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RESEARCH ARTICLE



Deinstitutionalisation and mental health activism in Australia: emerging voices of individuals with lived experience of severe mental distress, 1975–1985

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ABSTRACT

Starting in the 1960s, large numbers of patients in Australia's mental hospitals were released even though hardly any support services were available in the community. By the 1970s, a small number of psychiatrists, psychologists, social workers, volunteers, and consumer advocates were building alliances and coalitions with each other and with politicians and health bureaucrats to realise change. Using archival records and interviews as sources, we analyse how, in the early 1980s, Simon Champ, Meg Smith, and Janet Meagher, three pioneering Australian consumer advocates, started to speak out and influence discussions about mental health policy. They were also invited to join boards of non-government organisations in mental health care, foreshadowing later developments. Today, the participation of consumers of mental health care in mental health services is taken for granted and mandated, and most services have consumer advisory groups.

KEYWORDS

Community mental health; New South Wales; non-government organisations; consumer advocates

Introduction

Recently, artist Simon Champ reflected on his stay at Rozelle (Psychiatric) Hospital in Sydney in 1981. He recalled 'being herded into the main showers' and seeing 'writing, drawings in shit on the walls', which made him realise that 'people were desperate to express themselves in whatever way they could'.¹ After he was discharged, he wondered 'why people wound up there [Rozelle] ... and how it might be different'.² The same year, Meg Smith, a feminist psychologist associated with the Leichhardt Women's Community Health Centre, also spent time in Rozelle after experiencing a psychotic episode. She relates that 'it was like being thrust back 20 years ... coming from a polit-

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¹Simon Champ, in Re:Minding Histories, 'Mental Health from the Ground Up: Pioneering Consumer Activists Who Changed Mental Health', 11 September 2021, 00:59, <https://www.youtube.com/watch?v=eh0Cx3C9Cz0>, accessed 1 December 2021.

²Ibid.

ically active, feminist health approach, to the medical model of psychiatry', which viewed mental illness as an exclusively biological phenomenon.³ When Janet Meagher reflected on the more than 10 years she spent in mental hospitals around Sydney (1969–1980), most of which had been on the back wards of Gladesville Hospital, she referred to this decade as her 'university course in what not to do, and how not to do it in mental health'.⁴ 'What it taught me, and the qualification I got' at this 'brilliant university', she continued, 'was to be totally anti-institution of any description, in any context, for any vulnerable person. And I think most human beings are vulnerable'.⁵

For Simon Champ, Meg Smith, and Janet Meagher, the deeply disturbing experiences each of them had as individuals confined to mental hospitals motivated them to become mental health advocates. Around 1980, mental health care in New South Wales was undergoing fundamental changes. Under the policy of deinstitutionalisation that had commenced in 1965, many individuals diagnosed with severe mental illness had been discharged from the state's mental hospitals while alternative forms of care in the community had only been established to a very modest extent. Consumer advocacy had not yet developed. Yet all three are currently referred to as 'mad elders' or the 'elders of the consumer, consumer/survivor, or ex-patient movement' in Australia, indicating that they forged new roles and established effective alliances to realise change.⁶ In 1980, however, such roles did not yet exist. Meagher, for example, insists that 'we didn't do advocacy at all, we were not doing advocacy'.

We weren't public speakers, we were not experienced lobbyists or advocates, we were ourselves ... We were the advocacy, we were what was happening, we were what had to change. We could show people from our own experience and those of our peers: this is where we have to start. People need to be respected. Because if you have a psychiatric diagnosis or a series of symptoms that does not make you non-person.⁷

For all three, confinement in mental hospitals had greatly exacerbated the terrifying burden of their mental distress. Consequently, all three began to contemplate how care could be different, and what they could do to realise change.

In the 1970s, mental hospitals were increasingly considered unsuitable places for treating individuals with mental illness while public concern (at times even outrage) over their shortcomings increased. In 1980, the Chelmsford scandal broke: the ABC reported that psychiatrist Harry Bailey was using his controversial deep sleep treatment method at Chelmsford Private Hospital in Sydney, which eventually led to the deaths of at least 25 patients.⁸ The reputation of psychiatry consequently suffered. A small number of civic associations had been advocating for changes in mental health care while establishing viable alternatives to mental hospital-based treatments. When individuals with a lived experience of mental illness and institutionalisation started to speak out by joining debates about the future of mental health care, they found a receptive

³Meg Smith, 'Interview', by Paul Rhodes and Gemma Lucy Smart, *Oral History Project on the History of Community Mental Health in Australia*, 5 August 2020, 34:38.

⁴Janet Meagher, 'Interview 1', by ARC Research Group on the History of Community Mental Health in Australia, *Oral History Project on the History of Community Mental Health in Australia*, 8 July 2020, 38:35.

⁵Ibid.

⁶For example, Holly Kemp, in *Re:Minding Histories*, 'Mental Health from the Ground Up', 01:12.

⁷Janet Meagher, in *Re:Minding Histories*, 'Mental Health from the Ground Up', 35:38.

⁸Brian Bromberger and Janet Fife-Yeomans, *Deep Sleep: Harry Bailey and the Scandals of Chelmsford* (New York: Simon & Schuster, 1991).

audience among the members of these associations. We trace the emergence of the voices of pioneering consumers of mental health care, examine the strategies they followed to make themselves heard and the alliances they established to realise change. We track these voices from the 1970s, when they were generally silenced, unheard, and ignored, to the late 1980s, foreshadowing the time when consumer representatives and consumer advisory groups became standard elements in policy making and peer workers essential employees in mental health care. The appointment in late 2021 of consumer activist Mary O'Hagan as the first executive director of lived experience at the Mental Health and Wellbeing Division of Victoria's Department of Health, following a key recommendation of the Royal Commission into Victoria's Mental Health System, indicates how much has changed over the past 40 years.⁹

In this article, we argue that deinstitutionalisation, innovative initiatives in community mental health by civic associations, and a general enthusiasm for social reform, in particular the emergence of consumer activism, provided an optimal context for former patients of mental hospitals to have their voices heard and participate in debates on how to change and optimise mental health services. We focus specifically on Sydney during the period from the mid-1970s to the mid-1980s, partly because each Australian state followed a distinctive pattern of deinstitutionalisation and formation of community-based mental health services, and partly because initiatives in NSW preceded those in other states. We focus on three emerging leaders in the early years of the Australian consumer movement, and outline their involvement with local community mental health initiatives and the civic associations that had initiated them. We highlight the pivotal role they played in effecting changes in the way mental health care is organised and provided.

