been increasingly called to respond and assist with people with mental illness, especially in times of crisis. This places consumers at increased risk of coming into contact with the police and the possibility of entering the criminal justice system.

While Memorandums of Understanding and protocols have been drawn up, evidence suggests that further education is required to inform police about how to integrate with a range of services available to access treatment and support services and more clearly protect the rights of people with mental illness who come into contact with them and the criminal justice system. Police clearly expressed concern about their inability to access care and support for consumers when needed.

We have self harmers, people we have to watch in the watchhouses, but we don't have support and care.

(Police Officer, Australian Capital Territory, Canberra Forum #6)

We are looking for more staffing by Mental Health in the ACT. We need to know what services are available and how we can work better with them.

(Police Officer, Australian Capital Territory, Canberra Forum #6)

Despite the existence of an official Memorandum Of Understanding between police and mental health services in the ACT, consumers and families reported that there appears to be a need for clarification of responsibilities on a daily basis and at 'ground zero'. It is reported that mental health services frequently refuse to act and families report they are told by metal health services to phone the police.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

85% of prisoners in NSW have mental health problems. 65 % of prisoners in NSW have substance abuse problems. There has been a huge increase in the numbers of people with mental illness resorting to substance abuse.

(Advocate, Australian Capital Territory, Canberra Forum #7)

Young people should not be going into custody.

(Service Provider, Australian Capital Territory, Canberra Forum #20)

Those in attendance pointed to the apparently increasing role of emergency services personnel in responding to people with mental illness who are in crisis. The need for ongoing education, training and support for emergency services personnel from mental health services was stressed. Consumer and carer advocates and the Mental Health Consumer and Carer Caucus stated that it was important that they assist in such training.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

6.6.8.3.4 Lack of recognition of cross-border agreements

Concern was also raised about the lack of recognition of cross-border orders, transfers and admissions despite formal agreements.

Cross-border recognition of orders, transfers and admissions despite formal agreement and legislative base remain problematic.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

6.6.8.3.5 Housing

The lack of available housing and accommodation options for people with mental illness was raised as a critical gap in the attainment of mental, physical and social well-being of consumers. Reports suggest that access to any housing or accommodation option is almost impossible even in a crisis and no step down facilities are available after discharge from an inpatients unit. Concern was also expressed that the Department of Housing was not taking into consideration the accommodation needs of consumers. Also noted in other parts of this Report (e.g. Standard 11.4.B – Supported Accommodation), the lack of available housing and accommodation options and the inability to access community services has resulted in many people with mental illness becoming homeless or has placed intolerable strain on families and contributed to deteriorating mental and physical health and quality of life.

Those in attendance reported that a critical short fall in services in the ACT is absence of a system of person centred, flexible, community based housing and support options, that respond to a person's changing needs in a timely manner. Bedsits available through public housing were thought to be of a poor standard, inappropriate to the needs of people with mental illness and difficult to access. There is reported to be very little public accommodation for young people and single adults. Waiting lists are reported to be high. Accommodation in a crisis other than at Ainslie Village is difficult to obtain. Crisis accommodation funded by SAAP are reported to be frequently full and also have difficulty in accommodating a person who has been either discharged from a psychiatric inpatient unit or who has been refused inpatient care.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

People in attendance reported that in their experience the Dept Housing either hasn't taken notice of reports from psychologists and psychiatrist concerning the accommodation needs of people with mental illness or has been unable to act on the recommendations contained in these reports.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

6.6.8.3.6 Centrelink

[Y] said at one point his family were living on under $10,000 a year.

(14 year old Consumer and Carer, Son, Australian Capital Territory, CYCLOPS ACT Young Carers Consultation #2)

The Mental Health Community Coalition Consumer and Carer Caucus expressed concern regarding the financial vulnerability of many consumers and their families and the need for increased access to welfare payments. Some families, as a result of being unable to access supported accommodation or other treatment and support services for their family member, are often unable to maintain employment and the family is forced to rely on payments from Centrelink.

People experiencing mental illness as well as their families frequently experience financial problems. For the people with the illness themselves, the longer they are sick or the more episodes they experience the more likely it is that their only income is Centrelink payments. It is very difficult to subsist on Centrelink payments. A Centrelink payment barely covers board or rent and people are often left with little for food, transport, clothing and other necessities. People with mental illness frequently have difficulty in affording health care and medications as well.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

Family members and other carers are faced with having to cover the unmet costs of living for their loved one. These costs can be considerable – ranging, it is reported, not uncommonly from $60 to over $100 per week. Families also find themselves with unpaid bills, fines and unpaid rent when the loved one is hospitalised or is experiencing an episode of acute illness. Many families due to the burden of caring for a loved one with mental illness have not been able to maintain employment and hence are forced to rely on Centrelink payments. This results in many carers themselves not being able to afford health care and other necessities for themselves.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

One respondent wrote: 'We just become poorer and poorer... The payment I get is just not enough to live on. I can't remember our last holiday. I shop at St Vinnies, haven't had new clothes for ages. It is just so tiring trying to make ends meet. It can come down to, do I buy milk and food or go to the doctors.'

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

Service providers present reported that it is not uncommon for families to be unaware of the carer payment available through Centrelink.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

6.6.8.3.7 Employment

Access to welfare, the supported wage and finding suitable employment are all critical components in the process of social inclusion and living a meaningful life with dignity in the community. However, concern was raised regarding difficulties with job support, current welfare and employment systems and models in assisting consumers to remain in or access employment. As reported previously in this Report (Standard 4 – Promoting Community Acceptance), concern was expressed regarding discrimination in employment settings.

There is no supported employment program that meets the criteria of best overseas practice. My son would dearly love to work part-time, but in a field in which he has experience.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

[Y] said he thought the Government is screwing families who have a mental or physical disability. "There aren't really any facilities out there to train people and when they do get jobs it's like at a McDonald's level and when someone on a disability pension gets this type of low-paid job, their pension is docked."

(14 year old Consumer and Carer, Son, Australian Capital Territory, CYCLOPS ACT Young Carers Consultation #2)

6.6.8.3.8 Need to integrate mental health strategy with drug strategy

Concern was expressed for the need for mental health policies to be linked with drug strategies.

Drug law reform is required. Drug policy setting should be integral to mental health, especially relating to the prison population in NSW.

(Advocate, Australian Capital Territory, Canberra Forum #7)

Mental health problems are not a big predictor of criminal conduct but combinations of mental illness and substance abuse are causing big problems.

(Advocate, Australian Capital Territory, Canberra Forum #7)

A particular problem is the heroin drought leading to increased use of Crystal Method, also known as Ice. Parents are desperate for help. At least with opiates, the consumers are quiet as a baby, but there is a big difference with Ice. We aren't stopping these drugs coming in, despite the heroin busts.

(Advocate, Australian Capital Territory, Canberra Forum #7)

We need to look to the heroin trials in Switzerland and the social integration of people on these programs. These programs make an enormous contribution to people's lives.

(Advocate, Australian Capital Territory, Canberra Forum #7)

You must look at more than resources; you must look at the effects of policies on people. The stress of trying to access drugs is bringing on mental health problems. There is a need to change how we deal with these problems.

(Advocate, Australian Capital Territory, Canberra Forum #7)

6.6.9 STANDARD 9: SERVICE DEVELOPMENT

The MHS is managed effectively and efficiently to facilitate the delivery of coordinated and integrated services.

> *Mental health services are not implementing the National Standards for Mental Health Services and the Third Plan, despite government beliefs.*
>
> (Advocate, Australian Capital Territory, Canberra Forum #11)

Under this Standard, submissions and presentations indicate concerns about:

- the current state of mental health services in the ACT;
- focus on the medical model for service delivery is inadequate;
- lack of funding;
- low quality of services associated with staff shortage;
- staff attitudes;
- more services required to support young carers;
- research needed; and
- the need for an independent review to ensure ACT strategic plan and services conform to national mental health policies.

6.6.9.1 Concerns about the current state of mental health services in the ACT

The majority of submissions and presentation at forums conveyed a sense of despair that services were not available, a loss of hope that service delivery will ever improve, and the belief that the MHS is chronically under-resourced.

> *Mental health services are not available here in Canberra. People are being turned away.*
>
> (Service Provider, Australian Capital Territory, Canberra Forum #20)

> *In the ACT we have a chronically under-resourced system that simply is dealing with crisis care.*
>
> (Carers, Parents, Australian Capital Territory, Canberra Forum #10)

> *'Loss of hope that things will ever get better' was how several in attendance reported to view the current state of mental health services in the ACT. Other important comments made by consumers and carers included the following: 'I have lost a lot of hope, I have suffered a lot of stress as there has not been much improvement in my husband's treatment over the last 30 years – the cycle still comes and goes – the high – psychosis – depressions – normal. There have been many backward steps in this time including not being able to get help early or in a crisis and not being able to stay long enough in hospital.'*
>
> (Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

> *Major service gaps are on the rise, with plans, strategies, and government promises failing to meet the needs of this vulnerable community group. This results in carers, families and the community sector, being forced to take the brunt. As a result, the community sector feels under constant pressure to respond to hopelessness, helplessness, and the despair felt among consumers / carers as they attempt to do the impossible - fill the gaps, but at what cost?*
>
> (Mental Health Foundation ACT, Australian Capital Territory, Submission #256)

There is major despair from consumers. Contrast the ACT with New Zealand, which has well resourced and well initiated forums and look how decisions are made. We need programs for consumers to get faith in themselves.

(Consumer and Consumer Activist, Australian Capital Territory, Canberra Forum #2)

However, if and when I am no longer available, I have no confidence whatsoever that my son will receive what he needs.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

What of the future? Others see a light. I see a black hole. I am sad and every day I get sadder feeling as if I will die knowing that my son may live for a few decades after me in torment, loneliness and victimised.

(Carer, Father, Australian Capital Territory, Submission #208)

I want to speak about motivation. I don't know what the motivation of the mental health bureaucracy is. For mental health workers it is "Please God, don't let them die on my shift". For carers it is "Please God don't let them die and give me my life back". For consumers it is about wanting a quality of life.

(Consumer and Consumer Activist, Australian Capital Territory, Canberra Forum #2)

I have a problem with mental health; I call it a 'Mental Health Service Trauma' induced problem. I recently spent three weeks in a mental health service.

(Consumer, Australian Capital Territory, Canberra Forum #3)

Unless people are heard then the government of the day whether it be State or Federal will do nothing.

(Carer, Wife, Australian Capital Territory, Submission #149)

SANE Australia noted the following recent improvements in service delivery:

Community-based programs have been expanded, with a new outreach worker in the southern as well as the northern region; two dual diagnosis workers working with Aboriginal and Torres Strait Islanders, and introduction of a Forensic Mental Health Team.

(SANE Australia, National, Submission #302)

6.6.9.2 Focus on the medical model for service delivery is inadequate

Concerns were also expressed regarding the use of the medical model as the basis for the planning and delivery of treatment and support services and that this model was limiting the rights of people with mental illness.

I would like to know why mental health funding is dominated by the medical model when funding could be better used to develop mechanisms to provide assistance for when people are well. We need to give people an opportunity of a life worth living. In the ACT less than 5% of the funding for health goes into social programs to help people do what they want to do with their lives… The medical model is about risk management. We neglect people when we leave them out to rot – in front of a TV all day! I lost all my social skills – I see so many of my fellow consumers who can't do this because they have been dominated by the medical model. People go into self-medication with pills and drugs – we are now the dominant group in the criminal justice system. We need case workers who have no more than 8-10 clients and who can give due attention to people's long-term needs.

(Consumer and Consumer Activist, Victoria, Footscray Forum #3)

Finally, ADACAS is concerned at the prevalence of the medical model across all forms of service provision for people with mental illness and/or dysfunction who are living in the community. We do not believe that ACT MHS and community based services overall are in the "right relationship" with mental health consumers. Whilst we acknowledge the importance of the acute health system and long term clinical management for people with mental illness and / or dysfunction, we believe that their role is to support someone to have a good life, not to control it.

(ACT Disability, Aged and Carer Advocacy Service (ADACAS), Australian Capital Territory, Submission #139)

Our community could benefit from a return to the program of social health visitors initiated by Dr Brain Hennessy... Those selected received substantial training, were given a car, were at the call of, and assisted, psychiatrists, psychologists, doctors and social workers. [They] were mainly the first involved in crisis intervention and the main contact following up patients after their stay in psychiatric ward of the hospital. The difference in [their] position as compared with the other professionals was that [they] we were considered more as a friend to [consumers] and their family, someone on their side. Thus [they] were able to persuade clients to cooperate more fully with treatment plans. Gone are the social health visitors; the service has become more clinically oriented, replacing the human / personal involvement. This makes it more difficult for people to develop a good self image and experience hope for the future. In our endeavour to improve mental health we could do no better than re-examine Dr Brian Hennessy's approach and implement again the strategies that worked effectively in the past.

(Anonymous, Australian Capital Territory, Submission #132)

6.6.9.3 Lack of funding

As stated above, concern was expressed that the ACT has a chronically under-resourced system and is therefore unable to deliver quality mental health services. Claims were made that resources are not allocated to reflect national mental health policies (Standard 9.14) or in a manner which allows the MHS to respond promptly to the changing needs of the defined community (Standard 9.15).

The mental health system is collapsing Australia wide and Canberra included. We just don't have the resources.

(Consumer and Consumer Activist, Australian Capital Territory, Canberra Forum #2)

I am fully aware that resources, both financial and human are inadequate today. I am fully aware that treatment in the ACT does not match best practice in other parts of the world. I am fully aware that appropriate accommodation with appropriate support is almost non-existent in the ACT and I am sure that you will hear much about that.

(Carer, Australian Capital Territory, Submission #173)

The government don't understand the depths of psychiatric disability, which is reflected in the lack of funding as well as attitudes to this issue.

(Carer, Father, Australian Capital Territory, Canberra Forum #18)

A deeper level of resources to support people with mental illness are required.

(Carer, Father, Australian Capital Territory, Canberra Forum #18)

6.6.9.4 Low quality of services associated with staff shortage

Lack of resources, shortage of staff and high demand for services was seen to be impacting on the quality of care in the MHS. The inability of the MHS to recruit and retain skilled and experienced staff was also seen as a factor that impacted on attitudes and behaviour of staff. All of these factors prevented the MHS from delivering 'a range of high quality mental health treatment and support services' (Standard 11.4) and protecting the rights of people with mental illness and mental health problems.

Consumers and carers reported that the standard of care and treatment in in-patient facilities can be very unsatisfactory. Most present suggested that the reasons for this included a shortage of staff and difficulty in keeping sufficient numbers of skilled and experienced staff in the public system.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

I have recently noticed a deterioration in the care my son receives, apparently because there is a shortage of psychiatrists and clinical managers in public mental health services. Appointments are infrequent and very short. Little effort is made to explore the current state of my son's symptoms. His appointed clinical case-manager is most helpful, but, when he is on leave, there is insufficient back up.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

The reality is that there is a lack in staffing. Nurses in PSU don't have a choice about working double shifts.

(Consumer Consultant, Australian Capital Territory, Canberra Forum #23)

One carer described what happens when the case-manager goes on leave: 'I also need support to do what I do. I have fantastic support from my son's clinical manager, but when he has been on leave I am left very much unsupported.' Another said 'each time the case-manager changes, we, the family, start all over again. Sometimes the case-manager is receptive sometimes not.'

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

It was reported that ACT MHS services including PSU (Psychiatric Services Unit at Royal Canberra Hospital), CATT (Crisis Assessment Treatment Team) and regional Mental Health teams are critically understaffed and have difficulty in maintaining staff with appropriate skills and experience. New graduates are reported to not receive the professional support and supervision they require to 'survive in the job'.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

Consumers and carers reported staff shortages as a problem at the Canberra Hospital in particular, leading to limits being placed on acute care admissions.

(SANE Australia, National, Submission #302)

6.6.9.5 Concerns about staff attitudes

Concern was expressed about poor staff attitudes towards consumers and carers indicating that staff may be in need of training in order to change their attitudes and behaviours (decrease discrimination) and be more supportive when dealing with people with a mental illness.

At best, the mental health professionals we dealt with were genuinely concerned but were seemingly powerless within the system. At worst they were arrogant, inconsistent, disrespectful and uncaring… Above all, the mental health system failed to provide [X] with hope. Mental illness should not be terminal, and he wasn't beyond help. He need non-judgmental, respectful, professional care in times of crisis and beyond. He deserved so much more than he received.

(Carer, Sister, Australian Capital Territory, Canberra Forum #9)

The staff treating depressed inpatients should be educated about the potential adverse effect of negative comments on the patient's mental state. Education to staff that persons who attempt suicide can and do later succeed in suicide should be undertaken. (excerpt from a report prepared by an independent external reviewer)

(Carers, Parents, Australian Capital Territory, Submission #354)

The participation of the psychologist at [W] in apparently discouraging the patient from seeking more assertively E.C.T. warrants further investigation. The psychologist's comments, as reported by the patient to the girlfriend, that the patient had to do it the hard way, if reported correctly are concerning. (excerpt from a report prepared by an independent external reviewer)

(Carers, Parents, Australian Capital Territory, Submission #354)

6.6.9.6 More services required to support young carers

Consumers who attended the young carers forum expressed concern that more funding was required to provide services that support young carers.

[Y], in response to the discussion on what mental health services are available for young carers, said there needed to be more government funding, especially to groups like CYCLOPS. Governments should look into making sure there are enough groups like CYCLOPS.

(14 year old Consumer and Carer, Son, Australian Capital Territory, CYCLOPS ACT Young Carers Consultation #2)

[Y] also said there needed to be more recognition that there are kids who care for a parent or family member.

(13 year old Carer, Son, Australian Capital Territory, CYCLOPS ACT Young Carers Consultation #3)

[Y] explained in Canberra there is the St Vincent's Program which is a young carers recreation program, Hidden Theatre Company and CYCLOPS to assist young carers. The first two organisations offer social support. [Y] noted there was not a lot of support for young carers and there is no way CYCLOPS can support all the young carers in Canberra. CYCLOPS is funded through the ACT Youth Services Program and came about through lobbying by service providers and individuals.

(Young Carer Support Worker, Australian Capital Territory, CYCLOPS ACT Young Carers Consultation #3)

[Y] explained CYCLOPS is trying to consolidate, not expand at the moment. [Y] said one of the stresses for him is CYCLOPS is only touching the tip of the iceberg as to the number of young carers who need support. [Y] believes there needs to be more education. Young carers also often have problems at school and CYCLOPS is not about setting up a school, but about raising awareness in school of the issues and supporting young people in school.

(Young Carer Support Worker, Australian Capital Territory, CYCLOPS ACT Young Carers Consultation #3)

6.6.9.7 Research needed

Presentations were made at the forum held in Canberra expressing concern that more funding needs to be allocated to determine the problems currently being faced by consumers and the links between physical and consequent mental illness. According to Standard 9.31: 'The MHS conducts or participates in appropriate research activities' and Standard 9.30 states 'The MHS routinely monitors health outcomes for individual consumers using a combination of accepted quantitative and qualitative methods'.

> *On another issue, there is no systematic approach to studying the epidemic of mental illness. Funders at the federal level are out of touch with the actual problems.*
>
> (Consumer, Australian Capital Territory, Canberra Forum #14)

> *Is there research occurring on the connections between medical conditions - of physical problems leading to mental health problems? For example, research into hypoglycaemia leading to bi-polar leading to other mental health problems.*
>
> (Family Member, Australian Capital Territory, Canberra Forum #15)

6.6.9.8 Independent review required to ensure ACT strategic plan and services conform to national mental health policies

Mental Health Community Coalition Consumer and Carer Caucus suggested that an independent review of MHS against national standards was required. Standard 9.33 states: 'The MHS is able to demonstrate a process of continuous quality improvement'.

> *The meeting agreed that an independent review of mental health services in the ACT against national service and workforce standards would be timely and merited.*
>
> (Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

> *Consumers and carers called for an independent review of staffing levels and levels of experience and expertise.*
>
> (Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

6.6.10 STANDARD 10: DOCUMENTATION

Clinical activities and service development activities are documented to assist in the delivery of care and in the management of services.

Under this Standard, submissions and presentations indicate concerns that often clinical documentation fails to provide a comprehensive, factual and sequential record of treatment and support.

6.6.10.1 Documentation is not comprehensive

Standard 10.5 states 'Documentation is a comprehensive, factual and sequential record of the consumer's condition and the treatment and support offered' and Standard 10.6 states 'Each consumer has an individual care plan within their individual clinical record which documents the consumer's relevant history, assessment, investigations, diagnosis, treatment and support services required, other service providers, progress, follow-up details and outcomes'. Concern, however, was expressed by the Chief Coroner following the investigation of the death of a patient that such documentation was not available:

> *…there did not appear to be an updated, clear and continuous treatment plan for [X] in the period of admission prior to his death. …the availability of a continuously updated care and treatment plan with a multidisciplinary input is important. It must be clear, unequivocal and available to all persons who need access to it. (Excerpt from Report of findings by the Chief Coroner)*
>
> (Carer, Partner, Australian Capital Territory, Submission #305)

> *The Mental Health Services are developing a data base for patients and other information – MHAGIC. The issue of the inclusion of copies of incident reports on client files needs review. Integration of patient notes at a higher standard on the MHAGIC system would provide a much fuller and consistent base of clinical information for treatment, supervision and care for various patients. (Excerpt from Report of findings by the Chief Coroner)*
>
> (Carer, Partner, Australian Capital Territory, Submission #305)

6.6.11 STANDARD 11: DELIVERY OF CARE

Principles guiding the delivery of care: The care, treatment and support delivered by the mental health service is guided by: choice; social, cultural and developmental context; continuous and coordinated care; comprehensive care; individual care; least restriction.

6.6.11.1 Access

The MHS is accessible to the defined community.

Under this Standard, submissions and presentations indicate concerns about:

- inability to access services, even in a crisis;
- police becoming the de facto mental health service;
- lack of access to care - "right to access care, not be arrested";
- no access to treatment and support for consumers who are elderly;
- limited access for people from low socio-economic backgrounds;
- access denied if consumer has dual disability; and
- access denied if consumer has personality disorder.

> *My son deteriorates, he is then in and out of gaol, only ends up in hospital after he has harmed himself.*
>
> (Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

An inability for consumers to access treatment and support services, both within the community and inpatient care, often results in a whole series of rights being infringed for consumers, carers and the community. For the consumer, the consequences of these infringements can include increasing disability and hence consequent

inability to care for oneself or others, participate socially or work or study. In some cases, the potential for harm to self or others, incarceration, or becoming homeless and poor also can occur.

Similarly, increased burdens on carers disrupts their ability to participate socially and work when their family member became increasingly ill and require more care. The inability to access care for their family member can result in deteriorating mental health for carers as evidenced by the suicide attempt of one carer. Increasing disability also exposes consumers and their families to discrimination and social exclusion. This often results in the further deterioration of the consumers' mental illness.

6.6.11.1.1 Inability to access services, even in a crisis

I am providing 24 hour support to our clients, when ACT Mental Health are not.
(Service Provider, Social worker working with homeless people, Australian Capital Territory, Canberra Forum #20)

A constant theme throughout many submissions was not only an inability to access services when needed throughout the course of illness, but that access was also difficult when consumers were at risk of self harm or harm to others. According to this information it would appear that Standards 11.1.4 'The MHS is available on a 24 hours basis, 7 days per week' and 11.1.2 'The community to be served is defined, its needs regularly identified and services are planned and delivered to meet those needs' are not being met.

We have to fight for treatment every time a crisis occurs and the fight seems to be getting harder each time.
(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

The CATT said my relative was too dangerous and that we were to call the police. We then spent several weeks trying to get our relative mental health treatment. Our relative became sicker, hungrier, more mal nourished and more dangerous to himself. In the end he got I after seriously harming himself. He could have died from self inflicted injuries but a member of the family found him.
(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

It is always the same, getting help in a crisis means the family has to pit itself against the mentally ill member. Authorities need to understand just what this does to relationships and how long it takes, if ever, for the harm to mend.
(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

Consumers and carers both reported that to get help in a crisis generally means getting the police involved. Carers told of the consequences of police involvement and its impact on relationships. 'Once this occurs the person is carted off in handcuffs by police and we are never forgiven'. And 'We don't want to be seen as the enemy but we are put in this position all because we try to get help before something bad happens.'
(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

Those present at the meeting, urged Mental Health to compare the rates of people presenting at the PSU who are not admitted with the non-admission rates of similar inter-state admission units.
(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

The police have told us that the Mental Health people are now claiming that [X] was suffering from a personality disorder (Cluster B Personality Disorder), rather than the depression and obsessive-compulsive disorder diagnosed by other practitioners, and they believe that they are therefore absolved from any blame in their approach to him, which was basically to do nothing to help him. We researched this personality disorder and were unable to relate it to [X] at all. They also chose to regard his dependence on **small** *doses of Valium (prescribed by his doctors for anxiety) as a reason not to help him. This was a feeble excuse, given the life-threatening emergency situation he was in…While they were equivocating over the diagnosis – apparently looking for an excuse to deny [X] the care he needed – he was approaching the point of no return. We do not know what they said to him on the many occasions during his last days when he was reaching out to them for help, but whatever it was, they failed to save his life. (author's emphasis)*

(Carer, Mother, Australian Capital Territory, Submission #288)

6.6.11.1.2 Police becoming the de facto mental health service

Due to the inability of consumers and carers to access mental health services during times of crisis, police are called as a last resort as they are available 24 hours a day seven days a week. Police however acknowledge that they are not qualified to deal with mental illness and are left with the dilemma about what to do to help in these circumstances as they have a duty of care. As stated above Standard 11.1.4 states: 'The MHS is available on a 24 hour basis, 7 days per week'. Included in the notes to this Standard are crisis teams, extended hours teams and 'cooperative arrangements with other appropriately skilled service providers and community agencies including General Practitioners, private psychiatrists, general hospitals'. That is, according the Standard, an appropriately skilled service provider should be available to assist police in these situations.

On one occasion we were told to by the CATT to phone the police, the police came, two officers spent almost a day with my family members, gradually got him to cooperate and to agree to going to the PSU. But at no stage during this day as far we know, did mental health services assist the police.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

We are constantly attending incidents involving people with mental illness…Our concerns are that we are not qualified in dealing with people with mental illness. We rely on the Crisis Teams.

(Police Officer, Australian Capital Territory, Canberra Forum #6)

Beds are not always available. When this occurs, we are then left with the dilemma of how to help the person. We have a duty of care to this person.

(Police Officer, Australian Capital Territory, Canberra Forum #6)

6.6.11.1.3 Lack of access to care - "right to access care, not be arrested"

As mentioned previously, failure to access services when needed in some instances resulted in consumers entering the criminal justice systems. The failure of services to respond and intervene in these instances has had the regrettable outcome of both consumers being incarcerated for the consequences of their illness and the safety of the community being infringed.

I thought as a worker and a taxpayer I have a health system to full back on but this system is rotten. I have endured years of being injected with chemicals despite the effects on my system and my objections. I ended up in the criminal system as it is the only way I could be heard.

(Consumer, Australian Capital Territory, Canberra Forum #14)

6.6.11.1.4 No access to treatment and support for consumers who are elderly

One clinician expressed concern that older people with mental illness were not being provided with adequate treatment and support. Standard 11.1.1 states 'The MHS ensures equality in the delivery of treatment and support regardless of consumer's age'.

> *I have noticed lately something that worries me, elderly people with mental illness. Some are homeless. They have no home, no help, no hygiene. These people are wandering around the streets while psychotic.*
>
> (GP, Australian Capital Territory, Canberra Forum #5)

6.6.11.1.5 Limited access for people from low socio-economic backgrounds

Concern was expressed that the treatment and support needs of people from low socio-economic backgrounds were being denied. Increasingly, access to psychiatrists and general practitioners who bulk bill is becoming difficult and the trend in health, and particularly mental health, is towards a user pays private system. This effectively denies access to people who can not afford private medical insurance or to pay the difference beyond the Medicare rebate. Standard 11.1.1 states 'The MHS ensures equality in the delivery of treatment and support regardless of consumer's…socio-economic status'.

> *There is a need to back the rights of people with mental illness and act on this. There is a need to restore human rights, and look at the needs of people below the poverty line. I am now locked out of the mental health system. I am too afraid of them.*
>
> (Consumer, Australian Capital Territory, Canberra Forum #14)

6.6.11.1.6 Access denied if consumer has dual disability

Concern was expressed that people with dual diagnosis (mental illness and drug and/or alcohol problems or acquired brain injury) are frequently denied access to any treatment and support services by the MHS. Standard 11.1.1 states 'The MHS ensures equality in the delivery of treatment and support regardless of consumer's…physical or other disability'.

> *People with mental illness and drug and alcohol problems or brain injury are reported to be frequently denied service. Both groups frequently do not receive treatment unless an advocate becomes involved. It was reported that when denied psychiatric assessment, treatment and case management, people with dual disability are at risk of offending and coming to the attention of the criminal justice system.*
>
> (Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

6.6.11.1.7 Access denied if consumer has personality disorder

Concern was also expressed that a diagnosis of 'personality disorder' resulted in an inability to access treatment and support services form the MHS. Standard 11.1.1 states 'The MHS ensures equality in the delivery of treatment and support regardless of consumer's…previous psychiatric diagnosis…or other disability'. For many people with personality disorder, failure to access treatment resulted in deteriorating mental health and entry into the criminal justice system.

Assessment, treatment, engagement, case management and care for people diagnosed with borderline or thought to have personality disorder continues to be a failing of mental health services in the ACT. People with personality disorder are reported to be still frequently denied service. They are reported to be another group that frequently ends up in the criminal justice system.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

6.6.11.2 Entry

The process of entry to the MHS meets the needs of the defined community and facilitates timely and ongoing assessment.

No submissions or comments were received pertaining to this Standard.

6.6.11.3 Assessment and review

Consumers and their carers receive a comprehensive, timely and accurate assessment and a regular review of progress.

Under this standard, submissions and presentations indicate concerns about:

- the assessment process not being sufficiently comprehensive; and
- operations of the Mental Health Act.

6.6.11.3.1 Assessment process is not comprehensive

Concern was expressed that during the assessment process, insufficient information is considered for the assessment to be called 'comprehensive' and appropriate conclusions to be drawn either about diagnosis or safety. Standard 11.3.5 states: 'The assessment process is comprehensive and, with the consumer's informed consent, includes the consumer's carers (including children), other service providers and other people nominated by the consumer'. Included in the notes and examples to Standard 11.3.5 is the following: 'multidisciplinary assessment which includes physical, social and psychological strengths, risks, family and functional components' and 'information is gathered from a number of sources including, with the consumer's informed consent, the General Practitioner'.

I was horrified to see my DSM [Diagnostic and Statistical Manual] classification that my stress-induced disorder was classified as Bipolar…The psychiatrist would not listen to me, would not read my diaries. I saw the psychiatrist several times but he wouldn't listen. My GP rang the hospital five times about my work-related stress. My psychiatrist would not see me through the public system, and I was paying $275 to be put on Lithium. I was put on medication after only one episode, but this should not occur before adequate assessment.

(Consumer, Australian Capital Territory, Canberra Forum #3)

Even though he was a voluntary patient in a private psychiatric ward, restrictions on leave, if not disallowing all leave, could have been imposed on the patient. The matter of leave becomes very relevant after he took himself to the Telstra Tower…Assessment of suicidality when the patient denies that it exists and reassures staff that it is not present is very fraught with difficulty. (excerpt from a report prepared by an independent external reviewer)

(Carers, Parents, Australian Capital Territory, Submission #354)

6.6.11.3.2 Review of the Mental Health Act is needed

Concern was recently expressed regarding the operation of the Mental Health Act and how changes from 'involuntary' to 'voluntary' status are made. From the quote below, staff were constrained in their decision making and were following the Act, but the death of the patient indicate that this process may need revision:

> *The decision to take the patient off the involuntary section of the Act requires some comment. The Act, in s40, does not allow for the continued detention of a patient if that patient does not refuse to receive necessary treatment and care. In Mr. [X]'s case he was stating that he was accepting treatment and hospitalisation…His guarantee of his personal safety proved to be unreliable. However, the provisions of the Act constrain the actions of staff. (excerpt from a report prepared by an independent external reviewer)*
>
> (Carers, Parents, Australian Capital Territory, Submission #354)

> *The deceased's family is correct in their view that E.C.T. [Electroconvulsive Therapy] given to the patient shortly after the failed suicide attempt at Telstra Tower would have been clinically appropriate and may possibly have saved his life…The participation of the psychologist at [W] in apparently discouraging the patient from seeking more assertively E.C.T. warrants further investigation. The psychologist's comments, as reported by the patient to the girlfriend, that the patient had to do it the hard way, if reported correctly are concerning…In my opinion, after the patient was admitted to P.S.U. as an involuntary patient, he should have continued to be treated as an involuntary patient if the Act had allowed. Application could then have been made to give the patient E.C.T…However, it is understandable that psychiatrists with actual experience of the provisions of the Act, may well have the considered view that the Act doesn't have provisions that allow for [X]'s involuntary detention or compulsory application of E.C.T. (excerpt from a report prepared by an independent external reviewer)*
>
> (Carers, Parents, Australian Capital Territory, Submission #354)

6.6.11.4 Treatment and support

The defined community has access to a range of high quality mental health treatment and support services.

> *18 months ago we had no knowledge of mental health. Then our son fell into deep melancholy and depression. He took himself to Telstra Tower, where the police intervened and took him to Canberra Hospital where he entered into involuntary then voluntary care. He then transferred to Roselyn Green under chemical therapies. We requested he undergo ECT [Electro-Convulsive Therapy] but we were ignored. Still under chemical therapies, he threw himself in front of a vehicle. In the ACT we have a chronically under-resourced system that simply is dealing with crisis care.*
>
> (Carers, Parents, Australian Capital Territory, Canberra Forum #10)

Under this standard, submissions and presentations indicate concerns about:

- individual care plans not discussed with consumers and carers;
- lack of services for youth;
- lack of services for people with dual diagnosis (mental illness and drug and alcohol abuse);
- lack of services for people diagnosed with personality disorders; and
- problems with forensic care and the new forensic unit.

6.6.11.4.1 Individual care plans not discussed with consumers and carers

Despite Standard 11.4.9 acknowledging the involvement of consumers and carers ('there is a current individual care plan for each consumer, which is constructed and regularly reviewed with the consumer and, with the consumer's informed consent, their carers and is available to them'), reports were received indicating that both consumers and carers are repeatedly excluded from assessment and treatment planning. Standard 11.4.11 also states: 'The treatment and support provided by the MHS is developed collaboratively with the consumer and other persons nominated by the consumer'. Given the reported problems with access and limited services available in the community, practices which involve carers to assist with the delivery of care and achieve the best possible outcomes for consumers would both help recovery and protect many rights of people with mental illness.

I do not like people keeping records about me behind my back that they share with absolutely everyone but me and the people I designate as my supporters. These things make recovery SO MUCH harder. (author's emphasis)

(Consumer, Australian Capital Territory, Submission #287)

[Y] doesn't "…feel like they are making an effort to figure out what going on." [Y] also said as the youngest child of five children, she had been kept in the dark about her brother's situation, but her family has also been kept in the dark.

(17 year old Carer, Sister, Australian Capital Territory, CYCLOPS ACT Young Carers Consultation #1)

Professional advice and guidance for carers… Carers are on duty 24 hours per day for very little reward and certainly no thanks. They take what is 'dished' out to them. Peace of mind that they are performing their duty correctly would be to their advantage.

(Carer, Wife, Australian Capital Territory, Submission #149)

When we expressed our fear and worry about [X]'s premature discharge from the psychiatric unit after his first suicide attempt, we were told, "Family dynamics are not our concern."

(Carer, Sister, Australian Capital Territory, Canberra Forum #9)

I recommend that policies and procedures be put in place that ensure:

- *The family of the patient should not be used as a substitute for care of an inpatient, or replacing nursing care…*
- *The family and carers of inpatients are to be actively engaged in information sessions on illness, and to be encouraged to actively participate in treatment decisions*
- *The role of the family and carers as valuable partners in care should be recognised*

(excerpt from a report prepared by an independent external reviewer)

(Carers, Parents, Australian Capital Territory, Submission #354)

The attitude of the staff to us sometimes appeared to be that we, his family, were ignorant fools and a nuisance. They never asked us about [X]'s behaviour at home over the past years. If they had, they would have received valuable insights. We knew for instance, that for years he had shown many typical obsessive-compulsive behaviours, ***as well as*** *the morbid pre-occupations (depressive ruminations) that blighted his life. And we could have set them straight on the "personality disorder" they attributed to him. (author's emphasis)*

(Carer, Mother, Australian Capital Territory, Submission #288)

6.6.11.4.2 Lack of services for youth

Service providers, consumers and carers expressed concern at the paucity of services for youth and indicated that services need to be broader in their approach than treatment just for 'mental illness' as other mental health problems and life crises were generally associated with this age group. Standard 11.4.3 ensures access to a 'comprehensive range of treatment and support services which are, wherever possible, specialised in regard to a person's age and stage of development'.

> *Our clients are getting older (up to 25 years old); lots of our clients have dual diagnosis [mental health and drug and alcohol problems].*
>
> (Service Provider, Australian Capital Territory, Canberra Forum #20)

> *Young people were reported to fair poorly in the PSU. The need for a specialised and a purpose built unit for children and young people was emphasised.*
>
> (Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

> *[Y] said the mental health system hasn't helped at all, and when he needs counselling he comes to CYCLOPS (Connecting Young Carers to Life Opportunities and Personal Support).*
>
> (13 year old Carer, Son, Australian Capital Territory, CYCLOPS ACT Young Carers Consultation #3)

6.6.11.4.3 Lack of services for people with dual diagnosis - drug and alcohol

Standard 11.4.7 states: 'The MHS ensures access to a comprehensive range of services which are, wherever possible, specialised in regard to dual diagnosis' In the notes to this Standard, this includes dual case management with alcohol and other drug services. Concern was expressed that there is an insufficient number of mental health services to provide treatment and support to consumers with complex needs. One advocate expressed concern that an inability to access such treatment and support services for mental illness and drug and alcohol problems results in deteriorating mental health and entry into the criminal justice system.

> *Out of ACT Mental Health and Drug and Alcohol Services, we get the best response from the Drug and Alcohol Services. Drug and Alcohol Services are taking into account mental health issues a lot more than Mental Health Services are taking into account drug and alcohol issues.*
>
> (Service Provider, Australian Capital Territory, Canberra Forum #20)

> *Mental health problems are not a big predictor of criminal conduct but combinations of mental illness and substance abuse are causing big problems.*
>
> (Advocate, Australian Capital Territory, Canberra Forum #7)

6.6.11.4.4 Lack of services for people with personality disorders

Advocates and clinicians raised concerns about the inability to access treatment and support services for people with personality disorder. Concern was expressed that the inability to access care or appropriate care (more than medication) resulted in many people with personality disorder entering the criminal justice system.

> *People with borderline personality disorder are not receiving care. Pills are not the answer. These people need long term therapy.*
>
> (Consumer and Consumer Activist, Australian Capital Territory, Canberra Forum #2)

People with Borderline Personality Disorder are self harming …an example, a person with Borderline Personality Disorder seen by the PSU [psychiatric support unit]. This person said I'll try to kill myself if you leave. The PSU worker left and the person threw themself off a bridge and now has long term physical injuries to deal with as well… another example involves a person with BPD who cut her wrist. The injury was deliberately left untreated for several days as a lesson of the consequence of her action.

(Advocate, Australian Capital Territory, Canberra Forum #11)

People with borderline personality disorders get caught up in the criminal judicial system. There are 5 people under my organisation's care with BPD, all had problems with the criminal system… For example, a client with BPD who was charged with threatening to kill a worker whilst in Belconnen Remand Centre, despite the fact he had no means to carry this threat out.

(Advocate, Australian Capital Territory, Canberra Forum #11)

I see a lot of people with borderline personality disorder. I see lots of people with substance abuse problems.

(GP, Australian Capital Territory, Canberra Forum #5)

ACT MHS base their management approach of people with borderline personality disorder on the text of Watson and Kravitz which essentially argues that:

- *institutional care is not appropriate for people with borderline personality disorder; and*
- *there needs to be an immediate consequence for their actions.*

ADACAS agrees with this approach. However we believe that ACT MHS have misinterpreted it in their management of people with borderline personality disorder. Their implementation of this approach (in ADACAS experience with 4 different people), has been to deny access to PSU [Psychiatric Support Unit] when they have sought admission because they believe they are at risk of harming themselves, or others, or damaging property. They are turned away with no alternatives made available for them, which often leads to action by them that has been described as "criminal activity". The "immediate consequences" of this action is that ACT MHS has them charged eg with assault, damage to property etc. If the person is on bail, then they are charged with breach of bail etc. The ultimate conclusion to this approach is a custodial sentence. However, prisons are not treatment centres, and the likely outcome is the person is released back into their community even more disturbed and traumatised, effectively requiring increased support from MHS.

(ACT Disability, Aged and Carer Advocacy Service (ADACAS), ACT, Submission #139)

6.6.11.4.5 Problems with forensic care and the new forensic unit

A service provider, a police officer and the Mental Health Community Coalition Consumer and Carer Caucus all expressed concern at the lack of appropriateness of treatment and support received by people with mental illness or mental health problems who become subject to the criminal justice system. Problems included: heavy reliance on medication, consumers not being treated with dignity, poor outcomes for Indigenous peoples, and denial of any access to care for some consumers. Standard 11.4.7 states: 'The MHS ensures access to a comprehensive range of treatment and support services which are, wherever possible, specialised in regard to…consumers who are subject to the criminal justice system'.

Concerns were also raised with regard to the location of the new forensic unit proposed for the ACT, as it was considered this will not improve the delivery of treatment and support, or promote or protect the rights of people with mental illness who have become subject to the criminal justice system.

A matter of concern raised by several in attendance was the lack of appropriateness of the care received by forensic patients and other people with mental illness or disturbance who become subject to the criminal justice system. Reported short fallings included:

- *People not being treated with dignity e.g., cases where management plans involve no clothing or night shirts;*
- *Behaviour being controlled by high medication dosages;*
- *some prisoners having been apparently 'black listed' by mental health services including the forensic service;*
- *Aboriginal prisoners doing poorly in the forensic mental health system.*

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

We had 3 clients who were in Belconnen Remand Centre who were well known to ACT mental health services, but whom ACT MH couldn't manage. In all 3 cases there was a lack of management. One was released on an afternoon from the PSU [Psychiatric Support Unit] and taken the same day to the Belconnen Remand Centre because of self-harming.

(Service Provider, Australian Capital Territory, Canberra Forum #20)

The need for appropriate treatment facilities rather than gaol was emphasised. Some in attendance pleaded that the ACT should learn from the difficulties experienced by NSW when the forensic mental health inpatient facility was built within the grounds of Long Bay Gaol. It is hoped that all possible steps are taken to prevent the forensic hospital planned to be built adjacent to the new prison from being antithetical to the therapeutic needs and to the recovery of inmates with mental illness.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

We are setting up a forensic service in the ACT but until these facilities are available we don't have support in this area. We are dealing with people who are not offenders, but we do have a duty of care.

(Police Officer, Australian Capital Territory, Canberra Forum #6)

6.6.11.4.A Community living

The MHS provides consumers with access to a range of treatment and support programs which maximise the consumer's quality of community living.

Under this Standard, submissions and presentations indicate concerns about:

- lack of support services in community;
- need for family centred approaches;
- lack of recognition and support for young carers;
- the lack of social, vocational and rehabilitation programs;
- need for programs which teach self-care skills; and
- support services post suicide need to be improved.

6.6.11.4.A.1 Lack of support services in community

ADACAS' perception of what's available for people living in the community with mental illness is that their social and community living needs are not catered for. There is a prevalence of the medical model, even in the important areas of people's lives such as independent living skills.

(ACT Disability, Aged and Carer Advocacy Service (ADACAS), Australian Capital Territory, Submission #139)

The aim of deinstutionalisation was to provide treatment and support in the least restrictive setting, which for most people means living in the community. However, as discussed above, the necessary treatment and support services and effective systems have not materialised. This is true for both people with serious mental illness living in the community and people who, as a consequence of failure to access treatment and support services at the onset of illness, develop significant disability and require additional community support services to live independently or with their family.

> *Consumers and carers in the ACT reported that there is insufficient, appropriate support in the community including:*
> - *Sufficient numbers of paid consumer and carer advocates;*
> - *Peer support;*
> - *Support that can be accessed in a person's home not just from a center;*
> - *Affordable and appropriate accommodation linked to support;*
> - *Recovery and rehabilitation programs that are individually tailored;*
> - *Training and work options.*
>
> (Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

> *I do many things for my son that would normally be done by professional people. I do this for two main reasons. Firstly because it leaves more time for overworked professional people to attend to the needs of those whose families do not or cannot help them. Secondly because, even in a perfect world, I think families can do more than professional people and can do it in a way that allows people to feel more a part of the mainstream. I am more likely to be immediately available when my son needs treatment or reassurance. I can better judge when he can cope with appointments etc by himself and when he needs reminders or even accompanying etc. Sometimes he needs me to hear and remember what he has been told by doctors because he forgets so easily. I am here to judge whether symptoms are psychotic or medical, minor or potentially life threatening. I also provide some mainstream company for him and provide education in cooking and housekeeping. However, if and when I am no longer available, I have no confidence whatsoever that my son will receive what he needs.*
>
> (Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

> *I have no family or children so have had to cope on my own. Some good sound advice and suggestions from a mentor would be wonderful, but where can I go without it costing me an 'arm and a leg'.*
>
> (Carer, Wife, Australian Capital Territory, Submission #149)

6.6.11.4.A.2 Need for family centred approaches

As reported throughout this Report, concern was expressed about the incredible strain that has been placed on families as a result of an inability to access treatment and support at the earliest possible stage of onset of illness. For families, this was often further compounded by the lack of housing and accommodation options available for their family members.

Concern was expressed by carers, consumers and a service provider regarding the lack of family-centred approaches and access to support groups. Standard 11.4.A.12 states: 'the MHS ensures that the consumer and their family have access to a range of family-centred approaches to treatment and support' and Standard 11.4.A.11 states: 'The consumer has the opportunity to strengthen their valued relationships through the treatment and support effected by the MHS'.

The lack of access to other support services (e.g. respite, leisure, recreation, education, training, work, employment, respite, home and community care) also contributed to this strain for consumers and their families. Strain was also seen to emanate from discriminatory remarks made from members in the community towards family members, a general lack of community acceptance and increasing social isolation (family and individual).

As a carer I would ask where can I go to get professional help, rather than pay an arm and a leg for help? I don't have any support. When I go to my husband's psychiatrist he is not interested in me, only in my husband. What help can I as an individual access for professional assistance? I need to be with my husband 24 hours a day to him cope with situations or to prevent problems occurring.

(Carer, Wife, Australian Capital Territory, Canberra Forum #4)

I started being involved with mental health in 1970 with Dr Brian Hennessy, who was looking for social health visitors to work with dysfunctional families… That service was very effective. We worked with mental health nurses, psychiatrists, and the police force. Nowadays, social workers work as a team with psychiatrists and social visitors with depressed mothers who hurt their babies. When people rang me, you wouldn't book them an appointment, you would jump in the car and go visit them. The important thing was to have someone who could go and relate with them… Understanding is an emotional thing, and we get too caught up with "professionalism".

(Service Provider, Australian Capital Territory, Canberra Forum #8)

Though the ACT Mental Health Services receive training in family sensitive practice, families report that they are frequently told by the clinical case-manager that they can't be involved or that the case-manager can't talk to them or tell them anything. Families reported feeling 'fobbed off'. Families and other carers pleaded to be taken seriously and for clinicians to understanding their role and the difficult nature of that role.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

[X] turns more and more to cigarettes and the occasional blowout on dope. After all he has been living in a flat by himself because he can't live with anyone else. While this is happening he starts to resent any offers of assistance or help, obviously thinking that any help should have been while he was at home.

(Carer, Father, Australian Capital Territory, Submission #208)

6.6.11.4.A.3 Lack of recognition and support for young carers

Advocates and young carers expressed concern that young carers are being ignored by the MHS. This included a failure to recognise their contribution and needs for support, in both their caring capacity and as a child of a parent with mental illness. Provision of support is essential to these children and adolescents in order to promote their mental health and ensure that their rights are not infringed.

Young carers are doubly ignored and disadvantaged. There is lack of acknowledgement of their views and needs and values. The majority are aged 10 to 18 years of age, and they need to be supported. Some may start caring as young as 3 years old.

(Advocate, Australian Capital Territory, Canberra Forum #13)

These young carers have problems that are ignored by mental health services and others. Young carers need to be recognised, involved in their parent's care, and supported.

(Advocate, Australian Capital Territory, Canberra Forum #13)

When I found out about other kids, there were other kids; I'm not the only one. Wow.

(17 year old Carer, Sister, Australian Capital Territory, CYCLOPS ACT Young Carers Consultation #1)

[Y], in response to the discussion on what mental health services are available for young carers, said there needed to be more government funding, especially to groups like CYCLOPS. Governments should look in to making sure there are enough groups like CYCLOPS.

(14 year old Consumer and Carer, Son, Australian Capital Territory, CYCLOPS ACT Young Carers Consultation #2)

6.6.11.4.A.4 Lack of social, vocational and rehabilitation programs

Access to social, rehabilitation, education, training, work and employment programs are seen as critical for consumers to reintegrate and live in the community with opportunities to participate socially and economically. Concerns were expressed regarding access to such opportunities. Standards 11.4.A.4 to 11.4.A.9 ensure access to a wide variety of programs, activities and agencies to maximise the consumer's success in these endeavours. Specifically Standard 11.4.A.6 states: 'The MHS provides access to, and/or support for consumers in employment and work'.

I would like to know why mental health funding is dominated by the medical model when funding could be better used to develop mechanisms to provide assistance for when people are well. We need to give people an opportunity of a life worth living. In the ACT less than 5% of the funding for health goes into social programs to help people do what they want to do with their lives. People's expectations are so low… The medical model is about risk management. We neglect people when we leave them out to rot – in front of a TV all day! I lost all my social skills – I see so many of my fellow consumers who can't do this because they have been dominated by the medical model. People go into self-medication with pills and drugs – we are now the dominant group in the criminal justice system. We need case workers who have no more than 8-10 clients and who can give due attention to people's long-term needs.

(Consumer and Consumer Activist, Victoria, Footscray Forum #3)

[Y] said he thought the Government is screwing families who have a mental or physical disability. "There aren't really any facilities out there to train people and when they do get jobs it's like at a McDonald's level and when someone on a disability pension gets this type of low-paid job, their pension is docked."

(14 year old Consumer and Carer, Son, Australian Capital Territory, CYCLOPS ACT Young Carers Consultation #2)

There is no supported employment program that meets the criteria of best overseas practice. My son would dearly love to work pat-time, but in a field in which he has experience.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

There is no organised rehabilitation program which suits my son's needs. There are programs, but they do not suit him as he needs an individually tailored program… He was doing well, organising his own activities, but a change in his condition undid all of that and he has not had any strong encouragement to resume activities. A mother is not always the best person for an adult son to hear telling him what to do.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

I am now in the situation where [X] has become so introverted and nicotine dependant that he literally hocks everything in his unit to buy cigarettes. He is left walking around an empty flat without food, company, activity or even a radio to listen to… His days consist of simply pacing up and down an enclosed room, becoming more and more delusional. He trusts no one – least of all his family, who never contact him anyway. He no longer wants to come around to the family home except when he runs out of food, which is usually about half way through the week.

(Carer, Father, Australian Capital Territory, Submission #208)

After about 10 yrs in the 'system' [X] is literally left languishing in a flat without company or friends and being made responsible for every little thing that could go wrong. Housing ignore him except if they want to threaten him with making him pay.

(Carer, Father, Australian Capital Territory, Submission #208)

6.6.11.4.A.5 Need for programs which teach self-care skills

Living skills and self care programs enable consumers to live with dignity in society and are seen as critical. Standard 11.4.A.13 states: 'The MHS provides a range of treatment and support which maximises opportunities for consumers to live independently in their own accommodation' and 11.4.A.2 states: 'Self care programs or interventions provide sufficient scope and balance so that consumers develop or redevelop the necessary competence to meet their own everyday community living needs'.

As reported in many submissions and presentations, a lack of availability of supported accommodation forces many consumers to return to live with their families. In many instances, this placed strain on families as they waited for places to become available. An inability to access self care and living skills programs meant that consumers were not able to gain the necessary skills to live independently:

In the meantime after one of his stays in hospital [X] was given a Government flat. He had been kicked out at 16 and has received no training in budgeting, cooking or even cleaning, He finds himself in a flat and is expected to be self-sufficient. Many normal people can't do this yet [X] is expected to.

(Carer, Father, Australian Capital Territory, Submission #208)

6.6.11.4.A.6 Support services post suicide need to be improved

Concern was expressed in a recent report by the Chief Coroner that support services for family, friends and carers after the suicide of a person with mental illness needs to be improved:

An issue has arisen from the family in this case concerning the insufficiency of support, debriefing and consultation in the events of the present tragedy. Improvement certainly needs to be take[n]…The existence of support services, contact and debriefing for family, friends and carers are the responsibility of Mental Health Services and should be the subject of improvement as part of the model of care under present development. (Excerpt from Report of findings by the Chief Coroner)

(Carer, Partner, Australian Capital Territory, Submission #305)

6.6.11.4.B Supported accommodation

Supported accommodation is provided and/or supported in a manner which promotes choice, safety, and maximum possible quality of life for the consumer.

Under this Standard, submissions and presentations indicate concerns about:

- the lack of supported accommodation; and
- the need for interim (step up and step down) accommodation.

6.6.11.4.B 1 Lack of supported accommodation

As noted previously in this Report (8.3 Integration), the lack of housing and accommodation options, and supported accommodation options in particular, for people with mental illness is a serious barrier to consumers attaining the 'maximum possible quality of life' and integrating and contributing to the community. Many consumers who could not access supported accommodation became homeless complicating access to treatment and support and increasing chances of entry into the criminal justice system.

> *Crisis accommodation funded the SAAP are reported to be frequently full and also have difficulty in accommodating a person who has been either discharged from a psychiatric inpatient unit or who has been refused inpatient care.*
>
> (Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

> *I have a young soon in his early 20s. He has schizophrenia and lives with me. He is unmedicated… He is impossible to live with, and only lives with me because he has nowhere else to go. There is no mental health vacancy anywhere in the ACT and he is incapable of living independently. There is just nowhere for him.*
>
> (Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

> *The lack of supported and other forms of affordable accommodation is a persistent problem in the ACT. This shortage not only has a direct impact on people living with a mental illness, it also creates an additional stress on carers who feel pressured to provide accommodation as well as other support. The ACT government announced a $63.6 million Housing Affordability Strategy in 2004, and it remains to be seen whether this will alleviate the shortage.*
>
> (SANE Australia, National, Submission #302)

6.6.11.4.B.2 Need for interim (step up and step down) accommodation

Many submissions argued that a range of accommodation options were needed and that these needed to be flexible, for example, interim step-up and step-down facilities. Concern was also expressed regarding the need for specific accommodation facilities for consumers with complex needs (mental illness and drug and alcohol).

> *The mental health system failed [X] in so many ways. In summary the key failings were: … safe, secure accommodation was non-existent: there is nothing between the psychiatric unit and the charity-run refuges, which often have waiting lists and seem to pick up the pieces falling from the mental health system.*
>
> (Carer, Sister, Australian Capital Territory, Canberra Forum #9)

> *We believe that there should have been somewhere for [X] to be cared for safely and securely while he was stabilised on the new drug regimen prescribed for his profoundly-depressed and suicidal condition. Then the Valium dependency could have been addressed. (author's emphasis)*
>
> (Carer, Mother, Australian Capital Territory, Submission #288)

6.6.11.4.C Medication and other medical technologies

Medication and other medical technologies are provided in a manner which promotes choice, safety and maximum possible quality of life for the consumer.

Under this Standard, submissions and presentations indicate concerns about:

- the emphasis on medication as the only form of treatment.

6.6.11.4.C.1 Emphasis on medication

Concern was expressed that the major focus of treatment for mental illness is a reliance on medication without consideration for other necessary treatment and supports and overall well-being.

> *I have endured years of being injected with chemicals despite the effects on my system and my objections. I ended up in the criminal system as it is the only way I could be heard. Every time I spoke to doctors and said please don't give me more chemicals and had my liberty taken away, they didn't want to listen to me and get to the root of the problems. We are treated abominably by our own communities.*
>
> (Consumer, Australian Capital Territory, Canberra Forum #14)

> *My sister had a bad experience here. She had a drug related incident and has been stuck in the system ever since. I have been fighting for her case for many years now…she has been misdiagnosed for years. It hurts me so much to see the toxic chemicals that are being given to people and they can no longer think for themselves to protest. When they do protest the control system is very much swayed towards treating symptoms with mind numbing drugs which affect their personality and sense of well-being. I have seen this too many times.*
>
> (Carer, Sister, Australian Capital Territory, Submission #172)

6.6.11.4.D Therapies

The consumer and consumer's family/carer have access to a range of safe and effective therapies.

Under this Standard, submissions indicate concerns about the lack of access to a range of accepted therapies in the MHS.

6.6.11.4.D.1 Lack of access to a range of accepted therapies

According to Standard 11.4.D.2 'The MHS provides access to a range of accepted therapies according to the needs of the consumer and their carers'. However, concern was expressed that there is an over reliance on medication and access to such therapies in the public mental health system is difficult. It was suggested that lack of access to therapies resulted in one consumer refusing medication as he believed therapy was an important part of his recovery process.

> *Both consumers and carers reported that whilst a person is in hospital, very little 'therapy' or 'treatment', other then medication and injections, are available or provided.*
>
> (Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

There is a lack of therapy in the ACT other than medical treatment available through public mental health services. My son could benefit from CBT or other similar therapies, but such therapy is not offered. This is one of the reasons why he refuses medication, nothing else is offered and he believes rightly or wrongly that other therapies could help him.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

6.6.11.4.E Inpatient care

The MHS ensures access to high quality, safe and comfortable inpatient care for consumers.

For six years I was shoved in wards during which I had to deal with the loss of freedom and dignity. My views were not listened to.

(Consumer, Australian Capital Territory, Canberra Forum #14)

Under this Standard, submissions and presentations indicate concerns about:

- deaths while in care;
- lack of beds; and
- children of parents with mental illness are not being notified of admission of parent or their needs considered while their parent is receiving inpatient treatment and support.

6.6.11.4.E.1 Deaths while in care

Of most serious concern were reports of deaths of consumers while an inpatient and that hospitals did not provide safe settings or have adequate policies and procedures to ensure safety. Reports were also received of consumers who died very soon after discharge (See Standard 11.6).

[X] was admitted whilst suicidal to a psychiatric unit in the ACT. There were no permanent staff on the unit, and [X] wasn't under observation. A cleaner noticed that he had a plastic bag with him and informed the staff at the unit. There was no response from the staff, and [X] smothered himself with the bag. The length of time in responding to the coronial inquiry is too long. There has been a very slow response to [X]'s death. A report has been commissioned but won't be released until May. There has been a lack of follow up to [X]'s death. I am still waiting 3 ½ years later for the coronial inquiry – my human rights are being violated.

(Carer, Partner, Australian Capital Territory, Canberra Forum #17)

My partner died as a result of suicide at the HD [High Dependency] Unit of PSU [Psychiatry Support Unit] at the Canberra Hospital April 2001. Attached are findings of the Coroner of the appalling treatment he received…Mental Health Services in our Territory is not serious about change and improvement of that ward. Superficial changes have happened but many things are unresolved …"As to the manner and circumstances of death; the deceased was found lying on his bed (in the High Dependency Unit of the Psychiatric Unit of the Canberra Hospital) with a plastic bag over his head secured by rubber bands around his neck. The deceased was revived however significant brain damage had been caused and he died in the Intensive Care Unit on [date] 2001…Death occurred at the deceased own hand but at a time when he was in a delusional and psychotic state. As a consequence of his Bi-polar affective disorder he was suffering at the time of the incident resulting in death." (Excerpt from Report of findings by the Chief Coroner)

(Carer, Partner, Australian Capital Territory, Submission #305)

…our story of our youngest son and how he had taken his life even though he was in the care of a private psychiatric unit, Hyson Green, attached to Calvary Hospital in Canberra. He also spent time in the P.S.U. unit at the Canberra Hospital after he made an attempt to take his life at the Telstra Tower.

(Carers, Parents, Australian Capital Territory, Submission #354)

The patient had been given leave from the hospital accompanied by is girlfriend. He was walking behind her across a bridge. When she looked behind she found him throwing himself in front of a passing vehicle…The coronial inquest was held on [date], 2003. The family and the deceased's girlfriend were legally represented. The hospitals involved and the medical staff were not represented. Witnesses were called from the police and the deceased's girlfriend took the stand. Medical staff were not called to give evidence in the stand. The transcript of the coronial inquest indicates that written statements were received from [Dr. S] and [Dr. T]. No statement was tendered from [Dr. R], though Detective Senior Constable [V] did report back on the record of a conversation that was taped at Dr. [V]'s residence on 25 June, 2003. That was the day after the death. The Coroner called no expert witness. The Coroner did not call the medical staff to the stand. (excerpt from a report prepared by an independent external reviewer)

(Carers, Parents, Australian Capital Territory, Submission #354)

6.6.11.4.E.2 Lack of beds

The lack of available beds for acute care was also cited as a serious concern. As discussed previously, access to these beds for consumers in rural and regional areas was particularly problematical. Patients requiring admission were generally in desperate need of medical care, often life-saving medical care. It appears that demand far exceeds the number of beds available, which results in a whole series of other decisions which jeopardise the safety and rights of consumers including: non-admission and returned 'home', admission and someone else who is still unwell is discharged to vacate a bed or lengthy waits in emergency departments.

There are not enough beds for the numbers of "unwell" people in the ACT. Inpatient care/facilities are not well resourced - they are always experiencing staffing shortages. To add to this dilemma is the difficulty of accessing psychiatric hospitalisation when most needed. A treating psychiatrist needs to have admittance rights. Alternative options are to go through the trauma of casualty or via the Crisis and Assessment Treatment Team (CATT), either of which can take up to or over eight hours of waiting.

(Anonymous, Australian Capital Territory, Submission #256)

6.6.11.4.E.3 Children not notified of admission of parent or their needs considered

When a crisis occurs, these young carers are often forgotten, despite their knowledge of the consumer. For example, a young carer, arriving home from school, found no one there. No one had contacted this young person to tell them what had happened.

(Advocate, Australian Capital Territory, Canberra Forum #13)

An advocate and a young carer raised concerns that children of parents with mental illness are often not notified when their parent is admitted to hospital. Some of these children and adolescents fulfil the role as carer. Standard 11.4.E.7 states: 'The MHS assists in minimising the impact of admission on the consumer's family and significant others'. Included in the notes to this Standard is the 'care of dependant children'. Concerns expressed indicate that not only are children not being notified, but provisions are not being for their care if necessary.

There also needs to be some way of getting out people do care for a parent, family member and do need support. Hospitals need to be aware if someone is admitted, a child needs to be contacted.

(13 year old Carer, Son, Australian Capital Territory, CYCLOPS ACT Young Carers Consultation #3)

[Y]'s mother has depression. His mother went to her GP and was admitted to hospital and no one told [Y] she had been admitted.

(13 year old Carer, Son, Australian Capital Territory, CYCLOPS ACT Young Carers Consultation #3)

6.6.11.5 Planning for exit

Consumers are assisted to plan for their exit from the MHS to ensure that ongoing follow-up is available if required.

Under this Standard, submissions and presentations indicate concerns about: discharge plans being inadequate.

6.6.11.5.1 Inadequate discharge plans

Serious concern was expressed about the inadequacy of discharge plans, and that sometimes these plans are not even instigated. Reports also indicate that discharge plans had often not been developed in collaboration with the consumer or carer (Standard 11.5.2), that understandable information about the range relevant services and supports had not been provided (Standard 11.5.4) and that consumers have not established contact with the service providers prior to exit (Standard 11.5.6). These plans are vital in order to ensure ongoing recovery, prevent relapse and reintegrate as fully as possible into society.

Psychiatric disability is ongoing, not fixed on release from hospital. There needs to be an adequate discharge plan available for people discharged from hospital. These plans don't always occur. Many plans are not adequate enough.

(Carer, Father, Australian Capital Territory, Canberra Forum #18)

There is little to do, and little assistance is said to be given to preparing for discharge or for ongoing recovery in the community.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

Families report frequently not being informed about discharge or about what they are required to do. Consumers and carers also report that the practice of being 'discharged as a client' can have disastrous affects as it results in people being cut-off from follow up and having to start all over again if their condition deteriorates or if warning signs appear. Consumers argued that whilst they often welcome being discharged as a client or as an active client, there are times when follow-up for a further period might assist to prevent relapse following a major episode.

(Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

6.6.11.6 Exit and re-entry

The MHS assists consumers to exit the service and ensures re-entry according to the consumer's needs.

Under this Standard, submissions and presentations indicate concerns about:

- being discharged while still unwell; and
- suicide soon after discharge.

6.6.11.6.1 Discharge while still unwell

Concerns were expressed that discharge was not occurring to an agreed exit plan or health status of the consumer. Such exits could jeopardise the safety of the consumer, especially as entry is almost always on the basis of risk or actual self-harm, or harm to others. According to Standard 11.5.2: 'The exit plan is reviewed in collaboration with the consumer, and with the consumer's informed consent, their care's at each contact and as part of each review of the individual care plan'. Also, according to Standard 11.3.18, a review should be conducted when the consumer is going to exit the MHS, presumably to ensure that exit is occurring at and appropriate stage of the recovery process.

> *Consumers and family members and other carers reported that discharge occurs frequently too soon and that people are discharged despite being too ill to care for themselves. "It is just not possible to stay long enough. Maybe you can if you have private insurance but if you are a public patient your stay will be brief if you can get admitted in the first place."*
>
> (Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

> *It was reported that people are frequently discharged too early from inpatient units and are discharged apparently without firm plans in place.*
>
> (Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

6.6.11.6.2 Suicide soon after discharge

As noted above, concern was expressed about the inappropriate discharge of consumers when they were still unwell. Such concerns are confirmed by the reports below of consumers committing suicide soon after discharge:

> *Our 19 year old son committed suicide 18 months ago. He was at a mental health place 19 hours before he killed himself. He had a history of repeated admissions and discharge. He was let out before he killed himself. He had been in care at Mindalla Unit for 28 hours.*
>
> (Carer, Father, Australian Capital Territory, Canberra Forum #1)

> *His suicide was tragic, made all the more so because it was preventable, we believe, but for the inadequacy of the public mental health system. [X] died just two weeks after his first suicide attempt, eight days after his discharge from the Canberra Hospital psychiatric unit, two days after being refused admission to the psychiatric following a second suicide attempt, and within hours of contact with the mental health crisis team. On the day of his death, [X] had contact with the mental health system no less than three times. [X] had a ten-year history of depression and anxiety and a recent, conformed diagnosis of Obsessive Compulsive Disorder. He was openly suicidal. [X's suicide occurred in early 2004].*
>
> (Carer, Sister, Australian Capital Territory, Canberra Forum #9)

6.6.12 STORIES OF HOMICIDE AND SUICIDE IN THE AUSTRALIAN CAPITAL TERRITORY

Our 19 year old son committed suicide 18 months ago. He was at a mental health place 19 hours before he killed himself. He had a history of repeated admissions and discharge. He was let out before he killed himself. He had been in care at Mindalla Unit for 28 hours.

(Carer, Father, Canberra Forum #1)

His suicide was tragic, made all the more so because it was preventable, we believe, but for the inadequacy of the public mental health system. [X] died just two weeks after his first suicide attempt, eight days after his discharge from the Canberra Hospital psychiatric unit, two days after being refused admission to the psychiatric following a second suicide attempt, and within hours of contact with the mental health crisis team. On the day of his death, [X] had contact with the mental health system no less than three times. [X] had a ten-year history of depression and anxiety and a recent, conformed diagnosis of Obsessive Compulsive Disorder. He was openly suicidal. [X's suicide occurred in early 2004].

(Carer, Sister, Australian Capital Territory, Canberra Forum #9)

18 months ago we had no knowledge of mental health. Then our son fell into deep melancholy and depression. He took himself to Telstra Tower, where the police intervened and took him to Canberra Hospital where he entered into involuntary then voluntary care. He then transferred to Roselyn Green under chemical therapies. We requested he undergo ECT [electroconvulsive therapy] but we were ignored. Still under chemical therapies, he threw himself in front of a vehicle. In the ACT we have a chronically under-resourced system that simply is dealing with crisis care. The investigation into his death will be published as an ACT Coroner's Report.

(Carers, Parents, Australian Capital Territory, Canberra Forum #10)

[X] was admitted whilst suicidal to a psychiatric unit in the ACT. There were no permanent staff on the unit, and [X] wasn't under observation. A cleaner noticed that he had a plastic bag with him and informed the staff at the unit. There was no response from the staff, and [X] smothered himself with the bag. The length of time in responding to the coronial inquiry is too long. There has been a very slow response to [X]'s death. A report has been commissioned but won't be released until May. There has been a lack of follow up to [X]'s death. I am still waiting 3 ½ years later for the coronial inquiry– my human rights are being violated.

(Carer, Partner, Australian Capital Territory, Canberra Forum #17)

My partner died as a result of suicide at the HD [High Dependency] Unit of PSU [Psychiatry Unit] at the Canberra Hospital April 2001. Attached are findings of the Coroner of the appalling treatment he received… Mental Health Services in our Territory is not serious about change and improvement of that ward. Superficial changes have happened but many things are unresolved … "As to the manner and circumstances of death; the deceased was found lying on his bed (in the High Dependency Unit of the Psychiatric Unit of the Canberra Hospital) with a plastic bag over his head secured by rubber bands around his neck. The deceased was revived however significant brain damage had been caused and he died in the Intensive Care Unit on [date] 2001… Death occurred at the deceased own hand but at a time when he was in a delusional and psychotic state. As a consequence of his Bi-polar affective disorder he was suffering at the time of the incident resulting in death." (Excerpt from Report of findings by the Chief Coroner)

(Carer, Partner, Australian Capital Territory, Submission #305)

6.7 NORTHERN TERRITORY

ANALYSIS OF SUBMISSIONS AND CONSULTATIONS FROM THE NORTHERN TERRITORY AGAINST THE NATIONAL STANDARDS FOR MENTAL HEALTH SERVICES

In summary, information presented in this section was gathered from 8 submissions (see Appendix 8.3.7) and presentations made at community forums attended by approximately 130 people (see Appendix 8.1). A draft copy of this report was sent to the Chief Minister and Minister for Health for comment. No response was received from the Northern Territory Government to the draft report; however a submission from the Department of Health was received during the consultations (reproduced in Appendix 8.4.7) and an overall review of mental health service delivery in the NT is contained in Part 2.7.7.

6.7.1 NMH STANDARD 1: RIGHTS

The rights of people affected by mental disorders and/or mental health problems are upheld by the MHS.

Under this Standard, submissions and presentations indicate concerns about:

- lack of advocates;
- information is not being provided about mental illness, treatment or rights;
- fear of reprisal if a complaint is lodged; and
- a lack of interpreters.

6.7.1.1 Lack of advocates

Concern was raised that no specialist advocate was available for many consumers seeking such support in Central Australia. Standard 1.6 States that: 'Independent advocacy services and support persons are actively promoted by the MHS and consumers are made aware of their right to have an independent advocate or support person with them at any time during the their involvement with the MHS.' Additionally, for consumers admitted for inpatient care, Standard 11.4.E.6 states 'As soon as possible after admission, the MHS ensures that consumers receive an orientation to the ward environment, are informed of their rights in a way that is understood by the consumer and are able to access appropriate advocates'.

> *There is no specialist advocate for people in Central Australia for people with a mental illness. 30% of our case load are people with a mental illness.*
>
> (Service Provider, Northern Territory, Alice Springs Forum #16)

6.7.1.2 Information not provided about mental illness, treatment or rights

Standard 1.8 states: 'The MHS provides consumers and their carers with information about available mental health services, mental disorders, mental health problems and available treatments and support services.' Reports from the community and service providers indicate this does not always occur. This is of serious concern as this failure can impact on many levels with regards to consent, choice, the right of a person to know about their illness and the treatment plan (and any side-effects) and for carers to be informed regarding what is and will be happening and how they best support the consumer or access support for themselves. It is possible

these reports also suggest that consumers and carers had not been provided with a written or verbal statement about their rights and responsibilities as soon as possible after entering the MHS (Standards 1.2 and 11.4.E.6) in a manner that was understandable (Standard 1.3 and 11.4.E.6).

> *You're lost in space – you pick up bits of information as you go along.*
>
> (Service Provider, Northern Territory, Darwin Forum #26)

> *Early in his illness I wasn't aware I could be so vocal.*
>
> (Carer, Mother, Northern Territory, Darwin Forum #4)

6.7.1.3 Fear of reprisal if a complaint is lodged

Concern was expressed that many consumers and carers are not making complaints as they were afraid that services would be withdrawn if a complaint was lodged. To support this, a service provider who runs a complaint service remarked that few complaints were received regarding mental health service delivery.

This would imply that the complaints procedures were not easily accessed, responsive and fair (Standard 1.10), or that consumers and carers do not have faith in this process. Failure to have in place a system which allows patients and their families and carers to make complaints confidentially and ensure that complaints procedures are adhered and responded to weakens this right and fails to provide a mechanism by which to 'improve performance as a part of a quality improvement process' (Standard 1.12). This does not allow for the identification of single or systemic failures and thereby does not allow for personal redress or systemic improvement.

> *95 per cent of the reason why you don't get complaints – because they are exhausted and afraid of vindication.*
>
> (Anonymous, Northern Territory, Darwin Forum #27)

> *We run a complaint service, but receive not a lot of complaints about mental health.*
>
> (Service Provider, Northern Territory, Darwin Forum #25)

> *I was reluctant to lodge a complaint about the Top End mental health system because they were the only ones who were prepared to do anything. My son is not here speaking today. I did approach the community visitors program but my son is now in the judicial system so no one can go near him.*
>
> (Service Provider, Northern Territory, Darwin Forum #26)

6.7.1.4 Lack of interpreters

For people who have a hearing impairment or speak a language other than English, access to mental health care is further complicated by communication and cultural barriers. These barriers may make it difficult for the consumer and their family and carers to understand mental disorders, mental health problems and available treatment and support services and how to navigate the system. In many cases a person may be socially isolated or reluctant to have family or friends involved as carers or act as an interpreter for reasons of confidentiality or stigma.

Concern was expressed by the Melaleuca Refugee Centre that many consumers from a non-English speaking background (NESB) are unable to access skilled and experienced interpreters and therefore language and cultural barriers are not being overcome. An inability to access interpreters could also mean that people are not being made aware of their rights and responsibilities (unless it is provided in written form) as required by Standard 1.3 (written material in their language or via and interpreter):

Language and cultural barriers are often not overcome because skilled and experienced interpreters are not available. Also interpreters will often have to play a role as a bi-cultural worker, to bridge the gap in cultural understanding.

(Melaleuca Refugee Centre, Northern Territory, Submission #191)

6.7.2 NMH STANDARD 2: SAFETY

The activities and environment of the MHS are safe for consumers, carers, families, staff and the community.

Under this Standard, submissions and presentations indicate concerns about:

- inadequate treatment and support services to ensure the safety of consumers;
- carers and the community;
- the MHS is not communicating vital information with other accommodation service providers to ensure the safety of staff and other residents; and
- transport of consumers in a manner which is not 'safe and dignified'.

6.7.2.1 Inadequate treatment and support services to ensure the safety of consumers, carers and the community

Standard 2.3 states: 'Policies, procedures and resources are available to promote the safety of consumers, carers, staff and the community.' Concern was expressed that the MHS is not providing sufficient support to guarantee this safety. In one report, the MHS failed to keep contact with a consumer and her family as arranged even when they had assessed her life and her children's life as being at risk. Other reports indicate lack of after hours support to ensure the safety of the consumer, staff and other residents in a hostel, and inability to access treatment and support resulting in a member of the community being harmed.

…During an acute and particularly traumatic episode, [X] made an agreement with mental health services that the service would contact [X]'s the family on the weekend. According to [X], despite this assurance, no contact occurred either on the weekend or thereafter.

(Support and Equity Services, Charles Darwin University, Northern Territory, Submission #269)

If a client has an episode after hours it is difficult to get assistance even via the phone. Residents and other staff can be put at risk during these times. If assistance is unavailable for some time there is a concern that it may have a flow on effect to other residents.

(Supported Accommodation Service Provider, Northern Territory, Submission #217)

There was a person turned away from the hospital because they were told he was only looking for a bed for the night. He then went out into the community and harmed somebody.

(Anonymous, Northern Territory, Alice Springs Forum #21)

6.7.2.2 MHS not communicating vital information with other accommodation service provider to ensure safety of staff and other residents

A supported accommodation service provider expressed concern that due to a lack of access to information, their own limited resources and low staff to resident ratio, they are often placed in a difficult situation of potentially having to turn away a resident if they suspect there is a level of risk to the safety of the consumer, staff or other residents.

We are concerned that we may be seen as discriminating if we turn away a mental health patient when we don't know all the details and suspect that to have that person staying in the facility may cause a danger to staff and other residents. There is a very fine line between duty of care to current residents and staff and that of a potential resident.

(Supported Accommodation Service Provider, Northern Territory, Submission #217)

6.7.2.3 Transport of consumers in a manner which is not 'safe and dignified'

Standard 2.3 states: 'Policies, procedures and resources are available to promote the safety of consumers, carers, staff and the community'. Included in the notes to this Standard is 'policy on the transport of consumers from one location to another in a safe and dignified way'. Concern was expressed regarding the need to chemically and physically restrain people in order for them to access treatment and support services. Due to the current distribution of resources in the Northern Territory, this requirement has a disproportionate impact on Indigenous people. Concern was also raised with the need to be transported in the back of a police paddy wagon to access care.

Generally if a person's level of distress is of such concern to the clinic staff, themselves, family and / or community, the person will be evacuated, generally by air, to Alice Springs for assessment. The distances involved and the use of planes mean that evacuation to the acute service often requires chemical and/or physical restraint. Clearly there are significant safety issues that are evaluated in each case, however it does mean that Anangu are more likely to be chemically and physically restrained during an acute episode.

(Anonymous, Northern Territory, Submission #271)

I'm a manager of a hostel. We're in contact with the mental health service every day but the problem is in after hours. We seem to come unstuck. We have to try to get the person to the hospital. There is a poor response from police. The police do get some training but usually the transport occurs in the back of a paddy wagon. Only one worker on shift at night and if they do a home visit at night…

(Service Provider, Northern Territory, Darwin Forum #15)

6.7.3 NMH STANDARD 3: CONSUMER AND CARER PARTICIPATION

Consumers and carers are involved in the planning, implementation and evaluation of the MHS.

Under this Standard, submissions and presentations indicate concerns about:

- lack of progress and consultation fatigue.

6.7.3.1 Lack of progress – consultation fatigue

Carers expressed concern that they are tired of participating on committees and attending forums and consultations to no avail. In particular, one carer was concerned that consumers and carers are risking exposing themselves by repeatedly retelling their stories and airing any grievances. Standard 3.2 states: 'The MHS undertakes and supports a range of activities which maximise both consumer and carer participation in the service'.

My son and I have been involved with the Mental Health Association and been on lots of committees and attended many forums and consultations and where are we?

(Carer, Mother, Northern Territory, Alice Springs Forum #13)

We say if you help the consumer, you help us. We have lobbied, we've written to everyone but the majority of the money has gone to the hospital not to the consumer in the community.

(Carer, Mother, Northern Territory, Alice Springs Forum #13)

This is the fourth community forum, report for mental health services in the NT – we are exposing ourselves.

(Carer, Mother, Northern Territory, Darwin Forum #2)

The Mental Health Program, Department of Health and Community Services, suggests that involvement by consumers and carers has increased:

Increased Carer and Consumer Involvement: The Mental Health Coalition has now been endorsed as the mental health peak body in the Northern Territory. Funding has been allocated to support the work of the Coalition, including coordination of mental health promotion activities. A representative from the NT will take a seat on the Board of the Mental Health Council of Australia (MHCA), the National Peak Body. The Coalition will work together with the Northern Territory Consumer Advisory Group to increase consumer and carer representation. The NTCAG was one of the earliest to be established under the National Mental Health Strategy and has representation on such committees as the Approved Procedures and Quality Assurance Committee and The Mental Health and Police Liaison Committee and provides consumer and carers representation on selection panels for mental health appointments. Consumers and carers have also provided active participation in 2003/04 within the Top End and Central Australia Service Improvement Projects.

(Mental Health Program, Department of Health and Community Services, Northern Territory, Submission #259)

6.7.4 NMH STANDARD 4: PROMOTING COMMUNITY ACCEPTANCE

The MHS promotes community acceptance and the reduction of stigma for people affected by mental disorders and/or mental health problems.

Under this Standard, submissions and presentations indicate concerns about:

- high levels of stigma; and
- discrimination in employment settings.

6.7.4.1 High levels of stigma

My grandson feels he shouldn't live because he has no hope for job or marriage.

(Carer, Grandmother, Northern Territory, Darwin Forum #8)

Carers and advocates continue to express concerns about the high level of stigma and ostracism still being experienced by people with mental illness. This would indicate that campaigns and activities to address community acceptance and reduce stigma to date (Standard 4.1) have not been able to turn community attitudes around. As described below, perceived discrimination and lack of community acceptance are key barriers to people with mental illness accessing treatment and support and being able to participate socially, economically and politically in society. Lack of access to services also contributes to the high levels of stigma associated with mental illness due to people having to reach crisis point before they can access services:

Admission to mental health facilities or contact with mental health professionals results in fear of consequences for community and professional standing and this fear has a realistic base.

(Support and Equity Services, Charles Darwin University, Northern Territory, Submission #269)

A Student studying in a highly professional area is admitted to the one available acute care facility and is concerned about the impact this will have on their future professional standing. The Government database is currently a shared resource. Available confidential counselling avenues are limited without extensive financial family support.

(Support and Equity Services, Charles Darwin University, Northern Territory, Submission #269)

My daughter is also ill but she's afraid of the diagnosis.

(Carer, Grandmother, Northern Territory, Darwin Forum #8)

Stigma is a persistent issue in the NT. Some of the local media have repeatedly reported on anti-social behaviour by Aboriginal and Torres Strait Island people with mental illness in a way which blames those affected, rather than relate this to symptoms and lack of treatment, as they would with any other illness.

(SANE Australia, National, Submission #302)

6.7.4.2 Discrimination in employment settings

Employment and a supportive workplace are seen as key factors in preventing the rapid escalation of mental illness and essential in the process of rehabilitation and reintegration into society after a period of illness. In support of this, Standard 4.2 states: 'The MHS provides understandable information to mainstream workers and the defined community about mental disorders and mental health problems'. However, acceptance and understanding of mental illness seem to be lacking in the workplace and, according to one presentation made by a mother at the Darwin Forum, discrimination and high levels of stigma are still prevalent as her daughter was asked to leave upon return to work after a period of illness and recovery.

There is discrimination in employment. You become ill, get the treatment on sick leave, get well again and are asked to leave.

(Carer, Mother, Northern Territory, Darwin Forum #5)

6.7.5 NMH STANDARD 5: PRIVACY AND CONFIDENTIALITY

The MHS ensures the privacy and confidentiality of consumers and carers.

Under this Standard, submissions and presentations indicate concerns about:

- policies regarding privacy and confidentiality hindering communication with carers; and
- problems with access to databases and confidentiality.

6.7.5.1 Policies regarding privacy and confidentiality hindering communication with carers

Carers expressed concern that the policies and procedures to protect the confidentiality and privacy of consumers are hampering communication between consumers, carers and clinicians in the provision of treatment and support and potentially jeopardising the safety of consumers. Carers expressed feelings of frustration that some clinicians were very resistant to discussing anything with them.

