NATIONAL MENTAL HEALTH CONSUMER ALLIANCE

Submission to Reforms to Strengthen the National Mental Health Commission and National Suicide Prevention Office

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The National Mental Health Consumer Alliance (the NMHCA) has prepared this submission in response to the consultation document Reforms to Strengthen the National Mental Health Commission and National Suicide Prevention Office.

The NMHCA is the national mental health consumer peak body led by and representing the voices of people with direct lived experiences of mental health issues. This submission is based on a summary of the views of members of the NMHCA on the consultation paper about the structure for the National Mental Health Commission (NMHC) and the National Suicide Prevention Office (NSPO) obtained during a formal consultation session including the NMHCA, the National Mental Health Carers (supporters, family, kin) peak body, and Departmental officials held in Melbourne on Wednesday 13 November 2024.

The NMHCA identifies that neither key consumer advocates outside of the consumer peak bodies, nor those working in the areas of suicide response and prevention, were part of the consultation this submission is based on and recommends an in-depth conversation with these groups. We also recommend that the Commission's new structure is co-designed by mental health consumers.

In addition to the consultation session, this submission is also informed by data from a previous consultation with mental health consumers with lived experience of suicidality.

All references to 'Consumer' and 'lived experience' in this submission refer to mental health consumers with lived experience of mental health challenges and/or suicidality. We do not include family, carers, kin or the bereaved in our definition of lived experience as it appears in this report.

The NMHCA

The NMHCA is the national peak body representing mental health consumers. We work together with the state and territory consumer peak bodies to represent the voice of mental health consumers on national issues. We are the people experiencing mental health issues/distress; at the table advocating with government and policy makers; and working with a robust network of grassroots communities. More information is available on the NMHCA's website: nmhca.org.au.

Acknowledgement of Country

We acknowledge Aboriginal and Torres Strait Islander Peoples as the traditional custodians of the land on which we work and pay our respects to Elders past and present. Sovereignty was never ceded.

Contents

The NMHCA acknowledges the key points within the consultation documents provided by the Department of Health and Aged Care:

- identification of the need for a holistic collaborative approach (across the system) and attention to linkage between stakeholders;
- a search for solutions in respect to the reset of an effective National Mental Health Commission (NMHC) and National Suicide Prevention Office (NSPO) models that are inclusive of different stakeholders;
- little reference to and inclusion of mental health consumers noting the consultation process for generating perspectives about the NMHC and NSPO was not extensive enough and did not provide enough emphasis on the centrality of mental health consumers that is necessary for NMHC and NSPO optimal performance;
- emphasis on data driven planning and decision-making;
- understanding of the necessary distinction between NMHC and NSPO at the same time as recognising common interests; and
- recognition of the challenge and importance of the interface with state and territory bodies.

The NMHCA's submission is prepared in two parts. The first part considers the National Mental Health Commission, and the second part considers the National Suicide Prevention Office. A summary of the recommendations is provided at the end of this document on Page 16.

National Mental Health Commission

Concerns and issues of proposed structural options

Conflict of interest, barriers to independence, trust and transparency

The inherent conflict of interest with the proposed role of the Department of Health in the models offered is of universal concern to the consumer peak bodies, resulting in none of the structural options being acceptable.

The propositions put forward in the proposal fundamentally compromise the necessary independence of the National Mental Health Commission (NMHC). The narrow emphasis on financial efficiency at the expense of transparency, independence, and holding government to account for performance is a serious shortfall of the paper and proposed ways forward.

The lack of independence raised concerns around the potential politicisation of the NMHC and undue influence by any government/Minister of Health on public reporting and transparency – it is crucial for the NMHC to be politically neutral with a focus on system performance and holding governments to account. The NMHC must be allowed to report transparently and to be 'frank and fearless' in respect to its advice, and unequivocal in its focus on better outcomes for mental health consumers and improving performance of the mental health system.

The NMHC must be seen as a trusted body, particularly by mental health consumers, and its credibility and trustworthiness was seen to be seriously diminished by locating it in the Department.

Its visibility is also likely to be adversely affected if it were to sit partly or wholly within another government Department as was proposed – and this too is problematic.