Deinstitutionalisation, patients' voices and the historiography of mental health

Historians became interested in the history of psychiatry in reaction to the anti-psychiatry movement, which gained force during the late 1960s; they were particularly inspired by the writings of Michel Foucault, Erving Goffman, and Thomas S. Szasz.¹⁰ Their work focused almost exclusively on lunatic asylums and mental hospitals, which served as custodial institutions for individuals who had been certified as insane, which deprived them of their legal rights and declared them as incompetent to conduct their own affairs. These involuntary patients were at times subjected to harsh but ineffective treatments and restraint, while at other times they suffered from benign neglect, thereby providing apposite illustrations of the repressive and at times brutal force of

⁹Mary O'Hagan Appointed to Key Lived Experience Leadership Reform Role', Mental Health Reform: Victoria State Government, updated 12 November 2021, <https://www.mhrv.vic.gov.au/news/mary-ohagan-appointed-key-lived-experience-leadership-reform-role>, accessed 12 November 2021; Penny Armytage et al., *Royal Commission into Victoria's Mental Health System*, 5 vols. (Melbourne: Victorian Government Printer, 2021).

¹⁰Michel Foucault, *Madness and Civilization: A History of Insanity in the Age of Reason*, trans. Richard Howard (New York: Vintage, 1988 [1961]); Erving Goffman, *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates* (Hammondsworth, UK: Penguin, 1968); Thomas S. Szasz, *The Myth of Mental Illness: Foundations of a Theory of Personal Conduct* (New York: Hoeber-Harper, 1961); Thomas S. Szasz, *The Manufacture of Madness: A Comparative Study of the Inquisition and the Mental Health Movement* (Syracuse, NY: Syracuse University Press, 1970).

psychiatry and its role in segregating and disciplining individuals who failed to meet social expectations.¹¹ In the often-quoted words of Foucault, the European Enlightenment was accompanied by the great confinement, which saw the ‘mad’ – the idle, unproductive, and irrational – confined in newly erected institutions, thereby effectively silencing them. In this ‘rupture’, he continued, the ‘language of psychiatry’ developed: ‘a monologue of reason *about* madness’.¹² To break this monologue and make the voices of the ‘mad’ heard, asylum historians employed approaches from social history, which aim to shift the focus of historical inquiry away from the elite, the privileged, and ‘great man’ towards the experiences of labourers, farmers, the poor, and other non-privileged and marginalised people.¹³ Social historians aim to make silenced voices audible by reading legal proceedings, patient records, newspaper articles, and other sources ‘against the grain’.

The intense focus on asylums has led to a relative neglect of various forms of care and support provided outside their walls.¹⁴ Already during the asylum and mental hospital eras, most of the ‘mad’ lived outside their walls and never came to the attention of the authorities or physicians at all.¹⁵ The mental hygiene movement, which originated in North America in the first decade of the twentieth century, advocated for the establishment of mental health services outside mental hospitals, including Child Guidance Clinics, outpatient clinics, treatment programs in prisons, school counselling, and more.¹⁶ The ideas of mental hygienists were keenly received in Australia as well. After World War II, psychologists, social workers, psychiatric nurses, and occupational therapists joined psychiatrists providing care and treatment, initially in mental hospitals, and later in various other settings. Consequently, a greater variety of professional perspectives and treatment modalities became available, as well as occasional professional rivalries. Yet the most important change in mental health care during the twentieth century was the process of deinstitutionalisation, which commenced in Australia in the 1960s.¹⁷

To investigate the history of ‘madness’, the process of deinstitutionalisation, which moved inmates of mental hospitals to a variety of locations in the community, requires historians to take a broader range of sources into account, including printed sources,

¹¹See, for example, Nikolas Rose, *The Psychological Complex: Social Regulation and the Psychology of the Individual* (London: Routledge & Kegan Paul, 1985).

¹²Michel Foucault, *History of Madness*, trans. Jonathan Murphy and Jean Khalfa (New York: Routledge, 2006), xxviii.

¹³A major influence in social history was E. P. Thompson, *The Making of the English Working Class* (London: Victor Gollancz, 1963). In the history of medicine, this approach was encouraged by Roy Porter; see his ‘The Patients’ View: Doing Medical History from Below’, *Theory and Society* 14 (1985): 175–97.

¹⁴See, for example, David J. Rothman, *The Discovery of the Asylum: Social Order and Disorder in the New Republic* (Boston: Little Brown, 1971); Andrew Scull, *Museums of Madness: The Social Organization of Insanity in Nineteenth-Century England* (London: Allen Lane, 1979); Michael MacDonald, *Mystical Bedlam: Madness, Anxiety, and Healing in Seventeenth-Century England* (New York: Cambridge University Press, 1981); Roy Porter, *Mind-Forg’d Manacles: A History of Madness in England from the Restoration to the Regency* (London: Athlone, 1987).

¹⁵For various examples from the UK and Ireland see David Wright and Peter Bartlett, *Outside the Walls of the Asylum: The History of Care in the Community, 1750–2000* (London: Athlone, 1999).

¹⁶Hans Pols, “Beyond the Clinical Frontiers”: The Mental Hygiene Movement in the United States’, in *International Relations in Psychiatry: Britain, Germany, and the United States to World War II*, ed. Volker Roelcke, Paul J. Weindling and Louise Westwood (Rochester, NY: Rochester University Press, 2010), 111–33.