There is lack of consultation with carers under the guise of confidentiality.

(Carer, Mother, Northern Territory, Darwin Forum #2)

Because of client confidentiality I wasn't allowed to know about my son's accommodation.

(Carer, Mother, Northern Territory, Darwin Forum #21)

6.7.5.2 Problems with access to databases and confidentiality

Although Standard 5.4 states: 'Consumers give informed consent before their personal information is communicated to health professionals outside the MHS, to carers or other agencies or people', one consumer was worried about confidentiality, and potential discrimination, as a result of people who have authorised access to the database discovering their information.

> *A Student studying in a highly professional area is admitted to the one available acute care facility and is concerned about the impact this will have on their future professional standing. The Government database is currently a shared resource. Available confidential counselling avenues are limited without extensive financial family support.*
>
> (Support and Equity Services, Charles Darwin University, Northern Territory, Submission #269)

A supported accommodation service provider expressed concern that they were not given sufficient information to ascertain support and safety requirements for potential consumers, current residents and staff. Such information was seen as vital due a critical lack of resources and staff in these accommodation settings. The failure to provide relevant information could result in either the consumer being turned away on the basis of perceived and not actual possible risk, or being accepted without necessary information provided to staff.

> *When clients are booked into the accommodation we are given no details even though at times we may be putting staff and other residents at risk. We need to have some idea of the history and any potential problems so as to be able to provide the best (even though limited) safe service possible.*
>
> (Supported Accommodation Service Provider, Northern Territory, Submission #217)

6.7.6 NMH STANDARD 6: PREVENTION AND MENTAL HEALTH PROMOTION

The MHS works with the defined community in prevention, early detection, early intervention and mental health promotion.

Under this Standard, submissions and presentations indicated concerns about:

- the lack of focus on prevention and early intervention programs;
- the need for joint substance abuse and mental illness treatment programs;
- consequences of failure to intervene early and provide treatment and support; and
- suicide prevention strategies.

6.7.6.1 Lack of focus on prevention and early intervention programs

Standard 6.8 states: 'The MHS ensures that the consumer has access to rehabilitation programs which aim to minimise psychiatric disability and prevent relapse'. Concern was expressed however that the MHS places too much emphasis on crisis intervention and too little emphasis stopping the crises from occurring by providing other programs to intervene early, prevent relapse or promote recovery.

> *The resources need to be outsourced from the hospital. We need respite care, prevention education for the communities: it's too chemical.*
>
> (Anonymous, Northern Territory, Alice Springs Forum #21)

6.7.6.2 Prevention – substance abuse and mental illness need to be tackled jointly

Concerns were expressed regarding the high levels of substance abuse in Indigenous communities and associated mental health issues. Concern was expressed that as these rates are so high any mental health promotions programs need to address the problems jointly. This indicates greater attention to a preventive focus in the delivery of mental health services is required, as outlined by Standards 6.4 (capacity to identify and respond to the most vulnerable consumers in the community), 6.5 (capacity to identify and respond as early as possible) and 6.6 (treatment and support to occur in a community setting in preference to an institutional setting).

Given the known consequences of substance abuse, it is alarming that treatment and support services are not provided at the earliest possible moment to prevent deteriorating illness. Result of this failure can include deteriorating physical and mental health, risk of harm to self or others, unemployment and social withdrawal, and the need for acute care in restrictive settings with severe treatment regimes.

> *Significant substance abuse problems exist in Aboriginal remote communities, resulting in significant mental health problems.*
>
> (Anonymous, Northern Territory, Submission #188)

> *…funded by the Commonwealth Government through the National Illicit Drugs Strategies to provide support for youth at risk of substance misuse. The funding provides 1.4 EFT for all Anangu Pitjantjatjara Lands communities and 1 EFT in Western Australia. This includes 22 communities and nearly all of the 350,000km catchment area of NPY lands. In one community alone there are 40 people identified as petrol sniffers. This has significant short and long-term effects on the mental health system as people misusing substances are at a much higher risk of having contact with mental health services. Clearly with the workload of these positions any ability to also look at issues of mental health prevention or ongoing support for a person with a mental health diagnosis is virtually impossible.*
>
> (Anonymous, Northern Territory, Submission #271)

> *Substance misuse in indigenous communities, and its associated problems, are well documented. Over the last five years the increased availability and use of cannabis on the NPY Lands has become of increasing concern to the [Y] membership.*
>
> (Anonymous, Northern Territory, Submission #271)

> *As the incidence of substance misuse is so high it is essential that mental health issues are addressed within this context. According to NT/SA Remote Mental Health team in 2002 half of their referrals also involved substance misuse.*
>
> (Anonymous, Northern Territory, Submission #271)

6.7.6.3 Consequences of failure to intervene early and provide treatment and support

One carer reported the consequences to the mental health of her grandchildren of services presumably not providing support to the family and the children when required.

> *I have mentally ill grandchildren in their 20's. My daughter is also ill but she's afraid of the diagnosis. Grandchildren are angry with us because we didn't take them out of the family home when they were young.*
>
> (Carer, Grandmother, Northern Territory, Darwin Forum #8)

6.7.6.4 Suicide prevention strategies

The Mental Health Program, Department of Health and Community Services acknowledged that the Northern Territory has a higher than national suicide rate, which is increasing, for both Indigenous and non-Indigenous residents. In response, the Department of Health and Community Services has implemented a number of specific initiatives to address suicide prevention aimed at identifying and responding to vulnerable consumers and carers (Standard 6.4). The Department noted also work working in other organisations to promote mental health and prevent the onset of mental disorders and/or mental health problems (Standard 6.3):

> *Care needs to be taken when interpreting suicide rates in the Northern Territory because of the relatively small numbers and yearly fluctuations. However, it is clear that the suicide rate in the Northern Territory has been higher than the national rate for the past decade and continues to rise. Indigenous suicide rates have also increased significantly. A range of specific initiatives are in place to address suicide prevention, including the Life Promotion Program which provides an integrated approach to life promotion through collaborative partnerships and community education. Key initiatives developed by the program include the Youth at Risk Network safety net, The Youth Info Card – Life Promotion Contact Card; and the Indigenous Youth Forum. Inter-Agency Suicide Response Task Groups have also been developed in the Top End and Central Australia to provide a collaborative response with the Coroner's Constables in the event of a completed suicide. They provide follow up support to people who attempt suicide, and postvention support and referral for bereavement counselling for those who have lost someone through suicide.*
>
> (Mental Health Program, Department of Health and Community Services, Northern Territory, Submission #259)

> *In October 2003, the Northern Territory Strategic Framework for Suicide Prevention was launched. This framework acknowledges and builds on existing suicide prevention initiatives and confirms key directions and pathways for future activities.*
>
> (Mental Health Program, Department of Health and Community Services, Northern Territory, Submission #259)

6.7.7 NMH STANDARD 7: CULTURAL AWARENESS

The MHS delivers non-discriminatory treatment and support which are sensitive to the social and cultural values of the consumer and the consumer's family and community.

Under this Standard, submissions and presentations indicated concerns about:

- the lack of culturally appropriate treatment and support services for Indigenous consumers and their families;
- lack of treatment and support services for refugees and older immigrants;
- need for training of interpreters on mental health issues; and
- a need for additional cultural competency training for mental health professionals.

6.7.7.1 Lack of culturally appropriate treatment and support services for Indigenous consumers and their families

The unique challenges faced by the Northern Territory in providing quality mental health care were discussed by the Department of Health and Community Services.

There are also various characteristics of the Territory population that dramatically affect the demand for and cost of mental health services. The primary characteristic is that 28.5% of the Territory's population is Indigenous, compared to 2.2% in other jurisdictions in Australia. A very high proportion of the Indigenous population, 70%, live in remote areas (ABS, 2002) and English is often a second or even third language. Significant long-term primary health and environmental problems pose challenges to the delivery of mental health services to this population. Issues such as poverty, alcohol and drug misuse, domestic violence, sexual and other forms of abuse, high mortality rates as well as an increasing sense of grief and loss amongst the Aboriginal population increase the incidence of mental health problems whilst at the same time reducing individual and community capacity to respond to them. A natural consequence of this is a much higher demand for services, however, the complexity of many Indigenous issues, the need for services to be culturally appropriate and the general dispersion of the Indigenous population in the Territory, mean that it is also much more difficult to provide this services.

(Mental Health Program, Department of Health and Community Services, Northern Territory, Submission #259)

Evidence presented suggests that these and other factors have acted as a barrier to the delivery of mental health care in a manner which 'considers the needs and unique factors of social and cultural groups represented in the defined community and involves these groups in the planning and implementation of services.' (Standard 7.2). Furthermore, Standard 7.3 states: 'The MHS delivers treatment and support in a manner which is sensitive to the social and cultural beliefs, values and cultural practices of the consumer and their carers' and Standard 7.4 states: 'The MHS employs staff…with relevant experience in the provision of treatment and support to the specific social and cultural groups represented in the defined community'.

Given the considerable size of the Indigenous population in the Northern Territory and the distribution of Indigenous communities across the Territory, failure to adequately engage Indigenous communities to determine how best to meet the needs of consumers and their families in culturally appropriate ways and plan accordingly, would be a significant weakness in the ability of the MHS to promote and protect the rights of Indigenous consumers and their families.

Underlying this submission are several assumptions of knowledge: Indigenous Australians have significantly worse health outcomes than the general population, including higher rates of mental health concerns; The mental health concerns of indigenous Australians need to be viewed in the context of global disadvantage including poverty, reduced life expectancy and chronic ill health, as well as issues of cultural dislocation, trauma and grief; Anangu view mental health issues as part of a general concept that includes the health of the individual, family, community and land in a cyclic view of past, present and future.

(Anonymous, Northern Territory, Submission #271)

The issues of paranoid behaviour are difficult to deal with culturally.

(Service Provider, Northern Territory, Alice Springs Forum #9)

If the current mental health system works at its optimum level, there are still critical and serious service provision gaps. Anangu do not have access to a spectrum of interventions that are culturally appropriate and responsive to individual and / or community need. There is no access to counselling, grief and trauma support, early intervention programmes or ongoing rehabilitation programmes if someone has been diagnosed with an ongoing disability.

(Anonymous, Northern Territory, Submission #271)

As in many parts of Australian society, mental health issues are often difficult for Anangu & their families to discuss and are often only raised in relation to substance misuse. Anangu culture has many ways of supporting people at times of distress, so often help is sought only when the family's ability to care for a family member is stretched to crisis point. Ngangkari play a large role in providing ongoing mental health support in communities. They acknowledge, however, that they have little ability to deal with the effects of petrol and marijuana use.

(Anonymous, Northern Territory, Submission #271)

English is generally not the first language of Anangu families living on the NPY Lands. It can be the third or fourth language. Due to a range of factors including poor school attendance, there is a huge variation in literacy skills. Across the region literacy levels are well below the national average. The use of an interpreter is usually required, especially in the complex area of mental health, where there are often abstract and difficult concepts and choices involved.

(Anonymous, Northern Territory, Submission #271)

The indigenous community protects (hides) the mental illness until there's a crisis.

(Anonymous, Northern Territory, Alice Springs Forum #21)

However, a positive step taken by the Northern Territory Department of Health and Community Services to addressing culturally sensitive mental health care was reported.

One initiative to provide culturally appropriate mental health services is the employment of Aboriginal Mental Health Workers (AMHW). AMHWs play an instrumental role in overcoming challenges at the individual and community level by contributing to the delivery of well-informed information and interventions to Aboriginal people. They work hand in hand with mainstream mental health professionals to provide services and act as cultural brokers and mediators, as well as providing mental health assessments, management, and education at an individual, family and community level. A significant number of clinicians have also been supported to attend training programs to increase cultural competency.

(Mental Health Program, Department of Health and Community Services, Northern Territory, Submission #259)

6.7.7.2 Lack of treatment and support services for refugees and older immigrants

Concern was also expressed that issues associated with migration and cultural difference need to be considered in the planning of treatment and support for older immigrants. Standard 7.1 states: 'Staff of the MHS have knowledge of the social and cultural groups represented in the defined community and an understanding of those social and historical factors relevant to their current circumstances'.

Those with a different cultural background – there's now a situation where older immigrants are now developing mental health problems and I'm not sure the services, with limited resources, respond to these problems in a small community – older immigrants are losing partners and now grieving for their home country.

(Anonymous, Northern Territory, Alice Springs Forum #11)

Melaleuca Refugee Centre works with predominantly newly arrived refugees…from African background, Sudan, Liberia, Congo, Ethiopia and Somalia and belong to new and emerging communities. We also provide counselling for refugees who have been here longer and suffer from symptoms of Post Traumatic stress Disorder. These include people from East Timor, Indonesia, Burma, Vietnam and Cambodia. All of our clients are affected by years of trauma, loss and in some cases systematic torture. Most people suffer from some symptoms of PTSD. Some will need to access Mental Health Services. Cultural differences in the interpretation, understanding and meaning around mental health issues can form a major barrier to service provision. Western concepts of mental health are not necessarily understood and service provision might increase feelings of anxiety, disempowerment and displacement. The service provider can misinterpret symptoms or body language which might have a different cultural meaning.

(Melaleuca Refugee Centre, Northern Territory, Submission #191)

6.7.7.3 Need for training of interpreters on mental health issues

Concern was expressed by Melaleuca Refugee Centre that in order for mental health services to ensure that information is being translated accurately by interpreters, training needs to be provided to interpreters about mental health terminology and how the system works:

We rely heavily on interpreters who in most cases also come from a refugee background themselves and might not have been in Australia for a long time. Mental Health terminology and processes are usually not within their area of experience…So far there has been no training for interpreters on mental health issues in Darwin. Melaleuca has put in a funding submission to organise such training.

(Melaleuca Refugee Centre, Northern Territory, Submission #191)

6.7.7.4 Need for additional cultural competency training for mental health professionals

Concern was expressed by Melaleuca Refugee Centre that additional training needs to be provided to mental health professionals so that they 'have knowledge of the social and cultural groups represented in the defined community and an understanding of those social and historical factors relevant to their circumstances' (Standard 7.1) and can provide treatment and support which is sensitive to the social and cultural values of people with mental illness and their family and carers:

Also training for mental health professionals on refugee issues, cultural beliefs and practices has been very minimal. There have been several meetings between Mental Health management and Melaleuca staff to address the issue, and we hope that strategies are being put into place.

(Melaleuca Refugee Centre, Northern Territory, Submission #191)

6.7.8 NMH STANDARD 8: INTEGRATION

6.7.8.1 Service integration

The MHS is integrated and coordinated to provide a balanced mix of services which ensure continuity of care for the consumer.

Under this Standard, submissions and presentations indicate concerns about:

- lack of staff and resources to provide integrated care to remote communities;
- inability to provide coordinated care due to high staff turnover; and
- lack of staff to provide continuity of care across sites and services.

6.7.8.1.1 Lack of staff and resources to provide integrated care to remote communities

Another factor which was seen to inhibit the provision of integrated and continuous care was the lack of staff and resources to serve the defined community, especially as in this instance, the defined community was the entire southern area of NT and SA (Standard 8.1.1: There is an integrated MHS available to serve each defined community). The following submission describes a system where a lack of staff and resources means that visits are seldom made, the focus of service delivery is predominantly crisis management and individual case planning is minimal.

> *Follow up is then provided by a visiting psychiatrist and two community case managers who are funded to cover the entire southern area of NT and SA. This means that the focus of the service can only be crisis management at best. The ability for workers to provide ongoing support or any meaningful individual case planning is significantly impaired. Generally the workers will average a trip once a month to the region, which means even the larger communities may not see a worker for several months. The level of service is purely resource, rather than need, driven.*
>
> (Anonymous, Northern Territory, Submission #271)

One service provider commented that Lifeline is providing support for many consumers and carers.

> *Lifeline is definitely aware of calls from mental health consumers and carers. The quality of the training is there and has been recognised.*
>
> (Service Provider, Northern Territory, Alice Springs Forum #14)

6.7.8.1.2 Inability to provide coordinated care due to high staff turnover

Reports of high staff turnover also concerned one carer, as this meant that there was not one designated staff member who knew the individual care plan (Standard 8.1.2) and consumers were not receiving continuous care. According to Standard 8.1.4 'opportunity exists for the rotation of staff between settings and programs within the MHS, and which maintains continuity of care for the consumer'. Also Standard 8.1.1 states: 'There is an integrated MHS available to serve each defined community'.

> *Many times the service didn't even know where my son was when he was in treatment. Over the years there has been a continual change in case management, every 3 months different workers, incredible turnover. There is a high case load with over 30 clients.*
>
> (Carer, Mother, Northern Territory, Darwin Forum #4)

6.7.8.1.3 Lack of staff to provide continuity of care across sites and services

With regards to Standard 8.1.5 (the MHS has documented polices and procedures which are used to promote continuity of care across programs, sites, other services and lifespan), a submission indicated problems in the ability of the MHS to provide a balanced mix of services to ensure continuity of care for the consumer due to a long wait list for the service, location problems (difficult to access with public transport) and no follow-up with the consumer or referring agency when acute care was refused.

Referral to community agencies for therapeutic counselling is primarily available through one community organisation, which has an eight week waiting list. This service is difficult to access via public transport and impacts on approximately 20 students actively seeking this service.

(Support and Equity Services, Charles Darwin University, Northern Territory, Submission #269)

[X] … is escorted to the emergency department of the local hospital… [Y]… assessed [X] to be at high risk of suicide. No admission and no follow-up is arranged. Additionally, no contact was made with the referring agency and according to [X], no request of discussion with the referring agency was sought by mental health services.

(Support and Equity Services, Charles Darwin University, Northern Territory, Submission #269)

6.7.8.2 Integration within the health system

The MHS develops and maintains links with other health service providers at local, state and national levels to ensure specialised coordinated care and promote community integration for people with mental disorders and / or mental health problems.

Under this Standard, submissions and presentations indicate concerns about:

- physical health care neglected in MHS; and
- for Indigenous people mental health care is neglected due to poor physical health.

6.7.8.2.1 Physical health care neglected in MHS

Standard 8.2.1 states: 'The MHS is part of the general health care system and promotes comprehensive health care for consumers, including access to specialist medical resources'. Concern was expressed that the MHS is neglecting the physical health of consumers. One carer stated that physical health concerns were neglected as an inpatient in the MHS and it was not until the consumer was moved to a private hospital that comprehensive care was obtainable. This means that comprehensive health care is only available to those who can afford it, resulting in people from low socio-economic backgrounds being discriminated against.

I have had an experience where I wasn't treated for a physical health problem because I had a mental illness.

(Consumer, Northern Territory, Darwin Forum #16)

I couldn't get physical health treatment for my son at same time as mental health treatment.

(Carer, Mother, Northern Territory, Darwin Forum #21)

She actually presented to the emergency department with low blood pressure. She wasn't treated and when I saw the chart it has psych patient on it. She only got treated when she was moved to the private hospital.

(Carer, Mother, Northern Territory, Darwin Forum #5)

If a person has a mental illness and other disabilities it's very difficult for them to get assistance for their physical health problems. The difficulties experienced are unacceptable.

(Service Provider, Northern Territory, Darwin Forum #6)

6.7.8.2.2 For Indigenous people, mental health care is neglected due to poor physical health

Conversely, for Indigenous people, the following submission describes poor physical health acting as a barrier to the treatment and prioritisation of mental health issues except in times of acute episodes.

It is important to note that the health providers across the region are already critically under resourced. The issues relevant to indigenous physical health outcomes are well documented. With the ongoing critical physical health needs of the community, staff are already at full capacity. In this context issues of mental health cannot be prioritised, unless there is an acute need for treatment.

(Anonymous, Northern Territory, Submission #271)

6.7.8.3 Integration with other sectors

The MHS develops and maintains links with other sectors at local, state and national levels to ensure specialised coordinated care and promote community integration for people with mental disorders and/or mental health problems.

Under this Standard, submissions and presentations indicate concerns about:

- whole-of-government approach needed;
- higher education;
- the lack of cross-border agreements;
- youth; and
- the lack of support from Centrelink.

6.7.8.3.1 Whole-of-government approach needed

I've seen the petrol babies that come into the hospital. These babies are six months old and already have brain damage. We've been told about babies that have little cans strapped to their noses because petrol babies don't cry.

(Service Provider, Northern Territory, Alice Springs Forum #17)

Concerns were expressed that the lack of services, lack of integrated service delivery, poor resource distribution and layers of economic and social disadvantage in the Territory required a whole-of-government approach to solve the complex support needs required for people with mental illness to live in the community in a dignified manner. Problems were reported with education, health, welfare, community services, disability services and housing. Many submissions identified that a broader governmental, societal and community approach was urgently required to tackle poorer health, economic and social outcomes for Indigenous Territorians, high rate of substance abuse in Indigenous communities, the high rate of Indigenous suicide and lack of support for consumers with physical disability.

We're in a crisis here in NT, particularly indigenous suicides.

(Service Provider, Northern Territory, Darwin Forum #1)

I see the end result of petrol sniffing: cognitive functioning impaired and wheel chair bound. People's behaviour is becoming challenging. Many of these people could be managed in the community and so they come into town and then require accommodation. One of the big problems is boredom. There is nothing to do; it's very sad to see five year olds sniffing petrol.

(Service Provider, Northern Territory, Alice Springs Forum #6)

There is not enough bereavement support for Indigenous people. The whole community is grieving. Good postvention is the best prevention. NT has double the suicide rate of other states. For Indigenous people there's a lack of data, but by some estimates suicide is four times the national average. Suicide amongst 15-35 years is most prominent.

(Service Provider, Northern Territory, Darwin Forum #1)

The Commonwealth Government's decision to allocate funding for the Bringing Them Home Counsellors to the Department of Health and Aged Care through the Office of Aboriginal & Torres Strait Islander Heath to the Aboriginal Health Services has caused ongoing difficulties to Link-Up Services, not only in Central Australia but also in the other states, because access to the BTH Counsellors in an appropriate service delivery model and venue has not occurred. Instead there has been a division of services. The CASG&FAC document "Where is the $63 million? Discussion Paper" explains the views of CASG&FAC [Central Australian Stolen Generations & Families Aboriginal Corporation] on this issue.

(Anonymous, Northern Territory, Submission #281)

For me this is not strong language, during the ten years I have been a carer of a severely physically disabled mentally ill person, I feel I have been treated less then human, and the person I care for, as well as others with disabilities, looked upon as worthless citizens who the governments wished didn't exist. Our loved ones are offered inferior care, if care is what it can be called. Inferior housing. Low funding to the organisations and groups in place to provide help which has resulted in overprotection of those small limited funds and a lack of wanting to work with others for fear of loosing what little money they are given, a lack of co-operation at any cost, even at the expense of the mentally ill or their carers.

(Carer, Husband, Northern Territory, Submission #68)

6.7.8.3.2 Higher education

Standard 8.3.2 states: 'The MHS supports staff, consumers and carers in their involvement with other agencies wherever possible and appropriate' and Standard 8.3.3 states 'The MHS has formal processes to develop intersectoral links and collaboration.' These Standards apply to the education sector, including schools, TAFE and universities. Links with the education sector to assist with early identification and early intervention are critical in any set of strategies targeted at prevention and gaining the skills to attain qualifications necessary for employment and participation in society. One submission indicated that insufficient supports are available for consumers to consider training and study as a serious option.

People with mental health concerns, or maybe dilemmas, who attempt to recreate or regain their lives through training and study are currently not given the support they need to do this adequately. Student support services are not able to adequately meet student's needs independently…

(Support and Equity Services, Charles Darwin University, Northern Territory, Submission #269)

From everything we know about mental health, prevention is one of the best interventions. But now student services are being called upon to be the 'primary' supports. This is the message from student service managers nationally.

(Support and Equity Services, Charles Darwin University, Northern Territory, Submission #269)

Several students, with ongoing mental health issues have left their studies and Darwin following many unsuccessful attempts at securing professional mental health support services locally.

(Support and Equity Services, Charles Darwin University, Northern Territory, Submission #269)

6.7.8.3.3 The lack of Cross Border Agreements

Due to difficulties with the provision of treatment and support services to remote areas of Northern Territory, concern was expressed that access for consumers living close to the border could be enhanced through cross-border agreements with Western Australia, South Australia and Queensland. Such agreements could be used to the mutual benefit of all signatories and enhance access to scarce resources.

Lack of co-ordination between State Governments can lead to services gap and duplication. With the exception of the South Australian & Northern Territory agreement there is no coordination of services, increasing the risk of service duplication. It also means that more cost effective, co-ordinated, innovative service options are not explored.

(Anonymous, Northern Territory, Submission #271)

We want you people to listen to us & make good for us. We want family to live. We do not want to lose more people. We are still travelling to meetings and still talking same story. We do not want to send our kids to another community. We want people to come to the community & teach those kids in the bush.

(Anonymous, Northern Territory, Submission #271)

Currently, mental health services for the Northern Territory and South Australian region of the NPY Lands provided via Alice Springs regional office of the NT Department of Health. It has an inpatient service based at the Alice Springs Base Hospital and a community case management service. Geographically Alice Springs is approximately 450kms from the closest community on NPY lands. The furthest community is approximately 750 kilometres from the town (mostly on unsealed roads). The South Australian Government provides funding through its Visiting Medical Specialist program to the Remote mental health team based in Alice Springs for this cross-border region. This is one of the few examples of cross-state funding in the region.

(Anonymous, Northern Territory, Submission #271)

Anangu are affected by differences in mental health policies and funding among two States and a Territory, and the Federal Government. This includes three separate and different mental health Acts. This can be particularly difficult with issues of competency and a mobile population that moves between the three states. For example someone may have a community treatment order in Western Australia and then visit family 50 kms away in South Australia. The health service can encounter significant barriers to providing a service, especially in relation to issues of acute treatment. The borders between those two communities can mean the difference between being evacuated to Perth or Alice Springs. The incongruity of this situation raises serious and significant concerns about continuity of care.

(Anonymous, Northern Territory, Submission #271)

6.7.8.3.4 Youth

The Northern Territory also has the youngest population in Australia. Territorians under 18 make up 30% of the population, a greater percentage than anywhere else in the country. Of the 57 000 plus children in the Territory, more than 21 000, or 37%, are Aboriginal. The high number of youth in the Territory creates both challenges and opportunities for early intervention. A range of studies have also reported that young adults (18-24 years of age) have a greater likelihood of a mental disorder than older age groups. This group represents over 10% of the Northern Territory population.

(Mental Health Program, Department of Health and Community Services, Northern Territory, Submission #259)

Concern was expressed regarding the paucity of services and integrated services to assist young people with mental illness, mental health problems or substance abuse problems. Such services are seen as essential from an early intervention perspective to halt spiralling negative life consequences including deteriorating health and mental health, homelessness, suicide or entry into the criminal justice system. The need to examine these issues in the context of the education system and accommodation options was also raised.

I handle a lot of crisis management youth drop-in centres, youth accommodation. Currently working with 30 young people who are chronic sniffing, we've found the best way to alleviate some of this is prevention by giving something else to do. Schools only go up to grade seven in the communities so people either board in town or don't.

(Service Provider, Northern Territory, Alice Springs Forum #8)

I've been banging on doors and writing letters. My son became ill at 15, he's now 18 and in the justice system. They're not about rehabilitation, just containment. There are no facilities for people with mental health and drug and alcohol problems. I understand what [Y] says, you get worn out. You get fobbed off. There's like a blanket discrimination. If there is nothing for kids under 18, that's a terrible scenario. My son started with a mental illness, then substance abuse - many substances, petrol sniffing – so there's blanket discrimination.

(Carer, Father, Northern Territory, Darwin Forum #3)

6.7.8.3.5 Lack of support from Centrelink

Concerns were raised with regard to carers receiving financial assistance from Centrelink and how carers can minimise bills incurred by the consumer (e.g. credit cards) that they will have to pay. With limited access to mental health services, supported accommodation and access to early intervention treatment and support, the burden on families and carers to provide long-term and crisis support is immense. This often impacts on the financial income of the family by a reduced ability of carers to work. The shifting of care by governments to carers fails to recognise that carers are providing a significant cost-free service that is not being adequately supported by the community.

There is a discriminatory policy that funding packages given to some families to help provide care (nothing else) for a family member with a severe disability not be allowed to be paid to blood parents or the spouse of a disabled person, as it is considered inappropriate by the funding bodies…I am a spouse so I can't access a paid position as carer, but anyone else can even if it has been proven the job cannot be filled by anyone else. I have a package for my spouse to pay someone to help care for her, but as the months have passed it has not benefited us because I am the only one capable of caring for my spouse [X] appropriately. The paid carers, five in 18 months, have either used us or left because they couldn't cope with the situation. In the meantime we continue to live under the poverty line, while others earn money from our circumstances and invade our privacy, which lowers our feeling of self worth. I am not allowed to touch one cent of the money to help provide for my spouse's special needs and the extra associated bills. I have been told I can go and get a job while the government pays someone else the package. The package covers about four hours, five times a week. My spouse who suffers cerebral palsy, quadriplegia and schizophrenia with post trauma syndrome, is a 24-hour a day responsibility and I am still left with the bulk of the care.

(Carer, Husband, Northern Territory, Submission #68)

I and other full-time carers should be entitled to this money, as we each save the taxpayer $200,000 every year. It is discriminatory, it is unfair, and it is criminal. We are not slaves but might as well be. The Carers Payment is not help, it is an insult, and it is 25% of the average Australian's income. How can anyone live off that? The Carer Payment is the same as a Disability Support Pension, Carers should not be put on the same level of pay as pensioners, we are not pensioners but very hard workers who rarely (if at all) go on holiday or take adequate breaks from our charges. How many in the general community can say they save the taxpayer $200,000 annually?

(Carer, Husband, Northern Territory, Submission #68)

6.7.9 NMH STANDARD 9: SERVICE DEVELOPMENT

The MHS is managed effectively and efficiently to facilitate the delivery of coordinated and integrated services.

Under this Standard, submissions and presentations indicate concerns about:

- the current state of service delivery in the Northern Territory;
- carers are shouldering the burden of services which should be provided by the MHS;
- lack of community based support or prevention focus (crisis model of care);

- lack of resources, treatment and support services in rural and remote areas;
- lack of skilled staff;
- lack of funding;
- lack of funding to NGO's;
- staff attitudes; and
- a greater focus needed to meet the needs of Indigenous people with mental illness and mental health problems.

6.7.9.1 Current state of service delivery in the Northern Territory

> *There are many stories that illustrate the lack of services and support that contribute to the continued marginalisation and disadvantage that people with a mental illness experience. The three main areas that [Y] believe are major issues for this region are:*
> - *lack of services;*
> - *limited service options;*
> - *quality of services.*
>
> (Anonymous, Northern Territory, Submission #188)

A majority of submissions and presentations made at forums in Darwin and Alice Springs conveyed feelings of immense dissatisfaction with the scarcity and low quality of treatment and support services currently available. One service provider at the Darwin forum stated that improvements have been noted. However, concern was expressed that outside of Darwin and Alice Springs access to treatment and support was extremely limited, resulting in deteriorating mental health, unnecessary use of chemical and/or physical restraint when crisis intervention was required, and potential entry into the criminal justice system.

> *Criminalisation of behaviour or chemical restraint – no other option.*
>
> (Service Provider, Northern Territory, Alice Springs Forum #9)

> *..the standard of mental health care available is minimal*
>
> (Support and Equity Services, Charles Darwin University, Northern Territory, Submission #269)

> *Carers report ongoing dissatisfaction with this arrangement. They express frustration with the crisis driven care at the expense of community support and rehabilitation.*
>
> (Anonymous, Northern Territory, Submission #188)

[Y] described the lack of services in the following areas:

- *limited accommodation and support options exists to support people post acute care*
- *the range of community based accommodation options*
- *quality of life and rehabilitation options*
- *consumer support*
- *support groups*
- *range of therapeutic treatments and exposure and training in these therapies*
- *services targeted at particular groups*
    - *children and young people*
    - *indigenous*
    - *older people*
    - *NESB people*
- *lack of prevention and early intervention options*
- *limited service mix …*
- *quality of the services provided*
- *capacity issue for the sector – the demand exceeds supply, specifically ngo's are not able to respond due to limited capacity.*

(Anonymous, Northern Territory, Submission #188)

Demand for mental health services in both community and inpatient settings increased by an average 20% in 2003/04. Rising demand may be attributed to a number of factors including increased mental health promotion activities resulting in improved community awareness, higher community expectations and a greater willingness to seek help. A decrease in bulk billing by General Practitioners may also have contributed to the increased demand for services from the specialist mental health sector.

(Mental Health Program, Department of Health and Community Services, Northern Territory, Submission #259)

The Bansemer Review (2003) commissioned by the NT government found that the Territory's mental health services were 'despite the production and subsequent non-implementation of a series of reports and studies over the past decade, under-resourced, fragmented and poorly supported'.

(SANE Australia, National, Submission #302)

Positive achievements in the Northern Territory were also reported:

To its credit, the NT government has acted on the Bansemer recommendations with additional funding and a range of practical initiatives. From 2002 to 2004, the mental health budget allocation increased from $13.8 million to $25.8 million. New initiatives funded include:

- *establishment of 'step up/ step down' residential programs, to prevent the need for admission to acute wards and facilitate discharge*
- *psychiatric liaison nurses for hospital emergency departments*
- *four Aboriginal Mental Health Worker positions around the NT*
- *appointment of a Territory Child Psychiatrist, to operate in Tennant*
- *creek and Alice Springs as well as Darwin*
- *some increased support for non-government organisations.*

(SANE Australia, National, Submission #302)

In a submission from the Mental Health Program, Department of Health and Community Services complex factors associated with the planning and delivery of services in the Territory were noted and key achievements highlighted for the period 2003-2004. The Department also noted other initiatives designed to improve service delivery, in particular, a review of the Mental Health and Related Services Act (1998) and a Clinical Systems Improvement Project.

The Northern Territory has a range of unique characteristics that impact directly on service provision in terms of costs of services, the demand for services and the nature of services…The estimated NT population for 2003 was 198,358 (NTDHCS) of which 68% of people reside in either the Alice Springs or Darwin Urban areas. The remaining 32% of the population live in smaller, dispersed communities, Bartlett et al (1997) note that in Central Australia, which covers an area of 1.1million square kilometres there are only two communities with populations over 800; and there are 209 communities with populations of less than 75 people. There are also numerous outstations with fluctuating populations. The Top End, which covers an area of 614,000 square kilometres, has a population of approximately 153,000 people (NTDHCS). Mental Health Services are also provided to residents in the Anangu Pitjantjatjara Yankunytjatjara Lands across the border in South Australia…The relatively small population in the Northern Territory and the proportion of the population living in remote communities, significantly increases the complexity and costs of delivering mental health services. The tropical climate of the Top End means that access to many of the smaller communities in the NT is very limited during the wet season as unsealed roads become impassable. Outside of the metropolitan area there is also no public transport system. For those living in many communities outside of Alice Springs or Darwin, rapid access to inpatient services requires air evacuation.

(Mental Health Program, Department of Health and Community Services, Northern Territory, *Submission #259)*

Key Achievements for 2003/04 include:

- *additional funding of $2M allocated to recruit new clinical staff, including specialist child and adolescent clinicians and Aboriginal mental health staff across the NT and to strengthen consumer and carer support in the non-government sector;*
- *accreditation of the Top End Mental Health Service for two years by the Australian Council on Healthcare Standards;*
- *Ministerial endorsement of the Mental Health Coalition as the mental health peak body in the Northern Territory;*
- *Ministerial launch of The Northern Territory Strategic Framework for Suicide Prevention in October 2003;*
- *release of the Northern Territory Emotional and Social Wellbeing Strategic Plan in December 2003 by the Chair of the Aboriginal Health Forum The Mental Health Program played a key role in the development of the Plan, which is part of a Territory-wide effort to improve the emotional and social wellbeing of Aboriginal people; and*
- *in the Top End, Mental Health Program and Commonwealth Specialist Outreach Service funding has enabled visiting psychiatrist services to commence to the Tiwi Islands and communities in the Darwin Rural, Katherine and East Arnhem Regions. Medical Specialist Outreach Assistance Program funding has supported visits to Anangu Pitjantjatjara Lands and the Barkly region over the past 18 months.*

(Mental Health Program, Department of Health and Community Services, Northern Territory, Submission #259)

A review of the Mental Health and Related Services Act (1998) is being conducted. Some of the issues that will be addressed within this review include those that relate to administrative arrangements, reporting requirements, assessment and review time lines, levels of consent, carer and family rights to information and involvement in decision-making, powers of the Court, application of community management orders in remote locations and the capacity to facilitate Interstate Orders.

(Mental Health Program, Department of Health and Community Services, Northern Territory, Submission #259)

A Clinical Systems Improvement Project is also currently underway. The aim of the project is to implement and develop key quality systems, for example, Critical Incident Review, Complaints Management, case load acuity measurement and development of key performance indicators. Discharge Care Coordination Projects in TEMHS [Top End Mental Health Services] and CAMHS [Central Australian Mental Health Services] have also been established.

(Mental Health Program, Department of Health and Community Services, Northern Territory, Submission #259)

6.7.9.2 Carers are shouldering the burden of services which should be provided by the MHS

Carers expressed the opinion that the model underpinning the distribution of resources and service planning needs re-examining as currently carers are being factored into the service delivery model as 'slave labour' to provide the support which should be delivered by the MHS. This model does not ensure the protection of a broad range of rights of consumers and infringes on the rights of carers to participate socially and economically in the community.

> *It is lame to keep blaming lack of funds. The governments drain every cent they can from carers, and use them as slave labour. Since closing the institutions carers have saved the taxpayer billions of dollars each years, but to get only a few million dollars from the governments to help stabilise a serious problem within the mental health area is like asking for pearls to be thrown before swine.*
>
> (Carer, Husband, Northern Territory, Submission #68)

6.7.9.3 Lack of community based support or prevention focus - crisis model of care

Concerns were also expressed about the emphasis on inpatient and crisis care to be provided in Darwin and Alice Springs and the neglect of community based treatments and support and early intervention approaches for consumers and their families living in remote communities.

> *…95% of Mental Health Services in the NT are government based and centred almost exclusively on treatment provision.*
>
> (Anonymous, Northern Territory, Submission #188)

> *We desperately need funding but we didn't get any of the new funding. We continue to struggle and we feel that the consumers on the ground are not benefiting from this. I feel very frustrated at the lack of insight by the Government that funding into the community will prevent increasing demand on expensive acute and crises care.*
>
> (Service Provider, Northern Territory, Alice Springs Forum #17)

> *I've been working at the hospital for the last couple of years. We pick up people in crisis every day, all day. We need more resources so we can help community NGO's. There's only three Indigenous workers at the hospital. We're looking for the money but where's the money? We might see a community once in 12 months.*
>
> (Mental Health Worker, Northern Territory, Alice Springs Forum #19)

> *It is quite interesting that 95% of the resources go to 5% of the burden. If we looked at the data we only look at hospital admissions, not where the real burden is. We need the resources to support the people in the communities who are doing the work anyway. I am actually encouraged by the strength of the response here, but we don't support people well enough.*
>
> (Anonymous, Northern Territory, Alice Springs Forum #23)

> *In terms of the primary health care model, we are seeing people already in crises.*
>
> (Service Provider, Northern Territory, Alice Springs Forum #3)

6.7.9.4 Lack of resources, treatment and support services in rural and remote areas

The lack of resources to deliver treatment and support services to people with mental illness in remote communities and an inability for the MHS to provide early intervention or prevention programs was a theme expressed repeatedly throughout the submissions and at both forums. Instead, claims were made that the MHS was focusing on crisis care instead of the provision of community services (early intervention) and that resources were not being allocated to reflect national mental health policies (Standard 9.14) or in manner which allows the MHS to respond promptly to the changing needs of the defined community (Standard 9.15).

> *Currently within Central Australia, Mental Health Services (CAMHS) provide the public sector specialist mental health service. They offer child and adolescent services, remote services, adult case management, outpatient clinics and an extended hours crisis service. Clinical services dominate in Alice Springs with CAMHS government service employing approx 46 staff members. Social and Emotional Wellbeing programs are provided by a number of Indigenous organizations. However few resources to support people with mental illness exist in remote communities.*
>
> (Anonymous, Northern Territory, Submission #188)

> *There is a lack of services for clients. Central Australia has a lot of unique factors – the remoteness of the area, and lack of services for remote communities, in town for community based services, accommodation, consumer support programs, recruitment of staff and retention.*
>
> (Service Provider, Northern Territory, Alice Springs Forum #1)

> *Core clients: 7,500. 2,000 are remote and transient. We receive about $47k from Territory Government to provide those services. There is a very low contribution from the Territory Government.*
>
> (Service Provider, Northern Territory, Alice Springs Forum #3)

> *Visits to remote and rural communities have become more frequent as a result of an increase in the level of clinical staff and Aboriginal Health Workers and a substantial increase in the travel budget*
>
> (Mental Health Program, Department of Health and Community Services, Northern Territory, Submission #259)

6.7.9.5 Lack of skilled staff

Lack of funding and resources, problems associated with living in remote communities and high workloads were identified as part of a package of problems in recruiting staff to fill vacancies in rural and remote areas. Lack of resources, low staff numbers allocated to cover vast geographical areas and the inability to attract and retain staff in rural and regional areas were identified as a significant problem with continuity of care (see also Standard 8.1).

> *Whilst the Northern Territory has traditionally been a place that has tolerated differences, the standard of mental health care available is minimal and general practitioners and mental health workers are often the primary source of medical or professional intervention available to people with mental health issues.*
>
> (Support and Equity Services, Charles Darwin University, Northern Territory, Submission #269)

> *Staffing levels and skills stability is a problem.*
>
> (Service Provider, Northern Territory, Darwin Forum #11)

Having developed relatively good relationships with Mental Health Services in the past, it would appear that the demand on the people employed in these services allows support to be provided in only the most reactionary way and only to those who are unable to function within the community at a very basic level…

(Support and Equity Services, Charles Darwin University, Northern Territory, Submission #269)

There are recruitment and retention issues in Central Australia.

(Anonymous, Northern Territory, Submission #188)

Retention of staff and the management of workloads, secondary trauma and general occupational health and safety place further stress on services. The requirements of living in remote communities and extensive, difficult travel add an extra dimension to recruiting not faced in many other parts of Australia.

(Anonymous, Northern Territory, Submission #271)

6.7.9.6 Lack of funding

Associated with the complaints of lack of available resources to deliver quality mental health services are requests and demands that the level of funding needs to change in order that appropriate services are delivered and the rights of people with mental illness are protected. Overall, funding issues were raised both with regard to Federal and State Government contributions to the health budget and the provision of support services for people with mental illness and their families and carers. A submission from the Department of Health and Community Services indicated that funding has increased to address some of the deficits identified in the delivery of mental health services:

The allocation of an additional $12.7 million between 2003-2006 to improve the mental health service system underlines the Territory Government's commitment to the mental health of the Territory's population. The mental health operational budget in 2004/05 is $20.72M, an increase of approximately $2.7M (or 15%) on 2003/04 (18M). In 2003/04, new funding was allocated to address a range of critical service system requirements including enhanced resourcing of existing services to address historical under funding. This funding provided for:

- *new clinical positions;*
- *additional Aboriginal Mental Health Workers;*
- *consumer and carer support in the non-government sector;*
- *rehabilitation services;*
- *primary health care; and*
- *workforce development.*

In 2004/05, an additional $1.5 million will be invested to:

- *trial sub-acute 'step-up/step down' care options which include non-clinical support provided by the non-government sector and after hours clinical services;*
- *further extend non-government consumer support and rehabilitation services. The tendering process to allocate this funding has commenced;*
- *further enhance child and youth mental health services; and*
- *Increase visiting services to rural and remote communities.*

(Mental Health Program, Department of Health and Community Services, Northern Territory, Submission #259)

6.7.9.7 Lack of funding to NGO's

Concern was also expressed about the quantity of services the MHS has contracted out to the NGO sector, or expects the NGO sector to deliver, and the inadequate level of funding provided to support the delivery of such services. The lack of certainty attached to funding agreements also contributes to the inability of services to plan and recruit staff on a long-term basis. Increased funding to the NGO sector was reported in a submission from the Department of Health and Community Services to address this deficit.

Non government services receive less then 5% of funds allocated to mental health in Central Australia and yet are the sole providers of rehabilitation and community support. Funding to Central Australia was increased by $1.5m this year however mental health NGO's did not receive any of this.

(Anonymous, Northern Territory, Submission #188)

…funding is not benefiting the consumer on the ground. Only 5% goes to NGOs on the ground. Our funding is below the national average.

(Anonymous, Northern Territory, Alice Springs Forum #18)

Most have been here for a lifetime and we receive funding for 1 year at a time. We need triennium funding. You've got to fight for that funding each year. We need continuity and consistency of our staff.

(Service Provider, Northern Territory, Alice Springs Forum #4)

Decisions are made to close viable services down because there is no money coming in, but the costs come later.

(Service Provider, Northern Territory, Alice Springs Forum #4)

The MH Association has helped me a lot. But our resources are so low we don't have the capacity to help people who really need it.

(Carer, Northern Territory, Alice Springs Forum #5)

There is a change that is coming – it looks very promising. But we get half the funding this year and we sit and wait and we don't know about next year.

(Service Provider, Northern Territory, Alice Springs Forum #20)

95% of the MH budget in the NT is for government services. 5% for non government. 7.2 million new allocation of funding. NGO's have to compete with each other for this.

(Service Provider, Northern Territory, Darwin Forum #17)

The new funding will result in an increase in the proportion of the mental health budget allocated to the non-government sector. In total approximately $910K in additional funding will be invested in the non-government sector this financial year. Grants and subsidies to Non Government Organisations (NGO) in 2004/05 will represent 10.5% of the Mental Health Operational Budget. The national average for the proportion of mental health funding to the NGO sector is 5.4% (National Mental Health Report 2002). The new funding will mean that the Northern Territory will now be above the National average in terms of funding allocated to the sector.

(Mental Health Program, Department of Health and Community Services, Northern Territory, Submission #259)

6.7.9.8 Staff attitudes

Concerns were expressed about poor staff attitudes towards consumers and carers indicating that staff may be in need of training in order to change attitudes and behaviours and be more supportive when dealing with people with a mental illness. Standard 9.17 states: 'The MHS regularly identifies training and development needs of staff' and Standard 9.18 states: 'The MHS ensures that staff participate in education and professional development programs'.

> *First off wouldn't it be great if we could offer commitment, care and understanding.*
>
> (Service Provider, Northern Territory, Alice Springs Forum #14)

> *There is no sense that they want to help the consumer. I've seen things where the consumer is made to feel like they've committed a sin.*
>
> (Carer, Northern Territory, Alice Springs Forum #5)

6.7.9.9 Greater focus needed to meet the needs of Indigenous people with mental illness and mental health problems

As mentioned previously in Standard 7 (Cultural Awareness) and Standard 8.3 (Integration with other sectors), concerns were expressed that current services are not being delivered in a coordinated, integrated and culturally appropriate manner to meet the needs of Indigenous people with mental illness and/or mental health problems. This also suggests that Standards 9.7 ('the MHS regularly reviews a strategic plan which is made available to the defined community), 9.8 ('the strategic plan is developed and reviewed through a process of consultation with staff, consumers, carers, other appropriate service providers and the defined community') and 9.10 ('the strategic plan is consistent with national mental health policies and legislative requirements') may require greater attention.

Concerns were expressed regarding the failure to consider the delivery of mental health services within the broader context of poor health and social disadvantage. Submissions suggested that pilot programs and evaluation timeframes need to operate over longer periods of time for meaningful assessments to be made regarding effectiveness of program delivery. Concern was also expressed that sufficient research has been conducted in Indigenous communities and it was time to make decisions to change the model of service delivery and resource allocation.

> *Extreme stress on the resources available, allowing very little capacity to develop culturally appropriate and meaningful services, which are Anangu driven. Pilot funding and reporting requirements often take little consideration of the unique circumstances of the region and the length of time required to develop effective working relationships that can effect change.*
>
> (Anonymous, Northern Territory, Submission #271)

> *It is important to note that the health providers across the region are already critically under resourced. The issues relevant to indigenous physical health outcomes are well documented. With the ongoing critical physical health needs of the community, staff are already at full capacity. In this context issues of mental health cannot be prioritised, unless there is an acute need for treatment.*
>
> (Anonymous, Northern Territory, Submission #271)

> *There's a lot of funding to research mental health in indigenous communities but people were sick of being researched.*
>
> (Anonymous, Northern Territory, Darwin Forum #24)

6.7.10 NMH STANDARD 10: DOCUMENTATION

Clinical activities and service development activities are documented to assist in the delivery of care and in the management of services.

No submissions or comments were received pertaining to this Standard.

6.7.11 NMH STANDARD 11: DELIVERY OF CARE

Principles guiding the delivery of care: The care, treatment and support delivered by the mental health service is guided by: choice; social, cultural and developmental context; continuous and coordinated care; comprehensive care; individual care; least restriction.

Under this global Standard outlining the principles underlying care, submissions and presentations indicate concerns about the lack of services, implying lack of choice for consumers, carers and their families, and the inability of services to respond in a flexible manner to changing need or diverse needs for individuals. Concern was also expressed that social and cultural needs of Indigenous communities are not guiding the delivery of care to Indigenous consumers and their families.

> *I am writing to advocate for completely confidential services, choice of services, adequate support and flexibility to be offered in responding to mental health in the Northern Territory …*
>
> (Support and Equity Services, Charles Darwin University, Northern Territory, Submission #269)

> *Extreme stress on the resources available, allowing very little capacity to develop culturally appropriate and meaningful services, which are Anangu driven.*
>
> (Anonymous, Northern Territory, Submission #271)

6.7.11.1 Access

The MHS is accessible to the defined community.

Under this Standard, submissions and presentations indicate concerns about:

- inability to access services, even in a crisis;
- problems with access after hours;
- lack of access to services in general;
- access problems in remote areas; and
- lack of access to care - "right to access care, not be arrested".

An inability for consumers to access treatment and support services, both within the community and inpatient care, resulted in the infringement of a whole series of rights for consumers, carers and the community. For the consumer, the infringement of these rights resulted in increasing disability and hence consequent inability to care for oneself or others, participate socially or work or study, and in some cases, the potential for harm to self or others, incarceration, or becoming homeless and poor.

Similarly, increased burdens on carers disrupted their ability to participate socially and work when their family member became increasingly ill and required increasing care. The inability to access care for their family member resulted in deteriorating mental health for carers as evidenced by the suicide attempt of one carer. Increasing disability also exposed the consumer, and their family, to discrimination and social exclusion. This often resulted in the further deterioration of the consumers' mental illness.

6.7.11.1.1 Inability to access services, even in a crisis

A constant theme of the submissions and forums was that not only were consumers unable to access services when needed throughout the course of their illness or recovery, but that access was also difficult when consumers were at risk of self harm or harm to others. According to this information Standards 11.1.4 ('the MHS is available on a 24 hours basis, 7 days per week') and 11.1.2 ('the community to be served is defined, its needs regularly identified and services are planned and delivered to meet those needs') are not being met.

Service providers and carers expressed concern that access to treatment and support is often not an option, and as a result the only options available were a restriction of the rights of consumers: i.e. entry into the criminal justice system or restraint. Comments presented also indicated increasing difficulties, rather than improvement, in the ability for consumers to access services, and that even when access was denied, for consumers at risk of self harm or harm to other, no follow-up is occurring.

> *Why does it have to get to an extreme before it gets looked at?…my son is now in the judicial system so no one can go near him.*
>
> (Service Provider, Northern Territory, Darwin Forum #26)

> *Always, there is hanging over students in the Northern Territory, the confinement of one facility and the reality that they will only receive assistance when they can no longer control their actions.*
>
> (Support and Equity Services, Charles Darwin University, Northern Territory, Submission #269)

> *The hospital has gotten a lot tougher on people with a severe mental illness so it's made it hard for people to get admitted.*
>
> (Carer, Northern Territory, Alice Springs Forum #5)

> *It is recognised that there is a need for sub-acute care services to be developed in the Northern Territory, to provide an alternative to hospitalisation and improve transition between inpatient and community care. Tenders are currently being sought for Subacute Care trials for Mental Health consumers in the NT. The aim of this new service is to provide consumers with a time-limited, intensive level of support when they are experiencing a relapse of their mental illness. It will also provide an alternative to an inpatient admission where appropriate and facilitate early discharge from hospital. It is expected that this service will reduce the impact of an acute episode on the individual and their families and improve individual consumer choice through the options of sub-acute care in the community. Initially, the non- clinical component of sub-acute support services will be provided by NGO's through Individual Care Packages. Additional clinical positions have been funded to provide the clinical support to sub-acute care with a focus on after hours support.*
>
> (Mental Health Program, Department of Health and Community Services, Northern Territory, Submission #259)

6.7.11.1.2 Problems with access after-hours

Service providers and carers expressed concern regarding the inability to access treatment and support services after hours. As stated above Standard 11.1.4 states: 'The MHS is available on a 24-hour basis, 7 days per week'. The notes to this Standard include reference to crisis teams, extended-hours teams and 'cooperative arrangements with other appropriately skilled service providers and community agencies including General Practitioners, private psychiatrists, general hospitals'. That is, according the Standard, an appropriately skilled person should be available to assist services, consumers and carers requiring assistance after-hours.

> *There are no after-hours services, so people are turned away. The mental health services response is "it's because of full beds", but that's not always true.*
>
> (Service Provider, Northern Territory, Alice Springs Forum #16)

> *During work hours (7.6 hours per day, Monday to Friday) we receive back up and support from Mental Health Services. If a client has an episode after hours it is difficult to get assistance even via the phone. Residents and other staff can be put at risk during these times…When a patient needs assistance, the Ambulance usually will not transport and the caller is directed to phone the police. Police will transport the client to the hospital in the back of a police wagon. This is a very degrading experience!*
>
> (Supported Accommodation Service Provider, Northern Territory, Submission #217)

> *[Group Y], unknown to mental health services are not able to get assistance after hours through the after hours service other than through the Accident and Emergency Department of the Public Hospital.*
>
> (Support and Equity Services, Charles Darwin University, Northern Territory, Submission #269)

> *Many times I have phoned up for friends after hours to services and most times you get diverted to the ward and don't get the help we need.*
>
> (Carer, Northern Territory, Alice Springs Forum #5)

6.7.11.1.3 Lack of access to services in general

Other concerns were also raised regarding access to the MHS. These included access being denied due to a lack of service options, staff attitudes or challenging behaviour (which often was the result of an inability to access services).

> *I found it very difficult to get into the mental health system. What we need is a variety of services.*
>
> (Consumer, Northern Territory, Darwin Forum #16)

> *One friend of mine thought he was somebody else and he went to the ward but was turned away so it was me and my other friends that had to put up with this person believing he was somebody else.*
>
> (Carer, Northern Territory, Alice Springs Forum #5)

> *Challenging behaviours – people are often turned away from the system and don't get care because of the 'behaviour problem' but often the behaviour is a result of the frustration of the consumer not getting care.*
>
> (Service Provider, Northern Territory, Alice Springs Forum #16)

6.7.11.1.4 Access problems in remote areas

The distribution of the population in small remote communities over a vast geographical area poses serious challenges to the planning and delivery of services to meet Standards 11.1.3 ('mental health services are provided in a convenient and local manner and linked to the consumer's nominated primary care provider') and 11.1.5 ('the MHS ensures effective and equitable access to services for each person in the defined community'). For people living in these remote communities there are few services which could be described as 'convenient and local' (Standard 11.1.3). Access to care often involved driving long distances (for example, 5 hours to see a counsellor), contact with the police or being flown to Darwin or Alice Springs for acute care. Not only does this result in social dislocation for the consumer but reports indicated that sometimes consumers are flown to Alice Springs or Darwin and sent straight back home, presumably with minimal chances of follow-up services being arranged or available upon return.

> *People have to drive 5 hours to get counselling. There are some acute fly-in services but these are highly medicalised. Access to acute services requires either a flight into Alice or to Perth. Often if they are taken they are then sent out – that's it.*
>
> (Anonymous, Northern Territory, Alice Springs Forum #10)

> *This is the sum of mental health services provided in the Northern Territory & Anangu Pitjantjatjara lands. There is no access to counselling or ongoing support in communities. In some extreme cases people have been transported to Alice Springs to receive services from Central Australian Aboriginal Congress' (an Aboriginal health service based in Alice Springs) Social and Emotional Well Being Service for a short intensive "burst" of counselling. This model appears to work well for some individuals, however no service is funded to coordinate and fund the transport and accommodation costs required by this model. There is some provision of other diversionary social and emotional well being activities in some communities. However all of these services are significantly under resourced and sporadic across the region.*
>
> (Anonymous, Northern Territory, Submission #271)

> *Facilities for the treatment of acute mental illness are congregated in one area per locality in the major towns, and admission against will is often decided by specialist hook-up via Interstate video conferencing.*
>
> (Support and Equity Services, Charles Darwin University, Northern Territory, Submission #269)

> *The student residence caters for approximately 250 students. Many students are from interstate and without local or family supports. Each semester, on average, there are three students who require brief or long term admission to the acute care mental health facility. No contact or liaison occurs between the University and mental health services regarding ongoing support.*
>
> (Support and Equity Services, Charles Darwin University, Northern Territory, Submission #269)

The Department of Health and Community Services noted the progress of a research project to address mental health care in remote areas.

> *The Australian Integrated Mental Health Initiative 'AIMHI' is a National five-year research project for consumers suffering chronic mental illness. AIMHI has sites in NSW, VIC, QLD and NT. Its NT site, the remote Top End, is one of only two Indigenous sites in Australia. AIMHI NT is targeting remote Top End people with a chronic mental illness and aims to improve community-based interventions and improve the links between remote community services and urban services. To date the project has established a stakeholder network, feedback processes, an Indigenous reference group, and two Indigenous research officers.*
>
> (Mental Health Program, Department of Health and Community Services, Northern Territory, Submission #259)

6.7.11.1.5 Lack of access to care - "right to access care, not be arrested"

As mentioned previously, failure to access services when needed in some instances resulted in consumers entering the criminal justice system due to their escalating and untreated mental illness. The failure of services to respond and intervene in these instances has had the regrettable outcome of both consumers being incarcerated for the consequences of their illness and the right to safety of the community being infringed. As the majority of Indigenous people live in remote areas, this suggests higher numbers of Indigenous people with mental illness or mental health problems are represented in the criminal justice system.

> *People with mental health concerns and their families living on the NPY communities generally have two avenues to the mental health system: clinic staff or the police. This leads to people's mental health concerns being either medicalised or criminalised. While it is true that others in the general population may have police involvement in an admission, the lack of other services or intermediary steps greatly increase the chances of Anangu & Yanangu coming into contact with the criminal justice system, adding to their increased representation in this sector.*
>
> (Anonymous, Northern Territory, Submission #271)

6.7.11.2 Entry

The process of entry to the MHS meets the needs of the defined community and facilitates timely and ongoing assessment.

No submissions or comments were received pertaining to this Standard.

6.7.11.3 Assessment and review

Consumers and their carers receive a comprehensive, timely and accurate assessment and a regular review of progress.

Under this Standard, submissions and presentations indicate concerns about:

- the quality of the assessment and review process; and
- assessment problems for Indigenous people with mental illness or and/mental health problems.

6.7.11.3.1 Concerns about the quality of the assessment and review process

Concern was expressed regarding the quality of assessment procedures. One carer described an incident where emergency personnel who had been called examined blood pressure and then said that the 'crisis' they had been called to attend was not an emergency and the person with mental illness and/or mental health problems was not admitted as an inpatient or assessed any further.

> *An ambulance was called and they take your blood pressure and then say it's not an emergency. We need a review of admission procedures.*
>
> (Carer, Northern Territory, Alice Springs Forum #5)

Standard 11.3.1 states: 'Assessments are conducted by appropriately qualified and experienced mental health professionals' and Standard 11.3.5 states: 'The assessment process is comprehensive and, with the consumer's informed consent , includes the consumer's carers (including children), other service providers and other people nominated by the consumer'. A similar incident was reported with a referral from a service provider for a person assessed at risk of suicide:

> *[X]… is escorted to the emergency department of the local hospital…[Y]…assessed [X] to be at high risk of suicide. No admission and no follow-up is arranged. Additionally, no contact was made with the referring agency and according to [X], no request of discussion with the referring agency was sought by mental health services.*
>
> (Support and Equity Services, Charles Darwin University, Northern Territory, Submission #269)

Another submission also referred to systemic problems associated with assessment processes.

> *Systemic Issues…assessment processes for admitting client's,*
>
> (Anonymous, Northern Territory, Submission #188)

6.7.11.3.2 Assessment problems for Indigenous people with mental illness and/or mental health problems

Concern was expressed that culturally appropriate methods and tools were not available to assess risk for Indigenous youth. Standard 11.3.6 states: 'The assessment is conducted using accepted methods and tools' and Standard 11.3.10 states: 'Staff are aware of, sensitive to, cultural and language issues which may affect the assessment'. Included in the notes to this Standard is 'This is particularly important for the assessment of a person with an Aboriginal or Torres Strait Islander background'.

> *…Indigenous mental health. One of the most crucial things to do is to identify who is at risk and intercept. There is no culturally relevant tool in the Northern Territory for assessing risk. We need a validated tool on standardised procedures.*
>
> (Academic, Northern Territory, Darwin Forum #9)

6.7.11.4 Treatment and support

The defined community has access to a range of high quality mental health treatment and support services.

Under this Standard, submissions and presentations indicate concerns about:

- the lack of treatment and support services;
- lack of services for youth;
- lack of services for people with mental illness and intellectual disability;
- lack of services for people with mental illness and drug and alcohol problems;
- lack of services for people with mental illness and physical disability;
- lack of services for people with mental illness and Acquired Brain Injury (ABI);
- lack of services for people with Personality Disorders;
- lack of treatment and support for consumers in the criminal justice system; and
- carers not involved or informed with the development or review of the individual care plan.

6.7.11.4.1 Lack of treatment and support services

Many consumers and carers expressed feelings of frustration at being unable to access any treatment or support services from the MHS. This included the whole spectrum of interventions throughout the course of illness and recovery regardless of age and stage of development. Reports that services were not available until the consumer's health had deteriorated to the point requiring hospitalisation need to be considered in tandem with reports that access was often not possible even when the consumer had reached crisis point. Standards 11.4.3 – 11.4.8 state that the MHS will 'ensure' or 'provide' 'access to a comprehensive range of treatment and support services' which are specialised with regard to a person's ages and stage of development (11.4.3), stage in the recovery process (11.4.40), dual diagnosis (11.4.7) and which address 'the physical, social, cultural, emotional, spiritual, gender and lifestyle aspects of the consumer' (11.4.6). Additionally, Standard 11.4.10 states 'the MHS provides the least restrictive and least intrusive treatment and support possible in the environment and manner most helpful to, and most respectful to, the consumer'.

Clinical services leave clients till they are so unwell that they have to be hospitalised.

(Anonymous, Northern Territory, Submission #188)

Sure staff are busy but service isn't there – particularly when there is a dual diagnosis. He's referred back and forth.

(Carer, Mother, Northern Territory, Darwin Forum #2)

There is a lack of support services.

(Service Provider, Northern Territory, Darwin Forum #20)

No access to a spectrum of intervention, including whole of life span target groups. Anangu living on the NPY Lands have access only to a small range of acute mental health services whose responses are crisis driven and in circumstances where their involvement is most likely to be involuntary.

(Anonymous, Northern Territory, Submission #271)

There are some youth programs that provide diversionary activities, but they do not and cannot have a significant mental health focus.

(Anonymous, Northern Territory, Submission #271)

There are no services available for the 25 to 55-year age range beyond employment programs, whose existence and quality are inconsistent across the region.

(Anonymous, Northern Territory, Submission #271)

Lack of services for 24 – 50 year olds. This age group has no direct diversionary services working with them. Therefore with minimal employment options or further education options and high rates of substance abuse, this group is at high risk of developing mental health problems. The average age of completed suicide attempts in the Northern Territory is currently 30.9 years of age.

(Anonymous, Northern Territory, Submission #271)

TEMHS [Top End Mental Health Services] and the Royal Darwin Hospital, and CAMHS [Central Australia Mental Health Services] and Alice Springs Hospital have been selected to participate in the Mental Health Emergency Care Interface Project, auspiced by the National Institute of Clinical Studies (NICS). The aim of the project is to improve the processes of care based on best available evidence for people presenting to the emergency department with a mental health problem.

(Mental Health Program, Department of Health and Community Services, Northern Territory, Submission #259)

6.7.11.4.2 Lack of services for youth

Carers and service providers expressed concern at the paucity of services for youth and indicated that services need to be broader in their approach than treatment just for 'mental illness' as other mental health problems and family or community crises are also occurring.

In the Northern Territory, these problems are generally associated with high levels of substance abuse among Indigenous youth, starting as young as the age of five, and boredom in remote communities. Standard 11.4.3 ensures access to a 'comprehensive range of treatment and support services which are, wherever possible, specialised in regard to a person's age and stage of development', Standard 11.4.6 states that such services will address 'the physical, social, cultural, emotional, spiritual, gender and lifestyle aspects of the consumer' and Standard 11.4.7 states that, 'wherever possible, specialised in regard to dual diagnosis'. Included in the notes to Standard 11.4.7 is 'dual case management with alcohol and other drug services'.

> *We need a facility before we can get the youth to go. You're lost in space – you pick up bits of information as you go along.*
>
> (Service Provider, Northern Territory, Darwin Forum #26)

> *I see the end result of petrol sniffing, cognitive functioning impaired and wheel chair bound. People's behaviour is becoming challenging. Many of these people could be managed in the community and so they come into town and then require accommodation. One of the big problems is boredom. There is nothing to do; it's very sad to see five year olds sniffing petrol.*
>
> (Service Provider, Northern Territory, Alice Springs Forum #6)

Steps to address these problems were reported:

> *Child and youth mental health is a priority area for action. Some of the new mental health funding announced in 2003/04 and 2004/05 has been invested in specialist clinical positions including two child psychiatrists and three additional child and youth mental health workers. These positions will enhance expert consultancy and clinical services to young people and their families and extend service capacity to regional and remote areas across the Territory. Child Psychiatry visits to Top End communities commenced in September 2004. Child Psychiatry visits to Central Australian communities are expected to commence before the end of 2004.*
>
> (Mental Health Program, Department of Health and Community Services, Northern Territory, Submission #259)

> *The mental health program is undertaking planning and service development work to enhance the provision of child, youth and adult mental health consultation liaison services to major urban and regional centres in order to extend capacity across the Territory. A key priority for child and youth mental health teams is to work with families and develop better links with workers in other key agencies such as schools and youth and family support services.*
>
> (Mental Health Program, Department of Health and Community Services, Northern Territory, Submission #259)

6.7.11.4.3 Lack of services for people with dual diagnosis – mental illness and intellectual disability

Standard 11.4.7 states: 'The MHS ensures access to a comprehensive range of services which are, wherever possible, specialised in regard to dual diagnosis, other disability'. In the notes to this Standard, this includes collaborative treatment with disability services. Furthermore, Standard 11.1.1 (Access) states: 'The MHS ensures equality in the delivery of treatment and support regardless of consumer's age…or other disability'.

One service provider expressed concern that consumers with intellectual disability are being discriminated against as they are being denied treatment and support services on the basis of their intellectual disability.

> *People with intellectual disabilities are ignored because the Mental Health Services don't want to treat them because they say it is an intellectual disability not a mental illness, just like anyone else. I can't stress strongly enough the passing of the buck. People get put on a service merry-go-round. Some people have been to six different services and still haven't had the help they need.*
>
> (Service Provider, Northern Territory, Alice Springs Forum #7)

6.7.11.4.4 Lack of services for people with dual diagnosis – mental illness and drug and alcohol

Standard 11.4.7 states: 'The MHS ensures access to a comprehensive range of services which are, wherever possible, specialised in regard to dual diagnosis'. In the notes to this Standard, this includes dual case management with alcohol and other drug services. Concern was expressed that there were an insufficient number of such services to provide treatment and support to these consumers with complex needs. Given the widespread problem of substance abuse in the Northern Territory and high association of substance abuse and mental health issues, the need for mental health services to provide treatment and support to these consumers is vital.

> *We see a lot of drug and alcohol and mental health issues. We're not equipped to deal with them so we outsource to Cowdry or Tamarind. The response from services is improving. A lot of work has been done by Team Health and the response has improved.*
>
> (Service Provider, Northern Territory, Darwin Forum #11)

> *People that have mental health problems then develop substance abuse problems, they go around in circles.*
>
> (Anonymous, Northern Territory, Alice Springs Forum #2)

> *We do have predominantly dual diagnosis referred because we offer more counselling. Our staff are burnt out by these people, very limited accommodation, they come in in crisis. It's the after hours care that's the major concern. When you are remote your resources are really limited.*
>
> (Service Provider, Northern Territory, Alice Springs Forum #3)

> *Petrol sniffing is a major problem here. Our funding is from OATSIH's [Office for Aboriginal and Torres Strait Islander Health] and one position is funded by the State.*
>
> (Service Provider, Northern Territory, Alice Springs Forum #3)

> *There is no single service for drugs and alcohol and mental health.*
>
> (Carer, Mother, Northern Territory, Darwin Forum #2)

> *Comorbid substance abuse goes hand in hand. It continues because they are longing for relief.*
>
> (Carer, Mother, Northern Territory, Darwin Forum #4)

The NT Mental Health and Substance Misuse Project which includes key government and non-government stakeholders has been established to better meet the needs of people who have a substance misuse and mental health problem. During 2004, the project will identify what services are available for people with co-occurring mental health and substance misuse problems; and provide advice on areas of need and best practice approaches that are sustainable in urban and remote Aboriginal communities. Memorandums of understanding are currently being developed and a working party is identifying screening tools for both Mental Health and Alcohol and Other Drug problems. Accredited training programs for frontline workers were held in Darwin and Alice Springs in February 2004 to increase understanding of mental illness and substance abuse issues. Further Mental Illness and Substance Abuse training targeting a broader spectrum of the workforce is planned in 2004/05.

(Mental Health Program, Department of Health and Community Services, Northern Territory, Submission #259)

6.7.11.4.5 Lack of services for people with dual diagnosis – mental illness and physical disability

Included in Standard 11.4.7 with regard to the delivery of services to people with dual diagnosis are people with 'other disability'. Carers and service providers expressed feelings of anger that consumers with physical disability were experiencing extreme difficulty in accessing services and are being discriminated against. Standard 11 (Access) states that 'The MHS ensures equality in the delivery of treatment and support regardless of…physical or other disability' and Standard 11.1.7 states 'the MHS, wherever possible, is located to promote ease of physical access with special attention being given to those people with physical disabilities'.

For me this is not strong language, during the ten years I have been a carer of a severely physically disabled mentally ill person, I feel I have been treated less then human, and the person I care for, as well as others with disabilities, looked upon as worthless citizens who the governments wished didn't exist. Our loved ones are offered inferior care, if care is what it can be called.

(Carer, Husband, Northern Territory, Submission #68)

For Aboriginal people with disabilities…there is not enough help, not enough funding or commitment.

(Service Provider, Northern Territory, Darwin Forum #23)

I refused treatment for depression because of possible interactions with other drugs and treatments. I am a quadriplegic - discrimination against someone with severe disability is extreme.

(Consumer & Carer, Northern Territory, Darwin Forum #7)

6.7.11.4.6 Lack of services for people with dual diagnosis – mental illness and Acquired Brain Injury (ABI)

The lack of mental health services to provide treatment and support for people with Acquired Brain Injury (ABI) was raised as a serious concern in one submission due to the current, and expected increase in, rate of substance abuse related brain injury in the Northern Territory. Currently, the Mental Health Act specifically excludes provision of treatment and support for ABI and few professionals are available to services. Standard 11.4.7 states: 'The MHS ensures access to a comprehensive range of services which are, wherever possible, specialised in regard to dual diagnosis, other disability'. Furthermore, Standard 11.1.1 states 'The MHS ensures equality in the delivery of treatment and support regardless of consumer's…physical or other disability'.

In Alice Springs there is no specialist service for people with acquired brain injury. A neuropsychologist only visits Alice Springs three times a year. This especially problematic with the Northern Territory Mental Health act being very explicit in its exclusion of people with acquired brain injury from the act. Anecdotal evidence from services providers the rates of undiagnosed traumatic brain injury and substance related brain injury are high in NPY lands. This means a significant group of people is at risk of being excluded from the few supports available, or receiving inappropriate treatment.

(Anonymous, Northern Territory, Submission #271)

6.7.11.4.7 Lack of services for people with personality disorders

Concern was also expressed that people with Personality Disorder experience difficulties in accessing treatment and support services from the MHS and frequently fall through the gaps. Standard 11.1.1 states 'The MHS ensures equality in the delivery of treatment and support regardless of consumer's…previous psychiatric diagnosis…or other disability' and Standard 11.4 7 states: 'The MHS ensures access to a range of treatment and support services which are, wherever possible, specialised in regard to…other disability'.

People with Personality Disorder slip through the gaps – these people miss out and I believe their diagnosis is for 'everything else'.

(Service Provider, Northern Territory, Alice Springs Forum #16)

6.7.11.4.8 Lack of treatment and support for consumers in the criminal justice system

Standard 11.4.7 states: 'The MHS ensures access to a comprehensive range of treatment and support services which are, wherever possible, specialised in regard to…consumers who are subject to the criminal justice system'. Concern was expressed by a mother that a comprehensive range of treatment and support services is currently not available for consumers in the criminal justice system. Under such a model of service delivery, this would indicate that little protection would be afforded to rights of people with mental illness who have become subject to the criminal justice system.

I've been banging on doors and writing letters. My son became ill at 15, he's now 18 and in the justice system. They're not about rehabilitation, just containment.

(Carer, Father, Northern Territory, Darwin Forum #3)

6.7.11.4.9 Carers not involved or informed with the development or review of the individual care plan

Despite Standard 11.4.9 acknowledging the involvement of consumers and carers ('there is a current individual care plan for each consumer, which is constructed and regularly reviewed with the consumer and, with the consumer's informed consent, their carers and is available to them'), reports were received indicating that carers are being excluded from assessment and treatment planning. Given the reported problems with access and limited services available in the community, especially for youth, practices which involve carers to assist with the delivery of care and achieve the best possible outcomes for consumers would both help recovery and protect many rights of people with mental illness.

My son is 24. He had an acute episode five years ago – he has schizophrenia. I got to read the diagnosis off the script authorisation for Olanzapine.

(Carer, Mother, Northern Territory, Darwin Forum #2)

When my son was 15 he told me he was calling the shots. It takes you straight away out of the ball park; I get very little information.

(Carer, Father, Northern Territory, Darwin Forum #3)

6.7.11.4 A Community living

The MHS provides consumers with access to a range of treatment and support programs which maximise the consumer's quality of community living.

I coordinate family carer services. I focus mostly on urban carers. One of our carers has been a carer for a long time and I now advise carers now to develop their own support because it's too frustrating to try and get anything from the system.

(Service Provider, Northern Territory, Alice Springs Forum #12)

Under this Standard, submissions and presentations indicate concerns about:

- the lack of support for consumers and their families in the community;
- lack of leisure, recreation and employment programs;
- lack of access to family centred approaches; and
- lack of support for children of parents with mental illness.

6.7.11.4.A.1 Lack of support for consumers and their families in the community

The aim of deinstitutionalisation was to provide treatment and support in the least restrictive setting, which for most people means living in the community. However, as discussed above, the necessary treatment and support services and effective systems have not materialised for consumers living outside metropolitan areas in the Northern Territory and accommodation options are scarce.

This is true for both people with serious mental illness living in the community and people who, as a consequence of failure to access treatment and support services at the onset of illness or mental health problems, develop significant disability and require additional community support services to live independently or with their family in their communities.

Carers and service providers expressed concern that the lack of access to treatment and support services has placed considerable strain on them as carers and on their families and for parents who were carers, concern for what would happen to their children if they were not able to provide the necessary support. The lack of respite services was particularly noted.

I've been in Alice Springs since 1963, so I do know a little bit about it. Our son developed his illness when he was 28 years old. As a carer it's not easy it's very draining and frustrating.

(Carer, Mother, Northern Territory, Alice Springs Forum #13)

People are frustrated about confidentiality, a real lack of mental health specific respite beds, no day respite, no residential respite. We just have to cope with what we can because there is nothing available, no counselling for carers, no skill development for carers.

(Service Provider, Northern Territory, Alice Springs Forum #12)

My son is living away from home but if anything is wrong I am the one who gets the phone call. He wasn't diagnosed until he was 23 (he had his first symptoms at 15); he is now 30. I have seen a spiral decline over that time. As a carer there is only so much you can do.

(Carer, Mother, Northern Territory, Darwin Forum #4)

Unfortunately in Darwin there are no services in place for respite. There is nothing open over night or no day centre. There are nursing homes for elderly but not for others. Territory Health has not made resources available for carers of people with a mental illness.

(Service Provider, Northern Territory, Darwin Forum #18)

6.7.11.4.A.2 Lack of leisure, recreation and employment programs

Access to day programs to meet the needs for leisure, recreation and employment (Standard 11.4.A.4) were also reported to be declining. Access to such programs is seen as critical for consumers to reintegrate and live in the community with opportunities to participate socially and economically. Concerns were expressed regarding the lack of access to such programs and that consumers in the community 'are left dry', are bored and have no opportunity to develop any skills . Standards 11.4.A.4-11.4.A.9 ensure access to a wide variety of programs, activities and agencies to maximise the consumer's success in these endeavours. Specifically Standard 11.4.A.6 states: 'The MHS provides access to, and/or support for consumers in employment and work'.

Consumers in the community are left dry. They are put out into their flat and that's the end of it. The services we have are good but they lack staff resources and skill development. Some consumers are never given the opportunity to have rehabilitation.

(Carer, Mother, Northern Territory, Alice Springs Forum #13)

There is limited access to rehab services and lifestyle programs.

(Service Provider, Northern Territory, Alice Springs Forum #16)

I have a son who has lived with schizophrenia for 20 years. I've seen some improvements but he's also gone backwards. There is no rehab or respite. There's nothing on the weekends except for them to walk around and get into mischief.

(Carer, Mother, Northern Territory, Darwin Forum #19)

I'm really grateful for the opportunities for people with a disability to be able to work.

(Carer, Northern Territory, Alice Springs Forum #5)

6.7.11.4.A.3 Lack of access to family centred approaches

Many reports were received describing the incredible strain that has been placed on families. In particular, the lack of access to family-centred approaches and support groups was reported. Standard 11.4.A.12 states: 'The MHS ensures that the consumer and their family have access to a range of family-centred approaches to treatment and support' and Standard 11.4.A.11 states: 'The consumer has the opportunity to strengthen their valued relationships through the treatment and support effected by the MHS'. One carer described the impact of her husband's illness on her daughter, the strain on the family unit, and the lack of services to work with the family rather than individuals. The lack of access to other support services (e.g. respite, leisure, recreation, education, training, work, employment, respite, home and community care) also contributed to the strain experienced by the family.

My husband has bipolar and was sectioned in Cowdy Ward. I bashed my head against a wall for 2 years to try and get help for my husband and I was told by the MHS that I should get some counselling. I now have a 10 year old daughter who has been traumatised by this experience. My husband is getting support and so is my daughter. But there is no 'family' support to keep us together. There's a lack of early intervention.

(Carer, Wife, Northern Territory, Darwin Forum #14)

When you have a family member with a mental illness who won't acknowledge their illness, what do carers do? Do you leave children at risk?

(Service Provider, Northern Territory, Alice Springs Forum #12)

6.7.11.4.A.4 Lack of support for children of parents with mental illness

Concern was expressed that services are not responding to the needs of children of parents with mental illness who are carrying a lot of the burden. One clinician cited the needs of children whose parents are deaf and have a mental illness as access to interpreters is severely limited.

I'm concerned about children of deaf adults. My concern is that I'm probably the only interpreter from Darwin to Adelaide. Children of parents with a mental illness carry the burden. Services don't respond to children. I'm also an emotional relief counsellor.

(Mental Health Worker, Alice Springs Forum #15)

6.7.11.4.B Supported accommodation

Supported accommodation is provided and/or supported in a manner which promotes choice, safety, and maximum possible quality of life for the consumer.

Under this Standard, submissions and presentations indicate concerns about:

- lack of housing and supported accommodation options; and
- lack of resources and support for NGO accommodation service providers.

6.7.11.4.B.1 Lack of housing and supported accommodation options

Currently there is no interim or step down facility in Alice Springs, although apparently there are plans to develop such a service. Currently the options are the acute ward in the hospital or being flown back to the community.

(Anonymous, Northern Territory, Submission #271)

The lack of housing and supported accommodation options for people with mental illness is a serious barrier to consumers attaining the 'maximum possible quality of life' and recovering, integrating and contributing to the community. For many consumers in the Northern Territory these goals were unobtainable due to the limited services currently available and the distribution of resources and communities across the Territory. Standard 11.4.B.9 states 'Where desired, consumers are accommodated in the proximity of their social and cultural supports'. Concern was expressed regarding the limited number of services providing supported accommodation, and that as result many accommodation services operate as 'holding bays', people become homeless, or they are discharged straight back to their families with little support. The lack of step-down facilities was also noted.

There are nursing homes for elderly but not for others.

(Service Provider, Northern Territory, Darwin Forum #18)

There are three individuals living in our house with schizophrenia because of lack of other accommodation.
(Consumer & Carer, Northern Territory, Darwin Forum #7)

Some clients are evicted from mental health services. Accommodation services are lacking. Some accommodation is dormitory style, so you might have eight beds there.
(Anonymous, Northern Territory, Darwin Forum #10)

The main program is a housing program. Ranging from high support to independent - we can't deal with these kinds of problems. There are a great deal of problems with our relationship with Top End MHS but great deal of good will to address these problems. A lot of our problems would be resolved if we had a housing support worker.
(NGO Service Provider, Northern Territory, Darwin Forum #12)

Casey House Youth Refuge is the only youth refuge from here to Broome. In a crisis the mentally ill are homeless.
(Service Provider, Northern Territory, Darwin Forum #11)

Not all mental health patients are discharged to SAAP funded accommodation. Many of the clients from this group at times seem to be forgotten and slip through the net of support services.
(Supported Accommodation Service Provider, Northern Territory, Submission #217)

Non-SAAP funded accommodation facilities often end up being a 'holding bay' for clients waiting lengthy periods to access more appropriate housing. Non-SAAP funded accommodation facilities often end up being used to accommodate people who are 'unsuitable' / 'too hard' for the very sort of accommodation they are supposed to be providing for mental health clients.
(Supported Accommodation Service Provider, Northern Territory, Submission #217)

6.7.11.4.B.2 Lack of resources and support for NGO accommodation service providers

A supported accommodation service provider expressed concern with regard to the lack of support and resources available to NGO accommodation service providers. Problems included:

- lack of funding to employ and train sufficient staff for to provide support for the range of consumers requesting admission; and
- lack of access to MHS services to deal with crises, especially after hours.

Non-SAAP funded facilities are often unable to provide suitable accommodation as they are unable to provide adequate support.
- *Staff not trained*
- *Training expenses out of reach of many organisations*
- *Lack of staff*
- *Residents cannot be supervised*
- *Lack of social support / medical supervision*
- *Lack of after hour's assistance.*

(Supported Accommodation Service Provider, Northern Territory, Submission #217)

We go the extra mile in trying to provide accommodation for Mental Health Clients but are continually frustrated and concerned for both the client and ourselves at the lack of services and funding available. These are the same clients who cannot be accommodated more appropriately anywhere else.
(Supported Accommodation Service Provider, Northern Territory, Submission #217)

We would be able to provide a better service if: there was better after hours support from Mental Health Services; there was a wider range of accessible social activities and support.

(Supported Accommodation Service Provider, Northern Territory, Submission #217)

Not necessarily more agencies to provide the activities but more funding to existing ones so as to allow them to widen their horizons.