The consultation document is silent on the impediments to performance associated with large bureaucracies as well as on the risks of locating the NMHC within the Department which raised questions around the Department's approach to the redesign of the NMHC and process for arriving at the options presented in the consultation paper. The fact that no option outside of locating the NMHC and NSPO within the Department was canvassed – and the conclusion drawn that a small entity could not be run efficiently in respect to its corporate functions – is understood to evidence a narrow focus and possibly a bias toward the status quo. This is in contradiction to the fundamental purpose of a Commission which is to support performance improvement and positive changes at a systems level i.e. to shift the status quo in a positive direction including through innovation and rebalancing knowledge, power and voice.

Gaps and weaknesses in the NMHC and NSPO consultation paper

1. *First Nations voice and self-determination*

The NMHC and NSPO consultation paper does not address the question of First Nations self-determination and the pathways by which First Nations communities may choose to work in relation to the NMHC and NSPO or their involvement in the process that is currently underway to reset the two entities.

2. *The importance of the mental health consumer voice, and diversity within the consumer movement*

As indicated, the paper does not adequately address the significance and importance of elevating lived experience voice, leadership and expertise within the NMHC and NSPO. Similarly, the paper is not strong in respect to the importance of embedding diversity lenses into the DNA of the entities.

3. *Fundamental gaps – holding to account and human rights*

There are two very substantial 'framing' gaps in the paper. The first is its failure to recognise the role of the NMHC in holding government to account for performance of the mental health system and the importance of transparent public reporting. Mental health consumers are fully aligned in the view that for the NMHC to be effective it needs to hold a clear accountability role. In addition, the paper did not mention benchmarks/standards for measuring performance nor the process by which they will be agreed.

The second substantial and worrying framing gap is that the paper did not reference the importance of a human rights perspective as a critical underpinning of a modern mental health system and tool for shifting and improving mental health services - systemically and individually.

4. *Does not take the opportunity to learn from or build on the previous NMHC or NSPO*

The paper does not:

- look at either the strengths of the former NMHC or NSPO, particularly the features and strengths that should not be lost or diminished in a new structure. The full range of factors that may have impeded the work of the NMHC in its core functions are not identified or explored. In our view, these include the burden of additional tasks and responsibilities referred to it on an ad hoc basis – and related scope creep – and the structural allocation of authority within the NMHC.

- draw on the design or potential lessons from equivalent Commissions or other arrangements in other jurisdictions or the research and development processes that sit behind them e.g. the

work of Victoria's Royal Commission.

- explore the potential structures for the NMHC as a (statutory) entity including the differences between a statutory office (secondary statutory structure) or a primary statutory body and the associated functional differences. This is an important point that has been omitted, as the former is more often focused on advice giving and the latter has a stronger focus on accountability. The NMHCA would find it useful to know more about the legal structure under which other national entities have been established (e.g. Aged Care Quality and Safety Commission, the Australian Law Reform Commission, the Human Rights Commission etc.) as compared with the purpose and rationale for the proposed entity for NMHC.

5. Independent oversight

The paper does not propose any model that would provide the NMHC with an oversight role and ensure the NMHC remains within the scope of its purpose and core functions while remaining independent and transparent. Given the risk to a government body charged with accountability and performance improvement at a systems level which fails to perform to necessary standards, it is important to have a failsafe mechanism in place.

6. The importance of language: stigma or discrimination

The NMHCA notes that the term stigma used in the paper does not adequately reflect the fact that discrimination – systemic, collective and individual – is experienced in institutions as well as across the population around mental health challenges. It is proposed that the term stigma is swapped out for the term discrimination. This language change is understood to be an important and necessary reframe that recognises the human rights context of discrimination.

Towards a design solution that supports independence, effectiveness and transparency

Entity legal structure, purpose and functions

The NMHCA proposes that the NMHC is established as an independent, primary statutory body with the following purpose/objectives and functions:

1. To act as a catalyst for evidence-based change across the mental health system

Functions would include:

- formulating policy and providing policy advice based on evidence;

- promoting and facilitating research, evaluation and innovation – building and using the evidence base; and
- promoting service system integration and improved service access.