¹⁷The process of deinstitutionalisation and its consequences for the mental health professions and individuals with a lived experience of distress has not received sufficient attention by historians. But see, for example, Andrew T. Scull, *Decarceration: Community Treatment and the Deviant, A Radical View* (New York: Polity Press, 1984); Despo Kritsotaki, Vicky Long and Matthew Smith, ed., *Deinstitutionalisation and After: Post-War Psychiatry in the Western World* (Basingstoke, Hampshire: Palgrave Macmillan, 2016).

grey literature, and interviews, which reflect the voices of the ‘mad’ in a much more direct way than patient records. Despite these advances in the historiography of mental health, we remain conscious of various forms of post-modern critique, which has questioned the extent to which anyone can truly represent the opinions, feelings, and actions of others, as the attempt to talk ‘on behalf’ of someone always involves act of epistemic violence.¹⁸ Following Gayatri Chakravorty Spivak’s ideas, we argue that, of course, the ‘mad’ can speak – and they have spoken repeatedly with highly articulate voices.¹⁹ It is not possible to fully resolve the postmodernist critique of representation and epistemic violence, but there are ways to attenuate its effects. In our research project on the history of community mental health in Australia, we have invited peer workers and consumers of mental health care to become part of our research team. We have adopted the principles of co-production, where ‘mad’ voices are invited to formulate research goals, the topics to be investigated, the questions to be asked, and the ways they should be addressed.²⁰ During our interviews, we have invited interviewees to co-define the relevant questions and the topics they think are essential, and asked them how they wish to be represented. This approach decentres the authorial voices of historians and leads to much richer insights.

Mental hospitals and deinstitutionalisation in NSW

In Australia, for most of the twentieth century, general and mental health services were organised and funded separately. While the federal government contributed funding and support for state-run public hospitals, until the 1970s the primary responsibility for mental health services lay with state governments. Before then, mental health services were almost exclusively provided through long-term institutionalisation in state mental hospitals, and most patients were there involuntarily. Individuals could only be admitted after they had been declared insane by a legal process called certification, which indicated that they could not be held responsible for their actions and were not able to manage their own affairs. Certification generally occurred when individuals had been violent, were deemed a social nuisance or a danger to themselves or others, or were no longer able to take care of themselves.²¹ Certified individuals were disqualified from voting and were not entitled to receive the Commonwealth invalid pension. For most of the twentieth century, Australian mental hospitals were severely overcrowded while the quality of care was frequently criticised. The *Medical Journal of Australia* regularly brought the conditions in mental hospitals to the attention of its readers. An editorial in 1954 stated that those who were aware of the conditions in NSW mental

¹⁸See, for example, Kristie Dodson, ‘Tracking Epistemic Violence, Tracking Practices of Silencing’, *Hypatia* 26, no. 2 (2011): 236–57.

¹⁹Gayatri Chakravorty Spivak, ‘Can the Subaltern Speak?’, in *Marxism and the Interpretation of Culture*, ed. Cary Nelson and Lawrence Grossberg (Urbana, IL: University of Illinois Press, 1988), 271–313.

²⁰Co-production has become an innovative approach in mental health research. See, for example, Cath Roper, Flick Grey and Emma Cardogan, ‘Co-Production: Putting Principles into Practice in Mental Health Contexts’ (2018), https://healthsciences.unimelb.edu.au/__data/assets/pdf_file/0007/3392215/Coproduction_putting-principles-into-practice.pdf, accessed 1 December 2021.

²¹Stephen Garton, *Medicine and Madness: A Social History of Insanity in New South Wales, 1880–1940* (Sydney: New South Wales University Press, 1988), 18–20, 28.

hospitals would ‘surely feel inclined to resort to sackcloth and ashes’.²² The following year, psychiatrist Alan Stoller concluded in a national report on Australia’s mental health facilities that ‘the function of most [mental] hospitals had been distorted almost beyond recognition, and essential services to patients had been eliminated’.²³ Bill Barclay, former director of the state’s psychiatric services, recalled the ‘Dickensian conditions’ in most mental hospitals in the 1950s.²⁴ Although improvements were urgently called for, it does not appear that these calls were heeded.

In the mid-1950s, the introduction of new psychopharmacological treatments provided some reasons for optimism. Like their counterparts elsewhere in the western world, Australian psychiatrists eagerly experimented with chlorpromazine (‘Largactil’) and reserpine (‘Serpasil’) on mental hospital populations and reported highly promising results. Because of these new medications, they stated, patients had become much more manageable while the most florid symptomatic expressions had disappeared.²⁵ One psychiatrist optimistically argued that up to 20% of patients might eventually be discharged.²⁶ At this time, lithium became available for the treatment of bipolar disorder as well.²⁷ Yet unlike their counterparts in the United States, psychiatrists and health officials did not view the availability of these new treatments as a justification for full deinstitutionalisation.²⁸ From 1958, when a new Mental Health Act was adopted in NSW, policymakers hoped to transform the state’s mental hospitals into therapeutic institutions by enabling access to voluntary admissions while discharging patients with dementia and chronic schizophrenia.²⁹ Between 1965 and 1975, the number of mental hospital beds decreased by 40%, from 12,400 to 7,400. The outflow of these patients changed the nature of mental hospital populations over the next two decades, which now focused on treating less serious forms of mental disorder.³⁰ According

²²The Mental Hospitals Services of New South Wales [Editorial], *Medical Journal of Australia* 1, no. 9 (27 February 1954): 819–20.

²³Alan Stoller and K. W. Arscott, *Report on Mental Health Facilities and Needs of Australia* (Canberra: Government Printing Office, 1955), 162.

²⁴Rob Barclay and Philip Mitchell, ‘Doctor Helped Psychiatry Shed Dickensian Reputation [Obituary Bill Barclay, 1930–2020]’, *Sydney Morning Herald*, 23 July 2020, <https://www.smh.com.au/national/nsw/doctor-helped-psychiatry-shed-dickensian-reputation-20200714-p55buz.html>, accessed 1 December 2021.

²⁵See, for example, David R. Morgan, ‘The Combined Use of Chlorpromazine and Reserpine in the Treatment of Chronic Mental Illness: A Preliminary Report’, *Medical Journal of Australia* 2, no. 3 (1955): 77–80; and an editorial in the same issue: ‘Chlorpromazine, Reserpine and Chronic Mental Illness [Editorial]’, *Medical Journal of Australia* 2, no. 3 (16 July 1955): 99–101.

²⁶David R. Morgan, ‘The Use of Reserpine, Chlorpromazine and Allied Drugs in Medicine and Psychiatry’, *Medical Journal of Australia* 1, no. 25 (1956): 1029–35.

²⁷John F.J. Cade, ‘Lithium Salts in the Treatment of Psychotic Excitement’, *Medical Journal of Australia* 2, no. 10 (1 Sept 1949): 349–52. See also Greg De Moore and Ann Westmore, *Finding Sanity: John Cade, Lithium and the Taming of Bipolar Disorder* (Sydney: Allen & Unwin, 2016).