(Supported Accommodation Service Provider, Northern Territory, Submission #217)

We would be able to provide a better service if…issues of potential violence and episodes versus confidentiality and duty of care could be addressed.

(Supported Accommodation Service Provider, Northern Territory, Submission #217)

Occupational Health and Safety along with Work Health become issues for management of a facility such as our when untrained staff are asked to work in these areas.

(Supported Accommodation Service Provider, Northern Territory, Submission #217)

There is still a great need for day-to-day support services in the community, especially affordable, appropriate supported accommodation which is in extremely short supply. As well as putting Territorians affected by mental illness at risk of homelessness, this also places additional pressure on family and other carers and on mental health workers.

(SANE Australia, National, Submission #302)

The Top End Mental Health Services have been involved in a collaborative project delivering mental health education to Supported Assistance Accommodation Program (SAAP) funded agencies. The outcome of this project has been the development of an accredited SAAP funded agency mental health training package, which is due to be released at the end of 2004.

(Mental Health Program, Department of Health and Community Services, Northern Territory, Submission #259)

6.7.11.4.C Medication and other medical technologies

Medication and other medical technologies are provided in a manner which promotes choice, safety and maximum possible quality of life for the consumer.

No submissions or comments were received pertaining to this Standard.

6.7.11.4.D Therapies

The consumer and consumer's family / carer have access to a range of safe and effective therapies

Under this Standard, submissions and presentations indicate concerns about:

- the lack of access to a range of accepted therapies.

6.7.11.4.D.1 Lack of access to a range of accepted therapies

According to Standard 11.4.D.2 'The MHS provides access to a range of accepted therapies according to the needs of the consumer and their carers'. However, concern was expressed that access to such therapies in the MHS is difficult even for those who can afford to pay for such treatment in the private sector, because there are few clinicians available in the Northern Territory.

Access to the combination of pharmacological prescription and therapeutic counselling is not available to people who cannot afford to pay full private price and for those who can, remains extremely limited.

(Support and Equity Services, Charles Darwin University, Northern Territory, Submission #269)

My husband was diagnosed with bipolar 40 years ago. He's been on and off with depression. He's been treated every time with drugs, received no cognitive behaviour therapy.

(Carer, Wife, Northern Territory, Darwin Forum #13)

6.7.11.4.E Inpatient care

The MHS ensures access to high quality, safe and comfortable inpatient care for consumers.

Under this standard, submissions and presentations indicate concerns about:

- the lack of continuity of care and extreme distress for consumers and their families and carers if admission is required; and
- transport to hospital not the most respectful.

6.7.11.4.E.1 Lack of continuity of care and extreme distress for consumers and their families and carers if admission is required

For consumers living in remote communities, the requirement for acute care posed many problems, especially as this care was generally only available in Darwin or Alice Springs. As mentioned previously, transportation to such facilities would often require the need for chemical and/or physical restraint.

Also, the lack of access to treatment and support in the earlier phases of illness resulted in consumers being in desperate need of medical, often life-saving, medical care at point of admission. Concern was also expressed that having reached this level of distress, both the consumer and their family had to endure even further strain as they were separated for the period of admission as the distances and costs involved for visits were prohibitive and public transport not available. This also complicated any continuity of care and the involvement of carers in treatment planning and support.

The inability to access care at the earliest possible moment therefore resulted in a whole series of rights being jeopardised for consumers, impacting disproportionately as previously outlined on Indigenous people. In these situations, many of the criteria under Standard 11.4.E were not met. For example: the MHS offers the least restrictive alternative (11.4.E.1), admission assessment includes the views of other current service providers and the consumer's carers (11.4.E.4), the impact of admission is minimised on the consumer's family and significant others (11.4.E.7) and consumer's visitors are encouraged (11.4.E.8). The Department of Health and Community Services indicated that some of these concerns are being addressed.

As people are often evacuated, without the support of family, relatives may have no contact with the treating team. They may not be given information or able to provide information to the treating team. If a person is admitted to hospital for a period of time the costs associated with family visits are prohibitive. In communities diesel can be up to $1.60 / litre, which means that doing 1000km round trips is beyond the capabilities of most. There is no public transport available on NPY Lands. This leads to extreme distress within families and communities.

(Anonymous, Northern Territory, Submission #271)

Issues related to patient care and staffing in the specialist Mental Health Inpatient Units are being addressed with clinical staff, union representatives and other key stakeholders. Admission and discharge policies have been reviewed. Assessments in the Emergency Department are better managed with the creation of a new mental health consultation liaison nurse position and the redevelopment of the extended hours service, with a community mental health nurse rostered to the Emergency Department after hours 7 days a week.

(Mental Health Program, Department of Health and Community Services, Northern Territory, Submission #259)

6.7.11.4.E.2 Transport to hospital not the most respectful

Concerns were expressed regarding the use of police and police wagons to transport consumers to hospitals for treatment when this level of response was not required. It was stated that this response was 'degrading' and made young people 'lose their dignity'. Standard 11.4.E.3 states: 'The MHS ensures that a consumer who requires involuntary admission is conveyed to the hospital in the safest and most respectful manner possible'.

When a patient needs assistance, the Ambulance usually will not transport and the caller is directed to phone the police. Police will transport the client to the hospital in the back of a police wagon. This is a very degrading experience!

(Supported Accommodation Service Provider, Northern Territory, Submission #217)

These young people really lose their dignity when they are transported in paddy wagons.

(Carer, Mother, Northern Territory, Darwin Forum #21)

6.7.11.5 Planning for exit

Consumers are assisted to plan for their exit from the MHS to ensure that ongoing follow-up is available if required.

Under this Standard, submissions and presentations indicate concerns about:

- the lack of services and options available to assist with discharge planning.

Systemic Issues…quality of discharge planning.

(Anonymous, Northern Territory, Submission #188)

6.7.11.5.1 Lack of services and options available to assist with discharge planning

Concern was raised about the lack of options available to plan adequately for treatment and support of consumers after discharge. Due to the lack of supported accommodation, step-down facilities, community based treatment and support services and lack of rehabilitation services, care was seen to fall predominantly on carers.

A problem was identified for Indigenous carers that due to chronic ill health within Indigenous communities, the assumed burden must be presupposed to be high. This limited treatment options to medication only and very little overall support to the consumer. Also, the carer has generally not been present during the hospital stay to be familiar with treatment plans, exit plans and be informed about the illness and how best to support the consumer. Most criteria under Standard 11.5 would, according to concerns expressed throughout this Report, be difficult to meet. For example, the exit plan is reviewed with the consumer and their carer (11.5.2).

It also needs to be noted that due to the high level of chronic ill health within communities the burden on carers within families is often very high. Therefore it is important that health professional do not make assumptions about the level of family support available when making discharge plans.

(Anonymous, Northern Territory, Submission #271)

After the acute treatment episode people are discharged to their community. Generally they are flown home, with information for ongoing medical management by the clinic staff. This is mainly the administration of medication. Currently there is no interim or step down facility in Alice Springs, although apparently there are plans to develop such a service. Currently the options are the acute ward in the hospital or being flown back to the community.

(Anonymous, Northern Territory, Submission #271)

6.7.11.6 Exit and re-entry

The MHS assists consumers to exit the service and ensures re-entry according to the consumer's needs.

Under this Standard, submissions and presentations indicate concerns about:

- the lack of follow-up.

6.7.11.6.1 Lack of engagement with consumer after exiting inpatient care

Concern was expressed that after discharge from an acute mental health facility no contact was made by the MHS to ensure the health and safety of the consumer. This could indicate that no exit plan or follow arrangements were made or that no attempts were made by the MHS to re-engage with consumers who did not keep the planned follow-up arrangements (Standard 11.6.4).

A student returns to Uni after admission in the acute care mental health facility. No contact is made from mental health services…According to the student, no follow-up via mental health services has been offered.

(Support and Equity Services, Charles Darwin University, Northern Territory, Submission #269)

6.8 TASMANIA

ANALYSIS OF SUBMISSIONS AND CONSULTATIONS FROM TASMANIA AGAINST THE NATIONAL STANDARDS FOR MENTAL HEALTH SERVICES

In summary, information presented in this section was gathered from 14 submissions (see Appendix 8.3.8) and presentations made at a community forum attended by approximately 80 people (see Appendix 8.1). A draft copy of this report was sent to the Premier and Minister for Health for comment. An analysis of the response from the Tasmanian Government (reproduced in Appendix 8.4.8) and an overall review of mental health service delivery in Tasmania is contained in Part 2.7.8.

6.8.1 STANDARD 1: RIGHTS

The rights of people affected by mental disorders and/or mental health problems are upheld by the MHS.

Under this Standard, submissions and presentations indicate concerns about:

- lack of access to advocates;
- lack of access to interpreters;
- lack of respect for patient dignity and right to least restrictive form of treatment; and
- information not being provided to carers and families about mental illness, treatment and support services.

6.8.1.1 Lack of access to advocates

Advocacy Tasmania reported that until recently, access to advocates for consumers when they appeared before Mental Health Tribunals was rare despite the fact that the Mental Health Act grants such representation:

> *[T]he Tasmanian Mental Health Act 1996, s57, grants representation for people appearing before the Mental Health Tribunal in keeping with the United Nations Principles for the Protection of Persons with Mental Illness. Principle 18 states: "The patient shall be entitled to choose and appoint counsel to represent the patient, as such, including representation in any complaint or appeal". Until the Representation Project was commenced this had not happened… Of 102 hearings held in 1999 / 2000 only 2 clients were represented.*
>
> (Advocacy Tasmania Inc - Mental Health Tribunal Representation Scheme, Tasmania, Submission #189)

This report also suggests that consumers are not being made aware that they have a right to have an independent advocate or support person with them at any time during their involvement with the MHS. Standard 1.6 states: 'Independent advocacy services and support persons are actively promoted by the MHS and consumers are made aware of their right to have an independent advocate or support person with them at any time during their involvement with the MHS'.

As stated by Advocacy Tasmania, lack of representation of people with mental illness has meant that some of the most disadvantaged people in our communities have not had a voice during hearings or may not have understood what was happening and hence been powerless to promote or protect their rights. The recent commencement of Mental Health Tribunal Representation Scheme has allowed consumers access to trained volunteer advocates when appearing before the Mental Health Review Tribunal, although it is suggested that continued funding and operation of the Scheme is not assured:

> *…a program that has commenced in Tasmania, which focuses on the rights of those with mental illnesses, and which has been very successful. This program is known as the Mental Health Tribunal Representation Scheme. The Scheme is where volunteers have offered to represent those people appearing before the Mental Health Tribunal in relation to the automatic review of the person's Continuing Care Orders. This relates to people who have been detained in a hospital against their will, during the past 28 days. Previously, these people, who we acknowledge as some of our most disadvantaged community members, have not been represented; they have not had a voice with which to be heard at their hearings. By this, it is meant that often such people have felt disadvantaged, misunderstood and not listened to. They also have often not understood what has been happening, or been said, to them at the Mental Health Tribunal hearing. They have been powerless. This demonstrates the potential for abuse, not only of these people's rights, but also of the legislation governing the rights of the mentally ill.*
>
> (Advocacy Tasmania Inc - Mental Health Tribunal Representation Scheme, Tasmania, Submission #189)

> *The Scheme is funded for the 2004/2005 year, but has not been guaranteed funding after that time. Advocacy Tasmania is currently seeking a commitment from the Tasmanian Government to continue to fund the Scheme in the future.*
>
> (Advocacy Tasmania Inc. - Mental Health Tribunal Representation Scheme, Tasmania, Submission #189)

6.8.1.2 Lack of access to interpreters

For people who speak a language other than English, access to mental health care can be complicated by language and cultural barriers. These barriers compound understandings of mental health services, mental disorders, mental health problems and available treatment and support services, and how to navigate the system. In many cases a person may be socially isolated or reluctant to have family or friends involved as carers or act as an interpreter for reasons of confidentiality or stigma. Concern was expressed that many consumers, the elderly in particular, from a non-English speaking background (NESB) are isolated in their homes and are not accessing services due to language and service delivery barriers. This could also indicate health promotion and prevention campaigns are not reaching people who do not speak English as they are not aware of their illness or services available, including the 'right of the consumer and their carers to have access to accredited interpreters' (Standard 1.7). This was highlighted by a service provider attending the Hobart Forum:

> *People are isolated in their houses and no one is coming to their homes. They can't express themselves and everyone is in a hurry.*
>
> (NESB and Ageing Worker, Tasmania, Hobart Forum #5)

This report could also indicate that staff who come into contact with these consumers are not spending sufficient time to discuss these issues or arrange an interpreter or are not aware of the consumers' right to have access to an interpreter.

6.8.1.3 Lack of respect for patient dignity and the right to the least restrictive form of treatment

One consumer at the Hobart forum raised concerns about practices involving seclusion and degrading treatment during their involvement with the MHS. The practices referred to in the following quote indicate that relevant legislation, regulations and instruments protecting the rights of people with mental illness or mental health problems are not being complied with in all cases (Standard 1.1).

> *I stayed in the Psychiatric Intensive Care Unit at the Royal Derwent Hospital…There was no access to a toilet so I had to urinate in the corner of the room.*
>
> (Consumer, Tasmania, Hobart Forum #3)

6.8.1.4 Information not being provided to carers and families about mental illness, treatment and support services

Concern was expressed that carers and families were not receiving sufficient support and information about the illness or treatments available (Standard 1.8). For carers, information about the course of the illness and how they can best support their family member and access support for themselves is vital in achieving the best possible outcome for the consumer and minimising the impact of the illness on the family. The following quote indicates that this information is not always being provided:

> *There is a lack of education and support for families of people with a mental illness.*
>
> (Anonymous, Tasmania, Submission #254)

6.8.2 STANDARD 2: SAFETY

The activities and environment of the MHS are safe for consumers, carers, families, staff and the community.

Under this Standard, submissions and presentations indicate concerns about:

- lack of policies and procedures in hospitals to ensure the safety of consumers, carers and the community upon discharge; and
- lack of policies, procedures, resources and training to enable staff to respond safely to aggressive and difficult behaviours.

6.8.2.1 Lack of policies and procedures in hospitals to ensure the safety of consumers, carers and the community upon discharge

SANE Australia's *Sane Mental Health Report 2004* noted under its "Bad News" section claims of abuse and neglect in the inpatient unit at Launceston Hospital:

> *When a system is under pressure, things start to go wrong…a review of the Psychiatric Ward at Launceston Hospital is being undertaken by the Health Complaints Commissioner and the Nursing Board of Tasmania following claims of abuse and neglect.*
>
> (SANE Australia, National, Submission #302)

One consumer at the Hobart Forum also described the tragic consequences of her early discharge without an adequate risk assessment being undertaken or treatment and support services being organised prior to her exiting inpatient care and returning home:

> *They said it wasn't a positive thing for me to be there and I wasn't interviewed about my own safety so I went home and poured metho over myself and that's a much greater cost to the health system.*
>
> (Consumer, Tasmania, Hobart Forum #3)

The result for this consumer was complete disfigurement (extensive burns and scarring). This report suggests that policies, procedures and resources were not available to promote the safety of consumers (Standard 2.3) prior to discharge from the MHS to the community and was consistent with other evidence presented in submissions and at the community forum.

6.8.2.2 Lack of policies, procedures, resources and training to enable staff to respond safely to aggressive and difficult behaviour

Standard 2.4 states: 'Staff are regularly trained to understand and appropriately and safely respond to aggressive and other difficult behaviours'. Concern was expressed that staff may not be sufficiently trained to understand and safely respond to aggressive and other difficult behaviours. This could result in the unnecessary use of force to control situations and jeopardises the safety of the consumer, staff and other consumers in treatment settings.

Concern was also raised that staff are sometimes placed in potentially violent situations with no back-up systems in place (Standard 2.5). These concerns also suggest that policies (including occupational health and safety policy), procedures and resources are not available to promote the safety of consumers, carers, staff and the community (Standard 2.3):

> *There is a crisis in attracting all disciplines to work in Mental Health due to lack of support / training and poor working conditions and a lack of attractive career paths. This impacts on comprehensive care and there are recurrent safety issues due to Staff dealing with potentially violent and dangerous situations, sometimes without any back up.*
>
> (Anonymous, Tasmania, Submission #254)

6.8.3 STANDARD 3: CONSUMER AND CARER PARTICIPATION

Consumers and carers are involved in the planning, implementation and evaluation of the MHS.

Under this Standard, submissions and presentations indicate concerns about:

- barriers to effective participation by consumers and carers; and
- lack of meaningful consultation with consumers and carers.

6.8.3.1 Barriers to effective participation by consumers and carers

Concern was expressed that many staff lack the necessary knowledge and skills to allow consumers and carers to participate effectively. One consumer at the Hobart Forum stated that consumers are willing to contribute and have valuable information to offer, but that some staff need training in cooperation and consultation skills to enable consumers to contribute to service reform:

Let's celebrate us – we must stop apologising, use us, we are valuable but use us properly. Some psychiatrists have no idea how to cooperate with consumers or carers.

(Consumer, Tasmania, Hobart Forum #21)

Concern was also expressed that many consumers may not be aware that they have the opportunity to participate in the MHS (Standard 3.1) and that consumers and service providers may not have a shared understanding about what participation means (Standard 3.3). Both these factors would limit the potential contribution by consumers and carers in planning, implementing and evaluating the delivery of mental health services in order to makes services more responsive to the needs of consumers and the community:

...many consumers are unaware of their right to "participate". Many service providers do not have a shared understanding of the term consumer participation particularly with respect to WHO declaration of Alma-Ata. Participation is an ethical and democratic right and makes the services more responsive to the consumer needs.

(Anonymous, Tasmania, Submission #290)

6.8.3.2 Lack of meaningful consultation with consumers and carers

Associated with concerns expressed above were suggestions that other factors are inhibiting maximum participation by consumers and carers. These included: limited representation of consumer subgroups (Standard 3.6); lack of resources (Standard 3.4); lack of organisational commitment (Standard 3.2); fear of repercussions for speaking out during such activities; fears that privacy and confidentiality are not ensured (Standard 3.1); feelings that participation was tokenistic; and limited review and evaluation of participation processes (Standard 3.7):

It is still the case that dominant groups decide for consumers what kind of services should be provided, if any, without any meaningful consultations and when consumers are quite able to speak for themselves. This leads to a situation such as we have in Tasmania where consumers feel excluded and their different needs are overlooked or even worse dismissed. The anger and grief that results from such indifference then surfaces and very often labelling of those who complain then occurs.

(Anonymous, Tasmania, Submission #254)

There is a perception among consumers that more time and opportunities are given to consumers who are well, literate and not experiencing co-occurring disorders. Another concern is that consultation tends to focus on surveys, suggestion boxes and complaint forms.

(Anonymous, Tasmania, Submission #290)

To remove barriers to participation more resources need to be dedicated for consultation, organisational commitment and leadership and consumer participant.

(Anonymous, Tasmania, Submission #290)

I would like to submit to you the findings of a consultation with providers and consumers of mental health in the north and particularly in the Launceston area…consultation with 40 consumers and 28 service providers to potential barriers to effective consumer participation...Barriers identified:

1) *Limited participation opportunities and mechanisms*
2) *Consumer concerns regarding confidentiality and fear of repercussion*
3) *Consumer perception that their participation is not valued, [just] lip service*
4) *Limited awareness of consumer rights to participate*
5) *Limited shared agreement and understanding of effective consumer participation*
6) *limited consumer initiated participation*
7) *limited review and evaluation of effectiveness of participation methods*
8) *limited resources to begin, create or improve consumer participation methods*
9) *differing interpretation by consumers and service providers as to what constitutes appropriate feedback*

(Anonymous, Tasmania, Submission #290)

6.8.4 STANDARD 4: PROMOTING COMMUNITY ACCEPTANCE

The MHS promotes community acceptance and the reduction of stigma for people affected by mental disorders and/or mental health problems.

Under this Standard, submissions and presentations indicate concerns about:

- the high levels of stigma still prevalent within the community;
- offensive remarks made by police and accident and emergency staff towards consumers;
- exclusion by family members;
- discrimination in the workplace; and,
- activities to promote community acceptance of people with mental illness are not being supported.

6.8.4.1 High levels of stigma still prevalent within the community

Standard 4.1 states: 'The MHS works collaboratively with the defined community to initiate and participate in a range of activities designed to promote acceptance of people with mental disorders and/or mental health problems by reducing stigma in the community'. Consumers expressed concerns about the high level of stigma and ostracism still being experienced by people with mental illness, to the extent that the rights and needs of the people with mental illness who are homeless or in the criminal justice system are being ignored by society. These high levels of stigma would indicate that campaigns and activities to date to address community acceptance and reduce stigma have not been able to turn community attitudes around.

As described below, a lack of community acceptance is a key barrier to people with mental illness from accessing treatment and gaining employment or having a voice and thus being able to participate socially, economically and politically in society. The need for community education is evidenced by the following comments:

It is disgraceful that we don't do anything about the people on our streets or in our prisons – it's a bad reflection on our society.

(Consumer, Tasmania, Hobart Forum #21)

There is still a need for community education about mental illness to combat stigma and promote understanding of the needs of people with mental illness.

(Anonymous, Tasmania, Submission #254)

I'm a recovering alcoholic but as soon as I put that on the form I get excluded.

(Consumer, Tasmania, Hobart Forum #11)

6.8.4.2 Offensive remarks by police and accident and emergency staff

ARAFMI Hobart expressed concern about the lack of acceptance and understanding and discriminatory attitudes shown by police and emergency staff towards people with mental illness. This is of particular concern given that consumers in crises frequently come into contact with the police and staff in accident and emergency departments. Their views impact directly upon consumers, their carers and influences the attitudes held by other members of the community:

…that some police appear to be insulting people who appear to have obstreperous behaviour, using terms such as psycho for a young client of mine last week who does have mental illness and anger management problems & according to the client, a rather brutal take down, standing on his head for instance. Police need to have more MH education / training.

(ARAFMI Hobart, Tasmania, Submission #214)

Ditto for Accident & Emergency staff including medical heads of dept about personality disordered people in crisis. I was told personally by a medical head of DEM that 'they're arseholes', so imagine the working culture if that view is held at the top.

(ARAFMI Hobart, Tasmania, Submission #214)

6.8.4.3 Exclusion by family members

Consumers frequently expressed concern that not only does stigma and lack of understanding still shape community behaviour and result in the exclusion of people with mental illness in social and workplace settings, but that often this behaviour extends to close family members and intimate partners resulting in relationship breakdown:

The issue for me is stigma. I've been excluded from a couple of family functions since Christmas because of my behaviour and it's ended my relationship with someone I really love.

(Consumer, Tasmania, Hobart Forum #12)

6.8.4.4 Discrimination in the workplace

Being employed and working in a supportive workplace are seen as key factors in preventing relapse or deterioration of mental illness and essential in the process of rehabilitation and reintegration into society during the recovery phase. However, acceptance and understanding of mental illness seem to be lacking in the workplace and, according to one submission received, the perception is that if a history of mental illness or mental health problems is disclosed, this information will be used to the applicant's / employee's detriment. This suggests observance of Standard 4.2 is poor. Standard 4.2 states: 'The MHS provides understandable information to mainstream workers and the defined community about mental disorders and mental health problems'.

*…the rejection letters...was it because [I] answered the question…*YES *"Do you have a disability which is likely to last two years or more?" for this recovering alcoholic a Question like this one coupled with '(even if you personally have not been disadvantaged as a result of your disability)? Is VERY DANGEROUS STUFF…***Therefore you didn't get the Job because you told the Truth & how scary is that***…[Department of Health and Human Services Form…"It is not intended that information in this form will be used in any decisions on appointments, promotions or transfers. The information will only be used to monitor and develop Workplace Diversity policy and programs.] (author's emphasis)*

(Consumer, Tasmania, Submission #165)

…Commonwealth requirements for employment require people to identify whether they have been institutionalised or not because people are afraid to disclose.

(MP, Tasmania, Hobart Forum #2)

6.8.4.5 Activities to promote community acceptance of people with mental illness are not being supported

A submission by Cadence FM Inc. Community Radio and presentations by community radio providers at the Hobart Forum indicate concerns that activities that could be used to promote acceptance of people with mental illness and give people with mental illness a voice can be better supported. It was suggested that radio is an excellent medium to give people with mental illness a voice, promote acceptance and educate the community and that these activities are not occurring:

Lack of programs being hosted by people with a mental illness.

(Community Radio provider, Tasmania, Hobart Forum #6)

It is difficult for people with a mental illness to have a voice on radio.

(Community Radio Provider, Tasmania, Hobart Forum #7)

Cadence FM was uniquely placed supporting radio programmes for people with a mental disability. Our station commenced in 1997 entirely staffed by volunteer effort. A licence decision by the Australian Broadcasting Authority (ABA) in December of 2002, prevented our station continuing broadcast. Our submission is presented from first hand knowledge of the empowerment and benefit that broadcasting can bring to people with a mental disability. The aims of this submission are to address the ongoing rights of these people, to be heard.

(Cadence FM Inc, Community Radio, Tasmania, Submission #190)

We wrote letters to a number of stations representing each of these traditional broadcasting categories asking if they represented programmes hosted by people with a mental disability allowing for such programmes to be guided by persons with normal capacity. As of this submission date, none had replied affirmly…The peak body representing Community Radio in Australia is the Community Broadcasting Association of Australia (CBAA). We looked at the CBAA website and searched for Mental Disability no entries were found. We searched for Mental Disability Radio programmes no entries were found.

(Cadence FM Inc, Community Radio, Tasmania, Submission #190)

There appear to be no broadcasting stations now in Australia extending effort to provide their facility for people with mental disability to directly host their own programmes, allowing for programmes to be assisted by a person with normal capacity.

(Cadence FM Inc, Community Radio, Tasmania, Submission #190)

There are only a few programmes on Radio dedicating airtime to understanding mental health containing interviews, involvement and actual care for the mentally disabled. These programmes deserve reward and attention to continue and develop yet more inclusive programming.

(Cadence FM Inc, Community Radio, Tasmania, Submission #190)

A number of programmes are presented with Community Health focus not necessarily contributed by persons with a mental disability in any manner, or embracing their actual needs. These programmes require reassessment to refine their aims where mental health is discussed.

(Cadence FM Inc, Community Radio, Tasmania, Submission #190)

6.8.5 STANDARD 5: PRIVACY AND CONFIDENTIALITY

The MHS ensures the privacy and confidentiality of consumers and carers.

Under this Standard, submissions and presentations indicate concerns about:

- application of privacy and confidentiality rules without authority or failing to request permission from a consumer to share information or involve carers.

6.8.5.1 Application of privacy and confidentiality rules

Family carers indicate they have all responsibility but no rights. They are key players in caring for sick family members. The confidentiality / privacy act is an aberration. Carers observe a loved one's illness daily and can warn when episodes / relapses are imminent. Professionals deny themselves access to the wisdom of carers and hinder early diagnosis and accurate diagnosis.

(ARAFMI Tasmania, Tasmania, Submission #245)

Carers, carer advocates and a consumer advocate expressed concerns that a misunderstanding of policies and procedures to protect the confidentiality and privacy of consumers is impeding communication between consumers, carers and clinicians in the provision of treatment and the sharing of vital information. These concerns indicate that policies and procedures related to privacy and confidentiality are not being made available to consumers and carers in an understandable language and format (Standard 5.2) and that the mental health system is not encouraging and providing opportunities for consumers to involve others in their care (Standard 5.3). The following quotes indicate the level of frustration and despair experienced by carers:

We get a lot of calls from carers trying to get the person into care but the carer often isn't listened to and so valuable information isn't shared and this is done under the guise of the clinician is breeching the Privacy Act. The carers also need to know (from clinicians) how to respond to particular difficulties without / instead of just responding intuitively. The diagnosis itself isn't important – it's more the behaviours and how we should best respond.

(Carer Advocate, Tasmania, Hobart Forum #9)

There shouldn't be anything that the doctors can't disclose to carers. I think some doctors want to retain the power.

(Consumer Advocate, Tasmania, Hobart Forum #9)

Dual diagnosis. My life was in disarray when my wife was dealing with alcoholism and because of privacy I couldn't find out what was wrong with her.

(Carer, Husband, Tasmania, Hobart Forum #13)

My son disappeared. Centrelink couldn't tell me if they knew where he was.
(Carer, Mother, Tasmania, Hobart Forum #16)

6.8.6 STANDARD 6: PREVENTION AND MENTAL HEALTH PROMOTION

The MHS works with the defined community in prevention, early detection, early intervention and mental health promotion.

Under this Standard, submissions and presentations indicated concerns about:

- the lack of focus on early intervention or prevention (reactive, crisis driven approach); and
- the lack of rehabilitation programs.

6.8.6.1 Lack of focus on early intervention or prevention - reactive, crisis driven approach

Concern was expressed about the lack of focus on early intervention or prevention in the delivery of mental health services. This is reportedly occurring despite the rhetoric of 'capacity to identify and respond to the most vulnerable consumers in the community' (Standard 6.4), as early as possible (Standard 6.5), and that treatment and support is to occur in a community setting in preference to an institutional setting (Standard 6.6):

Burden of care on families. Department of Health documents specifically confirm that "families of people who need rehabilitation and find it hard to access are also disadvantaged themselves as a result". Government reports state that "earlier rehabilitation and the hope and purpose it generates are important for families who have to support a member long tern with resultant family stress and economic disadvantage."
(Sue Napier, MHA, Liberal Shadow Minister for Health, Tasmania, Submission #261)

We simply don't have the community services to help people before they become acutely unwell.
(MP, Tasmania, Hobart Forum #25)

Services are currently reactive as opposed to proactive, which leads to a "Band-Aid" resolution of any crises or issues. Needs to be a focus on prevention and management instead.
(Anonymous, Tasmania, Submission #254)

The Tasmanian Suicide Prevention Steering Committee, in its Annual Report, notes the steady and substantial increase in suicide rates in Tasmania and identifies the need to focus on relapse prevention, and for greater community support. The Committee also raises concerns about the lack of intervention strategies and undiagnosed depression…
(Sue Napier, MHA, Liberal Shadow Minister for Health, Tasmania, Submission #261)

These views can be contrasted with the positive progress reported in the *Sane Mental Health Report 2004* for suicide prevention strategies:

Community and school education on suicide prevention has been well-implemented in the State, and has been widely praised.
(SANE Australia, National, Submission #302)

6.8.6.2 Lack of rehabilitation programs

Standard 6.8 states: 'The MHS ensures that the consumer has access to rehabilitation programs which aim to minimise psychiatric disability and prevent relapse'. Yet, similarly to above, concern was expressed that the mental health system places little emphasis on rehabilitation programs or other programs to prevent relapse or promote recovery and instead waits for a crisis to occur before responding:

> *The lack of ongoing rehabilitation programs also means that we see a lot of young people, especially, being discharged after treatment but then without the necessary support, quickly becoming unwell again and the cycle constantly being repeated.*
>
> (Carer, Mother, Tasmania, Submission #315)

> *Staff also describe a "Revolving Door Syndrome" where only short-term crises are dealt with and long-term structured support for clients is not obtainable.*
>
> (Anonymous, Tasmania, Submission #254)

Concern was also expressed by a carer that insufficient funding is being provided to support non-government organisations who are offering rehabilitation programs that are working well and meeting the needs of consumers. The lack of funding jeopardises the quality and sustainability of such programs:

> *I support a lady from Devonport. The only rehab program functioning well in Tasmania is the Richmond Fellowship but funding is abysmal.*
>
> (Carer, Tasmania, Hobart Forum #17)

6.8.7 STANDARD 7: CULTURAL AWARENESS

The MHS delivers non-discriminatory treatment and support which are sensitive to the social and cultural values of the consumer and the consumer's family and community.

No submissions or comments were received pertaining to this Standard.

6.8.8 STANDARD 8: INTEGRATION

6.8.8.1 Service Integration

The MHS is integrated and coordinated to provide a balanced mix of services which ensure continuity of care for the consumer.

Under this Standard, submissions and presentations indicate concerns about:

- the chronic under-resourcing of mental health services resulting in an inability for consumers to access integrated and coordinated care.

6.8.8.1.1 Chronic under-resourcing of MHS resulting in an inability for consumers to access integrated and coordinated care

Concern was expressed regarding the shortage of clinical staff to provide the necessary treatment and support services to deliver integrated and coordinated care. This was reported by consumers trying to access care and service providers trying to organise referrals for treatment:

> *We live in Devonport, 30,000 population. We have one psychiatrist at the service one day a week. It's not enough! They are beautiful people but they are under resourced.*
>
> (Carer, Mother, Tasmania, Hobart Forum #15)

> *Limited psychiatrists in community team for clients to access. If a client misses an appointment they may not be able to have another appointment for several weeks.*
>
> (Colony 47, Tasmania, Submission #227)

> *A Consumer Survey, conducted in September 2003, found that 49% of respondents mentioned they had experienced barriers when attempting to access mental health rehabilitation services. The most common barriers identified were the long distances travelled to access services (29%), the necessity to have a case manager in order to participate (29%) and the long wait time incurred before entering such services (13%). Further, in that survey 24 consumers voiced their opinions about the negative aspects of current services, including 'there isn't enough resources and there is a lack of access to psychologists", 'the need for services to be offered on more days for a greater length of time', and 'the absence of staff'.*
>
> (Sue Napier, MHA, Liberal Shadow Minister for Health, Tasmania, Submission #261)

> *The Southern Tasmania GP Practice Division also report earlier in 2004 that 'due to overload in MHS generally, it can take up to three months for patients to receive CBT or case management' and "best practice would allow the CATT team to have a psychiatrist to attend on-site crises and review cases, but this is currently impossible. The team had a locum psychiatrist for 6 hours a week until recently. Now, they are waiting some months for another locum."*
>
> (Sue Napier, MHA, Liberal Shadow Minister for Health, Tasmania, Submission #261)

> *The Australian Nurses Federation have said their members are unable to deliver `the standards of care because of inappropriate resourcing and back-up in the mental health system.*
>
> (Sue Napier, MHA, Liberal Shadow Minister for Health, Tasmania, Submission #261)

The scarcity of staff and resources was also cited as the principle reason for fragmented service delivery and lack of cohesion between government and non-government service providers in the provision of holistic and integrated care:

> *Those reports state: "the lack of a definitive model of rehabilitation and of case management impacted on the clients who were not receiving adequate care as a consequence. The members were concerned that clients fell through the net by no one person taking overall coordination for the care of the client in the community".*
>
> (Sue Napier, MHA, Liberal Shadow Minister for Health, Tasmania, Submission #261)

> *The sector is currently very fragmented. Continuity of care between Government services and NGOs is difficult to maintain given the current restrictions of time and scarce resources.*
>
> (Anonymous, Tasmania, Submission #254)

> *These comments are backed by the Chair of the Mental Health Council of Tasmania who has publicly said that organisations such as Anglicare and Colony 47 were in urgent need of more funds for mobile counselling teams and group homes. "Demand for these services [is] now more than three times the level of services provided'.*
>
> (Sue Napier, MHA, Liberal Shadow Minister for Health, Tasmania, Submission #261)

Concern was also expressed about the lack of accessible information for clinicians and consumers to assist consumers who can not afford to pay for treatment in the private sector or who have complex needs (for example consumers who are homeless):

> *As service providers it is difficult to support clients to access special assistance from GP's regarding their mental health – in relation to involving them in coordinating care or being able to access programs such as the 'Integrated Care for Better Mental Health'. We know that there are additional services that are available – but that information is not in the public domain. This is less than helpful, particularly when working with clients who may be homeless and or transient and may not have a regular GP. These are scarce resources that people who are on income security payments need to have access to.*
>
> (Colony 47, Tasmania, Submission #227)

6.8.8.2 Integration within the health system

The MHS develops and maintains links with other health service providers at local, state and national levels to ensure specialised coordinated care and promote community integration for people with mental disorders and/or mental health problems.

No submissions or comments were received pertaining to this Standard.

6.8.8.3 Integration with other sectors

The MHS develops and maintains links with other sectors at local, state and national levels to ensure specialised coordinated care and promote community integration for people with mental disorders and/or mental health problems.

Under this Standard, submissions and presentations indicate concerns about:

- housing and accommodation options;
- home and community services;
- employment;
- lack of support from Centrelink; and
- the need for a whole-of-government approach to tackle poverty and mental illness.

6.8.8.3.1 Housing and accommodation options

The lack of available housing and accommodation options for people with mental illness was repeatedly raised as a critical gap in the achievement of mental, physical and social well-being. Concerns were expressed that the lack of available supported accommodation or other accommodation options resulted in people becoming homeless or remaining in care for longer periods of time than necessary because there were no viable alternatives (see also stories described in Standard 11.4.B Supported Accommodation). Access to secure and safe accommodation is seen as an essential component in the process of reintegration into the community and improved mental health. The lack of available housing and accommodation options and the process of deinstitutionalisation and consequent lack of community services, have resulted in many people with mental illness becoming homeless; placed intolerable strain on families; and contributed to a decline in health and quality of life:

Accommodation is inadequate for crisis and long term demand.

(Colony 47, Tasmania, Submission #227)

Caroline House Hobart (which moved from its prime purpose as a women's shelter) to concentrate on offering medium to long term accommodation for women, is regularly (at least twice a week) contacted by hospitals, GPs, the police looking for short term accommodation for people needing to have their medication stabilised; those who are at risk of suicide should they return home - this request usually from a GP as the psychiatric wards are full.

(The Australian Family Association Tasmanian Branch, Tasmania, Submission # 263)

A major crisis exists in the supported accommodation area. Not only has there been very little growth in the number of beds available but also many of the previous options have disappeared.

(Anonymous, Tasmania, Submission #254)

Caroline House in southern Tasmania has five beds dedicated to mental health clients, and only accept referrals from mental health services. The service will not take referrals from transitional services, including SAAP services.

(Colony 47, Tasmania, Submission #227)

Our organisation wishes to stress the need for substantially more respite places, as against either acute care or long term assistance for those with a mental health problem and for their families.

(The Australian Family Association Tasmanian Branch, Tasmania, Submission # 263)

Multiple reports obtained from the Department of Health in Tasmania reveal "there is widespread agreements across the State that there is a lack of supported accommodation which inhibits rehabilitation for people who need stability and security when pursuing longer term rehabilitation goals" and "confirm the belief that there is a lack of supported accommodation choice in MHS supported accommodation".

(Sue Napier, MHA, Liberal Shadow Minister for Health, Tasmania, Submission #261)

6.8.8.3.2 Home and community services

The ineligibility of people with mental illness to qualify for Home and Community Care (HACC) services was described as an example of direct discrimination when compared with people with physical illness if both are unable to perform the same tasks of daily living. An inability to access HACC services makes it difficult, if not impossible, for some people with mental illness to continue or chose to live independently or adds additional strain to their parenting role:

Some support services such as some HCC programmes still discriminate against people with mental illnesses by denying them access to needed services for a range of reasons i.e. 1) lack of knowledge about mental illness and how to care for those effected 2) lack of understanding of their needs and the way in which certain conditions affect their ability to care for themselves, i.e. an attitude that a person is lazy when they lack the motivation to clean their home.

(Anonymous, Tasmania, Submission #254)

6.8.8.3.3 Employment

Access to welfare, the supported wage and finding suitable employment are all critical components in the process of social inclusion and living a meaningful life with dignity in the community. However, many concerns were raised regarding difficulties with the current welfare and employment systems and models to support consumers to gain employment and employers to alter their practices:

Governments must find a way to support & foster encouragement *for folk who feel, that discrimination is directed at them because of their age (AGEism) or their addictive personality (alcohol / drugs). Often the bi-products are some form of mental illness. i.e. Depression… We must try to convince Governments that they have no option but to* FUND PROJECTS *and try harder to* ***persuade the system AND employers to change their habits /*** *attitudes. (author's emphasis)*

(Consumer, Tasmania, Submission #165)

This in turn feeds the Bureaucrats' fascination with "Recovery" which, again, sounds very noble but is used to justify withdrawal and denial of service to all those who are unable to assert themselves, thus achieving budget savings within the mutual obligation framework. Clinicians can be trusted to use "Recovery" concepts with fair expectations but anyone who has encountered a bean counter challenging the need for increased support in terms of it restricting a clients right to recovery will know the depths of cynicism that persists.

(Anonymous, Tasmania, Submission #254)

6.8.8.3.4 Lack of support from Centrelink

With limited access to mental health services, supported accommodation and access to early intervention treatment and support, the burden on families and carers to provide long-term and crisis support is immense. This often impacts on the financial income of the family by a reduced ability of carers to work. The shifting of care by governments to carers fails to recognise that carers are providing a significant cost-free service that is not being shouldered by the community. Concerns were raised with regard to the financial hardship experienced by carers due to the lack of services in the community to provide appropriate treatment and support to people with mental illness and/or mental health problems:

This nexus between poverty and serious mental illness extended to the lives of the carers. The task of caring for people with serious mental illness tends to fall heavily on their families, usually parents. This research highlights the high toll taken in terms of their health in addition to their social, emotional and financial wellbeing. The dollar cost of care is no measure of the real price of anxiety and grief expressed by carers, yet it is a significant and largely unmeasured impost on families. This report documents the real cost for carers of providing accommodation, food, clothing and support to people with serious mental illness. This significant cost remains largely hidden, picked up by carers, who, if they are themselves on a low fixed income, may be forced on to income support, emergency relief services, charities, and crisis accommodation services. In addition to the financial impost of caring, carers report a critical lack of support in the form of community-based services, clinical, counselling, information and respite options. In particular they identified the lack of appropriate supported accommodation which denied their adult son or daughter the chance to live a meaningful independent life.

(Anglicare Tasmania, "Thin Ice: Living with Serious Mental Illness and Poverty in Tasmania", Tasmania, Submission #144)

6.8.8.3.5 Whole-of-government approach – tackling poverty and mental illness

As a worker what I see is that poverty and mental health go hand-in-hand.

(Carer, Mother and NGO Service Provider, Tasmania, Hobart Forum #14)

Concern was expressed about the link between poverty and mental illness and the need for a whole-of-government approach to tackle the myriad layers of social, economic and personal disadvantage experienced by this group. The submission by Anglicare Tasmania "*Thin Ice: Living with Serious Mental Illness and Poverty in Tasmania"* outlines some of the issues to be addressed by cross-government approaches:

The research uncovered a disturbing cycle of poverty and ill-health for many people with serious mental illness in Tasmania. Participants reported patterns of unstable housing, food insecurity, with a heavy reliance on emergency relief agencies, inadequate clothing, and regular disconnections from essentials such as telephones and electricity. Access to services such as general practitioners, the public dental service and public transport is made difficult by issues of cost. Without adequate support in the community to manage their accommodation, their finances and the tasks of everyday living, many found the stress of trying to survive alone exacerbated the symptoms of their illness, often resulting in relapse and re-hospitalisation.

(Anglicare Tasmania, "Thin Ice: Living with Serious Mental Illness and Poverty in Tasmania", Tasmania, Submission #144)

Although representing a relatively small proportion of the population, approximately three percent, the social, economic and personal disadvantages experienced by this group are multiple and extreme.

(Anglicare Tasmania, "Thin Ice: Living with Serious Mental Illness and Poverty in Tasmania", Tasmania, Submission #144)

This report confirms that people with serious mental illness are among the most disadvantaged in the community. They face significant difficulties in finding and maintaining stable housing. They are often extremely socially isolated and face multiple barriers to participating in the community. A high proportion of people with serious mental illness are not able to study or find full-time employment and as a result the majority are dependent on government pensions or benefits as their sole source of income. Generally their physical health is much worse than the rest of the community.

(Anglicare Tasmania, "Thin Ice: Living with Serious Mental Illness and Poverty in Tasmania", Tasmania, Submission #144)

A number of emergent factors over the past decade have created a socio-political context that makes life very difficult for many people with serious mental illness. The size of this group is growing at a time of significant cutbacks in real terms in government expenditure to health and community services; there is a national crisis in the availability of affordable housing and the agenda of both mental health reform and welfare reform is pushing towards greater social independence and individual financial autonomy. As a result people with serious mental illness are increasingly reliant on under-resourced carers in the community, either family or non-government support services.

(Anglicare Tasmania, "Thin Ice: Living with Serious Mental Illness and Poverty in Tasmania", Tasmania, Submission #144)

6.8.9 STANDARD 9: SERVICE DEVELOPMENT

The MHS is managed effectively and efficiently to facilitate the delivery of coordinated and integrated services.

Under this Standard, submissions and presentations indicate concerns about:

- the current state of mental health services in Tasmania;
- lack of resources to support community based care following deinstitutionalisation;
- lack of funding;
- lack of staff and the impact this has on staff work practices;
- staff recruitment and retention issues;
- lack of education and training of workforce;
- training programs for GPs;

- lack of consultation with consumers staff and NGO service providers in the planning and delivery of services;
- management and accountability problems; and
- the need for more research.

6.8.9.1 Concerns about the current state of mental health services in Tasmania

The majority of submissions and presentations at forums conveyed feelings of anger that since the Burdekin Report and the closure of institutions and promise of community care, services have been seriously declining and deteriorating rather than any noteworthy improvements to improve service delivery or protect the rights of consumers. The following quotes highlight these problems:

The momentum built around Burdekin but then it fizzled away.

(Consumer, Tasmania, Hobart Forum #21)

I have been a consumer since 1995. I have had some particularly bad experiences. I think the move away from institutional care was a good one but no resources in the community.

(Consumer, Tasmania, Hobart Forum #3)

I've been associated with RD [Royal Derwent] Hospital for 50 years. What I have noticed since 5 years ago is that they have been closing down services.

(NESB & Ageing Worker, Tasmania, Hobart Forum #5)

Funding for mental health is the Cinderella in health and funding for NGO's is the worst of the worst.

(Carer, Tasmania, Hobart Forum #17)

That the government is having a review of mental health services is great but people are falling through the cracks now.

(MP, Tasmania, Hobart Forum #25)

But at present there is no where to send such people should they need a place to stay.

(The Australian Family Association Tasmanian Branch, Tasmania, Submission # 263)

The dream of closing psychiatric institutions and moving towards community based care has turned into a nightmare. Community care is under resourced and integrated services are lacking. Too many people are denied treatment and slip through the gaps.

(ARAFMI Tasmania, Tasmania, Submission #245)

Thin Ice is an examination of the failure of systems to support people with serious mental illness. It outlines how this systems failure ultimately makes people sick and forces them into the costly acute care sector. The conclusion of the report is the urgent need for an increased range and supply of support services in the community to support people and assist recovery.

(Anglicare Tasmania, Tasmania, Submission #144)

Documents obtained through FOI – the State Government's Rehabilitation Plan (dated 29/8/03) – states that "coherent infrastructure and processes to address clinical issues, operational issues and provide transparent systems of entry, exit and follow-up for clients is not there. It is urgent that these issues are addressed."

(Sue Napier, MHA, Liberal Shadow Minister for Health, Tasmania, Submission #261)

The Tasmanian Council of Social Services in its 2004 pre-Budget submission told the State Government that "mental health continues to be the poor relation of health services, with people with a mental health problem often left unsupported and without adequate services".

(Sue Napier, MHA, Liberal Shadow Minister for Health, Tasmania, Submission #261)

6.8.9.2 Lack of resources to support community based care following deinstitutionalisation

The lack of community based services across Tasmania was reported extensively in most submissions and at the community consultation in Hobart. As discussed in more detail later in this report (see particularly Standard 11.4, Treatment and Support), the lack of community based services to deliver treatment and support throughout the course of the illness to prevent a crisis, or to assist with recovery and prevent relapse, was reported across Tasmania.

In particular, the following services were noted as lacking: services in rural and regional areas; child and adolescent services; services for the elderly; and supported accommodation. This would indicate that planning is not occurring 'through a process of consultation with staff, consumers, carers, other appropriate service providers and the defined community' (Standard 9.8) and that resources are not being allocated 'in a manner which follow the consumer and allows the MHS to respond promptly to the changing needs of the defined community' (Standard 9.15). The following comments describe the extent of need and current limited capacity to respond due to lack of resources:

There was never enough funding to support the move from institutions to community based care. Very little funding for ongoing support followed the clients into the community. Mostly their needs were expected to be absorbed by the existing community resources. This placed enormous stress on the community sector in terms of accommodation, support services and Staff. While the policy, undoubtedly, had its merits, some people with mental illness and their families were left unsupported in the community, and without a range of meaningful activities to occupy their time. Some clients preferred the asylum that the old facilities had to offer. With the exit from the hospitals also went much of the State's responsibility to care for those most vulnerable. There is nowhere to go if a safe place is needed for any length of time.

(Anonymous, Tasmania, Submission #254)

Mental health services have been successfully mainstreamed in Tasmania, but the system remains severely under-resourced.

(SANE Australia, National, Submission #302)

The mental health sector understands the pressing need for a comprehensive range of support services in the community. Policies specifically address the benefits of clinical and social support in the community to ensure the wellbeing of people with mental illness. Nonetheless there is no commensurate commitment in funding from governments at either the State or Commonwealth level, and the system of community support fails for the lack of resources. Specifically, the expenditure on mental health services represents only 5.6% of state health expenditure; the Tasmanian Government funded financial administration service for people under guardianship has the highest client costs in Australia; co-payments to the public dental services have recently been increased; funding to carer and community support services is woefully inadequate and proposed changes to the income support system appears set to drive people with serious mental illness further into stress and poverty.

(Anglicare Tasmania, "Thin Ice: Living with Serious Mental Illness and Poverty in Tasmania", Tasmania, Submission #144)

Mrs Napier said as well as increased community-based support, and long-term strategic planning, the State Government's package must include better discharge procedures to ensure that people with mental illness who do present to hospital, and are then released, have support mechanisms in the community to prevent them falling into a situation where they require repeat hospitalisation.

(Media Release, Sue Napier, MHA, Shadow Minister for Health, 13 October 2004, Tasmania, Submission #261)

'Projectitis' funding is rampant now, one year's funding for a new project that is then expected to self sustain for the future but no Gov Dept wants to fund ongoing new services to meet rising need.

(ARAFMI Hobart, Tasmania, Submission #214)

6.8.9.3 Lack of funding

Concern was expressed that insufficient funding had been allocated to mental health within the overall health budget to meet the needs of people with mental illness and that their needs will continue to be neglected in comparison people with physical illness while this deficit continues. Concern was also expressed that continual budget cuts and lack of funding to community based care had further reduced the quality of mental health services. This indicates the level and model of funding needs to change in order that appropriate services are delivered and the rights of people with mental illness are protected. These concerns suggest resources were not being allocated to reflect national mental health policies (Standard 9.14) or in manner which allows the MHS to respond promptly to the changing needs of the defined community (Standard 9.15). The lack of funding was cited as a concern for both government services and services provided by non-government organisations:

Deinstitutionalisation has not failed. What has failed is the political will to fund essential support services in the community. The existing services are overwhelmed by the heavy demand they currently face and they are not able to provide the level of care and support required to assist recovery. This lack of support options dramatically increases the hardships faced by people who have a mental illness and their families, in terms of their health and their budgets. Ultimately, it is a failure of systems which is making people sick and forcing them into the costly acute care sector.

(Anglicare Tasmania, "Thin Ice: Living with Serious Mental Illness and Poverty in Tasmania", Tasmania, Submission #144)

Neglect of the mentally ill will continue until Mental Health is seen as a legitimate component of public health. It is vital that Mental Health not remain the poor relation attracting less than 7% of the health budget. Implementing mental health reform is an investment not an expense.

(ARAFMI Tasmania, Tasmania, Submission #245)

The ability of Mental Health Services to deliver quality care has been severely restricted by continual budget cuts and the lack of funding to community services.

(Anonymous, Tasmania, Submission #254)

The Mental Health Council of Tasmania has called for the State Government to increase its funding on mental health services to represent 12% of the total health budget within the next five years. The Council has said "there are no savings to be obtained from neglecting this issue, only a transfer of the burden to other health, correctional justice and community service systems".

(Sue Napier, MHA, Liberal Shadow Minister for Health, Tasmania, Submission #261)

A colleague is running 7 groups. Participation growing at a rate of knots – there's an increase in demand but no increase in funding. I'm a group facilitator, PR, receptionist. State Government funding is about $53,000 per year.

(NGO Service Provider, Tasmania, Hobart Forum #19)

Both government and private sector services are finding themselves having to band-aid the gaps in services, which takes them away from their core business.

(Anonymous, Tasmania, Submission #254)

Documents obtained through Freedom of Information show Departmental reports and plans dating back to 2001, which clearly spell out the service gaps, yet despite this, no meaningful increase in funding in corresponding budgetary years occurred.

(Sue Napier, MHA, Liberal Shadow Minister for Health, Tasmania, Submission #261)

While the mental health budget increased by $1.9 million to $63.8 million in 2004-05, this still represents less than 6% of State health expenditure, and services suffer accordingly. (Tasmanians concerned about services contrasted this increase with grants of $26.5 million to prop up the horseracing industry.)

(SANE Australia, National, Submission #302)

Community services provided by non-government organisations are poorly funded, leading to a shortage of supported accommodation, rehabilitation, and support for carers.

(SANE Australia, National, Submission #302)

6.8.9.4 Lack of staff and the impact this has on staff work practices

As mentioned previously concern was expressed about insufficient staff numbers and resources to ensure the delivery of quality treatment and integrated and coordinated support to consumers and their carers. Feelings of burnout were reported as a result of staff shortage, and as also mentioned earlier in this Report (Standard 2 - Safety). Lack of staff also raises safety concerns for consumers and staff. High caseloads and decreased opportunities were also mentioned as areas of concern:

There is not only a need for bricks and mortar but more importantly there is the need for staff - not necessarily as stated earlier - staff trained to a high professional level but the staff must be able to offer twenty-four hours a day seven days a week supervision.

(The Australian Family Association Tasmanian Branch, Tasmania, Submission # 263)

Additional staffing has been made available for CAT (Crisis and Treatment) Teams which are now available in the north as well as the south of the Island, although not around-the-clock in all locations.

(SANE Australia, National, Submission #302)

There is a shortage of psychiatrists.

(Anonymous, Tasmania, Submission #254)

Day workers are currently not replaced, unless they are absent for three or more weeks. This puts further pressure on teams and creates an inability to deliver quality service. It also results in "burnout" for Staff having to increase their workload and difficulties getting relief Staff.

(Anonymous, Tasmania, Submission #254)

Staff do not have opportunities for supervision and debriefing, due to the workload.

(Anonymous, Tasmania, Submission #254)

More "outreach" workers have been employed but their case loads are beyond what can reasonably be coped with then several of their clients are experiencing severe bouts of illness. At present, such clients deteriorate to the extent that they then need acute care in a hospital setting. Earlier intervention in a respite situation with access to professional care plus supervision by staff, familiar with their needs but not necessarily fully trained professionals would be quite appropriate and less costly.

(The Australian Family Association Tasmanian Branch, Tasmania, Submission # 263)

High case loads for community Mental Health teams for example Gavitt House, Bellerive Centre. Clients in the past state that they get to spend very little time with their case worker.

(Colony 47, Tasmania, Submission #227)

6.8.9.5 Staff recruitment and retention issues

Concerns were expressed with regard to the ability of under-resourced services to retain current staff and successfully recruit new and experienced staff:

I don't think the acute services people should be blamed. We are losing the staff we have. Ward 1 is a huge problem.

(MP, Tasmania, Hobart Forum #25)

There is a crisis in attracting all disciplines to work in Mental Health due to lack of support / training and poor working conditions and a lack of attractive career paths.

(Anonymous, Tasmania, Submission #254)

Filling of positions here also seems to take an incredibly long time, with one currently outstanding for over a year.

(Carer, Mother, Tasmania, Submission #315)

Can't attract psychiatrists to North West, though can get one from ethnic background but difficult for our consumers to understand.

(NGO Worker, Tasmania, Hobart Forum #18)

The retention and recruitment of workers in mental health is also a problem. One former employee wrote to us: "I left the Mental Health in September 2003 (in the North-West), my old position was advertised only last week (April 2004). It will take 12 weeks to complete the recruitment cycle, if it runs smoothly. 11 months to fill a vacancy – a critical front line position"…

(Sue Napier, MHA, Liberal Shadow Minister for Health, Tasmania, Submission #261)

6.8.9.6 Lack of education and training of workforce

Concern was expressed that due to staff shortages, services are often unable to release staff to attend training or professional development based on identified needs (Standard 9.17) or funding is not available to pay for training or replacement staff:

While Mental Health policies promote the need for furthering the skill level of Staff the reality is that they are often unable to attend such training due to: (1) the lack of funding to do so or (2) the lack of replacement Staff in the agency.

(Anonymous, Tasmania, Submission #254)

6.8.9.7 Training programs for GPs

With regards to mental health training for general practitioners, one general practitioner noted concerns with the lack of committed funding to ensure the continued delivery of such programs. It was suggested that the 'stop-start approach' had the potential to jeopardise completion of such programs and impede the delivery of improved treatment and support by general practitioners to consumers and their carers in the community:

I am writing as a mental health education provider. The mental health program in the North West Tasmania Division of General Practice has been very active with good GP participation. Unfortunately at this time of year, while giving lip service to funding for mental health programs, neither the State Govt or Federal Govt have said what the funding will be for the forthcoming 12 months. As a result, the programs have largely ground to a halt. This stop-start approach is not helpful to the community as a whole, to the GPs or to the program managers and educators attempting to deliver on-going education to the GPs. This is disappointing, as the mental health programs in NW Tasmania have been some of the most successful and well-attended by GPs in Australia. I feel that while the spirit of government is willing (I applaud that), the practicalities are weak.

(General Practitioner, Tasmania, Submission #111)

The Federal government has already commenced some good moves in addressing the mental health problems e.g. the training of GPs in becoming more expert in handling patients so afflicted.

(The Australian Family Association Tasmanian Branch, Tasmania, Submission # 263)

6.8.9.8 Lack of consultation with consumers, staff and NGO service providers in the planning and delivery of services

Concern was expressed that consumers, staff and NGO service providers are not being consulted about key changes to service delivery. As a result staff confidence in management and morale has plummeted. For NGO service providers, associated with concerns about an inability to contribute in a positive manner to service improvement, were concerns about speaking up and consequent withdrawal of funding. Standard 9.8 states: 'The strategic plan is developed and reviewed through a process of consultation with staff, consumers, carers, other appropriate service providers and the defined community'. However, as the following quotes from one extensive submission highlight, this was not occurring at some services:

As funding decreases, NGO services have been reluctant to speak up about the current crisis and their lack of resources due to the fear of having what little funding they have cut even further.

(Anonymous, Tasmania, Submission #254)

During the last four years there has been a lack of acknowledgement and even denial of the developing crisis in Mental Health. Staff and consumers have continually warned of the consequences of some of Managements decisions. Some of the major issues the Mental Health Services were warned about prior to the redevelopment of Royal Derwent Hospital were: - (1) The underestimation of the number of beds needed in the new development (2) The configuration and locations of some of the new establishments were in some cases not appropriate for the needs of the proposed client groups (3) There were too few inpatient beds to provide for the needs of the existing client group much less any increased need. (4) There was no extra provision made for support services for clients who moved back into the community in terms of ADL support or supported accommodation.

(Anonymous, Tasmania, Submission #254)

Staff confidence in senior management involved in the redevelopment is at an all time low due to their refusal to listen to grass roots workers, consumers and carers. Front line continue to be pressured to provide more with less, services are fragmented, Staff are burning out, and positions are vacant for long periods due to the appalling pressure and conditions.

(Anonymous, Tasmania, Submission #254)

Some Mental Health Services Managers in Tasmania have reframed any attempt to change the system as "misinformed" or "nefarious". Consumers, carers, Staff and concerned members of the community have therefore been forced to take to the streets to have their voices heard.

(Anonymous, Tasmania, Submission #254)

There is a perception and fear that funding will be threatened if an individual or organisation speaks out. Many NGO volunteers make enormous contributions with a pittance of funding from Mental Health volunteers.

(Anonymous, Tasmania, Submission #254)

6.8.9.9 Management and accountability problems

Failure to ensure accountability jeopardises protection of rights of people with mental illness and delivery of quality care. Concern was expressed regarding the lack of accountability and the lack of resources to implement policies (Standard 9.2). Problems with accountability also impedes the resolution of complaints and inhibits processes which allow for continuous quality improvement to ensure the best outcomes for consumers, carers and the community as indicated by the following comments:

At the same time the constant struggle to achieve best practice has been fraught with difficulties against a backdrop of increased accountability and devolution of administrative duties to clinical Staff. We have wonderful policies but no resources to implement them.

(Anonymous, Tasmania, Submission #254)

For the Mental Health system in Tasmania to improve the system has to change. Those who wield the power need to take responsibility for their decisions and the outcomes of those decisions. They need to stop trying to silence those who complain and to engage in open and honest dialogue and shared projects identified by those who have an interest in developing them.

(Anonymous, Tasmania, Submission #254)

Our Political leaders may have achieved fine ends in terms of our economy but they have been ruthless in the cost that they have been willing to impose on others esp. the mentally ill, to achieve this. Their actions have been ably supported by the senior management in Mental Health who have been negligent in their advocacy for the people they have been charged to care for. It is interesting to note how many of those individuals have been successfully promoted for their efforts.

(Anonymous, Tasmania, Submission #254)

6.8.9.10 More research needed

Concern was expressed at the Hobart Forum that more funding needs to be allocated to research (Standard 9.31) to determine the rise in mental illness in the community (Standard 9.30):

I am appalled at the increase in mental illness in the community but there seems to be a real lack of research in this area.

(Carer, Mother, Tasmania, Hobart Forum #4)

We are also informed that "there seems to be no knowledge of the extent of mental illness in Tasmania, nor the level of unmet need. Records are kept, but only at the ground level and generally not collated."

(Sue Napier, MHA, Liberal Shadow Minister for Health, Tasmania, Submission #261)

6.8.10 STANDARD 10: DOCUMENTATION

Clinical activities and service development activities are documented to assist in the delivery of care and in the management of services.

Under this Standard, submissions and presentations indicate concerns about:

- the data collected to assist in the delivery of care and management of services.

6.8.10.1 Problems with the data collected and its usefulness in the delivery of care and management of services

Concern was expressed about current data collection methods and tools used. Specifically, concern was raised about the extent to which the data provides valuable information to guide the appropriate delivery of care to consumers or the identification of systemic issues to assist with decisions to improve service delivery. Concern was also raised about lack of action when systemic issues have been identified:

> *There has been a failure to address issues identified by current Mental Health reporting. There has been no commitment to instigate long-term change when gaps have been identified. Lots of ideas – very little action.*
>
> (Anonymous, Tasmania, Submission #254)

> *Management Key Performance Indicators (KPIs) are disconnected from what clients identify as their needs. For example, management regard the rate of people that are discharged from a service 'throughput' as a significant KPI. However, this notion not only does not reflect client feedback about what they consider to be a measure of success but actually creates fear in some clients. Anyway, what does throughput tell you about client satisfaction or if their needs were actually met? This type of KPI encourages the revolving door syndrome. Opposition to these mindless directions have led to derogatory comments i.e. "creating dependence," Instead, clients have identified that the time they spend well (i.e. out of hospital) is a more appropriate KPI. The pressure on inpatient beds forces hospital Staff to discharge clients early, often before they are well enough. This practice puts clients at risk and increases the pressure on the overstretched community resources.*
>
> (Anonymous, Tasmania, Submission #254)

> *There is an obvious lack of consultation between management and clients or those who advocate for clients. What happened to the client-focused approach? There is no reliable data collection program as yet, despite the time spent by clinicians collecting information. Decisions appear to be made based on economic rather than clinical reasons.*
>
> (Anonymous, Tasmania, Submission #254)

6.8.11 STANDARD 11: DELIVERY OF CARE

Principles guiding the delivery of care: The care, treatment and support delivered by the mental health service is guided by: choice; social, cultural and developmental context; continuous and coordinated care; comprehensive care; individual care; least restriction.

Under this global Standard outlining the principles underlying care, one consumer spoke of the fragility of the 'whole package of treatment and support' needed to promote and protect the rights of people with mental illness to participate socially and economically in the community. This consumer outlined the marked improvements in her life since the Burdekin Report and deinstitutionalisation through community based treatment, and access to educational programs and employment, and the threat to this posed by changes to her treatment choices:

> *I'm a person with a severe mental illness and I appeared before the Burdekin Inquiry many years ago. Following the inquiry I got an education and part-time employment. About a year ago there was a very strong rumour that I cannot legally be prescribed certain drugs. It seems to me that if deinstitutionalisation is to work then medications need to work.*
>
> (Consumer, Tasmania, Hobart Forum #8)

6.8.11.1 Access

The MHS is accessible to the defined community.

Under this Standard, submissions and presentations indicate concerns about:

- inability to access services during a crisis;
- lack of access to treatment resulting in entry into the criminal justice system;
- lack of access to treatment and support for people diagnosed with personality disorders; and,
- lack of access to psychologists for those who cannot afford to purchase care in the private sector.

Problems with access to treatment and support services, both within the community and inpatient care, resulted in a whole series of rights being infringed for consumers, carers and the community. Consumers reported that as a result of these infringements, a range of consequences occurred, such as increasing disability and hence consequent inability to care for oneself or others, barriers to participating socially or work or study, in some cases, the potential for harm to self or others, incarceration, and becoming homeless and poor.

Similarly, increased burdens on carers disrupted their ability to participate socially and work when their family member became increasingly ill and required increasing care. When unable to access care for their family member, the mental health of carers also suffered. Increasing disability also exposed the consumer and their family to discrimination and social exclusion. This often resulted in the further deterioration of the consumers' mental illness. For consumers in rural and smaller regional areas, their inability to access care often required long trips to metropolitan or large regional centres and social dislocation if hospitalisation was also required.

6.8.11.1.1 Inability to access services during a crisis

A constant theme throughout many submissions was not only an inability to access services when needed throughout the course of illness, but that access was also difficult when consumers were experiencing a crisis or at risk of self harm or harm to others. This stands in contrast to Standards 11.1.2 ('the community to be served is defined, its needs regularly identified and services are planned and delivered to meet those needs') and 11.1.4 ('the MHS is available on a 24 hour basis, 7 days per week'). Lengthy delays in emergency departments were experienced with inappropriate treatment and support being given or organised:

When unwell we travel to Burnie for hospital treatment. Here the problems are similar with lack of doctors as well as number of available beds being critical issues. The admittance to hospital for mental cases also badly needs reviewing. Currently, even though previous episodes are well documented, distraught and in crisis patients (and family members) must wait in the emergency department to see a resident doctor before admission. This frequently takes hours.

(Carer, Mother, Tasmania, Submission #315)

One pressing issue applies to people in the acute system don't have the resources or capacity to deal with the people who need care, who have been referred by CAT teams.

(MP, Tasmania, Hobart Forum #25)

Shadow Health Minister Sue Napier said the number of people with mental illnesses presenting to hospital emergency departments was a tragic demonstration of how badly existing services were failing the community.

(Media Release, Sue Napier, MHA, Shadow Minister for Health, 13 October 2004, Tasmania, Submission #261)

Figures contained in response to a Question on Notice placed by the State Liberals reveal that only half of the 2642 people presenting to Emergency Departments were admitted in the first nine months of the 2003 / 04 financial year.

(Media Release, Sue Napier, MHA, Shadow Minister for Health, 13 October 2004, Tasmania, Submission #261)

The inadequate resourcing of the non-government sector – and the fantastic people who work in the area - can be summed up by these comments (letters to the Liberals in 2004):

> *"I spent the early part of yesterday evening providing crisis counselling to a man contemplating killing himself. The man had been referred to (a non-Government agency) by another professional because they could not get an appointment for him at Mental Health Services in the North-West and did not know what to do. I could have said we were closed, not funded to provide this service or referred him on. Instead I listened to him and his despair and helped him tease out his options. In my own time…"*
>
> (Sue Napier, MHA, Liberal Shadow Minister for Health, Tasmania, Submission #261)

The State Liberals have heard from many consumers, families and mental health workers / supporters about the revolving door of hospitalisation for many with a mental illness in the State. One worker in the non-government sector put it like this:

> *"What happens is this: because mental illness is episodic in nature, when a person with a mental illness has an episode, police are called to escort that person down to the local emergency sector of the hospital. Because of bed shortages, people are often not admitted and police spend several hours waiting with them in Emergency waiting rooms. Then comes the issue of finding them a bed for the night. Often they cannot go back to their own homes (if they're lucky enough to have them) so the police do the ring-around of emergency crisis accommodation and if there's nothing to be found (which is often the case) they go into a hotel for the night using State Government brokerage funding. Quite often the police are called back to the hotel again during the night. Police effectively have become mental health babysitters".*
>
> (Sue Napier, MHA, Liberal Shadow Minister for Health, Tasmania, Submission #261)

6.8.11.1.2 Lack of access to treatment resulting in entry into the criminal justice system

ARAFMI Tasmania expressed concern regarding the increasing number of people with mental illness ending up in the criminal justice system due to the inability of mental health services to respond to people needing to access treatment and support services. Submissions and presentations pointed to an inability to access services when needed, which in some instances resulted in consumers entering the criminal justice system because of their deteriorating and untreated mental illness. The failure of services to respond and intervene in these instances has had the regrettable outcome of consumers being incarcerated because of the consequences of their untreated illness and the right to safety of the community being infringed and, in extreme cases, homicide:

> *As psychiatric services struggle to respond to the needs of the mentally ill the criminal justice system becomes a substitute. Prisons are now accommodation for more mentally ill people. How many will remain incorrectly diagnosed and return to the community without psychiatric treatment? Adolescents detained in Ashley detention centre present with mental health issues. The criminal justice system is a bleak future for their young lives.*
>
> (ARAFMI Tasmania, Tasmania, Submission #245)

6.8.11.1.3 Lack of access to treatment and support for people diagnosed with personality disorders

One consumer expressed concern regarding the difficulties faced by people with Borderline Personality Disorder when seeking treatment and their pleas for help have been ignored:

> *I suffer from Borderline Personality Disorder - real lack of access to treatment and my pleas for help have been ignored.*
>
> (Consumer, Tasmania, Hobart Forum #3)

6.8.11.1.4 Equity – lack of access to psychologists for those who cannot afford to purchase care in the private sector

While access to mental health services is assumed regardless of socio-economic status (Standard 11.1.1), ARAFMI Tasmania expressed concern that access to psychologists is not routinely an option for consumers living in Tasmania. If consumers required access to psychologists, these services were only available in the private sector, and scarce. This would prohibit people who could not afford to pay for such services in receiving the treatment they require. ARAFMI Tasmania described this situation as 'immoral':

> *The Burdekin report stated that "restriction to access to psychologists results in important treatment options being denied to many individuals affected by mental illness and that the lack of access is incompatible with human rights and is economically unsound". It seems immoral that in 2004 clinical psychologists are not routinely available to people suffering mental disorders.*
>
> (ARAFMI Tasmania, Tasmania, Submission #245)

6.8.11.2 Entry

The process of entry to the MHS meets the needs of the defined community and facilitates timely and ongoing assessment.

Under this Standard, submissions and presentations indicate concerns about:

- the long wait times with entry via emergency departments and the lack of appropriately qualified mental health professionals.

6.8.11.2.1 Long wait times with entry via emergency departments and lack of appropriately qualified mental health professionals

Standard 11.2.4 states: 'The entry process to the MHS can be undertaken in a variety of ways which are sensitive to the needs of the consumer, their carers and the defined community'. Concerns were expressed about entry via hospital emergency departments including problems with the assessment process and consumers having to repeat their stories many times even though their history is documented with the service. Notes to this Standard state that this process should be non-traumatic and non-damaging. Concern was also expressed that often appropriately qualified mental health professionals are not available, in contravention of Standard 11.2.6:

> *For an emergency you'd go to the hospital at Burnie and sit there for however long it takes. You've always got to go through casualty before you get into the service – even though he has a long history of mental illness. Then he sees a registrar who knows nothing about mental illness.*
>
> (Carer, Mother, Tasmania, Hobart Forum #15)

6.8.11.3 Assessment and review

Consumers and their carers receive a comprehensive, timely and accurate assessment and a regular review of progress.

Under this Standard, submissions and presentations indicate concerns about:

- assessment problems for children and youth under the age of 18; and
- large staff caseloads.

6.8.11.3.1 Assessment problems for children and youth under the age of 18 with mental illness and/or mental health problems

Concern was expressed regarding the difficulty in obtaining proper assessments for children and youth under the age of 18. This could be due to the lack of child and adolescent services (Standards 11.3.1 and 11.4.3) and appropriate methods and tools not being available to assess this age group (Standard 11.3.6):

> *[T]he inability to get proper assessments for children under the age of 18.*
>
> (MP, Tasmania, Hobart Forum #25)

6.8.11.3.2 Large staff caseloads

As mentioned previously (Standard 9: Service Development) many submissions acknowledged that the failure to deliver quality treatment and support services was not the fault of individual staff but more related to broader systemic issues such as large caseloads, management of work and overall lack of resources that restricted the ability of clinicians to deliver timely and accessible quality care. The following quote indicates that services may not be routinely 'monitoring of staff case loads in terms of number and mix of cases, frequency of contact and outcomes of care' (Standard 11.3.19):

> *Case managers carry large caseloads and I understand that these can be in excess of 70/80 with some even over 100 clients. The majority of the focus is crisis centred which leaves very little time for the other much-needed issues.*
>
> (Carer, Mother, Tasmania, Submission #315)

6.8.11.4 Treatment and support

The defined community has access to a range of high quality mental health treatment and support services.

> *The thing that concerns me most is that moral judgements are made about our illness and used to exclude us from treatments, yet we are told that our illnesses are like diabetes but no one with diabetes is told to just convince themselves to fix their insulin levels.*
>
> (Consumer, Tasmania, Hobart Forum #21)

Under this Standard, submissions and presentations indicate concerns about:

- lack of treatment and support services only available when in a crisis;
- lack of services for people living in rural and regional areas;
- lack of services for children and youth;
- lack of services for people with dual diagnosis – mental illness and drug and alcohol;
- difficulties for consumers from a non-English speaking background (NESB);
- lack of services for people diagnosed with personality disorders;
- lack of treatment and support services for consumers who are homeless; and
- lack of forensic care in separate facilities.

6.8.11.4.1 Lack of treatment and support services only available when in crisis

Many consumers and carers expressed feelings of frustration at being unable to access any treatment or support services from the MHS in metropolitan, rural and regional areas. This included the whole spectrum of interventions throughout the course of illness and recovery regardless of age and stage of development (Standard 11.4.3), stage in the recovery process (Standard 11.4.4), presence of diagnosis (Standard 11.4.7) and which address 'the physical, social, cultural, emotional, spiritual, gender and lifestyle aspects of the consumer' (Standard 11.4.6).

Reports that services were not available until the consumer's health had deteriorated to the point requiring hospitalisation need to be considered in light of reports that access was often not possible even when the consumer had reached crisis point (Standard 11.4.10). Concern was expressed that this pattern of service delivery led to consumers continuously being readmitted to hospital with no long-term structured support to assist with recovery and prevention:

> *The Mental Health Act fails to deal with community treatment and only really provides for acute intervention. The client has to fall over completely before they are eligible for help, that is, the Act does not help unless that client is in crisis.*
>
> (Anonymous, Tasmania, Submission #254)

> *Staff also describe a "Revolving Door Syndrome" where only short-term crises are dealt with and long-term structured support for clients is not obtainable.*
>
> (Anonymous, Tasmania, Submission #254)

> *Mrs Napier said the lack of support services in the community for people with mental illness created a shocking merry-go-round. "The lack of support services in the community means people's health deteriorates to such an extent that they then require emergency hospital treatment," Mrs Napier said.*
>
> (Media Release, Sue Napier, MHA, Shadow Minister for Health, 13 October 2004, Tasmania, Submission #261)

6.8.11.4.2 Lack of services for people living in rural and regional areas

Standard 11.1.5 states: 'The MHS ensures effective equitable access to services for each person in the defined community'. Concerns were expressed regarding problems with access to services in rural and regional areas. For people living in many areas of Tasmania there were no services which were convenient and local. Reports also indicated a lack of accommodation options in these areas and a lack of rehabilitation services and recreational and vocational programs. Delivery of care for many consumers effectively meant delivery of inpatient care some distance away and being isolated from social and support networks during this period:

> *There is a lack of community outreach to rural areas and for specific programs such as child and adolescent, forensic. The focus is on inpatient care rather than community support*
>
> (Anonymous, Tasmania, Submission #254)

> *People in rural and isolated areas have very little access to services due to the shortage of appropriately trained Staff allocated to rural teams*
>
> (Anonymous, Tasmania, Submission #254)

> *My son (33) has severe schizophrenia. We are from the North West Coast and we have a real lack of services, accommodation. There is nowhere that my son can go apart from home. There is a lack of rehab and recreational services. I see people going into hospital and then coming out but no support in community so they end up back in hospital. There is nothing for him to do to keep him occupied.*
>
> (Carer, Mother, Tasmania, Hobart Forum #15)

Documents obtained through FOI show that the State Government had been aware for some time of "lack of services for the rural population". Reports state that "for rural consumers, there is no access to MHS rehabilitation outside of Launceston and Hobart" and "inconsistency with access and equity to rehabilitation services between the north and south rehabilitation services", there was "no access to rehabilitation e.g. Midlands area, Burnie and West Coast. In the south, the East Coast, Huon and Oatlands has no rehabilitation MHS local services. There are insufficient resources for the provision of a specialist rehabilitation team to work outside of the Launceston region" and "most access to MHS rehabilitation is very limited or non-existent outside of urban areas".

(Sue Napier, MHA, Liberal Shadow Minister for Health, Tasmania, Submission #261)

Documents obtained through FOI point to a consumer survey conducted in 2002 which indicated that 29% of respondents said that having to travel a long distance in order to access rehabilitation services was a barrier for them (Project Management Plan v. 1.4 dated 20 September 2002 regarding rehabilitation planning for 2002).

(Sue Napier, MHA, Liberal Shadow Minister for Health, Tasmania, Submission #261)

6.8.11.4.3 Lack of services for children and youth

Standard 11.4.3 ensures access to a 'comprehensive range of treatment and support services which are, wherever possible, specialised in regard to a person's age and stage of development'. Carers expressed concern at the paucity of services for children and youth and indicated that adult services were inappropriate to fill the gap. In particular, concern was expressed that services for children and youth need to be broader in their approach than treatment just for 'mental illness' as other mental health problems and life crises were generally associated with this age group:

Parents have difficulty accessing limited child psychiatrists and psychologists for their disturbed youngsters. Adult facilities are inappropriate, overburdened and inaccessible. Early intervention and accurate diagnosis, stressed as priorities in the National Mental Health Plan 2003 – 2008, remain as rhetoric instead of reality.

(ARAFMI Tasmania, Tasmania, Submission #245)

I have 2 teenagers who self-harm. It's very hard to understand and hard to get care. When we have sought care the service providers say 'they don't want help, bring them back when they want help'. Why are so many girls self-harming and having eating disorders?

(Carer, Mother and NGO Service Provider, Tasmania, Hobart Forum #14)

Young people with mental health and substance use issues have no specific programs/facilities for early intervention or long-term recovery. This group have no appropriate accommodation options in the community.

(Anonymous, Tasmania, Submission #254)

Inpatient facilities for young people are nonexistent and they are placed in the general children's ward or in adult facilities.

(Anonymous, Tasmania, Submission #254)

6.8.11.4.4 Lack of services for people with dual diagnosis – mental illness and drug and alcohol

Standard 11.4.7 states: 'The MHS ensures access to a comprehensive range of services which are, wherever possible, specialised in regard to dual diagnosis'. Concern was expressed that there were an insufficient number of such services to provide treatment and support either directly or in dual management with alcohol and other drug services to these consumers with complex needs. As the following quotes highlight these consumers continuously 'fall between the gaps':

> *There are no services that deal specifically with mental illness and drug and alcohol problems, or abuse and emotional control issues. These groups are put into the "too hard" basket and fall through the cracks in service provision. People with these issues have specific needs and thus require a separate service with specialist Staff.*
>
> (Anonymous, Tasmania, Submission #254)

> *Young people with mental health and substance use issues have no specific programs / facilities for early intervention or long-term recovery. This group have no appropriate accommodation options in the community*
>
> (Anonymous, Tasmania, Submission #254)

> *People with co-existing mental health / drug and alcohol also fall between the gaps. Mental health services in the past state that they are unable to work with these people and often referrals are made to Alcohol and Drug services. The reverse can occur from A&D services.*
>
> (Colony 47, Tasmania, Submission #227)

> *Services are lacking to help consumers, of all ages, with combined drug addiction and mental illness. Drug and alcohol services and psychiatric services still work in isolation. This causes additional trauma to the sick person and families.*
>
> (ARAFMI Tasmania, Tasmania, Submission #245)

> *The State has a particular need for specialised services, for people with a dual diagnosis of mental illness and a drug or alcohol problem, for example. Frequent liaison problems between drug and alcohol services and mental health services were reported in Tasmania.*
>
> (SANE Australia, National, Submission #302)

6.8.11.4.5 Difficulties for consumers from a non-English speaking background (NESB) in accessing treatment and support

Concerns were expressed that consumers from a NESB are experiencing difficulties in accessing appropriate treatment and support services and that due to language and cultural barriers, these consumers are 'isolated in their houses' (Standard 11.4.8):

> *People are isolated in their houses and no one is coming to their homes. They can't express themselves and everyone is in a hurry.*
>
> (NESB & Ageing Worker, Tasmania, Hobart Forum #5)

6.8.11.4.6 Lack of services for people diagnosed with personality disorders

Concerns were raised about the lack of treatment and support services for people with personality disorder and that problems associated with the disorder are not being recognised or acknowledged by some clinicians and services. The carer reported that treatment programs are available in other states but not in Tasmania, and that lobbying for these has not resulted in these therapies being made available. The devastating consequences of services failing to provide adequate treatment and support for people with Borderline Personality Disorders was recounted by one consumer:

> *My early release from PCU [Psychiatric Intensive Care Unit] led to my current disfigurement [extensive burns and scarring]. I was positively excluded from care because I self harm a lot. They said it wasn't a positive thing for me to be there and I wasn't interviewed about my own safely so I went home and poured metho over myself and that's a much greater cost to the health system.*
>
> (Consumer, Tasmania, Hobart Forum #3)

> *People who have a personality disorder are rarely treated by mental health services due to this condition not being identified as a mental illness. People with a personality disorder/s often fall between service delivery gaps and due to their behaviour, at times their housing and mental health / well being needs are not met.*
>
> (Colony 47, Tasmania, Submission #227)

> *Programs in Sydney more helpful than here. I've been to the Minister here and others asking for different therapies but they're not available.*
>
> (Carer, Mother, Tasmania, Hobart Forum #4)

6.8.11.4.7 Lack of treatment and support services for consumers who are homeless

Standard 11.4.6 states: 'The MHS ensure access to a comprehensive range of treatment and support services which address physical, social, cultural, emotional, spiritual, gender and lifestyle aspects of the consumer'. Concerns were expressed regarding the lack of treatment and support services for consumers who are homeless. The increasing number of people who are homeless and who have a mental illness and/or mental health problems has also risen with deinstitutionalisation and the subsequent lack of community based treatment and support services to meet the community's needs.

One mother described her frustration at trying to organise support for her son who had become homeless. She was horrified at the response she had been given by mental health services and Centrelink when they said to her: 'how do you know he needs help if you don't live with him?'. Problems regarding the lack of supported accommodation and services to provide structured support and follow-up to this group were identified as follows:

> *Clients who most often "fall through the gaps". People who are: Homeless; Take prescribed medication.*
>
> (Colony 47, Tasmania, Submission #227)

My son was contacted by a social worker who found him in Devonport. He wouldn't speak to anyone in the family, he was completely isolated. The Caravan Park kicked him out and he ended up in a tent in the bush, then moved on by the police. Many years later I was informed that my son's pension was cut off because he hadn't returned his forms. My husband passed away and left him some money so I sent him the cheque, but he didn't cash it. When I contacted Centrelink again I pleaded with them to go and see him. He was scared of meeting people. He snuck out at closing time to get his groceries. Centrelink and the mental health service couldn't do anything for him. They said to me 'how do you know he needs help if you don't live with him?' At Easter the shop keeper noticed my son hadn't been in the shop for a number of days so he called the hospital and they went out and found my son who couldn't get out of bed with leg ulcers, dehydration. He was very ill and was taken to hospital. I saw him twice in the hospital but I didn't recognise him as the son I knew.