2. *To hold government and other system actors accountable for mental health system performance and to promote transparency at all levels of the system*

Functions would include:

- monitoring mental health system performance;
- publicly reporting on the performance of the mental health system and key actors;
- establishing and coordinating an effective national data collection and analysis system; and
- establishing and overseeing an accessible complaint and redress mechanism modelled on international best practice.

3. *To shift the mental health system to a consumer lived experience-centred, culturally respectful and inclusive rights-based system that effectively addresses system level discrimination[1] and bias*

Functions would include:

- acting to ensure First Nations decisions and ways of being and doing are respected within the NMHC and across the mental health system
- negotiating/setting timelines to phase out coercive practices, such as seclusion, restraint, and involuntary treatment, replacing them with consumer-led, community-based alternatives
- promoting alignment of anti-vilification laws across the country, and
- promoting and supporting the elevation of mental health consumer expertise across the mental health system
- identifying and addressing system level bias leading to discrimination and/or adverse impacts on consumer and carer populations

[1] Community or system level role in respect to discrimination: the consultation session included a productive conversation around the NMHC role on the potential focus of its work in respect to discrimination. Options considered included:

- leading community education and campaigns
- facilitating common messaging and approaches to education and campaigns at state and territory and commonwealth levels
- focusing on systemically driven or influenced discrimination

It is broadly agreed that it is not the role of the NMHC to design and deliver community (public facing) anti-discrimination campaigns and education initiatives as it risks diluting the focus of the NMHC away from systemic change and there are appropriate, alternate bodies for campaigns and education. It is, however, noted that the NMHC focus on integration could usefully include promoting and actively supporting coordinated and well-aligned public health messaging nationally on mental health and anti-discrimination campaigns and education

4. *To promote mental health system integration and a national approach to mental health governance that aligns with international human rights standards*

Functions would include:

- promoting coherence across state and territory and commonwealth roles in mental health service delivery and service pathways;
- advising on, and monitoring and reporting on performance against Commonwealth/State agreements;
- promoting and supporting collaborative effort across diverse statutory and other influential stakeholders (including with Commissions in other jurisdictions) working with the principle of non-duplication[2]; and
- promoting human rights-based approaches to policy and to service design and practice.

Oversight of the NMHC

It is also seen to be necessary for the legal structure and requirements for the NMHC to include mechanisms that provide for oversight of the Commission and its independence – this may be through the Auditor General's Office and (or) a requirement for the NMHC to report to Parliament or through different but explicit and viable approaches. It is recognised that such mechanisms require further exploration and discussion.

NMHC role in elevating lived experience

The role of the NMHC in elevating mental health consumers was discussed and the NMHCA supports the following:

- designated lived experience Commissioners (with power);
- mental health consumer advisory bodies (potentially statutory);
- requirements for NMHC to seek advice from, consult with, and feedback to lived experience communities;
- designated lived experience staff roles at all levels;
- the option of codesigned and collaborative projects;
- sound relationships with the lived experience peak bodies; and

[2] The NMHC will work in areas and on issues where there is a risk of duplication of effort and/or role with other stakeholders/statutory bodies. This may include in respect to complaints and the Human Rights Commission, professional standards and Australia Health Practitioner Regulation Agency, Department of Health on mental health policy advice, peak bodies around consultation functions and, possibly, in relation to other matters and other stakeholders. It will be important for NMHC to be able to collaborate without compromising independence and for role boundaries and interface with other bodies to be clear and well-articulated.

- the provision of a budget that adequately covers the cost of lived experience expertise and contribution.

An organisation skills matrix

It was agreed that to be a robust Commission with capability matched to role, it will be necessary to develop and apply an organisation-wide skills matrix recognising that some skills and expertise will be required specifically at the governance and/or management levels and others may sit at the advisory or operational level.