²⁸This connection is explicitly made in Edward Shorter, *A History of Psychiatry: From the Era of the Asylum to the Age of Prozac* (New York: John Wiley, 1997), 246–55. The most outspoken critique of this argument is provided by Andrew T. Scull; see his ‘The Decarceration of the Mentally Ill: A Critical View’, *Politics and Society* 6, no. 2 (1976): 173–212; and Scull, *Decarceration*.

²⁹See, for example, the policy document by C. J. Cummings: Health Advisory Council of NSW, ‘Interim Report on Preventive Psychiatry in New South Wales’, *Medical Journal of Australia* (12 August 1961): 280–2. See also the annual reports by William A. Barclay, the director of state psychiatric services of New South Wales: William A. Barclay, *Annual Report of the Director of State Psychiatric Services for the Year Ended 30 June 1963* (Sydney: Parliament of New South Wales, 1964) and following years.

³⁰In 1975, the number of ex-psychiatric patients housed in nursing homes was equivalent to 40% of the total number of beds in mental hospitals; 24% of all nursing home patients were ex-psychiatric patients or individuals with intellectual impairment. Concetta Rizzo et al., *A Study of Nursing Homes in New South Wales* (Sydney: Health Commission of New South Wales, 1976), 1.

to the NSW Health Commission statistician Nick Shiraev in 1979, 'the proportion of neurotic re-admissions has increased to the point where it is the main cause of re-admissions and total admissions'.³¹

Apart from enhancing the therapeutic efficacy of mental hospitals and decreasing the average length of institutionalisation, cost-shifting played a considerable role in the discharge of psychiatric patients. Many discharged elderly patients with dementia were transferred to nursing homes, which received federal funding. Discharged patients with chronic schizophrenia were eligible for social security benefits for the aged and 'invalid'; many moved to boarding houses and paid the fees from their new (federal) pensions.³² After 1965, this process was accelerated with new federal subsidies to nursing homes.³³ Unfortunately, conditions in boarding houses and nursing homes were not very good. Visitors observed that, 'apart from poverty, the main patient problems were loneliness and boredom; many patients spent their time just staring into space'.³⁴ The *Medical Journal of Australia* again struck a critical note, stating that it was deplorable that patients had been transferred to less desirable institutions. It exhorted psychiatrists to recognise that their 'professional responsibility for discharged patients does not end at the gates of the asylum'.³⁵ In its opinion, psychiatrists were responsible to provide treatment and care to all individuals with mental illness, irrespective of whether they were in mental hospitals or elsewhere.

The poor state of the mental hospitals in NSW was indicated by the opinions of former mental hospital inmates. Most indicated that they were happier in nursing homes and boarding houses, and did not want to return to a mental hospital because they now enjoyed more freedom.³⁶ Their counterparts in mental hospitals 'resented what they saw as an unnecessarily restrictive and authoritarian ward regime'.³⁷ These insights were based on systematic research which surveyed the opinions of individuals in mental hospitals, boarding houses, and nursing homes in the 1970s. The decision to interview them was controversial within the research team and provoked long discussions, because it was thought that such data would be unreliable.³⁸ For people discharged from hospital, there were very few community-based facilities to support them. This started to change from the mid-1970s, a time of heady activism and the rapid development of initiatives in community mental health.

³¹N. Shiraev, *Psychiatric Statistics II: Recent Trends in Public Psychiatry in New South Wales* (Sydney: Health Commission of NSW, 1979), 31. See also C. J. Cummins, *A History of Medical Administration in New South Wales, 1788-1973* (Sydney: Health Commission of NSW, 2003).

³²N. Shiraev, *Psychiatric Statistics I: Notes Towards a History of Public Psychiatry in New South Wales* (Sydney: Health Commission of NSW, 1979), 23; Shiraev, *Psychiatric Statistics II*, 13-4, 18-21.

³³Rizzo et al., *Nursing Homes NSW*, 34.

³⁴From Ingrid Reynolds and A. Fleming, *A Study of Nursing Homes* (Sydney: Gladesville Hospital, 1973), 44; cited in Rizzo et al., *Nursing Homes NSW*, 44.

³⁵'The Mental Hospitals of New South Wales [Editorial]', *Medical Journal of Australia* [MJA] (18 March 1939): 797.

³⁶Ron Barr and Gordon Parker, 'The Effects of Discharge on Long-Stay Psychiatric Hospital Patients', *Australian & New Zealand Journal of Psychiatry* 9, no. 1 (1975): 47-9; Gordon Parker and Ron Barr, 'The Exodus of Long-Stay Psychiatric Patients', *Medical Journal of Australia* 62, 1, no. 26 (1975): 801-3. See also Maree Flaherty, Bruce Flaherty, and Gordon Parker, 'A Comparative Study of Long-Stay Psychiatric Patients Discharged to Boarding Houses and Sattelite Houses', *Australian & New Zealand Journal of Psychiatry* 11 (1977): 193-5.

³⁷Laurie Young and Tina Ermoll, *The Experience of Psychiatric Hospitalization: An Evaluation Based on Interviews with Inpatients* (Sydney: Health Commission of New South Wales, 1975), 18.

³⁸Matina Pentes, 'Interview', by Roslyn Burge and Hans Pols, *Oral History Project on the History of Community Mental Health in Australia*, 5 November 2020, 03:11. Note that Tina Ermoll and Matina Pentes are the same person.

The Whitlam government and community mental health in NSW

The 1970s was a period of outspoken and at times radical social activism in Australia, witnessing massive protests opposing Australia's involvement in the Vietnam War, increasingly combative feminist and gay rights movements, a growing awareness of environmental issues, and activism around Aboriginal land rights.³⁹ In November 1972, the Labor party led by Gough Whitlam won the federal election. During the three years it was in power, it initiated several significant changes. Its Australian Assistance Plan, for example, aimed to empower community organisations by stimulating citizens' participation in local welfare initiatives.⁴⁰ The Whitlam government also introduced Australia's universal health insurance program, Medibank (today: Medicare), and the Community Health Program, which financed local primary health care initiatives such as community nurses, women's refuges, and services for geriatric patients.⁴¹ In 1973, it introduced a funding scheme for initiatives in community mental health, which marked the first time the Commonwealth funded mental health care. Mental hospitals, however, remained the responsibility of the states.⁴² These health programs were guided by the conviction that 'the needs of communities will be best served if there is real community participation in the decision-making process' in the management of health services.⁴³ They led to increases in the number of non-hospital health facilities across the country. By early 1976, more than 700 community health projects had been funded, although a lack of clear guidelines led to a diverse and at times even fragmentary array of projects.⁴⁴