(Carer, Mother, Tasmania, Hobart Forum #16)

The issues some of these people may face

- *Unable to access medication due to homelessness or take erratically*
- *Vulnerable and stressed*
- *No structured support*
- *Limited or no accommodation options to match needs.*

(Colony 47, Tasmania, Submission #227)

Hobart has few places where the homeless can shower or wash their clothes if they don't have any money or have been banned from the few places that provide this type of service.

(Anonymous, Tasmania, Submission #254)

6.8.11.4.8 Lack of forensic care in separate facilities

Standard 11.4.7 states: 'The MHS ensures access to a comprehensive range of treatment and support services which are, wherever possible, specialised in regard to…consumers who are subject to the criminal justice system'. Concern was expressed regarding the lack of separate facilities to provide treatment and support to people with mental illness or mental health problems who have become subject to the criminal justice system. In the absence of separate forensic facilities housing of these consumers with the general prison population was described as an inappropriate environment in which to receive treatment and support:

People who have been found guilty of crimes by reason of insanity are still being housed in prisons because there is no secure facility to treat them.

(Anonymous, Tasmania, Submission #254)

It should have been good news that Tasmania has started work a new forensic hospital, but this is now being built within the Risdon Vale prison grounds. As in NSW, this co-location sends a clear message to the community that the patients are effectively 'prison inmates' with all that that implies about culpability and punishment – regardless of which Department actually administers the Secure Mental Health Unit when it opens in 2005.

(SANE Australia, National, Submission #302)

6.8.11.4.A Community living

The MHS provides consumers with access to a range of treatment and support programs which maximise the consumer's quality of community living.

Under this Standard, submissions and presentations indicate concerns about:

- lack of treatment and support services to maximise consumer's quality of living in the community;
- lack of access to family centred approaches;
- lack of support for children of parents with mental illness;
- lack of vocational programs and employment opportunities; and,
- lack of recreational, social and rehabilitation programs.

6.8.11.4.A.1 Lack of treatment and support services to maximise consumer's quality of living in the community

The aim of deinstitutionalisation was to provide treatment and support in the least restrictive setting, which for most people means living in the community. However, as described above (Standard 11.4 – Treatment and Support), concerns have been expressed that the necessary treatment and support services and effective systems have not materialised. This is true for both people with serious mental illness living in the community and people who, as a consequence of failure to access treatment and support services at the onset of illness, develop significant disability and require additional community support services to live independently or with their family. The reality being experienced by consumers and carers after being discharged from acute care is revealed by the following account by a carer:

> *The thing I found is that once he walked out the door of the MHS no one cared about him or what happened to him… He got very depressed, very ill and became very violent. He broke someone's arm and was arrested and taken to the hospital. They said he was okay and released him with no shoes, no where to go and blood all over him. I spoke to the Dr and [X] died 10 days later – he jumped. There are so many suiciding. Nobody to help me. I should have had more help, I couldn't do it…Everybody like that needs someone to care for them.*
>
> (Carer, Tasmania, Hobart Forum #22)

> *The overwhelming conclusion from this research is the urgent need for an increased range and supply of support services to assist people with serious mental illness and their families to live successfully in the community.*
>
> (Anglicare Tasmania, "Thin Ice: Living with Serious Mental Illness and Poverty in Tasmania", Tasmania, Submission #144)

> *In addition to the financial impost of caring, carers report a critical lack of support in the form of community-based services, clinical, counselling, information and respite options.*
>
> (Anglicare Tasmania, "Thin Ice: Living with Serious Mental Illness and Poverty in Tasmania", Tasmania, Submission #144)

> *In summary I feel the main factors inhibiting the provision of effective mental health care on the North-West coast of Tasmania are: a critical lack of trained, competent staff both in treatment and rehabilitation areas , an urgent need for increased activity and rehabilitation programs, and the lack of professional support available to affected families…*
>
> (Carer, Mother, Tasmania, Submission #315)

6.8.11.4.A.2 Lack of access to family centred approaches

Standard 11.4.A.11 states: 'The consumer has the opportunity to strengthen their valued relationships through the treatment and support effected by the MHS'. Standard 11.4.A.12 states 'The MHS ensures that the consumer and their family have access to a range of family-centred approaches to treatment and support'. However, many reports were received from carers and NGO service providers describing the incredible strain that is being experienced by families. In particular, the lack of access to family-centred approaches was repeatedly mentioned. Also, the lack of access to other support services for the consumer and the family (e.g. respite, leisure, recreation, education, training, work, employment, home and community care) also contributed to this. Of most serious concern was a report regarding the lack of support provided to single parents with mental illness, often resulting in the removal of the children causing further distress to the children and the parent:

> *Single parents with a mental illness have very little help (if any) to care for their children and are usually forced to put them into state care. Sometimes the children are split up causing further trauma to both the parent and the children*
>
> (Anonymous, Tasmania, Submission #254)

> *There is a lack of education and support for families of people with a mental illness.*
>
> (Anonymous, Tasmania, Submission #254)

> *There is a severe lack of services that support families, especially packages to keep families in their own home.*
>
> (Anonymous, Tasmania, Submission #254)

> *I work primarily with boys and their families. Many of our client's families have mental health problems and it's very difficult to get help for their family.*
>
> (NGO Service Provider, Tasmania, Hobart Forum #20)

> *I found it very difficult in the early stages of [X]'s illness particularly to get information – it was suggested to me that I should go and see a psychologist. I think communications is so important. We need back up for the whole family.*
>
> (Carer, Mother, Tasmania, Hobart Forum #4)

> *Bi-Polar disorder is often difficult to treat. We have six children, three boys and three girls, and these illnesses have a ripple effect on them… I've found there's been little support for me as well. Found out about a camp for them and that's great but only part time worker. Mediation between parents if one has a mental illness is very difficult. She has spent time in and out of hospital for rehab – it's something I have to deal with too. I get depressed, no one explained the term bi-polar to me.*
>
> (Carer, Husband, Tasmania, Hobart Forum #13)

> *[O]ur eldest son was diagnosed with OCD and found the bottle. Our son found activities through AA. He was a high achiever until he became ill and then it all fell apart. I felt very guilty as a mother. I thought 'what have I done?' The professionals also tried to help our family. I didn't feel understood by the counsellors. It was only through AA that I felt understood and supported. Our family is now divided. The first two children are unemployed. The eldest is completely broken. She's 44 and she has not had 1 single offer of a job even after being on Job Search.*
>
> (Carer, Mother, Tasmania, Hobart Forum #16)

6.8.11.4.A.3 Lack of support for children of parents with mental illness

Standard 11.4.A.12 states: 'The MHS ensures that the family has access to a range of family centred approaches to treatment and support'. The notes to this standard refer to '…support for children of parents with a mental disorder'.

Concern was expressed regarding the lack of support being provided to children of parents with mental illness both while the parent is receiving treatment and support while living at home and as an inpatient. Specifically concerns were expressed that support is not being provided to minimise the impact on children, about children having trouble with attending school, completing homework and lacking overall family support. This jeopardises educational achievement and risks negative life outcomes for these children as indicated by these reports:

> *Especially vulnerable are the children who are being cared for by parents with a mental illness. Should the parent (quite often the mother) be admitted to hospital then the children need either a person to come into the home to "take over" the normal household chores. Too often, there is a single parent involved. As one such parent stated "a holistic in-home help in the real life environment of the family home is of much greater value than "counselling" in an office environment.*
>
> (The Australian Family Association Tasmanian Branch, Tasmania, Submission # 263)

> *One child whose mum has a mental illness can't get to school and has requested to be placed in care. But nowhere for him to go – no help with homework. Also had problems with the CAT team who fobbed off as behaviour problems.*
>
> (NGO Service Provider, Tasmania, Hobart Forum #20)

6.8.11.4.A.4 Lack of vocational programs and employment opportunities

Access to education, training, work and employment programs are seen as critical for consumers to live in the community with opportunities to participate socially and economically. Concerns were expressed regarding the lack of access to a wide variety of programs, activities and agencies to maximise the consumer's success in these endeavours (see Standards 11.4.A4-9). Concern was also expressed that these programs and employment opportunities are scarce in Tasmania and generally only offered to consumers who are 'high functioning':

> *Throughput and allowing "fair access" to all clients, means that those who need much longer training and support time, as well as much lower expectations, are excluded and doomed to fail with recurrent loss of self-esteem. This structural approach almost guarantees the clients will self identify with failure in the face of all the noble rhetoric about empowerment. This in turn feeds the Bureaucrats' fascination with "Recovery" which, again, sounds very noble but is used to justify withdrawal and denial of service to all those who are unable to assert themselves, thus achieving budget savings within the mutual obligation framework.*
>
> (Anonymous, Tasmania, Submission #254)

> *Employment services that advocate for people with mental illness are scarce. They don't seem interested in putting in the effort unless clients are very high functioning (Few get jobs).*
>
> (Anonymous, Tasmania, Submission #254)

6.8.11.4.A.5 Lack of recreational, social and rehabilitation programs

Despite Standard 11.4.A.4, which states: 'The MHS ensures that the consumer has access to an appropriate range of agencies, programs and/or interventions to meet their needs for leisure, recreation, education, training, work, accommodation and employment', consumers in the community are described as bored and having little opportunity to develop social and employment skills. This points to a lack of lack programs to meet needs for leisure, recreation and rehabilitation. Access to such programs is seen as critical for consumers to reintegrate and live in the community and carers and consumers reported the benefits from involvement and access to such programs. One carer described the spiralling negative consequences that resulted from their son being excluded from a recreational program due to lack of funding:

> *The lack of ongoing rehabilitation programs also means that we see a lot of young people, especially, being discharged after treatment but then without the necessary support, quickly becoming unwell again and the cycle constantly being repeated.*
>
> (Carer, Mother, Tasmania, Submission #315)

> *Apart from accommodation our biggest problem is the lack of recreation and rehabilitation programs available. [X] struggles at the best of times with no real motivation to do much at all and this coupled with constant tiredness leaves him incredibly bored for most of the time… There have been a couple of programs run over the last year by the Richmond Fellowship of Tasmania Inc During these [X] would get to go out with the group twice a week. Not only did he really enjoy it and looked forward to it, but it was beneficial for him… the 'Kicking Goals Program'… the rapport he has built up with the coordinator has made such a difference to his behaviour and to our family unit.*
>
> (Carer, Mother, Tasmania, Submission #315)

> *He had support through Eureka. He looked forward to it – he did it for 2 years then they told him he had to stop because there wasn't enough funding and someone else had to have a go. He got very depressed, very ill and became very violent. He broke someone's arm and was arrested and taken to the hospital.*
>
> (Carer, Tasmania, Hobart Forum #22)

> *Eureka Clubhouse - I love that place and what they have done for me. I have friends but not many friends; I have 2 boys who have stuck by me.*
>
> (Consumer, Tasmania, Hobart Forum #1)

> *Richmond Fellowship has been great but due to the lack of funding their programs are ending. Once a week, for a full hour, a lady from RF comes and picks up my son and others and they do activities. Myself, my husband and my family don't know enough about programs or education to help ordinary people to cope. You lose your life looking after someone who is that disabled.*
>
> (Carer, Mother, Tasmania, Hobart Forum #15)

> *Further Department of Health reports state there is "not enough activities for people with long-term needs – e.g. social needs. Longer-term meaningful activity is necessary through social groups, recreational groups, work skills groups, which aim to target stress, boredom and increase socialisation".*
>
> (Sue Napier, MHA, Liberal Shadow Minister for Health, Tasmania, Submission #261)

6.8.11.4.B Supported accommodation

Supported accommodation is provided and/or supported in a manner which promotes choice, safety, and maximum possible quality of life for the consumer.

Under this Standard, submissions and presentations indicate concerns about the:

- lack of supported accommodation;
- need for interim and step-down accommodations options;
- lack of respite options; and,
- lack of respite options for parents with mental illness who have children.

6.8.11.4.B.1 Lack of supported accommodation

As noted previously in this Report (8.3 Integration), the lack of housing and accommodation options, and supported accommodation options in particular, for people with mental illness is a serious barrier to consumers attaining the 'maximum possible quality of life' and integrating and contributing to the community. Many consumers who could not access supported accommodation returned to live with their families, and many became homeless, complicating access to treatment and support and increasing their chances of entry into the criminal justice system. Overall, numerous submissions and presentations at the Hobart Forum spoke of the need to increase the range of options and number of places available to protect the rights of people with mental illness and those of their families and carers:

> *In addition to the financial impost of caring, carers report a critical lack of support in the form of community-based services, clinical, counselling, information and respite options. In particular they identified the lack of appropriate supported accommodation which denied their adult son or daughter the chance to live a meaningful independent life.*
>
> (Anglicare Tasmania, "Thin Ice: Living with Serious Mental Illness and Poverty in Tasmania", Tasmania, Submission #144)

> *There is very little supported accommodation…I recently left a 50 year old man in a hotel room with a bed and a wardrobe. It's so humiliating for me to leave him there so how did he feel. There are models that work – for example, a cluster system.*
>
> (NGO Worker, Tasmania, Hobart Forum #18)

> *I would like to see some supported accommodation that has someone to help with cooking and tasks and social comfort. Someone to check on medications. My son can never remember whether he's taken his medication. I'd like one of those as soon as possible. He was sick for a couple of years before he was diagnosed – he's been sick for 10 years.*
>
> (Carer, Mother, Tasmania, Hobart Forum #15)

> *There is a lack of different models of supported accommodation.*
>
> (Anonymous, Tasmania, Submission #254)

> *Consumers are only consulted in a tokenistic way. When they have been consulted and have reached agreement about plans often they find that the bureaucracy has changed their plans. Mostly their identified needs are denied and they are told what they can have.*
>
> (Anonymous, Tasmania, Submission #254)

> *Gaps in long-term tenancy support for clients with mental health issues.*
>
> (Colony 47, Tasmania, Submission #227)

> *Duty of care issues for clients who present as "unwell" at transitional services for accommodation, including SAAP services. May not be able to be accommodated appropriately to match the level of support required.*
>
> (Colony 47, Tasmania, Submission #227)

...son [X], who was diagnosed with schizophrenia some 10 years ago. His condition is such that he requires a supported environment to ensure he has the basics of life and in the absence of this type of accommodation anywhere on the coast, he lives at home with my husband and I. While this is far from satisfactory for both [X] and ourselves we are currently coping.

(Carer, Mother, Tasmania, Submission #315)

We have considered arranging alternative accommodation for our son, possibly even in partnership with other Devonport families, with the idea of sourcing staff who could assist with his / their care. However there are not the people in the area with the necessary skills and certainly not in the number that would be required to successfully run such a place / home…

(Carer, Mother, Tasmania, Submission #315)

In summary I feel the main factors inhibiting the provision of effective mental health care on the North-West coast of Tasmania are: …the unavailability of private and supported accommodation for people with mental illness…

(Carer, Mother, Tasmania, Submission #315)

The Liberals are informed that case managers in mental health are overloaded – "some managing up to 70 clients" and also spend hours searching for accommodation for their clients. "I recently spent three days trying to find accommodation for a mental health client whose [family member] had fallen ill and was no longer able to care for the consumer. There was no supported accommodation, nor crisis accommodation, to be found".

(Sue Napier, MHA, Liberal Shadow Minister for Health, Tasmania, Submission #261)

Families and carers of people with a mental illness are concerned that the Tasmanian Government is opting for boarding houses over other supported accommodation options. One commented to us: "this will become a one-stop-shop for mental health- quite similar to institutionalisation". Another has said "this is a cost-saving measure and an insult to what is needed in terms of support for people with a mental illness". The non-government sector in Tasmania acknowledge the need for alternative options, commenting to us that a "massive revenue injection is needed in the area of supported accommodation" and that "some of the waiting lists for long-term supported accommodation have been closed off for two or three years now – accommodation is usually only available if someone dies".

(Sue Napier, MHA, Liberal Shadow Minister for Health, Tasmania, Submission #261)

6.8.11.4.B.2 Need for interim and step-down accommodations options

There is a need for appropriate transitional models of care between hospital and community.

(Anonymous, Tasmania, Submission #254)

ARAFMI Tasmania also argued that a range of accommodation options was desperately needed and that these needed to be flexible; for example, interim step-down facilities after consumers have been discharged from acute care, long and short-stay settings and transitional accommodation (Standard 11.4.B.8):

Supported and step down accommodation is desperately needed for clients requiring support after leaving acute care and for those people who have difficulty living by themselves or are too big a burden on their family members (often aged parents).

(ARAFMI Tasmania, Tasmania, Submission #245)

6.8.11.4.B.3 Lack of respite options

Included in the notes to Standard 11.4.B.8 is respite accommodation. Standard 11.4.B.8 states: 'There is a range of accommodation options available and consumers have the opportunity to choose and move between options if needed'. Concern was also expressed that there is insufficient accommodation geared to provide respite care:

> *The client must feel safe and the families of those who are mentally ill need respite not only from the care of their loved ones but also from the knowledge that they may be in harm's way.*
> (The Australian Family Association Tasmanian Branch, Tasmania, Submission # 263)

> *But the pressing need is for accommodation geared to respite care.*
> (The Australian Family Association Tasmanian Branch, Tasmania, Submission # 263)

> *Clients cannot be accommodated in "respite" without a mental health case worker.*
> (Colony 47, Tasmania, Submission #227)

> *Yet another problem we experience is where to leave [X] when we go away for any length of time. Until recently my husband's mother assisted but she has since died…*
> (Carer, Mother, Tasmania, Submission #315)

6.8.11.4.B.4 Lack of respite options for parents with mental illness who have children

Concern was also expressed regarding the lack of respite accommodation to support parents with mental illness and their children (Standard 11.4.B.8):

> *There are no respite facilities where a mother with mental illness can be cared for with her children*
> (Anonymous, Tasmania, Submission #254)

> *Access for respite for clients with children is non-existent.*
> (Anonymous, Tasmania, Submission #254)

6.8.11.4.C Medication and other medical technologies

Medication and other medical technologies are provided in a manner which promotes choice, safety and maximum possible quality of life for the consumer.

No submissions or comments were received pertaining to this Standard.

6.8.11.4.D Therapies

The consumer and consumer's family/carer have access to a range of safe and effective therapies

Under this Standard, submissions and presentations indicate concerns about:

- the lack of access to psychologists (emphasis on medication); and
- lack of access to treatment programs for people diagnosed with Borderline Personality Disorder.

6.8.11.4.D.1 Lack of access to psychologists – emphasis on medication

Concern was expressed that access to a range of accepted therapies according to the needs of the consumer and their carers is not being provided by the mental health service (Standard 11.4.D.2). Specifically one consumer reported that many people cannot afford to access such therapies as access via the public mental health system is difficult and Medicare rebates are not available for treatment by psychologists. Concern was also expressed that the major focus of treatment for mental illness is a reliance on medication without consideration for other necessary treatment and supports and overall well-being:

> *Psychologists are not available in the public health system. It's inaccessible and it's impossible to ask people to do that themselves. People with a mental illness don't get help to deal with normal life stress - they get their meds increased.*
>
> (Carer, Mother and NGO Service Provider, Tasmania, Hobart Forum #14)

6.8.11.4.D.2 Lack of access to therapies for people diagnosed with Borderline Personality Disorder

One carer expressed concern that therapies to assist people with Borderline Personality Disorder were not available in either the public sector or at private hospitals. According to Standard 11.4.D.2: 'The MHS provides access to a range of accepted therapies according to the needs of the consumer and their carers'.

> *Dialectical Support Programs need to be available in the public sector and perhaps at private hospitals.*
>
> (Carer, Mother, Tasmania, Hobart Forum #4)

6.8.11.4.E Inpatient care

The MHS ensures access to high quality, safe and comfortable inpatient care for consumers.

Under this standard, submissions and presentations indicate concerns about:

- the lack of beds.

6.8.11.4.E.1 Lack of beds

As noted in other sections of this Report (e.g. Standard 11.1 – Access and Standard 11.4 – Treatment and Support) a lack of available beds for acute care was also raised as a concern. For consumers in rural and regional areas this was particularly problematical as this was often the only care they could access due to the lack of community-based services. Patients requiring admission were generally in desperate need of medical care, often life-saving medical care. It appears that due to the inability to access care at an earlier point in the course of the illness, the demand for acute care exceeded the number of beds available. This resulted in a whole series of other decisions which jeopardised the safety and rights of consumers including: non-admission and being returned 'home', admission and someone else who was still unwell was discharged to vacate a bed, lengthy waits in emergency departments and being held in seclusion.

> *The Psychiatric Care Unit is pretty full all the time and it could certainly do with more beds.*
>
> (Carer, Mother, Tasmania, Hobart Forum #4)

6.8.11.5 Planning for exit

Consumers are assisted to plan for their exit from the MHS to ensure that ongoing follow-up is available if required.

Under this Standard, submissions and presentations indicate concerns about:

- planning for exit on the basis of need to vacate beds; and
- discharge occurring without adequate planning.

6.8.11.5.1 Planning for exit on the basis of need to vacate beds

Concerns were expressed that discharge was not occurring to an agreed exit plan (Standard 11.5.2) or health status of the consumer (Standard 11.3.18) but rather according to the need to vacate beds for new admissions. Such exits could jeopardise the safety of the consumer, especially as entry is almost always on the basis of risk or actual self-harm, or harm to others, and frequently results in almost immediate readmission:

> *It should be noted that discharge is largely driven by the assessment that another incoming client has a greater need rather than the client is ready for discharge.*
>
> (Anonymous, Tasmania, Submission #254)

6.8.11.5.2 Discharge without adequate planning

Concern was expressed about the inadequacy of discharge plans and that sometimes they do not exist at all. Concerns were expressed that indicate that discharge plans have not been developed in collaboration with the consumer or carer (consistent with Standard 11.5.2), that understandable information about the range of relevant services and supports had not been provided (Standard 11.5.4) and established contact with the service providers had not been arranged prior to discharge (Standard 11.5.6):

> *The Hospital (e.g. RHH) is outside the community mental health structure and therefore has no commitment to the care of clients once it perceives them as ready for discharge. Despite frequent attempts to establish coordinated discharge planning ("discharge planning begins on admission") the community services are still often left out of the loop and find the client has been discharged without proper arrangements for continued support.*
>
> (Anonymous, Tasmania, Submission #254)

> *Figures contained in response to a Question on Notice placed by the State Liberals reveal that only half of the 2642 people presenting to Emergency Departments were admitted in the first nine months of the 2003/04 financial year… Half were treated and discharged with little apparent follow-up as to where they are going, and no apparent plans to provide ongoing support. What these figures also do not reveal is how many of the 2642 presentations involve the same person, representing over and over again… Yet even with these figures now in the public domain, Labor has still not acted to address the crisis in mental health.*
>
> (Media Release, Sue Napier, MHA, Shadow Minister for Health, 13 October 2004, Tasmania, Submission #261)

> *Similarly, Department of Health reports state that "discharge planning from hospital is problematic due to lack of case management" and recommend that "adequate resources of case managers [is required}" and "case manger need to follow their clients through the system from in-patient to out-patient and to community client status".*
>
> (Sue Napier, MHA, Liberal Shadow Minister for Health, Tasmania, Submission #261)

6.8.11.6 Exit and re-entry

The MHS assists consumers to exit the service and ensures re-entry according to the consumer's needs.

Under this Standard, submissions and presentations indicate concerns about:

- consumers being discharged while still very ill with no arrangements for ongoing treatment and support.

6.8.11.6.1 Discharge while still very ill with no planning for treatment and support

Standard 11.6.1 states: 'Staff review the outcomes of treatment and support as well as ongoing follow-up arrangements for each consumer prior to their exit from the MHS. Concerns were expressed that discharge was occurring without staff reviewing the outcomes of treatment and support. One carer reported her disbelief that consumers could be discharged while still very ill with out any plans being made for ongoing treatment and support. This would indicate that an individual care plan had not been devised and an exit plan (see Standard 11.5.1) and a clinical review of the consumer had not been conducted prior to discharge (see Standard 11.3.18):

> *The thing I found is that once he walked out the door of the MHS no one cared about him or what happened to him… They said he was okay and released him with no shoes, no where to go and blood all over him. I spoke to the Dr and [X] died 10 days later – he jumped. There are so many suiciding. Nobody to help me. I should have had more help, I couldn't do it… Everybody like that needs someone to care for them.*
>
> (Carer, Tasmania, Hobart Forum #22)

> *And other mental workers confirm the story of the revolving door of hospitalisation and hopelessness for people with mental illness in Tasmania:*
>
> > *"One client was in Psychiatric Intensive Care Unit (PICU) in hospital on weekend, transferred to Department of Psychological Medicine (DPM) of hospital on Monday, sent back over to Mistral House on Tuesday, sent back to PICU, then discharged into the community. Still unwell, MH services told him to go back to hospital (Emergency Services), admitted again to PICU, discharged into the community and readmitted within 6 hours".*
> >
> > (Sue Napier, MHA, Liberal Shadow Minister for Health, Tasmania, Submission #261)

> *One mental health client who contacted the Liberals said he was held for 72 hours, discharged with bare feet and no money and was back hours later in hospital after a suicide attempt.*
>
> (Sue Napier, MHA, Liberal Shadow Minister for Health, Tasmania, Submission #261)

6.9 NATIONAL

ANALYSIS OF NATIONAL SUBMISSIONS AGAINST THE NATIONAL STANDARDS FOR MENTAL HEALTH SERVICES

This section discusses the submissions that did not focus on services in any one state or territory, but took a national perspective.

In summary, information presented in this section was gathered from 15 submissions (see Appendix 8.3.9). A draft copy of this report was sent to the Minister for Health and Ageing for comment. An analysis of the response from the Federal Government (reproduced in Appendix 8.4.9) and an overall review of mental health service delivery in Australia is contained in Part 2.7.9.

6.9.1 STANDARD 1: RIGHTS

The rights of people affected by mental disorders and/or mental health problems are upheld by the MHS.

Under this Standard, submissions indicate concerns about the rights of carers not being upheld.

6.9.1.1 Rights of carers not being upheld

Standard 1.1 states: 'Staff of the MHS comply with relevant legislation, regulations and instruments protecting the rights of people affected by mental disorders and/or mental health problems'. Included in the notes to this Standard are The Australian Health Ministers' Statement of Rights and Responsibilities, the UN Principles on the Protection of People with a Mental Illness and Improvement in Mental Health Care, departmental codes of conduct and mental health legislation.

Concern was expressed that staff of some mental health services are not complying with all relevant legislation, regulations and instruments protecting the rights of carers of people affected by mental disorders and/or mental health problems at all times. This was seen as particularly problematic given the subsequent reliance on carers while the system is in crisis. Specifically, the lack of sufficient support, information and education about the illness or treatments available was noted. Standard 1.8 states: 'The MHS provides consumers and their carers with information about available mental health services, mental disorders, mental health problems and available treatments and support services'.

For carers, information about the course of the illness and how they can best support their family member and access support for themselves is vital in achieving the best possible outcome for the consumer and minimising the impact of the illness on the family. The following quotes indicate that this information and support is not always being provided:

Under the National Mental Health Strategy, the Mental Health statement of rights and responsibilities, which was adopted by the Australian Health Ministers in 1991, carers and advocates have rights and responsibilities, which include the right to respect; provision of information, education, training and support; to seek further opinions in respect of treatment and diagnosis of the consumer; to limit their availability to the consumer; to have access to appropriate complaint processes; and to have access to assistance in managing their own difficulties in their caring role. A carer also has the right, where the consumer consents, to have access to the consumer, to be consulted by service providers in relation to the consumer's treatment, to be able to access support services for the consumer, and to be able to exchange information with the service providers regarding the consumer…It must be recognised that a mental health system which does not meet the needs of consumers or provide basic human rights to treatment for mental illness, also has a severe and unrelenting impact on the families and carers of the consumer. In this regard, any actions recommended by the Commission as a result of the current investigation, must take into account the effect on the hidden workforce in mental health care - the families and carers of the mentally ill. The rights of carers, as agreed by all Australian Health Ministers in 1991, are effectively being ignored while the system is in crisis.

(Carers Australia, National, Submission #276)

The following issues are of grave concern to us… Within the private sector, the burden of care for people with a mental illness or disorder has fallen largely to their ***carers****. While the current Government has increased the Carers allowance, there is little other support or education for this hidden army of service providers. This alone can affect the quality of and ability to deliver continuity of care (author's emphasis)*

(The National Network for Private Psychiatric Sector Consumers and Carers, National, Submission #225)

6.9.2 STANDARD 2: SAFETY

The activities and environment of the MHS are safe for consumers, carers, families, staff and the community.

No submissions or comments were received pertaining to this Standard.

6.9.3 STANDARD 3: CONSUMER AND CARER PARTICIPATION

Consumers and carers are involved in the planning, implementation and evaluation of the MHS.

Under this Standard, submissions indicate concerns about the lack of participation by consumers who are young.

6.9.3.1 Lack of participation by consumers who are young

Standard 3.1 states: 'The MHS has polices and procedures related to consumer and carer participation which are used to maximise their roles and involvement in the MHS' and Standard 3.6 states 'consumers and carers are supported to independently and individually determine who will represent the views of each group to the MHS'. The Australian Infant, Child, Adolescent and Family Mental Health Association expressed concern that children and young people are not being involved at any level and therefore their needs are not being effectively lobbied for or considered in the planning and implementation of services:

Children and young people have a right to participate in and provide input into decisions that are likely to affect them. Parents and caregivers also play a crucial role in advocating for children and young people. While infants and children may find it difficult to speak for themselves, it is also commonplace that young people are not given the opportunity to express their views. Raphael (2000) noted: "Advocacy for and on behalf of children and young people requires recognition of their rights and needs to ensure that appropriate responses and systems of care are provided. It involves providing opportunities for children and young people to have a say in decisions that are likely to affect them. Parents and other caregivers also play a crucial role in advocating for children and young people." (Raphael 2000, Page 1)

(The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

6.9.4 STANDARD 4: PROMOTING COMMUNITY ACCEPTANCE

The MHS promotes community acceptance and the reduction of stigma for people affected by mental disorders and/or mental health problems.

Under this Standard, submissions indicate concerns about:

- high levels of stigma;
- feelings of isolation experienced by consumers and their families due to the rejection by the extended family and the community;
- the need for community education campaigns; and
- stigma and stereotypes perpetuated by the media.

6.9.4.1 High levels of stigma

Various organisations spoke of the high levels of stigma associated with mental illness and prejudice experienced by people with mental illness in community, workplace, school, healthcare and family settings. Reports were also received of families being discriminated against. Community awareness campaigns to increase understanding of mental illness, acceptance of people with mental illness and information about how to support people with mental illness and their families and carers were described as being critical. The following extracts show how stigma is preventing people with mental illness from 'being able to participate in the activities of daily living to which they are entitled':

The stigma around mental illness and a history of abuse, and lack of effective responses, prevent many from accessing what should be an integrated approach, drawing on informed and comprehensive community-based appropriate professional and welfare assistance.

(Advocates for Survivors of Child Abuse, National, Submission #262)

There is no doubt that in any forum or group where beyondblue / blueVoices was present that the issue of stigma was a major issue that was raised. Stigma presents in a whole range of ways and we have had significant feedback around stigma in the work place, stigma within families, and stigma within younger Australians at school who experience these illnesses. Stigma presents itself in subtle ways, and blatantly. The overall effect of stigma however, whether it is subtle or blatant, is the further alienation of people from being able to participate in the activities of daily living to which they are entitled. There is also little doubt that the issues of stigma prevents some people from seeking treatment for their illness which can result in further fractured relationships within the family and work environment. Recommendation: That attending public awareness campaigns around the areas of Depression and Anxiety such as beyondblue, continue, that there is active education in the work place and schools on the issues of Depression and Anxiety and that an active school program is instituted nationally on these matters.

(blueVoices, National, Submission #355)

Our research has proven to us that the root cause of inequity and social injustice is stigma. Therefore, as a society we need to continue with public awareness and education and to demonstrate our intolerance of stigma and discrimination in the workplace, the schoolyard and our health care system.

(blueVoices, National, Submission #355)

Australia: The Seven Types of Stigma:

1 Political Australians affected by mental illness are almost completely ignored by government and opposition. The crisis in mental health services is rendered invisible – rarely mentioned in Parliament and kept firmly off the agenda.

2 Funding allocation The proportion of Australia's health budget spent on mental health services is under 8%. In comparable OECD [Organisation for Economic Co-operation and Development] countries, the proportion is 12% or more. This shortfall has a drastic effect on the capacity of services. Research funding in the area is also inadequate.

3 Planning and service delivery Decision-making on mental health services at the highest levels is characterised by low prioritisation, and lack of commitment. Service delivery in some States is being 're-institutionalised' by stealth – with programs being moved back into institutions and hospitals to save money. Effective treatments are rationed because of budget restrictions.

4 Professional Mental health professionals are overwhelmingly focused on treating people when acutely ill – often ignoring the need for recovery-focused rehabilitation and support for family and other carers. Some also treat consumers and carers in a disrespectful manner.

5 Legislative The 2004 Review of the Disability Discrimination Act 1992 revealed that vilification of people with a mental illness is not unlawful in any State or Territory except Tasmania.

6 Media Despite some improvement, news and entertainment media persist in promoting inaccurate and insulting stereotypes of mentally ill people as violent and unpredictable.

7 Community Eighty per cent of people affected by mental illness reported experiencing stigma in the past two years. This day-to-day abuse (fuelled by the media and lack of legal protection) is rated as nearly as distressing as their symptoms by many.

(author's emphasis)

(SANE Australia, National, Submission #302)

SANE Stigma Survey 2004: Conducted during June-August 2004, the survey asked consumers and carers to report on their experience of stigma in the past two years. Analysis of over 300 responses suggests that being treated unfairly and disrespectfully – by health professionals as well as the general community – is a regular occurrence for many Australians whose lives are affected by mental illness.

(SANE Australia, National, Submission #302)

Both consumers and carers alike are seeking acceptance in the broader society in which they live…

(blueVoices, National, Submission #355)

6.9.4.2 Feelings of isolation – rejection by family members and the community

Standard 4.1 states: 'The MHS works collaboratively with the defined community to initiate and participate in a range of activities designed to promote acceptance of people with mental disorders and/or mental health problems by reducing stigma in the community.' However, concern was expressed that not only does stigma and lack of understanding still shape community behaviour and result in the exclusion of people with mental illness in social and workplace settings, but that often this behaviour extends to close family members and intimate partners resulting in relationship breakdown. As the following quotes indicate, the need for activities to promote community acceptance not only for the community but for family members as well is critical.

…three members of my family who have been diagnosed with Schizophrenia. This has had a devastating effect on not only the immediate family but also on extended family relationships, namely the isolation we have suffered since the diagnoses were made.

(Carer, Anonymous, Submission #224)

People such as myself who've suffered really want friendship, acceptance and kindness, we don't have a need for things.

(Consumer, Anonymous, Submission #133)

6.9.4.3 Need for community education campaigns

Carers expressed concern about the stigma and lack of understanding that still surrounds mental illness and how frequently this resulted in members in the community distancing themselves from consumers and their families and providing little support. Non-acceptance and lack of understanding by some mental health workers and administrators was also noted. This would indicate that campaigns and activities to address community acceptance and reduce stigma (Standard 4.1) to-date have not yet successfully changed community attitudes to mental illness and that more activities to address this are needed:

To overcome this debilitating situation we (as so many other families in our situation) need more public awareness campaigns to reduce the number of misconceptions/stigmas surrounding mental illness; particularly those attached to Schizophrenia.

(Carer, Anonymous, Submission #224)

[mental health and drugs] …I feel it is an epidemic in our society, that is so little supported.

(Carer, Mother, Anonymous, Submission #164)

There is a place in the lives of those who've been abused to accept help from those in the community, that is the average person who just wants to listen, who is more on a par with these people who don't sit in an ivory tower. The senior mental health community is well trained, educated and hence wealthy and they are therefore advisory, however do they really understand individuals.

(Consumer, Anonymous, Submission #133)

6.9.4.4 Stigma and stereotypes perpetuated by the media

SANE Australia raised concern that activities to reduce stigma in the community must also address education of media personnel to modify their portrayal of people with mental illness and comparative references. The 'Mindframe Strategy' was noted as a positive initiative to address this issue:

While there has been some improvement in media coverage of mental illness, this is not sufficient to counter systemic stigma. Some newspapers and TV dramas also continue to portray mental illness in an inaccurate, sensationalised and disrespectful way. This can suit political leaders, as it displaces blame for the consequences of poor service delivery onto the mentally ill themselves.

(SANE Australia, National, Submission #302)

While our mental health system is in crisis, a number of positive initiatives by the Australian government deserve acknowledgement. Examples of praiseworthy individual programs include:…Mindframe Strategy. A sophisticated, wide-ranging strategy promoting responsible reporting of mental health and suicide issues in the media.

(SANE Australia, National, Submission #302)

6.9.5 STANDARD 5: PRIVACY AND CONFIDENTIALITY

The MHS ensures the privacy and confidentiality of consumers and carers.

Under this Standard, submissions indicate concerns about:

- the complicated system of legislation protecting the privacy and confidentiality of consumers and carers; and
- privacy laws hindering communication with and involvement of carers.

6.9.5.1 Complicated system of legislation protecting privacy and confidentiality of consumers and carers

Standard 5.1 states: 'Staff of the MHS comply with relevant legislation, regulations and instruments in relation to the privacy and confidentiality of consumers and carers' and Standard 5.2 states 'the MHS has documented policies and procedures which ensure the protection of confidentiality and privacy for consumers and carers and these are available to consumers and carers in an understandable language and format'. The consumer is to be encouraged and provided with opportunities for others to be involved in care (Standard 5.3) and they are to give 'informed consent before their personal information is communicated to health professionals outside the MHS, to carers or other agencies or people' (Standard 5.4).

Carers Australia expressed concern regarding the multiple pieces of legislation covering privacy and confidentiality in each State and Territory and that this system imposes a barrier to the potential sharing of information and involvement of carers to achieve the best possible outcome for consumers:

> *A common problem for carers is the impact of privacy laws and recognition of their role. Each State and Territory has different legislation governing rights of carers and the release of information to carers so that a three-tier system must be overcome prior to information being shared with the mental health service or recognition of their role being granted. This tiered system is comprised of the relevant State or Territory mental health legislation, State or Territory privacy or health legislation and the Federal privacy laws.*
>
> (Carers Australia, National, Submission #276)

6.9.5.2 Privacy laws hindering communication with and involvement of carers

Carers Australia expressed concern that barriers associated with policies and procedures designed to protect the confidentiality and privacy of consumers are impeding communication between consumers, carers and clinicians in the provision of treatment and the sharing of vital information. These concerns indicate that policies and procedures related to privacy and confidentiality are often not being made available to consumers and carers in an understandable language and format (Standard 5.2) and that frequently the mental health system is not encouraging and providing opportunities for consumers to involve others in their care (Standard 5.3). The following quote indicates the level of frustration experienced by carers:

Unfortunately, carers quite often experience barriers with privacy issues where they are not recognised in their role, or they are unable to give information to the mental health service about the consumer, whether or not they are seeking information in return. This leads to frustration and anger by families and carers regarding the treatment and care of the consumer and reduces the opportunity to aid the recovery of the consumer and prevent further relapses in illness. This can also entrench the rejection of the carer role or family input by a consumer into their care and treatment when valuable information can be provided to the mental health service.

(Carers Australia, National, Submission #276)

The essential feature which came through from carers in our research is that they be included as part of the treatment program. In order to maximise the health benefits of treatment, consumers and carers should be seen as key members of the treatment team. The issue of confidentiality is always a significant issue. However, if carers are engaged from the commencement of treatment then many of these confidentiality issues can be overcome. However, the desire and right of consumers to have certain facets of their story remain confidential must be respected.

(blueVoices, National, Submission #355)

6.9.6 STANDARD 6: PREVENTION AND MENTAL HEALTH PROMOTION

The MHS works with the defined community in prevention, early detection, early intervention and mental health promotion.

Under this Standard, submissions indicate concerns about:

- lack of rehabilitation programs and recovery services;
- lack of promotion, prevention and early intervention programs; and
- lack of focus and early interventions to assist children and youth with mental illness or mental health problems.

6.9.6.1 Lack of rehabilitation programs and recovery services

Standard 6.1 states: 'The MHS has policy, resources and plans that support mental health promotion, prevention of mental disorders and mental health problems, early detection and intervention' and Standard 6.8 states 'the MHS ensures that the consumer has access to rehabilitation programs which aim to minimise psychiatric disability and prevent relapse'.

Rehabilitation programs are acknowledged as a critical step in the reintegration process back into full life after a period of illness and the prevention of relapse for many people with mental illness. Such programs would include living skills programs, respite and social programs. Concern was expressed that the mental health system has not placed sufficient emphasis on developing rehabilitation programs or other programs to prevent relapse or promote recovery and instead has focussed on acute services for consumers who have reached crisis point:

Rehabilitative and recovery services are poorly developed for people with a mental illness with few exceptions. The regaining of social and life skills following an episode of mental illness or psychosis is essential to aid recovery and has the potential to avoid continuing illness and over reliance on acute systems. Rehabilitative and on-going support services for those with an enduring mental illness will reduce the incidence of acute episodes of illness and provide individuals with hope and a pathway to recovery.

(Mental Illness Fellowship of Australia, National, Submission #331)

6.9.6.2 Lack of promotion, prevention and early intervention programs

The Australian Infant, Child, Adolescent and Family Mental Health Association expressed serious concern about the lack of programs and preventive focus in the delivery of mental health services, despite the emphasis of such an approach in Standards 6.4, 6.5 and 6.6 and the development of the National Action Plan for Promotion Prevention and Early Intervention for Mental Health 2000.

In particular, this submission as well as one from Drug Free Australia highlighted the need for programs providing treatment and support services to intervene at the earliest possible moment to prevent deteriorating illness, prevent problems from becoming entrenched and minimising impact:

> *Promotion, Prevention and Early Intervention (PPEI) Framework. The promotion of mental health, prevention of mental health problems and disorders, and early intervention are key approaches for ensuring health, well being and social inclusion in adult life. Investment within a PPEI framework is critical and should span the period prior to conception and encapsulate childhood and adolescence. "Where effective treatments and interventions are available, intervening in the early stages, when difficulties of symptoms first start to appear, can prevent problems from becoming entrenched and thereby minimise the impact of these problems or disorders on the lives of young people" (Raphael, 2000, Page 1)*
> (The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

> *In Australia, the National Action Plan for Promotion Prevention and Early Intervention for Mental Health 2000 outlines many evidence based programmes that could be implemented across the entire lifespan, yet many of these programmes have not been uniformly rolled out.*
> (The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

> *Surely, however, where it is possible, preventing such mental illness would be preferable. Particularly of concern must be those individuals whose mental illness is directly attributable to illicit drug use, the correlation is very strong indeed. Although I do believe the question needs to go back another level again regarding the causal triggers and not merely be distracted by the symptom.*
> (Drug Free Australia, National, Submission #74)

6.9.6.3 Lack of focus and early interventions to assist children and youth with mental illness or mental health problems

Standard 6.1 states: 'The MHS has policy, resources and plans that support mental health promotion, prevention of mental disorders and mental health problems, early detection and intervention' and Standard 6.2 states 'the MHS works collaboratively with health promotion units and other organisations to conduct and manage activities which promote mental health and prevent the onset of mental disorders and/or mental health problems across the lifespan'.

The availability of services to provide treatment for children and youth with mental illness or mental health problems is acknowledged as critical in terms of averting serious life repercussions. The Australian Infant, Child, Adolescent and Family Mental Health Association expressed concern about the lack of mental health services for children and adolescents and that access to adult services could not be considered as an appropriate alternative to fill the gap. The lack of funding and services for children and adolescents was noted as a significant failure by the mental heath service in their ability to identify and respond as early as possible (Standard 6.5), especially to vulnerable groups (for example, children of parents with mental illness, Indigenous youth, refugees, child abuse victims) (Standard 6.4) and to prevent negative life consequences:

Current research evidence emphasises the cost effectiveness of intervening in the early years. However the funding allocated to child and adolescent mental health does not currently reflect the proportion of the population comprising children and young people and is significantly less than funding allocated to adult services. There are also significant socioeconomic inequalities in infant, child and adolescent mental health, including inequities in accessing services.

(The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

Effective mental health promotion, prevention and early intervention strategies targeting children and young people involve a range of stakeholders and settings that are different to those for the adult population. Environments and systems play an important role in child and adolescent mental health and include schools, childcare settings, child protection agencies and youth services. Parents play a critical role in children and young people's mental health and in the treatment of mental health problems and disorders.

(The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

Mental health problems and disorders in children and young people left untreated can have far-reaching and long-term implications for the individual and the community as a whole. Insufficient appropriate interventions impacts on children's and young people's social, academic and emotional development and can create instability in their families (Rutgers University, US Dept of Health and Human Services & Annie E Casey Foundation, 2002). Sawyer et al (2000) in the National Survey also found that children and young people with mental health problems and disorders reported a lower quality of life.

(The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

Certain populations of children and young people have been identified as having a greater risk of developing mental health problems than their peers (e.g. children of parents with a mental illness, indigenous youth, refugees).

(The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

AICAFMHA recognises that within the infant, child and adolescent population there are particular subgroups that have special needs or may be more at risk due to family or environmental factors. An effective mental health service system needs to consider and accommodate these 'at risk' groups.

(The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

A subgroup of the infant, child and adolescent population is children of parents with a mental illness. This group of children and young people present a special challenge for services as they themselves will not necessarily access or require a mental health service. They do however have particular needs around support, respite, information and protection, as identified within the National Practice Standards for the Mental Health Workforce, 2003 (Commonwealth Department of Health and Ageing, 2002) and the Principles and Actions for Services and People Working With Children of Parents with A Mental Illness (AICAFMHA, 2004).

(The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

Suicide is the leading cause of death in young people. Child abuse victims represent a high percentage of those with suicidal ideation and attempts, successful and otherwise – independent of age.

(Advocates for Survivors of Child Abuse, National, Submission #262)

SANE Australia highlighted the following prevention and early intervention programs for children and adolescents:

While our mental health system is in crisis, a number of positive initiatives by the Australian government deserve acknowledgement. Examples of praiseworthy individual programs include:...Mental Health Matters. An excellent school-based education program on mental health issues being implemented nationally. Other positive initiatives supported include the COPMI (Children of Parents with a Mental Illness) project and associated programs, beyondblue – the national depression initiative, and the Mental Health First Aid program developed at the ANU Centre for Mental Health Research.

(SANE Australia, National, Submission #302)

6.9.7 STANDARD 7: CULTURAL AWARENESS

The MHS delivers non-discriminatory treatment and support which are sensitive to the social and cultural values of the consumer and the consumer's family and community.

SANE Australia commented on the need for services for Indigenous people:

Services for indigenous people: Community-based mental health services are especially important to indigenous Australians in urban as well as rural and remote areas for a range of reasons – cultural, geographic, socio-economic and relating to general health status. Mental health services around the country can also learn from indigenous services in terms of treating 'the whole person' not just immediate symptoms. The SANE Mental Health Report recommends adequately-funded, culturally-appropriate indigenous community mental health services be established in all States and Territories.

(SANE Australia, National, Submission #302)

6.9.8 STANDARD 8: INTEGRATION

6.9.8.1 Service integration

The MHS is integrated and coordinated to provide a balanced mix of services which ensure continuity of care for the consumer.

Under this Standard, submissions indicate concerns about the transition from adolescent to adult mental health services.

6.9.8.1.1 Problems with the transition from adolescent to adult mental health services

Standard 8.1.5 states: 'The MHS has documented policies and procedures which are used to promote continuity of care across programs, sites, other services and lifespan' and 'has specified procedures to facilitate and review internal and external referral processes within the programs of the MHS'. Performance is to be monitored and data collected is to be utilised to improve performance and quality.

Not only were concerns raised at the scarcity of services for children and youth, but concerns were also raised with regards to the continuity of care between adolescent and adult mental health services and the need for greater flexibility in policies and procedures:

AICAFMHA [The Australian Infant, Child, Adolescent and Family Mental Health Association] also believes that reliance on age as a sole criterion for transitioning between child and adolescent and adult services is inappropriate and that some flexibility be built into state run services to enable appropriate transitions. This is particularly the case for young people in the 16-18 year age range.

(The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

6.9.8.2 Integration within the health system

The MHS develops and maintains links with other health service providers at local, state and national levels to ensure specialised coordinated care and promote community integration for people with mental disorders and / or mental health problems.

No submissions or comments were received pertaining to this Standard.

6.9.8.3 Integration with other sectors

The MHS develops and maintains links with other sectors at local, state and national levels to ensure specialised coordinated care and promote community integration for people with mental disorders and/or mental health problems.

Under this Standard, submissions indicate concerns about:

- the need for whole-of-government approaches to assist consumers;
- lack of integrated and coordinated services for children and adolescents, including child refugees;
- whole of government approach needed to tackle mental health problems and drug use;
- the need for whole-of-government approaches to care for children who have been made wards of the state;
- training and support for General Practitioners;
- lack of support from Centrelink; and
- national legislative reform of anti-discrimination legislation to cover vilification and harassment

6.9.8.3.1 The need for whole-of-government approaches to assist consumers

Mental Illness Fellowship of Australia expressed concern regarding the lack of integrated service delivery and a whole-of-government approach to solve the complex support needs required for people with mental illness and their families and carers to live in the community in a dignified manner. This was identified as resulting in an over-representation of people with mental illness among the homeless and in the criminal justice system.

The lack of adequate integrated and coordinated support at the earliest possible moment was also seen to result in negative life consequences for consumers and their families resulting in increased reliance on justice, drug and alcohol, housing, welfare and health systems and sometimes ending in suicide. The need for broader governmental approaches and reform of services was seen as necessary to protect and promote the rights of people with mental illness and avert deteriorating mental health and negative life outcomes as indicated by the following quotes:

> *People with a mental illness and long term disability resulting from such illness impact heavily on the justice, drug and alcohol, housing and welfare systems as well as the health system. The failure to provide adequate support services has resulted in an overrepresentation of people with a mental illness among the homeless and in the criminal justice system. MIFA calls for structural reform of services, which incorporates a whole of government approach to address the structural impediments and the failure to provide sufficient support systems to address the overrepresentation.*
>
> (Mental Illness Fellowship of Australia, National, Submission #331)

Dr Richard Matthews, Chief Executive Officer of the NSW Corrective Health Service gave evidence in 2002 to a House Representative Committee that 90.1% of women on reception in NSW have some form of mental illness or disorder as do 78.2% of men. On substance abuse he reported that compared to 2.8% in the general community, 74.5% of women on reception in NSW corrective institutions are dependent on or abuse alcohol or another drug. For men the figures are 7.1% and 63.3%. The drugs concerned are interesting. 20.5% of the men were dependent on or abused cannabis, 35.2 % on an opioid, 11.9% on a sedative, 30.8% on a stimulant and 22.4% on alcohol. The levels of dependency or abuse by women was much higher for all categories of drug.

(Families and Friends for Drug Law Reform, National, Submission #336)

It is evident that prisons have become receptacles for people with a mental illness or disorder or substance dependence. What is more, the existence of a mental illness or disorder and substance dependence are not independent factors associated with imprisonment. The coexistence of substance abuse, including abuse of alcohol, with other mental illness or disorders dramatically increases the risk of offending behaviour. Whatever the myth, schizophrenia is not particularly associated with violence or other offending behaviour. It is substance abuse that makes a difference. This is shown in a survey of the literature by Dr Paul Mullen, clinical director of the Victorian Institute of Forensic Mental Health and Professor of Forensic Psychiatry at Monash University (Mullen 2001).

(Families and Friends for Drug Law Reform, National, Submission #336)

Another recently published Victorian study found that if a person had schizophrenia their chances of attracting a criminal conviction was 11.7%. If they had schizophrenia and a substance use disorder their chance of obtaining a criminal conviction rose to 68.1% (Wallace et al. 2004, 721).

(Families and Friends for Drug Law Reform, National, Submission #336)

There are no coherent national strategies covering key issues such as dual diagnosis, rehabilitation, supported accommodation, education and training for family and other carers.

(SANE Australia, National, Submission #302)

Suicide Prevention Strategy. The Australian government takes this issue seriously, with establishment of a National Advisory Council and funding of a wide range of programs. It still needs to publicly acknowledge, however, that provision of adequate mental health services is essential to reducing suicide rates.

(SANE Australia, National, Submission #302)

6.9.8.3.2 Lack of integrated and coordinated services for children and adolescents, including child refugees

Standard 8.3.2 states: 'The MHS supports its staff, consumers and carers in their involvement with other agencies wherever possible and appropriate'. Support may be in the form of referral, sharing of resources, sharing of expertise to agencies like Department of Housing, Disability Services, CES, Police Services, schools, Commonwealth Rehabilitation Services and Court Liaison Services.

However, concern was expressed regarding the paucity of services and lack of integrated services to assist young people with mental illness or mental health problems. Such services are seen as essential from an early intervention perspective to halt spiralling negative life consequences. Specifically, children of parents who misuse drugs, children who are exposed to domestic violence and child refugees were particularly noted as being a vulnerable group requiring coordinated service delivery for identification and provision of appropriate treatment and support services. The Australian Infant, Child, Adolescent and Family Mental Health Association reported the growing number of children and adolescents requiring treatment and support indicating that integration with other sectors would be vital to ensure specialised and coordinated care:

In Australia surveys indicate that between 14 – 18% of children and young people experience mental health problems of clinical significance. This equates to in excess of 500 000 individuals nationally. These findings are comparable with findings internationally.
(The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

Recent evidence compiled by the World Health Organization (WHO) indicates that by the year 2020, childhood neuropsychiatric disorders will rise by over 50 percent internationally to become one of the five most common causes of morbidity, mortality, and disability among children. These childhood mental disorders impose enormous burdens and can have intergenerational consequences. They reduce the quality of children's lives and diminish their productivity later in life. No other illnesses damage so many children so seriously.
(The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

Two landmark Australian studies undertaken relatively recently are the Child and Adolescent Component of the National Survey of Mental Health and Wellbeing (Sawyer et al., 2000) and the Western Australian Child Health Survey: Developing Health and Wellbeing in the Nineties (Zubrick et al, 1995). These surveys indicate that between 14 – 18% of children and young people experience mental health problems of clinical significance. This equates to in excess of 500 000 individuals nationally. These findings are comparable with findings internationally.
(The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

The adverse consequences for children with parents who misuse drugs are typically multiple and cumulative and will vary according to the child's stage of development. They include a wide range of emotional, cognitive, behavioural and other psychological problems. (Hidden Harm: UK Advisory Council on the Misuse of Drugs, 2003, p.2)
(The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

Children who are exposed to domestic violence are also at high risk.
(The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

There is an increasing body of literature surrounding the effects of re-location on the mental health of children and youth, particularly those as refugees. The Professional Alliance For The Health Of Asylum Seekers And Their Children Submission to the HREOC Inquiry (2002) states "Current practices of detention of infants and children are having immediate, and are likely to have longer-term, effects on their development and their psychological and emotional health." The submission goes on to note that "in young children, disruptions of attachment relationships, such as removal from a primary carer or multiple changes of carer, are severe stressors and may produce immediate symptoms of distress and behavioural disturbance." The absence or limited availability of mental health services for these infants, children and adolescents compounds the issue for these families.
(The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

6.9.8.3.3 Whole of government approach needed to tackle mental health problems and drug use

Families and Friends for Drug Law Reform expressed concern that 'the overlap of the problems of mental health and drug abuse is falling between stools' and that the National Mental Health Plan and Drug Strategy are failing to address the links and problems in a meaningful way. The need for a coordinated and integrated approach was identified as vital as current strategies and plans are only paying lip service to the ideals while the situation is worsening:

…the current National Mental Health Plan and Drug Strategy. These peak policy documents fail in any meaningful way to address the links between mental health and illicit drug substance abuse. The National Mental Health Plan 2003-2008 passes responsibility for drug and alcohol problems to the national drug strategy. The National Drug Strategy: Australia's integrated framework 2004-2009 makes the platitudinous point that there should be strong partnerships with the treatment services and integration of policies and programs.

(Families and Friends for Drug Law Reform, National, Submission #336)

…the inquiry needs to look at the negative impacts on mental health of existing drug policy responses. It is not enough to point to the obvious correlation between illicit drug use and mental illness or disorders and observe that there would be less mental illness or disorders if there was less such use. A recommendation that ignores the impact of existing responses and urges intensification of those responses will only intensify the mental health crisis that so many families are going through.

(Families and Friends for Drug Law Reform, National, Submission #336)

In this submission Families and Friends for Drug Law Reform is calling on the Commission and Council to examine the link with mental illness or disorders of both illicit drugs and the measures taken in accordance with existing drug policy against those drugs. The evidence is there that the worsening crisis in mental health is largely contributed by this link. The demand for treatments and services is continuing to outstrip what is available. The suffering of those with mental health problems and their families intensifies.

(Families and Friends for Drug Law Reform, National, Submission #336)

Federally, the overlap of the problems of mental health and drug abuse is falling between stools. The National Mental Health Plan 2003-2008 shoves responsibility for drug and alcohol problems to the national drug strategy. For example, it states that: "In Australia, drug and alcohol problems are primarily the responsibility of the drug and alcohol service system and have a separate, but linked, national strategy" (AHM 2003, 5 &, similarly, 36).

(Families and Friends for Drug Law Reform, National, Submission #336)

The current National Drug Strategy 2004–2009 subtitled Australia's integrated framework states the platitude that mental health and drug services should work together:

- *"During this phase of the National Drug Strategy, action will be taken to…build strong partnerships between drug treatment services and mental health services to enhance responses to co-existing drug and mental health problems" (Ministerial Council on Drug Strategy, 2004, 7)*
- *and that "policies and programs" under the strategies be "integrated":*
- *"There will also be integration between the National Drug Strategy and other relevant strategies, for example, the National Supply Reduction Strategy for Illicit Drugs, the National Hepatitis C and National HIV/AIDS Strategies, the National Mental Health Strategy, the National Suicide Prevention Strategy, and the Aboriginal and Torres Strait Islander Peoples Complementary Action Plan. Such integration will ensure relevant trends in these areas are incorporated in the development of policies and programs under the National Drug Strategy" (Ministerial Council on Drug Strategy 2004, 11)*

(Families and Friends for Drug Law Reform, National, Submission #336)

This examination of the various links between mental health and abuse of illicit substances should not lead to a defeatist conclusion that treating effectively and humanely those with comorbid conditions is incompatible with policies that effectively reduce supply of dangerous drugs to young people. The Commission and Council, therefore, should consider what measures can reasonably be expected to make dangerous drugs associated with a mental illness or disorder less available.

(Families and Friends for Drug Law Reform, National, Submission #336)

After considering the negative impacts of current illicit drug policy on mental health, this submission examines three main obstacles to securing improvement. These is, firstly, a moral belief of dominating influence, though probably not widely shared, that overcoming addiction should take precedence over all other issues. Secondly, there is a fear that existing policies, whatever their negative effect, have worked to make dangerous drugs less available. In fact the net effect of existing policies is most probably to promote the distribution of illicit drugs among vulnerable populations. The third obstacle examined is the failure to be guided by the best available evidence in formulating measures to give effect to drug policy.

(Families and Friends for Drug Law Reform, National, Submission #336)

The absolutist view that addiction is the paramount evil is also inconsistent with the values reflected in human rights instruments.

(Families and Friends for Drug Law Reform, National, Submission #336)

Given the recognised links that exist between measures taken to implement existing drug policies and poor physical and mental health, aspects of such policies would seem to be inconsistent with art. 12 of the International Covenant on Economic and Social Rights which obliges parties to "recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health" and to take steps necessary for "the creation of conditions which would assure to all[,] medical services and medical attention in the event of sickness." Even more explicit provisions are found in art. 24 of the Convention on the Rights of the Child. It refers to "the enjoyment of the highest attainable standards of health and to facilities for the treatment of illness and rehabilitation of health". Drug policy bears heavily on children because a high proportion of children use illicit drugs. The 1999 national survey of secondary students found that 50% of 17-year-olds had used cannabis at least once and 12% used it weekly (White 2001). Over the years drugs have become more and more available to young people and more and more are using at a younger age.

(Families and Friends for Drug Law Reform, National, Submission #336)

6.9.8.3.4 The need for whole-of-government approaches to care for children who have been made wards of the state

One submission highlighted the need for the Government to adequately care, through a whole-of-government approach, for those children and adolescents placed in the State's care as this group of children have been identified as having higher rates of mental health problems and severe and enduring mental illness:

Research shows that more children under the care of the State ("looked after children") have mental health problems than other young people, including severe and enduring mental illness. (The Mental Health of Looked After Children, UK 2001 p. 2)

(The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

6.9.8.3.5 Training and support for General Practitioners

Concern was expressed by blueVoices and SANE Australia about the variability in availability and quality of treatment and support provided by General Practitioners across Australia. The need to increase accessibility to non-pharmacological treatments, either provided by training general practitioners or via referrals from general practitioners to psychologists under the Better Outcomes in Mental Health Care initiative, was also noted. In particular, SANE Australia noted that limitations on referrals to psychologists under Medicare, with the number of sessions limited to five and those with 'complex and chronic' mental illness. This would assist with early intervention and rehabilitation and recovery.

As has been recorded elsewhere, the majority of people who seek help for mental health problems do so through General Practice. The standard of General Practice has been reported as extremely variable with many practices not appearing to be particularly interested in caring for persons with a mental illness.

(blueVoices, National, Submission #355)

The Better Outcomes in Mental Health Care initiative would appear to have enhanced treatment for some persons, but it remains deficit in many areas of the country.

(blueVoices, National, Submission #355)

Recommendation: That a range of subsidised non-pharmacological interventions be made through General Practices to assist persons with Anxiety and Depression.

(blueVoices, National, Submission #355)

While our mental health system is in crisis, a number of positive initiatives by the Australian government deserve acknowledgement. Examples of praiseworthy individual programs include:

- *Better Outcomes for Mental Health. Twenty-five per cent of GP surgeries now have a doctor trained to provide mental health care (40% in rural areas).*
- *Medicare Plus. GPs can now refer people to a psychologist under Medicare – while welcome in principle, this is still only for those with 'complex, chronic needs' and limited to five sessions.*

(SANE Australia, National, Submission #302)

6.9.8.3.6 Lack of support from Centrelink

With limited access to mental health services, supported accommodation and access to early intervention treatment and support, the burden on families and carers to provide long-term and crisis support is immense. This often impacts on the financial income of the family by a reduced ability of carers to work. The shifting of care by governments to carers fails to recognise that carers are providing a significant service, the expense of which is not being shouldered by the community. Concerns were raised with regard to the financial hardship experienced by carers due to the lack of services in the community to provide appropriate treatment and support to people with mental illness and/or mental health problems:

There needs to be a significant recognition of the role of carers in assisting consumers in recovery and the significant financial hardship which some carers face through offering care needs to be recognised. Recommendation: That the Government review its approach in offering financial assistance to carers and that non-financial support for carers such as respite becomes readily available.

(blueVoices, National, Submission #355)

6.9.8.3.7 National legislative reform of anti-discrimination legislation to cover vilification and harassment

SANE Australia raised concern that anti-discrimination legislation needs to be amended to ensure that people with mental illness are protected against vilification and harassment. Currently, Tasmania is the only state to offer such protection.

In most parts of Australia it is unlawful under anti-discrimination Acts to vilify people on the grounds of race, religion, sexuality or gender identity. In NSW it is also unlawful to vilify people with HIV/AIDS. Under current Australian legislation, however (apart from Tasmania), people with a psychiatric or other disability do not enjoy this protection. It is totally unacceptable that vilifying the mentally ill remains a legal activity in mainland Australia.

(SANE Australia, National, Submission #302)

> *Anti-discrimination legislation excludes people with a psychiatric or other disability from protection against vilification and harassment (Tasmania excepted)…[Report recommendation] Legislative change at Federal and State levels to outlaw vilification and harassment of people with a psychiatric or other disability.*
>
> (SANE Australia, National, Submission #302)

6.9.9 STANDARD 9: SERVICE DEVELOPMENT

The MHS is managed effectively and efficiently to facilitate the delivery of coordinated and integrated services.

> *The National Mental Health Strategy is in retreat on many fronts, with old-style psychiatric institutions still in place, community-based services being drawn back into hospitals, prison psychiatric units being built instead of discrete forensic hospitals, and prisons becoming de facto psychiatric institutions.*
>
> (SANE Australia, National, Submission #302)

Under this Standard, submissions indicate concerns about:

- the current state of mental health services in Australia;
- loss of direction and lack of leadership and vision;
- the need for a national audit of mental health services;
- lack of community-based services and the crisis care model;
- re-institutionalisation: rising rates of people with mental illness in prisons and the transfer of community based care back to hospital settings;
- quality of care;
- inadequate funding;
- shortage of mental health professionals;
- staff attitudes – need for training;
- care for children of parents with mental illness and families neglected;
- public versus private sector – problems with access to care, type of care and affordability;
- affordability and health insurance;
- Pharmaceutical Benefits Scheme;
- care for children of parents with mental illness and families neglected;
- service development and increased funding for child and adolescent services urgently required;
- the need for more research; and
- accountability and quality improvement.

6.9.9.1 Current state of service delivery in Australia

Concern was expressed that since the Burdekin Report and the closure of institutions and promise of community care, the requisite treatment and support services have not materialised, resulting in inadequate services and a 'system lacking the basic ability to meet the needs of people with mental illness'. The following quotes highlight these problems:

> *MIFA has raised concerns with government about the inadequacy and imbalance in mental health services in Australia and the neglect experienced by many Australians as a consequence. Failure to address the structural and endemic problems of mental illness in Australian society is contributing to continued suffering by people with mental illness and those who care for them.*
>
> (Mental Illness Fellowship of Australia, National, Submission #331)

Since the National Mental Health Policy was signed by the Australian Health Ministers in 1992 to deinstitutionalise mental health care and move treatment of mental illness to a community based system, the community has had to attempt to establish some system of care with insufficient funding resulting in a system lacking the basic ability to meet the needs of people with mental illness. In an interview between the Hon Peter Costello MP and Alan Jones on 23 September 2004, the Treasurer openly admitted in relation to this policy of moving treatment into the community 'I don't think that policy has been a great success'.

(Carers Australia, National, Submission #276)

It must be recognised that a mental health system which does not meet the needs of consumers or provide basic human rights to treatment for mental illness, also has a severe and unrelenting impact on the families and carers of the consumer.

(Carers Australia, National, Submission #276)

We feel it is imperative that we bring the subject if mental illness into the political arena particularly now, since in our opinion, in our opinion, mental health no longer appears to be a high priority on any political parties agenda. It is crucial that all politicians of all political parties are aware of this situation and take active steps to address this issue.

(The National Network for Private Psychiatric Sector Consumers and Carers, National, Submission #225)

The extensive impact of mental illness in Australia is also reflected in joint research by the MHCA and The Australian Foundation for Mental Health Research, ANU in their publication 'Mental illness: every family in Australia is at risk'. In this publication it is reported that approximately one in five people in Australia will experience mental illness each year and that 'two-thirds of all disability in people aged 15-30 is caused by mental illnesses'. The report notes, significantly, that 3.1 million people are affected by mental illness each year and approximately 62% of these people do not receive treatment for their illness. This leaves approximately 1.9 million untreated people each year either in the care of family and friends, or left to deal with their illness on their own.

(Carers Australia, National, Submission #276)

The Carers of People with Mental Illness Project, completed through a partnership between Carers Australia (known as Carers Association of Australia Inc at the time of publication) and the Mental Health Council of Australia had the aim to identify actions to better support and recognise carers of people with mental illness in Australia. It was revealed in the final report of the project that 'individual carers on average contribute 104 hours per week caring for a person with mental illness' and 'that it is primarily [unpaid] carers who are sustaining the fabric and operational effectiveness of mental health service systems across Australia'. The report also identified that carers of people with mental illness 'are experiencing undue responsibilities and pressures in their caring roles due to significant gaps or inadequate practice in formal consumer mental health service delivery'. This was reflected recently by stories told in the ACT consultation by HREOC and the MHCA, when families presented tragic situations of being ignored by the mental health service when trying to seek help and provide information to the service, being unable to obtain support from crisis teams in emergency situations and ultimately bearing the guilt and overwhelming helplessness when the consumer took their own life.

(Carers Australia, National, Submission #276)

Australia's National Mental Health Strategy is in disarray and in urgent need of reform: in leadership, additional funding and delivery of services

(SANE Australia, National, Submission #302)

The first SANE Mental Health Report, released in 2002, found Australia's mental health system far from 'reasonable' – close to collapse, and urgently in need of revitalisation and additional resources in order to do its job. Since that date there have been at least six major inquiries into mental health services in Australia [Mental Health Council of Australia: Out of Hospital, Out of MindReport; NT - Department of Health and Community Services: Bansemer Review; SA - Ombudsman: Inquiry into Treatment of Mental Health Patients; Victorian Auditor General: Mental Health Services for People in Crisis; NSW Legislative Council: Inquiry into Mental Health Services'; WA - Legislative Council: Inquiry into Mental Health Services]. All of these have uncovered gross underfunding and mismanagement, confirming the first SANE Mental Health Report's conclusions. The plethora of inquiries in a two-year period provides clear proof that this is not simply a State or Territory-specific issue, but that Australia's mental health system is dysfunctional at a national level. The 2004 SANE Mental Health Report finds that the National Mental Health Strategy is in crisis, with services in disarray and in need of urgent reform.

(SANE Australia, National, Submission #302)

6.9.9.2 Loss of direction and lack of leadership and vision

SANE Australia expressed concern that stigma surrounding mental illness is also having an impact on politicians and the prioritisation of mental health within the political arena. SANE Australia commented that the mental health system has lost direction and is working in an ad hoc manner that is inconsistent with the aims and strategies enshrined in the National Mental Health Strategy and needs to refocus:

Stigma is systemic in decision-making at the highest political levels. Ultimate responsibility for mental health services lies with government leaders at Federal and State levels. It is they who have ensured these services have had such a low priority in policy-making and funding. Federal government has a national responsibility to challenge this institutionalised stigma and lead reform, as it did in the early 1990s.

(SANE Australia, National, Submission #302)

Lack of direction. Health Minister, Tony Abbott, has shown disappointing lack of interest and leadership in this area. There is no longer a Branch dedicated solely to Mental Health in his Department, he has delegated the issue to his Parliamentary Secretary and failed to acknowledge that the crisis in mental health services requires any action from him. From January 2004 up to the Federal Election in October, Hansard shows he spoke over 400 times in Parliament; in all this time he mentioned mental health services just once, in answer to a question.

(SANE Australia, National, Submission #302)

[Report recommendation] Leadership by the Australian government of all States and Territories in reform of the National Mental Health Strategy to focus on:

- *closure of all psychiatric institutions, and properly-funded implementation of community-based care for all those in need*
- *national strategies for early intervention, dual diagnosis, and treatment of borderline personality disorder*
- *Medicare-funded access to psychological treatments provided by clinical psychologists*
- *forensic mental health services to replace prison psychiatric units*
- *urgent action to recruit and retain mental health professionals*
- *genuine involvement of consumers and carers in planning services.*

(SANE Australia, National, Submission #302)

6.9.9.3 The need for a national audit of mental health services

The Mental Illness Fellowship of Australia expressed concern regarding the service inequities between states and territories. It was suggested that a national audit was required to determine compliance with agreed national strategies and targets and assist with service delivery and planing and ensuring equality across Australia:

> *MIFA (Mental Illness Fellowship of Australia) has called on government for a national audit of services across states and territories. The gross service inequities between states – evident in many reports and in verbal feedback from consumers and carers - is evidence of failure by a number of states to comply with agreed national strategies. These inequities could be exposed and highlighted by an national audit of state and territory compliance with national targets for mental health.*
>
> (Mental Illness Fellowship of Australia, National, Submission #331)

6.9.9.4 Lack of community-based services and the crisis care model

Concern was expressed that due to the lack of community based treatment and support services, including early intervention and rehabilitation, people with mental illness must wait for their mental health to deteriorate to a point where acute care is necessary. Additionally, due to the demand for such care and the lack of beds, early discharge and the lack of rehabilitation programs, a system of 'revolving door' admissions is perpetuated.

The crisis model as the basis for the planning and delivery of treatment and support services is seen as failing to promote or protect the rights of people with mental illness or those of their families and carers, and as indicated by the Mental Illness Fellowship of Australia, is considered a more costly model for the health system. Carers Australia also expressed concern that this model relies on the burden of care being shifted to carers without adequate recognition or support for their role. The following quotes describe the situation:

> *A constant catch-cry in feedback is the lack of community services. Failure to provide adequate community services perpetuates a revolving door outcome for the acute sector. There are numerous studies which demonstrate that well-structured community and support services are cost-saving to the health system in the long term.*
>
> (Mental Illness Fellowship of Australia, National, Submission #331)

> *[Report recommendation] Implementation of evidence-based, recovery-focused rehabilitation, supported accommodation and employment services for people affected by mental illness, as well as education, training and support for family and other carers through coherent national strategies and provided by non-government organisations.*
>
> (SANE Australia, National, Submission #302)

> *What this information does not reflect is where the burden of care rests, when the community-based system of care fails to provide adequate care to persons with mental illness. The answer in many cases is the hidden workforce of the mental health sector, the carers and families of the person with mental illness. This is in stark contrast to the second aim of the National Mental Health Policy 'to reduce the impact of mental disorders on individuals, families and the community'.*
>
> (Carers Australia, National, Submission #276)

Mental illness has the potential to impact every family in Australia at some stage. With mental illness representing approximately 20% overall disease burden in Australia, the contribution that carers already make in mental health care is enormous, saving the government and communities economically in the short term. However, the continued lack of professional treatment and available support services in mental health can only result in an increase in the cost of this disease to the government in the future and increased pressure on the families and carers of people with mental illness. In reviewing the provision of mental health care in Australia, the significant impact on the families and carers of a person with mental illness must also be counted.

(Carers Australia, National, Submission #276)

6.9.9.5 Re-institutionalisation: rising rates of people with mental illness in prisons and the transfer of community based care back to hospital settings

SANE Australia expressed concern regarding recent decisions to relocate some community based services to hospital sites, primarily for financial reasons. It was suggested that this effectively "re-institutionalises" services and works against all the aims of community based service delivery.

The increasing rate of incarceration of people with mental illness is also suggested as another form of "re-institutionalisation". This pattern will undermine stigma reduction campaigns and do little to assist with access to a variety of treatment and support services in the community or the promotion of the rights of people with mental illness to participate socially and economically.

Re-institutionalisation. The National Mental Health Strategy was launched in 1992 to transfer services from an institutional to a community setting. After 12 years, four of the five mainland States still have standalone psychiatric hospitals! These institutions continue to soak up around $420 million a year – 14% of the entire cost of mental health services of around $3 billion per annum. In several States, community-based services are being withdrawn onto hospital grounds to make short-term savings. Prisons are also becoming de facto psychiatric institutions – in NSW, for example, 46% of inmates at reception have a mental disorder, and the prevalence of psychosis is 30 times greater than the norm.

(SANE Australia, National, Submission #302)

Re-institutionalisation: The pulling back of 'community services' into hospitals is an increasingly popular short-term cost saving measure which contributes to de facto reinstitutionalisation of mental health care in Australia. The SANE Mental Health Report recommends immediate comprehensive implementation of genuine community-based clinical services.

(SANE Australia, National, Submission #302)

6.9.9.6 Concerns about the quality of care

Associated with the concerns expressed elsewhere in this report regarding the lack of services, staff and funding, were concerns regarding the quality of those services which are operating.

Service delivery = Crisis management. Despite carefully non-specific language in policy documents about 'quality of care', ordinary Australians – as this Report [Dare to Care! SANE Mental Health Report 2004] shows – daily endure the distress of inadequate services.

(SANE Australia, National, Submission #302)

Mental health services are in crisis to varying degrees all around Australia, barely able to cope with people experiencing acute episodes of illness, let alone provide ongoing treatment and support.

(SANE Australia, National, Submission #302)

The standards of service vary from adequate to excellent in the major cities around this country, to almost nothing existing in rural Australia. When services can be accessed, the issue of the quality of the service offered has caused us some concern.

(blueVoices, National, Submission #355)

6.9.9.7 Inadequate funding

Associated with the complaints of lack of community based services, are requests and demands that the level and control of funding needs to change in order that appropriate services are delivered and the rights of people with mental illness are protected. Funding issues were raised both with regard to Federal Government contributions to the health budget and the provision of support services for people with mental illness and their families and carers:

…the issue of inadequate funding to mental health services is a major concern. Compared to other OECD [Organisation for Economic Co-operation and Development] countries Australia is falling behind in the level of funds to mental health and the distribution of those funds. As an example New Zealand has increased their overall funding to mental health by 174% in nominal terms over the last decade and by 6.8% in the year 2002/2003. 28% of funds go to services provided by NGOs and 69% of funds are spent on community services with only 31% spent on in-patient services. Australia urgently needs to increase the overall funding to mental health in line with best practice in OECD countries and to avoid being classed as having a 'banana republic mental health system'.

(Mental Illness Fellowship of Australia, National, Submission #331)

Funding to meet the need for mental health services: Funding of mental health services is inadequate in all jurisdictions. The Australian government needs to take the lead in reforming the National Mental Health Strategy to 'bite the bullet' and tackle this at a national level. The SANE Mental Health Report recommends the Australian, State and Territory governments conduct a comprehensive review of funding mechanisms for mental health services and implement a coherent, national, population-based funding model to meet the urgent need for improved clinical and community support services.

(SANE Australia, National, Submission #302)

Underfunding in health services have too often led to a lack of effective treatment for our relatives.

(Carer, Anonymous, Submission #224)

Families who care for their relatives would also be able to function more effectively to reduce the costs on the national purse if more funds were made available to these services.

(Carer, Anonymous, Submission #224)

Unless Australia increases its mental health budget from 5 - 7% to at least 17%; as recommended by the WHO inadequacies will continue to plague the Mental Health System in years to come.

(Carer, Anonymous, Submission #224)

The prevalence of mental health problems and disorders in children and young people in Australia is significant and represents a large public health problem. AICAFMHA believes greater investment is required for infants, children, adolescents and their families within the mental health system.

(The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

Current research evidence emphasises the cost effectiveness of intervening in the early years. However the funding allocated to child and adolescent mental health does not currently reflect the proportion of the population comprising children and young people and is significantly less than funding allocated to adult services.

(The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

Within the mental health funding system there is a lack of equity in the way funds are divided, with the child and adolescent mental health services receiving approximately 7% of the mental health dollar to service 30% of the population.

(The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

Support for the non-government sector: Supported accommodation, rehabilitation, respite, employment support, help and training for carers….all of these are just as important as clinical care yet receive minimal funding in most States. The SANE Mental Health Report recommends that the essential role of non-government organisations be recognised, and that they be adequately funded to provide supported accommodation and other services at a level which meets need in the community.

(SANE Australia, National, Submission #302)

[Report recommendation] An increase in the proportion of the health budget allocated to mental health services, from 8% to at least 12%.

(SANE Australia, National, Submission #302)

Despite the welcome increase in the mental health budget, almost all of this has gone to fund clinical services. Support for non-government organisations has increased too, but only accounts for around 5% of the budget.

(SANE Australia, National, Submission #302)

6.9.9.8 Shortage of mental health professionals

Associated with the lack of services are reports of an excessive demand for the services that exist, and reports that these services often had difficulties recruiting and retaining staff. The shortage of mental health nurses was particularly noted:

The shortage of psychiatric nurses and other mental health professionals is a major issue. Low recruitment and retention is due in part to perceived low status, inadequate training and extreme workloads.

- *Average age of a psychiatric nurse (2004) 46 years*
- *% of nursing graduates entering mental health system 4%*

The SANE Mental Health Report recommends that this workforce issue be urgently addressed at a national level.

(SANE Australia, National, Submission #302)

6.9.9.9 Staff attitudes – need for training

Concerns were expressed about poor attitudes by some staff towards consumers and carers, suggesting that these staff members may be in need of training in order to change their attitudes and behaviours and be more supportive when dealing with people with a mental illness:

People with mental health disorders are at times treated as idiots. People who've been professionals and for whatever reason have gone "off the road" so to speak. Whether they've had a split from a relationship, have been in a severe accident or the like, there is a tendency for mental health staff to treat people such as this as stupid, when in reality they are often in agony yet still quite capable.

(Consumer, Anonymous, Submission #133)

In my experience I'd say there is a place for psychiatry, however a limited place. There are other ways and at times it's more healing to be away from mental health staff who have had such different lives and advantage compared to those who are seeking their help.

(Consumer, Anonymous, Submission #133)

I go one step further to suggest that it should be made mandatory for all health professionals working in the Mental Health System to attend Carer Support Group meetings as part of their training.

(Carer, Anonymous, Submission #224)

In many settings there appears to be no multi-disciplinary approach to care, and in some cases, the seeking of care can be further stigmatised by the attitudes of the treating mental health care professionals.

(blueVoices, National, Submission #355)

It is further recommended that all staff who work in Health Care facilities are educated around the impact of mental health care problems, and how to work with Consumers and Carers who are experiencing these problems.

(blueVoices, National, Submission #355)

In order to decrease stigmas [sic] in health care settings, a program be devised and implemented to educate staff at all levels on issues pertaining to mental health care. Attendance at these training courses must be compulsory and should be seen as part of the orientation of all staff to their position.

(blueVoices, National, Submission #355)

It is further recommended that the helping profession become well versed in the needs of carers in their role of care and support for consumers and that carers become seen as vital members of the health care team.

(blueVoices, National, Submission #355)

6.9.9.10 Public versus private sector – problems with access to care, type of care and affordability

The National Network for Private Psychiatric Sector Consumers and Carers outlined significant concerns regarding access and type of care in both the public and private sectors, affordability of care and concerns for the future:

The following issues are of grave concern to us…A significant number of same-day hospital based psychiatry services require a co-payment to be met by the consumer, as the full cover of the services are not met by certain levels of cover offered by private health insurance funds. This effectively limits access to those services. If these co-payments increase, then some consumers will have to consider the option of dropping their private health insurance cover thus placing more strain on the public system. (author's emphasis)

(The National Network for Private Psychiatric Sector Consumers and Carers, National, Submission #225)

The Private sector treats a significant number of Australians suffering from a mental illness or disorder and over 60% of people receive their treatment and care in a private sector setting. According to the Australian Institute of Health and Welfare, in 2002-2003, private hospitals provided 68% of all same-day mental health services, 43% of all hospital-based psychiatry services, and treated almost 100,000 consumers. Additionally, private hospitals provided 91% of all same-day alcohol use disorder and dependence services.

(The National Network for Private Psychiatric Sector Consumers and Carers, National, Submission #225)

We understand that no one system, public or private can do everything in health care, or for the significant number of people who receive treatment and care in a private sector setting. The private sector is however, striving to meet growing community expectations about access, safety, affordability, choice and equality.

(The National Network for Private Psychiatric Sector Consumers and Carers, National, Submission #225)

The following issues are of grave concern to us… We hold concerns regarding the ***deregulation of the private health industry*** *and the impact this may have on mental health consumers and carers. (author's emphasis)*

(The National Network for Private Psychiatric Sector Consumers and Carers, National, Submission #225)

We are indeed anxious to avoid the disastrous experiences of other countries, which in our view will only be achieved when the viability of the private mental health system in Australia is both sustained and improved.

(The National Network for Private Psychiatric Sector Consumers and Carers, National, Submission #225)

In particular, the maintenance of the private health insurance rebate, the integrity of the PBS [Pharmaceutical Benefits Scheme], and the availability of atypical antipsychotic medications are crucial to sustaining the viability of the private mental health system and the care it is able to deliver.