Staffing and Governance of the NMHC

Governance model and responsibilities of Commissioners

It is agreed that the NMHC will ideally work from a corporate governance model with the Commissioners acting in an equivalent role to a board of governance. The Commissioners, within the role and functions of the NMHC, should be responsible for:

- overarching stewardship of the NMHC within the parameters provided for in legislation;
- strategic planning and setting annual priorities;
- budget setting and monitoring;
- approval of policy positions and formal advice to government; and
- approval of substantive publications/reports; and
- appointing (or co-appointing), ensuring supports for, and holding to account the Chief Executive/ Chief Executive Officer (CE/CEO) as well as delegations to the CE/CEO including for speaking on behalf of and representing the Commission.

Commissioner powers expertise

In addition to any advice provided by First Nations communities in respect to a First Nations Commissioner:

- at least one consumer and one “carer” (supporter, kin, family member) lived experience Commissioner must be appointed;
- Commissioner appointment processes must be transparent and follow due process; and
- Commissioners should be appointed in advance of the CE/CEO and Commissioners should be involved in a merit-based appointment process for the CE/CEO.

In summary the key message is that Commissioners should be empowered and accountable and that there should be a diversity of experience and expertise amongst Commissioners. The NMHC Commissioners will need to have the power to require access to data pertaining to performance.

Role of the Chief Executive and relationship with the Commissioners

The NMHC will require an experienced CE/CEO with sound knowledge of the mental health system and government/stakeholder relations, understanding of the diverse perspectives including lived experience perspectives, and preferably experience within a statutory body.

The CE/CEO will report to the Commissioners (likely though a lead Commissioner) and will hold responsibility for all aspects of the operations of NMHC and delegated responsibility for (some) communications and stakeholder relations.

It will be important that alongside the role differentiation between Commissioners and the CE/CEO that Commissioners and the CE/CEO work in a mutually respectful relationship in the best interests of the NMHC and offer complementary skills and expertise. The Commissioners and CE/CEO will, ideally, be jointly responsible for setting and modelling the desired organisation culture – one that is matched to the NMHC purpose and role.

Requirement to seek advice and feedback

The NMHCA advises that the NMHC Commissioners should be required to regularly seek advice including from the diversity of mental health communities and to also provide feedback to them on how their advice is used. This requirement should be included in the NMHC formation or guiding documents. In addition to mental health consumer advisory mechanisms there is likely to be a need for the NMHC to access technical advice in the human rights and ethics space, and on evidence and data gathering and analysis. It was noted that some flexibility on how advisory functions would operate could be useful and that advisory bodies/mechanisms do not replace broad-based consultation as a key method of engagement particularly with mental health consumer communities.

National Suicide Prevention Office

The NMHCA supports and believes in a social model approach to mental health services, and as such, proposes the Government start from scratch to focus on the systemic harm caused by incarceration (including in mental health services), lack of housing support and un(der) employment that directly relate to suicide. This is fundamentally opposed to National Suicide Prevention Office's (NSPO) remit focussing on preventing something "bad" from happening, which requires a risk mitigation way of working.

The NMHCA does not support the ongoing funding of the NSPO. The NMHCA would prefer to see government departments and the remodelled NMHC focus on reducing the systemic harms of suicide and supports working towards the use of a social model to reduce rates of suicide. To achieve this, governments need to focus on the causes of systemic harms including, but not limited to, the deficiency of housing support, incarceration by mental health services, under- and unemployment, and the lack of funding for alternative mental health support services.

As such, improvements should be made to initiatives such as the provision of safe and accessible housing, employment opportunities, and increased funding of unemployment benefits and Disability Support Pensions, which in turn would reduce the impact of many of the life stresses that may lead to psychological distress such as poverty, homelessness, chronic unemployment and underemployment.

This focus is fundamentally and directly opposed to the NSPO's focus on risk mitigation.

Until society funds and provides basic societal supports for the most vulnerable people in our communities, we believe the current suicide rate will persist.

Further, the recent National Suicide Prevention Plan Draft for Consultation (NSPS) left people with lived experience of suicidality disappointed. Despite the NSPO identifying its focus as using the 'social determinants of health as a preventive strategy'[3], the NSPS did not reflect this focus.

The NMHCA calls on the money currently used to fund the NSPO to be redirected and invested into social supports to address the systemic harms outlined below.

Incarceration

The incarceration of people with lived experience of suicide and suicidality needs to end.