The social activism of the 1970s was also expressed in an increasingly outspoken critique of Australia's rather traditional and at times paternalistic health care system. The Medical Consumers Association (MCA) was established in Melbourne in July 1973, guided by the conviction that patients should be actively involved in treatment decisions and health care delivery. Bill Hayden, the Minister for Social Security, attended the Association's first meeting and gave a rousing speech.⁴⁵ The MCA published the journal *Patient Power*, through which it advocated grassroots and rights-based approaches to health. In 1976, the NSW branch was established and shared office space with the Australian Consumers Association, publisher of the journal *Choice*. The MCA applied the latter's approach to health care, supporting the rights of patients in the medical marketplace.⁴⁶ At the same time, psychiatry came under increasing

³⁹Michelle Arrow, *The Seventies: The Personal, the Political and the Making of Modern Australia* (Sydney: NewSouth, 2019).

⁴⁰For a discussion of the Australian Assistance Plan in the Hunter-Newcastle Region and broader reflections on regionalism, see Erik Eklund, Melanie Oppenheimer and Joanne Scott, "'Developing a Community Soul': A Comparative Assessment of the Australian Assistance Plan in Three Regions, 1973-1977", *Australian Journal of Politics and History* 62, no. 3 (2016): 419-34.

⁴¹Anne-Marie Boxall and James Gillespie, *Making Medicare: The Politics of Universal Health Care in Australia* (Sydney: UNSW Press, 2013). See also Frances Baum, Denise Fry and Ian Lennie, ed., *Community Health: Policy and Practice in Australia* (Sydney: Pluto Press for Australian Community Health Association, 1992).

⁴²Mental Health and Related Services Assistance Act 1973, No. 154 of 1973 (assented to 27 November 1973).

⁴³Hospitals and Health Services Commission, *Review of the Community Health Program: Report from Hospitals and Health Services Commission* (Canberra: Australian Government Publishing Service, 1976), 21.

⁴⁴Hospitals and Health Services Commission, *Review*, 2, 88.

⁴⁵"Medical Consumers" Enter Public Health Fray', *Tribune* (Sydney), 31 July 1973.

⁴⁶Jan Patterson, 'Consumers and Complaints Systems in Health Care' (PhD thesis, University of Adelaide, 1996), 94, 96-7.

critique.⁴⁷ In August 1973, a conference with the theme ‘Psychiatry and Liberation Movements’ was convened by Neil McConaghy, Australia’s leading proponent of conversion therapy.⁴⁸ Although Women’s Liberation, CAMP (Campaign Against Moral Persecution, a gay rights group), and Gay Liberation boycotted the conference, they were present when McConaghy attempted to give his paper. Mayhem broke out when activists threw rotten eggs to express their displeasure.⁴⁹ Radical psychologist Robin Winkler had already published a booklet criticising conversion therapy the year before.⁵⁰ In 1974, Winkler had replicated American David Rosenhan’s pseudo-patient experiment and had student-researchers pretend to experience severe mental distress to get admitted to Australian mental hospitals, only to find that it could take weeks before they were discharged.⁵¹ Winkler had also sent pseudo-patients to general practitioners with presentations of depression; most of them were prescribed medication while psychotherapy was rarely mentioned.⁵² Winkler’s studies infuriated psychiatrists and physicians, judging by the many irate letters to the *Medical Journal of Australia* and the editor’s elaborate justification for publishing Winkler’s studies.⁵³ For at least one of his students, who had been an in-patient in a psychiatric clinic, a discussion of these experiments led to her feeling ostracised because of her experience of institutionalisation. Meg Smith recalled in 2021 that Winkler asked his students ‘who has had experience in a mental hospital?’

So people put up their hands and say, you know what, I worked as a psychiatric nurse again, you know, during the holidays, etc., etc. And I put up my hand and said: ‘Yeah, well, I spent three months in a psychiatric clinic in Newcastle.’ And there was dead silence. And Robin just flicked on to somebody else and changed the topic. And I thought, what the hell just happened here? ... Robin, to his credit came up to me and said: ‘What’s up?’ You know, clearly something was up.⁵⁴

Even in the classroom of one of the most radical psychologists in Australia, the voice of a former patient in a psychiatric clinic led to a distinct sense of discomfort.

The NSW Association for Mental Health

‘The abusive regime [at Gladesville Hospital] was monstrous beyond belief. ... I thought, if I ever get out of here, this stuff is going to drive me, be my outboard motor. It’ll keep me going when everything else falls over, because I am not going to let them

⁴⁷Paul Laffey, ‘Antipsychiatry in Australia: Sources for a Social and Intellectual History’, *Health & History* 5, no. 2 (2003): 17–59.

⁴⁸For the proceedings see N. McConaghy, *Liberation Movements and Psychiatry* (Sydney: Ciba-Geigy, 1974).

⁴⁹Sasha Soldatow, ‘Psychiatric Liberation’, *Camp Ink* 3, no. 6 (1974): 6–7.

⁵⁰Robin Winkler, *A Critique of Aversion Therapy for Homosexuals* (Sydney: Sydney Gay Liberation, 1972).

⁵¹Robin Winkler, ‘Research into Mental Health Practice Using Pseudopatients’, *Medical Journal of Australia* 61, 2, no. 11 (1974): 399–403. Winkler replicated Rosenhan’s experiments as reported in D.L. Rosenhan, ‘On Being Sane in Insane Places’, *Science New Series* 179, no. 4070 (19 January 1973): 250–58. It has recently been revealed that Rosenhan’s experiment was (mostly) fraudulent: see Susannah Cahalan, *The Great Pretender: The Undercover Mission that Changed Our Understanding of Madness* (New York: Grand Central Publishing, 2019).

⁵²Alan Owen and Robin Winkler, ‘General Practitioners and Psychosocial Problems: An Evaluation Using Pseudopatients’, *Medical Journal of Australia* 61, 2, no. 11 (14 Sept 1974): 393–98. The same issue contained a strongly worded editorial condemning both articles as unscientific: Neil McConaghy, ‘Pseudopatients and Evaluation of Medical Practice [Editorial]’, *Medical Journal of Australia* 61, 2, no. 11 (1974): 383–85.