(The National Network for Private Psychiatric Sector Consumers and Carers, National, Submission #225)

6.9.9.11 Affordability and health insurance

The National Network for Private Psychiatric Sector Consumers and Carers expressed concern regarding the private health rebate, capping of services and the cost of private health insurance and the impact of these on access to care:

*Maintaining the **private health rebate** – it is crucial to the ongoing viability of the private health insurance industry that the private health rebate be maintained to ensure private health insurance remains available to all Australians. (author's emphasis)*

(The National Network for Private Psychiatric Sector Consumers and Carers, National, Submission #225)

*The following issues are of grave concern to us…The integrity of private health insurance is based on **choice** – the current Minister for Health and Ageing has given a commitment that there will be no further "rule changes" to allow health funds to require people transferring from an existing health insurance fund to another on the same level of cover to serve a further waiting period of 12 months for psychiatric care. This commitment should be maintained by Federal Government. (author's emphasis)*

(The National Network for Private Psychiatric Sector Consumers and Carers, National, Submission #225)

***Capping** of services by some health funds is in direct contravention to good care. Are persons with an ongoing physical illness, such as kidney failure, penalised by having a cap placed on their service? (author's emphasis)*

(The National Network for Private Psychiatric Sector Consumers and Carers, National, Submission #225)

Some of the people we represent put the cost of health insurance before food and clothing, so that they can be treated in private sector settings.

(The National Network for Private Psychiatric Sector Consumers and Carers, National, Submission #225)

6.9.9.12 Pharmaceutical Benefits Scheme

The National Network for Private Psychiatric Sector Consumers and Carers expressed concern about any changes to the Pharmaceutical Benefits Scheme:

*The following issues are of grave concern to us…The integrity of the **Pharmaceutical Benefits Schedule (PBS)** must be maintained and the costs of medications must not be compromised. (author's emphasis)*

(The National Network for Private Psychiatric Sector Consumers and Carers, National, Submission #225)

6.9.9.13 Care for children of parents with mental illness and families neglected

The wide range of programmes recommended in the Burdekin report to meet children's and families' varying needs (e.g. during a parent's hospital admission, ongoing support after their discharge and a range of home based, centre-based, school based and community-based activities) are currently not available to children and families in any Australian State or Territory.

(The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

Concern was expressed by The Australian Infant, Child, Adolescent and Family Mental Health Association regarding the lack of coordinated and integrated services for children of parents with mental illness across Australia and that great disparity existed between various States and Territories. In addition to the lack of wide range of programs discussed in the quote above, problems with data collection procedures and interagency collaboration and planning were also mentioned:

> *It is through this aspect of AICAFMHA's work that we have become aware of vast discrepancies between jurisdictions in their response to the needs of children, parents and families affected by mental illness.*
> (The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

> *Despite the specific recommendations of the Burdekin report relating to children of parents with a mental illness (pages 927- 928), mental health services and professionals still do not consistently seek and record information about dependant children in cases where people present for treatment for a mental illness. As a result, the number of dependant children of people seeking mental health services in Australia remains unquantifiable.*
> (The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

> *In most States and Territories government departments such as health, education, family services and community services do not cooperatively plan, develop, fund and implement services for parents affected by mental illness and their dependant children and in the States where this does occur, many of the programmes have short-term funding only.*
> (The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

> *Where government has allocated resources to non-government agencies to provide programs for children and family members where there is a mentally ill parent, this has also often been on a time-limited project basis only. In consultations with family members and service providers alike we have heard of successful programmes being discontinued, or being unavailable to people living outside of particular geographic areas or of applying restrictive age-limits for participants.*
> (The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

> *The challenge for service providers across a range of jurisdictions remains the same as it was in 1993; to work together to promote mental health of these children, prevent problems occurring and intervene early when and if issues are identified. The 'Principles and Actions for Services and People Working with Children of Parents with a Mental Illness' document calls for service providers tostrengthen and support families and children to enhance protective factors that contribute to the parents' and children's mental health, and identify and reduce risk factors in parents with a mental illness, their family and community that contribute to their children's health, well-being and safety.*
> (The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

6.9.9.14 Service development and increased funding for child and adolescent services urgently required

The Australian Infant, Child, Adolescent and Family Mental Health Association raised serious concerns about the scarcity of services, lack of funding and lack of planning to provide appropriate treatment and support services for children and adolescents with mental illness and/or mental health problems:

> *Current research evidence emphasises the cost effectiveness of intervening in the early years. However the funding allocated to child and adolescent mental health does not currently reflect the proportion of the population comprising children and young people and is significantly less than funding allocated to adult services. There are also significant socioeconomic inequalities in infant, child and adolescent mental health, including inequities in accessing services.*
> (The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

Recognition of Developmental Milestones and Specific Needs. Children are not small adults. They have particular emotional, social and physical needs that should be considered within a child focused developmental framework. Services should be designed specifically for children that work within this framework and addresses these specific needs

(The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

It should be noted that unlike adult mental health services where there is a higher need for inpatient beds, the majority of child and adolescent mental health problems can be treated effectively in community settings, including clinic-based and more intensive outreach models.

(The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

In Australia, the majority of CAMHS [Child and Adolescent Mental Health Service] inpatient facilities have an age criteria of 0-18 years. AICAFMHA believes that state governments in the respective jurisdictions should seriously consider allowing flexibility with this upper age range and where appropriate allow a young person to continue to receive services from the child and adolescent focussed facility until they attain the age of 19 years.

(The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

In a similar way AICAFMHA believes that adult mental health services also need to be able to exercise some flexibility to allow young people over the age of 16 years who are developmentally mature, early access to an adult mental health facility, in line with the criteria outlined by the Royal College of Psychiatrists. AICAFMHA recognises that this has funding implications and therefore further analysis of the number of young people that are likely to utilise these more flexible arrangements would need to be determined.

(The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

Specific services for young adults in the 18-25 age range, that takes into account their legal status as adults, should be developed to cater for young adults with early psychosis.

(The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

The National Action Plan for Promotion, Prevention and Early Intervention for Mental Health 2000 identifies key locations for action in the early childhood and childhood years as "childcare settings, preschools, primary health care settings, community, sport and recreation settings, schools, child and family welfare services and mental health services". This document recognises the need to design interventions that are available and linked to the multiple environments that a child or young person may access. Building the capacity of these communities to respond appropriately and effectively to children and young people who may be experiencing mental health problems will enable delivery of the most effective intervention.

(The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

Most mental health problems experienced by children and young people can be effectively managed by community based services, in clinic-based and outreach models of care. Only a relatively small number of infants, children and young people require hospitalisation or access to hospital emergency departments for mental health problems.

(The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

AICAFMHA supports the development and expansion of a system of care that addresses the needs of infants, children and young people along the developmental spectrum and across different service sectors. AICAFMHA also believes that wherever possible young people should be treated within the context of their family within a community setting.

(The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

6.9.9.15 Need for more research

Standard 9.31 states: 'The MHS conducts or participates in appropriate research activities' and Standard 9.30 states: 'The MHS routinely monitors health outcomes for individual consumers using a combination of accepted quantitative and qualitative methods'. Concern was expressed that more funding needs to be allocated to research to potentially reduce demands on health and welfare services, improve treatment options and service delivery and identify causative factors:

> *Australia has contributed to groundbreaking research in the neurosciences. Adequate funding to enable Australia to continue such research is vital. Successful research outcomes have the potential to reduce demand on the health and welfare systems as improvements in treatments are realised and causative factors are identified.*
>
> (Mental Illness Fellowship of Australia, National, Submission #331)

> *A more targeted approach to guide research activities is required. For example, in the United States, the National Institute of Mental Health has established a blueprint for research priorities in the area of child and adolescent mental health (Hoagwood & Olin, 2002). This targeted approach to developing a clear research agenda would be an excellent action step to complement the broad statements made in this section.*
>
> (The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

> *Implicit in measuring progress is the need to ensure that indicators are appropriate across the lifespan. For example there would be little point in just asking child and adolescent mental health services to report on Primary Care with General Practitioners when an equal amount of their work should be with School Counsellors.*
>
> (The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

6.9.9.16 Accountability and quality improvement

Standard 9.28 states: 'There is documented accountability for the evaluation of the MHS' and Standard 9.29 states that the service evaluation strategy should 'promote participation by staff, consumers, carers, other service providers and the defined community'. Consumer health outcomes are to be routinely monitored using a combination of accepted quantitative and qualitative methods (Standard 9.30).

However, concern was expressed that current systems to evaluate services, measure outcomes and ensure quality improvement for all consumers, including children and adolescents, are inadequate. SANE Australia suggested the establishment of a Mental Health Commission to monitor and report effectiveness of mental health services:

> *AICAFMHA strongly supports the need for accountability. It also supports the development of specific indicators for progress against the Mental Health Plan 2003-08. AICAFMHA recognises that the National Mental Health Report provides a comprehensive overview of mental health service activity in Australia, however this document is primarily focussed on the activities of adult mental health services.*
>
> (The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

> *AICAFMHA supports commitment to community capacity building to enhance sustainability of effective mental health promotion, prevention and early intervention programs through a capable and supported worker base, enhanced by systems which identify and disseminate good practice within the existing mental health promotion framework.*
>
> (The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

[Report recommendation] Establishment of a National Mental Health Commission to monitor and report on effectiveness of mental health services.

(SANE Australia, National, Submission #302)

6.9.10 STANDARD 10: DOCUMENTATION

Clinical activities and service development activities are documented to assist in the delivery of care and in the management of services.

No submissions or comments were received pertaining to this Standard.

6.9.11 STANDARD 11: DELIVERY OF CARE

Principles guiding the delivery of care: The care, treatment and support delivered by the mental health service is guided by: choice; social, cultural and developmental context; continuous and coordinated care; comprehensive care; individual care; least restriction.

6.9.11.1 Access

The MHS is accessible to the defined community.

Under this Standard, submissions indicate concerns about the inability of consumers to access treatment and support services, even when in crisis.

6.9.11.1.1 Inability to access services, even when in crisis

Standard 11.1.2 states: 'The community to be served is defined, its needs regularly identified and services are planned and delivered to meet those needs and Standard 11.1.4 states: 'The MHS is available on a 24 hour basis, 7 days per week'.

Serious concern was expressed that not only are treatment and support services difficult to access when needed throughout the course of illness, but that access is also difficult even when consumers are experiencing a crisis or at risk of harm to self or others. One carer stated that her son had to be 'at deaths door' before access was granted and that access was difficult even though she could afford to pay for services if required:

Sadly it is too late for my son who died at the age of 30, 8 weeks ago. For ten years I tried to get help for him, but it seemed he had to be at deaths door for anyone to do anything. As a mother I knew how serious his condition was, but they just kept saying not bad enough. I found in all that time no support from the medical profession, even though I was better off then most people in that I could pay. It is tragic to just watch your child with mental pain, and drugs suffer and have no where to turn…if it had been physical, cancer, a broken leg, I would have had as much care as I needed.

(Carer, Mother, National, Submission #164)

6.9.11.2 Entry

The process of entry to the MHS meets the needs of the defined community and facilitates timely and ongoing assessment.

No submissions or comments were received pertaining to this Standard.

6.9.11.3 Assessment and review

Consumers and their carers receive a comprehensive, timely and accurate assessment and a regular review of progress.

No submissions or comments were received pertaining to this Standard.

6.9.11.4 Treatment and support

The defined community has access to a range of high quality mental health treatment and support services.

> *Consumers and carers want treatments available that give them choice.*
>
> (blueVoices, National, Submission #355)

Under this Standard, submissions indicate concerns about:

- lack of treatment and support services for people with dual diagnosis – mental illness and drug and alcohol problems;
- problems with treatment and support services for people with mental illness in the criminal justice system;
- lack of services for people with mental illness and/or mental health problems who have a hearing impairment;
- lack of mental health services in rural and remote areas, especially for children and adolescents;
- lack of appropriate treatment and support services for Indigenous people with mental illness and/or mental health problems;
- lack of treatment and support for people diagnosed with Personality Disorders;
- carers are not being heard or involved in the planning of treatment and support; and
- lack of support services for families post-suicide.

6.9.11.4.1 Lack of treatment and support services for people with dual diagnosis – mental illness and drug and alcohol problems

Standard 11.4.7 states: 'The MHS ensures access to a comprehensive range of services which are, wherever possible, specialised in regard to dual diagnosis' including dual case management with alcohol and other drug services.

Concern was expressed that there are an insufficient number of services to provide treatment and support, either directly or in dual management with alcohol and other drug services, to people with mental illness and drug and alcohol problems. As the following quotes highlight, treatment and support services are struggling to cope with the demand and to work together, and an increasing number of consumers continuously 'fall between the gaps':

Drug dependency and mental illness or disorders work on each other. The difficulties flowing from one – the distress, economic hardship, stigma and shame – magnify the difficulties of the other. The scarcity and inadequacy of services for one are even more so for people with both conditions. The predicament of families known to Families and Friends for Drug Law Reform where a member is dependent on illicit drugs is often desperate. Their predicament is aggravated more than twofold where comorbidity with a mental illness or disorder is involved. The mental illness or disorder we refer to is over and above that of substance dependence that is regarded as a mental disorder (Ward et al. 1998, 419; FFDLR 2004, para. 6).

(Families and Friends for Drug Law Reform, National, Submission #336)

The co-occurrence of mental illness and substance abuse is a growing problem in services and creates a huge problem for carers. Close to two-thirds of all people admitted to the acute sector with a mental illness have a co-occurring substance use problem. Effective treatment regimes with a focus on rehabilitation provided in a collaborative model between mental health and drug and alcohol services is essential.

(Mental Illness Fellowship of Australia, National, Submission #331)

In order to cope with crises, scarce resources are being siphoned away from already chronically underfunded services providing low and medium level interventions – that is, from most cost effective to least cost effective interventions. Of course, this deprivation of resources from where needs are low or medium leads more people into crisis thus compounding the health, social and fiscal problems.

(Families and Friends for Drug Law Reform, National, Submission #336)

It is clear that much still needs to be done to "build strong partnerships" between treatment services but however well mental health and drug treatment services work together there is only so much that they can do. For one thing the demand on resources to fund the ever increasing demand for services is already becoming unsustainable. Therefore, an important focus of the Council's and Commission's inquiry should be how policies and programs should be integrated so as to minimise the distress that is already so evident of mental illness or disorders associated with drug abuse.

(Families and Friends for Drug Law Reform, National, Submission #336)

What is more, all the evidence points to a high and still increasing level of comorbid substance abuse and mental illness or disorders. "The use of illicit drugs such as cannabis and psychostimulants such as amphetamines and cocaine is … higher amongst young adults with severe mental illness compared to either the general population or to other psychiatric comparison groups" (Baker et al. 2004, 155).

(Families and Friends for Drug Law Reform, National, Submission #336)

This is putting more pressure on the health system and families than they can bear.

(Families and Friends for Drug Law Reform, National, Submission #336)

"Hospital morbidity data show a dramatic rise in the number of psychotic disorders due to psychostimulant use from 200 in 1998-99, to 1,028 in 1999–2000 and a further but smaller increase to 1,252 in 2000-01" (ibid., 156).

(Families and Friends for Drug Law Reform, National, Submission #336)

6.9.11.4.2 Problems with treatment and support services for people with mental illness in the criminal justice system

Standard 11.4.7 states: 'The MHS ensures access to a comprehensive range of treatment and support services which are, wherever possible, specialised in regard to…consumers who are subject to the criminal justice system'.

Concern was expressed regarding the lack of separate facilities to provide treatment and support to people with mental illness or mental health problems who have become subject to the criminal justice system. In the absence of separate forensic facilities, housing of these consumers with the general prison population was described as an inappropriate environment in which to receive treatment and support:

> *It is reasonable to conclude that many with a mental illness or disorder find themselves in prison as a result of their drug problem. The prison environment is about the worst environment they could be in. Families and Friends for Drug Law Reform can do no better than quote the words of Professor Paul Mullen, Professor of Forensic Psychiatry at Monash University and Clinical Director of the Victorian Institute of Forensic Mental Health, which attest to this:*
>
> > *"The correctional culture and the physical realities of prisons are rarely conducive to therapy. Rigid routines, the pedantic enforcement of a plethora of minor rules, the denial of most of that which affirms our identity, add to the difficulties of managing vulnerable and disordered people. Separation and seclusion are all too often the response of correctional systems to troublesome prisoners, irrespective of whether those difficulties stem from bloody mindedness, distress, mental disorder or even suicidal and self damaging behaviours. Hierarchy and coercion which tends to rule in the official structure is often mirrored in the subculture of the prisoners. Mental disorders and intellectual limitations are frequently constructed by staff and prisoners alike as a sign of vulnerability and vulnerable is not a safe label to wear in prison. Those who do seek mental health treatment are at risk of being seen by staff as attempting to evade the rigours of prison, and by fellow prisoners as weak and unacceptably alien. Prisons and jails are intended to be punishing and they provide hard and unforgiving environments which often amplify distress and disorder. Equally however they provide remarkably predictable environments with clear rules and limited but well delineated roles. Some mentally disordered individuals thrive in this world stripped of the contradictions and complexities of the outside world. Sadly thriving in total institutions is rarely conducive to coping in the community" (Mullen 2001, 36)*
>
> (Families and Friends for Drug Law Reform, National, Submission #336)

> *Forensic services: When mental health services are inadequate, people affected by mental illness are often failed by other social services too (such as drug and alcohol services) and end up in prison. This should not be allowed to happen in Australia. The SANE Mental Health Report recommends humane treatment and rehabilitation-oriented forensic services be established in each State and Territory, with in-patient units located and managed totally separately from the prison system.*
>
> (SANE Australia, National, Submission #302)

6.9.11.4.3 Lack of services for people with mental illness and / or mental health problems who have a hearing impairment

Contrary to Standard 11.4.7, concern was expressed that consumers who have a hearing impairment were experiencing excessive difficulty in accessing appropriate treatment and support services to meet their mental health needs:

> *"Most of the clients here do have mental health issues. They do. And they're not being resolved. We refer [people] to mental health services and I've gone there to the interview with them and given [staff] the background, but they tend to treat [hearing impaired people] the same as a hearing person. They give them… stress management stuff and its always sounds 'Listen to music, sounds crashing onto the beach, etc.' It's not modified to suit deaf or hearing impaired people." (Queensland Health, 2001, Deafness and Mental Health A Report on the Mental Health Needs of Deaf and Hearing Impaired People in Queensland, Mental Health Unit: Queensland Health, p.10.)*
>
> (Deafness Forum Australia, National, Submission #267)

"A close friend of my daughter, a girl she grew up with, has been in the Sutherland Hospital psychiatric ward for over a month now with a mystery illness / disorder. It is heartbreaking to see a beautiful thirty-year-old woman in such a bad way. It would be infinitely worse if she had a hearing disorder. How do the relatives and carers of Hearing Impaired (HI) / Deaf psychiatric patients survive? How do medical professionals converse with psychiatric patients? Does anybody care? I can still remember when the government made the decision to basically empty out our psychiatric institutions. It was a terrible decision that created an under-class of lonely street people that live day to day without adequate support or care. Some of those people will be hearing impaired, or have a chronic ear disorder such as Tinnitus." (Person with chronic ear disorder).

(Deafness Forum Australia, National, Submission #267)

For those that are already deaf, hearing health can go beyond the ears. Deafness and hearing impairment can impact on mental health and this goes largely ignored by the medical establishment.

(Deafness Forum Australia, National, Submission #267)

If nothing else, a person with a mental health problem, who also has a hearing loss, would be in an extremely difficult situation.

(Deafness Forum Australia, National, Submission #267)

"Hearing Impaired elderly report significantly more depressive symptoms, lower self-efficacy and mastery, more feelings of loneliness, and a smaller social network than normally hearing peers. Whereas chronic diseases show significant associations with some outcomes, hearing impairment is significantly associated with all psychosocial variables." (A study of over 3000 people, aged 55 to 85, with a variety of chronic diseases including hearing impairment, investigating links with psychosocial variables by Kramer et al 2002).

(Deafness Forum Australia, National, Submission #267)

Conflicting data exists in relation to the prevalence of mental illness in Auslan-using Deaf people. Some studies suggest that the incidence of mental illness is higher for Deaf people than for the general population. Other studies suggest the incidence is similar to the hearing population and that the disproportionately higher number of Deaf people within mental health services is accounted for as a result of communication difficulties and misdiagnosis of behaviour and communication disorders.

(Deafness Forum Australia, National, Submission #267)

The Step by Step Project is a national education project focused on building mental health in young deaf people. It was initiated in response to significant concerns about the mental health of many young deaf people. It produced some excellent resources, including Guidelines for Mental Health Service Providers aimed at improving access to mental health services for young deaf Australians. That publication lists numerous other useful resources.

(Deafness Forum Australia, National, Submission #267)

6.9.11.4.4 Lack of mental health services in rural and remote areas, especially for children and adolescents

The Report into the National Inquiry into the Human Rights of People with Mental Illness (1993) repeatedly received evidence regarding the inadequacy of mental health services in rural Australia.

(The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

Concerns were expressed regarding problems with access to services in rural and remotes areas. In particular, The Australian Infant, Child, Adolescent and Family Mental Health Association expressed concern regarding the scarcity or complete absence of child and adolescent treatment and support services (Standard 11.4.3) and lack of training for mental health and health professionals in rural and remote areas to work with children and adolescents with mental illness or mental health problems:

The irony is that in many of the areas where the need is greatest the services are fewest. This is particularly the point in small country communities where mental health services - and certainly mental health services for children and adolescents - are almost entirely non-existent. (p.678)
(The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

The Report also noted that training and support for mental health, health and other professionals involved in working with children and adolescents with mental health problems, in rural and remote areas, was totally inadequate.
(The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

The efficacy of using innovative training and service delivery methods such as Telehealth, have been well described in the literature, yet there are no concrete recommendations on how this technology could be used to assist rural clients and practitioners. (Mitchell, Robinson, McEvoy, Gates (2001); Mitchell, Robinson, Seiboth, Koszegi (2000)).
(The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

There is a need to recognise that the staffing levels in country areas are in general inadequate to meet the needs of the rural community. Special formulas need to take into account travel and other factors such as the remoteness of the location in determining staffing levels.
(The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

AICAFMHA supports investment in the effective expansion of existing rural and remote mental health services for infants, children and youth. The utilisation of technological aids has been demonstrated as an effective means of enhancing services.
(The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

6.9.11.4.5 Lack of appropriate treatment and support services for Indigenous people with mental illness and / or mental health problems

Concerns were expressed regarding the scarcity of appropriate treatment and support services for Indigenous consumers and their families, particularly for youth and those living in remote communities. In particular, the need for culturally appropriate services, consideration of geographical isolation, high rates of physical illness, and social and wellbeing problems were mentioned as important associated factors impacting on access and service delivery:

Aboriginal and Torres Strait Islander (ATSI) people experience disproportionately high rates of mental health and social and emotional well being problems" and the "frequency of child, youth and adult mental health disorders in the community are higher" (Consultation Paper for the National Strategic Framework for Aboriginal and Torres Strait Islander Mental Health and Social and Emotional Well Being 2004-2009, 2003). The delivery of mental health services to ATSI children and youth needs to consider cultural and belief system differences. Geographical issues also affect the accessibility of appropriate mental health services for this 'at-risk' subgroup.
(The Australian Infant, Child, Adolescent and Family Mental Health Association, National, Submission #221)

6.9.11.4.6 Lack of treatment and support for people diagnosed with personality disorders

Concern was expressed about the paucity of appropriate treatment and support services for people diagnosed with Personality Disorders. Discriminatory attitudes towards people with Personality Disorder were also noted, as was the stigma that surrounds the 'label' of this diagnosis:

"Personality disorders" which constitute an increasing percentage of psychiatric diagnoses, lead to many criminal behaviours, drug abuse and social dysfunction. They usually have child abuse aetiologies. While the label of – 'personality disorders' often implies a sense of hopelessness. It is highly probable that dealing with the underlying trauma might reap better results than simply attempting to modify current behaviours. The provision of resources and research into effective interventions would be valuable. Currently, successful treatment is very limited.

(Advocates for Survivors of Child Abuse, National, Submission #262)

A range of psychiatric disorders including anxiety disorders, PTSD [Post Traumatic Stress Disorder], dissociative disorders, and a range psychotic disorders, have a high percentage of sufferers revealing histories of the trauma of childhood abuse. Often people are treated for their label, rather than taking a holistic approach, encompassing their history, repercussions of their past, social situation and illness.

(Advocates for Survivors of Child Abuse, National, Submission #262)

6.9.11.4.7 Carers are not being heard or involved in the planning of treatment and support

Despite the Standards (11.4.9 and 11.4.11) acknowledging the involvement of carers, carers repeatedly reported being excluded and feeling frustrated. Given the reported problems with access and limited services available in the community, practices which involve carers to assist with the delivery of care and achieve the best possible outcomes for consumers would help recovery, assist with the detection of early warning signs and assistance to care and protect many rights of people with mental illness:

A second complaint, so familiar to most families dealing with mental illness on a daily basis, is the lack of ongoing support carers usually receive from the medical profession, particularly by treating Psychiatrists. We as carers recognise patterns of behaviour in our relatives that indicate they are not coping with the symptoms of their illness - which often leads to another episode of psychosis (past experiences help to form our judgments) Too often we are not taken seriously until the situation gets out of hand. This situation could be avoided if Carers were given greater recognition as 'credible' participants in the medical process/system of maintaining stability in their relatives' lives.

(Carer, Anonymous, Submission #224)

6.9.11.4.8 Lack of support services for families post-suicide

Concern was expressed that as there are insufficient treatment and support services for people with mental illness even when they are in crisis, there is a complete lack of hope that services will be available to assist family members after a suicide:

I now feel such pain from a broken heart, and now feel as if I am going mad, but where would I turn, after the experience of my son, there seems no point.

(Carer, Mother, Anonymous, Submission #164)

6.9.11.4.A Community Living

The MHS provides consumers with access to a range of treatment and support programs which maximise the consumer's quality of community living.

Under this Standard, submissions indicate concerns about:

- the lack of programs and services to provide access and/or support to consumers in employment and work; and
- the lack of carer information, education support programs.

6.9.11.4.A.1 Lack of programs and services to provide access and/or support to consumers in employment and work

Standard 11.4.A.4 states: 'The MHS ensures that the consumer has access to an appropriate range of agencies, programs and/or interventions to meet their needs for leisure, recreation, education, training, work, accommodation and employment' and Standard 11.4.A.6 promotes access to, and/or support for consumers in employment and work. The Standards also support and promote access to vocational training (Standard 11.4.A.7), right to fair pay, conditions, award (and above) payments, opportunities for union membership (Standard 11.4.A.8) and support further or continuing education (Standard 11.4.A.9).

Access to education, training, work and employment programs are seen as critical for consumers to live in the community with opportunities to participate socially and economically. Despite presence of these Standards, concern was specifically expressed regarding the lack of access to a wide variety of programs, activities and agencies to maximise the consumer's success in employment and supported employment. Concern was expressed that relevant programs and employment opportunities are scarce in Australia:

> *Australia is poorly served with employment programs for people with a mental illness and associated psychiatric disability. Traditional vocational rehabilitation services are far less effective than supported employment. As an example successful employment programs Trieste in northern Italy report an employment rate of 60% of people with schizophrenia whereas in Australia over 75% of people with schizophrenia are not working and on a disability pension.*
>
> (Mental Illness Fellowship of Australia, National, Submission #331)

> *Consumers and carers also want employment opportunities to be available in a work force which is empathic to people with special needs.*
>
> (blueVoices, National, Submission #355)

6.9.11.4.A.2 Lack of carer information, education support programs

Standard 11.4.A.12 ensures access to a range of family-centred approaches to treatment and support. It includes family involvement in hospital care, psycho-education, training in family communication and problem-solving, counselling and ongoing support, support for the children of parents with a mental disorder and contact with relevant support/self-help groups.

However, concern was expressed regarding the lack of support and services for carers which are vital to ensure the best possible outcomes for consumers. This suggests a lack of access to family-centred approaches as indicated by the following quotes:

Comprehensive programs to support carers of people with a mental illness are still not routinely available. The programs should not just focus on early intervention. Although early intervention is a vital phase for the provision of information and education at the beginning of an illness for both the individual and carers, there is a need for referral to on-going support and information networks which can often be conducted within the NGO sector. Despite advances in research, many mental illnesses are whole of life and carers often require on-going support and assistance to continue as a partner in maintaining the optimum health of their loved one.

(Mental Illness Fellowship of Australia, National, Submission #331)

It is therefore recommended that the report prepared by the Human Rights and Equal Opportunities Commission and the Mental Health Council of Australia on the current investigation into mental health care in Australia:

a) acknowledges the impact that the failure of this system has on families and carers of people with mental illness;
b) reinforces the need for greater recognition and support of the carer contribution to mental health in all aspects of treatment and care and
c) calls on the Australian Health Ministers to take immediate action to:
    I. improve the range and quality of mental health services for people with a mental illness and their carers and
    II. ensure that the rights of carers that have previously been agreed to, (as part of the National Mental Health Strategy in 1991) are implemented.

(Carers Australia, National, Submission #276)

Support for family and other carers: While there are varying degrees of commitment to peer support groups for carers around the country, there is none for evidence-based family interventions which are proven to reduce the frequency and severity of psychotic episodes as well as reduce stress and distress in family members. The SANE Mental Health Report recommends implementation of evidence-based carer education and training in all States and Territories as part of a reformed National Mental Health Strategy.

(SANE Australia, National, Submission #302)

6.9.11.4.B Supported accommodation

Supported accommodation is provided and/or supported in a manner which promotes choice, safety, and maximum possible quality of life for the consumer.

Under this Standard, submissions indicate concerns about the lack of supported accommodation.

6.9.11.4.B.1 Lack of supported accommodation

While Standard 11.4.B.8 states: 'There is range of accommodation options available and consumers have the opportunity to choose and move between options if needed' and 11.4.B.9 states 'where desired, consumers are accommodated in the proximity of their social and cultural supports, the Mental Illness Fellowship of Australia and SANE Australia expressed concern about the lack of supported accommodation in all Australian States and Territories.

The lack of supported accommodation was cited as a reason for deteriorating mental health resulting in increased admission rates for acute care, increased contact with and entry into the criminal justice system and increased reliance on welfare support. The lack of housing and accommodation options, and supported accommodation options in particular, for people with mental illness is a serious barrier to consumers attaining the 'maximum possible quality of life' and integrating and contributing to the community:

Supported accommodation Research shows that people with a mental illness in adequate housing, with a variable level of support based on assessed on need, have fewer remissions with less demand on health, welfare and the justice system. Supported housing for people with a mental illness is inadequate in all states and territories and critically so in several states.

(Mental Illness Fellowship of Australia, National, Submission #331)

Supported accommodation: Providing support to people living in their own homes is a keystone of community-based mental health services – but this is dependent on suitable housing being available. The SANE Mental Health Report recommends adequate levels of affordable, appropriate supported accommodation for people with a psychiatric disability be planned in all States and Territories.

(SANE Australia, National, Submission #302)

6.9.11.4.C Medication and other medical technologies

Medication and other medical technologies are provided in a manner which promotes choice, safety and maximum possible quality of life for the consumer.

Under this Standard, submissions indicate concerns about the limited access to safe and effective medications for consumers being treated by psychiatrists in the private sector.

6.9.11.4.C.1 Limited access to safe and effective medications for consumers being treated by psychiatrists in the private sector

The Standards state that 'medication and other technologies used are evidence-based and reflect internationally accepted medical standards' (Standard 11.4.C.1) and that the consumer has access to the 'safest, most effective and most appropriate medication and/or other technology' (Standard 11.4.C.10).

However, the National Network for Private Psychiatric Sector Consumers and Carers expressed concern that psychiatrists in private practice are not always able to ensure that consumers in their care have access to evidence-based best practice and 'to the safest, most effective and most appropriate medication' (Standard 11.4.C.10) in comparison to consumers being treated in the public system:

The following issues are of grave concern to us…The new atypical anti-psychotic medications should be available to consumers who suffer a mental illness, apart from schizophrenia. There is strong evidence that these medications can be used in low doses to very usefully to treat other disorders, particularly mood disorders. Currently, psychiatrists working in the public hospital system are able to prescribe these medications for disorders other than schizophrenia. However, psychiatrists in private practice are not, which effectively prohibits them from providing evidence-based best practice for many of their patients.

(The National Network for Private Psychiatric Sector Consumers and Carers, National, Submission #225)

6.9.11.4.D Therapies

The consumer and consumer's family/carer have access to a range of safe and effective therapies.

Under this Standard, submissions indicate concerns about the lack of access to a range of accepted therapies in the MHS.

6.9.11.4.D.1 Lack of access to a range of accepted therapies

According to Standard 11.4.D.2 'The MHS provides access to a range of accepted therapies according to the needs of the consumer and their carers'.

However, blueVoices expressed concern that there is an over reliance on medication and access to other therapies according to need in the public mental health system is difficult for people experiencing anxiety and depression:

> *A predominant finding in our experience has been the difficulty in seeking non-pharmacological treatments for persons who experience Anxiety and Depression.*
>
> (blueVoices, National, Submission #355)

6.9.11.4.E Inpatient care

The MHS ensures access to high quality, safe and comfortable inpatient care for consumers.

Under this Standard, submissions indicate concerns about adult consumers in inpatient settings not being treated with dignity and respect.

6.9.11.4.E.1 Adult consumers in inpatient settings not treated with dignity and respect

Concern was expressed that some consumers in inpatient settings are not being treated in a manner which 'add's value to the consumer's life' (Standard 11.4.E.1). Instead, and contrary to Standard 11.4.E.9 and Standard 11.4.E.10, these consumers are offered activities which are not age appropriate:

> *They are then put in a hospital and in my experience have been treated like children – put on drugs, taken to play group to do colour-ins and stick on craft really suitable for 5 year olds. This does life long harm.*
>
> (Consumer, Anonymous, Submission #133)

6.9.11.5 Planning for exit

Consumers are assisted to plan for their exit from the MHS to ensure that ongoing follow-up is available if required.

No submissions or comments were received pertaining to this Standard.

6.9.11.6 Exit and Re-entry

The MHS assists consumers to exit the service and ensures re-entry according to the consumer's needs.

No submissions or comments were received pertaining to this Standard.

6.9.12 STORIES OF SUICIDE

Sadly it is too late for my son who died at the age of 30, 8 weeks ago. For ten years I tried to get help for him, but it seemed he had to be at deaths door for anyone to do anything. As a mother I knew how serious his condition was, but they just kept saying not bad enough. I found in all that time no support from the medical profession, even though I was better off then most people in that I could pay. It is tragic to just watch your child with mental pain, and drugs suffer and have no where to turn… if it had been physical, cancer, a broken leg, I would have had as much care as I needed. I now feel such pain from a broken heart, and now feel as if I am going mad, but where would I turn, after the experience of my son, there seems no point.

(Carer, Mother, Anonymous Submission #164)

PART SEVEN: REFERENCES

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8.1 LIST OF COMMUNITY CONSULTATIONS BY STATE / TERRITORY

Table 8.1.1: List of community forums held by State/Territory

State/Territory	Approximate Combined Number of Attendees	Forum Location	Forum Date
Australian Capital Territory	100	Canberra	16 August 2004
New South Wales	163	Sydney Broken Hill Parramatta Parramatta (NESB)*	12 July 2004 15 July 2004 10 September 2004 14 October 2004
Northern Territory	130	Darwin Alice Springs	1 September 2004 2 September 2004
Queensland	110	South Brisbane Rockhampton	12 July 2004 13 July 2004
South Australia	120	Adelaide Murray Bridge	16 July 2004 16 July 2004
Tasmania	80	Hobart	7 September 2004
Victoria	210	Melbourne Morwell Footscray West	6 September 2004 6 September 2004 6 October 2004
Western Australia	280	Bunbury West Perth Geraldton Geraldton (Civic and Local Government Service Leaders)	5 July 2004 6 July 2004 13th September 2004 13th September 2004
Total	1183	19	

* Focus of forum was on issues for people from a Non-English speaking background

Table 8.1.2: List of consultations

Organisation	Individual(s)	Date
National Disability Advisory Council	Ian Spicer AM, Chair	30 July 2004
Catholic Social Services Victoria	Theresa Lynch, Senior Policy Officer	17 August 2004
CYCLOPS ACT (Connecting Young Carers to Life Opportunities and Personalised Support)	Young carers from CYCLOPS ACT	19 August 2004
South Australian Prison Health Service	Dr Chris Holmwood, Clinical Director	29 September 2004
South Australian Chief Magistrate	Chief Magistrate, Kelvyn John Prescott	29 September 2004
Australian Nursing Federation	Rob Bonner, Senior Industrial Officer	29 September 2004
Victorian Mental Illness Awareness Council (VMIAC)	VMIAC group	6 October 2004
Mental Health Review Board of Victoria	John Lesser, President	12 October 2004
The Australian Capital Territory Community and Health Services Complaints Commissioner	Philip Moss, Community and Health Services Complaints Commissioner	15 October, 2004
Australian Federal Police	Superintendents Quade and Kilfoyle	20 October 2004
Equal Opportunity Commission of South Australia	Linda Matthews, Commissioner for Equal Opportunity	20 October 2004
Forensicare: Victorian Institute of Forensic Mental Health	Michael Burt, CEO Professor Paul Mullen, Clinical Director	15 November 2004

8.2 SUMMARY OF SUBMISSIONS RECEIVED BY STATE / TERRITORY

Table 8.2.1: Number of submissions received by State/Territory

State/Territory	Submissions #
Australian Capital Territory	14
New South Wales	82
Northern Territory	8
Queensland	47
South Australia	31
Tasmania	14
Victoria	94
Western Australia	46
National (including 4 unknown)	15
Total	**351**

8.3 LIST OF SUBMISSIONS RECEIVED BY STATE / TERRITORY

8.3.1 LIST OF SUBMISSIONS RECEIVED - NEW SOUTH WALES

Anonymous x 19
Bennett, Elizabeth
Beverley, Satu
Butler, Jennifer
Carrington, Ros
Casey, Desley
Chapman, Chris & Gordon
City of Sydney
Comely, Christina
Community Offender Services, Probation and Parole Service. NSW Department of Corrective Services
Comprehensive Area Service Psychiatrists (CASP) Group
Cooke, Cecelia
Council of Social Service of NSW (NCOSS)
Deaf Society
Double, Allison
Drummond, Rita
Eastern Area Interagency NSW
Fisher, Wilma
Flynn, Kate
Glanville, Phil
Goldsmith, John & Bettina
Holt, Gillian & Warren
Gloria
Graham, Rex
Harman, Lyn
Harris, Myree; St Vincent de Paul NSW
Homelessness NSW.ACT
Indigenous Social Justice Association (ISJA) and Justice Action (JA)
Kelly, Warwick & Bronwyn
Leseberg, John
Littley, John
Macqueen, Dr Rod
Makarewicz, Richard
McArthur, Lee
McKenzie, Lindy
Mental Health Coordinating Council
Mental Health Workers Alliance
Morrison, Pat
Neaves, Anna
NSW Association for Adolescent Services
NSW Association for Adolescent Health (NAAH)
NSW Consumer Advisory Group Mental Health Inc
NSW Department of Corrective Services
NSW South Coast Mental Health Community Consultative Committee
Police Association of NSW
Raison, Pauline & John
Reid, Jenni
Rigley, Chris
Rosen, Adjunct Professor Alan

Schofield, Elaine
Scott-Orr, Donald
Snowdon, John
Stevenson, Bob & Shirley
Stuart, Cath
Tamer, Caroline
Taylor, Anna
Van Epen, Lorraine
W, Jacqui
Walgett SAAP Services
Walker, June
Wallace, Michael
Whyte, Denise
Wilkes, Dave
Wright, Ron, St Vincent de Paul, Swansea Conference

8.3.2 LIST OF SUBMISSIONS RECEIVED - VICTORIA

Anonymous x 28
Anex
Association of Relatives and Friends of the Mentally Ill (ARAFEMI) Victoria
Australian & New Zealand College of Mental Health Nurses
Australian Nursing Federation (Vic Branch)
Australian Polish Community Services
Blaikie, John
Bond, Graeme
Brotherhood of St Laurence and Catholic Social Services Victoria
Bryant, Therese
Bush, Gabrielle
Cannard, Gwenda
Carers Victoria
Centre for Psychiatric Nursing Research and Practice
Chamley, Wayne
Clark, Laurel
Cohan, David
Cusworth, Joan
Disability Employment Action Centre (DEAC) Inc.
Delaney, Kath
Di Guglielmo, Mario
Douglas, Lyn
Drummond, Roma
Dwyer, Matthew
Epstein, Merinda
Filando, Frank
Franklin, Majella
Grand, Kathryn
Grieb, Elizabeth
Halloran, John
Health and Community Services Union
Hewitt, Trish
Hyndman, Stephanie
Insane Australia
King, Susan
Kirkham, Judith A

Lewisohn, Penelope
Lillie, Pauline
Lloyd-Thomas, Gina
Lockwood, Peter
Luxford, Pat & Kevin
Lyon, Pat
Margaret
McDonald, Beth & Peter
McGorry, Professor Patrick
Mental Health Legal Centre
Monash, Dr David
Network for Carers
Office of the Public Advocate
Olsen, Anne
Orygen Research Centre
Peninsula Carers Council; Nyorie Lindner
Pinches, Allan
Robinson, Jan
Rose, Peggy
Sayers, Rhonda
Singer, Esther, Youth Participation Worker
Spencer, Reverend Barbara
Steward, Kirsty
Stewart, Carolyn
Storm, Caroline
Thompson, Barry
Tine, Claudio
Vance, Heather
Verdon, Debbie; Grampians disAbility Advocacy Association
Victorian Mental Illness Awareness Council Inc.

8.3.3 LIST OF SUBMISSIONS RECEIVED - QUEENSLAND

Anonymous x 15
Abell, Julie & Joanne
Berrill, Julie
Bird, Gavin
Brain Injury Association of QLD
Burgess, Pat
Campbell, Cathy
Cassar, Simeon
Cesare, Maxine
Cesari-White, Judith
Cook, Brigitte
Cox, Raymond
Daniell, Allan
Down, Judi
Duncan, Jane
Flegg, Dr Bruce, MP; Liberal Party of Queensland
Franklin, Christine
Gunn, Dr Andrew
Kubainski, Peter
Laughton, Ted
Lie, Dr David

McDiarmid, Carolyn
Mental Health Unit, Queensland Health
Miller, Des
Queensland Alliance of Mental Illness and Psychiatric Disability Groups
Quinton, Mal & Elda
Salvage, Rod
Smith, Daryl
Stock, Rhonda
Thomson, Les
Ubaldi, Vera
White Wreath Association
Wyllie, Hazel & Allen

8.3.4 LIST OF SUBMISSIONS RECEIVED - SOUTH AUSTRALIA

Anonymous x 10
beyond...(Kathleen Stacey & Associaties) Pty Ltd
Carers SA, Rosemary Warmington
Cord-Udy, Nigel
Evans, Sheila
Gibbs, Helen
Guther, Pamela
Harding, Stephen
Healey, Maureen
Health and Community Services Network, Murray Mallee Strategic Task Force
Jureidini, Jon
Muir-Cochrane, Eimear
Office of Crime Statistics and Research, Attorney-General's Department, Government of South Australia
Poole, Dennis & Rosemary
Quick, Pam
Roach, Ronald
Ross, Jayne
Sharon
Smith, Janice
Spurrier, Michael
Taylor, Dawn
Youth Affairs Council of South Australia

8.3.5 LIST OF SUBMISSIONS RECEIVED - WESTERN AUSTRALIA

Anonymous x 22
Bunbury Pathways; Joscelyn Jones
Carers WA
Cook, Margaret
Courtis, Alva
D'Agostino, Rob
Health Consumers' Council WA
Evans, Peter
Fowke, Tony
Greater Bunbury Division of General Practice
Hindle, John
Jackson, Colin
Loader, Kim, Bunbury Pathways Carer Support Program

Lord, Dr David
Martin, Debbie
McIntosh, Bill
McPherson, Jann
Mitchell, Melva
Mostafanejad, Karola
Prendergast, Margaret
Shanley, Dr Eamon
Sharp, Noel, Senior
St Bartholomew's House; Lyn Evans
Wakely, Carol
Watson, Giz, MLC, Member for North Metropolitan Region, Parliament of Western Australia

8.3.6 LIST OF SUBMISSIONS RECEIVED - AUSTRALIAN CAPITAL TERRITORY

Anonymous x 6
ACT Disability, Aged & Carer Advocacy Service (ADACAS)
Barker, Geoff
Bone, Linette
Egan, Sheelah
McGeechan, Kathleen
Mental Health Community Coalition Consumer and Carer Caucus
Mental Health Foundation ACT Inc
Wylde-Browne, Margy

8.3.7 LIST OF SUBMISSIONS RECEIVED - NORTHERN TERRITORY

Anonymous x 4
Darwin Red Shield Hostel
Davies, Sam
Mental Health Program, Department of Health and Community Services
Support and Equity Services, Charles Darwin University

8.3.8 LIST OF SUBMISSIONS RECEIVED – TASMANIA

Anonymous
Advocacy Tasmania Inc – Mental Health Tribunal Representation Scheme
Anglicare Tasmania (Report by Prue Cameron & Jo Flanagan, Social Action and Research Centre)
ARAFMI Hobart
ARAFMI Tasmania
Australian Family Association Tasmanian Branch
Cadence FM Inc Community Radio
Campbell-Smith, Mollie
Colony 47
Fairbrother, Thea
Graham, James (Migloo)
Konetschnik, Beris
Malaher, Terrence
Napier, Sue, MHA

8.3.9 LIST OF SUBMISSIONS RECEIVED - NATIONAL

Anonymous x 4
Advocates for Seminars of Child Abuse
Australian Infant, Child, Adolescent and Family mental Health Association (AICAFMHA)
BlueVoices
Carers Australia
Constable, Michael
Deafness Forum Australia
Drug Free Australia
Families and Friends for Drug Law Reform
Mental Illness Fellowship of Australia
National Network of Private Psychiatric Sector Consumers and Carers
SANE Australia

8.4 RESPONSES FROM STATE, TERRITORY AND FEDERAL GOVERNMENTS

8.4.1 RESPONSE FROM NEW SOUTH WALES GOVERNMENT

NEW SOUTH WALES

MINISTER FOR HEALTH

H05/ 3214

04 MAY 2012

Mr John Mendoza
Chief Executive Officer
Mental Health Council of Australia
PO Box 174 Deakin West
ACT 2600

Facsimile: 02 6285 2166

Dear Mr Mendoza

Thank you for your letter of 24th March 2005 and the copy of the *Mental Health and Human Rights* Draft Report.

I am enclosing a brief NSW Health Department's response, as invited, for inclusion in the report.

If you would like to have any additional information about the service developments in the response, the person to contact is Dr Michael Paton in the Department's Centre for Mental Health on 02 9391 9309.

Yours sincerely

Morris Iemma MP
Minister for Health

Locked Mail Bag 961 North Sydney NSW 2059 Telephone (02) 9228 4299 Facsimile (02) 9228 4277

NSW Health Response to Mental Health and Human Rights Report

NSW Health welcomes the opportunity to comment on the report of the Mental Health Council of Australia, The Brain and Mind Institute, in association with the Human Rights and Equal Opportunity Commission.

The principal objective of NSW mental health services is to improve the health, wellbeing and social functioning of people with disabling mental disorders and to reduce the incidence of suicide, mental health problems and mental disorders in the community.

To meet those objectives in 2004-05, the NSW Government allocated a $783 million to serve an estimated consumer population of about 100,000, focusing primarily on those people with severe and disabling mental health disorders. NSW mental health services comprised (in 2003-04) 5,573 full-time equivalent clinical staff, who provided 24,642 episodes of acute overnight inpatient care, 261,327 days of non-acute inpatient care and about 2 million community contacts.

In addition, NSW Health continued its telephone survey program to assess population levels of psychological distress in adults and parent-reported problems in children and young people, finding that the levels of both were about the same as in previous years and other countries. In 2003-04 hospitals in NSW admitted 9,500 people after suicide attempts, and the death rate by suicide dropped to 9.6 per 100,000 population, the lowest rate in Australia and the lowest level reached in more than 20 years.

Based on views expressed by those who attended consultations and made submissions, the MHCA report prepared with the assistance of Professor Hickie from the Brain and Mind Research Institute at Sydney University, in association with the Human Rights Commissioner Dr Ozdowski, is critical of mental health services provided by States and Territories.

In the section of the report covering NSW there are about 470 quotations judged to reflect “matters of concern”, including more than 100 citations regarding Standard 9 (service development). More than half of those 100 quotations come from just six submissions, all made by clinicians or clinical groups, each cited between 5 and 15 times. In NSW Health’s view, the report’s methodology places excessive emphasis on the opinions of service development expressed by a very small number of clinicians.

There is an important distinction to be made between what mental health services usually do, and what happens when, on occasion, services do not deliver what consumers and carers expect of them. While it is acknowledged that consumers and carers have reported unacceptable care and treatment, NSW Health does not accept that the report provides convincing evidence of NSW mental health services generally failing in their duty of care.

Mental health is a priority for the NSW Government. The Mental health budget is now at record levels, having increased 121 per cent since 1994-95. Demand for services continues to grow, and many existing services are under pressure. There is no doubt more needs to be done and NSW Health has plans to accelerate this growth in services over the next four years. Details are set out below:

Hospital and Emergency Services

Since June 2001, an additional 257 mental health beds have opened with a further, 40 beds to open by June 2005. These include additions or new units at:

- *Wyong, Tweed Valley, Coffs Harbour, Taree, Kempsey, Tamworth, Wagga Wagga, Albury, Wollongong and Bloomfield Hospital in Orange*
- *child and adolescent beds at Westmead Hospital, Gna Ka Lun at Campbelltown, the Nexus Unit at John Hunter in Newcastle, Sydney Children's Hospital and Westmead Children's Hospital; and*
- *refurbishments and additional beds at Prince of Wales, St George, Sutherland, Westmead, Cumberland and Nepean Hospitals.*

Over the next three years the NSW Government will open 246 more mental health beds. They include:

- Acute units at Lismore, Dubbo, Liverpool and Blue Mountains
- 100 longer stay beds in four 20 bed units at Campbelltown, St George, Shellharbour, Coffs Harbour and the Hunter
- A new child and adolescent unit in Lismore
- An older person's unit in Wollongong
- Additional forensic mental health beds in a new stand alone Forensic Hospital; and
- A brand new 174 bed mental health facility to be built at Concord Hospital replacing the existing facilities at Rozelle. The first phase of this has begun, with the transfer of 40 psycho-geriatric beds from Rozelle Hospital to the new community health facility in Croydon.

Clinical Nurse Consultants have been employed in Emergency Departments to identify, triage and provide specialist care to patients with a mental illness in hospitals at:

- Bankstown, Campbelltown, Gosford, Hornsby, Liverpool, Nepean, Prince of Wales, Royal North Shore, Royal Prince Alfred, St George, Sutherland, St Vincent's, Westmead, Albury-Wodonga, Blue Mountains, Coffs Harbour, Lismore, Maitland, Shellharbour, Tamworth and Taree.

Psychiatric Emergency Care Centres (PECCs) are dedicated services, situated adjacent to the Emergency Department, staffed 24 hours a day, 7 days a week by specialist mental health staff. PECCs have been successfully trialled at Liverpool and Nepean Hospitals and the program is being expanded with PECCs at St Vincent's, St George and Hornsby Hospitals and other centres to follow.

Based on its Mental Health – Clinical Care and Prevention planning model, NSW Health has been building up the less-resourced Areas while maintaining and improving those with higher resource levels. NSW Health has ensured that community as well as inpatient services are being enhanced, with the following developments:

Community Mental Health Services The NSW Government invests 45 per cent of the total mental health budget on community mental health services. In 2004/05, 2,570 mental health staff are working in the community – up from 1,398 in 1994-95.

Housing: A joint initiative between Health, Housing and non-government organisations - the Housing, Accommodation and Support Initiative (HASI) - is providing coordinated disability support, accommodation and health services to over 118 people requiring high-level support to live in the community. HASI Phase 2 is now being implemented with successful tenders awarded to NGOs to provide disability assistance to a further 460 people in public and community housing across NSW.

Court Liaison: In 2003/4 the NSW Government formally established the Statewide Court Liaison Service - a partnership between Health, Police, the Attorney General and Corrective Services. That year it screened 18,902 court attendees, referred 1,945 people for assessment and found 1,413 to have an identifiable mental illness. Of these, 204 were treated in hospital and 702 were provided with treatment by community mental health services. The Court Liaison Service now operates in 19 courts across metropolitan and regional NSW, starting from a two court pilot in 2000.

Human Rights and Legislative Issues

There seems to be a misapprehension in some submissions that NSW Health is over-emphasising the provision of acute inpatient services and adopting a custodial attitude. This is not so. The recent emphasis on adding acute inpatient beds and psychiatric emergency care is driven by the identified need to improve access to acute mental health services in NSW. As noted above, this has not occurred at the expense of community mental health.

NSW Health is not moving to a more custodial mode of service provision in mental health. The NSW Mental Health Act 1990 received favourable mention in the original Burdekin Report of 1993 for its efforts to place key definitions in law, and this requires constant review. The current review of the Mental Health Act sought views on these elements - there was strong endorsement of these definitions and there is no intention to amend them. The discussion papers are available at www.health.nsw.gov.au/pubs/2004/menthealthrev.html.

The formal submission phase of the review concluded in October 2004, but additional input will be sought when an exposure draft Bill is circulated. A further public consultation process on the review of the Mental Health Act has commenced, and NSW Health encourage all to consider the discussion papers and provide comment on to the exposure draft Bill.

Obtaining and responding to consumer and carer feedback

The NSW approach to this area is a direct result of consumer requests in 2001. We have now been working for several years with the NSW Consumer Advisory Group (NSWCAG) on the MH-CoPES (Consumer Perceptions and Experiences of Services) project. MH-CoPES was requested, planned, and managed by consumers. Results are documented at www.mentalhealth.asn.au/members/nswcag under “Projects”.

The aim of MH-COPES is to identify the best way for mental health services across NSW to hear and respond to consumers' views about those services.

The first phase of the project is almost complete, with consultations having been held across NSW in Bega, Yass, Broken Hill, Morisset, Port Macquarie, Tamworth and Griffith in September-December 2004, and Leichhardt, Newcastle and Penrith in February-March 2005. The instrument and process have been developed through a technical working group of twelve (eight of whom are consumers), and via open workshops in which about 130 consumers and service providers have collaborated.

The project team expects to move to Phase 2 of MH-CoPES via large-scale pilot implementation in 2005-06. The MH-CoPES questionnaire should soon be available for inspection, so that readers can verify for themselves what kind of feedback NSW consumers believe NSW Health services should receive and respond to.

The MHCA report notes that state or national authorities with "a genuine commitment to quality improvement" might adopt such mechanisms. NSW Health acknowledges and appreciates this endorsement of its consumer initiative.

Conclusion

If we are to achieve lasting results beyond the headlines, public support for mental health services is essential. The views of mental health consumers and carers are welcomed and their active participation in service provision and planning is essential.

All service improvement starts with open and frank discussion by consumers, carers and staff. To that end NSW Health accepts the report as an expression of legitimate opinion about problems faced in providing appropriate care and treatment of people who live with mental illness.

NSW Health makes many reports and Government responses on mental health issues available in the Publication Section of its website, and we invite readers to view those at http://www.health.nsw.gov.au/pubs/subs/sub_mental.html.

8.4.2 RESPONSE FROM VICTORIA GOVERNMENT



Minister for Health

555 Collins Street
GPO Box 4057
Melbourne Victoria 3001
DX210081
www.dhs.vic.gov.au
Telephone: (03) 9616 8561
Facsimile: (03) 9616 8355

e321723

Mr John Mendoza
Chief Executive Officer
Mental Health Council of Australia
PO Box 174
DEAKIN WEST ACT 2600

Dear Mr Mendoza

Thank you for your letter dated 24 March 2005 inviting States and Territories to provide a formal summary response for inclusion in the Mental Health and Human Rights draft report and detailed comments on the Victorian section.

Attached please find Victoria's response, based on the material that you have provided to date.

I understand that you have recently met with officers from the Victorian Mental Health Branch, who have raised some issues with you regarding the draft report. The key issues were:

- The emotive style of the title page;
- The lack of balancing information – while negative experiences can occur in any system, I believe that these should be considered relative to the number of positive experiences and other supporting information; and
- The absence of a chapter on the Commonwealth jurisdiction's responsibilities to people with mental disorders –including Medicare, Pharmaceutical Benefits Scheme, private psychiatrists, General Practitioners, and vocational rehabilitation. Much of this information is currently contained in the state level sections.

At the meeting you were provided with copies of documents that were produced by the Victorian Department of Human Services to assist you in further developing the report. These documents were:

- Summaries of the 2003/04 surveys of consumer and carer experience of Victorian public mental health services;
- *Victorian strategy for safety and quality in public mental health services;*
- *Annual Report 2003: Office of the Chief Psychiatrist;*

Victoria
The Place To Be

- *Victoria's implementation of the national standards for mental health services; progress report September 2004*; and,
- *Caring Together: an action plan for carer involvement in Victorian public mental health services.*

Exemplar services in Victoria in the forensic and youth early psychosis areas, such as Thomas Embling Hospital and Orygen Youth Health, were also discussed at the meeting. Further, I would like to highlight the innovative service models that have been developed in Victoria in the areas of Psychiatric Disability Rehabilitation and Support, sub acute, primary mental health, and dual diagnosis service delivery. Victoria is recognised as a leader in these areas.

As I mentioned earlier in this letter, Victoria's written response to the draft report is based on the material that you have currently provided. Should you change the report, the response may require adjustment, and I would welcome the opportunity to revise the response.

I look forward to considering the next draft of the report.

Yours sincerely

Hon Bronwyn Pike MP
Minister for Health

Victorian Context

There is widespread agreement that Victoria has laid the foundations of a comprehensive age based specialist mental health system, which is now well established and contains most of the elements needed to effectively treat and support people with mental illness. As a specialist system, the bulk of external funding is directed towards the clinical treatment of serious mental illness, supplemented by disability support for consumers to live independently in the community. Victoria, when compared nationally, has proportionally the largest community based system of clinical assessment and treatment and non-clinical support, and the greatest number of people treated in psychiatric wards co-located with general hospitals.

Clinical services treat approximately 56,000 continuing care clients per annum in inpatient and ambulatory settings with up to 12,000 clients also using disability support services with a clinical workforce of over 5000 staff. These services are resourced from a total mental health budget of $652 million in 2004-05.

Victorian Service Developments

In Victoria, the current operating environment is one of sustained demand pressure with an average growth of 7% per annum in clients over the last five years. In response to these pressures and the ongoing need to build on past reforms and improve services access, efficiency and effectiveness the Victorian Government has systematically invested more than $198 million in service improvement strategies since 1999-00. This funding has been directed to strengthening core services, implementing early intervention and relapse prevention initiatives, and creating an environment that enables clinical practice and service models to better align with the changing needs of consumers and their carers. Some major new and innovative initiatives include:

- **Primary Mental Health Teams** that build the capacity of general practitioners and other primary health providers to support people with a mental illness through the provision of specialist consultation.
- **Early Psychosis** programs which provide early intervention for young people with an emerging disorder.
- **Dual Diagnosis** services which provide integrated responses to clients with co-existing mental illness and substance abuse.
- **Sub-acute services** that provide transitional step down support from inpatient care to home.
- **Intensive housing support services** for consumers with complex needs.

Mental Health continues to be high priority for the Victorian Government. It's social policy action plan *A Fairer Victoria: Creating Opportunity and Addressing Disadvantage* released on 28 April 2005 makes a substantial commitment of **$180 million over the next four years** for mental health service growth and improvement, including $55.5 million for planned capital developments. Mr Jeff Kennett, Chair of Beyondblue stated in the Melbourne Age on 29 April 2005 that this is "the largest contribution to mental health by any state government ever".

Further improvements will focus on early intervention across the age groups by providing:

- **Intervention and prevention during the early stages** of an emerging disorder (in order to prevent the illness progressing and/or avert escalation and the need for a long period of support).
- A **quicker** service response (to prevent a crisis developing or worsening).
- A **more intensive** service response (to ensure treatment is effective).
- **Better follow-up** after discharge (to prevent relapse of the condition).

Victorian Response to the Report

A formal response for inclusion in the final report was requested in relation to sections of the Mental Health and Human Rights Draft Report forwarded to the Victorian Minister for Health on 24 March 2005. Consequently, the following comments are based on an incomplete draft version of the report.

Whilst information about specific consumer and carer experiences of the mental health system provide a critical contribution to the understanding of its performance, these experiences form part of the picture and do not on their own provide evidence of systemic problems in relation to human rights and national standards. However, Victoria accepts that the views expressed are legitimate and reflect the real experiences of particular individuals and wishes to express regret for the negative experiences described in the Victorian section of the report. Victoria also wishes to assure those people who are concerned with services in this state that any feedback received is taken very seriously and that Victoria will continue to improve its services for consumers and their carers.

Notwithstanding the above statements, Victoria has significant concerns with the report's methodology and findings. These concerns are summarised below.

- **The report lacks balance** as it:
    - Draws heavily on the opinions and perspectives of particular individuals and interest groups.
    - Currently excludes publicly available information about service improvement, expansion and reform available at a state and national level.
    - Shows little evidence of any efforts to elicit or report positive views during the consultation process.
    - Gives no weight to the constraints the states and territories operate under including capped budgets and high levels of non-discretionary expenditure.

- **The report has questionable validity** as it:
    - Draws on the results of two surveys with very low response rates, and in Victoria, four meetings and 97 submissions (primarily from individuals), which is hardly representative of Victoria's large consumer, carer and provider base.
    - Generalises the experiences of a limited number of organisations and often aggrieved individuals to the whole system.

- **The report lacks objective data and evidence to support its findings** and therefore makes an unconvincing and uninformed case regarding these findings. For example, it has disregarded the accreditation system for national standards, assessments made by the accreditation agency and level of compliance by services. In Victoria, 82% of area mental health services have completed the accreditation process.

- **The report draws simplistic conclusions about poor consumer and carer experiences** which cannot always be attributed to specialist mental health system failures but may be:
    - The result of relatively isolated and infrequent events.
    - Linked to the diversity of views about involuntary treatment with it's inherent and complex balancing of rights and protections.
    - Related to events which occurred many years previously.

- **The report employs an emotive and adversarial style** that undermines its credibility and is likely to prove unproductive in an area of health where strong collaboration and partnership has underpinned progress to date.

Ultimately, the report is misleading and may undermine the confidence of the community, consumers and carers in the public mental health system. Available data in Victoria indicates that the system operates reasonably well most of the time despite sustained and increasing pressure. It should also be noted that the system contains high levels of accountability with checks and balances that are enshrined in legislation and practice. Service and clinical standards and guidelines are the subject of continued improvement and review. Recent amendments to the Mental Health Act have further embedded good practice into legislation.

The report also risks setting unrealistic expectations about what can be delivered by a publicly funded specialist system of care. A number of issues raised in the report sit well outside the mandate of the specialist mental health system and will require vigorous and sustained effort by the many different areas and levels of government, including the Commonwealth Government, to address.

Points from HREOC report draft

Standard no	Issues raised in report	Victoria's issues	Victoria's response
1- Rights	• Fear of retribution if person complains • Information not provided to clients and carers • Unclear who should explain rights to service users • Rights are not explained in an understandable manner	• Unable to quantify extent of the problem from the report. • Report findings appear to contradict Victorian 2003/04 consumer and carer participation survey results that show that 67% of consumers of adult mental health services who responded to the survey thought that Victorian services were good to excellent on consumer rights.	• Consumer consultants are employed in all mental health services and carer consultants in many mental health services to assist clients and to represent consumer and carer views to the organisation. • Independent Third Persons and the Office of the Public Advocate are available to provide assistance and support to individuals who have concerns about their treatment. • Apart from internal complaints mechanisms of individual services, the Office of the Chief Psychiatrist and the Health Services Commissioner can investigate consumer and carer complaints about treatment. • The Mental Health Review Board independently reviews the need for the involuntary treatment of individual clients.
2- Safety	• Use of sedation and restraint during bed waits in Emergency Departments • Concerns about client safety in mixed gender units • Lack of supported accommodation • Poor response to carer safety concerns • Staff safety concerns regarding the behaviour of consumers with co morbid mental health and substance misuse issues.	• Unable to quantify extent of problem from the report. • The report implies that waiting in Emergency Departments for a bed is a form of consumer abuse.	• Initiatives are being introduced to improve bed access and increase staffing to reduce waiting times in Emergency Departments. New subacute services should also help ease the demand for mental health acute inpatient beds. In 2004/05, an extra $8.6 million is being used to reduce the need for acute inpatient beds through diversion, early intervention and relapse prevention services. • The need to maximise acute inpatient bed use preclude the creation of gender specific wards except in some specialist services eg mother-baby/eating disorder services, some forensic services • Additional intensive clinical and rehabilitation resources are being provided to improve service responsiveness and the level of support to clients with complex needs to assist relapse prevention eg in 2004/05, an additional $1.4 million has been provided for housing and support, supported accommodation and residential rehabilitation for young people with dual diagnosis. • Dual diagnosis services are being extended and integrated into adult mental health services eg in 2004/05 an additional $0.75 million was provided for dual diagnosis services.

Standard no	Issues raised in report	Victoria's issues	Victoria's response
3 – Consumer & carer participation	• Poor consumer peak representation nationally • Carers ignored • People with Borderline Personality Disorder (BPD) not considered State or nationally	• The quotes are very general and seem to relate more to consumer and carer participation at the national level. • There is a focus on the availability of diagnosis-specific services rather than services for people with severe mental illness regardless of diagnosis • Responses to the 2003/04 Victorian consumer and carer participation survey showed that carers were usually more dissatisfied with services than consumers.	• Victoria focuses on providing public mental health services to people with serious mental illness regardless of diagnosis, although it does have a statewide specialist borderline personality disorder service that provides consultation to broader mental health services • Carer consultants are employed in many Victorian public mental health services to provide assistance to carers and ensure that the carer views are represented in the organisation • Victoria released a new carer policy, *Caring Together*, in 2004. • Consumers and carers are represented on the Ministerial Advisory Committee on mental health and associated subcommittees.
4 – Community acceptance	• Lack of social supports for consumers • National Mental Health Strategy campaigns to reduce stigma have been unsuccessful • Campaigns focus on psychotic illness & depression and do nothing for other disorders such as Borderline Personality Disorder • Discrimination shown by mental health service providers • Unresponsive, unsympathetic services • Family rejection • Housing discrimination • Later service response means greater acuity seen in community. • Therapy seen as less legitimate than medication	• There appears to be a focus on the lack of diagnosis-specific services and a particular type of treatment. • The Commonwealth is also responsible for universal mental health promotion campaigns aimed at reducing stigma.	• Victoria has extensive psychosocial rehabilitation and support services for consumers with mental illness and their carers (receiving $57.7 million in 2004/05). These supplement the personal support that should be available through generic social services. • Paid consumer and carer consultants in area services often participate in in-house staff training to ensure that consumer and carer perspectives are presented to staff. • Public mental health services provide a variety of treatments that include therapeutic as well as medicinal treatments. Limited counselling is available through generic community health services. The Commonwealth is responsible for improving access to private psychologists and counsellors through Medical Benefits Scheme and private health insurance schemes. • Treatment in the least restrictive environment means that people are not admitted to the more restrictive hospital environment unless they cannot be satisfactorily treated in the community. • Additional funding is being provided to Victorian public mental health services to improve service responsiveness and shift the focus from crisis treatment to earlier intervention and relapse prevention (eg an additional $3.2 million funding was provided for early intervention and relapse prevention in 2004/05). • There is redress under legislation for discrimination by businesses based on disability.

Standard no	Issues raised in report	Victoria's issues	Victoria's response
5 – Privacy & confidentiality	• Lack of carer involvement in consumer treatment	• All the issues raised relate to carers. The report ignores the dichotomy between consumer and carer views	• Privacy and confidentiality provisions regarding client treatment are incorporated in the Mental Health Act. While carer involvement is recommended, it is up to the consumer to decide the extent to which this occurs. • Carer consultants are employed in many services to assist carers and ensure that carer views are presented in the organisation. • Carers are incorporated in treatment plans under Mental Health Act amendments.
6 – Prevention & promotion	• Services only respond to crises • Service providers do not listen to carers • Need increased General Practitioner involvement, less stigma and discrimination, and more promotional strategies	• All the comments in the report about early intervention problems are from carers. Only the community promotion concerns appear to have been raised by consumers.	• Victoria is continuing to expand its early psychosis services for young people (an additional $0.96 million funding provided in 2004/05). • Increased resources are being used to shift service system focus more towards early intervention and relapse prevention and away from crisis intervention (eg an additional $3.2 million funding was provided for early intervention and relapse prevention in 2004/05). • Primary Mental Health Teams (PMHT) continue to build relationships and establish service arrangements with primary care providers through shared care, education and consultation services. • Funding for universal mental health promotion is also the responsibility of the Commonwealth government.
7 – Cultural awareness	• Lack of sensitivity to spiritual beliefs • Lack of understanding about recent immigrants	• It is hard to quantify the extent of this problem since the report presents one case and a general statement that did not indicate whether the service response was an issue.	• Victoria funds the *Victorian Transcultural Psychiatry Unit*, *Victorian Foundation for Survivors of Torture* and *Victorian Aboriginal Health Service* for consultation, staff education and training. • Services employ paid consumer consultants to assist consumers and ensure consumer views are represented in the organisation. • Consumers and carers are represented on the Ministerial Advisory Committee on mental health and associated subcommittees.

Standard no	Issues raised in report	Victoria's issues	Victoria's response
8 – Integration 8.1 Service integration	• Non responsiveness of crisis services • Diminished service access & duration • Lack of bulkbilling General Practitioners & private psychiatrists. • Lack of counselling/psychotherapy services • Staff turnover • Lack of communication across treatment settings	• This standard relates to integration of mental health service components and continuity of client care, not integration with other services nor access to services, which are dealt with under other standards.	• Additional staff have been funded to improve service responsiveness, particularly for clients with complex needs such as homelessness and dual diagnosis (eg in 2004/05, an additional $1.6 million funding has been provided for consumers who are homeless and/or has a dual diagnosis). • General Practitioner & private service access (cost & distribution) is a Commonwealth responsibility. • Workforce is flagged as a national issue under the *National Mental Health Plan 2003-2008*. • Communication across treatment setting is covered in Standard 10 - Documentation
8.2 Integration with health system	• Neglect of physical health • Shared care arrangements	• The quotes about physical health problems are from carers. It is unclear if this was an issue for consumers.	• All services except Forensic are mainstreamed with generic health services. • Primary Mental Health Teams (PMHT) continue to build relationships and establish service arrangements with General Practitioners and primary care providers for shared care, education and consultation services. • Discharge planning guidelines provide protocols for General Practitioner and share care arrangements
8.3 Integration with other services	• Difficulties accessing housing • Financial support • Vocational rehabilitation programs needed • Cross-program linkages • Domestic violence • Children of parent with mental illness • Carer support – social, financial • Early intervention for young people • Support services after suicide • Police involvement in transport & restraint • Medicare rebates – rebate delays, psychologists (no rebates), General Practitioner reimbursement • Lack of employment & support	• Specialist mental health services are not core accommodation providers, although they work in partnership with housing services. • Vocation rehabilitation, employment, Centrelink and Medicare are Commonwealth responsibilities. • Suicide is not the sole responsibility of mental health services and requires a whole-of-government approach.	• Additional funding has been provided for supported accommodation and intensive housing support services to assist people with mental illness maintain stable accommodation (in 04/05 an extra $0.86 million). This is apart from the existing partnership with Office of Housing (Housing & Support program), where public housing properties are provided in conjunction with mental health outreach services. • Victoria is currently expanding its early psychosis services for young people (an additional $0.96 million funding provided in 04/05). • A new protocol was recently released between Victorian mental health services and Victoria Police clarifying the role of police in transport and restraint of mental health clients. • Vocational rehabilitation and employment programs are a Commonwealth responsibility. • Medicare and General Practitioner reimbursement are also a Commonwealth responsibility.

Standard no	Issues raised in report	Victoria's issues	Victoria's response
			• Suicide services are broader than mental health services. There has been considerable whole of government effort in responding to the issue of suicide in Victoria since the release of the Victorian Suicide Prevention Taskforce Report in 1997.
9 – Service development	• Cuts to inpatient funding over past 10 years • Culture of blame • Disaggregation of system when mainstreaming occurred • Worse than 12 years ago. • Better than 20 years ago • Deinstitutionalised people now homeless or in jail • Not able to deliver best possible service. • Shortage of acute & short-term beds. • Reliance on carers. • Reform stagnated. • No longer consumer focus. Focus is govt protection. • New institutions created, patchy leadership, poor morale and work practices • The Office of the Chief Psychiatrist not independent of government • Minister out of touch. • Workforce review program late • Auditor-General's concerns correct. • Planning without consultation and inflexible resource distribution. • Service for life • Lack of support services eg after hours, counselling, Psychiatric Disability Residential and Support Services • Dual Diagnosis service • Poorer quality services because service diluted. • Variable quality of care • Unsatisfactory levels of service • Need for more intensive inpatient care.	• This section contains a number of personal opinions that do not appear to be supported by facts. • Many of the issues included in this standard relate to other standards. • Rebates for General Practitioners and private medical services and distribution are Commonwealth responsibilities.	• The Victorian government has consistently increased funding for mental health services. Since 1999, the Government has provided additional funding to the mental health system of over $198 million or 30 per cent. • As standalone institutions were closed, funding was redirected to local, community-based services, where most consumers are treated. Long-term inpatient beds in particular were targeted for redevelopment as community-based services. The *National Mental Health Report 2004* shows that there has been minimal change in the numbers of acute inpatient beds over the last 10 years in Victoria. The 2004 Report also shows that there were more non-acute and community residential beds in June 2002 than in June 1993 (a total of 1,217 non-acute and community residential beds in 1993 compared with a total of 1,353 non-acute and community residential beds in 2002). • Investment in ambulatory services enables greater flexibility in meeting client needs rather than tying up large amounts of resources in bed-based facilities. • Victorian planning for public mental health services focuses on addressing areas of greatest need. It is expected that services use the most efficacious treatment model to improve individual client wellness. • Victorian resource allocation is informed by a weighted population formula, which adjusts for area differences in population characteristics such as socioeconomic status, rurality and availability of private mental health services. • Recent funding initiatives have included funding for additional acute inpatient beds (eg in 2004/05 an additional $2.75 million funding). • Workforce has been identified as a national issue. • Distribution of General Practitioners and private psychiatrists, and Medicare funding are Commonwealth responsibilities. • A Ministerial advisory subcommittee is currently examining service catchments with a view to improving service access.

Standard no	Issues raised in report	Victoria's issues	Victoria's response
	• Staff turnover therefore staff continuity problem • Staff shortage • Heavily accented staff • Inadequate funding level & control • Federal funding increased by $1.2 million but State funding decreased by $1million. • New Zealand provides twice the per capita funding • Progressive inpatient budget cuts. • More funding to primary care via Medicare. • No care in rural areas. • In Melbourne, distribution of public mental health services, private psychiatrists and primary care is direct inverse of need. • Because of catchments, if cannot get care in own area, cannot seek care elsewhere. • Under funding of rural areas. • Planning uses medical model only. • Nurse training • Insensitive staff attitudes • Clinician exposed to negative emotions & burn out		• It is unclear how Victoria is alleged to have reduced its funding for mental health services when it has been progressively increasing funding. Since 1999/2000, the Government has provided additional funding to the mental health system of over $198 million or 30 per cent.
10 – Documentation	• Incomplete documentation • Too much paperwork • Limited or no client engagement by staff • Documentation not accessible across service settings	• Some of the examples seem to relate to issues other than documentation and are covered under other standards.	• Clinical reviews highlighted variability in documentation standards across services but have also noticed improvements over time. • The Office of Chief Psychiatrist is unaware of any complaints from psychiatrists about excessive paperwork associated with Community Treatment Orders and is concerned at the suggestion that a clinician would risk a client's health because of paperwork.

Standard no	Issues raised in report	Victoria's issues	Victoria's response
11 – Delivery of Care 11.1 Access	• Cannot access services even if harming • Carers not heard • Telephone triage – messages not passed on, people rejected • Lack of access to private psychiatrists, General Practitioners, counsellors, Psychiatric Disability Residential and Support Services • People absconding and self-medicating • Short case management • Crisis management means treatment more intrusive & restrictive than if undertaken earlier • Need 24hr clinics • Crisis only service responses • Non-responsive services • Crisis in the community perpetuates stigma • Carers cannot initiate treatment	• Victoria is unable to quantify the extent of the problem from the report. • This section highlights the consumer/carer dichotomy relating to treatment.	• Demand for services has grown faster than growth funding. Additional funding has been earmarked to improve service access and shift service focus more to early intervention and relapse prevention (in 2004/05 an additional $3.2 million was provided for early intervention and relapse prevention). • Victoria has recently released the outcomes of a triage project to standardise access across mental health services.
11.2 Entry	• Entering the system via Emergency Departments – the environment & the wait • Mixed reports about triage	• All the comments reported are from carers. It is unclear if consumers have similar views about Emergency Departments.	• Victoria is aware of increasing wait times in Emergency Departments for mental health treatment and is providing additional resources for more intensive services to people with complex needs who frequently attend Emergency Departments, as well as expanding services to become more responsive earlier in an illness episode (eg in 2004/05 an additional $7.4 million to expand existing service capacity, relapse prevention and early intervention).
11.3 Assessment & review	• telephone assessment • assessments but no obvious treatment	• The comments reported are from carers. It is unclear if consumers have similar views.	• Treatment responses are focused primarily on assessment of consumer needs. There are occasions when consumer and carer views may differ about consumer needs.

Standard no	Issues raised in report	Victoria's issues	Victoria's response
11.4 Treatment & support	• lack of youth services & carer support • lack of dual diagnosis services • rural & regional areas under serviced • lack of personality disorder services • lack of carer involvement	• Availability of private services is a Commonwealth responsibility. • Access to public mental health services (voluntary and involuntary) is based on illness acuity not diagnosis. • Multiple quotes from one or two submissions presented as separate quotes create the illusion of multiple submissions from different people on the same issue. • Victoria focuses on providing public mental health services to people with a serious mental illness regardless of diagnosis.	• Victoria has continued expansion of early psychosis services for young people and dual diagnosis services for people with co morbid mental illness and substance misuse (in 2004/05 an additional $2.6 million for additional early psychosis and dual diagnosis services). Dual diagnosis services are seen as a core part of specialist mental health services. • Victoria has a statewide personality disorder service that provides consultation and liaison to other services. • Carer consultants ensure carer views are represented in many services. • The extent of carer involvement in consumer treatment is dependent on the consumer. • Carers are incorporated in treatment plans under Mental Health Act amendments.
11.4A Community living	• lack of community support services • discharge from community services • lack of leisure, recreation & employment programs • need for self-care programs and supported accommodation	• It is not the responsibility of specialist mental health services to provide all types of services to clients. Under mainstreaming, generic services are funded to provide many services, although this may be done in partnership with mental health services initially.	• Victoria has a well developed Psychiatric Disability Rehabilitation and Support service system (funded for $57.7 million in 2004/05). This is complemented by personal support services available from generic community services. • Generic leisure & recreation programs are funded to provide services to people with mental illness. The provision of these programs is not seen as core business for specialist mental health services. • The Commonwealth government is responsible for employment and vocational rehabilitation. • Victoria has increased funding to and monitoring of services to ensure better post-discharge follow-up of clients (eg an additional $3.56 million funding in 2004/05 to support discharge functions).

Standard no	Issues raised in report	Victoria's issues	Victoria's response
11.4B Supported accommodation	• lack of support accommodation • step up/step down services, especially for dual diagnosis consumers	• Most of the quotes in this section of the report are from clinicians or carers. It is unclear what views consumers have on this issue.	• Victoria has funded intensive supported accommodation services to increase housing stability for complex clients (an additional $0.86 million funding in 2004/05 to expand housing and support and supported accommodation services). This is apart from existing outreach programs that assist clients in maintaining stable accommodation. • The Housing and Support program is the result of a partnership between the Office of Housing and mental health services where public housing is provided in conjunction with mental health services. • Subacute services are being piloted as an alternative to hospitalisation, facilitate earlier intervention and support discharge (an additional 10 places were funded in 2004/05).
11.4C Medication & medical technologies	• Clients unable to get a second opinion	• The example used appears to relate more to the service access standard.	• Victoria is not responsible for the funding or distribution of private services. • Victoria is currently examining its catchment areas to facilitate service access.
11.4D Therapies	• Reliance on medicinal treatment, no behavioural change programs	• Multiple quotes from one submission make it difficult to quantify the extent of this problem.	• Victorian public mental health services provide a variety of therapies. Services are expected to provide the most efficacious treatment for clients.

Standard no	Issues raised in report	Victoria's issues	Victoria's response
11.4E Inpatient care	• death in inpatient care • lack of beds • police transport • restraint • consumers not involved in treatment plans	• Except for the section on restraint, most quotes are from clinicians or carers. It is difficult to assess consumer issues with this standard. • Consumer involvement in treatment plans is covered under other standards eg Standard 1.	• Victoria has recently released a new protocol between public mental health services and Victoria police that clarifies transport arrangements. • Victoria is currently increasing the number of acute beds in under-bedded areas of the state (an additional 26 adult acute beds were funded in 2004/05). • Victoria has increased funding to and monitoring of services to ensure better post-discharge follow-up of clients (eg an additional $3.56 million funding in 2004/05 to support discharge functions). • Apart from consumer consultants, Independent Third Persons and the Office of the Public Advocate are available to provide independent assistance and support to individuals who have concerns about their treatment. • Apart from internal complaints mechanisms of individual services, the Office of the Chief Psychiatrist and the Health Services Commissioner can investigate consumer and carer complaints about treatment. • The Mental Health Review Board independently reviews the need for the involuntary treatment of individual clients.
11.5 Planning for exit	• exit based on access to beds not wellness of client • exit plans not authorised by medical staff	• All the quotes are from carers, so it is difficult to assess consumer issues with this standard.	• See Standard 10 – documentation • Victoria is currently increasing the number of acute beds in under-bedded areas of the state (an additional 26 adult acute beds were funded in 2004/05). • Victoria has increased funding to and monitoring of services to ensure better post-discharge follow-up of clients.
11.6 Exit & re-entry	• carers not consulted when consumers discharged from inpatient units • consumers discharged while ill • no follow-up after inpatient discharge • no review of accommodation arrangements prior to exit	• All the quotes are from carers, so it is difficult to assess consumer issues with this standard.	• Victoria has increased funding to and monitoring of services to ensure better post-discharge follow-up of clients (eg an additional $3.56 million funding in 2004/05 to support discharge functions). • Consumer and carer views do not always align. • Carers are incorporated in treatment plans under Mental Health Act amendments.

Standard no	Issues raised in report	Victoria's issues	Victoria's response
Homicide & suicide	• Homicide – Victorian client in New South Wales • Suicide – after discharge/on leave, carers not heard • need safe place to stay till OK	• Victoria is not responsible for what occurred in New South Wales. • The report is focused on purported performance of services against national standards. Suicide and homicide do not have a separate standard so should not be reported separately.	• Although a Victorian client was involved, the episode occurred interstate, and the client was treated by the interstate services, which are outside Victoria's jurisdiction. • Victoria has increased funding to and monitoring of services to ensure better post-discharge follow-up of clients. • Carers are incorporated in treatment plans under Mental Health Act amendments.