[3] National Suicide Prevention Office update from Michael Gardner - Suicide Prevention Australia

Incarceration includes involuntary inpatient treatment, the use of restraints and seclusion as part of inpatient treatment and the use of restraints in long term care facilities.

The NMHCA reiterates the disappointment expressed by consumers that the NSPO's NSPS gave implicit support for restrictive practices, the result being those experiencing suicidality will continue to be punished and ostracized for experiencing what are common human thoughts and feelings[4]. This inclusion went against the UN-CRPD and its Optional Protocol, recent recommendations of the Royal Commission into Victoria's Mental Health System[5] and the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability[6] recommendations supporting the removal of seclusion and restraint in all treatment settings.

Housing

The NMHCA notes that employment and housing were part of the NSPS but also note that no budgets were provided to ensure this occurred. A blanket appeal for housing does not provide what people need and is not going to occur because of the NSPS. People not only require housing, but the security and safety that goes with it – the choice of where to live and who they have as neighbours.

Underemployment and unemployment

While some consumers see the push for increased employment as a response to make more revenue, other consumers believe that providing supports for people to obtain inclusive, open employment options in a range of settings with the required employer supports would assist in reducing suicide. To effectively increase employment opportunities, consumers need to be safe while searching for and undertaking employment. National anti-discrimination programs regarding suicidality are necessary, along with the workplace supports required for the consumer to maintain their employment alongside managing their health.

Consumers have expressed concern that an 'any job' policy could see the return of Australian Disability Enterprises (ADEs) scheme which goes against Recommendation 7 of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability[7].

Additionally, the supports provided to people who are unemployed and underemployed such as the

[4] https://being.org.au/storage/2024/07/Position-Statement-no.6-Suicidality-Suicide-Suicidism.pdf
[5] Royal Commission into Victoria's Mental Health System - final report | vic.gov.au, Accessed 21/10/2024
[6] Final Report - Complete Volume - formats | Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, Accessed 21/10/2024
[7] https://disability.royalcommission.gov.au/system/files/2023-11/Final%20report%20-%20Executive%20Summary%2C%20Our%20vision%20for%20an%20inclusive%20Australia%20and%20Recommendations.pdf

Disability Support Pension and the JobSeeker allowance, which many people with mental health challenges are receiving as they do not qualify for the Disability Support Pension, need to be raised above the poverty line so people can live their lives without the additional cost of living concerns.

Alternative supports

The funding of successful alternative supports for people experiencing suicidality that are not coercive would assist more people to reach out for help at times they need it. These services provide somewhere a person who is finding things tough (grief, sadness, anger, frustration) or experiencing suicidality without the fear of coercion.

There are a wide range of difficulties with the current piecemeal approach to the funding and running of Safe Havens and Alt2Su services, which guaranteed funding would relieve. Consumers from around Australia were interested in how Australian governments could ensure such services were available throughout Australia. These services are ripe for being authentically designed, run and managed by lived experience governance frameworks, yet some are being overrun by clinical governance.

Coercion and restrictive practices

Traditionally, suicide prevention has used coercion to stop people from dying. Through coercion, consumers are silenced, resulting in many consumers experiencing distress alone out of fear of ending up in the hands of police or clinicians. Our preferred approach is to have an open dialogue about suicide with other people with lived experience (which might include peer workers), so that suicidality can be openly spoken about along with options about why we might want to stay alive, without the fear of being punished or discriminated against.

As BEING Mental Health Consumers[8], New South Wales Peak Body for Mental Health Consumers articulated in their Position Paper on suicidality, people who experience suicidality are treated in an acute setting, with their care based on a risk equation. These risk-averse environments tend to violate the human rights of individual consumers, and yet were supported by the NSPS[9], p.39.

Harm minimisation instead of risk management

The NMHCA supports moving from a risk management focus to a harm minimisation focus

[8] https://being.org.au/storage/2024/07/Position-Statement-no.6-Suicidality-Suicide-Suicidism.pdf, Accessed 21/10/2024

[9] Advice on the National Suicide Prevention Strategy | National Suicide Prevention Office | National Mental Health Commission

emphasizing dignity of risk. Providing a person the right to live the life they choose, even if that choice involves some risk or does not fit into social norms is a human right under the United Nations Convention on the Rights of Persons with Disabilities (UN-CRPD)[10] to which Australia was one of the first signatories. Acute response services need to be able to provide harm minimisation supports such as agreeing to take a person in distress to an alternative support service instead of leaving them home or taking them to an emergency department.