⁵³McConaghy, ‘Pseudopatients’.

⁵⁴Smith, in *Re/Minding Histories*, ‘Mental Health from the Ground Up’, 09:59.



Image 1. March by several mental health groups from Belmore Park at Central Station to St Andrew's Cathedral during mental health month, October 1989. Simon Champ is holding the banner (on the right). Photo courtesy of One Door Mental Health.

get away with it'.⁵⁵ This is how Janet Meagher discussed her anger at conditions at Gladesville Hospital, where she spent several years in a long-stay ward, and her determination to do everything in her power to change mental health services in Australia.⁵⁶ In 1969, following an experience of severe mental distress, Meagher was admitted to a private mental hospital where she was diagnosed with paranoid schizophrenia. This was the first of what turned out to be several stays in various mental hospitals. She was eventually admitted to Gladesville Hospital, where she experienced considerable trauma by experiencing and witnessing many acts of physical, sexual, and emotional abuse, perpetrated 'out of sight, out of mind' behind the locked doors.⁵⁷ At the time, such abuse remained unreported and unpunished as accounts by mentally ill persons were considered untrustworthy and invalid.⁵⁸

In 1979, to her own surprise, Meagher and several other patients were placed in a 'Domestic Retraining' project in preparation for discharge. She recalled her unfamiliarity with the world 'outside' after a decade of institutionalisation: 'Things that happened

⁵⁵Meagher, 'Interview 1', 38:35.

⁵⁶Janet Meagher, 'Witness Statement of Janet Meagher AM', *Royal Commission into Victoria's Mental Health System* (1 July 2019). See also Bianca Hall, "'There Were Monsters': Mental Health Advocate Pleads for Real Change', *The Age*, 3 July 2019, <https://www.theage.com.au/national/victoria/there-were-monsters-mental-health-advocate-pleads-for-real-change-20190703-p523om.html>, accessed 1 December 2021.

⁵⁷Abuse in mental health facilities has been documented in Jane Davidson, *Every Boundary Broken: Sexual Abuse of Women Patients in Psychiatric Institutions* (Sydney: Women and Mental Health, 1997).

⁵⁸Meagher, 'Interview 1', 38:35.

... out in the wide world, such as bank cards, pieces of plastic with which you could buy things, we didn't know about that, and ABBA and things like that'.⁵⁹ When she expressed her anger about conditions at Gladesville to her psychiatrist, the latter urged her to become a mental health activist because 'the only people who can bring about change are people like you'.⁶⁰ As a patient, rather than a mental hospital employee, her psychiatrist thought she was ideally placed to provide insights into what went on there. Following her psychiatrist's advice, Meagher began to learn everything she could about mental health services, their legislative basis, professional codes of conduct, health policies, and ways that change could be realised.⁶¹ She began her life's work of changing the system from within and attempting to fulfil her goal that consumers of mental health services will have 'no risk of being emotionally damaged by their treatment, by insensitive policies or by inappropriate personnel'.⁶²

At the time, several civic associations were involved in advocating changes in mental health systems and providing support services. The NSW Association for Mental Health was founded as the NSW Council for Mental Hygiene in 1932; in the 1970s, it became increasingly concerned with the fate of individuals who had been discharged from mental hospitals and advocated for initiatives in community mental health.⁶³ In 1975, the Association of Relatives and Friends of the Mentally Ill (ARAFMI) was founded by Margaret Lukes after she found that families and carers needed information and support when they faced the challenging and at times frustrating task of taking care of relatives who had been discharged from mental hospitals. Family members were generally ignored by physicians and mental health professionals, and excluded from discussions about treatment and care.⁶⁴ Aftercare was established in 1907 with the aim of providing accommodation and employment assistance to individuals leaving mental hospitals.⁶⁵ The Psychiatric Rehabilitation Association, founded in 1955, sought to provide social activities and protected workplaces.⁶⁶ The ex-patient self-help group GROW was launched two years later by Catholic priest Father Con Keogh after he had been discharged from a Sydney psychiatric hospital, and was modelled on Alcoholics Anonymous.⁶⁷ Self-help groups are often experienced as empowering by participants because they do not need to rely on friends, family, or medical professionals.

⁵⁹Ibid.

⁶⁰Ibid.

⁶¹Meagher, 'Witness Statement', 3. Janet Meagher, 'Interview 1', 38:35.

⁶²Janet Meagher, *Partnership or Pretence: A Handbook of Empowerment and Self Advocacy* (Sydney: Psychiatric Rehabilitation Association, 1995), 6.

⁶³'The Council for Mental Hygiene for New South Wales', *Medical Journal of Australia* 1, no. 22 (1932): 780. On ARAFM see the *New South Wales Association for Mental Health Newsletter*, issue 10/11 of 1978. The NSW Association of Mental Health is now known as Way Ahead.

⁶⁴Margaret Lukes, *The ARAFM Story: A Decade of Support 1975-1985* (Sydney: ARAFM, 1985). Soon after its founding in Sydney, chapters were established in other cities, states, and overseas. In New South Wales, ARAFM is now known as Mental Health Carers NSW. Organisations like these had been active before; see, for example, Nicholas Herve, 'Advocacy or Folly: The Alleged Lunatics' Friend Society, 1845-63', *Medical History* 30, no. 3 (1986): 245-75.

⁶⁵Judith Godden, *Aftercare: Our Journey 1907-2017* (Sydney: Aftercare, 2017). Aftercare recently renamed itself 'Stride'.

⁶⁶Jon Chesterson, Sacha Maller, and Bunty Turner, *PRA: The Story, Celebrating 50 Years* (Sydney: Psychiatric Rehabilitation Association, 2005).

⁶⁷For an inside history see C. B. Keogh, *GROW Comes of Age: A Celebration and a Vision!* (Sydney: GROW, 1979).