Further supporting information can be found in:

- Summaries of the 2003/04 surveys of consumer and carer experience of Victorian public mental health services;
- *Victorian strategy for safety and quality in public mental health services*;
- *Annual Report 2003: Office of the Chief Psychiatrist*;
- *Victoria's implementation of the national standards for mental health services; progress report September 2004*; and,
- *Caring Together: an action plan for carer involvement in Victorian public mental health services*.

Copies of these documents were provided to Mr John Mendoza, Chief Executive Officer, Mental Health Council of Australia, on Wednesday 13 April 2005 at his meeting with Dr Ruth Vine, Director, Mental Health, Victorian Department of Human Services.

8.4.3 RESPONSE FROM QUEENSLAND GOVERNMENT





Queensland Government

Premier of Queensland
and Minister for Trade

Please quote MN04598/LR04/Social Policy

27 APR 2005

Mr John Mendoza
Chief Executive Officer
Mental Health Council of Australia
PO Box 174
DEAKIN WEST ACT 2600

Dear Mr Mendoza

Thank you for your letter of 24 March 2005 inviting a Queensland response to the draft report *'Not for Service' Experiences of Injustice and Despair in Mental Health Care in Australia.*

I would like to take this opportunity to commend the work of the Mental Health Council of Australia and the Human Rights and Equal Opportunity Commission in documenting the experiences of those Queensland consumers and community members who participated in community forums and surveys. As invited in your previous letter, the attached Queensland submission takes the opportunity to address issues raised in the draft report. It also provides additional information on the considerable changes to mental health services which have occurred in the past decade in Queensland through implementation of the Ten Year for Mental Health Services (1993) and achievements measured under the National Health Strategy.

Queensland will continue to strive to improve consumer and carer input and linkages with the non-Government sector to deliver responsive mental health services. The enclosed submission also discusses the need for Queensland's services to meet the challenges of a growing and diverse population and the increasing impact of drug and alcohol problems in the community.

Thank you again for contacting me about this important national project.

Yours sincerely

PETER BEATTIE MP
PREMIER AND MINISTER FOR TRADE

Executive Building
100 George Street Brisbane
PO Box 185 Brisbane Albert Street
Queensland 4002 Australia
Telephone +61 7 3224 4500
Facsimile +61 7 3221 3631
Email ThePremier@premiers.qld.gov.au
Website www.thepremier.qld.gov.au

QUEENSLAND HEALTH RESPONSE TO THE HUMAN RIGHTS EQUAL OPPORTUNITIES COMMISSION AND MENTAL HEALTH COUNCIL OF AUSTRALIA REPORT

Executive Summary

In response to the report – *'Not For Service'* by the Mental Health Council of Australia and The Human Rights and Equal Opportunity Commission it is advised:

- A submission was previously completed by Queensland Health in response to a request from the Human Rights and Equal Opportunity Commissioner.
- The submission completed in January 2005 and forwarded to the Commission was not acknowledged in the *'Not For Service'* report, nor were issues raised incorporated into the final report.
- *'Not For Service'* indicates a number of processes occurred to assist in the preparation of the report. The document indicates that:
    - A survey was undertaken to assist in the preparation of the report;
    - Open community forums were conducted and written submissions were received.
- While the report offers some individual insights, it is important that the information it contains is considered in the context of the small sample used.
    - Of the 714 surveys, 95 were for Queensland.
    - This represents a very small proportion of the service contacts for the State (779,527 for 2002/2003) and the projected number of individual community clients (75,300 - 76,240 for 2004/2005).
- In addition, the report should be considered in the context of other data which are used to inform the system of key issues:
    - Mental Health Services in Queensland have changed considerably over the last ten years.
    - Queensland leads other States in terms of the implementation of the National Mental Health Strategy with this exemplified by the Outcomes data system.
    - Queensland Health through their District Services has developed Consumer and Carer consultant roles that are providing significant input into services.
    - District Services have an active complaint management system that is monitored through the mental health service management process in each district.
    - However, services continue to confront rapid changes due to the rapid population growth and the impacts of drug and alcohol use.
    - Recruitment and retention issues are linked to a variety of issues including the rate of graduation of mental health professionals from tertiary education units.
- Notwithstanding the questions about the representative nature of material presented in the report and the limited acknowledgement of positive aspects and progress in Queensland Mental Health Services, Queensland Health will actively work to incorporate suggestions for improvement into its forward planning.
- Queensland Health acknowledges that the continued maturation of services and agencies is required particularly with respect to the links with NGOs and Consumer and Carer groups.
- The response to the report reflects the format adopted in *'Not For Service'*.

SUPPORTING DOCUMENTATION

NMH STANDARD 1: RIGHTS

Queensland Health has implemented training in relation to the Mental Health Act [2000] with this training provided to staff in all District Services. Training in the Mental Health Act [2000] emphasises the rights of those with mental illness and the need to provide treatment that takes into account the importance of the dignity and respect of the individual.

Each person within the mental health system is able to access Complaint's Managers should they perceive their rights have not been addressed. Services have introduced information brochures and signs that provide advice to carers and patients/consumers about rights and responsibilities. Mental Health Services have developed a number of mechanisms for increasing knowledge of rights and responsibilities with one service producing an introductory DVD that is provided to Patients/Consumers and Carers and is used during ward activities as a method of evoking group discussion.

With respect to the criminal justice system, it advised that police are receiving training in relation to mental health matters and that Queensland Health has developed a number of mechanisms that have improved dialogue between Police, Emergency Services and Mental Health Services. The improved communication has assisted in improving the care and treatment of those with mental illness, particularly during the initial phase of contact with Mental Health Services especially in the Emergency Departments.

The Mental Health Review Tribunal has adopted a model that addresses the need to respect the rights of the individual and aims to provide a maximum level of support to individuals. The Tribunal is comprised of a legal person, doctor (usually a psychiatrist) and a community member. Carers and Patients/Consumers attend the hearings and may be legally represented.

In relation to those within the prison service, Queensland Health and Corrective Services have developed a Prison Mental Health Service for those who are identified as having a mental illness. This service seeks to assist those within the Prison setting and, when necessary, facilitate their transfer to an Authorised Mental Health Service.

The Transcultural Mental Health Service has assisted in emphasising the importance of translators and services in Queensland regularly use translators although the cultural and linguistically diverse nature of Queensland impacts on the capacity of services to access some language groups. These rights are linked to those pertaining to all groups, especially to Aboriginal and Torres Strait Islanders.

All District Mental Services via the EQUIP Survey address the rights of individuals.

NMH STANDARD 2: SAFETY

Services in Queensland are confronted with a rapid growth in population and changes in demographics. This growth of between 80-85,000 per year over the last few years has placed stress on services in terms of availability of resources, increases in occasions of service and recruitment and retention of staff. Despite these pressures, services in Queensland have developed new initiatives such as recovery, alternative models of care programs and integrated models of service delivery.

Services now provide extended hours assessment programs. Outside of those hours an assessment can be received through the Emergency Department of a hospital. Queensland Health has developed mobile service teams and single point of entry processes. Services in Queensland are participating in studies that benchmark access issues with many adopting models that reflect priority systems that give specific time frames for patient reviews by Mental Health staff

Queensland Health has developed a policy on restraint to provide guidance for management of individuals who require restraint. Services are now involved in Aggression Management Training which will involve all staff within services.

The development of integrated Risk/Management processes and the Queensland Health Incident Management Policy has occurred on a state wide basis with services now using a standardised mechanism.

Queensland Health has developed a model for residential care that seeks to improve communication with residential care agencies and improve the safety and care of individuals within these services. New Queensland laws have been introduced to improve residential safety, and cross government committees have been developed to assist this process.

NMH STANDARD 3: CONSUMER AND CARER PARTICIPATION

Mental Health Services aim to provide care in the least restrictive manner and with the active involvement of the patient/consumer and carer. The approach for Queensland Health has been the active inclusion of consumers and carers in the delivery of mental health services. The *Action Plan for Consumer and Carer Participation in Queensland Mental Health Services* is currently being implemented. Consumer consultants are employed in 11 districts. Consumer and Carer Advisory Groups operate throughout the state. A new state wide advisory model for consumer and carer participation has been developed and a consultation process will commence in the near future.

Some services have developed consumer/patient and carer discharge surveys that are utilised to evaluate the service and contribute to service improvement with respect to activities such as information on medication, diagnosis and post discharge planning.

A curriculum for clinician education in consumer and carer participation has recently been developed and has been piloted in three District Services. This training is to be evaluated in 2005.

The involvement of consumer/carer groups in the early phase of treatment has commenced in one service with others beginning to explore this in relation to provision of care. Psycho-education programs for patients/consumers and carers have been developed in some services

NMH STANDARD 4: PROMOTING COMMUNITY ACCEPTANCE

Mental health services within Queensland provide education to the community both by way of direct contact, or involvement within community-based programmes such as those associated with Rotary, beyondblue, PPP programs and educational programs for health care professionals, NGOs and other government services. The total funds allocated to NGOs and some research institutions are $6.9 million.

Public Health as part of the promotion of prevention has undertaken activities within Queensland to highlight issues related to mental health including early recognition and de-stigmatisation.

Queensland Health is progressing mental health promotion, prevention and early intervention in this State under the *National Mental Health Plan 2003-2008*. This process includes the mental health promotion, prevention and early intervention initiatives that seek to focus on the needs of priority groups identified in the Queensland Health implementation framework. The program aims at increasing the understanding and knowledge of mental health and the importance of maintaining mental health, and is linked to the recognition of these aspects in all environments and settings.

Mental Health week in Queensland has been actively used to highlight issues pertaining to Mental Health. Rural services are involved with media issues that emphasize the importance of early intervention, the multifactorial nature of mental illness, the importance of carers and the role of therapy in treatment and relapse and prevention.

NMH STANDARD 5: PRIVACY AND CONFIDENTIALITY

The problems raised within the report highlight the difficulties which confront clinicians, patients/consumers, carers and the broader community on a regular basis. Provision of information to family/carers is recognised as an important issue by Queensland Health. However, services are at times confronted with the competing desires of the patient/consumer versus the needs of the family/carers. This clearly, on occasions, causes concern for the community especially family members. However, despite being a difficult matter to overcome, in many cases with appropriate support and counselling communication with the family/carer can be achieved. The document indicates that for person's diagnosed with cancer and other significant illnesses the whole family is involved with this, contrasted with what occurs in mental illness. Unfortunately, this ideal is at times not achieved even when cancer, heart disease and diabetes is diagnosed with some patients refusing to have information divulged to family members.

Services have attempted to deal with this issue by adopting education programs and family focussed groups.

Privacy of patient/consumer and carers is recognised as important but at times is difficult to provide due to building design or the number of individuals presenting to services. The capital works program has resulted in the construction or modification of units with rooms that are single or 2-4 bed units. Units are provided with open space and services have implemented policies that seek to protect privacy and the individual's property.

NMH STANDARD 6 – PREVENTION AND MENTAL HEALTH PROMOTION

It is acknowledged that there are concerns in relation to the provision of rehabilitation programmes. Queensland Health has identified non-government organisations as integral to service delivery and is moving towards the development of programmes that integrate with external agencies and assist in the rehabilitation of people into the community. Mental Health Services are adopting a *Recovery Focus* that promotes maximising the persons and families/carers capacities.

The Mental Health Unit, in partnership with Health Promotion Queensland, is funding a multi-strategy health promotion project which promotes resiliency in children of primary school age in school, family and community settings. The project involves the measuring of elements that promote resiliency in individual children of primary school age.

Early Intervention and Prevention Officers have been appointed to services. At present this program is in its early phase and is still developing its full capacity. The problem of Alcohol and Drugs and its link to mental

illness is well documented. Queensland is continuing to develop strategies to improve assessment and intervention for those with dual diagnosis.

Queensland Health has funded programs for the deaf and has granted further funding for a Centre based in a major teaching hospital. This Centre is widely recognised and from time to time its services are used by bodies from other jurisdictions.

NMH STANDARD 7: CULTURAL AWARENESS

All staff in Queensland Health are required to undergo training in relation to cultural awareness with respect to Aboriginal and Torres Strait Islanders. Queensland Health has developed an active state wide policy which promotes the involvement of the Indigenous mental health workers within services with these staff actively involved in improving the delivery of services to Aboriginal and Torres Strait Islanders within local regions.

Examples of the working relationships forged across the networks include the link established with the Aboriginal and Torres Strait Islander Health Unit and the consultation and input towards the following key activities:

- Queensland Health Aboriginal and Torres Strait Islander Workforce Management Strategy;
- Partnership Framework (Working party for ATODS/MH/Chronic Disease);
- Cultural Respect Framework;
- Outcome measures for Mental Health Services;
- National Aboriginal and Torres Strait Islander Framework for Mental Health and Social and Emotional Wellbeing; and
- Structures have been established on zonal and district levels and these structures/processes contribute to furthering the implementation of the Queensland Health Mental Health Policy – Aboriginal and Torres Strait Islander People 1996. These structures will also play a part in the implementation of the National Strategic Framework for Aboriginal and Torres Strait Islander Peoples' Mental Health and Social and Emotional Well Being 2004-2009 for Queensland.

Queensland Health perceives Aboriginal and Torres Strait Islander people as a priority target group. The adoption of a holistic definition of health and mental health as defined by Aboriginal and Torres Strait Islander people is part of Mental Health Policy and aims to address Aboriginal and Torres Strait Islander social and emotional well being.

The establishment of Centre for Rural and Remote Mental Health is being explored with Aboriginal and Torres Strait Islander groups intimately involved in the working party. This Centre has attracted support from a variety of groups integral to the development of rural and remote mental health services including Royal Flying Doctor Service, Queensland Health, mining companies, Aboriginal and Torres Strait Islander groups and the Division of General Practice.

NMH STANDARD 8: INTEGRATION

Queensland has adopted an integrated model of care involving inpatient and community mental health services. The integration of services provides continuity of care with a single point of entry across the span of services. This continuity of care also reflects a model care for both the child and youth and older person's mental health services.

In relation to the issue of staff turnover and its impact on integration and care it is evident this reflects, not only the mobility of professional groups involved in mental health services, but problems related to staff resources which reflects decisions made in relation to training in the 1980s. These decisions have had a negative impact in the number of mental health professionals graduating from 1990 to beyond 2005. Governments at every level are attempting to address this issue but it is evident that the resolution of staff shortages will not occur in the short term and, as a consequence, there will continue to be difficulties in terms of the recruitment and retention of staff.

Factors related to the care of individuals within the private sector are not within the direct province of Queensland Health. Strategies seeking to improve communication between the public and private sector have been developed at a service level. The difficulties in accessing appropriate resources within the private sector are also affected by rapid changes in population, the aging of trained professionals, changes in the culture of medical, nursing and allied health professional expectations and, as with the public sector, the impact of decisions made a number of years previously in relation to university numbers in the various disciplines. Despite the development of new medical schools within Queensland, the likelihood of any increase in the number of Australian trained psychiatrists will not occur for approximately 8-10 years due to the need for undergraduate and post-graduate training positions which is linked to the provision of funded, supervised training posts with in the public and private sector.

> *In recognition of the importance of increasing the numbers of trained mental health professionals, Queensland Health has funded scholarships for nurses and allied health staff and is funding the Director of Training (psychiatry). The Director of Training's position has a role in the provision of information to those doctors desirous of entering specialist training in psychiatry and assist in the development of training processes within the State. The state wide position has assisted in the recruitment of registrars within Queensland. Recruitment into training positions has demonstrated growth and is in contrast to other jurisdictions that are experiencing a decline in applicants.*

The Commonwealth Government through the development of innovative general practice programmes has improved the training of General Practitioners. These programmes have improved the capacity to provide integration and increased resources to manage individuals within the community in shared-care arrangements. Services have developed Memorandums of Understanding with Divisions of General Practice that in some cases have permitted General Practitioners to refer patients to services for specific treatment groups while continuing as the 'case manager'.

The management of individuals with complex needs is clearly, as indicated in the document, difficult, however, Queensland Health has developed a number of programs that have begun to address the issue of people with mental health disabilities which reflect a whole of Government approach. This process involves linkages with housing, Disability Services Queensland and non-Government Organisations (NGOs). The State Suicide Prevention Strategy is an example of this whole of Government approach and includes representatives from Housing, Police, Education, Premiers, Aboriginal and Torres Strait Islanders and the Commonwealth.

As part of the continued improvement in care, Queensland Health is developing a consultation liaison model of service delivery project that addresses the issues of the physical health of individuals with mental illness in relationship to general hospital inpatient care, outpatient services and primary care positions. This project is due for completion towards the end of 2005 and will have a focus on a broad range of issues related to physical illness and mental health across the state.

The Queensland Government has recently announced the provision of affordable accommodation for homes within Central Brisbane and a number of districts have begun to implement strategies that reflect a whole of Government approach.

As part of this broad strategy, there has been an increase in educational processes related to the care of people with mental illness with the services being provided to Police, Ambulance and other groups within the community.
In relation to the management of people with mental illness and their involvement with the judicial system, Queensland has adopted a model of care and a strategy for managing those with mental illness within the judicial system that is progressive. Those charged with an offence and who have a mental health defence are brought before the Mental Health Court rather than the judicial system. This model is judged by many as reflective of best practice and at the leading edge in terms of the care of those with mental illness who become involved with the legal system. The process allows early intervention for those identified with mental illness and management in a manner that respects their rights and in a less restrictive manner with integration across the prison and mental health systems.

Child and Youth services continue to face problems especially when confronted with the population growth, divorce/separation rates and the rate of child abuse. Following a major review, a new Department of Child Safety has been developed. Queensland Health and the Department of Child Safety, along with other agencies, are developing programmes for children most at risk.

NMH STANDARD 9: SERVICE DEVELOPMENT

The *Queensland Mental Health Plan 1994*, represented the first strategic plan for mental health reform in this State. The plan focussed on integrated systems across regions. The document provided broad based principles that enabled the reform process to commence.

The Plan resulted in the mainstreaming of integrated services to promote continuity of care across service components, the local availability of care through more equitable distribution of mental health resources despite the geographical and demographic complexities of a rapidly growing and developing state, and consumers' and carers' involvement in the planning, operation and evaluation of services.

The Plan has resulted in the progressive reform of psychiatric hospitals, establishment and maintenance of links with Primary Health Care services and implementation of quality management systems including the Minimum Service Standards.

In 1996, this Plan was replaced by a more comprehensive planning document designed to set the framework for the full system of care, and providing the basis for a more equitable distribution of services throughout the State.

The *Ten Year Mental Health Strategy for Queensland* (TYMHSQ) advanced the directions already identified in the *Queensland Mental Health Policy* (1993) and *Queensland Mental Health Plan* (1994).

The TYMHSQ became the key strategic document for mental health reform in this State until 2003. The TYMHSQ assisted in planning and equitable resourcing of services throughout the State.

By 2002/2003, a review of progress of mental health reform found that with the exception of the full complement of community positions, the objectives of the TYMHSQ had generally been reached. The results of

the review did not imply reform was complete but the State was able to progress with the *National Mental Health Plan 2003-2008.* It identified issues related to decentralisation and community positions.

The *Queensland Strategic Plan for Mental Health (2003-2008)* seeks to foster mental health in Queensland for the next five years and beyond. The Strategy aims to promote the mental health of the community, while continuing to build the capacity.

The Strategic Plan aims to address the mental health issues broadly across the community. Specific areas have been identified as a priority. Priority areas include:

- Enhancement of core specialised mental health services.
- Improving service quality and safety.
- Improving service responsiveness.
- Improving the capacity to meet the needs of specific groups within the population.
- Strengthening partnerships across the spectrum of intervention.
- Improving utilisation of data and information in service evaluation and planning.
- Ensuring the availability of a strong and skilled workforce.

Care is seen as a service to be covered across a broad spectrum of providers including primary health care which participates in the continuum of care. Support of primary care providers will be enhanced by technology, the development of consultation/liaison and skills development programs.

Specialised mental health services are secondary and tertiary services are provided by specialist mental health personnel. These services, while focussing on the serious mental health problems, will also provide assessment and care for the high prevalence disorders. It is recognised that the high prevalence disorders negatively impact on quality of life and have the capacity for adverse social consequences.

Services across the state provide continuum of care for individuals. This is assisted by a variety of service activities including:

- Acute Care and Assessment teams
- A continuing care case management approach, which includes the following components:
  - community treatment services
  - outreach services
  - acute inpatient services, with provision for short to medium term treatment, including secure treatment
  - psychiatric crisis response and treatment
  - specialist intensive treatment and support for identified 'at risk' individuals (mobile intensive treatment teams)
  - extended inpatient services for treatment and rehabilitation, with services organised around five clinical programmes
  - a recovery focus that has been endorsed by the Queensland Human Services Chief Executive Officers' Committee.

The Strategy has developed a focus for improvement of Mental Health Services for Rural and Remote Communities and improvement in the Mental Health Services for People Involved in the Criminal Justice System.

The *Queensland Forensic Mental Health Policy 2002* targets adults and young people with mental disorders or severe mental health problems who are also subject to criminal justice processes.

> *Access to secure inpatient treatment has been improved with the opening of a medium and high secure facility in Townsville allowing mentally ill offenders from North Queensland to receive treatment closer to their families and support networks.*
>
> *Specialised community forensic services have developed active outreach processes to provide closer support to mental health services across the State, which assist in local patient management and ensure compliance with formal monitoring requirements. In North Queensland, outreach services extend as far as Papua New Guinea. This care of this group has been enhanced with the development of forensic liaison service positions.*
>
> *A visiting service has been established to the Brisbane Youth Detention Centre integrating both mental health and drug and alcohol workers, and the Child and Youth Forensic Outreach Service facilitates transition from detention to the community.*

The Prison Mental Health Service was established as a joint initiative between the Department of Corrective Services and Queensland Health to provide mental health services to people who have a mental illness and are resident in a correctional centre.

Mental health reform in Queensland has decentralised inpatient beds from the large psychiatric facilities based in Toowoomba, Charters Towers and West Moreton. Inpatient beds have been relocated to regional centres to ensure a more equitable distribution of resources across the State and to facilitate access. Decentralisation of inpatient beds was completed in 2002.

Inpatient programmes have been developed to encompass a range of services including acute inpatient, dual diagnosis, child and youth, psycho-geriatrics, acquired brain injury, medium and high secure services and community care units in suburban settings.

With changes in the inpatient services there has been a progressive expansion of community mental health services throughout the State during the life of the TYMHSQ. Planning targets were established at 30 per 100,000 total population for adult mental health services, 25 per 100,000 for the under 19 population, 10 per 100,000 of the 65+ population, whilst Indigenous workers are set at 5 and 6 per 10,000 for child and youth and adult services respectively.

Community Mental Health provides a range of services including extended hours, Acute Care Teams, Crisis Assessment Teams and Mobile Intensive Treatment Teams. In addition, dual diagnosis projects are being developed. The suicide prevention strategy and aged care strategy have been developed along with specific programs for trans-cultural mental health and those with hearing impairment. The P300 project has assisted in the transition of patients/consumers from hospital to the community.

Queensland Health, as part of the development of Mental Health Services, has fostered research in a variety of settings including the University of Queensland, The Park and in hospital appointments that have both clinical and academic roles

NMH STANDARD 10: DOCUMENTATION

Documentation remains a difficult area for services despite records remaining fundamental to the mechanism of recording clinical information and a significant issue in the medico-legal arena. Poor documentation and lack of access to documents has been demonstrated to contribute to negative outcomes and has been noted by coroners to be a key issue in contributing to patient deaths.

Services in Queensland have been confronted with the difficulty of having separate charts for inpatients, community and other services such as alcohol and drugs. This separation has impacted on patient care. Over the last few years where separate charts existed, the services have moved towards integration of medical records. However, the lack of common record numbers across the State continues to cause some difficulties.

A number of services have introduced comprehensive audit processes that review the comprehensiveness of records, explores adequacy of notes, risk assessment, care plans and discharge planning. The audit mechanism reviews several charts each month in a random fashion with the audit reporting against specific criteria.

NMH STANDARD 11: DELIVERY OF CARE

The Queensland Mental Health Act 2000 is an Act about treating and protecting those with mental illness with this occurring in an environment that seeks to respect the rights of the individual and provide respect for the person's dignity. The Act aims to aid the provision of care in the least restrictive manner.

The broad approach to the management of individuals within Queensland Health Services involves the use of individual care plans, with these care plans developed in consultation with each patient/consumer.

Services are developing pathways of care that involve the recognition of the need for increased consumer involvement, explanation of the nature of the illness and advice on treatment modalities including the pharmacological methods.

Services adopt a broad treatment approach that addresses the psychological, social and pharmacological treatment of mental illness. A number of services provide not only individual but also group therapy and family therapy sessions.

Services are provided, irrespective of an individual's past. Assessment and care are related to the current needs of the person. On accessing a Mental Health Service a comprehensive assessment is undertaken with this reflecting those processes outlined in accreditation guidelines that are required of each district.

8.4.4 RESPONSE FROM SOUTH AUSTRALIAN GOVERNMENT

Hon Lea Stevens MP

Minister for Health
Minister Assisting the
Premier in Social Inclusion

Level 6, ING Building
45 Pirie Street
Adelaide 5000
South Australia

GPO Box 2559
Adelaide 5001
DX 275

Telephone (08) 8207 1855
Facsimile (08) 8207 1950
Email: Minister.Health@health.sa.gov.au

05MHE/1449

9 May 2005

Mr John Mendoza
Chief Executive Officer
Mental Health Council of Australia
PO Box 174
DEAKIN WEST ACT 2600

Dear Mr Mendoza,

Thank you for your letter of 24th March 2005 regarding the Mental Health and Human Rights Draft Report. Thank you for providing South Australia with the opportunity to comment on the relevant sections of the Draft Report.

In acknowledging the significance of the report and in taking this report seriously, I will provide South Australia's detailed response to the Cabinet this week and aim to forward you a copy as soon as possible thereafter.

I appreciate that you require the full report but regrettably the current budget cycle and business of government is such that the report can not be provided within your timeframe.

The importance of the Draft Report is appreciated by the South Australian Government. Over 250,000 South Australians are predicted to have mental health problems/disorders. Of these 38,000 are estimated to have a severe condition. The prevalence of mental health problems/disorders differs across the age ranges[1].

SA acknowledges that mental illness is a whole of government and whole of population matter. Any adequate response to improving services for mentally ill consumers is built on cross-government planning, education, training and review and must involve a number of organisations including health, employment, housing, justice etc. Narrowing mental health focus to the health system will not suffice.

This whole of government commitment is articulated in the South Australian Strategic Plan including a key objective to improve the Health and Wellbeing of South Australians of which mental health is a key factor. Additionally, this state's Social Inclusion agenda specifically targets strategies for people who are the most vulnerable to the co-existence of homelessness, substance abuse, and social

[1] Australian Bureau of Statistics, 2002.

disadvantage, whereby mental illness is a major contributor. Also the government has established a cohesive advocacy sector including the Mental Health Coalition and the Health Consumer Alliance to ensure consumers have a voice in the planning and delivery of mental health services.

National Mental Health Strategy and Plans – achievements to date
SA accepts this framework for reform of mental health services in Australia in accordance with international trends. However, complexities of funding across Australian Government and State/Territory governments lead to patchy and uncertain planning and development of services. For example, enhancement monies from the Australian Government will promote development of specific aspects of a service, sometimes to the detriment of other aspects of the service.

Service models in SA have, to date, predominantly focused on acute care, with hospital services remaining highly significant. For example, SA is criticised as nearly 50% of direct dollars for mental health still goes towards the running of one hospital (Glenside Campus). However, it must be recognised that much has been achieved in collaboration with other departments within the confines of the resources available.

Government commitment
The Labor government came to office with a clear commitment to improve mental health in SA. Immediately funds were injected for a range of services including services for children, young people and Aboriginal people; workforce development, and care packages.

Since coming to government there has been an additional recurrent commitment of $20 million dollars to the reform and delivery of mental health services in this state. Also $80 million dollars was allocated to build better facilities for consumers of mental health services and to enable incremental closure of Glenside Campus, whilst reconfiguring the Mental Health System. In addition, the government funded $56 million dollars to provide support to people residing in marginal accommodation, through the supported residential facility program. This program targets people with a mental illness who require additional services and supports to be able to maintain a level of independence.

As evidenced by the Mental Health and Human Rights Draft Report, SA has significant challenges ahead, in spite of this government's increased investment. However, there has been progress achieved through the commitment and work of many individuals and organisations. Further progress will be made through the government's ongoing pledge to improve not only the resources available, but also the legislation, structures and systems required to support reform.

A population based resource funding approach – the way forward
One of the key outcomes of SA's Generational Health Review was recognition that governance and funding arrangements were required to concentrate the health system 'towards improving the health of the population, enhance capacity to promote population health and meet the equity objectives of the South Australian Government'.

A population approach to mental health provides a framework which can respond to identified problems; unmet need (disorders which could be effectively prevented or treated but which are currently not); and accountability in population terms for improving health and lessening disease prevalence, morbidity, disability and mortality.[2]

The initial focus of the South Australian Reform Agenda is to reorientate the whole health system to a population health planning approach, achieving gains in population health outcomes and improving health status by moving emphasis towards a primary health care focussed system.

Immediate responses

The new regional health structures within SA allow for immediate initiatives to focus on:

- Reducing hospitalisation through extended hours of mobile emergency mental health teams working with ambulance; and a single point of access to mental health care in metropolitan Adelaide;
- Avoiding people entering the hospital system through alternatives to admission with intensive community treatment and support;
- Assisting people to leave hospital earlier through post discharge intensive community follow-up;
- Adequately skilled workforce by developing a single co-ordinated education and training strategy for all disciplines including non-clinical staff.
- Building the capacity of the non-government community based sector to assist in supporting people in their home, out of hospital.

Strategies for sustainability

A number of new initiatives are proposed for SA within the current planning environment. The resources and services required to deliver best practice in mental health care for SA have been assessed and six (6) new strategies have been identified to bridge existing service gaps.

Strategy 1: The specific targeting of prevention and early intervention services where there is a risk of mental health problems and disorders.

Strategy 2: Accessible and responsive community based treatment and care to those for whom the failure to receive it is likely to result in relapse, or social disruption.

Strategy 3: Responsive partnership support to the broader human service sector where the interface has a significant impact.

Strategy 4: Recovery focused support services, which demonstrate outcomes in improved functioning, and reduced demand on high cost specialist services.

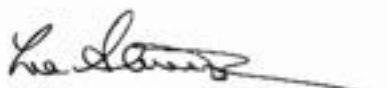
Strategy 5: A system of service allocation and monitoring, which facilitates appropriate streaming of consumers into packages of care.

Strategy 6: The development of an available and appropriately skilled workforce that supports the building of a sustainable system of mental health care.

[2] Planning in South Australia is premised on the Mental Health Clinical Care and Prevention Model (MH-CCP) as a mechanism for developing population based estimates of the level of resources required.

I note that you have discussed the draft report and initiatives underway in South Australia in detail with Ms Leame Durrington, Deputy Director, Mental Health Unit, Department of Health. In the mean time, should you require any additional information please contact Ms Durrington directly on (08) 82260777.

Yours sincerely



HON LEA STEVENS MP
Minister for Health
Minister Assisting the Premier in Social Inclusion

Hon Lea Stevens MP
Minister for Health
Minister Assisting the
Premier in Social Inclusion

Level 4, ING Building
45 Pirie Street
Adelaide 5000
South Australia

GPO Box 2555
Adelaide 5001
DX 275

Telephone (08) 8207 1855
Facsimile (08) 8207 1950
Email: MinisterHealth@health.sa.gov.au

DH05MHU/0307

12 May 2005

Mr John Mendoza
Chief Executive Officer
Mental Health Council of Australia
PO Box 174
DEAKIN WEST ACT 2600

Dear Mr Mendoza

Thank you for your letter of 24 March 2005, regarding the Mental Health and Human Rights Draft Report. South Australia appreciates the opportunity to comment on the relevant sections of the Draft Report.

Please find attached a response prepared by the Mental Health Unit, Department of Health, South Australia. For your ease, the submission has also been collated under the National Standards for Mental Health Services including both a response and list of significant achievements relating to the concerns raised in the Draft Report.

I note that you have discussed the draft report and initiatives underway in South Australia in detail with Ms Learne Durrington, Deputy Director, Mental Health Unit, Department of Health. Should you require any additional information please contact Learne directly on (08) 82260777.

Yours sincerely

HON LEA STEVENS MP
Minister for Health
Minister Assisting the Premier in Social Inclusion

RESPONSE TO THE MENTAL HEALTH AND HUMAN RIGHTS DRAFT REPORT

EXECUTIVE SUMMARY

This response to the Mental Health and Human Rights Draft Report has been prepared by the Mental Health Unit, Department of Health, South Australia (SA).

Over 250,000 South Australians are predicted to have mental health problems/disorders. Of these 38,000 are estimated to have a severe condition. The prevalence of mental health problems/disorders differs across the age ranges[1]*.*

SA acknowledges that mental illness is a whole of government and whole of population matter. Any adequate response to improving services for mentally ill consumers is built on cross-government planning, education, training and review and must involve a number of organisations including health, employment, housing, justice etc. Narrowing mental health focus to the health system will not suffice.

This whole of government commitment is articulated in South Australia's Strategic Plan including a key objective to improve the Wellbeing of South Australians. The priorities are to focus on quality of life and the wellbeing of the community and individual citizens of which mental health is a key factor. Additionally, this state's Social Inclusion agenda specifically targets strategies for people who are the most vulnerable to the co-existence of homelessness, substance abuse, and social disadvantage, whereby mental illness is a major contributor. Also the government has established a cohesive advocacy sector including the Mental Health Coalition and the Health Consumer Alliance to ensure consumers have a voice in the planning and delivery of mental health services.

National Mental Health Strategy and Plans – achievements to date

SA accepts this framework for reform of mental health services in Australia in accordance with international trends. However, complexities of funding across Australian Government and State/Territory governments lead to patchy and uncertain planning and development of services. For example, enhancement monies from the Australian Government will promote development of specific aspects of a service, sometimes to the detriment of other aspects of the service.

Service models in SA have, to date, predominantly focused on acute care, with hospital services remaining highly significant. For example, SA is criticised as nearly 50% of direct dollars for mental health still goes towards the running of one hospital (Glenside). However, it must be recognised that much has been achieved in collaboration with other departments within the confines of the resources available.

Government commitment

The Labor government came to office with a clear commitment to improve mental health in SA. Immediately funds were injected for a range of services including services for children, young people and Aboriginal people; workforce development, and care packages.

[1] Australian Bureau of Statistics, 2002.

Since coming to government there has been an additional recurrent commitment of $20 million to the reform and delivery of mental health services in this state. Also $80 million was allocated to build better facilities for consumers of mental health services and to enable incremental closure of Glenside Hospital, whilst reconfiguring the Mental Health System. In addition, the government funded $56 million to provide support to people residing in marginal accommodation, through the supported residential facility program. This program targets people with a mental illness who require additional services and supports to be able to maintain a level of independence.

As evidenced by the Mental Health and Human Rights Draft Report, SA has significant challenges ahead, in spite of this government's increased investment. However, there has been progress achieved through the commitment and work of many individuals and organisations. Further progress will be made through the government's ongoing pledge to improve not only the resources available, but also the legislation, structures and systems required to support reform.

A population based resource funding approach – the way forward

One of the key outcomes of SA's Generational Health Review was recognition that governance and funding arrangements were required to concentrate the health system 'towards improving the health of the population, enhance capacity to promote population health and meet the equity objectives of the South Australian Government'. A population approach to mental health provides a framework which can respond to identified problems; unmet need (disorders which could be effectively prevented or treated but which are currently not); and accountability in population terms for improving health and lessening disease prevalence, morbidity, disability and mortality.[2]

The initial focus of the South Australian Reform Agenda is to reorientate the whole health system to a population health planning approach, achieving gains in population health outcomes and improving health status by moving emphasis towards a primary health care focussed system.

Immediate responses

The new regional health structures within SA allow for immediate initiatives to focus on:

- Reducing hospitalisation through extended hours of mobile emergency mental health teams working with ambulance; and a single point of access to mental health care in metropolitan Adelaide;
- Avoiding people entering the hospital system through alternatives to admission with intensive community treatment and support;
- Assisting people to leave hospital earlier through post discharge intensive community follow-up;
- Adequately skilled workforce by developing a single co-ordinated education and training strategy for all disciplines including non-clinical staff;
- Building the capacity of the non-government community based sector to assist in supporting people in their home, out of hospital.

[2] Planning in South Australia is premised on the Mental Health Clinical Care and Prevention Model (MH-CCP) as a mechanism for developing population based estimates of the level of resources required.

Strategies for sustainability

A number of new initiatives are proposed for SA within the current planning environment. The resources and services required to deliver best practice in mental health care for SA have been assessed and six (6) new strategies have been identified to bridge existing service gaps.

Strategy 1: The specific targeting of prevention and early intervention services where there is a risk of mental health problems and disorders.
Strategy 2: Accessible and responsive community based treatment and care to those for whom the failure to receive it is likely to result in relapse, or social disruption.
Strategy 3: Responsive partnership support to the broader human service sector where the interface has a significant impact.
Strategy 4: Recovery focused support services, which demonstrate outcomes in improved functioning, and reduced demand on high cost specialist services.
Strategy 5: A system of service allocation and monitoring, which facilitates appropriate streaming of consumers into packages of care.
Strategy 6: The development of an available and appropriately skilled workforce that supports the building of a sustainable system of mental health care.

Detailed supporting documentation in response to Part Six: South Australia

National Mental Health Standard 1: RIGHTS

ACHIEVEMENTS:
- Comprehensive review of Mental Health Legislation in SA undertaken
- Community Based Information System (CBIS) has been developed and implemented

Human rights legislation, particularly in the form of mental health acts, criminal law acts, ombudsman's acts, public guardianship acts and privacy acts are critical in preventing erosion of fundamental human rights of mental health consumers.

In recognition of this, the Review of Mental Health Legislation in SA was commissioned by the Department of Health last year and involved extensive consultation in metropolitan and country areas with carer and consumer groups, Aboriginal organisations, professional organisations and government agencies from August 2004 to March 2005. The Review Committee received and considered 60 submissions and its report is near completion however, it is yet to be formally received by the SA Government.

In relation to mental health and guardianship the broad themes that have emerged are:

- The rights of carers and consumers should be articulated more clearly in the legislation, as other States have recently done;
- Confidentiality should not be interpreted as a barrier to proper sharing of information in the best interests of consumers;
- The particular needs of Aboriginal people need to be recognised as a matter of principle;
- There must be an emphasis on community care, not just hospital services;
- There should be more flexibility as to who can intervene to assist someone in need of care, or make initial orders for admission and detention;

- Greater flexibility with orders to suit the individual is needed (for example, short-term detention orders to avoid inappropriate transfer of consumers from the country to the city);
- The treatment plan should be a pivotal requirement of involuntary orders;
- The Guardianship Board needs to be humanised from arrival at the door (eg through social work assistance or consumer representation);
- A specialist appeal body should replace the court to ensure appeals and procedural fairness arguments are considered in a therapeutic context.

A Health and Community Services Complaints Commission has been recently established in SA. The government on coming to office has developed and passed legislation and appointed a commissioner. The legislation is the most comprehensive in Australia and includes both public and private health, and the full range of community services. It seeks to resolve complaints whilst developing, implementing and monitoring a Charter of Rights for Consumers. The Complaints Commission also has an educative role regarding rights of consumers and complaints management, coupled with monitoring the overall health system for improvement and quality performance.

The Rights Analysis Instrument recommends that consumers of a mental health service must have a representative whose task it is to advise and protect their rights as long as that person wishes. Consultation in SA also recommends that all consumers subject to involuntary treatment should have comprehensive treatment and discharge plans. Carers and consumers request such plans incorporate their views, goals for recovery and be regularly reviewed.

Advanced directives can be made by a consumer to empower others to make treatment decisions on his/her behalf during temporary and permanent incapacity. However, in SA consumers are not currently empowered by law to express, in writing, their own wishes or treatment preferences in advance for periods of temporary incapacity. Ulysses Agreements are one form of advanced directives that has been used in many countries in various ways. There is strong consumer support for legislative recognition of this concept in SA.

Concern: Information not provided

Mental Health Adverse Event investigations and coronial inquiries in SA have supported this concern by highlighting communication problems in the mental health area, a need for better electronic records and rapid exchange of information.

To achieve this a purpose built Community Based Information System (CBIS) has been developed to enable capture of consistent data to complement in-patient information. When fully operational, the system will provide demographic and contact data, Outcome measures (National Outcome & Casemix Collection – NOCC), risk assessment, triage, Management Plans as well as Crisis and Relapse Prevention Plans.

The intent of CBIS is to collect, analyse and use consistent relevant information to better inform decision-making at both the individual consumer level (eg care planning) and at a regional statewide level (eg resource allocation). Compliance with the National Standards for Mental Health Services and national reporting against minimum data sets are fundamental elements of the system. Access to this system will facilitate information transfer and shared care options and will be particularly helpful in emergency or crisis responses.

CBIS has a primary means of

Capturing consistent client information;
Providing functions to prepare management plans;
Giving security to client information;
Providing access to current and historical client information;
Being accessible from mental health locations across SA; and,
Interfaces to other mental health services' information (eg inpatient).

The National Mental Health Strategy seeks to ensure a jurisdiction's ability to identify "Who receives what services from whom, at what cost, and with what effect?" to support the reporting and management needs of clinical managers and service administrators. CBIS provides the capacity to record this information for Ambulatory and Community Residential services and will eventually link with inpatient systems to provide a comprehensive repository of information that can be retrieved and utilised at the local, regional and statewide levels.

National Mental Health Standard 2: SAFETY

ACHIEVEMENTS:

- *Establishment of quality systems to ensure increased safety and to facilitate the reporting of adverse events*
- Embedding safety and quality systems for mental health services within mainstream quality systems
- *Established a monitoring system for coronial inquiry recommendations to enable system-wide change*
- Incorporation of the National Standards for Mental Health Services into the Service Excellence Framework

Concern: Lack of services for children and youth with behaviour problems

ACHIEVEMENTS:

- Establishment by Child and Adolescent Mental Health Services (CAMHS) partnerships with primary health care providers, the Department of Education, and Family and Youth Services in the provision of programs that focus on resilience and recovery for young people
- Partnership between CAMHS and the Lyell McEwin Health Service for the development of models of care that assist adolescents in successful transition to adult mental health services. This model will be extrapolated to other services
- Additional funds for the provision of mental health services to children and young people outside the metropolitan area
- Provision of funds for a behavioural intervention service to children and young people in the northern metropolitan area
- Increased investment in the provision of a mental health emergency triage service at the Women's and Children's Hospital

The Mental Health Unit have contracted in the NSW Institute of Psychiatry to provide a range of short courses (to December 2005) in the areas of: Introduction to Mental Health; Rehabilitation in Mental Health; Relapse Prevention; Mental Illness and Substance Use; Consumer Advocacy and Carer Advocacy. Some of these courses will include elements of aggression management.

The longer term plan is to develop a systemic approach to training across the sector provided through a single point of co-ordination. With a clear agenda for training to accompany the mental health reform agenda of SA, this will include issues related to recovery, relapse prevention and rehabilitation. Critical to these will be the management of associated behaviours which may arise, including aggression management.

The *Mental Health Act 1993* is not explicit that it applies to children. Since children rarely seek review of or appeal against involuntary orders, it has been recommended that legislation should provide for advocacy to ensure children's legal rights are exercised and protected and that any orders are reviewed on a regular basis. It is accepted best practice that, where possible, treatment for children should be provided in the community.

In calling for legislative clarity around the rights and treatment of children recommendation 27 of the Layton Child Protection Review Report called for the removal of barriers that prevent the appropriate exchange of information about children, young people and families involved with the child protection system and calls for a close working relationship between mental health and child protection services.[3]

The Department of Health has commenced a statewide planning process to ensure that mental health services provided to children and young people are seamless, coordinated with consistent access and entry pathways.

Concern: Requirement for staff to be trained to respond appropriately to aggressive and difficult behaviour

The Mental Health Unit have contracted in the NSW Institute of Psychiatry to provide a range of short courses (to December 2005) in the areas of: Introduction to Mental Health; Rehabilitation in Mental Health; Relapse Prevention; Mental Illness and Substance Use; Consumer Advocacy and Carer Advocacy. Some of these courses will include elements of aggression management. The longer term plan is to develop a systemic approach to training across the sector provided through a single point of coordiation. With a clear agenda for training to accompany the mental health reform agenda of SA, this will include issues related to recovery, relapse prevention and rehabilitation. Critical to these will be the management of associated behaviours which may arise, including aggression management.

National Mental Health Standard 3: CONSUMER AND CARER PARTICIPATION

Concern: Tokenistic approach to consumer and carer involvement

ACHIEVEMENTS:

- Establishment of a memorandum of understanding between the SAn branch of the Royal Australian and New Zealand College of Psychiatrists and the Mental Health Coalition declaring a commitment to the involvement of consumers and carers in all aspects of treatment and care
- *Establishment of Consumer and Carer Advisory Committees within metropolitan and country health units*
- Increased rural consumer and carer representation on government committees and advisory groups including rural areas
- Employment of consumers and carers as peer support workers in a number of health services

Expanding a peer support programme is a priority in SA and would include training for participants. Appropriately trained and funded peer consumer therapists have a significant place in mental health services in other jurisdictions, but require appropriate funding and training. In keeping with overseas experience, consumers could ultimately provide up to 20% of the workforce and reduce, amongst other matters, the current workforce crisis.

[3] Recommendation 27, Layton, R. A. (2003). Our Best Investment: A State Plan to Protect and Advance the Interests of Children, Child Protection Review. South Australia cited by the Review of Mental Health Legislation.

Peer support workers in SA are a developing concept and the northern metropolitan area is leading the way in developing a programme. The vision is to have a paid, skilled and competent peer support workforce working alongside specialist staff at all points of the continuum.

Concern: Lack of funding for consumer and carer participation

ACHIEVEMENTS:

- The Mental Health Unit has provided funding to the Health Consumers' Alliance to implement formal structures and processes to ensure consumers and carers contribute to the planning and delivery of local mental health services
- The Mental Health Unit has also provided 'one off' funds to the Carers Association to enable them to undertake a metropolitan/rural education and support forum for carers
- The Mental Health Unit also provides funding to the Association of Relatives and Friends of the Mentally Ill SA to provide counselling, support services, educational programs and respite care for relatives of friends of people with a mental illness

Future directions in Mental Health in SA include strengthening participation by increasing consumer and carer participation reported through regional Health Service Agreements.

A significant development in SA involved the close working partnership between a Consumer and Carer Steering Committee and Mental Health Unit in developing a *Framework for Developing Partnership Between Consumers and Carers and the Mental Health Sector.* It is intended this document form the major mental health policy and directions in regard to carers and consumers. The Mental Health Unit has worked across the Department of Health to ensure the Framework informs the development of the broader participation mechanisms being developed and to ensure that a focus on mental health consumers and carers is maintained at all levels.

In view of Generational Health Review recommendations, the Department has sought to ensure that there is one consumer peak body supported by the Department and that resources are not dissipated through duplication of participation mechanisms or systems. The Health Consumer Alliance (HCA) has been endorsed as the peak consumer body in SA for the purposes of consumer/carer government interface.
The HCA is as an important mechanism to provide a strong independent and effective voice for consumers, carers and community groups in the SA health system and to ensure that mental health is integrated into broader health reforms at this state.

National Mental Health Standard 4: PROMOTING COMMUNITY ACCEPTANCE

Concern: High levels of stigma and discrimination

ACHIEVEMENTS:

- Collaboration with the Commonwealth Government on programs such as Headroom, MindMatters and beyondblue and the National Suicide Prevention Strategy, with the goals of raising awareness and reducing stigma

SA recognises the following facts:

- Community and population level studies have consistently shown the association between higher levels of self reported discrimination and poorer mental health (Krieger 2000)[4]
- Greater levels of community participation, social support and trust in others in the community have been associated with reduced experience of psychological distress (Berry & Rickwood)[5]
- People who are socially isolated have between two and five times the risk of dying prematurely from all causes compared to those who maintain strong ties with family, friends and community (Berkman & Glass 2000)[6]
- …socially isolated people feel fear, they feel alienated and they lose their sense of belonging, of value and opportunities to contribute in any meaningful way to their community[7]
- "One of the biggest barriers to recovery is discrimination. That is why stopping discrimination and championing respect, rights and equality for people with mental illness is just as important as providing the best treatments and therapies."[8]
- The impact of mental illness, stigma and discrimination and the subsequent burden on the Australian population has been estimated to affect up to one in five people within a 12-month period[9]

Education involving consumers/carers and the community is very important. This will promote health literacy and help to minimise stigma. The work of *beyondblue* (National Depression Initiative) is a good example for this and uptake in SA has been high.

Jorm, Christensen and Griffiths[10], in evaluating the impact of *beyondblue* found that awareness of *beyondblue* in states that funded the program was approximately twice as high as in those that did not. The high-exposure states had a greater change in beliefs about some treatments including counselling and medication and help-seeking.

The continued operation of an ageing and outdated Glenside Campus contributes to discriminatory perceptions of mental illness, and barriers to people accessing mental health care. The realisation of the government's mental health capital works program ($80 million) will result in modern integrated facilities over the next 5-7 years.

Concern: Discrimination directed towards children of parents with mental illness

The Children of Parents with Mental Illness (COPMI) organisation is proudly supported by SA and many initiatives have been driven from this state. For example, COPMI have produced a document titled *"Principles and Actions for Services and People with Children of Parents with a Mental Illness"* which has been published as a National Mental Health Strategy document and has set a framework for Australian agencies working with children of parents with mental illness.

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[4] Krieger N 2000, "Discrimination and Health", In: Berkman L, Kawachi I, eds. *Social epidemiology.* Oxford: Oxford University Press, 36-75

[5] Berry HL, Rickwood DJ 2000, "Measuring social capital at the individual level: personal social capital, values and psychological distress". *International Journal of Mental Health Promotion* 2(3); 35-44.

[6] Berkman LF & Glass T 2000, "Social integration, social networks, social support and health", In: *Social epidemiology, eds ,* Berkman L, Kawachi I. *Social epidemiology.* Oxford: Oxford University Press.

[7] Connections Directions –ideas for taking action. Together We Do Better. VicHealth, 2003.

[8] Blueprint for Mental Health Services in New Zealand, November 1998

[9] McLennan A 1997, "Mental Health and Wellbeing: Profile of Adults: Australia". Canberra: Australian Bureau of Statistics. 1998.

[10] Jorm, A. F., Christensen, H. and Griffiths, K. M. (2000, p. 1).

Another publication is "*The Best for Me and My Baby*" which is a booklet for women with mental health problems and their partners who are thinking about having a baby. In addition, *"Family Talk"* is information for families where a parent has a mental health problem or disorder. In addition, these publications are underscored by the COPMI website www.copmi.net.au. COPMI has worked with various jurisdictions to determine how to implement the published guides. COPMI has worked with the Royal Australian and New Zealand College of Psychiatrists (RANZCP) to develop a position statement for Psychiatrists regarding the need to work with a whole family as more of a holistic systems view.

The Perinatal and Infant Mental Health in the Community project is a 2-year project, funded under the Department of Health Innovative Initiative Grants program. It is a partnership between Helen Mayo House, the South Australian Divisions of General Practice and Community Mental Health Services, Royal Adelaide Hospital. This project is ground breaking in terms of identifying and implementing training and workforce needs in relation to children of parents with a mental illness.

National Mental Health Standard 5: PRIVACY AND CONFIDENTIALITY

Concern: Negative consequences to relationships when carers are not involved

ACHIEVEMENTS:

- The Review of Mental Health Legislation has recommended that:
- Barriers to proper disclosure of information should be removed as a matter of urgency by legislative change
- There should also be professional development of mental health staff on mental health law, and duties of care and confidentiality

There are approximately 250,000 carers in SA and it is estimated that the value of family carers in this State alone is in excess of $2 billion per annum.

Carers have a recognised need for educational assistance, not only in relation to aspects of assistance for their relative/friend with a disability, but also in techniques of personal resilience. The Department of Health has made available funding for 12 carer forums in 2005 across SA to assist family carers of mental health consumers to link with one another and to provide opportunities to meet and network. The forums aim to make local service providers more accessible and provide carers with opportunities to hear about new initiatives.

The National Privacy Principles[11] have clarified issues of privacy and confidentiality. In response a – Code of Fair Information Practice was developed by Government and the Department runs training sessions including training for regional mental health services. Additionally, a document called "Achieving the Balance" targeted at mental health workers to explain ways in which privacy / confidentiality can be balanced with duty of care, will be incorporated into a training manual / module for mental health workers to be delivered as part of training for code of fair information practice.

Work will also be undertaken to convert this "Achieving the Balance" document into a format for consumers and carers including training through the Health Consumer Alliance to ensure consumers understand their rights.

[11] The National Privacy Principles in the Privacy Amendment (Privacy Sector) Act 2000 cited by the Review of Mental Health Legislation (2005, p. 22).

National Mental Health Standard 6: PREVENTION AND MENTAL HEALTH PROMOTION

Concern: Prevention not a focus of mental health services

ACHIEVEMENTS:

- Development of the next phase of activity with beyondblue is currently underway
- Increased funding for suicide prevention activities
- Support workforce development regarding mental health promotion, illness prevention and early intervention in partnership with national workforce development initiatives (additional funds provided to establish statewide over 1.5 years)
- Development of a SA Mental Health First Aid training program that will aim to increase the mental health literacy

Advancing mental health promotion, illness prevention and early intervention is a key priority for government. This direction will lead to improving community awareness and knowledge about mental illness in order to reduce stigma and discrimination that is unfortunately associated with having mental health problems or illness.

The State Government, through the Department of Health, has established several partnerships that complement the directions contained within the National Mental Health Plan 2003-2008. These focus on the promotion of mental health and prevention of mental illness. For example, the State Government currently funds and supports the coordination of regular public education programs and activities that include Mental Health Week, the Dr Margaret Tobin Awards, Rotary Forums and Mental Health First Aid Training programs that contribute to increasing the mental health literacy of the community.

Concern: Lack of services to provide early intervention for youth is a critical problem

ACHIEVEMENTS:

- SA participation in beyondblue-Schools Research Initiative projects across 16 high schools
- Distribution of thousands of copies of the *Mental Health First Aid* booklet to government agencies and service providers
- Continued development and support to SA media and communication outlets using national resource packages that include the national media initiative *Mindframe* that promotes respectful and responsible reporting
- Supporting rural communities in the prevention of suicide and deliberate self harming practices through a range of community led projects and programs with a focus on young men and indigenous communities

The State Government, through the Departments of Health and Education, are working collaboratively in promoting the mental health and well-being of SA children and young people in areas of service provision (including service pathways) reducing depression (through the beyondblue School Research Initiative) and developing the skills and knowledge of the workforce (mental health and education and early childcare).

The State Government has developed a range of collaborative partnerships with key organisations and initiatives that include *beyondblue* (the national depression initiative), *Auseinet* (the Australian Network for Promotion, Prevention and Early Intervention for Mental Health) and MindMatters (national secondary schools mental health promotion initiative).

National Mental Health Standard 7: CULTURAL AWARENESS

Concern: Lack of culturally appropriate practices for Indigenous people

'Aboriginal culture has a different, broader concept of mental illness. In essence, health is seen not just as the well-being of the individual, but also involves the extended family, and indeed, the social, emotional, spiritual, and cultural well-being of the whole community. Kinship ties, responsibilities and obligations place a strong emphasis on sharing and mutual support. Dispossession and racism have had a profound effect on families. Drug and alcohol abuse, depression and other forms of mental illness have followed. [12]'

In March 2005, a coronial inquest into the deaths of four Aboriginal men in the Anangu Pitjantjatjara Yankunytjatjara (APY) Lands between May 2003 and March 2004 commented on future policy formulation including:

- A need for high quality interpreting services and video-conferencing facilities;
- A fast-tracked training program / supported employment of Aboriginal workers;
- A longer-term and innovative program for the selection, support and training of Aboriginal Medical Officers and ultimately psychiatrists;
- Further consideration of the role of Adelaide-based mental health services because of disincentives for patients to come to an Adelaide-based facility.

ACHIEVEMENTS:

- Investment in the provision of specialist Aboriginal mental health services in the Pitjantjatjara Lands
- Appointment of Aboriginal workers within the Aboriginal Youth Mental Health Partnership Project and Cavan and Magill Youth Training Centres to work with young people who are part of the juvenile justice system
- Development of strategies in the western suburbs for mental health promotion and prevention, early intervention and illness recovery within the Aboriginal community
- Additional funds for the development of a culturally appropriate mental health service for Aboriginal people in the metropolitan area to link to mainstream services
- Funds for the provision of specialist Aboriginal mental health workers across the state including services to children and young people
- Funding to assist with liaison between rural and remote inpatient services and country services for people from Aboriginal communities
- Funding for a project for enhancement of primary health care for Aboriginal people in the western metropolitan area
- Funding for Aboriginal Mental Health Liaison Services at the Noarlunga Health Services

The Commonwealth Government has made a commitment to invest in the construction of a Substance Misuse Facility on the APY Lands in the far northwest of SA. Additional facilities that are designed and operated to provide improved care for Aboriginal sufferers of mental illness and respite for their carers would be beneficial as would be the facilitation of Aboriginal self-management and community-controlled governance structures.

[12] See for example, Aboriginal Health – Everybody's Business, Social and Emotional Well-Being, A South Australian Strategy for Aboriginal and Torres Strait Islander People 2005-2010, South Australian Aboriginal Health Partnership.

National Mental Health Standard 8: SERVICE INTEGRATION

Mental Health Services as they are currently configured in SA do not comprise an integrated system. The current mental health system is made up of a number of component services. The performance of each service component is contingent upon the effectiveness of other related service components.

However, the SA mental health reform is consistent with international and national directions, and has as a fundamental principle, that the hub of service delivery is the community mental health team. As far as practicable, people with mental health disorder should be treated within their community, and therefore within each region, specialist inpatient facilities and a range of community rehabilitation programs should be made available. Specialist statewide services, such as forensic mental health services, focus on specific target populations and should support and augment adult community mental health services.

Concern: Problems with continuity between adolescent and adult mental health services

A transitional program has commenced between Child and Adolescent Mental Health Services and Eastern Community Mental Health Services to cater for 16-18 year old young people who will require adult mental health care in the future.

The Department of Health has commenced statewide planning into mental health services for children and young people which will feature a specialised service for people with first episode of mental illness. The target age range will be 15-24 years.

Concern: Link between mental health services and general practitioners

ACHIEVEMENTS:

- Establishment of the Metro GP Access program which, in partnership with GPs, provides a range of flexible psychiatric disability support services to people experiencing disability as a result of a mental illness
- Implementation of standardised referrals between GPs through a partnership between the South Australian Divisions of General Practice and Mental Health Services and Programs
- Establishment of partnerships between community mental health teams and local GPs, including mental health staff consultancy and advice via telephone or face-to-face

However in SA, primary health care is a central focus for health system reform and a Primary Health Care Policy has been released to inform the implementation of this focus.

However, despite significant development of GP services eg Better Outcomes in Mental Health (BOIMH), delivery of services through general practices is sub-optimal. A lack of first class electronic communication between general practice and the public sector leads to safety and quality concerns.

Parallel with this policy direction are ongoing changes to the health system in SA in moving to a regional model with mental health as a priority concern. Primary health care networks are being formed at a regional level with the main focus being on the management of chronic diseases. Mental health and in particular depression is a major co-morbidity for all leading chronic diseases and is a concern for health professionals and consumers. A range of models are also being considered in line with the National Chronic Disease Strategies.

Work with the Divisions of General Practice has commenced in SA developing shared care models including the role of mental health nurse practitioners within the general practice to provide improved mental health services to clients. These models seek to ensure the effective integration of care across service boundaries and to enhance the overall knowledge and capacity of general practice to identify and manage mental health complaints.
Concern: Problems with integration with NGO services

ACHIEVEMENTS:

- Incorporation of the National Standards for Mental Health Services into the DHS Service Excellence Framework to assist in standardisation of service provision for non-government organisations
- Provision of in-home support assisting people with a psychiatric disability to manage everyday living tasks through the Community Support Inc Scheme and the Metro Access Program
- Establishment of partnerships between the government and non-government sectors in the delivery of programs for young people such as Primetime, a vocational rehabilitation program for young people with mental health problems

Integration between NGOs and specialist mental health services is a recognised priority of the Department of Health and strategies for capacity building and integration across human services has commenced.

The Mental Health Coalition is the newly established peak body for mental health non-government organisations. The Integration Project is funded as a one off grant to the Mental Health Coalition of SA (MHCSA). The aim of the project is to increase the viability of the smaller agencies by building their capacity via integrated management and administration.

Funding allocation has also been given to urgently address the lack of service integration across the mental health NGO sector and to modernise service delivery in accord with contemporary policy agendas.

Key Deliverables include:

- Increased service viability and integration of services;
- Established links between the NGO sector and key partners in service provision including primary care, education, disability, housing, welfare, aged care and other services;
- A coherent service mix and model of service across the non government sector;
- Services reshaped to better reflect contemporary models of care and support;
- Sector capacity to function as a partner in delivering proposed rehabilitation packages;
- Protocols and procedures to co-ordinate service delivery to consumers;
- Meet required national quality standards.

Concern: Lack of access to services to meet physical health needs

The Mental Health Emergency Demand Management Policy and Procedure series developed by the Mental Health Unit seeks to ensure appropriate medical assessment is undertaken when necessary. Additionally the recent National Institute of Clinical Studies (NICS) Mental Health Emergency Care Interface Project ensures that mental health services within the Emergency Department are mainstreamed and efficient.

The shared care models between mental health services and general practitioners provide greater access to mainstream medical care when required.

Concern: Housing

ACHIEVEMENTS:

- Initiation of a national research project on the support of people with a mental illness who have been provided with emergency accommodation through the Supported Accommodation Assistance Program
- Implementation of the SRF Reform Strategy which aims to provide better outcomes for people, many of whom have psychiatric disabilities, who are residents within Supported Residential Facilities or are affected by the closure of an SRF
- Integrated care and support of homeless people with a mental illness into the Inner City Homelessness Strategy
- Significant expansion of access to supported accommodation facilities
- Homelessness initiatives:
  - Transfer Liaison Officer positions,
  - Boarding house outreach service,
  - Best practice program for homeless persons with complex needs,
  - Integrated services for homeless persons with dual mental health and drug and alcohol problems

There is currently a draft Memorandum of Understanding, developed by the SAHT, between the Minister for Housing (South Australian Housing Trust, Aboriginal Housing Authority and Australian Community Housing Authority) and the Minister for Health (South Australian Mental Health Services).

The MOU has been developed as a broad inclusive strategy to guide the coordinated delivery of mental health services and housing support services. The aim of the MOU is for the parties to the agreement to work collaboratively, to improve the well being and housing outcomes for people with mental health disorder.

Concern: Health and Community Care (HACC)

It is an objective of the Department of Health to increase the proportion of HACC funding allocated to psychiatric disability and to build HACC agencies' capacity around mental health. An increasing proportion of HACC funding is allocated for disability services.

Mental Health Services for Older People have been contracted to provide mental health training to HACC agencies and build sustainable local networks to give support and assistance to both workers, coordinators and managers of HACC programs as required.

Country — Ageing & Community Care have committed to the provision of funding for an additional suitably qualified person to join the Country team so that the Country team now has the capacity to expand their training program across all seven country regions and develop sustainable networks with local HACC agencies.

Metro — Ageing & Community Care have committed to the provision of funding for Metro Mental Health Services for Older People to expand their existing mental health training programs and support to all metro HACC agencies.

Concern: Police

ACHIEVEMENTS:

- MOU developed between SA Police, Mental Health, SA Ambulance Service and the Royal Flying Doctors Service.

A Memorandum of Understanding (MOU) has been developed between SA Police, Mental Health, SA Ambulance and Royal Flying Doctor Services. This has been signed off by all parties and the final publication will be coordinated by SA Police.

The Memorandum seeks to clearly define the roles and responsibilities of each of the service providers and provides an endorsed strategy for implementation at an operational level.

The implementation strategy seeks to ensure that there is a consistent and coordinated state-wide response, provided by the parties to this agreement, to ensure that people with known and suspected mental disorder are provided with access to available mental health services.

Concern: Education

ACHIEVEMENTS:

- Specific strategies for recruitment, retention and maintenance of a specialist mental health workforce ($1 million)
- Support workforce development for mental health and related workforce regarding mental health promotion, illness prevention and early intervention (in partnership with national workforce development initiatives) establishment phase over 1.5 years
- Funding provided for training and development for the non-government sector
- 30 scholarships to support staff undertaking post graduate studies in mental health nursing (20 metropolitan, 10 country
- Two additional positions (one within each metropolitan region) to facilitate practice development within the mental health nursing
- Additional funding to support the education of appropriate staff as supervisors, and to encourage the implementation of clinical supervision
- Provision of a wide range of training programs, for example:
  - Training of direct care workers through TAFE
  - Education and training for police officers
  - Training for staff in emergency departments and Assessment and Crisis Intervention Services
  - Clinical training in emergency mental health and drug and alcohol misuse for general clinical staff, including country health workers, the South Australian Ambulance Association and the Royal Flying Doctor Service

Development of mental health system workforce strategy has commenced. This integrates with regional health units and health system-wide workforce strategies and creates collaborative arrangements with relevant national committees, industrial bodies, academic institutions and peak bodies which support:

- The development of new models of care;
- Improved workforce utilisation (i.e., nurse practitioners);
- Appropriate workforce mix and distribution;
- A sustainable and competent workforce.

Establishment and funding for a training consortium has commenced in order to provide ongoing education and staff development programs for the workforce across the spectrum of service provision (including non-government service providers). Targeted recruitment and training for Aboriginal and Torres Strait Islander, and culturally and linguistically diverse mental health workers has taken place. Support for the existing workforce to transition to the provision of new models of care has commenced.

Concern: Centrelink

Centrelink and the lack of access to welfare and employment systems of centrelink for Mental Health consumers is a recognised issue in SA. The state recommends that the issue be addressed at the national level at the National Mental Health Policy interface with Welfare Policy.

Concern: Transport

SA Health Commission Guidelines for Patient Transport were developed in 1997 and are currently under review and the Mental Health Unit of the Department of Health is ensuring that they reflect best practice for mental health consumers.

Additionally, the Department of Health published a policy as part of the Mental Health Emergency Demand Management Strategy on *'Emergency Transport of Mental Health Consumers from Country Locations*', which includes principles of care, legal and professional issues and specific procedures relating to transport. This policy promotes transport by the least restrictive means possible, in a manner that ensures the safety of the person and others with regard for the rights, dignity and privacy and with the with the involvement of consumers and carers in choices. A collaborative approach between health professionals, consumers, family members and emergency services, encourages good communication and agreed values, which will ensure timely access to metropolitan hospitals, including Emergency Departments and inpatient units.

Additionally, a Memorandum of Understanding (MOU) has been developed between SA Police, Mental Health, SA Ambulance and Royal Flying Doctor Services.

Concern: Wards of the State – Need for a whole-of-government approach

Research shows a number of underlying and interrelated factors contribute to environments where children are harmed which also includes mental illness and substance misuse. There has been an overall 35% increase in notifications in the last 3 years.

The South Australian Government's child protection reform program 'Keeping Them Safe' commenced in May 2004. Child protection cannot be separated from policies that benefit children in many areas. The government is injecting significant resources to match our policy commitment to the wellbeing of children.

This child protection strategy seeks to provide the levels of safety, opportunity and choice that will enable children, families and communities to flourish.

The role of the Department of Health is to promote greater awareness and understanding amongst health services and health workers in relation to their responsibilities in the area of child protection and to aid in the integration of this work across health service policy and direction. In essence, to provide a well connected child centred approach, across the continuum of care, from promotion and prevention to acute assessment and therapeutic intervention.

'Keeping Them Safe' identifies 5 key directions for reform, all directly related to Health:

1. Support to children and families
2. Effective, appropriate intervention
3. Reforming work practices and culture
4. Collaborative partnerships
5. Improved accountability

Health already has a significant role in the promotion of the health of families and children, including, target strategies for children of parents with a mental illness. The Department has provided Child and Adolescent Mental Health Services (CAMHS) with specific funds in order to prioritise referrals from this vulnerable group.

Concern: Health in rural and remote areas - Collaboration between state and federal governments to improve services in rural and remote areas.

ACHIEVEMENTS:

- Investment for improved availability of inpatient country mental health services
- Recurrent funding provided to Whyalla, Port Augusta, Port Lincoln and Wallaroo hospitals and Port Lincoln Aboriginal Health Services to improve mental health inpatient services

Approximately 28% of South Australians live in rural or remote areas. The dispersed nature of the population and service distribution, as well as fewer mental health clinicians per capita than metropolitan services, results in significantly reduced access to mental health care for country people. Of the young people waiting for service from Child and Adolescent Mental Health Service (CAMHS) nearly half are living in country regions. The Department of Health also recognises a need for psychogeriatric services to country regions.

Country SA is unique as there are no major rural bases and tertiary care is mostly provided by metropolitan Adelaide. Therefore, there is a requirement to build clinical networks that capitalise on the use of technology due to this reliance on Adelaide based services.

Significant funds from the Social Inclusion Board to develop suicide prevention programs in each rural region that are based upon collaborative care arrangements specifically designed to join up state and federal initiatives. Additionally, increase in access to both non-government organisations and primary health care services are key priorities for the Department of Health especially for Aboriginal people. This will be linked with the Commonwealth Aboriginal Primary Health Care Access Program (APHCAP).

Commitment has been made by the Department of Health in the form of Strategic Directions for Country Health 2005-2010. These state that the objectives for mental health will be met by cooperation and collaboration with other agencies on integrated mental health; ensuring consumer and community participation; provision of supportive environments for the safe and effective delivery of mental health care; ensure a highly skilled, well-supported, confident and sustainable health workforce.

Concern: Criminal Justice System - Collaboration with the Adelaide Magistrates Court to provide services to, and reduce offending by, people with mental illness.

ACHIEVEMENTS:

- Establishment of the Mental Impairment Implementation Reference Committee (MIIRC) to address coordination of services across portfolios and to improve mental health outcomes for prisoners and offenders
- Provision through the Magistrates Court Diversion Program of alternatives to incarceration for criminal offenders

Recent reviews[13] have recommended the expansion of current capacity of Forensic Mental Health Services and Department of Correctional Services (DCS) professional staff to meet specialist inpatient, consultative and treatment needs of DCS clients and licensees who are in prison or in the community.

Diversion programme operations within the judicial system in the Magistrates / Children's Courts, are a cost-effective way of avoiding institutionalisation and the problems caused by institutionalisation.

It should be possible for a court to dismiss a charge and/or refer an offender for mental health services to prevent increasing use of the section 269 Mental Impairment Provisions (1995) of the Criminal Law Consolidation Act (1935) which results in clogging up of the courts and acute forensic mental health facilities. This issue is being addressed in the current review of the Mental Health Act and the con-current review of the Criminal Law Consolidation Act specifically section 269.

Planning for a new 40-bed forensic facility and a new secure 30-bed secure rehabilitation facility has commenced. Planning for the forensic facility will include a capacity to expand to a possible total of 50-beds. Consultants are to be engaged by mid-2005 and construction is due to commence in mid-2006 with completion expected by early 2008.

National Mental Health Standard 9: SERVICE DEVELOPMENT

Concern: Lack of resources and services and the impact of this on clinicians

Services models in SA have traditionally focused on acute care, with hospital services remaining highly significant. The initial focus of the SAn Reform Agenda is to reorientate the health system to a population health approach, achieving gains in population health outcomes and improving health status by moving emphasis towards a primary health care focussed system.

In acknowledging and proactively addressing criticisms, the South Australia Government has committed approximately eighty million dollars to a mental health capital program from 2002 to 2007.

[13] Joint Stakeholder Survey (2005, p. 95).

Concern: Distribution of services – lack of services in rural and regional areas

ACHIEVEMENTS:

- Investment for improved availability of inpatient country mental health services
- Increased funding for country mental health services and linkages with the rural and remote mental health service
- Expanded telepsychiatry, leading to better access for consumers in rural areas to specialist resources
- An increase in the number of psychiatrists visiting rural areas to undertake shared care and provide support to GPs via a partnership between the Commonwealth Medical Specialist Outreach Assistance Program and the Rural Doctors Workforce Agency
- Development of a Health and Community Services Complaints Commission in SA

In country regions, the focus is on increasing the availability of consultation and liaison services provided by community mental health services, distance consultation services and visiting specialist services to better support GPs and other local services. Then the priority will be to get the services to work as a single system of mental health care.

Concern: Model of mental health care needs to change – inappropriate focus on inpatient and crisis care

A Transition plan for consumers from Glenside has commenced entitled: – Returning Home Project.

Ongoing community support services will be provided by a non-government organisation to up to twenty people who will be assisted to transfer their care to the northern metropolitan area from residential rehabilitation on Glenside Hospital. This represents the post assessment phases of the Returning Home Project (transfer planning and preparation).

The Department has provided funding to assist with establishment of households, purchase of furniture and appliances, and recruitment of staff. Further discussions are being held regarding assisting other groups transfer their care from Glenside to the community, in light of the information generated by the assessments.

Concern: Lack of consultation with consumers, carers and staff

There has recently been extensive and detailed consultation in SA with carers, consumers and other stakeholders in relation to mental health.

The Review of Mental Health Legislation in SA was commissioned by the Department of Health in mid-2004 and involved extensive consultation in metropolitan and country areas with carer and consumer groups, Aboriginal organisations, professional organisations and government agencies from August 2004 to March 2005. The Review Committee received and considered 60 submissions.

At the same time, on behalf of the Departments of Health, Justice and the Attorney-General's Department, Ms Margaret Bonesmo carried out a Joint Stakeholder Survey and for this she interviewed more than 60 stakeholders to gauge understanding and awareness of the principles and operation of the 1995 mental impairment provisions of the Criminal Law Consolidation Act 1935 and the Magistrates Court Diversion Program. Another review, the SA Review of Health Services and Programs for Prisoners and Young People in Custody was carried out by consultants Jocelyn Auer and Belinda Chapman.

Concern: Lack of mechanisms to improve service delivery and accountability

The Guardianship and Administration Act includes as a function of the Public Advocate 'to give support to and promote the interests of carers of mentally incapacitated persons'. The Public Advocate therefore has an important information role in supporting carers through systems advocacy and the provision of information about requirements.

The SA mental health legislation is seen as taking a minimalist approach when compared with statements of objectives and principles in the Model Mental Health Legislation. In particular, the Mental Health Act 1993 does not reflect principles of care in the community, consumer and carer rights, the concepts of early intervention and recovery, service standards, treatment plans, services to children and the particular needs of Aboriginal people.

In addressing this, the Mental Health Unit of the Department of Health carried out a review of mental health legislation from August 2004 to March 2003. The report which is being finalised contains specific recommendations for legislative change. For example, it has been recommended that in order to ensure continuity of care from acute to community services, community treatment orders (CTOs) should be specific about who is responsible for monitoring and follow up.

A Health and Community Services Complaints Commission has been recently established in SA. The government on coming to office has developed and passed legislation and appointed a commissioner. The legislation is the most comprehensive in Australia and includes both public and private health, and the full range of community services. It seeks to resolve complaints whilst developing, implementing and monitoring a Charter of Rights for Consumers. The Complaints Commission also has an educative role regarding rights of consumers and complaints management, coupled with monitoring the overall health system for improvement and quality performance.

Concern: Training of GPs

ACHIEVEMENTS:

- Establishment of training programs in emergency psychiatry for mental health services and GPs in country and metropolitan regions

The training of GP's is predominantly a Commonwealth policy agenda and is largely enacted via the Better Outcomes in Mental Health Care initiative which seeks to overcome barriers to GP involvement in the management of mental health disorders by providing financial and other supports, particularly training.

The Department continues to fund shared care programs which seek to develop clear pathways between specialist mental health and general practice. These programs provide a model of care which enables GPs to access consultancy support from specialist mental health workers. As such, these programs seek to enhance GP's knowledge and confidence in managing mental health consumers.

Concern: Lack of funding

Current expenditure on Mental Health Services (2004/2005) in SA is $158 million and future expenditure is dependant upon pending budget processes. However, as highlighted through this document, significant achievements have been made in SA through provision of additional targeted funding.

Concern: Affordability of care: Public vs Private

Services provided by private consultant psychiatrists are not optimised. Current Health Insurance Commission funding encourages specialised treatment services, rather than consultation services.

National Mental Health Standard 10: DOCUMENTATION

Concern: Documentation systems not being utilised

Adverse event investigations and coronial inquiries in SA have highlighted communication problems in the mental health area, a need for better electronic records and rapid exchange of information. It is also well-recognised that communication and information exchange between correctional services, prison health services forensic mental health services and community mental health services should be improved.

As part of the *2nd National Mental Health Plan 1998-2003*, all Health Ministers agreed to the mandatory implementation of routine consumer outcome measurement across mental health services. In SA, the Mental Health – Consumer Information, Assessment and Outcomes (MH-CIAO) initiative captures the state's commitment to improving data collection, outcome measures and quality control for monitoring and evaluating mental health services. To achieve this commitment, a purpose built Community Based Information System (CBIS) has been developed to enable capture of consistent data to complement in-patient information. When fully operational, the system will provide demographic and contact data, Outcome measures (National Outcome and Casemix Collection – NOCC), risk assessment, triage, Care Plans as well as Crisis and Relapse Plans.

The intent of the initiative is to collect, analyse and use consistent, relevant information to better inform decision-making at both the individual consumer level (eg care planning) and at a regional and statewide level (eg resource allocation). Compliance with the NSMHS and national reporting against minimum data sets are fundamental elements of the MH-CIAO initiative.

Concern: Carers' plea for access with request to be corroborated with documentation ignored

The Emergency Demand Management Policy & Procedure Series which was introduced in 2003 has resulted in the mandatory use of a detailed risk assessment tool across SA. All consumers are also expected to have a relapse prevention plan and a crisis management plan.

It has been recommended that, like legislation in other Australian jurisdictions, the SA Mental Health Act should emphasise an individual and comprehensive treatment plan as crucial to continuity of treatment and services. It should also be the cornerstone of compulsory orders for detention or community treatment. It is further recommended that legislation should provide that carers should be consulted in the development of treatment and discharge plans for a consumer, where practical and appropriate.

In particular, recent reviews have recommended that Aboriginal people need support and advocacy from family when they are receiving involuntary treatment and that children need support from family and/or advocates to ensure their rights are upheld.

National Mental Health Standard 11: DELIVERY OF CARE

Concern: No choice, no continuous care, no individual care

As stated at '*Carer's plea for access with request to be corroborated with documentation ignored'* (see page 24), SA legislation should emphasise individual and comprehensive treatment plans as crucial to continuity of treatment and services. Recommendations that are currently being considered include that treatment plans, including Community Treatment Orders (CTOs) should be broader than medication and should be regularly reviewed/revised to note progress and provide for:

- The wishes of the person and carers to be indicated
- Beneficial alternative treatments to be indicated including options such as counselling, training/education, therapeutic/rehabilitation programmes
- Treatment agencies or providers to be specified
- Where a person should reside if necessary for the treatment and
- Goals for recovery

Concern: Difficulties being experienced by Indigenous people

See Standard 7, page 12.

Concern: Operational policies are limiting access (opening hours and mode of contact)

ACHIEVEMENTS:

- Establishment of hospital at home programs in two metropolitan regions resulting in decreased mental health presentation to emergency departments

In February 2005, SA announced an Australian-first pilot programme between mental health services and ambulance services which will see specially trained crews of mental health staff and ambulance paramedics available (initially only in the northern and southern metropolitan areas) to attend call-outs to crisis situations throughout the night. The move effectively expands the existing Assessment and Crisis Intervention Service (ACIS), which currently operates from 8am to 10pm.

Concern: Crisis required before access is permitted

Consumers and carers in SA have indicated that early intervention should be legislated for and that treatment in the community is a desirable first option in preference to detention in hospital.

The Review of Mental Health Legislation has recommended that it should be possible for a range of approved health professionals to make a Community Treatment Order (CTO) or an order for assessment and admission (with appropriate review) to facilitate early intervention and access to services. It is proposed that legislation should provide for intervention to prevent imminent harm or serious deterioration in a person's mental or physical condition rather than on the basis of health or safety.

The Department of Health is finalising a cabinet submission to facilitate the drafting of regulations to enable the planned treatment and transfer of mental health consumers in other jurisdictions. This would be of particular benefit to Aboriginal consumers in the APY Lands who would be able to access treatment in Alice Springs.

The increasing availability of audio-visual facilities continues to assist South Australian country consumers in accessing appropriate specialist services.

Concern: Carers not heard

Carers have a recognised need for educational assistance, not only in relation to aspects of assistance for their relative/friend with a disability, but also in techniques of personal resilience. The Department of Health has made available funding for 12 carer forums in 2005 across SA to assist family carers of mental health consumers to link with one another and to provide opportunities to meet and network.

The forums aim to make local service providers more accessible and provide carers with opportunities to hear about new initiatives. For service providers the forums are an opportunity to build relationships with carers, collect feedback from carers on services and to be informed of needs and priorities.

Concern: Long wait lists or no clinicians available

ACHIEVEMENTS:

- Improved emergency mental health care through greater consistency of access to acute and emergency services demonstrated through reduction in waiting times
- Establishment of hospital at home programs in four metropolitan health services resulting in decreased mental health presentation to emergency departments

Key future priorities for implementation over the next five years are increased community based treatment and care services with caseload or clinical load ratios that permit relapse prevention and recovery focussed service delivery.

Concern: Lack of services for people with mental illness and complex needs

ACHIEVEMENTS:

- Establishment of the Exceptional Needs Unit, which enables people who would have once remained in institutional care to be supported in the community

SA is having to respond to the growing number of people with long term complex and multiple needs.

The Exceptional Needs Unit (ENU) is a collaborative between the Department of Health and Department of Families and Community Services. The ENU looks for solutions through enhanced relationships between government departments in providing holistic care planning and delivery to assist people to function in the community in the best possible way.

People with mental illness represented 80% of their client group requiring special funding packages.

Concern: Lack of services for people with personality disorders

In addition, it is proposed to retain a broad definition of mental illness as including 'any illness or disorder of the mind' in order to ensure that people in need of help are not excluded from short-term assistance. This would continue to assist with short-term intervention to stabilise a person suffering from a drug or alcohol induced psychosis where there are no other services available eg country locations.

Funding has been provided for extensive education and training package for mental health workers in evidence based assessment and treatment for people with personality disorders currently being rolled out across all services.

Concern: Concerns about the quality of the assessment and review process

See Standard 11, pages 24-25.

Concern: Restrictive and intrusive practices

See Standard 1, page 3.

Concern: Lack of involvement of carers

See Standard 3, page 7.

Concern: Services for refugees and newly arrived immigrants

ACHIEVEMENTS

- Ongoing allocation of significant funding to the significant allocation of funds to the Survivors of Torture and Trauma Rehabilitation Service (STTARS) to provide counselling and resettlement support services for clients with refugee backgrounds who suffer from post traumatic stress disorder
- Mental Health Unit provides a STTARS is a member of the National Forum of Services to Survivors of Torture and Trauma

Approximately 20% of South Australians were born overseas, and significantly higher numbers are of culturally and linguistically diverse backgrounds[14]. There is a lower level of access to hospital and community based mental health services[15] among many people from these backgrounds.

SA has an increasing number of asylum seekers, refugees and Temporary Protection Visa holders entering the State. Many people are traumatised and require the delivery of clinically relevant integrated mental health services in order to build resilience and capacity. Culturally appropriate Interventions to promote mental health and reduce the impact of mental health and mental health problems must be developed.

Various strategies are in place to progress support for clients with refugee backgrounds including, the establishment of a Central Northern Adelaide Health Region in improving mainstream health services access to:

- Members of emerging communities eg in the northern suburbs
- People residing here 20 years or more but not part of strongly established communities
- Refugees who go straight to their sponsor and miss some links into the service system
- Refugees who have received settlement services but for whom problems emerge subsequently.