Embedded lived experience

Finally, if it is decided that the NSPO will continue to be funded, the NMHCA would expect:

1. the embedding of lived experience so that the systems, structures, policies, processes, practices, programs and services become more responsive increasing trust, delivering improved outcomes to the improvement of lives through the avoidance of harm and the prioritization of healing[11]; and

2. the NSPO be a separate body to the NMHC, be moved out of the Department of Health, and report directly to a central office such as Prime Minister and Cabinet to ensure a whole of government approach as NSPO was originally conceived. This would allow the NSPO to provide an independent national perspective on suicide prevention, working across Departments, and recognising that no single government portfolio can undertake the breadth of actions required to reduce suicide or respond to distress.

[10] https://humanrights.gov.au/our-work/disability-rights/united-nations-convention-rights-persons-disabilities-uncrpd

[11] Hodges, E., Leditschke, A., Solonsch, L. (2023). The Lived Experience Governance Framework: Centring People, Identity and Human Rights for the Benefit of All. Prepared by LELAN (SA Lived Experience and Leadership Network) for the National Mental Health Consumer and Carer Forum and the National PHN Mental Health Lived Experience Engagement Network, Mental Health Australia, Canberra

Recommendations

National Mental Health Commission

1. The NMHC must
    - be an independent, primary statutory body;
    - be politically neutral focussing on system performance and holding governments to account with transparent reporting to improve the mental health system as a whole; and
    - not be located within the Department of Health (or any other Department) to ensure it is seen as credible and trustworthy by mental health consumers and to shift the status quo in a positive direction.
2. The NMHC should elevate the voice, leadership and expertise of mental health consumers.
3. The NMHC should be adequately funded to cover the cost of lived expertise and contribution and ensure it has:
    - at least one consumer lived experience Commissioner and senior decision making staff;
    - lived experience advisory bodies;
    - the ability to regularly seek advice including from the diversity of mental health communities and to also provide feedback to them on how their advice is used;
    - the option of codesign and collaborative projects; and
    - sound relationships with the lived experience peak bodies.
4. Commissioners must be empowered and accountable.
5. The NMHC must include a Human Rights perspective throughout the NMHC and the use of the word *discrimination* instead of *stigma* to reframe and recognise the human rights context of discrimination.

National Suicide Prevention Office

6. Disband the NSPO and use the funding to
    - promote activity to meet the key social determinants of suicide (housing, under- and unemployment);
    - move services and supports to focus on harm minimization, emphasising dignity of risk and limiting incarceration (involuntary inpatient treatment);
    - remove restrictive practices and seclusion from all care settings; and
    - support community based, non-clinical, non judgemental, non-risk-based supports that promote dignity of risk such as Recovery Colleges, Safe Havens and Alternatives to

Suicide (Alt2Su).

7. If the NSPO remains funded, it needs to be established as a distinct and separate organisation, with distinct and separate functions. The NSPO and NMHC could collaborate on areas of shared interest possibly including (some) joined up projects and data sharing arrangements. It was suggested that a Memorandum of Understanding would be a useful tool for describing a focused, collaborative and mutual benefit relationship with well-defined boundaries between the two bodies.

Recognition of Lived Experience

As a consumer lived experience-led organisation, the National Mental Health Consumer Alliance values the skill and expertise of consumers with lived experience. We pay tribute to those we have lost for the work that they have done to advocate for our rights. We acknowledge that we stand on the shoulders of giants who have paved the way for the rights we have today, and we will continue their work today and every day until the mental health system recognises and upholds our human rights. Nothing about us without us.

Submission prepared November 2024.
National Mental Health Consumer Alliance.
See nmhca.org.au for more information about the NMHCA.
For questions about this submission, please contact us at policy@nmhca.org.au.