When she was living in shared accommodation, Meagher attempted to become involved in groups advocating for mental health reform. She was rebuffed by ARAFM; its members were uncomfortable working with someone with severe mental illness and doubted that Meagher could contribute much.⁶⁸ When she started attending meetings discussing the revision of the NSW Mental Health Act, she was invited to join the NSW Association for Mental Health by Donald Scott-Orr, an energetic psychiatrist who was keenly involved in community mental health initiatives and had recently been appointed as chairman, giving a 'boost of energy' to the Association.⁶⁹ Meagher joined the board of the Association in 1981, the International Year of Disabled Persons.⁷⁰ Here she met Lukes. Meagher later highlighted the importance of the mentoring she received from Lukes and Scott-Orr; not surprisingly, the decade spent in mental hospitals had not equipped her with the skills to become a mental health advocate. Both Lukes and Scott-Orr gave her practical advice on writing formal documents and policies, on how to make her opinions known and have impact, and how to act as a member of various committees.⁷¹ In 1981, the year Meagher joined the board, the Association set up a committee to organise a campaign to break down the stigmas associated with mental illness; Meagher contributed to this committee and to the Association's *Newsletter*.⁷²

In a 1982 issue of the *Newsletter*, Meagher reported on the difficulties she had encountered in securing accommodation. She asked, rhetorically: 'Does psychiatric illness predispose one to the evils of accommodation problems or do accommodation problems cultivate mental illnesses and their recurrence?'⁷³ Meagher's article was the first one in the *Newsletter* written by someone who had been a resident of a mental hospital. Meagher did not elaborate on the nature of schizophrenia or mental illness, on the terrible conditions in mental hospitals, or the state of psychiatry. Instead, she focused on the practical challenges she had faced in finding accommodation after she had been discharged from Gladesville Hospital. In her short article, Meagher highlighted problems often encountered by former patients in mental hospitals and other individuals with a lived experience of mental distress: making ends meet on a disability pension and finding accommodation. Her modest disability pension was barely enough to cover rent, let alone post a bond. In addition, mentioning her past in psychiatric institutions scared most real estate agents and private accommodation providers away. These were issues not traditionally addressed by mental health services but became of focal points for various civic groups active in mental health at that time.

⁶⁸Janet Meagher, 'Interview 2', by Hans Pols, *Oral History Project on the History of Community Mental Health in Australia*, 9 October 2020, 29:21.

⁶⁹'From the Executive Secretary', *New South Wales Association for Mental Health Newsletter*, no. 3 (March 1981): 2. Meagher joined the board of the NSW Association in 1981. On Scott-Orr and community mental health see: Robyn Dunlop, 'Mental Health as History: Psychiatry, Community, and General Practice', *Health & History* 21, no. 2 (2019): 1–22.

⁷⁰Donald Scott-Orr, 'Interview', by Robyn Dunlop and Hans Pols, *Oral History Project on the History of Community Mental Health in Australia*, 27 October 2020, 29:27.

⁷¹Meagher, 'Interview 2', 35:45.

⁷²'Stigma and Mental Illness: IYDP Project', *New South Wales Association for Mental Health Newsletter*, no. 3 (March 1981): 10–11.

⁷³Janet Meagher, 'Psychiatric History and Tenancy: A Personal Tale of My Experience', *New South Wales Association for Mental Health Newsletter*, no. 10 (1982): 3.

Shh

Fellow former mental hospital patients and others who had been diagnosed with severe and persistent forms of mental illness understand the challenges of trying to live a meaningful life. Support and understanding provided by peers about the extra-medical challenges of living outside psychiatric hospitals is therefore very helpful. In 1982, Meagher and several friends (including Simon Champ) organised an informal support group named the Schizophrenia Self Help group (*Shh*), primarily for individuals who had been discharged from mental hospitals who were trying to build a life 'on the outside'.⁷⁴ They often met in public places in central Sydney, such as Hyde Park, bringing a green esky to mark their meeting place. To most bystanders, they probably appeared like a group of apparently normal, average, and everyday people, which indicates the radical nature of this initiative: individuals with schizophrenia were not supposed to be present in public places as the stigma around this condition was severe. Janet later recalled that they struggled to name themselves: '[W]e did not want to be identified as ex-patients. That was the only term we had to explain why we were speaking out ... we thought, surely we deserve an identity'.⁷⁵ The name of the group – *Shh* – had overtones of a 'secret society': '[W]e wanted to feed off each other, the power that each of us had, and say: "I want to do this, but I'm not sure, what do you think?" And then we met around the green esky'.⁷⁶ The initiative to start this group highlighted its members' desire for independence, to support each other in acquiring the skills necessary for living in 1980s Australia, and to not rely on the assistance of others. The ultimate goal of all of Meagher's activities – and, according to her, ideally the goal of all mental health interventions – was to assist individuals in becoming sufficiently empowered to lead a contributing life. By focusing on the conditions that needed to be fulfilled for individuals to lead meaningful lives – irrespective of their underlying diagnosis or whether symptoms of their conditions were present or not – this ideal transcended what medical and psychiatric services were offering. Yet Meagher's ideals are those of most individuals with a lived experience of mental distress.

As Meagher herself indicates, her ideas were influenced by the language of the health consumer rights movement. She recalled that the consumer rights movement 'educated us to know that if we were paying psychiatrists, psychologists, or whoever to speak with us, then as people who are utilising their services, we had a right to something that was more than what we were getting ... we had a right as a customer'.⁷⁷

So we started very powerfully taking on the term consumer, not as people use it today, but as a rights-oriented, powerful statement that we were no longer prepared to take sub-standard treatment and care. And we wanted what we'd paid for. And as taxpayers, we all paid for psychiatric care. And we were not getting what we paid for. ... This is when we moved away from being ex-patients, or schizophrenics, or other loonies of different varieties.⁷⁸

⁷⁴'Schizophrenia Self Help Group', *New South Wales Association for Mental Health Newsletter*, no. 1 (1983): 4. *Newsletter of the Schizophrenia Self-Help Group*, April 1983, from the collection of Janet Meagher.

⁷⁵Janet Meagher, in Re:Minding Histories, 'Mental Health from the Ground Up', 17:38.