A steering group with wide membership has been meeting since November 2004 to address key areas of concern including the development of transition programs to enable people to move confidently to locally based programs by people from culturally & linguistically diverse backgrounds.

[14] South Australian Multicultural and Ethnic Affairs Commission, An Overview of South Australia's Multicultural Population, 2001

[15] McDonald, B.& Steel, Z., Immigrants and mental health, An epidemiological analysis, Transcultural Mental Health Centre, Sydney, 1997.

It is intended that a raft of ongoing and proposed activities across sector planning, training and mental health promotion will enable mental health services and mainstream agencies to respond effectively to the special needs of migrants, refugees and other people from non-English speaking backgrounds, aided by interpreters and culturally trained staff. It is intended measures across these activities facilitate access to language and culture specific services and support.

Regarding immigration detainees, a Memorandum of Understanding between the Commonwealth of Australia and the State Government of SA (represented by the Department of Health) in relation to the provision of health services to immigration detainees is being finalised and detailed protocols have been developed to describe the process by which immigration detainees held within Baxter Immigration Detention Facility and Port Augusta Housing Project will access specialist mental health services in SA.

Concern: Lack of services for people with mental illness and drug and alcohol problems

Preliminary work has commenced to develop a jointly agreed policy as well as protocols and pathways to improve the responsiveness of both alcohol and other drug services and mental health services to people with co-occurring mental health and substance misuse issues.

A reference group has been formed to provide advice to the Department of Health on the development of protocols, and to aid the process of improving the service response for this client group.

One specific project is auspiced by Catherine House, a non-government organisation run by the Catholic Church. This is a Social Inclusion Project which involves Drug and Alcohol Services together with Mental Health. This project is a collaborative aimed at developing best practice responses for homeless women suffering from mental health and drug and alcohol issues.

Concern: Lack of services for people with physical disability and mental illness

It is a priority for government to ensure a pathway exists for the joint assessment and management for people with dual diagnosis including physical disability and mental illness.

Promoting Independence: Disability Action Plans for SA have resulted from a whole of government strategy to ensure systems are in place for the development and delivery of non-discriminatory services which promote access to vulnerable groups. All Department Chief Executives must report annually against 5 key outcome areas.

Also within Supported Residential Facility (SRF) projects, many of the residents have both physical disability and mental illness. The mental health reform strategy is ensuring that both the health needs psycho-social support needs are being adequately met.

Concern: Lack of mental health services for the aged

Addressing lack of Mental health services for the aged, including information about aged care forum was held 19th April 2005.

The principle of "aging in place" should underpin reform of mental health services for older people. Aim is to engage mainstream aged care providers in delivering services to older people with mental illness.

The objective is to develop "integrated" models of care that wrap services around older people with mental illness based on individual need. Shared care between aged care provider, mental health of older people, and GPs etc. based on comprehensive assessment of need across all life domains is a priority.

A forum was held for aged care providers to begin to talk to mental health services re development of new integrated models of care. The forum attracted a large number of NGO aged care providers.

Discussion also commenced with Commonwealth Aged and Community Care Section of the Department of Health and Aged Care re how the topic of mainstreaming of aged care services for older people with mental illness might be progressed.

Collaborative work is proceeding with mainstream aged care providers to work with mental health services for older people to develop alternative models of care which are more in keeping with philosophy of ageing. This will occur either within aged care residential settings or for supporting older people with packages in their own home. Work has commenced to provide education and training to all Health and Community Care (HACC) workers to better recognise and respond to older people with mental heath needs.

Acute aged mental health care beds are moving from Glenside Hospital to a modern purpose built facility at Repatriation General Hospital (RGH) and residents within the Aged Extended Care beds will be moved to more appropriate mainstream aged care services with support from mental health services for older people. Also work is occurring with aged care providers to encourage the provision of more appropriate and specialised services for older people with mental illness.

Concern: Lack of services for people with eating disorders

The Department of Health via the Mental Health Unit provides annual funding to the Eating Disorder Association of SA Inc. EDASA provide services to people with eating disorders, their families and other interested community members. They provide individual support, support groups, referrals, information and education resources.

It is intended that a review take place of this service in the wider context of mental health policy in SA.

Concern: Lack of family-centred approaches and support services

The Perinatal and Infant Mental Health in the Community project is a 2-year project, funded under the Department of Health Innovative Initiative Grants program. It is a partnership between Helen Mayo House, the South Australian Divisions of General Practice and Community Mental Health Services, Royal Adelaide Hospital.

The project's goal is to improve the diagnosis and management of perinatal and maternal infant mental health problems in the community, primarily by increasing the skills and knowledge of GP's and community mental health workers in perinatal and infant mental health, improving communication and collaboration among providers involved in providing care to mothers and babies, and developing a framework for co-ordinated service delivery of perinatal and infant mental health services in the community.

The project has an exciting focus in bringing together a diverse spectrum of health and community service providers who work with these population groups.

Concern: Lack of self care and living skills programs

See *Concern: Discharge used as a threat, inappropriate discharge and lack of follow-up*, page 32.

Concern: Lack of community support services to maximise opportunities to live independently

See *Concern: Discharge used as a threat, inappropriate discharge and lack of follow-up*, page 32.

Concern: Lack of available supported accommodation including providers and options for young people

ACHIEVEMENTS:

- Introduction of the Supported Accommodation Program, which has established 16 projects across metropolitan and country regions ($3.4 million)
- Development of Supported Accommodation projects across 16 metropolitan and country locations to provide integrated services, such as housing, clinical and non-clinical support, to people at risk of homelessness because of complex needs, including psychiatric disability
- Implementation of the Supported Residential Facilities (SRF) Reform Strategy ($57million over 5 years) which aims to provide better outcomes for people, many of whom have psychiatric disabilities, who are residents within Supported Residential Facilites or are affected by the closure of an SRF.

It is widely recognised that there is a need for community accommodation options to accommodate flexible and staged levels of supervision and support to free up demand for treatment of acute forensic and mental health patients in hospitals.

One such project for women exiting Glenside Hospital is auspiced by Catherine House, a non-government organisation run by the Catholic Church. This is a supported accommodation model to enable these women to be able to move back to the community to live independently with appropriate supports. It is a model of integrated service provision between Glenside Hospital, community mental health, Catherine house and social housing providers.

Efficient and effective use of acute inpatient beds is highly dependent on improving the availability and responsiveness of non-acute services (including sub-acute, rehabilitation care, intensive supported accommodation and psycho-social rehabilitation support) and strengthening assessment processes in all parts of the service system, with common thresholds for entry/exit and detention.

Currently, SA offers in-home supports through the:

- Community Support Inc Scheme under the Home and Community Care (HACC) program, funded by the State and Commonwealth governments;
- A variety of programs funded through NGOs which provide psycho-social rehabilitation for people in independent housing across metropolitan and country regions.

The SRF Reform Strategy provides a subsidy to all residents living in licensed SRFs. Additional supports are provided for those residents with high and complex needs. In addition dental, optical and allied health services are provided to residents. A quality management project (Service Excellence Framework) is being implemented to assist the sector to improve standards and quality of service to residents.

South Australia's mental health system is currently out of balance. Over 50% of its resources are tied up in acute hospital care. Most of it in Glenside Hospital. Beds on Glenside will not be closed until new beds are in place, which will be modern hospital units placed with general hospitals. These new hospital units will be closer to where people live and more accessible when needed. This is part of the state government's $80 million plus capital works program to rebuild the state's mental health facilities.

For people with a longer-term illness, three Community Recovery Centres, with a total of 60 places will be located within metropolitan Adelaide. The three facilities will provide intensive rehabilitation services to people with mental health disorders from country and metropolitan regions.

Consumers with a complex needs will have an option of care in a secure rehabilitation facility (30 beds), which will open early in 2008.

Concern: Medication the only treatment option

As stated at *'No choice, no continuous care, no individual care'* (see page24), it has been documented in SA that legislation should emphasise individual and comprehensive treatment plans as crucial to continuity of treatment and services. Recommendations that are currently being considered include that treatment plans, including Community Treatment Orders (CTOs) should be broader than medication and should be regularly reviewed/revised to note progress and provide for:

- The wishes of the person and carers to be indicated
- Beneficial alternative treatments to be indicated including options such as counselling, training/education, therapeutic/rehabilitation programmes
- Treatment agencies or providers to be specified
- Where a person should reside if necessary for the treatment and
- Goals for recovery

Concern: Concerns about the use of antidepressants for children

Recent reviews of the published and unpublished literature have established that a number of Serotonin Specific Reuptake Inhibitors (SSRIs) have been insufficiently researched to demonstrate their effectiveness or otherwise in young people under 18 years of age. This also applies to SSRIs with adequate research data available where the cost/benefit ratio (when patient safety is taken into account) is at best marginal or in some cases inadequate in the treatment of mild and moderately severe adolescent depression[16],[17],[18],[19]. It is the expectation of the Department is that all prescriptions will meet with current practice guidelines which are evidence based.

[16] Jureidini et al 2004, Whittington et al 2004, March et al, 2004.
[17] Jureidini J, Doecke C, Mansfield P, Haby M, Menkes D, Tonkin A (2004), Efficacy and safety of antidepressants for children and adolescents, BMJ 328:879-83
[18] Whittington CJ, Kendall T, Fonagy P, Cottrell D, Cotgrove A, Boddington E (2004), Selective serotonin reuptake inhibitors in childhood depression: systematic review of published versus unpublished data, The Lancet, 2004; 363 (9418) 1341-1345).
[19] March, J et al (2004), Fluoxetine, cognitive behaviour therapy and their combination for adolescents with depression. Journal of the American Medical Association, 292, 7, 807-820

Concern: Excessive use of restraint and seclusion

Detention/seclusion are practices to be avoided if possible. Neither is compatible with the central dictum of mental health best practice guidelines, specifically that treatment must occur in the least restrictive setting in individual circumstances.

Whilst there will be very occasional need to seclude a consumer such action should be highly controlled with clear indicators for seclusion, mandated observation/review and specified periods of seclusion. Seclusion should only be considered where the consumer is causing immediate danger to him/herself and/or others.

To this end, policy on restraint and seclusion in health units (including mental health situations) which incorporates minimum standards and reporting requirements has been developed and promulgated by the Department of Health.

Concern: Consumers and carers not informed or involved in treatment plan

Please refer to responses at *'Medication the only treatment option'* (see page 30) and *'No choice, no continuous care, no individual care'* (see page 24).

It is well-known that carers nationally contribute significantly to the care of mental health consumers and have felt frustrated at, what is perceived to be, a lack of recognition and involvement with service providers. Carers have said that consumer rights and the importance of family and carers in the care and treatment of people with mental illness should be acknowledged in legislation, a view that is consistent with the National Mental Health Plan ie that 'the rights of consumers and their families and carers must shape reform' and 'a recovery orientation should drive service delivery'.[20] These issues are being systematically addressed in SA.

Concern: Inadequate planning

Again, refer to responses at *'Medication the only treatment option'* (see page 30) and *'No choice, no continuous care, no individual care'* (see page 24). The challenges in relation to continuum of care that have been highlighted through coronial inquests and adverse events are being systematically addressed.

Communication in the interest of providing streamlined care in SA is being enhanced by:

Community Based Information System (CBIS)

- CBIS allows Assessment Crisis Intervention Service (ACIS) staff in hospital Emergency Departments to view historical information and clients' movements. If the client has been seen in the community and has some alerts recorded, these will be visible which will be a significant improvement on the current situation.
- Because of privacy and confidentiality safeguards, not all staff will have this level of access, only those who need the information in order to provide appropriate care to the individual.

[20] National Mental Health Plan 2003-2008, Australian Health Ministers, July 2003, at pp. 10-11.

Open Architecture Clinical Information Service (OACIS)

- OACIS is a clinical information system within the major metropolitan hospitals.
- OACIS links the clinical data across the hospitals into a single cohesive patient record which makes available to the treating clinician a comprehensive view of recent activity.
- If a patient then attends another participating site and has a unit record number the summaries are available to the treating clinicians.

Concern: Discharge used as a threat, inappropriate discharge and lack of follow-up

This Government has committed $3.5 million urgently to provide comprehensive support to consumers in the community. A preferred provider panel has been established with a range of local and interstate providers. The panel process will enable a transparent and time effective approach to allocate funds associated with packages of care. To date 12 organisations have been approved to provide these services to support recovery.

A typical care package will consist of a range of services including support services to assist the person to achieve optimal function and independence in self care, house hold management and other daily activities that facilitate community living skills, encompassing:

- Support and case management services to assist the consumer to manage self and health care, including personal hygiene and nutrition.
- Social support including social skills, communication and self esteem.
- Home management including assistance to establish and care for a home, managing finances and shopping.
- Behaviour support including motivation, healthy living skills and personal safety.
- Community engagement including vocation, recreation and other community living skills.
- Support for the consumer in the development of goals, individual case plan and provision of housing.

HOMICIDE AND SUICIDE

The Minister for Health has established a Ministerial Advisory Council on the Prevention of Suicide and Deliberate Self Harm (SuiMAC) under Section 18 of the *South Australian Health Commission Act 1976*, in consultation with the Minister for Families and Communities.

- Information systems required in SA to ensure that suicide and self-harm patterns are carefully monitored and that service responses are meeting the needs of vulnerable groups and individuals.
- Effective links with a range of committees, including Aboriginal Advisory Committees and the Aboriginal Health Council to ensure that strategies are culturally relevant for Aboriginal people.
- Existing research and best practice initiatives, and, where necessary, on new projects to inform future prevention strategies.

In February 2005, the Social Inclusion Board, through SuiMAC provided $680,000 over two years for suicide prevention initiatives in country SA, in particular initiatives focusing on young men.

8.4.5 RESPONSE FROM WESTERN AUSTRALIAN GOVERNMENT

Author's Note: The Western Australian Government's response was received on 3 June 2005, well after the deadline of 22 April 2005. As a result, the author's were unable to incorporate their feedback into the report.

Our Ref: 4-31688

MINISTER FOR HEALTH

ATTORNEY GENERAL; ELECTORAL AFFAIRS

FOR WESTERN AUSTRALIA

Mr John Mendoza
Chief Executive Officer
Mental Health Council of Australia
PO Box 174
DEAKIN WEST ACT 2600

Dear Mr Mendoza

Thank you for your letter dated 24 March 2005 concerning the Mental Health and Human Rights Draft Report and the opportunity to comment on the sections of the report relevant to my jurisdiction.

Please find attached the Government of Western Australia's written submission to be included in the final report to be released in July 2005. Please note that this submission has also been lodged electronically as requested.

I look forward to receiving a copy of the final report once completed.

Yours sincerely

JIM McGINTY MLA
MINISTER FOR HEALTH

3 JUN 2005

30th Floor Allendale Square
77 St George's Terrace Perth WA 6000
Tel: +61 8 9220 5000 Fax: +61 8 9221 2068
ABN: 61313082730

WESTERN AUSTRALIAN RESPONSE

Executive Summary

Our State's mental health system has been under significant pressure for many years and improving mental health services for all Western Australians is one of the Gallop Government's top health priorities.

In recognition of the need in this area, the State Government has allocated $173.4 million in additional funding over the next three years for the implementation of a comprehensive package of mental health reform initiatives.

Next year, total annual funding from the State Government for mental health will be more than $300 million, over nine per cent of the total health budget, making Western Australia the first state to achieve this level of funding.

It will also mean that total spending on mental health will have increased by 50 per cent from the $208 million annual expenditure when the Gallop Government came to office in 2001[21].

This strong commitment to funding a range of new initiatives and the expansion of existing mental health services will have significant benefits for many individuals, carers and families in Western Australia who need support.

The *Mental Health Strategy 2004-07* outlines the key reforms, which will address the most pressing areas of need within our current mental health system. The aim is to meet demand for services, improve access to appropriate inpatient services, increase intermediate care options, provide more community support services and improve safety for consumers, staff and the community.

The *Mental Health Strategy 2004-2007* is the culmination of an extensive consultation process and reflects the significant consideration the mental health sector has given to developing better services for mental health consumers.

The reforms will see the provision of 19 new observation beds in Emergency Departments for people with mental illness, 113 additional acute inpatient and intermediate care beds and the creation of 420 community beds statewide.

In addition community mental health services will be expanded through new post natal depression services, expanded community adult, child and adolescent services, day treatment programs, services for children of parents with a mental illness, multisystemic therapy services and a new community based eating disorders service.

In total these initiatives will see the recruitment of more than 475 new mental health staff into the Western Australian Health System, representing the greatest commitment to mental health by a Western Australian Government.

These key strategies form part of the first phase of the innovative longer term plans for public health system reform outlined in the Health Reform Committee's final report *A Healthy Future for Western Australians – Report of the Heath Reform Committee 2004*.

Dr Neale Fong, Director General, Department of Health, Western Australia and Executive Chairman of the Health Reform Implementation Taskforce, is leading the implementation of mental health reform, in partnership with the Department of Health's Division of Mental Health.

Implementation of mental health reform and the provision of significant funding for new mental health initiatives provide a comprehensive approach by this Government to better meet community need for mental health services in Western Australia.

[21] Department of Health and Ageing (2003) *National Mental Health Report 2004: Eighth Report-Summary of changes in Australia's Mental Health Services under the National Mental Health Strategy 1993-2002.* Commonwealth of Australia, Canberra.

There is a recognition that more needs to be done in mental health to achieve our aim of a high quality, effective and efficient mental health system in Western Australia. To achieve this, the Government is committed to a process of ongoing mental health service reform.

The Government has recently undertaken a number of community consultations to further gauge the community's priorities for mental health service development. These consultations have provided us with a detailed picture that will enable us to move forward with mental health reform over the next five years.

PART 1: GENERAL REMARKS

The Western Australian Government welcomes the opportunity to provide comment on the Human Rights and Equal Opportunity Commission (HREOC), Mental Health Council of Australia and the Brain and Mind Institute draft report Not For Service: Experiences of Injustice and Despair in Mental Health Care in Australia, draft dated the 9th March 2005, henceforth referred to as the Report.

The Government recognises that there are shortcomings in the mental health system in Western Australia. The Government is committed to ongoing processes of reform and quality improvement and is pursing a number of mechanisms to promote this.

The Department of Health (DoH) has gathered a large amount of information regarding the performance of the mental health system, information on gaps in current service delivery, needs of mental health service consumers and community priorities for mental health reform that may provide another source of information for your report. Some of the recent key mechanisms are:

- Statewide consultations undertaken to inform the Mental Health Strategy 2004-2007;
- Statewide consultations undertaken to inform the development of the draft Mental Health Action Plan 2005-2010;
- Snapshot surveys of treatment and accommodation needs of mental health inpatients undertaken in 2002, 2003 and 2004;
- Consumer and carer consultations held to inform consumer/carer participation structures;
- Feedback from Consumer Advisory Groups and consumer satisfaction surveys;
- 2004 Survey of People in Perth with Serious and Persistent Mental Illness who are Homeless;
- The reports of in depth reviews of mental health services by the Australian Council of Healthcare Standards (ACHS) against the National Standards for Mental Health Services;
- The Chief Psychiatrist's Reviews of Mental Health Services;
- The National Survey of Mental Health Services; and
- WA mental health information systems, notably the Mental Health Information System and PSOLIS (the mental health clinical information system).

This broad base informs the Government about the status of the people who access the mental health service system in Western Australia. This submission draws on these and other sources of information to inform the authors of the Report of recent initiatives that may not have been revealed during the community consultations.

This submission will not respond to each issue discussed in the Report, but will concentrate on some of the key areas raised.

Part 2: Mental Health Reform in Western Australia – an overview

The latest per capita figures for 2002-2003 show that Western Australia had the highest per capita gross recurrent expenditure for mental health of $119 per person[22]. This figure does not include funds for the recently announced mental health initiatives under the Mental Health Strategy 2004-2007 (The Strategy). The total funding for this Strategy, including the Department of Housing and Works contribution of $42 million, is $173.4 million. This Strategy will boost expenditure on mental health services to more than 9 per cent of the total health budget in Western Australia. In 2001, expenditure on mental health totalled $204 million (current prices). By 2006, more than $300 million will be spent on mental health, an increase of 50 per cent since 2001.

The Report on Government Services 2005 also showed that Western Australia had the highest national number of direct care staff per 100,000 people in specialist mental health services (104.2)[22].

Mental health consumers are the highest bed day users in the Western Australian health sector. Hospital demand modelling undertaken by the Department of Health indicates that inpatient demand by people with mental illness will continue to grow rapidly during the period 2004 to 2016.

Overall, Western Australia ranks fifth nationally in the number of acute and non-acute general psychiatric beds that it provides per 100,000 population. There continues to be unprecedented and protracted demands on inpatient beds in the acute mental health sector. In addition, there is an unprecedented demand for services within Emergency Departments with a notable increase in presentations of psychiatric illness and drug overdose. Access block to inpatient services is exacerbated where mental health units are not authorised and therefore cannot accommodate involuntary patients.

The Western Australian Government supports the National Mental Health Strategy, which proposes the development of a comprehensive mental health system consisting of a wide range of services that both promote mental health and provide treatment services for those who do develop mental illness. This includes a range of services across the continuum of mental health care, from inpatient and community based specialist services, to primary health care services as well as mental health promotion and prevention initiatives. The Government also supports a system of care that includes responses from a range of sectors and across government partnerships and collaborations.

Improving mental health is a high priority in Western Australia and the Government has introduced a number of initiatives over the past year, as part of the Strategy, aimed at increasing the responsiveness of mental health services to the demands on services and is continuing to assess new ways to improve mental health.

The Western Australian Government has recently announced a range of reforms to build the capacity of the mental health sector to respond to the needs of people with mental illness, through Western Australia's Mental Health Strategy 2004-07.

The Mental Health Strategy 2004-2007 consists of 5 key initiatives:

- Key Initiative 1 - Mental Health Emergency Services
- Key Initiative 2 - Adult Inpatient Services
- Key Initiative 3 - Community Mental Health
- Key Initiative 4 - Supported Community Accommodation
- Key Initiative 5 - Workforce and Safety Initiatives

[22] SCRGSP (Steering Committee for the Review of Government Service Provision) 2005 *Report on Government Services 2005*, Productivity Commission, Canberra

Table 1: Western Australia's Mental Health Strategy 2004-07 funding

Source of Funds	*value*
Department of Health	*$131,265,000*
Operating	*$ 93,115,000*
Capital	*$ 15,700,000*
Land value for Housing	*$ 22,450,000*
Department of Housing and Works	*$ 42,140,000*
TOTAL	*$173,405,000*

Further details of the Mental Health Strategy 2004-2007 can be found at Appendix 1.
This package of initiatives represents the greatest single commitment by any Western Australian Government to mental health care in this state. It is important to note that these reforms are a major step on the path to better mental health care for Western Australians. These strategies will be of benefit to the more than 35,000 people who use public mental health services in Western Australia each year. These strategies form the first part of an ongoing plan to deliver better patient care, help ease pressure on public hospitals and deliver much needed community support including supported accommodation.

The Government recognises that there will need to be a continuous process of health sector reform that responds to the predicted growth in mental illness and disability in our society. Western Australia is currently undertaking continued planning for mental health service reform. The Government is in the process of developing a five year Action Plan for Mental Health that will outline the Government's continued commitment to providing mental health services that are alongside the best in this country. Initial consultations have been held in Western Australia to inform the development of the Action Plan.

Over 300 people from around WA participated in these consultations through attendance at community forums or through written feedback. Feedback was received from consumers, carers, government and non-government mental health service providers, and other interested parties. Initial feedback has indicated priorities for further reform include increasing the level mental health services in the community and mental health promotion, prevention and early intervention initiatives. Work is also progressing on enhancing the service interface between primary, secondary and tertiary mental health care.

The Government recognises that a comprehensive mental health service requires activities beyond the health sector. Promoting mental health and well being and reducing the impact of mental illness is a concern for, and the responsibility of, our whole community. The Government will continue to build on existing whole of government and community wide partnerships to enhance our capacity to promote mental health and respond to mental illness. Key partners include the Disability Services Commission, the Department of Education and Training, Department of Justice, Department of Community Development, consumers and carers, non-government organisations, general practitioners and other private health providers.

PART 3: National Standards Mental Health Services

As a general comment, the reviews of all public mental health services conducted by the ACHS, which specifically assess compliance against the National Standards for Mental Health Services, provide an excellent source of information for measurement against the Standards.

Services are required to provide evidence of meeting these standards and are progressively introducing mechanisms to be in a better position to do so. For example, in Western Australia, services are increasingly introducing mechanisms to gauge consumer satisfaction with the services they provide. Services are obliged to follow recommendations made by the ACHS and this has encouraged a continuous process of quality improvement.

A number of activities have recently been undertaken in relation to mental health service reform and the following section will briefly highlight some of the developments that have been put into place during the past year.

3.1 National Mental Health Standard 1: Rights

There are a number of mechanisms in place to assess whether rights of consumers are being upheld. Legislation is a key mechanism for this as is the former Mental Health Review Board, which has been subsumed within the State Administrative Tribunal.

Mental health services themselves also have systems in place to promote rights of mental health service consumers and to investigate instances where these may not have been upheld.

The Council of Official Visitors plays a key role in upholding rights of people with a mental illness through visits to health services and complaints management process. The Council would be an excellent source of independent advice on the extent to which public mental health services in Western Australia uphold the rights of people with a mental illness.

Consumers Rights are supported through access to free legal services through the Mental Health Law Centre.

The Chief Psychiatrist of WA has legislative responsibilities to ensure standards of care and protect the rights of people who have mental illness.

On 28 October 2004 the Minister for Health laid before Parliament the Report on the Review of the Mental Health Act*. In his speech the Minister noted that the vast majority of the recommendations of the review have been accepted. The recommendations advance the rights of people with mental illness while further supporting the responsibilities of mental health clinicians to provide quality care.*
The Minister accepted the recommendation of a new Mental Health Act, which will include:

- Revising the definition of mental illness in accord with internationally accepted standards.
- Expanding the objects of the Act to include principles related to Aboriginal and Torres Strait Islanders and carers.
- Providing more information to consumers related to their care, including a mandatory discharge plan.
- Prohibiting the use of Electroconvulsive Therapy as an emergency treatment or in relation to children under 12 years of age.
- Expanding the role of the Council of Official Visitors and the Chief Psychiatrist to offer a more comprehensive advocacy and monitoring service.
- Conducting mandatory reviews by the Mental Health Review Board significantly earlier than in the present Act; and
- Introducing a part of the legislation that will deal with children and adolescents, and have a new part of the Act to deal with complaints.

3.2 National Mental Health Standard 2: Safety

WA public mental health services have legislative requirements and a philosophy of 'least restrictive care' that guides clinical practice in this state. Staff and patient safety are taken seriously and are of paramount concern.

The state and local infrastructure that ensures a systematic and integrated approach to assuring healthy outcomes for Western Australian mental health consumers includes:

- WA Clinical Governance Framework and the more specific mental health clinical governance framework. The Office of the Chief Psychiatrist makes reviews of mental health services against the mental health clinical governance framework;
- The National Standards for Mental Health Services are reviewed by the Australian Council of Healthcare Standards;
- Safety and health in Western Australian workplaces is regulated by the Occupational Safety and Health Act 1984 and the Occupational Safety and Health Regulations 1996 supported by codes of practice and guidance notes.

WA mental health services have Occupational Safety and Health officers who establish and monitor safe systems of work in the workplace that ensures the safety of staff, consumers and their carers; and
- Reviews of safety of workplaces conducted by WorkSafe.

The DoH meets with a number of organisations to address broader safety issues. These collaborations include the Western Australian Police Service, St John Ambulance and the Royal Flying Doctor Service to review safety issues, specifically around safe transportation of people with a mental illness.

Recent work has focused on reviewing models for community to hospital transfer of patients as well as hospital-to-hospital transfers and the need to broaden the training for police officers in mental health issues and mental illness. Further, a review of the existing protocol between the WA Police Service and the Division of Mental Health, which provides a framework for outlining the relationships between the Police and Mental Health Services, is being undertaken.

The WA Mental Health Safety Working Group, established under the Mental Health Strategy 2004-2007 began meeting in 2004 to address many of the complex outstanding WorkSafe notices that had statewide implications. The group's key priorities for implementation included; conducting risk assessments, duress alarm systems, safe design of mental health facilities, safe transportation of patients, core competency training, safety considerations for home and community visiting, and safe and sustainable communication in the field. The working group have developed draft Safety Guidelines with the aim of providing sensible, practical suggestions on how clinicians and managers can work toward ensuring a safe environment for consumers, carers, families, staff and the community.

The Prevention of Workplace Aggression and Violence, Policy and Guidelines produced by the DoH makes it mandatory for all staff to complete training in this area. Although all mental health services currently have in place training programs for the management of aggression and violence in the workplace, the DoH is developing a state standardised training program applicable across all age specialties and service settings.

The WA Guideline Development Group for Short-term Management of Disturbed/Violent Behaviour in In-Patient Psychiatric Settings is preparing clinical guidelines for Western Australian public mental health services for the short-term management of disturbed (violent) behaviour in inpatient psychiatric settings, including consideration of pharmacological, physical (including seclusion and restraint), preventative and psychosocial interventions. This is aimed at establishing best practice for these difficult situations were there is often marked variability of standards.

The DoH provides an education program that includes sessions on the rights of patients as provided for under the Mental Health Act 1996. Further to this a newsletter is published four times per year that includes information about patient or consumer 'rights' when appropriate to highlight this and other such important issues.

3.3 National Mental Health Standard 3: Consumer and Carer Participation

The WA Government has a strong commitment to consumer and carer participation. There are a number of mechanisms in place to promote this, and the Government is currently looking at ways to enhance consumer and carer participation. For instance

- Consumers and carers provide input to state mental health planning, implementation and service evaluation through consultations, advocacy and committee memberships.
- Consumers and carers are members of a range of mental health service management and operational committees. Consumers and carers are also consulted about and sit on committees developing state mental health policies.
- Consumers and carers sit on committees progressing the current Western Australian *Mental Health Strategy 2004-2007*. The consumers and carers participating on these committees have recently formed a consumer and carer communication group, to provide support and increase awareness and progress of projects.
- Consumers and carers have also provided feedback to the draft *Mental Health Action Plan 2005-2010* through the community consultation process.

As recognised in the Report, the DoH previously funded the Health Consumers Council for mental health consumer participation and training.

The DoH has now established a separate process whereby authorised payment of consumers and carers for participation in mental health service activities such as attendance on committees and other formal meetings is ensured. A revised Consumer Participation Payments Policy was released on 1 January 2005.

A consumer has been employed as a consultant by the Division of Mental Health to assist with the implementation of the policy, assist with problem solving with consumers about participation issues and advise on the process to develop long-term consumer participation structures.

Although the Division of Mental Health continues to pay consumers for their participation it is recognised that a dedicated service is needed to coordinate and support mental health consumer participation, advocacy, training, information exchange and support.

To address this, the Division of Mental Health hosted two consumer and carer workshops in November 2004 and January 2005. These workshops sought consumer and carer input on potential structures for participation in mental health services. The workshops were attended by a total of 66 consumers and carers (33 people attended both workshops).

The outcomes from these workshops highlighted the agreed need for good support, including training and education, and effective structures for mental health consumer and carer participation in Western Australia. At the workshops consumers indicated that some key areas need to be progressed in WA are:

- support structures which coordinate consumer participation;
- guaranteed funding to support consumer and carer participation;
- education and training for consumers; and
- greater commitment of mental health services to involvement of consumers.

The process to develop the statewide mental health consumer and carer participation framework is ongoing. A steering group has been established to guide the development of participation structures. The framework will incorporate a range of services including consumer coordination, advocacy, training and research.

WA is the first State to have legislation aimed at recognising the role of carers, reflecting the prominence that the Western Australian Government gives to supporting carers. A key part of the Act requires service providers to comply with the Western Australian Carers Charter. The Charter provides clear direction on how carers are to be treated and how carers are to be involved in the delivery of services. The Act:

- formally recognises carers as key partners in the delivery of care;
- provides a mechanism for the involvement of carers in the assessment, planning and delivery of services that impact on them and their caring role; and
- allows carers to make a complaint about non-compliance with the Carers Charter and if necessary to seek remedies through the Office of Health Review.

Carers WA is the dedicated peak body for carers in Western Australia. It provides specialised mental health carer advocacy and support. Carers have expressed their satisfaction with this arrangement.

3.4 National Mental Health Standard 4: Promoting Community Acceptance

The WA Government recognises that more needs to be done to address community acceptance of people with a mental illness. Recent community consultations have identified increasing community acceptance and decreasing stigma and discrimination as central issues in which Western Australia needs to be more proactive.

Actions to address community acceptance to date include: Mental Health Week, radio and print media attention to issues and contributions by mental health professionals to the Health and Medicine lift-out of the West Australian newspaper. Workforce discrimination towards people with mental health issues is being addressed through the Family Partnerships training program.

The Healthway Scoping Project tested the Victorian "Together We Do Better" campaign for its applicability in Western Australia. This campaign aimed to determine current beliefs and concepts of mental health, social connection, valuing diversity and physical and emotional health and wellbeing in the Western Australian community. The project sought to promote community acceptance and understanding of mental health issues and the socio-behavioural factors contributing to 'mental healthiness'.

In addition, Western Australia joined beyondblue, the national depression initiative, in November 2004. Beyondblue is a national, independent, not-for-profit organisation working to increase awareness and understanding of depression, anxiety and related disorders throughout Australia.

Finally, two Western Australian mental health services have formed a partnership with the Social Inclusion Project run by the UK NHS as part of developing shared learning across different countries and cultures to minimise the social exclusion of people suffering from serious mental illness.

3.5 National Mental Health Standard 5: Privacy and Confidentiality

Upholding rights to privacy and confidentiality are of extreme importance. There are a number of mechanisms in place to ensure that this occurs. There are also a number of initiatives underway to further enhance the systems capacity to uphold these rights.

The Confidentiality in Mental Health Settings Guidelines were developed by the Division of Mental Health and are available in all mental health services.
The Guidelines are aimed at ensuring people with mental health problems have their confidentiality respected while receiving the best possible care. It outlines the legal and ethical obligations faced by mental health professionals in order to assist them in making informed decisions concerning confidentiality. These guidelines can be made available on request.

The guiding principles of the Guidelines are:

- that the establishment of trust, based on a mutual understanding about confidentiality, is an important part of the therapeutic relationship;
- good patient management generally requires that information is obtained from, and shared between, professional staff, patients families and other caregivers; and
- confidentiality issues should, at the commencement of care, be discussed by clinicians with their patients.

The balance between confidentiality and communication with families and carers is of paramount importance in achieving better health outcomes for patients. In practice factors such as increasing specialisation, multidisciplinary team management and the need to involve the family and other carers can result in conflict between a persons wish for absolute confidentially and their desire to receive the best possible care. In view of this, the DoH is working with carers of people with mental illness to more specifically define the confidentiality issues that arise between carers and general practitioners in the treatment process.

3.6 National Mental Health Standard 6: Prevention and Mental Health Promotion

The Government acknowledges the need for growth of mental health promotion and illness prevention (MHP&IP) programs. This was recognised in A Healthy Future for Western Australians, the Health Administrative Review Committee Report (HARC), the WA Mental Health Strategic Plan and the Statewide Audit of Mental Health Promotion and Illness Prevention.

There are a range of MHP&IP services currently operating in WA. These include FRIENDS (anxiety prevention): The Resourceful Adolescent Promotion Program, the Positive Parenting Program (social behavioural problems prevention and early intervention) and Aussie Optimism (anxiety and depression prevention program/resilience enhancement). These initiatives are provided across the range of community health services, in collaboration with other sectors (eg Department of Education and Training, Department for Community Development).

The DoH also supports a range of specific suicide prevention and intervention services and projects. This funding is provided for public sector services, public funded services in non-government organisations and private organisations. Work in progress includes the development of a comprehensive suicide prevention strategy, through a collaborative and coordinated approach involving all Government Departments. This involvement includes a broad range of non-government and community organisations.

Many of the above programs have a statewide focus and are offered in both metropolitan and rural regions.

The Statewide Perinatal Reference Group is organising the implementation of statewide services expansion through funding allocated under the Mental Health Strategy 2004-2007. The service expansion will have a particular focus on people from culturally and linguistically diverse backgrounds and Aboriginal people.
Promotion, prevention and early intervention activities are also undertaken at a service level, with services offering early intervention as an option for referral and some having dedicated promotion prevention and early intervention positions. First episode psychosis programs are also in place. The expansion of community mental health services under the Mental Health Strategy 2004-2007 will expand the scope for services to further undertake prevention, promotion and early intervention programs.

3.7 National Mental Health Standard 7: Cultural awareness

Three programs will be developed and implemented to increase the cultural competency of the mental health workforce. Firstly, a training package entitled Managing Cultural Diversity in Mental Health (a Culturally and Linguistically Diverse (CALD) program) will be adapted and delivered to WA clinicians. Secondly, a Cultural Competency Audit Tool will be piloted and implemented in services.

In keeping with the National Practice Standards for the Mental Health Workforce, the cultural competency for staff working with indigenous clients will be improved through the development of training programs. Cultural education can promote a clearer understanding of the processes involved in establishing and maintaining links with social and cultural community groups and how to access these resources. Training programs aim to target staff awareness of other cultural beliefs, values and practices and encourage broader consideration when planning and delivering appropriate care.

The WA Multicultural Forum for Mental Health Practitioners promotes and facilitates culturally sensitive management practices for culturally and linguistically diverse clients with mental health issues through education, quality assurance and input into policy development.

3.8 National Mental Health Standard 8: Integration

Developing mechanisms that support integration between and within services is a key target for the Western Australian Government.

At a whole of Government and whole of community level, the Government has established a number of mechanisms to promote integration of services for people with mental health concerns. The key partners in promoting integration include the Department of Health, Department of Justice, Department of Premier and Cabinet (including the Social Policy Unit and the Office of Crime Prevention), West Australian Police Service, Department of Housing and Works, Disability Services Commission, Department of Education, Department for Community Development, Divisions of General Practice, local government, non-government organisations, public mental health services and consumer and carer representatives.

The key mechanisms that promote integration include:

- The Children First Strategy, which includes numerous activities for children and youth across a number of portfolio areas. Of particular mention is the Early Years Strategy aimed at improving the well being of children under the age of 8 years.
- The Children of Parents with a Mental Illness Interagency Advisory Committee, established to improve service coordination and delivery for children where they have a parent with a mental illness. These children face a range of social, emotional, behavioural and physical disadvantages.
- Collaborations to address the interrelationship of mental illness and crime. These include the Crime Prevention Strategy, the Interagency Access to Justice Committee and the Offender Health Council.
- Collaborations between the Department of Health and the Department of Housing and Works to support people with serious and persistent mental illness to live in the community;
- Ministerial Council Of Suicide Prevention;
- State Government Homelessness Strategy Monitoring Committee;
- State Perinatal Reference Group, which is representative of key stakeholder groups and oversees perinatal service development across WA;
- Disability Services Commission/Department of Health, Mental Health Quarterly Interagency Meeting; and
- Supported Accommodation Assistance Program State Advisory Committee.

Agreements to clarify roles and service responsibilities and promote integration between services include:

- The Protocol between the Disability Services Commission and the Department of Health People with Intellectual Disabilities and Mental Disorders: Guidelines for Service Providers;
- WA SAAP Protocols between the Health Department of Western Australia and Family and Children's Services to improve linkages between mental health services and Supported Accommodation Assistance Program (SAAP) services;
- The draft Children of Parents with a Mental Illness Interagency Protocol, which define roles and responsibilities of a range of the eight partners party to the Protocol and outlines good practice in interagency collaboration;
- Protocol between the Western Australia Police Service and the Mental Health Division of the Department of Health, Western Australia;
- Memorandum of Understanding between the Department of Health and Department of Education and Training to support implementation of the Aussie Optimism Program;
- Department of Health and Department of Housing and Works Mental Health Housing Strategy 2004-07 Memorandum of Understanding; and
- The Ministerial Council for Suicide Prevention.

At a program level, there are also a number of interagency initiatives underway these include:

- MulitSystemic Therapy Program;
- Triple P (Positive Parenting) Program;
- Aussie Optimism Program;
- Independent Living Program;
- Children of parents with a Mental Illness Project;
- Intensive Community Youth Service and Youthlink; and
- Early Psychosis Program.

Within the health sector there are also a variety of activities occurring to promote continuity of care for people with a mental illness across the health sector. These include:

- Collaborations to improve the interface between specialist mental health services and primary health care;
- Collaborations to improve the interface between inpatient and community services;
- Collaborations to promote integration between mental health and drug and alcohol services. This is guided by the Statewide Strategic Dual Diagnosis Planning Group;

- Development of the draft Aboriginal Social and Emotional Wellbeing and Mental Health Strategy;
- Assertive case management (which will be expanded through resources available to community mental health services under the Mental Health Strategy 2004-2007)
- The Child and Adolescent Mental Health Services Advisory Committee Cohesion Group (looking at the interface between community mental health services and inpatient services for children and adolescents); and
- Rural and remote communication strategy (seeking to enhance integration between rural and remote and metropolitan mental health services).

3.9 National Mental Health Standard 9: Service Development

In Western Australia there is an ongoing process of quality improvement and education and training to promote the quality of services provided. The following areas will be addressed commencing in 2005 with emphasis on working to achieve the National Practice Standards for the Mental Health Workforce.

- Orientation Program. With over 470 new positions to be established under the Mental Health Strategy 2004-2007. The expectations of the new staff coming into the WA mental health system from interstate and overseas will be met with a standardised, efficient and thorough orientation program that is currently being developed.
- Clinical Supervision: At present there is no agreed framework for clinical supervision for all disciplines in WA mental health services. Consultation with health services will occur to develop a framework for clinical supervision for all disciplines across mental health services. Clinical supervision enables clinicians to develop and reflect on their practice in a peer or individual relationship.
- Leadership and Management Program for Mental Health Professionals. A program for approximately 45 mental health senior staff is being developed. This program will include leadership development, strategic planning, managing and implementing change and managing performance. This program is aimed at ensuring senior managers are well equipped to implement the National Standards for Mental Health Services.
- Core Competency Training. Statewide training packages will be developed and implemented in core areas of clinical practice. A central warehouse of training courses available throughout mental health services will be created enabling clinicians throughout the state to access courses specific to their needs.

A coordinated graduate programme for nurses specifically in mental health began in February 2005. This programme provided 6 weeks of intensive theoretical and practical experience for newly graduated comprehensive nurses at the start of their 12-month graduate programme, hence making it a 58 week programme

Service quality is measured through the use of customer satisfaction surveys and other customer satisfaction measurements (such as the provision of feedback forms, establishing community advisory bodies and surveys of specific areas of concern).

Some of the findings that the investigators should note include:

- Psychiatric Emergency Team conducts annual Consumer Stakeholder Perception Survey. The 2004 Consumer and Stakeholder Perception Survey of the Psychiatric Emergency Team surveyed 76 randomly sampled consumer and cares. The results of the survey showed that the majority of participants were satisfied to very satisfied with the services. The majority of the negative feedback was associated with involuntary admission under the Mental Health Act 1996. Staff management and knowledge impressed the majority of stakeholders.
- The South Metropolitan Area Mental Health Service conducted a Child and Adolescent Mental Health Service Customers Satisfaction Survey. 700 survey forms were distributed. Results showed that nearly 1 in 2 carers reported the service they received as excellent, with only 13% of carers reporting the service to be fair or poor. The majority of young people (80.7%) gave the service a grade of either A or B. This demonstrates a high satisfaction with CAMHS services from both carers/parents and consumers.

Non-government organisations also measure customer satisfaction with the services they provide. NGOs provide this information to the DoH as a part of their contractual requirements or as evidence of quality service provision. For instance;

- Southern Cross Care Consumer Satisfaction Survey of June 2004 found that 99% of consumers felt that they were getting the services they required and that staff show open communications skills and explain things clearly.

The Chief Psychiatrist has been conducting clinical reviews of mental health services since 1999. These reviews are a key element in the quality improvement cycle for mental health services. Eleven clinical reviews have been conducted with two of the eleven being the pilots for the mental health clinical governance framework. This new framework includes consumers and carers in the review process who are trained and participate as team members alongside clinicians.
The reviews enable the Chief Psychiatrist to assess mental health services' attention to the continuous quality improvement processes that ensure the provision of optimal mental health care. A specific process facilitates collection of data on consumer and carer concerns directly from those individuals by consumer and carer reviewers. The data collected as part of the review process also enables the staff, consumers and carers to acknowledge those areas, which mental health services excel in and those that require further attention.

The Government believes that this approach to an independent comprehensive assessment of Mental Health Services against a specific mental health clinical governance framework to be the most progressive in Australia and places this State in a position to further ensure the quality of care to mental health consumers into the future.

The DoH has developed and implemented a statewide policy on complaints management. Some individuals may have indicated that they had problems with the complaint procedures because they did not agree with the outcome of their complaint investigation.

There are also a number of complaint agencies external to health services available for patients/clients including:

- the Office of Health Review,
- professional registration boards; and
- the Ombudsman's Office.

All public Mental Health Services have implemented the routine collection of consumer outcome measures. Clinicians and key administrative staff have received training in the use of nationally agreed consumer outcome measures; including a consumer self report tool, and the National Outcome and Casemix Collection (NOCC) protocols. Managers and clinicians in public Mental Health Services receive monthly reports on the NOCC data. This information is currently being used to inform quality improvements in clinical practice. Projects are underway to ensure that training is provided in the interpretation of the data and use of the information in everyday clinical practice. Consumer outcome measurement assists in the assessment of service effectiveness and the establishment of benchmarks.

3.10 National Mental Health Standard 10: Documentation

PSOLIS is the mental health clinical information system that has been developed for use by all government mental health staff throughout Western Australia. It allows for information sharing, within the bounds of confidentiality, across inpatient and community services. PSOLIS is built using leading edge technology and aims to provide mental health services with the ability to share, analyse and retrieve information about clients in an efficient and effective manner.

PSOLIS, has been implemented in all public Mental Health Services (inpatient and community-based) throughout Western Australia. PSOLIS is a centrally based clinical information system that is used by medical, nursing, allied health, management and clerical staff and it is linked to the core health application TOPAS. Information related to patient demographics, referrals, admissions, discharges, transfers, diagnoses and service events related to staff and client activity is collected and stored in PSOLIS. Functionality includes:

- enhanced search functions which allows a client to be tracked across community-based and inpatient service settings;
- alerts, incidents and investigations to inform clinicians of potential risks and assist client-specific management strategies and treatment plans;

- client reviews to support the clinician and clinical team in the client review process;
- on-line management and crisis plans to improve communication within and between clinical teams at each service as well as with external services; and
- the collection and reporting of mandatory data collections, for example, the National Outcome and Casemix Collection (NOCC)and the National Minimum Data Sets for Mental Health Care.

The Government believes that PSOLIS is the only complete integrated electronic mental health information system in Australia that collects all information required for all National Minimum Datasets, NOCC, essential clinical information as well as have a unique patient identifier and an episode of care identifier.

3.11 National Mental Health Standard 11: Delivery of Care

The delivery of care by mental health services is guided by quality improvement mechanisms as outlined above in response to Standard 9: Service Development.
In regards to the particular issues of access, entry, assessment and review, treatment and support, medication, therapies and planing for exit and re-entry; these are measured and quality improvement supported through these mechanisms outlined above.

In regards to the level of access to community and inpatient services, as opposed to the quality of those services, the implementation of the Mental Health Strategy 2004-07 is a major step in increasing capacity of the mental health system.

The Department of Health has supported the development of quality improvement initiatives such as the Service Standards for Non-government Providers of Community Mental Health Services and the Agency Self-Assessment Guide and Supporting Resources Kit.

Current support to non-government organisations included $19.3 million in 2004-05 in funding for statewide services. This includes:

- 570 Independent Living Program places statewide. This service grows at 60 places per year;
- support to 560 residents living in private psychiatric hostels; and
- community support services including psychosocial support, recreation, advocacy, carer support and respite, mental illness prevention, suicide prevention.

Appendix 1: Mental Health Strategy 2004-2007

The mental health reform initiatives outlined in the *Mental Health Strategy 2004-2007* aim to increase the capacity of mental health services to meet the increase in demand.

The focus will be on relieving pressures in the mental health system, especially where this impacts on other parts of the health system such as Emergency Departments, increasing access to appropriate inpatient services and addressing the lack of intermediate care treatment options and community support services.

During the past few years a number of reports have been generated to plan for the delivery of mental health care in Western Australia. These include:

- *Western Australia's Mental Plan* (previously the Draft State Mental Health Strategic Plan);
- *A Healthy Future for Western Australians – Report of the Health Reform Committee*; and
- *Enhancing the Capacity of Mental Health Services*.

Specifically, the *Mental Health Strategy 2004-2007* addresses five main areas in the health system where targeted interventions have the capacity to immediately and significantly increase access to mental health services and reduce demand on acute hospital beds. The five strategy areas are:

- Mental health emergency services
- Adult inpatient services
- Community mental health services (Adult & Young people)
- Supported community accommodation
- Workforce and safety initiatives

These strategies are aligned with the innovative and longer term plans outlined in the Health Reform Committee's final report, which is being rolled out by the Health Reform Implementation Taskforce.

The development of these individual strategies is the culmination of a significant amount of consultation involving consumers, carers, mental health professionals, government and non-government mental health bodies and peak industry organisations.

To assist with the implementation of major reforms to mental health services in Western Australia, a Mental Health Advisory Group has been established. The Advisory Group of mental health specialists will oversee implementation of the *Mental Health Strategy 2004-2007* and play an integral role in the development and monitoring of activities. The Advisory Group will also be involved in engaging consumers, carers, community bodies and other stakeholders in the provision of advice and feedback and assist with communicating information out to the community.

Key Initiative 1 - Mental Health Emergency Services

Objective

To expand statewide mental health emergency services to meet the demand for services within Emergency departments.

Actions

1. Increasing the number of specialist mental health nurses within hospital emergency departments. The service ill provide 24-hour coverage for people presenting with mental health problems. An additional 42 (FTE) mental health nurses will be employed to provide specialised mental health triaging and clinical support within emergency departments across the metropolitan area.
2. Expansion of the Psychiatric Emergency Team (PET) to ensure comprehensive cover across the metropolitan area. This service will provide dedicated emergency coverage north and south of the river.
3. Increasing the number of On Duty Psychiatric Registrars for after hours cover across the metropolitan area, to provide psychiatric assessment, treatment and support for mental health patients in the Emergency Department.
4. Establishing 19 new mental health beds consisting of five-bed admission holding units at Sir Charles Gairdner Hospital, Fremantle Hospital and Royal Perth Hospital and a four-bed admissions unit at Graylands Hospital. These units will provide a safe and secure environment for both patients and staff.

Key Initiative 2: Adult Inpatient services

Objective

To increase access to adult inpatient beds for people with severe mental illness.

Actions

1. Provision of an additional 113 beds in the following locations:
    a. *Graylands Hospital* – conversion of an existing facility (the Fitzroy Administration complex) to provide 12 new acute secure beds.
    b. *Armadale Hospital* – creation of 8 new beds within the current facility.
    c. *Bentley Hospital* – provision of an additional 20 beds through the reconfiguration of inpatient services.
    d. *Mother and Baby Unit* – the mother and baby unit at Graylands Hospital will be transferred to King Edward Memorial Hospital for the establishment of an 8 bed authorised unit.
    e. *Bunbury Regional Hospital* – expansion of the acute psychiatric unit to provide an additional 18 beds.
    f. *Intermediate Care* – establishment of 47 new intermediate care beds, 22 beds in the north and 25 beds in the south metropolitan areas, to provide rehabilitation, disability and clinical support services.
2. Provision of additional psychiatrist cover in Albany, Bunbury and Geraldton to ensure inpatient services in these rural areas are maintained.

Key Initiative 3 Community Mental Health Services

a) ADULTS

Objective

To improve clinical outcomes for people with a mental illness through provision of accessible community services which encourage early identification, intervention and recovery.

Actions

1. Expansion of community mental health clinical services, through an assertive case management approach. These services will be undertaken by multidisciplinary community teams.
2. Establishment of day therapy services to individuals with a major mental illness. The services will provide structured individual and group based clinical programs. Therapy services may include intensive rehabilitation and be provided in the person's own home or in a community facility.
3. Extension of the statewide Post Natal Depression (PND) services for mothers with babies through the statewide expansion of non-government community services, particularly in areas with a high number and projected growth of young families. Research will also be undertaken to inform the development PND services for Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse backgrounds.

b) YOUNG PEOPLE

Objective

To enhance service coverage and accessibility and provide a whole of service/government approach to ensure that young people with a mental health problem are given the best opportunities for early intervention.

Actions

1. Development of two Multi Systemic Therapy (MST) teams for young people aged 12-16 years at risk of developing mental illness in the south and the north metropolitan areas.

2. Establishment of the Intensive Community Youth Service to provide intensive counselling, access to stable accommodation, education and employment access for homeless youth at risk of mental illness, with little family or guardian support, in the south metropolitan area.
3. Expansion of the Bentley Child and Adolescent Mental Health Service's transition unit for its Day Treatment Program, to support 10 extra children and treat others at home to prevent unnecessary hospital admission.
4. Recruitment of additional clinical staff to expand existing Child and Adolescent Mental Health Services into areas of rapid youth population growth to provide services to young people with severe and complex mental disorders.
5. Development of a service to assess and treat people with an eating disorder, particularly young adults. The service will have strong links with regional and rural services.

Key Initiative 4 Supported Community Accommodation

Objective

To expand community supported accommodation services for people with severe mental illness.

Action

1. Creation of 420 community beds statewide through the following programs:
    a. *Supported Community Residential Units* – provision of 200 beds in cluster accommodation for up to 25 people with 24 hour on-site staff support in locations including the metropolitan area, Albany, Bunbury and Geraldton.
    b. *Licensed Psychiatric Hostels* – increase in the personal care subsidy to improve service quality to hostel residents.
    c. *Specialist Residential Services* – development and construction of an extended care service at Graylands Hospital to provide rehabilitation and a home-like environment for 20 people with chronic mental illness and severe disability, currently in acute inpatient beds.
    d. *Community Options 100* – transition of 30 people with long-term support needs from Graylands Hospital to community living with associated support services in the metropolitan area.
    e. *Psychosocial Support Services* – expansion of statewide non-clinical psychosocial/disability support services to assist people to live in their own homes. This includes the construction of 120 housing units for the Independent Living Program.
    f. *Supported Accommodation* – establishment of non-government services in Perth inner city, Fremantle and Armadale to support 50 homeless people with a mental illness. The services will provide 24 hour support, 'drop in' services and community outreach.

Key Initiative 5 Workforce And Safety Initiatives

Objective

To ensure services are adequately staffed with the appropriate skills and discipline mix and that Mental Health Services are safe places where innovative clinical practice is fostered.

Actions

1. Recruitment and retention of 425 staff through the following:
    a. A major recruitment drive in Australia and overseas. Mental health staff including psychiatrists, nurses, social workers and occupational therapists will be recruited.
    b. Provision of incentives to practice in areas of greatest need and workforce shortage to ensure adequate staff coverage in rural and remote areas.
    c. Improvement of workforce re-entry processes for staff that have left the workforce. Education and training will be tailored to address the projected workforce requirements. Innovative education and training models will equip the workforce with the skills, knowledge and attitudes to competently do their work.

d. Improvement of workplace safety through convening a statewide safety working group that will make recommendations for many current complex safety issues. The safety working group will address issues such as the use and availability of duress alarms, communication (including mobile phones), the safe transportation of patients and safe, flexible working environments. Mental health staff will be provided with improved education and training in key areas of practice such as assessment, risk assessment and dealing with aggression.
e. Expansion of the electronic mental health clinical information system PSOLIS to provide intermediate information to all clinicians to assist them with day to day clinical decision making.

8.4.6 RESPONSE FROM AUSTRALIAN CAPITAL TERRITORY GOVERNMENT



Simon Corbell MLA

MINISTER FOR HEALTH MINISTER FOR PLANNING

MEMBER FOR MOLONGLO

Mr John Mendoza
Chief Executive Officer
Mental Health Council of Australia
PO Box 174
DEAKIN WEST ACT 2600

Dear Mr Mendoza

Thank you for your letter of 24 March 2005 presenting the draft Human Rights and *Mental Health* report for comment.

As reported to you in my previous correspondence (28 March 2005), the ACT Government welcomes any review that provides representative and meaningful information and guidance regarding the protection of human rights, particularly of those individuals living with mental illness, and their carers.

The ACT Government and ACT Health, through Mental Health ACT, are committed to providing accessible, safe, responsive and quality mental health care for the ACT community. Since election in 2001, the Stanhope Government has increased funding for mental health in each of its three budgets as a clear demonstration of its commitment to improving mental health in the ACT.

This Government has overseen an extensive community consultation and collaboration process to develop the ACT Mental Health Strategy and Action Plan 2003-2008 (the Plan). This Plan reflects the identification of mental health as a key priority area within the ACT Health Action Plan and the reform agenda of the National Mental Health Plan 2003-2008.

We have worked to build partnerships with other government agencies and community organisations to improve mental health services in the ACT. Much has already been achieved and significant additional work is still in progress.

I am therefore disappointed in the draft of this report as it currently stands. The current draft presents a collection of anecdotal observations and inference drawn from those anecdotes. There is no evidence of any attempt at strategic analysis, which greatly detracts from the criticisms raised.

This is not to say that I wish to dismiss the issues raised. The size of the cohort does not invalidate the level of concern expressed in relation to these perceptions of care. These findings tell us that, twelve years into a national mental health strategy, we may have achieved some significant reform but there is still much to be done to ensure that mental health care meets the needs and expectations of the community.

One of the problems with a report such as this is that there is a risk that our mental health professionals, the majority of whom work extremely hard in often difficult circumstances, might bare the brunt of the criticism about the level and quality of care provided within complex mental health care systems.

It will be important for the final report to be clear that the issues raised are about systems and processes in place to plan and monitor quality mental health care and not about individual clinicians or the work that they do in the field. .

ACT Specific Comments:

NMH STANDARD 1: RIGHTS

As stated in my letter of 28 March 2005, the ACT is the first jurisdiction in Australia to have a Bill of Rights with the enactment of the ACT Human Rights Act in 2004. In 2004 ACT Health engaged the Castan Centre for Human Rights Law at Monash University to conduct an audit of all legislation for which ACT Health has responsibility, for consistency with the HRA. This included components of the *Mental Health (Treatment and Care) Act 1994*. The ACT Government has committed to a full review of the ACT *Mental Health, (Treatment & Care) Act 1994* to commence later in 2005. A component of this review will be to test the Act in its entirety against the Human Rights Act.

Consumers and carers are also provided with information about the Mental Health (Treatment and Care) Act 1994 as well as advice about their rights under that Act and the National Standards for Mental Health Services. Mandatory training is provided to all Mental Health ACT staff to provide them with skills to treat all consumers and carers with dignity and respect.

NMH STANDARD 2: SAFETY

The ACT Government has commissioned a number of significant reviews in response to concerns about the safety of mental health care in the ACT, particularly in the inpatient facilities.

The internal quality review of ACT Mental Health Services in 2002 resulted in a number of recommendations about improving the quality and safety of systems to provide mental health care.

*The ACT Health Complaints Commissioner "*Investigation into Risk of Harm to Clients of Mental Health Services November 2002 *(Patterson Report) was tabled in the ACT Legislative Assembly in December 2003. This review provided 58 recommendations for improving consumer safety in mental health care, all of which have been implemented. The Patterson Report supported the majority of the findings of the Quality Review.*

*The Mann/La Roche report on "*The review of the design and operation of the Psychiatry Services Unit (PSU), Canberra Hospital December 2002 - January 2003*" was commissioned as a direct response to one of the recommendations of the Patterson Report. The Government has allocated $1.35 million dollars for the recommended refurbishments to the PSU following this review. The recommended work is almost completed. In response to ongoing consumer, carer and staff concerns about the safety of the PSU, even with the recommended refurbishments, the Government has committed a further $10 million dollars for a replacement unit in the longer term.*

The Australian Protective Services Review of Mental Health ACT was completed late in 2003. This Review has provided a range of recommendations in relation to infrastructure and systems to improve safety for consumers, staff and visitors to Mental Health ACT facilities. Mental Health ACT is progressing through the workplan developed to implement the recommendations of this review.

The Australian Incident Monitoring System (AIMS) is being utilised across ACT Health to monitor adverse events and inform a systems response to such events.

NMH STANDARD 3: CONSUMER AND CARER PARTICIPATION

The ACT Government and Mental Health ACT have committed significant resources to support and facilitate consumer and carer participation in the planning of mental health care in the ACT. The ACT has two paid consumer consultants, has both a consumer and carer representative sitting on its executive management group and a range of other consultative and advisory committees. The Mental Health ACT Carers Committee is supported by the organisation and actively contributes to organisational policies. MHACT provides carer peer support workers to assist carers of people admitted to the acute inpatient unit. ACT Health also funds separate consumer and carer organisations in addition to a mental health "Peak Body".

ACT Health has undertaken significant work in developing a standardised consumer/carer feedback/complaints procedure and policies. Timeframes for managing complaints are set in policy and compliance with this process is monitored by the Executive. I am advised that information about the feedback process is made widely available in all areas of the service and consumers and carers are encouraged, and even assisted if required, to use the system as necessary. In the past eighteen months, approximately 240 consumers/ carers have availed themselves of the opportunity to use the consumer/carer feedback process. Of the total number 164 have raised issues of concern and 76 have provided compliments on the level of service they have received. The most common issues of concern are (i) attitude; (ii) medication issues and (iii) treatment coordination. MHACT acknowledges these concerns and will be seeking to address these and other issues in planning services in the future.

There has been a significant emphasis in recent years on improving the level of information provided to carers about services and supports available to assist them in caring for their loved ones. The Minister for Disability, Housing and Community Services launched the ACT Caring for Carers Policy in 2004. This policy was developed after extensive consultation with the community and provides an agreed framework for working with carers, respecting their rights and supporting their role in the community. The ACT Caring for Carers Policy has wide support within the Territory and implementation of the policy is being closely monitored by a multi-agency implementation committee.

Mental Health ACT acknowledges the significant expertise and contribution provided by carers and consumers through their representatives on the Mental Health ACT Executive group and the range of other committees and structures within the organisation. Mental Health ACT also funds or supports a range of specific programs for carer and consumer support including the Mental Health Carers' Committee, the Canberra Schizophrenia Fellowship, the Mental Health Foundation, The ACT Mental Health Consumer Network, the ACT Mental Health Community Coalition and the Children of Parents with a Mental Illness (COPMI) project.

Carers' groups have also worked with MHACT staff to develop a flip chart for carers to keep on the fridge with a range of contact details including who to contact and where to go in an emergency and other important information to assist in the care of people with a mental illness. I will be launching this new aid for carers in the near future.

NMH STANDARD 4: PROMOTING COMMUNITY ACCEPTANCE

The issue of raising community awareness and acceptance of mental illness is one that engages the minds of all who work in the area of mental health and it is clear that we all need to be doing more in this area. As identified in some of the comments in the report, the stigma associated with mental illness can be particularly problematic in seeking to access a range of other services, including safe, appropriate and affordable housing and employment.

The ACT Government has supported a number of programs aimed at raising awareness, understanding and acceptance of mental illness in our community.

The ACT Government funds Mental Illness Education ACT (MIEACT) to provide mental health programs in secondary schools. This program utilises consumers and carers who share their stories and has been very effective in generating more informed discussion and understanding of mental health issues in the schools where it has been presented.

In addition, the Government provides funding to a community organisation, OzHelp, to provide suicide prevention and other mental health programs for the building industry. This program is well-recognised and highly regarded locally and nationally. The success of this model in the difficult environment of the building industry has generated considerable interest from other jurisdictions.

I am advised that the MHACT Community Education Officer provides sessions for Government agencies, community organisations, sporting clubs and other businesses to try to raise the level of awareness and support for people with a mental illness more broadly.

The ACT also funds the Canberra Schizophrenia Fellowship to provide vocational rehabilitation programs for mental health consumers to help transition them into the mainstream workforce. The ACT Mental Health Strategy and Action Plan 2003-2008 acknowledges that vocational rehabilitation is an area of mental health that still requires significant reform. The need to work with businesses to raise their awareness and understanding of mental illness is a key to facilitating access for people with a history of mental illness back into the workplace.

MHACT staff and a range of key stakeholders have recently developed a brochure "Helping a friend with mental illness" which also includes a section for workplaces and supervisors with advice about how work colleagues can assist in supporting a worker who might be experiencing a level of mental illness. I will be launching this publication in the near future.

The issue of the perpetuation of stigma and stereotypes in the media is an ongoing one. As one of your respondents also indicates, the Government and MHACT frequently seek to remind relevant media outlets in the ACT of the "*Reporting suicide prevention and mental illness – a resource for media professionals*" guidelines for reporting mental health issues. We will continue to try to work with the media to try to encourage them to moderate their reporting of these important issues.

NMH STANDARD 5: PRIVACY AND CONFIDENTIALITY

The balance of protecting consumers' rights to confidentiality and the need for carers to be informed to enable them to care for their loved ones is an ongoing dilemma for mental health clinicians.

MHACT clinicians are bound by the Health Records (Privacy & Access) Act 1997. This can at times hinder family involvement in the care of their loved ones. It is very difficult for staff in such situations to decide what information to provide to family. There is no doubt that at these times carers and family members can be left feeling quite frustrated and uninformed

It is important to note that the ACT Health Records & Privacy Act 1997 is being reviewed in detail to clarify the role of caregivers and any restrictions placed on their by the Act. This was one of the recommendations of the Investigation into Risk of Harm to Clients of Mental Health Services.

MHACT, in collaboration with the Australian National University is currently trialling advanced agreements where consumers, clinicians, carers and others involved in care sign an agreement when the consumer is well that enables an agreed plan to be followed if the consumer becomes unwell. The project is in the early stages and will be evaluated after 12 months.

NMH STANDARD 6: PREVENTION AND MENTAL HEALTH PROMOTION

The ACT Mental Health Strategy and Action Plan 2003-2008 (the Plan) proposes a shift in culture towards a mental health promotion and early intervention model for mental health care in the ACT. The Plan supports the development of an ACT Mental Health Promotion, Prevention and Early Intervention Strategy which promotes a whole of population approach to promoting and maintaining good mental health across the Territory.

It is clear that the promotion of mental health and the prevention of mental illness cannot be achieved without whole of government cooperation. Provision of specialist clinical mental health care is only a small component of what is needed to achieve and maintain good mental health. The ACT Mental Health Strategy and Action Plan promotes a whole of government approach to mental health through strong partnerships with agencies for housing, education, welfare support, employment, drug and alcohol programs, policing and corrections.

The ACT Mental Health Promotion, Prevention and Early Intervention Strategy is being developed in consultation with all these groups and other key stakeholders to try to improve our capacity to identify those at risk of developing a mental illness and intervene early with the aim or reducing that risk.

I am advised that MHACT is also participating in a Collaborative Therapy project in collaboration with the Australian National University. This project aims to work with consumers, their carers, clinical managers, GPs and others involved in their care to develop an agreed management plan while providing consumers with enhanced skills to enable them to be able to identify signs of relapse and when they may need to seek additional support or other care to reduce the risk of relapse. The project is in the early stages and will be evaluated after 12 months.

NMH STANDARD 7: CULTURAL AWARENESS

ACT Health is currently developing a Cultural Respect Implementation Plan for all staff to raise awareness of cultural issues in the workforce and provide training to enhance staff capacity to work effectively with people from Aboriginal and Torres Strait Islander descent.

NMH STANDARD 8: INTEGRATION

Mental Health ACT is committed to providing quality, integrated services that are timely and responsive. The comments in the draft report highlight that some consumers and carers feel frustration that services are not as integrated as they should be to ensure a seamless continuum of care.

The ACT Government has acknowledged these concerns and has provided funding for discharge planners for the inpatient units to facilitate planning for transition from the acute inpatient unit back into the community. I am advised that MHACT is monitoring re-admission rates and follow-up within 7 days of discharge to further improve the integration of the services provided and ensure that consumers are discharged with appropriate care plans and support.

Mental Health ACT is also part of a broad ACT Health portfolio wide project, in collaboration with the ACT Division of General Practice, to develop and implement agreed and consistent discharge planning systems and documentation.

The Chief Executive of ACT Health has recently signed-off on a revised structure for MHACT which sees the management of both community and inpatient services come under the one director which should also assist in the development of more integrated services across the care continuum.

MHACT has Memorandums of Understanding (MOUs) with a range of other Government agencies including ACT Housing, the Australian Federal Police, Drug and Alcohol Program, etc. These formal MOUs and other less formal mechanisms seek to ensure a collaborative and integrated approach to managing people with a mental illness. Two very successful programs are the Dual Disability Program and the work of the Dual Diagnosis worker. Both these programs have assisted in improving collaboration and integration across services to achieve better health outcomes for consumers.

Apart from the discharge planning project, MHACT is also working with the ACT Division of General Practice on a project to improve the physical health of people with a mental illness. My Government and Department are fully aware of the poor physical health of people with a mental illness and the difficulties encountered by a number of disadvantaged groups seeking primary health care, including those with mental illness. This is in part due to the undersupply of GPs in the ACT as a result of Australian Government Policy and the fact that there are now very few GPs who provide bulk billing services.

The joint project with ACTDGP provides a primary care nurse to work within a community mental health team to facilitate and coordinate access to GP practices for participating consumers. Participating GPs and mental health clinicians will develop collaborative care plans that address the physical and the mental health need of consumers. The project will be evaluated at the completion of the 12 month trial.

MHACT works closely with the Australian Federal Police (AFP) within the terms of their MOU to facilitate appropriate management by the police of people with a mental illness. The MHACT Community Education Officer also provides information and education sessions for the AFP to develop their skills in dealing with people with a mental illness who come in contact with the police.

The Minister for Disability, Housing and Community Services launched "*Breaking the Cycle - the ACT Homelessness Strategy"* in 2004. This Strategy identifies a number of target groups who are at particular risk of becoming homeless, including those with an enduring mental illness. The Government has committed significant funding ($13.3 million) to implement this strategy aimed at improving housing options for the most vulnerable in our community.

Developing and coordinating appropriate funding models across government to support clients who are homeless or at risk of homelessness are key initiatives under the strategy and the actions include:

- ***Action 1.1.3:*** Assess and develop current funding models to ensure they adequately support service viability and sustainability in providing outcomes for clients.
- ***Action 3.1.2:*** Develop an investment strategy for social housing in the ACT.

Theme 3 of *Breaking the Cycle* recognises that access to appropriate housing is a keystone to health and well being for the community. In addition to housing, access to a range of social and community support services assist people with mental health issues to participate in the broader community and provide opportunities for management of mental health issues

The existing MOU between Housing ACT and MHACT provides a good framework for the two agencies to work together in trying to provide safe, appropriate and affordable housing for people with a mental illness, including an agreement that ensures that ACT Housing tenants who have to be admitted to a mental health facility for any length of time will not lose their tenancy. There is a clear recognition of the importance of appropriate accommodation in achieving and maintaining good mental health.

As with a number of other comments in the report, the need for additional accommodation options for people with a mental illness has been identified as an area for action in the ACT Mental Health Strategy and Action Plan. In the interim, in the 2003-04 budget, the Government provided an additional $240,000 for supported accommodation and respite places. A further $200,000 was made available for mental health respite as part of a broader respite care package in the same funding period. This brings the total amount of funding for supported accommodation for people with a mental illness to $1.2 million.

NMH STANDARD 9: SERVICE DEVELOPMENT

The ACT Government and MHACT have made significant changes to the way in which mental health services are organised and provided within the ACT. It is clear that there is still much to be done and we continue to work proactively to implement a range of initiatives to provide better mental health outcomes for the ACT community.

The ACT Government has demonstrated its on going commitment to mental health by increasing funding for mental health initiatives in the last three budgets. The National Mental Health Report of 2002 noted the ACT Government's expenditure on Mental Health services was lagging behind the national average with a per capita expenditure of $67 in 1999-2000 compared to the national average of $81 per capita. Under the present ACT Government, this level of funding has increased significantly and in the ACT 2004 – 2005 budget handed down on 4 May 2004 an estimated target per capita expenditure of $131 was announced. This records a substantial growth in mental health funding and will be validated in future *National Mental Health Reports*.

In May 2004 I launched the *ACT Mental Health Strategy & Action Plan 2003-2008 (the Plan)* which is the principal document guiding the ACT's mental health service delivery. The Plan was developed after an extensive consultation period and represents a genuine collaborative agreement on mental health priorities and actions for the people of the ACT. Many of the issues round effective involvement of consumers, their families and carers in all areas of the mental health system, access to appropriate coordinated and quality treatment services including supported accommodation for mental health consumers, raised in the HREOC *Report,* have already been identified as priorities for action in the *ACT Mental Health Strategy & Action Plan 2003-2008*.

Priority 5 of the plan focuses on system or organisational level issues with the following objectives:

- To establish transparent and accountable quality systems that promote and support innovation in the mental health care sector and complies with the National Standards for Mental Health Services;
- To develop an appropriate skilled workforce that provides quality service delivery;
- To develop a comprehensive epidemiological base for the planning and long-term evaluation of mental health services in the ACT;
- To facilitate data collection and reporting that is meaningful to the operation and outcomes of the ACT mental health system;
- To develop and apply a funding model that ensures effective and accountable allocation of resources; and
- To promote and facilitate a whole of government and whole of Territory approach to mental health service provision in the ACT.
-

There is an emphasis on strategies to recruit and retain appropriately skilled staff and to develop a robust education and training program to support them in their work and professional development,
Work to undertake a systemic analysis of current and future needs for mental health services is in progress to enable the appropriate allocation of human and financial resources to meet these identified needs and improve mental health outcomes.

In response to concerns about access to forensic mental health services expressed by some member of the ACT community, including the Chief Magistrate, the ACT Chief Minister established an Interdepartmental Committee (IDC) to undertake a full review of forensic mental health issues within the ACT in 2004. One of the recommendations of the IDC was to undertake a feasibility study into high secure mental health care for the ACT. The feasibility study has been completed and the recommendations from the study, together with all the recommendations from the IDC, are currently being considered by Government. The expected outcome of this work is that the ACT will have a quality forensic mental health service that provides care across the care continuum as required. This will include linkages in the community and in-reach into the proposed new ACT prison.

In the 2004-2005 budget the ACT Government also allocated a total of $230,000 to undertake a comprehensive services planning project and feasibility studies for acute adult mental health services, child and adolescent mental health services, crisis assessment and treatment services. The consultation process of this project is in progress. The consultant is due to report to ACT Health before the end of the 2004-2005 financial year. It is intended that this work will guide the provision of mental health services for the ACT projected needs to the year 2014.

MHACT is in the process for preparing for accreditation through the Australian Council of Healthcare Services EQuIP program. This will be the first time that MHACT has been through accreditation as a stand-alone organisation and will provide an independent evaluation of our services against the EQuIP quality improvement framework and the National Standards for Mental Health Services. .

In addition to this, substantial funds have been provided to specific suicide prevention, early intervention and mental health promotion projects.

One of the criticisms directed at mental health services is that there has been too little commitment to evaluating reforms and new initiatives to determine their effectiveness in improving mental health outcomes. I am advised that, as a apart of the revised clinical and corporate governance arrangements for MHACT, the Executive is developing a key set of corporate and performance measures that will enable transparent and accountable operation of the service and clinical care delivery.

NMH STANDARD 10: DOCUMENTATION

Mental Health ACT has developed its clinical information management system – MHAGIC - *Mental Health Assessment Generation & Information Collection System* which is aligned with mental health legislation, meets local and national data requirement, links Outcome Measurement to Care Planning and has recently been externally assessed (as part of the ACHS EQuIP pre-accreditation survey) as meeting these requirements, as well as providing information that supports safety and other *National Standards for Mental Health Service*. There is also an established clinical governance committee that regularly reviews, monitors and advises of all matters relating to MHAGIC

NMH STANDARD 11: DELIVERY OF CARE

Mental Health ACT as a division of ACT Health aims to collaborate with their community partners to provide quality mental health care across the lifespan and the care continuum. The organisation operates within the core values of professionalism, respect and integrity; collaboration and teamwork, commitment to quality and recovery, performance accountability, innovation and sustainability.

Underpinning principles for mental health care provision are consumer and carer focus, empowerment and participation for consumers, equitable and timely access and mutual respect.

It is acknowledged that, even with these values and principles as our guide, there is still much work to be done to ensure that our service meets the care needs of our community more comprehensively.

As identified in other areas of this response, this Government and MHACT have identified a number of gaps in the range of services required to achieve and maintain good mental health for the ACT community and has funded a number of initiatives to address these gaps.

In the last three budgets the ACT Government has provided significant additional funding to enhance services to support people in the community, including;

$400,000 per annum for additional regional outreach programs
$400,000 for a 7 Day extended service for Community Mental Health Teams
$80,000 for a dedicated Drug and Alcohol/Mental Health Worker
$240,000 for additional Supported Accommodation
$80,000 for a Discharge Planner Service for inpatient services
$35,000 for Carer Support.
$300,000 for Forensic Mental Health Community Team

The Government, has also increased funding to Child and Adolescent and Older Persons Mental Health Services, to enable them to provide earlier intervention and more comprehensive treatment and support services for these two identified at risk groups .The planned 20 bed acute psychogeriatric inpatient unit is expected to be commissioned in the 2006-2007 financial year and will form an integral part of the overall older personals mental health care continuum.

Programs funded to improve the delivery of specialist mental health care include:

- Child and adolescent mental health services
- Older persons mental health services
- Enhanced community mental health teams including outreach teams for new suburbs
- Mobile intensive treatment teams
- Dual disability and dual diagnosis teams
- Discharge planning
- Forensic community mental health team

Programs funded to enhance the level of support for people with a mental illness in the community include:

- Consumer and carer support
- Community education
- Psychosocial and vocational rehabilitation programs
- Suicide prevention programs
- Supported accommodation and respite services

The National Mental Health Plan 2003-2008 provides us with a clear direction for ongoing mental health reform. The ACT Mental Health Strategy and Action Plan 2003-2008 reflects the principles and is underpinned by our ongoing commitment to ensure that the National Standards for Mental Health Services are fully implemented and that this is reflected in how consumers and carers perceive our care into the future.

Thank you for the opportunity to comment on the draft report. I trust that the report will be used to generate a renewed enthusiasm for mental health reform and will not simply be seen as a vehicle for criticising those working in the system without trying to determine an agreed way forward.

Yours sincerely

Simon Corbell MLA

8.4.7 RESPONSE FROM NORTHERN TERRITORY GOVERNMENT

During preparation of this report, all jurisdictions including the Northern Territory were formally offered the opportunity to comment on the draft sections of the report pertaining to that jurisdiction as well as other relevant sections of the draft report.

No response was received from the Northern Territory Government, as represented by The Honourable Peter Toyne, MLA, Minister for Health.

8.4.8 RESPONSE FROM TASMANIAN GOVERNMENT

Tasmania

MINISTER *for*
HEALTH *and* HUMAN SERVICES

9 May 2005

Mr John Mendoza
Chief Executive Officer
Mental Health Council of Australia
PO Box 174
DEAKIN WEST ACT 2600

Dear Mr Mendoza

Thank you for the opportunity to review the draft report on your recent consultations. Unfortunately the timeframes you provide do not allow for a considered response to each individual item collected during your consultations.

You may be aware that the Department of Health and Human Services also conducted broad consultation with service providers, non-government organisations, consumers, carers and community representatives during 2004. A number of the issues identified in your report were raised during those consultations.

In November 2004 I released "*The Bridging The Gap Report.*" I commend this report to you. The report identifies key priority areas for attention and makes a set of relevant recommendations.

The Government has committed $47M to address the recommendations over a four year period. This represents the largest ever funding increase for service expansion in the 170 year history of Tasmania's Mental Health Services. The funding addresses the following initiatives:

- $4.36 million to create a total of 62 additional packages of care to support options for clients to live in the community, ranging from independent living to support in provided accommodation;
- $7.45 million to establish a 12-bed high support community facility in Northern Tasmania;
- $3.7 million to establish a 12-bed Cluster House for 24 hour seven day a week supported accommodation in the North West;
- $3.7 million to establish a 12-bed Cluster House for 24 hour seven day a week supported accommodation in the South;
- $7.32 million for an additional 26 full time equivalent clinical positions in Child and Adolescent Mental Health Services – more than double the current establishment of 21.5 FTEs;
- $5.85 million for an additional 16 FTE clinical positions in adult mental health services – an increase of more than 21 %;

- $2.55 million for an additional 6 FTE clinical positions to work with elderly mental health clients – an increase of one third on current numbers;
- $3.78 million to drive quality and safety improvements; assist with implementation of the Mental Health Act; and develop a mother and baby service, including:
  - Three additional quality positions – one Senior Quality Office statewide; one in the North and one in the North West to focus on quality and safety issues;
  - Establishment of four consumer and carer/family representative positions – two in the South and two in the North – to work with Mental Health Services to improve service quality and safety;
  - Appointment of a Senior Consultant Psychiatrist and additional support positions to support administration of the Mental Health Act and ensure the rights of consumers and advocates are protected in the delivery of all mental health services; and
  - Provision of a specialised mother and baby inpatient service to accommodate women with young children, experiencing mental health problems;
- $3.74 million to establish Recovery Programs in each region to provide activity, social and vocational skills-based programs to support recovery alongside community clinical and supported accommodation services; and
- $4.52 million to upgrade existing facilities, places and services to bring them into line with current specifications in the supported accommodation framework.

In addition, the Government funded an additional 18 mental health clinical positions in the community as part of the 2004/2005 budget.

2004 also saw the commencement of the Kids In Mind Tasmania strategy to provide support to children, young people, parents and carers and service reform and improvement in the mental health area. The Department of Premier and Cabinet has provided $1.05 million over two years for this strategy.

I am confident that these investments represents an important first step in recognising the need and continuing a planned, systematic approach to improving mental health services in Tasmania.

Thank you for writing to me on this matter.

Yours sincerely,

David Llewellyn, MHA
DEPUTY PREMIER

8.4.9 RESPONSE FROM FEDERAL GOVERNMENT

THE HON CHRISTOPHER PYNE MP

Parliamentary Secretary to the
Minister for Health and Ageing

Mr John Mendoza
Chief Executive Officer
Mental Health Council of Australia
PO Box 174
DEAKIN WEST ACT 2600

Dear Mr Mendoza John

Thank you for your letter of 5 April 2005 to the Minister for Health and Ageing, the Hon Tony Abbott MP, regarding the invitation to the Australian Government to provide a written response to the Mental Health Council of Australia's report on experiences of care entitled *Not for Service*. As Parliamentary Secretary with executive responsibility for this matter, I am responding on behalf of the Australian Government.

It is clear that the Mental Health Council of Australia and the Brain and Mind Research Institute, together with the Human Rights and Equal Opportunities Commission, have invested considerable time and effort in consulting with mental health consumers, carers and service providers, and gathering the data to produce such a report, which comes at a critical time in our consideration of the state of mental health services in Australia.

We supported the development of an independent Mental Health Council of Australia to provide us with direct community perspective on issues in mental health and related policies.

The report clearly highlights that there are concerns about the mental health system in Australia and the delivery of services to those experiencing mental illness. The Australian Government recognises that there is more to be done.

New areas of Australian Government program support include innovations in relevant areas of education, employment and training, with a specific emphasis on enhanced youth mental health. We maintain and reinforce our commitment to reducing the exposure of our young people to illegal drugs, alcohol and other forms of substance abuse.

The Report has bought us back to an essential aspect of monitoring health care. It is necessary to talk openly with those who use the systems, those who have had poor experiences and those local providers of services who are frustrated by current approaches. Australia's National Mental Health Strategy has been applauded as world-leading. We need to respond constructively to critical incidents, especially when they highlight major system failures.

Since 1996, the Australian Government has emerged as a leader in critical aspects such as the development of a national suicide prevention strategy, the first ever conduct of a national household survey of mental health problems, redevelopment of primary mental health care services and support for community education, schools-based programs and destigmatisation. While our emphasis has been on modes of prevention or early intervention, there is more to be done in the area of increased access to everyday mental health services.

Parliament House Canberra ACT 2600 • Telephone: (02) 6277 4842 Facsimile: (02) 6277 8581

The instigation and recent funding of major new programs such as Better Outcomes in Mental Health and *beyondblue: the national depression initiative* are clear evidence of our ongoing commitment. For the first time, we are supporting access to non-medical specialists such as clinical psychologists, mental health nurses and social workers to work in partnership with general practitioners. These programs are now being expanded to increase that access to treatments other than medication.

Under the National Mental Health Strategy, the Australian Government has a strong and proud record in mental health reform since 1992, beginning with the development of the National Mental Health Policy. It has not only provided substantial funding directly to States and Territories, through Medicare and the Pharmaceutical Benefits Scheme and more indirectly through the income and disability support it provides, but has acted as leader in progressing significant national mental health initiatives.

Through the Australian Health Care Agreements 2003-2008 funding for mental health services is provided to all States and Territories. Over the five years of the Agreements, the Australian Government will provide $42 billion for public hospital funding. Of this, up to $331 million is being provided to States and Territories for improving the delivery of mental health services, including community-based services. Over the period 1993 to 2002 Australian Government funding on mental health has increased by 128% or $643 million.

The increased funding described above is in accordance with the aims articulated in the *National Mental Health Plan 2003 -2008* and is further evidence of the commitment of the Australian Government towards building a sustainable evidenced based mental health reform sector and building upon initiatives that have shown positive results.

I believe there are some inaccuracies in the report you may like to consider. In that regard, I have attached a summary of suggested amendments.

The Australian Government is supportive of any activity aimed at improving the efficiency and effectiveness of mental health services in Australia and remains committed to continue this work with jurisdictions and other key stakeholders.

Yours sincerely

Christopher Pyne MP

11 MAY 2005

Attachment

Australian Government comments on the Mental Health Council of Australia's *Not for Service* report

> *"The National Mental Health Strategy was developed over a decade ago to respond to obvious service failures and human rights abuses. An analysis of the current manifestations of that strategy, namely the 2004 National Mental Health Report and the 2003-2008 National Third Plan, make it clear that we do not yet have a national process for translating the policy rhetoric into real increases in resources, enhanced service access, accepted service standards or service accountability" (Section 2.2.1 p8)*

> *"Within the National Report (2004) many of the key indicators of the failure of all governments to live up to their commitments under the National Mental Health Strategy over the last decade are evident" (Section 2.5, p14)*

Comment: The *National Mental Health Report 2004* provides substantial evidence of significant service change and resource growth. The National Report states "Many of the major structural reforms proposed at the outset of the Strategy ten years ago have been followed through by all jurisdictions, and are near completion in some cases" (p30). It is not accurate to suggest that 'we do not yet have a national process for translating the policy rhetoric into real … (change)". It should be noted that the Mental Health Council of Australia is in fact a component of this national process.

> *"Most importantly, the growth in government mental health spending (64.9%) has only just outpaced the growth in overall health expenditure (61.1%) indicating no real change in the overall pattern of health expenditure" (Section 2.5, p14)*

Comment: There would seem to be a misunderstanding of the expenditure agreement that underpinned the First and Second National Mental Health Plans (and AHCAs). Maintenance, was the agreement made by all parties and indeed all jurisdictions have met this commitment. It also does not acknowledge that the Strategy was driven by a need to stop the 'bleeding' of funds perceived to have occurred in the decade prior to the Strategy, and that this has been achieved.

> *"Actual total public sector inpatient beds per 100,000 fell from 45.5 to 30.4 from June 1993 to June 2002, a staggering 33% decrease during a period of increased demand for services" (Section 2.5, p14)*

Comment: This statement ignores the growth in community residential beds presented in the *National Mental Health Report 2004* and promotes the false view that bed reduction is a result of the National Mental Health Strategy. The vast majority of beds were closed before the Strategy and the rate of closure actually decreased under the Strategy.

Attachment

"No appreciable increase in resources has been allocated for ... patients cared for within the community" (Section 2.1A, p1)

"There have been no significant proportional increases in resources for mental health care" (Section 2.1A, p1):

Comment: The *National Mental Health Report 2004* indicates a 65% increase (in real terms) in government spending on mental health since 1993. It also highlights 109% growth in clinical staff working in public sector community services.

" ... the report highlights, much of the change is accounted for largely by radical changes within one state, namely Victoria" (Section 2.5, p14) –

Comment: The *National Mental Health Report 2004* highlights that the early dominance of Victoria is being moderated by more recent changes in other jurisdictions. It states the following: "National trends in the first five years were largely dominated by ... Victoria, but as noted in the National Report 2002, the restructuring of other jurisdictions became more prominent in the first two years of the *Second National Mental Health Plan*." (p19)

There would seem to be a misapprehension of various past initiatives, and the report ignores a number of current and planned initiatives being taken under the *National Mental Health Plan 2003-2008*. Those initiatives are specifically designed to address issues raised in the report and that has been considered by the AHMAC National Mental Health Working Group.

"Mental health promotion has been supported in Australia, but the reach and intensity of programs is extremely limited in reach and duration. Little has been done to tackle stigma... while increased mental health literacy programs are now promoted to some schools and in some workplaces, actual access to care is not mandatory" (Section 2.6, p17)

Comment: This statement ignores that there has been an internationally recognised and successful national community education campaign supported by the Australian Government to reduce stigma and improve mental health literacy. There is no acknowledgement of the substantial other initiatives to combat stigma, such as *MindFrame* national media guidelines and support for SANE's *StigmaWatch*. The recognition given to Australia's mental health promotion and prevention efforts, as documented in the *International Review of the Second National Mental Health Plan* (2001, Thornicroft & Betts), has been ignored as has the uptake of *MindMatters*, which is now in over 80% of secondary schools.

Attachment

"Current proposed Key Performance Indicators for Public Mental Health Services ... not only do not include regular measures of consumer or carer outcome, or safety, but also do not propose such innovative measures of experiences of care" (Section 2.4, p13))

Comment: This does not give any recognition to the intensive and extensive work being undertaken to implement routine consumer outcome measures, and that Australia leads the international field in this area. The Key Performance Indicator Framework – outcome measures, perceptions of care and safety- are identified as highest priorities for the next stage of development and implementation, and are not part of the originally agreed indicators solely because work is first being undertaken on developing the necessary measures to collect this information. No recognition is given to the extensive initiatives in these areas to be undertaken through the *National Mental Health Information Priorities 2nd Edition.*

"The Mental Health Council is committed to continuation of this process of active review of individual experiences of care. It is not yet at all clear that the responsible governments in Australia, or any of those other bodies who share responsibility for the provision of services, are also committed to this goal. (Section 2.4, p13)

Comment: Development of a measure of perceptions of care (consumer and carer) identified as a priority national project to be undertaken over next years, via the *National Mental Health Information Priorities 2nd Edition.* This has been available since October 2004 and the Mental Health Council of Australia participated in the national workshop that produced the original drafts.

"Currently, services provided by psychiatrists in the private sector are in decline (Section 2.6, p17)

Comment: This overlooks evidence presented in the *National Mental Health Report 2004* that the decline in private psychiatry is a corollary of growth in the medical workforce employed in the public sector. The report states: "It is important to note that in parallel with the reducing levels of private sector activity, medical staffing in the public mental health sector has increased by 36% since 1994, with most growth occurring in the psychiatric registrar and consultant psychiatrist categories." (*National Mental Health Report 2004*, p37)

"... our mental health care services provide only short-term and limited care despite the fact that many people have recurrent or chronically-disabling disorders" (Section 2.1A, p2)

Comment: It is apparent that in the public sector mental health services, the 'typical' consumer is an individual who has been under care for several years. The report also does not recognise that a key contributor to access problems faced by new clients presenting is the fact that the majority of public resources are directed to long term clients.

Attachment

" ... mental health is not resourced appropriately relative to its disease burden" (Section 2.6, p17)

Comment: This statement is based on a discredited argument concerning health system funding. No health system in the world is funded in proportion to its disease burden. To do so, without taking into account the cost of reducing the burden and other social and economic factors, can lead to pronounced inequities in resource allocation.

"..changes in the attitudes of health professionals [are needed].. little evidence now of a systematic response" (Section 4.7, p13)

Comment: This statement ignores the development of the *National Mental Health Practice Standards* (2003), which identifies the attitudes, knowledge and skills needed by all mental health professionals which have been agreed with each clinical disciplines professional organization, endorsed by the Australian and all State and Territory Governments, and currently being implemented.

8.5 SURVEY – IMPLEMENTATION OF COMMUNITY PRIORITIES IN MENTAL HEALTH

REVIEW OF MENTAL HEALTH SERVICES IN AUSTRALIA FOR 2003-2008.

Introduction: Community review of services

In April 2003, the Mental Health Council of Australia launched its national review of mental health services in Australia: "Out of Hospital, Out of Mind!". The report highlighted the obvious deficiencies in care but also presented community priorities for further action. A key proposal was increased accountability. To date, we have insufficient data from government agencies about what really happens in mental health at local, regional and state/ territory levels. Consequently, the Mental Health Council of Australia, with academic support from the Brain & Mind Research Institute, is undertaking a state-by-state review of services in 2003. Our goal is to produce a report in each state/ territory to underpin urgent reform in your local area.

The study is being conducted by Professor Ian Hickie, Professor of Psychiatry and Executive Director, Brain & Mind Research Institute, The University of Sydney; and, Dr Grace Groom, Chief Executive Officer, Mental Health Council of Australia.

If you agree to participate in this study, you will be asked to complete the following questionnaire. It is not expected that you will experience any discomfort from this process. It should take you no more than 15-20 minutes to complete.

All aspects of the study, including results, will be strictly confidential and only the investigators named above and research staff will have access to information on participants except as required by law. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

Participation in this study is entirely voluntary: you are not obliged to participate and - if you do participate - you can withdraw at any time. Whatever your decision, it will not affect your relationship with the investigators, The University of Sydney, or the Mental Health Council of Australia.

If you would like to know more at any stage, please feel free to contact Professor Ian Hickie on 02 9556 9418. This information sheet is for you to keep.

Any person with concerns or complaints about the conduct of a research study can contact the Manager for Ethics Administration, The University of Sydney on 02 9351 4811 or at gbriody@mail.usyd.edu.au.

Instructions for completing the survey

Our intention is to evaluate the extent to which national and community priorities have been supported and are being implemented at both the local and state level. We believe that this is a unique opportunity for genuine and broad mental health sector input to priorities for the next five years.

This survey is divided into three sections:

- The first asks some demographic information about you or your service.
- The second asks you to rate how the priorities have been supported or implemented within your **LOCAL** area.
- The third asks you to rate how the priorities have been supported or implemented at the **STATE** level.

Please return the completed survey in the **reply paid** envelope enclosed or **fax to 02 9556 9171**. For any further queries, our contact details are:

Brain & Mind Research Institute
Top Floor, Broughton Hall
PO Box 1
ROZELLE NSW 2039
PH: (02) 9556 9113
Fax: (02) 9556 9171

SECTION ONE: Your details.

As part of the survey, we would like to ask you some details about yourself and the area of the mental health sector you represent. Your name (or organisation) will not be reported in connection with your responses to the remainder of the survey, so your opinions and comments remain confidential.

Are you completing this survey as an individual or on behalf of an organisation?

❑ Individual ❑ Organisation

Name of organisation (optional): _____

Please tick ONE of the following descriptions which BEST describes your position or role in the mental health sector, or the position or role of your organisation:

- ❑ Consumer of mental health services
- ❑ Carer of a person with a mental illness
- ❑ Consumer or carer advocacy group
- ❑ Public provider of specialist treatment
- ❑ Private provider of specialist treatment
- ❑ Provider of early intervention services
- ❑ General practitioner
- ❑ Divisions of General Practice
- ❑ Non-government community service provider
- ❑ Mental health promotion or education
- ❑ Mental health research or evaluation
- ❑ Health policy maker or advisor
- ❑ Human services agency other than health
- ❑ Other (please specify):

What is your postcode/ the postcode of your organisation: | | | | |

Today's date: | | | – | | | – | 2 | 0 | 0 | |

day month year

SECTION TWO: Local area.

This section asks you to rate the extent to which each of the following priorities have been implemented or supported IN YOUR LOCAL AREA. Please mark the appropriate box with a cross.

		No action taken OR no support	Discussion and planning OR low level support	Implementation begun OR moderate support	Nearly complete OR high level support	Fully implemented OR full support
1.	Implementation of early intervention services	☐	☐	☐	☐	☐
2.	Development of innovative services for people with mental health and alcohol or substance abuse disorders	☐	☐	☐	☐	☐
3.	Development of a wider spectrum of acute and community-based care settings	☐	☐	☐	☐	☐
4.	Implementation of the national standards for mental health services	☐	☐	☐	☐	☐
5.	Programs that promote attitudinal change among mental health workers	☐	☐	☐	☐	☐
6.	Increased support for stigma reduction campaigns	☐	☐	☐	☐	☐
7.	Development of specific inter-governmental service agreements (eg. between health, education, housing, employment, and social security)	☐	☐	☐	☐	☐
8.	More genuine consumer participation	☐	☐	☐	☐	☐
9.	Direct support for 'innovation', 'research' and 'service evaluation' in mental health	☐	☐	☐	☐	☐
	Please rate the extent to which each of the following priorities have been implemented or supported IN YOUR LOCAL AREA.	No action taken OR no support	Discussion and planning OR low level support	Implementation begun OR moderate support	Nearly complete OR high level support	Fully implemented OR full support
10.	Introduction of specific schemes to enhance access to mental health specialists	☐	☐	☐	☐	☐
11.	More genuine carer participation	☐	☐	☐	☐	(
12.	Support for enhanced role of non-government organisations in all aspects of care	(	(	(	(	(
13.	Clear accountability for expenditure of mental health strategy funds	(	(	(	(	(
14.	Specification of clear primary care and specialist workforce roles	(	(	(	(	(

SECTION THREE: State level.

This section asks you to rate the extent to which each of the following priorities have been implemented or supported IN YOUR STATE. Please mark the appropriate box with a cross:

		No action taken OR no support	Discussion and planning OR low level support	Implementation begun OR moderate support	Nearly complete OR high level support	Fully implemented OR full support
1.	Development of specific inter-governmental service agreements (eg. between health, education, housing, employment, and social security)	(	(	(	(	(
2.	Direct support for 'innovation', 'research' and 'service evaluation' in mental health	(	(	(	(	(
3.	Introduction of specific schemes to enhance access to mental health specialists	(	(	(	(	(
4.	Support for specific disease prevention initiatives (eg. in anxiety, depression, alcohol or substance abuse)	(	(	(	(	(
5.	Support for general mental health promotion	(	(	☐	☐	☐
6.	Support for enhanced role of non-government organisations in all aspects of care	☐	☐	☐	☐	☐
7.	Clear accountability for expenditure of mental health strategy funds	☐	☐	☐	☐	☐
8.	Ongoing support for suicide prevention campaigns	☐	☐	☐	☐	☐
9.	Development of datasets for monitoring the quality of local services	☐	☐	☐	☐	☐

	Please rate the extent to which each of the following priorities have been implemented or supported IN YOUR STATE.	No action taken OR no support	Discussion and planning OR low level support	Implementation begun OR moderate support	Nearly complete OR high level support	Fully implemented OR full support
10.	Service development for those in forensic (i.e. prison-based) services	☐	☐	☐	☐	☐
11.	Specification of clear primary care and specialist workforces	☐	☐	☐	☐	☐
12.	Service enhancement for persons from culturally- and linguistically-diverse backgrounds	☐	☐	☐	☐	☐
13.	Support for community leadership in mental health	☐	(	(	(	(
14.	Support for professional leadership in mental health	(	(	(	(	(
15.	Development of specific procedures for reporting Human Rights abuses or neglect	(	(	(	(	(
16.	Increased support for stigma reduction campaigns	(	(	(	(	(
	If you are in a regional or rural area of Australia, please answer the following question.					
17.	IN YOUR STATE, what is the level of support for service development in rural and regional areas?	(	(	(	(	(
	If you are in a poorly resourced area of Australia, please answer the following question.					
18.	IN YOUR STATE, what is the level of support for service development in poorly resourced areas?	(	(	(	(	(

Other comments:

Thank you for completing this survey.
Please return it in the reply paid envelope.

8.6 SURVEY – CONSUMER AND CARER EXPERIENCES OF CARE

REVIEW OF MENTAL HEALTH SERVICES IN AUSTRALIA FOR 2003-2008:

PART II: CONSUMERS & CARERS Direct Experiences of Care

Introduction: community review of services

In April 2003, the Mental Health Council of Australia launched its national review of mental health services in Australia: "Out of Hospital, Out of Mind!". We continue to have insufficient data about what really happens in our mental health services. Consequently, the Mental Health Council of Australia, with academic support from the Brain & Mind Research Institute, is committed to ongoing review of these services. The study is being conducted by Professor Ian Hickie, Executive Director, Brain & Mind Research Institute, The University of Sydney; and, Dr Grace Groom, Chief Executive Officer, Mental Health Council of Australia.

If you agree to participate in this study, you will be asked to complete the following questionnaire. It is not expected that you will experience any discomfort from this process. It should take you no more than 15-20 minutes to complete.

All aspects of the study, including results, will be strictly confidential and only the investigators named above and research staff will have access to information on participants except as required by law. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

Participation in this study is entirely voluntary: you are not obliged to participate and - if you do participate - you can withdraw at any time. Whatever your decision, it will not affect your relationship with the investigators, The University of Sydney, or the Mental Health Council of Australia.

If you would like to know more at any stage, please feel free to contact Professor Ian Hickie on 02 9556 9418. This information sheet is for you to keep. If you wish to add any details of your ongoing care, or any other detailed comments, please forward them directly to Professor Ian Hickie at: ianh@med.usyd.edu.au

Any person with concerns or complaints about the conduct of a research study can contact the Manager for Ethics Administration, The University of Sydney on 02 9351 4811 or at gbriody@mail.usyd.edu.au.

Instructions for completing the survey

Our intention in this second survey is to evaluate the direct experience of mental health care by consumers, carers and family members. This is the second survey. The first survey, which you can also complete (http://www.mhca.com.au/Survey/default.html), asks about your knowledge of service developments at your local and state level. These surveys provide a unique opportunity for genuine and broad community input to priorities for the next five years.

This survey is divided into two sections:

- The first asks consumers, carers and family members about their experiences with mental health services as well as some demographic information. It basic domains are drawn from those identified by the Picker Institute Europe as critical elements of quality health care.
- The second asks consumers only more specific questions about their experiences with mental health services. It is based on a current survey being undertaken also in the United Kingdom to evaluate consumer's direct experiences of care.

Please return the completed survey in the reply paid envelope enclosed or fax to 02 9556 9171. For any further queries, our contact details are:

Brain & Mind Research Institute
Top Floor, Broughton Hall
PO Box 1
ROZELLE NSW 2039

Phone: (02) 9556 9418
Fax: (02) 9556 9171

SECTION 1: TO BE COMPLETED BY CONSUMERS, CARERS OR FAMILY MEMBERS

BACKGROUND INFORMATION:

i. Have you, or someone else very close to you, received treatment for a mental health problem in the last 12 months?

- o Yes
- o No [STOP HERE]

ii. Who provided this treatment?

- o Public health services (eg. emergency department, public hospital, community health centre)
- o Private health services (eg. general practitioner, private psychiatrist, private hospital)
- o Public and private health services

iii. Was the main provider a…

- o A general practitioner
- o ***A clinical psychologist/ counsellor***
- o A specialist psychiatrist
- o Hospital/ emergency service
- o Community mental health service
- o Other non-government organisation

iv. Have you, or someone else very close to you, been admitted to a hospital as a mental health inpatient in the last 12 months?

- o No
- o ***Yes, once***
- o Yes, two or three times
- o Yes, more than three times

A. IF YOU, OR SOMEONE ELSE VERY CLOSE TO YOU, DID RECEIVE TREATMENT FOR A MENTAL HEALTH PROBLEM IN THE LAST 12 MONTHS:

1. To what extent were you/ they treated with respect and dignity by health professionals?

- o ***Always***
- o Nearly always
- o Sometimes
- o Not often
- o Never

2. How much information about your/ their condition or treatment was given to <u>you</u>?
- o Too much
- o Right amount
- o Some
- o Not enough
- o None

3. To what extent were you able to access adequate services for your/ their mental health problems?
- o *Always*
- o Nearly always
- o Sometimes
- o Not often
- o Never

4. Did you find a health professional to talk to about your concerns?
- o Yes, definitely
- o Yes, to some extent
- o Yes, a little
- o No
- o I had no concerns

5. If your family or someone else close to you wanted to talk to a health professional, did they have enough opportunity to do so?
- o Yes, definitely
- o Yes, to some extent
- o No
- o No family or friends were involved
- o My family didn't want or need information
- o I didn't want my family or friends to talk to a health professional

6. How much information about your condition or treatment was given to your family or someone else close to you?
- o Not enough
- o Right amount
- o Too much
- o No family or friends were involved
- o My family didn't want or need information
- o I didn't want my family or friends to have any information

7. If you/ they were prescribed any medication for a mental health problem, was its purpose, benefits and/or side-effects fully explained?
- o Yes, definitely
- o Yes, to some extent
- o Yes, a little
- o No
- o I was not prescribed any medications

8. If you/ they were admitted as a hospital inpatient for treatment of a mental health problem, did staff attend to your/ their physical health needs (eg. assistance eating, or getting to a bathroom) in a timely manner?
- o Yes, definitely
- o Yes, to some extent
- o Yes, a little
- o No
- o I did not require assistance with any physical health needs

9. Sometimes, one health professional will say one thing and another health professional will say something quite different. Did this happen to you?

- o Always
- o Nearly always
- o Sometimes
- o Not often
- o Never

B. OVERALL

1. Did you have enough say in decisions about your/ their care and treatment?
- o Yes, definitely
- o Yes, to some extent
- o No

2. Has your/ their diagnosis been discussed with you?
- o Yes, definitely
- o Yes, to some extent
- o No

C. ABOUT YOU

1. Gender?
- o Male
- o Female

2. Age? ☐☐

3. Postcode? ☐☐☐☐

4. What is the geographical nature of the area you live in?
- o Rural/ district (less than 10,000 people)
- o Regional centre (greater than 10,000 people)
- o Major urban area (greater than 100,000 people)

5. In which country were you born?
- o Australia
- o Overseas (please specify)_____

6. Are you an Aboriginal or Torres Strait Islander?
- o *Yes*
- o No

7. What language do you most commonly speak?
- o English
- o Other (please specify)_____

8. What language do you most commonly speak *at home*?
- o English
- o Other (please specify)_____

9. Who else, if anybody, do you live with?
- o No-one, I live alone
- o Partner
- o Child/ children under 18
- o Child/ children over 18
- o A parent or guardian
- o With other family members
- o With people other than family members

10. Are you a:
- o Consumer (i.e. receive care yourself)
- o Carer
- o Family member or close friend

11. During the past four weeks how much have you been bothered by emotional problems (such as feeling anxious, depressed or irritable?)
- o Not at all
- o Slightly
- o Moderately
- o Quite a lot
- o Extremely

12. In general, how is your mental health right now?
- o Excellent
- o Very good
- o Good
- o Fair
- o Poor
- o Very poor

You can finish this survey here [SUBMIT] or, if you are a consumer (that is, directly receive mental heath care yourself) you can go onto complete a series of more specific questions about the mental health services you have received in the last 12 months. These questions are based on a survey from the National Health Service in the United Kingdom. For more information please visit http://www.nhssurveys.org. [CONTINUE]

SECTION 2: TO BE COMPLETED BY CONSUMERS ONLY

D. YOUR CARE AND TREATMENT

1. How long have you been in contact with mental health services?
- o One year or less
- o One to five years
- o More than five years
- o Don't know/ Can't remember
- o I have never been in contact with mental health services [STOP HERE]

2. Overall, how would you rate the health care you have received for your mental health problem in the last 12 months?
- o Excellent
- o Very good
- o Good
- o Fair
- o Poor
- o Very poor

E. HEALTH PROFESSIONALS

Psychiatrists

1. Have you seen a psychiatrist in the last 12 months?
- o Yes
- o No GO TO Q7, SECTION E

The LAST time you saw a psychiatrist…

2. Did the psychiatrist listen carefully to you?
- o Yes, definitely
- o Yes, to some extent
- o No

3. Did you have trust and confidence in the psychiatrist you saw?
- o Yes, definitely
- o Yes, to some extent
- o No

4. Did the psychiatrist treat you with respect and dignity?
- o Yes, definitely
- o Yes, to some extent
- o No

Still thinking about the LAST time you saw a psychiatrist…

5. Were you given enough time to discuss your condition and treatment?
- o Yes, definitely
- o Yes, to some extent
- o No

6. The last two times you had an appointment with a psychiatrist, was it…?
- o With the same psychiatrist both times
- o With two different psychiatrists

Community psychiatric nurse (CPN)

7. Have you seen a CPN in the last 12 months?
- o Yes
- o No GO TO Q11, SECTION E

The LAST time you saw a CPN…

8. Did the CPN listen carefully to you?
- o Yes, definitely
- o Yes, to some extent
- o No

9. Did you have trust and confidence in the CPN?
- o Yes, definitely
- o Yes, to some extent
- o No

10. Did the CPN treat you with respect and dignity?
- o Yes, definitely
- o Yes, to some extent
- o No

Other health professionals

11. Have you seen anyone else in mental health services in the last 12 months?
- o Yes
- o No GO TO Q1, SECTION F

12. The last time you saw someone, other than a psychiatrist or CPN, who did you see?
- o A social worker
- o An occupational therapist
- o A psychologist
- o Someone else

The LAST time you saw this person…

13. Did they listen carefully to you?
- o Yes, definitely
- o Yes, to some extent
- o No

14. Did you have trust and confidence in the person that you saw?
- o Yes, definitely
- o Yes, to some extent
- o No

15. Did the person treat you with respect and dignity?
- o Yes, definitely
- o Yes, to some extent
- o No

F. MEDICATIONS

1. In the last 12 months have you taken any medications for your mental health problems?
- o Yes
- o No GO TO Q1, SECTION G

2. Do you have a say in decisions about the medication you take?
- o Yes, definitely
- o Yes, to some extent
- o No

3. In the last 12 months, have any **new** medications (eg. tablets, injections, liquid medicines) been prescribed for you by a psychiatrist?
- o Yes
- o No
- o Can't remember

The LAST time you had a new medication prescribed for you…

4. Were the purposes of the medications explained to you?
- o *Yes, definitely*
- o Yes, to some extent
- o No

5. Were you told about possible side-effects of the medications?
- o Yes, definitely
- o *Yes, to some extent*
- o No

G. TALKING THERAPIES

1. In the last 12 months have you had any talking therapy (eg. counselling) from mental health services?
- o Yes
- o No

2. In the last 12 months, did you want talking therapy?
- o *Yes*
- o *No*

H. YOUR CARE PLAN (CPA)

A care plan shows your mental health needs and who will provide services to you. It might be a document given to you by one of the mental health team, or it might be a letter, explaining how your care has been planned.

1. Have you been given (or offered) a written or printed copy of your care plan?
- o Yes
- o No GO TO Q4, SECTION H
- o Don't know/ Not sure

2. Do you understand what is in your care plan?
- o Yes, definitely
- o Yes, to some extent
- o No
- o Don't know
- o I do not have a care plan

3. Do you agree with what is in your care plan?
- o Yes, definitely
- o Yes, to some extent
- o No
- o Don't know

Your care review

A care review is a meeting with you and the people involved in your care in which you discuss how your care plan is working.

4. In the last 12 months have you had a care review?
- o *Yes, I have had more than one*
- o Yes, I have had one
- o No, I have not had a care review in the last 12 months GO TO Q8, SECTION H

5. Were you told that you could bring a friend or relative to your care review meetings?
- o Yes
- o No
- o Don't know/ Can't remember

The LAST time you had a care review meeting…

6. Were you given a chance to express your views at the meeting?
- o Yes, definitely
- o Yes, to some extent
- o *No*

7. Did you find the care review helpful?
- o Yes, definitely
- o Yes, to some extent
- o *No*

Your care co-ordinator

A care co-ordinator (or keyworker) is someone from mental health services who keeps in regular contact with you. For example, this person could be a community psychiatric nurse (CPN) or a social worker.

8. Have you been told who your care co-ordinator is?
- o Yes
- o No GO TO Q1, SECTION I
- o Not sure/ Don't know

9. How long is it since you last saw your care co-ordinator?
- o Less than one month
- o One to three months
- o Three to six months
- o More than six months

10. Can you contact your care co-ordinator if you have a problem?
- o Yes, always
- o Yes, sometimes
- o No

I. SUPPORT IN THE COMMUNITY

Day centres or day hospitals

Some mental health service users go to a day centre where staff are available to help with problems, and activities are arranged.

1. In the last two months, how often have you visited a day centre?
- o Most days
- o Once or twice a week
- o Once or twice a month
- o I have not visited a day centre in the last two months GO TO Q3, SECTION I

2. Were the activities provided by the centre helpful?
- o Yes, definitely
- o Yes, to some extent
- o No

Where you live

3. In the last 12 months, have you received any help with accommodation?
- o Yes
- o No, but I would have liked help
- o I did not need any help

Other support in the community

4. In the last 12 months have you received help with finding work?
- o Yes
- o No, but I would have liked help
- o I did not need any help
- o I am unable to work because of my mental health problems

5. Are you currently in paid work?
- o Yes
- o No
- o No, but I work on a casual or voluntary basis
- o No, but I am a full-time student

6. In the last 12 months have you received help with getting benefits?
- o Yes
- o No, but I would have liked help
- o I did not need any help

7. In the last 12 months have you received any information about local support groups for mental health service users?
- o Yes
- o No, but I would have liked information
- o I did not need any information

8. When was the last time you saw someone about your mental health problem?
- o Less than one month ago
- o One to three months ago
- o Three to six months ago
- o More than six months ago

9. In the last 12 months, have any appointments been cancelled or changed by mental health services?
- o No
- o Yes, one appointment was cancelled or changed
- o Yes, two or three appointments have been cancelled or changed
- o Yes, four or more appointments have been cancelled or changed

J. CRISIS CARE

1. Do you have the number of someone in mental health services that you can call out of office hours?
- o Yes
- o No GO TO Q1, SECTION K
- o Not sure/ Don't know

2. In the last 12 months, have you called this number?
- o Yes
- o No

3. The last time you called the number, how long did it take you to get through to someone?
- o I got through immediately
- o I got through in one hour or less
- o A few hours
- o A day or more
- o A could not get through to anyone

K. STANDARDS

Mental Health Act

1. In the last 12 months, have you been detained (sectioned or scheduled) under the Mental Health Act?
- o Yes
- o No GO TO SECTION L

2. When you were detained, were your rights explained to you?
- o Yes
- o No

L. OTHER COMMENTS

If there is anything else you would like to tell us about your experiences of mental health care in the last 12 months, please do so here.

Is there anything particularly good about your care?

Is there anything that could be improved?

Any other comments?

THANK YOU VERY MUCH FOR YOUR HELP.
Please check that you answered all the questions that apply to you. [SUBMIT]

8.7 NATIONAL STANDARDS FOR MENTAL HEALTH SERVICES

The Standards can be downloaded at:
www.health.gov.au/internet/wcms/publishing.nsf/Content/mentalhealth-mhinfo-standards-nsmhs.htm/

Standard 1 - Rights

The rights of people affected by mental disorders and/or mental health problems are upheld by the MHS.

Criteria

1.1 Staff of the MHS comply with relevant legislation, regulations and instruments protecting the rights of people affected by mental disorders and/or mental health problems.

1.2 Consumers and their carers are provided with a written and verbal statement of their rights and responsibilities as soon as possible after entering the MHS.

1.3 The written and verbal statement of rights and responsibilities is provided in a way that is understandable to the consumer and their carers.

1.4 The statement of rights includes the principles contained in the Australian Health Ministers Mental Health Statement of Rights and Responsibilities (1991) and the United Nations General Assembly Resolution on the Protection of Persons with Mental Illness and the Improvement of Mental Health Care (1992).

1.5 The right of the consumer not to have others involved in their care is recognised and upheld to the extent that it does not impose imminent serious risk to the consumer or other person(s).

1.6 Independent advocacy services and support persons are actively promoted by the MHS and consumers are made aware of their right to have an independent advocate or support person with them at any time during their involvement with the MHS.

1.7 The MHS upholds the right of the consumer and their carers to have access to accredited interpreters.

1.8 The MHS provides consumers and their carers with information about available mental health services, mental disorders, mental health problems and available treatments and support services.

1.9 The MHS recognises the rights of people with mental disorders and/or mental health problems in their service goals and staff job descriptions.

1.10 The MHS has an easily accessed, responsive and fair complaints procedure for consumers and carers and the MHS informs consumers and carers about this procedure.

1.11 Documented policies and procedures exist and are used to achieve the above criteria.

1.12 The MHS monitors its performance in regard to the above criteria and utilises data collected to improve performance as part of a quality improvement process.

Standard 2 - Safety

The activities and environment of the MHS are safe for consumers, carers, families, staff and the community.

Criteria

2.1 The MHS and its staff comply with relevant legislation, regulations and other instruments.

2.2 Treatment and support offered by the MHS ensure that the consumer is protected from abuse and exploitation.

2.3 Policies, procedures and resources are available to promote the safety of consumers, carers, staff and the community.

2.4 Staff are regularly trained to understand and appropriately and safely respond to aggressive and other difficult behaviours.

2.5 A staff member working alone / solo has the opportunity to access another staff member at all times in their work settings.

2.6 A consumer has the opportunity to access a staff member of their own gender.

2.7 The MHS monitors its performance in regard to the above criteria and utilises data collected to improve performance as part of a quality improvement process.

Standard 3 - Consumer and Carer Participation

Consumers and carers are involved in the planning, implementation and evaluation of the MHS.

Criteria

3.1 The MHS has policies and procedures related to consumer and carer participation which are used to maximise their roles and involvement in the MHS.

3.2 The MHS undertakes and supports a range of activities which maximise both consumer and carer participation in the service.

3.3 The MHS assists with training and support for consumers, carers and staff which maximise consumer and carer participation in the service.

3.4 A process and methods exist for consumers and carers to be reimbursed for expenses and/or paid for their time and expertise where appropriate.

3.5 The MHS has a written statement of roles and responsibilities (code of conduct) for consumers and carers participating in the service which is developed and reviewed with consumers and carers.

3.6 Consumer and carers are supported to independently and individually determine who will represent the views of each group to the MHS.

3.7 The MHS monitors its performance in regard to the above criteria and utilises data collected to improve performance as part of a quality improvement process.

Standard 4 - Promoting Community Acceptance

The MHS promotes community acceptance and the reduction of stigma for people affected by mental disorders and/or mental health problems.

Criteria

4.1 The MHS works collaboratively with the defined community to initiate and participate in a range of activities designed to promote acceptance of people with mental disorders and/or mental health problems by reducing stigma in the community.

4.2 The MHS provides understandable information to mainstream workers and the defined community about mental disorders and mental health problems.

4.3 Documented policies and procedures exist and are used to achieve the above criteria.

4.4 The MHS monitors its performance in regard to the above criteria and utilises data collected to improve performance as part of a quality improvement process.

Standard 5 - Privacy and Confidentiality

The MHS ensures the privacy and confidentiality of consumers and carers.

Criteria

5.1 Staff of the MHS comply with relevant legislation, regulations and instruments in relation to the privacy and confidentiality of consumers and carers.

5.2 The MHS has documented policies and procedures which ensure the protection of confidentiality and privacy for consumers and carers and these are available to consumers and carers in an understandable language and format.

5.3 The MHS encourages, and provides opportunities for, the consumer to involve others in their care.

5.4 Consumers give informed consent before their personal information is communicated to health professionals outside the MHS, to carers or other agencies or people.

5.5 Consumers have the opportunity to communicate with others in privacy unless contraindicated on safety or clinical grounds.

5.6 The location used for the delivery of mental health care provides an opportunity for sight and sound privacy.

5.7 Consumers have adequate personal space in regard to indoor and outdoor physical care environments.

5.8 Consumers are supported in exercising control over their personal space and personal effects in residential and inpatient settings.

5.9 Confidential processes exist by which consumers and carers can regularly feedback their perception of the care environment to the MHS.

5.10 Consumers have appropriate space and privacy in order to practice their cultural, religious and spiritual beliefs.

5.11 The MHS monitors its performance in regard to the above criteria and utilises data collected to improve performance as part of a quality improvement process.

Standard 6 - Prevention and Mental Health Promotion

The MHS works with the defined community in prevention, early detection, early intervention and mental health promotion.

Criteria

6.1 The MHS has policy, resources and plans that support mental health promotion, prevention of mental disorders and mental health problems, early detection and intervention.

Promotion of Mental Health

6.2 The MHS works collaboratively with health promotion units and other organisations to conduct and manage activities which promote mental health and prevent the onset of mental disorders and/or mental health problems across the lifespan.

6.3 The MHS provides information to mainstream workers and the defined community about mental disorders and mental health problems as well as information about factors that prevent mental disorders and/or mental heath problems.

Prevention of Mental Disorders and Psychiatric Disability

6.4 The MHS has the capacity to identify and appropriately respond to the most vulnerable consumers and carers in the defined community.

6.5 The MHS has the capacity to identify and respond to people with mental disorders and/or mental health problems as early as possible.

6.6 Treatment and support offered by the MHS occur in a community setting in preference to an institutional setting unless there is a justifiable reason consistent with the best outcome for the consumer.

6.7 Each consumer receives assistance to develop a plan which identifies early warning signs of relapse and appropriate action.

6.8 The MHS ensures that the consumer has access to rehabilitation programs which aim to minimise psychiatric disability and prevent relapse.

6.9 Wherever possible and appropriate, vocational and social needs are met through the use of mainstream agencies with support from the MHS.

6.10 The MHS monitors its performance in regard to the above criteria and utilises data collected to improve performance as part of a quality improvement process.

Standard 7 - Cultural Awareness

The MHS delivers non-discriminatory treatment and support which are sensitive to the social and cultural values of the consumer and the consumer's family and community.

Criteria

7.1 Staff of the MHS have knowledge of the social and cultural groups represented in the defined community and an understanding of those social and historical factors relevant to their current circumstances.

7.2 The MHS considers the needs and unique factors of social and cultural groups represented in the defined community and involves these groups in the planning and implementation of services.

7.3 The MHS delivers treatment and support in a manner which is sensitive to the social and cultural beliefs, values and cultural practices of the consumer and their carers.

7.4 The MHS employs staff or develops links with other service providers/organisations with relevant experience in the provision of treatment and support to the specific social and cultural groups represented in the defined community.

7.5 The MHS monitors and addresses issues associated with social and cultural prejudice in regard to its own staff.

7.6 Documented policies and procedures exist and are used to achieve the above criteria.

7.7 The MHS monitors its performance in regard to the above criteria and utilises data collected to improve performance as part of a quality improvement process.

Standard 8 - Integration

Standard 8.1 - Service Integration

The MHS is integrated and coordinated to provide a balanced mix of services which ensure continuity of care for the consumer.

Criteria

8.1.1 There is an integrated MHS available to serve each defined community.

8.1.2 The consumer's transition between components of the MHS is facilitated by a designated staff member and a single individual care plan known to all involved.

8.1.3 There are regular meetings between staff of each of the MHS programs and sites in order to promote integration and continuity.

8.1.4 Opportunity exists for the rotation of staff between settings and programs within the MHS, and which maintains continuity of care for the consumer.

8.1.5 The MHS has documented policies and procedures which are used to promote continuity of care across programs, sites, other services and lifespan.

8.1.6 The MHS has specified procedures to facilitate and review internal and external referral processes within the programs of the MHS.

8.1.7 The MHS monitors its performance in regard to the above criteria and utilises data collected to improve performance as part of a quality improvement process.

8.1.8

Standard 8.2 - Integration within the Health System

The MHS develops and maintains links with other health service providers at local, state and national levels to ensure specialised coordinated care and promote community integration for people with mental disorders and/or mental health problems.

Criteria

8.2.1 The MHS is part of the general health care system and promotes comprehensive health care for consumers, including access to specialist medical resources.

8.2.2 Mental health staff know about the range of other health resources available to the consumer and can provide information on how to access other relevant services.

8.2.3 The MHS supports the staff, consumers and carers in their involvement with other health service providers.

8.2.4 The MHS has formal processes to promote inter-agency collaboration.

8.2.5 The MHS monitors its performance in regard to the above criteria and utilises data collected to improve performance as part of a quality improvement process.

Standard 8.3 - Integration with Other Sectors

The MHS develops and maintains links with other sectors at local, state and national levels to ensure specialised coordinated care and promote community integration for people with mental disorders and/or mental health problems.

Criteria

8.3.1 Mental health staff know about the range of other agencies available to the consumer and carers.

8.3.2 The MHS supports its staff, consumers and carers in their involvement with other agencies wherever possible and appropriate.

8.3.3 The MHS has formal processes to develop intersectoral links and collaboration.

8.3.4 The MHS monitors its performance in regard to the above criteria and utilises data collected to improve performance as part of a quality improvement process.

Standard 9 - Service Development

The MHS is managed effectively and efficiently to facilitate the delivery of coordinated and integrated services.

Criteria

Organisational Structure

9.1 The MHS is managed by an appropriately qualified and experienced person with authority over, and accountability for, mental health service resources and planning.

9.2 There is single point accountability for the MHS across all settings, programs and age groups.

9.3 The MHS has an organisational structure which identifies it as a discrete entity within the larger organisation.

9.4 The organisational structure of the MHS ensures continuity of care for consumers across all settings, programs and age groups.

9.5 The organisational structure of the MHS reflects a multidisciplinary approach to planning, implementing and evaluating care.

9.6 A system exists which ensures that staff are aware of their roles and responsibilities within the MHS.

Planning

9.7 The MHS produces and regularly reviews a strategic plan which is made available to the defined community.

9.8 The strategic plan is developed and reviewed through a process of consultation with staff, consumers, carers, other appropriate service providers and the defined community.

9.9 The strategic plan includes:
- consumer and community needs analysis
- quality improvement plan
- service evaluation plan including the measurement of health outcomes for individual consumers
- plan for maximising consumer and carer participation in the MHS
- plan for improving the skills of staff, and
- relevant financial information.

9.10 The strategic plan is consistent with national mental health policies and legislative requirements.

9.11 The MHS has operational plans based on the strategic plan, which establish time frames, responsibilities of organisations and/or individuals and targets for implementation.

Funding

9.12 The MHS manages a dedicated budget using nationally accepted accounting practices.

9.13 The MHS allocates a portion of its budget for the provision of staff development and, in the public sector, for the promotion of consumer and family / carer participation in the MHS.

Resource allocation

9.14 Resources are allocated according to the documented priorities of the MHS and reflect national mental health policies.

9.15 Resources are allocated in a manner which follow the consumer' and allows the MHS to respond promptly to the changing needs of the defined community.

9.16 Where the MHS has redeployed staff according to demand, it ensures that staff are a dequately trained for new and/or changing roles and ensures that continuity of care for consumers is maintained.

Staff training and development

9.17 The MHS regularly identifies training and development needs of its staff.

9.18 The MHS ensures that staff participate in education and professional development programs.

9.19 New staff are provided with an orientation program to the MHS.

9.20 The MHS ensures that staff have access to formal and informal supervision.

9.21 The MHS has a system for supporting staff during and after critical incidents.

Information systems

9.22 The MHS collects and aggregates data which promote effective care for consumers and their family/carer, assist with the management and evaluation of the MHS, and promote staff training and research.

9.23 Data are collected in a manner which ensures reliability, validity and timeliness of reporting.

9.24 Data collected are analysed and used to promote continuous quality improvement within the MHS.

9.25 Information is made available to funders, staff and the defined community in an understandable format within the bounds of confidentiality requirements.

9.26 Data collection is consistent with statutory requirements and State/Territory/ National requirements for mental health services.

9.27 Data collected are stored and reported in a manner which ensures confidentiality and complies with relevant legislation.

Service evaluation, outcome measurement, research and quality improvement

9.28 There is documented accountability and responsibility for the evaluation of the MHS.

9.29 The MHS has a service evaluation strategy which promotes participation by staff, consumers, carers, other service providers and the defined community.

9.30 The MHS routinely monitors health outcomes for individual consumers using a combination of accepted quantitative and qualitative methods.

9.31 The MHS conducts or participates in appropriate research activities.

9.32 Research proposals are reviewed by an ethics committee constituted and functioning in accordance with the National Health and Research Medical Council Statement on Human Experimentation and Explanatory Notes.

9.33 The MHS is able to demonstrate a process of continuous quality improvement.

9.34 The MHS monitors its performance in regard to the above criteria and utilises data collected to improve performance as part of a quality improvement process.

Standard 10 - Documentation

Clinical activities and service development activities are documented to assist in the delivery of care and in the management of services.

Criteria

10.1 The MHS complies with relevant legislation and regulations protecting consumer confidentiality and ensures that documentation processes are such that confidentiality is protected.

10.2 Treatment and support provided by the MHS are recorded in an individual clinical record which is accessible throughout the components of the MHS.

10.3 Documentation in the individual clinical record is dated, signed (with designation), shows the time of each intervention and is legible.

10.4 A system exists by which the MHS uses the individual clinical record to promote continuity of care across settings, programs and time.

10.5 Documentation is a comprehensive, factual and sequential record of the consumer's condition and the treatment and support offered.

10.6 Each consumer has an individual care plan within their individual clinical record which documents the consumer's relevant history, assessment, investigations, diagnosis, treatment and support services required, other service providers, progress, follow-up details and outcomes.

10.7 The MHS ensures that only authorised persons have access to information about the consumer.

10.8 Documented policies and procedures exist and are used to achieve the above criteria.

10.9 The MHS monitors its performance in regard to the above criteria and utilises data collected to improve performance as part of a quality improvement process.

Standard 11 - Delivery of Care

Principles guiding the delivery of care

The care, treatment and support delivered by the mental health service is guided by:

Choice: Access to a range of specialised mental health treatment and support options and information to assist in the selection of the most appropriate option(s) in the setting most empowering for the consumer.

Social, cultural and developmental context: Specialised mental health treatment and support which respect and utilise for optimal benefit, the consumer's social and cultural values, beliefs, practices and stage of development.

Continuous and coordinated care: Specialised mental health treatment and support are provided in a continuous and coordinated manner by a range of service providers in and between a range of settings.

Comprehensive care: Access to specialised mental health treatment and support services is available throughout the consumer's lifespan and is able to meet their specific needs during the onset, acute, rehabilitation, consolidation and recovery phases of their mental disorder and/or mental health. Each component of the mental health service, such as the psychiatric unit and the community mental health team, is equally valued by the organisation.

Individual care: Specialised mental health treatment and support are tailor-made for each individual.

Least restriction: Specialised mental health treatment and support which impose the least personal restriction of rights and choice in balance with the need for treatment.

Standard 11.1 - Access

The MHS is accessible to the defined community.

Criteria

11.1.1 The MHS ensures equality in the delivery of treatment and support regardless of consumer's age, gender, culture, sexual orientation, socio-economic status, religious beliefs, previous psychiatric diagnosis, past forensic status and physical or other disability.

11.1.2 The community to be served is defined, its needs regularly identified and services are planned and delivered to meet those needs.

11.1.3 Mental health services are provided in a convenient and local manner and linked to the consumer's nominated primary care provider.

11.1.4 The MHS is available on a 24 hour basis, 7 days per week.

11.1.5 The MHS ensures effective equitable access to services for each person in the defined community.

11.1.6 The MHS informs the defined community of its availability, range of services and the method for establishing contact.

11.1.7 The MHS, wherever possible, is located to promote ease of physical access with special attention being given to those people with physical disabilities and/or reliance on public transport.

11.1.8 Documented policies and procedures exist and are used to achieve the above criteria.

11.1.9 The MHS monitors its performance in regard to the above criteria and utilises data collected to improve performance as part of a quality improvement process.

Standard 11.2 - Entry

The process of entry to the MHS meets the needs of the defined community and facilitates timely and ongoing assessment.

Criteria

11.2.1 The process of entry to the MHS is made known to the defined community.

11.2.2 The MHS has documented policies and procedures describing its entry process, inclusion and exclusion criteria and means of promoting and facilitating access to appropriate ongoing care for people not accepted by the service.

11.2.3 The MHS can be entered at multiple sites which are coordinated through a single entry process.

11.2.4 The entry process to the MHS can be undertaken in a variety of ways which are sensitive to the needs of the consumer, their carers and the defined community.

11.2.5 The entry process to the MHS is specialised and complementary to any existing generic health or welfare intake systems.

11.2.6 An appropriately qualified and experienced mental health professional is available at all times to assist consumers to enter into mental health care.

11.2.7 The process of entry to the MHS minimises the need for duplication in assessment, care planning and care delivery.

11.2.8 The MHS ensures that a consumer and their carers are able to, from the time of their first contact with the MHS, identify and contact a single mental health professional responsible for coordinating their care.

11.2.9 The MHS has a system for prioritising referrals according to risk, urgency, distress, dysfunction and disability.

11.2.10 The MHS has a system that enables separate assessment of more than one consumer at a time.

11.2.11 The MHS has a policy which acknowledges that assessment and the entry process to the service are linked.

11.2.12 The MHS has a system which ensures that the initial assessment of an urgent referral is commenced within one hour of initial contact and the initial assessment of a non-urgent referral is commenced within 24 hours of initial contact.

11.2.13 Documented policies and procedures exist and are used to achieve the above criteria.

11.2.14 The MHS monitors its performance in regard to the above criteria and utilises data collected to improve performance as part of a quality improvement process.

Standard 11.3 - Assessment and Review

Consumers and their carers receive a comprehensive, timely and accurate assessment and a regular review of progress.

ASSESSMENT

Criteria

11.3.1 Assessments are conducted by appropriately qualified and experienced mental health professionals.

11.3.2 Wherever possible, the assessment is conducted in a setting chosen by the consumer. The choice of setting is negotiated by the consumer and the MHS and considers the safety of those people involved.

11.3.3 The MHS has a procedure for appropriately following up people who decline to participate in an assessment.

11.3.4 The MHS has a system for commencing and recording assessment during the consumer's first contact with the service.

11.3.5 The assessment process is comprehensive and, with the consumer's informed consent, includes the consumer's carers (including children), other service providers and other people nominated by the consumer.

11.3.6 The assessment is conducted using accepted methods and tools.

11.3.7 The MHS has documented protocols and procedures describing the assessment process.

11.3.8 The assessment is recorded in an individualised clinical record in a timely and accurate manner.

11.3.9 There is opportunity for the assessment to be conducted in the preferred language of the consumer and their carers.

11.3.10 Staff are aware of, and sensitive to, cultural and language issues which may affect the assessment.

11.3.11 Diagnosis is made using internationally accepted medical standards by an appropriately qualified and experienced mental health professional.

11.3.12 Where a diagnosis is made, the consumer and carers (with the consumer's informed consent) are provided with information on the diagnosis, options for treatment and possible prognoses.

11.3.13 Wherever possible, the MHS conducts face-to-face assessments but may use telephone and video technologies where this is not possible due to distance or the consumer's preference.

REVIEW

11.3.14 The MHS ensures that the assessment is continually reviewed throughout the consumer's contact with the service.

11.3.15 Staff of the MHS involved in providing assessment undergo specific training in assessment and receive supervision from a more experienced colleague.

11.3.16 New assessments are subjected to a clinical review process by the MHS.

11.3.17 All active consumers, whether voluntary or involuntary, are reviewed at least every three months. The review should be multidisciplinary, conducted with peers and more experienced colleagues and recorded in the individual clinical record.

11.3.18 A review of the consumer is additionally conducted when:
- the consumer declines treatment and support
- the consumer requests a review
- the consumer is injures themself or another person
- the consumer receives involuntary treatment
- there has been no contact between the consumer and the MHS for three months
- the consumer is going to exit the MHS
- monitoring of consumer outcomes (satisfaction with service, measure of quality of life, measure of functioning) indicates a sustained decline.

11.3.19 The MHS has a system for the routine monitoring of staff case loads in terms of number and mix of cases, frequency of contact and outcomes of care.

11.3.20 Documented policies and procedures exist and are used to achieve the above criteria.

11.3.21 The MHS monitors its performance in regard to the above criteria and utilises data collected to improve performance as part of a quality improvement process.

Standard 11.4 - Treatment and Support

The defined community has access to a range of high quality mental health treatment and support services.

Criteria

11.4.1 Treatment and support provided by the MHS reflect best available evidence and emphasise positive outcomes for consumers.

11.4.2 Treatment and support provided by the MHS, including any participation of the consumer in clinical trials and experimental treatments, are subject to the informed consent of the consumer.

11.4.3 The MHS ensures access to a comprehensive range of treatment and support services which are, wherever possible, specialised in regard to a person's age and stage of development.

11.4.4 The MHS ensures access to a comprehensive range of treatment and support services which are specialised in regard to a consumer's stage in the recovery process.

11.4.5 The MHS provides access to a comprehensive range of treatment and support services which cater for the needs of people compelled to receive treatment involuntarily, whether in an inpatient or community setting.

11.4.6 The MHS ensures access to a comprehensive range of treatment and support services which address physical, social, cultural, emotional, spiritual, gender and lifestyle aspects of the consumer.

11.4.7 The MHS ensures access to a comprehensive range of treatment and support services which are, wherever possible, specialised in regard to dual diagnosis, other disability and consumers who are subject to the criminal justice system.

11.4.8 The MHS ensures access to a comprehensive range of treatment and support services which are, wherever possible, specialised in addressing the particular needs of people of ethnic backgrounds.

11.4.9 There is a current individual care plan for each consumer, which is constructed and regularly reviewed with the consumer and, with the consumer's informed consent, their carers and is available to them.

11.4.10 The MHS provides the least restrictive and least intrusive treatment and support possible in the environment and manner most helpful to, and most respectful to, the consumer.

11.4.11 The treatment and support provided by the MHS is developed collaboratively with the consumer and other persons nominated by the consumer.

11.4.12 Documented policies and procedures exist and are used to achieve the above criteria.

11.4.13 The MHS monitors its performance in regard to the above criteria and utilises data collected to improve performance as part of a quality improvement process.

Standard 11.4.A - Community Living

The MHS provides consumers with access to a range of treatment and support programs which maximise the consumer's quality of community living.

Criteria

Self Care

11.4.A.1 The setting for the learning or the re-learning of self care activities is the most familiar and/or the most appropriate for the generalisation of skills acquired.

11.4.A.2 Self care programs or interventions provide sufficient scope and balance so that consumers develop or redevelop the necessary competence to meet their own everyday community living needs.

Leisure, Recreation, Education, Training, Work and Employment

11.4.A.3 The MHS ensures that settings for day programs provide adequate indoor and outdoor space for consumers.

11.4.A.4 The MHS ensures that the consumer has access to an appropriate range of agencies, programs and/or interventions to meet their needs for leisure, recreation, education, training, work, accommodation and employment.

11.4.A.5 The MHS supports the consumer's access to education, leisure and recreation activities in the community.

11.4.A.6 The MHS provides access to, and/or support for consumers in employment and work.

11.4.A.7 The MHS supports the consumer's access to vocational training opportunities in appropriate community settings and facilities.

11.4.A.8 The MHS promotes access to vocational support systems which ensure the consumer's right to fair pay and conditions, award (or above) payment for work and opportunities for union membership.

11.4.A.9 The MHS supports the consumer's desire to participate in Further or Continuing Education.

11.4.A.10 The MHS provides or ensures that consumers have access to drop-in facilities for leisure and recreation as well as opportunities to participate in leisure and recreation activities individually and/or in groups.

Family, Relationships, Social and Cultural System

11.4.A.11 The consumer has the opportunity to strengthen their valued relationships through the treatment and support effected by the MHS.

11.4.A.12 The MHS ensures that the consumer and their family have access to a range of family-centred approaches to treatment and support.

11.4.A.13 The MHS provides a range of treatments and support which maximise opportunities for the consumer to live independently in their own accommodation.

11.4.A.14 Documented policies and procedures exist and are used to achieve the above criteria.

11.4.A.15 The MHS monitors its performance in regard to the above criteria and utilises data collected to improve performance as part of a quality improvement process.

Standard 11.4.B - Supported Accommodation

Supported accommodation* is provided and/or supported in a manner which promotes choice, safety and maximum possible quality of life for the consumer.

* Psychiatric inpatient accommodation is addressed under Inpatient Care (Standard 11.4.E)

SUPPORTED ACCOMMODATION PROVIDED BY THE MHS

Criteria

11.4.B.1 The MHS has guidelines for the provision of accommodation which are adhered to.

11.4.B.2 Consumers and carers have the opportunity to be involved in the management and evaluation of the facility.

11.4.B.3 The accommodation program is fully integrated into other treatment and support programs.

11.4.B.4 Accommodation is clean, safe and reflects as much as possible the preferences of the consumers living there.

11.4.B.5 Access to the accommodation is non-discriminatory and determined on priority of need alone.

11.4.B.6 A range of treatment and support services is delivered to the consumers living in the accommodation according to individual need.

11.4.B.7 Consumers living in the accommodation are offered maximum opportunity to participate in decision making with regard to the degree of supervision in the facility, decor, visitors, potential residents and house rules.

11.4.B.8 There is a range of accommodation options available and consumers have the opportunity to choose and move between options if needed.

11.4.B.9 Where desired, consumers are accommodated in the proximity of their social and cultural supports.

11.4.B.10 The accommodation maximises opportunities for the consumer to participate in the local community.

11.4.B.11 The accommodation maximises opportunities for the consumer to exercise control over their personal space.

11.4.B.12 Wherever possible and appropriate, the cultural, language, gender and preferred lifestyle requirements of the consumer are met.

11.4.B.13 Consumers with physical disabilities have their needs met.

ACCOMMODATION PROVIDED BY AGENCIES OTHER THAN THE MHS

11.4.B.14 The MHS supports consumers in their own accommodation and supports accommodation providers in order to promote the criteria above.

11.4.B.15 The MHS provides treatment and support to consumers regardless of their type of accommodation.

11.4.B.16 The MHS does not refer a consumer to accommodation where he / she is likely to be exploited and/or abused.

11.4.B.17 Documented policies exist and are used to achieve the above criteria.

11.4.B.18 The MHS monitors its performance in regard to the above criteria and utilises data collected to improve performance as part of a quality improvement process.

Standard 11.4.C - Medication and Other Medical Technologies

Medication and other medical technologies are provided in a manner which promotes choice, safety and maximum possible quality of life for the consumer.

Criteria

11.4.C.1 Medication and other technologies used are evidence-based and reflect internationally accepted medical standards.

11.4.C.2 Medication and other technologies are prescribed, stored, transported, administered and reviewed by authorised persons in a manner consistent with legislation, regulations and professional guidelines.

11.4.C.3 The MHS obtains the informed consent of the consumer prior to the administration of medication or use of other medical technologies such as Electro Convulsive Therapy.

11.4.C.4 The consumer and their carers are provided with understandable written and verbal information on the potential benefits, adverse effects, costs and choices with regard to the use of medication and other technologies.

11.4.C.5 Wherever possible and appropriate, the MHS provides the option of medication being prescribed and administered in a setting of the consumer's choice.

11.4.C.6 The MHS ensures that a system exists which monitors to prevent - and promptly provides the consumer with appropriate treatment for any adverse effects of medication.

11.4.C.7 Where the consumer's medication is administered by the MHS, it is administered in a manner which protects the consumer's dignity and privacy.

11.4.C.8 "Medication when required" (PRN) is only used as a part of a documented continuum of strategies for safely alleviating the consumer's distress and/or risk.

11.4.C.9 The use of medication and other technologies is monitored and reported utilising nationally accepted clinical indicators and other benchmarks.

11.4.C.10 The MHS ensures access for the consumer to the safest, most effective and most appropriate medication and/or other technology.

11.4.C.11 The MHS promotes continuity of care by ensuring that, wherever possible, the views of the consumer and, with the consumer's informed consent, their carers and other relevant service providers are considered and documented prior to administration of new medication and/or other technologies.

11.4.C.12 The consumer's right to seek an opinion and/or treatment from another qualified person is acknowledged and facilitated and the MHS promotes continuity of care by working effectively with other service providers.

11.4.C.13 Where appropriate, the MHS actively promotes adherence to medication through negotiation and the provision of understandable information to the consumer and, with the consumer's informed consent, their carers.

11.4.C.14 Wherever possible, the MHS does not withdraw support or deny access to other treatment and support programs on the basis of a consumer's decision not to take medication.

11.4.C.15 Documented policies and procedures exist and are used to achieve the above criteria.

11.4.C.16 The MHS monitors its performance in regard to the above criteria and utilises data collected to improve performance as part of a quality improvement process.

Standard 11.4.D - Therapies

The consumer and the consumer's family/carer have access to a range of safe and effective therapies.

Criteria

11.4.D.1 Therapies offered or recommended by the MHS reflect best available evidence and are conducted by appropriately qualified and experienced mental health professionals.

11.4.D.2 The MHS provides access to a range of accepted therapies according to the needs of the consumer and their carers.

11.4.D.3 The extent to which therapies are directly provided by the MHS is determined according to the assessed need of the defined community and the documented priorities of the MHS.

11.4.D.4 The consumer is supported to make an informed choice on the most acceptable form of therapy from the range available.

11.4.D.5 The consumer is informed by the MHS of the potential benefits, potential adverse effects, financial costs and any other foreseeable inconvenience associated with the provision of a particular therapy.

11.4.D.6 The MHS promotes continuity of care for consumers referred outside the MHS for a particular therapy.

11.4.D.7 Therapies provided by the MHS are provided in an environment which is safe, private, comfortable and affords minimal disruption.

11.4.D.8 Documented policies and procedures exist and are used to achieve the above criteria.

11.4.D.9 The MHS monitors its performance in regard to the above criteria and utilises data collected to improve performance as part of a quality improvement process.

Standard 11.4.E - Inpatient Care

The MHS ensures access to high quality, safe and comfortable inpatient care for consumers.

Criteria

11.4.E.1 The MHS offers less restrictive alternatives to inpatient treatment and support provided that it adds value to the consumer's life and with consideration being given to the consumer's preference, demands on carers, availability of support and safety of those involved.

11.4.E.2 Where admission to an inpatient psychiatric facility is required, the MHS makes every attempt to promote voluntary admission for the consumer.

11.4.E.3 The MHS ensures that a consumer who requires involuntary admission is conveyed to hospital in the safest and most respectful manner possible.

11.4.E.4 The MHS ensures that the admission assessment includes the views of other current service providers and the consumer's carers.

11.4.E.5 The MHS ensures that there is continuity of care between inpatient and community settings.

11.4.E.6 As soon as possible after admission, the MHS ensures that consumers receive an orientation to the ward environment, are informed of their rights in a way that is understood by the consumer and are able to access appropriate advocates.

11.4.E.7 The MHS assists in minimising the impact of admission on the consumer's family and significant others.

11.4.E.8 The MHS ensures that the consumer's visitors are encouraged.

11.4.E.9 The MHS ensures that there is a range of age appropriate day and evening activities available to consumers within the inpatient facility.

11.4.E.10 The MHS provides opportunities for choice for consumers in regard to activities and environment during inpatient care.

11.4.E.11 The MHS seeks regular feedback from consumers on the activities and environment associated with inpatient care.

11.4.E.12 The MHS, where appropriate, enables consumers to participate in their usual religious and/or cultural practices during inpatient care.

11.4.E.13 Consumers and their carers have the opportunity to communicate in their preferred language.

11.4.E.14 The MHS provides a physical environment for inpatient care that ensures protection from harm, adequate indoor and outdoor space, privacy, and choice.

11.4.E.15 Documented policies and procedures exist and are used to achieve the above criteria.

11.4.E.16 The MHS monitors its performance in regard to the above criteria and utilises data collected to improve performance as part of a quality improvement performance as part of a quality improvement process.

Standard 11.5 - Planning for Exit

Consumers are assisted to plan for their exit from the MHS to ensure that ongoing follow-up is available if required.

Criteria

11.5.1 Each consumer's documented individual care plan includes an exit plan which is begun during entry to the MHS to ensure ongoing continuity of care once the consumer has exited from the MHS.

11.5.2 The exit plan is reviewed in collaboration with the consumer and, with the consumer's informed consent, their carers at each contact and as part of each review of the individual care plan.

11.5.3 The exit plan is made available to consumers and, with the consumer's informed consent, their carers and other nominated service providers.

11.5.4 The consumer and their carers are provided with understandable information on the range of relevant services and supports available in the community.

11.5.5 A process exists for the earliest appropriate involvement of the consumer's nominated service provider.

11.5.6 The MHS ensures that consumers referred to other service providers have established contact and that the arrangements made for ongoing follow-up are satisfactory to the consumer, their carers and other service provider prior to exiting the MHS.

11.5.7 All services provided by the MHS are planned and delivered on the basis of the briefest appropriate duration of contact consistent with best outcomes for the consumer.

11.5.8 Documented policies and procedures exist and are used to achieve the above criteria.

11.5.9 The MHS monitors its performance in regard to the above criteria and utilises data collected to improve performance as part of a quality improvement process.

Standard 11.6 - Exit and Re-entry

The MHS assists consumers to exit the service and ensures re-entry according to the consumer's needs.

Criteria

11.6.1 Staff review the outcomes of treatment and support as well as ongoing follow-up arrangements for each consumer prior to their exit from the MHS.

11.6.2 The MHS ensures that the consumer, their carers and other service providers and agencies involved in follow-up are aware of how to gain entry to the MHS at a later date.

11.6.3 The MHS ensures that the consumer, their carers and other agencies involved in follow-up, can identify an individual in the MHS, by name or title, who has knowledge of the most recent episode of treatment and/or support.

11.6.4 The MHS attempts to re-engage with consumers who do not keep the planned follow-up arrangements.

11.6.5 The MHS assists consumers, carers and other agencies involved in follow-up to identify the early warning signs which indicate the MHS should be contacted.

11.6.6 The MHS ensures that the individual clinical record for the consumer is available for use in any potential future contact with the MHS.

11.6.7 Documented policies and procedures exist and are used to achieve the above criteria.

11.6.8 The MHS monitors its performance in regard to the above criteria and utilises data collected to improve performance as part of a quality improvement process.

8.8 SNAPSHOT OF MEDIA REPORTS REGARDING CRISIS IN MENTAL HEALTH CARE

Table 8.8: Snapshot of media reports regarding crisis in mental health care

DATE	TITLE	AUTHOR	SOURCE
19 Aug 2003	Families, Counsellors Respond To Tale Of Hidden Tragedy	Steven Waldon & Julie-Ann Davies	The Age
2 Sept 2003	Mental Health Suicides Shock – Call For A Time-Out Facility	Danielle Cronin	The Canberra Times
12 Nov 2003	Psychiatric Procedures Questioned	Roderick Campbell	The Canberra Times
6 Dec 2003	System To Blame For Suicide – Coroner	Roderick Campbell	The Canberra Times
6 Dec 2003	Ex-Wife Blames Lack Of Support For Deaths	Emma Chalmers	The Courier Mail
26 Dec 2003	Mental Suicide Up – HOSPITALS IN CRISIS		The Daily Telegraph
30 Dec 2003	Fatal Error And Demand For Royal Commission – HOSPITALS IN CRISIS	Katherine Janks	The Daily Telegraph
31 Dec 2003	Hospital Failures Blamed For Suicides – HOSPITALS IN CRISIS	Zoe Taylor	The Daily Telegraph
25 Jan 2004	Flaw In Mental Health Service		The Canberra Times
28 Jan 2004	Jail Should Include Mental-Health Space: Advocate	Catherine Naylor	The Canberra Times
31 Jan 2004	Dilemma For Judges Who Deal With Mentally Ill		The Canberra Times
14 Feb 2004	Prison Politics	Ian Gerard & Drew Warne-Smith	The Australian
17 Feb 2004	Mental Health Patient Outcry: Courts 'Being Blackmailed'	Monika Boogs	The Canberra Times
19 Feb 2004	Worker Admits He Failed To Monitor At-Risk Patient	Roderick Campbell	The Canberra Times
19 Feb 2004	Suicide Warning For Mentally Ill	Carol Nader	The Age
20 Feb 2004	Patients Suffer As Mental Health Plans Fail – Essential Service Failure	Gosia Kaszubska	The Australian
20 Feb 2004	Hospitals Say Chief Psychiatrist 'Out Of Touch'	Carol Nader	The Age
21 Feb 2004	Let Those Who Know Speak: Call For Consumers, Carers To Be Involved In New Working Party	Danielle Cronin	The Canberra Times
21 Feb 2004	Coroner May Probe Patients' Suicides	Catharine Munro	The Age
27 Feb 2004	Mental Health: Call To Action		The Canberra Times
28 Feb 2004	Coroner Slates Care Of Mentally Ill	Roderick Campbell	The Canberra Times
28 Feb 2004	The Doctors Of Despair	Sandra McLean	The Courier Mail
12 Mar 2004	Mentally Ill Merit Much More Of A Fair Go From Us		The Canberra Times
17 Mar 2004	Critical Condition	Graeme Bond	The Age
23 Mar 2004	Officer Hid Her Dark, Sad Secret	Nicolle Fenech	The Daily Telegraph
25 Mar 2004	Inquiry Into Suicide Ordered	Danielle Cronin	The Canberra Times
27 Mar 2004	Suicides: Coroner's List Grows	Roderick Campbell	The Canberra Times

31 Mar 2004	We Can't Stop Suicides, But With Better Services We Could Save Some		The Canberra Times
12 Apr 2004	Suicide Risk Claim In Hospital Change	Cathy O'Leary	The West Australian
5 May 2004	Rally Brings Suicide Into Spotlight	Pamela Magill	The West Australian
14 May 2004	Psychiatric Unit Under Fire	Carol Nader	The Age
24 May 2004	High Rates Of Mental Illness In Jail Inmates	Ian Munro	The Age
27 May 2004	Probe On Suicide After Hospital Turns Away Man	Danny Rose	The Hobart Mercury
27 May 2004	Be Aware Of Young People's Distress	Daniel Landon	The Canberra Times
30 May 2004	Patient Acted On Death Threats After Release	Alexandra Economou	The Advertiser
4 Jul 2004	Jail Should Not Become Refuge	Terry Sweetman	The Sunday Mail
31 Jul 2004	No Follow-Up On Mentally Ill Criminals	Leanne Craig	The Advertiser
2 Aug 2004	Inquiry Plea After Mental Health Deaths	Dawn Gibson	The West Australian
3 Aug 2004	Tragic Toll Hits Our Young – Not-For-Profit Organisations – A Special Advertising Report		The Daily Telegraph
4 Aug 2004	Psychosis 'No Excuse' To Escape Prison Cell	Leanne Craig	The Advertiser
14 Aug 2004	Singh Now A Crusader For Women In Jail		The Canberra Times
21 Aug 2004	Judge Hits Treatment Of Insane	Nick Clark	The Hobart Mercury
25 Aug 2004	Jail System A 'Sump' For The Mentally Ill	Rebecca DiGirolamo	The Australian
26 Aug 2004	Teenagers Locked Away With Criminally Insane	Dawn Gibson & Peta Rasdien	The West Australian
26 Aug 2004	Govts 'All Talk, Not Much Action' On Mentally Ill	Catherine Naylor	The Canberra Times
26 Aug 2004	Drugs Linked To Mental Health Crisis	Meaghan Shaw	The Age
3 Sept 2004	Three Sons Lost To The Island Of Despair	Tony Koch	The Australian
10 Sept 2004	Spotlight On A Dark Road	Steve Waldon	The Age
30 Sept 2004	Dawes Bond 'Manifestly Inadequate'	Lisa Miller	The Daily Telegraph
28 Oct 2004	Police To Decide Mental Health Treatment	Julie Robotham	The Sydney Morning Herald
30 Oct 2004	When A Girl's Mum Is The Only One Listening	Vanessa McCausland	The Daily Telegraph
5 Nov 2004	Police Left To Prop Up Ailing Mental Health System	Ruth Pollard	The Sydney Morning Herald
6 Nov 2004	Agony Over System That Failed Nigel	Michelle Paine	The Hobart Mercury
10 Dec 2004	Save Our Children – Society Fails The Innocent	Lillian Saleh	The Daily Telegraph
12 Dec 2004	Holding Bays Doling Out 'Subhumane Care'	Peter Ellingsen	The Sunday Age
12 Dec 2004	Suicide A Risk After Hospital	Liz Porter	The Sunday Age
12 Dec 2004	Threat To Oneself No Guarantee Of Care	Peter Ellingsen	The Sunday Age
12 Dec 2004	The Shame Of Our 'Forgotten People'	Peter Ellingsen	The Sunday Age
19 Dec 2004	80% Of Homeless Have Mental Disorder	Peter Ellingsen	The Sunday Age
18 Jan 2005	Prison Boom Will Prove A Social Bust	Eileen Baldry	The Sydney Morning Herald
31 Jan 2005	Brogden Wants More For Mental Health		The Daily Telegraph
5-6 Feb 2005	She's Australian And Mentally Ill – Yet Immigration Locked Her Up	Andra Jackson	The Sydney Morning Herald
5-6 Feb 2005	Mentally Ill Aussie In Detention Centre	Andrew McGarry	The Weekend Australian
7 Feb 2005	My Sister Lost Her Mind, And Australia Lost Its Heart When It Imprisoned Her	Chris Rau & John MacDonald	The Sydney Morning Herald

8 Feb 2005	Queensland Hospitals Fail Patients	Jeff Sommerfeld	The Courier Mail
8 Feb 2005	Shameful Case Forces Change	Stephanie Peatling & Mark Todd	The Sydney Morning Herald
8 Feb 2005	Message Of Love For A Lost Child	Lisa Davies	The Daily Telegraph
8 Feb 2005	When Detention Begets Its Own Madness		The Age
8 Feb 2005	Shameful Case Forces Change	Stephanie Peatling & Mark Todd	The Sydney Morning Herald
8 Feb 2005	Funds For Mentally Ill Lowest In Nation	Jeff Sommerfeld	The Courier Mail
9 Feb 2005	Rau Is Only An Extreme Example – Our Prisons Are Full Of Mentally Ill People	Allan Fels	The Sydney Morning Herald
9 Feb 2005	Brogden Pledges Action On 'Mental Asylum' Jails	Anne Davies	The Sydney Morning Herald
12 Feb 2005	Out Of Mind	Ruth Pollard	The Sydney Morning Herald
12 Feb 2005	Loose Ends Thrown Up By		The Canberra Times
15 Feb 2005	Prison System Close To Crisis	Fergus Shiel & Meaghan Shaw	The Age
15 Feb 2005	Mentally Ill Trapped In Casualty	Carol Nader	The Age
18 Feb 2005	Battling Guilt And Society's Stigma	Pat Sutton	The Advertiser
18 Feb 2005	Mental Health Inquiry Tackles System In Crisis	Aban Contractor & Mark Metherell	The Sydney Morning Herald
19 Feb 2005	Suicidal Woman Who Drowned Son Not Guilty	Geesche Jacobsen	The Sydney Morning Herald
19 Feb 2005	Prescribing Passion For A Healthier System		The Canberra Times
20 Feb 2005	It's Time To Admit We've Created A Gulag	Russell Skelton	The Sunday Age
21 Feb 2005	Mental Health Care Called To Account	Kate Legge	The Australian
21 Feb 2005	NSW Govt Backs Senate Mental Health Inquiry	Sharan Burrow	Health Business Daily News
22 Feb 2005	Shock May Have Saved Man: Report	Danielle Cronin	The Canberra Times
25 Feb 2005	States 'Starving' Mental Health Sector Of Funds	Dan Brown	Health Business Daily News
2 Mar 2005	Training Needed, Says Report On Suicide	Danielle Cronin	The Canberra Times
5 Mar 2005	Treatment Of Mentally Ill As Bad As Ever: Expert	Danielle Cronin	The Canberra Times
5 Mar 2005	Agency Of Hate And Anguish	Dawn Gibson	The West Australian
5 Mar 2005	No Hospital Bed For Suicide Women	Wendy Pryer	The West Australian
5 Mar 2005	Suicide Woman Wanted Treatment	Wendy Pryer	The West Australian
16 Mar 2005	Crisis System 'Failed' Man Later Charged With Murder	Carol Nader & Stephen Moynihan	The Age
18 Mar 2005	Plea For Action On Prevention Plan As Tragic Toll Jumps Alarmingly: State Suicide Crisis	Gavin Lower	Hobart Mercury
24 Mar 2005	Country Set To Lose $1m Mental Funds	Jessica Strutt	The West Australian
29 Mar 2005	Shot Man Had Been Left Without Supervision	Jeff Sommerfeld	The Courier Mail
30 Mar 2005	Suicide Figures Justify Building 'Time-Out' Facility: Stefaniak	Danielle Cronin	The Canberra Times
31 Mar 2005	Jail Birds	Ian Munro	The Age
2 Apr 2005	Shedding Light On Despair's Dark Side		The Canberra Times

2 Apr 2005	When Blue Turns Black	Ruth Pollard	The Sydney Morning Herald
5 Apr 2005	Mentally Ill Warehoused In Jails, Says Parole Board Chief	Jessica Strutt	The West Australian
6 Apr 2005	Grown Men Should Have The Courage To Break Out Crying	Rex Jory	The Advertiser
9 Apr 2005	Suicide Rate High After Mental Unit Discharge	Gerard Noonan	The Sydney Morning Herald
13 Apr 2005	Black Kids Facing Mental Health Crisis	Amanda Banks	The Australian
18 April 2005	When jail becomes a psychiatric ward	Stephen Gibbs	The Sydney Morning Herald
19 Apr 2005	Call To Fix Mental Health Care Crisis	Ruth Pollard	The Sydney Morning Herald
19 Apr 2005	Alarm At Lack Of Treatment For Mental Illness Sufferers	Ruth Pollard	The Age
19 Apr 2005	System Fails Mentally Ill: Report	Rosemary Desmon	The Courier Mail
23 Apr 2005	Sick System Victim	Wayne Crawford	The Hobart Mercury
23 Apr 2005	Case Closes On Tragic Tale Of Gary Lee-Rogers		The Canberra Times
28 Apr 2005	Mental Health Patients Turned Away	AAP	The Sunday Telegraph
28 Apr 2005	Government 'Failing' The Mentally Ill	Saffron Howden	The Weekend Australian
5 May 2005	Govt Seeks Detainee Judgment Advice	AAP	The Herald Sun
10 May 2005	Mentally ill missing out on help, says AMA	Danielle Cronin	The Canberra Times

8.9 STATE / TERRITORY FUNDING ANNOUNCEMENTS

Table 8.9: State / Territory Funding Announcements 2004/05

S/T	Amount	Date of Announcement	Details of Announcement
ACT	$610,000	May 2005	Awarded to University of Canberra to operate a Centre for Health, Promotion and Wellbeing over 3 years
NSW	-	April 2005	Strategy to recruit 400 mental health nurses in NSW. 150 in 2005 building to a target of 400 in 2006
	$13.8 million	April 2005	Program to provide disability support to 460 people across the state with a mental illness.
	Four new 20 bed sub-acute mental health units	February 2005	Funded from the $241 million to enhance mental health services as announced in the April 2005 budget.
	$68 million real increase	February 2005	$783 million dedicated to mental health services in 2005 up from $715 million the previous year. All money seems to be allocated to beds and not community services.
	$1.6 million	August 2004	New acute 8 bed paediatric in-patient ward at The Children's Hospital at Westmead
NT	Extra $1.5 million for MH services	May 2005	Extra $1.5 million per year for MH services. This is a repeated commitment from the previous year. Funding breakdown includes $200,000 for improved 24 hr emergency response and $350,000 for four extra rural child and adolescent psychiatrist positions
	$1.2 million	May 2005	For community based residential facilities in Darwin and Alice Springs for 24 hour support for those with a mental illness.
		October 2004	Launch of animated indigenous character and mental health seminar
		October 2004	Launch of 'Mind your Mind kit' to promote positive youth mental health.
	$1.5	June 2004	Extra $1.5 million per year for MH services reported.
	$490,000	April 2004	$490,000 over three years to help those with a mental disorder access individual rehab programs.
QLD	$63,000	October 2004	New money from Qld Health for Mental illness Fellowship of Nth Qld ' Family Participation Program
	$6.9 Million	July 2004	Funding for community organisations for new and expanded mental health services
SA	$80 million	March 2004	Mental health building program for 3 new 20 bed specialist community rehab facilities. To be completed by the end of 2007
	$13 million recurrent funds and $56 million over five years	August 2004	Announcement of audit on State's MH Act. $13 million in new funding and $56 million to support residential facilities in the community.

TAS	$47 Million over 3 years	November 2004	To be used for; 62 packages of care to support clients living in the community new 12 bed cluster house new 12 bed high support community facility $3.78m to drive quality and safety reform $4.52 upgrade of existing govt and non-govt facilities and services.
		April 2005	Govt announcement that offenders with acute mental illness will be managed within secure mental health units rather than prison.
		April 2005	Govt announcement that it has accepted all 26 recommendations from the Ward 1E report in mental health facilities conducted by the Health complaints commissioner.
VIC	$180 million and some new money	April 2005	Govt announces extra money for crisis assessment teams, rebuilding of Bunjil House and building a 50 bed facility at Maroondah hospital
	$9.45 million	March 2005	Govt announces that work on the new $9.45 million adult acute inpatient unit and specialist MHS at Austin hospital had begun.
	$8 million	December 2003	Govt announces that work on the new $8 million community MH facility at Traralgon would commence by the end of the year. Will take 12 months to construct and 80 staff based there will service a 14 bed community care unit.
	$200,000	October 2004	Govt announces that 5 separate rural health services would each receive $40,000 to improve consultation-liaison psychiatry services.
	$483,870	October 2004	Govt announces that new early psychosis services in Hume and Loddon Mallee will receive $483,870 for five additional clinical positions. Govt announces nearly $200 million in additional recurrent funding for MH since 1999 and $650 million would be provided in 2004.
	$447,000	September 2004	Govt announces that new early psychosis service has opened at Barwon
	$75,000	August 2004	Govt announces that a Young Persons' Psychiatric Disability and Rehabilitation support service in Wodonga would be strengthened.
		August 2005	Govt announces that a new ministerial advisory committee would be established.
		July 2004	Govt announces frontline feedback to the Government could assist in how the Govt spend an additional $15 million on rural MH services
	$500,000	June 2004	Govt announces opening of a new mental health service in Flemington. The service is an 8 bed community mental health facility.
	$1.1 million	March 2004	Govt announces opening of a new country 'mid way house' for those with mental illness located at Shepparton in the Goulburn Valley.
	$500,000	March 2004	Govt announces opening of a new high dependency unit in Dandenong.
	$200,000	March 2004	Govt announces 3 hospitals to share funding for new obstetric consultation liaison psychiatry service for new mothers.
	$126,000	March 2004	Govt announces Seniors in Victoria with a serious mental illness will be able to access an $126,000 in social and recreational support.
	$1.5 million	January 2004	Govt announces new money for mental health beds in Sunshine, Burwood East and Melbourne.

WA	$173 million	October 2004	Govt announces establishment of a Mental Health Advisory Group to oversee the implementation of the Govt's $173 million mental health strategy.
	$173 million	October 2004	Govt announces $173 million mental health strategy. This includes • $65m – 113 new impatient beds and 425 new staff • 420 extra community beds • $23.6m for specialist MH teams in emergency departments • $11m for MHS targeting school aged children • $8.7m to improve safety for MH staff
		November 2004	Govt announces allocation of $700,000 from the Govt's $173 million mental health strategy to the beyondblue to raise awareness of the issue of depression in WA.