⁷⁶*Ibid.*

⁷⁷*Ibid.*

⁷⁸*Ibid.*

Being a consumer constituted a positive identity not inherently linked to a pathology, to deviance, or stigma. It encouraged consumers to identify what needs they had to live a contributing or meaningful life, including accommodation and employment and appropriate and effective medical attention. It also encouraged consumers to actively participate in their medical treatment and in organising their lives, in addition to advocating for medical and psychiatric treatment that encouraged active participation rather than mere deference to medical opinion (Image 1).⁷⁹

The Richmond and Schizophrenia Fellowships of NSW

The Richmond Fellowship of NSW was founded in Sydney in 1970 and was one of the first non-government community mental health initiatives established there since the 1950s. The son of its founder, businessman Peter Bartok, had been diagnosed with schizophrenia in 1963; Bartok was therefore intimately familiar with this condition and the challenges it poses for family members.⁸⁰ Bartok and his wife had realised that there was hardly any support for their son or for themselves, medical or otherwise. When deinstitutionalisation started in the 1960s, they were deeply concerned about the number of people who needed advice and support. Bartok hoped to introduce new initiatives in Sydney along the lines of the Richmond Fellowship in Britain, which had been established in 1959 to provide accommodation and support services for former residents of mental hospitals.⁸¹ The envisaged facilities would provide supported accommodation, not merely functioning as ‘halfway houses’ but also as therapeutic communities, assisting individuals to develop skills needed to live in the community.⁸² In 1974, the Fellowship received a subsidy from the Whitlam government, which – along with its own fundraising – enabled it to act. Two attempts to establish residential facilities failed because of vigorous community opposition; the idea of ‘mad’ people living in the neighbourhood scared many, highlighting a general misunderstanding and discriminatory attitudes towards individuals with mental illness. The Fellowship succeeded in buying a large house in Glebe, then a run-down inner-city neighbourhood. Work could start.

The Richmond Fellowship initiative was supported by the superintendent of Callan Park Mental Hospital. Liz Tow, a senior social worker at Broughton Hall mental hospital, was seconded to the Fellowship for a year; Robert Ramjan, a social work student, soon joined her. Ramjan later recounted: ‘I spent two days [at the Glebe House] and

⁷⁹Meagher expected that the presence of peer workers in mental health services would be an improvement. See Janet Meagher, Anthony Stratford, Fay Jackson, Erandathie Jayakody and Tim Fong, ed., *Peer Work in Australia: A New Future for Mental Health* (Sydney: Richmond PRA and Mind Australia, 2018).

⁸⁰Matt Watson and Ella Legg, *The History of Richmond Fellowship of NSW and the People Who Made it Happen* (Sydney: Richmond PRA, 2015), 13. Similarly, Anne Deveson—whose son was diagnosed with schizophrenia and whose family experienced the lack of support services—followed the example of National Schizophrenia Fellowship, established in the UK in 1972, and stimulated the establishment of similar associations in Australia. For an autobiographical account see Anne Deveson, *Tell Me I'm Here: One Family's Experience of Schizophrenia* (Ringwood: Penguin, 1991).

⁸¹The founder of the Richmond Fellowship in the UK was Dutch theology student Elly Jansen. The houses the Fellowship operated were run as therapeutic communities. For reports on its various initiatives see Elly Jansen, ed., *The Therapeutic Community: Outside the Hospital* (London: Croom Helm, 1980).

⁸²Watson and Legg, *History Richmond Fellowship NSW*. For the history of therapeutic communities see Catherine Fussinger, “Therapeutic Community”, *Psychiatry's Reformers and Antipsychiatrists: Reconsidering Changes in the Field of Psychiatry after World War II*, *History of Psychiatry* 22, no. 2 (2011): 146–63.

just fell in love with what was happening there, and although I was a full-time student, Liz and I split the work up 50/50, we were doing about 110 hours a week each because we were sleeping over'.⁸³ Andy Campbell, a psychiatrist associated with the Glebe Community Health Centre, visited the house once a month to monitor the residents' medication, and held weekly group therapy sessions in his office.⁸⁴ In addition to medication and psychotherapy, the house was run with a focus on daily living activities. Every resident had a contract with goals to be achieved during a period of three months. When these contracts were reviewed, celebrations were held.⁸⁵ At the Glebe House, living together, shared decision-making, and shared responsibility for running the household were key.

Simon Champ first experienced deep mental distress during the fifth form in high school and had to repeat that year. He lived with his parents in a country town, some '300 miles from Adelaide and 300 miles from Melbourne'.⁸⁶ Because his parents did not want to send him for treatment far away, he 'bumbled along and kept having weird experiences'.⁸⁷ From an early age, Champ had wanted to become an artist. He enrolled in an art school in Adelaide, but soon decided to move to Sydney. He stayed at the share-farm of his photography lecturer at Nimbin, picking mangoes from the large mango tree. He took 'a lot of mangoes into town and exchanged them for peanut butter'.⁸⁸ Simon increasingly lost touch with reality. In 1979, he bought a ghetto blaster, 'put it on the edge of the platform near the Opera House and put the headphones into the water and the dolphins were going to swim into it'.⁸⁹ The police were called and took Champ to Rozelle Hospital, where he was diagnosed with paranoid schizophrenia.

Champ was discharged in late 1980 and became a resident of Richmond Fellowship's Glebe House. After he was sufficiently recovered, he was hired to work there, which made him one of the first consumers to be employed as a peer worker in Australia.⁹⁰ Champ recalled: 'When we all went up to the local pub, there were more of us than the sane people, and we'd also save up and go to the restaurants at Glebe Point Road as a gang. And I think that's sort of where my pride ... [and] my recovery of self, began. In those situations where we'd all be together'.⁹¹ Yet he never intended to become a peer worker as he still wanted to pursue his ambition to become an artist. He enrolled at the Sydney College of the Arts and joked later that he kept his 'psychosis to the holidays, which was pretty true, actually'.⁹² In one of his artworks, which he had

⁸³Robert Ramjan, 'Interview, 1 Nov. 2019', by ARC Research Group on the History of Community Mental Health in Australia, *Oral History Project on the History of Community Mental Health in Australia*, 1 November 1999, 04:06.

⁸⁴Andy Campbell, 'Interview', by Leila Cheikh, Hans Pols and Ian Shoebridge, *ARC Research Group on the History of Community Mental Health in Australia*, 11 June 2021, 03:05. Campbell was chairman of the Board of the Richmond Fellowship of NSW for over thirty years. See also Simon Champ, 'Interview', by Anthony Harris, Tina Kenny and Hans Pols, *Oral History Project on the History of Community Mental Health in Australia*, 25 September 2020, 02:41; Ramjan, 'Interview, 1 Nov. 2019', 1:21:22.

⁸⁵Ramjan, 'Interview, 1 Nov. 2019', 40:06.

⁸⁶Simon Champ, in *Re/Minding Histories*, 'Mental Health from the Ground Up', 09:59.

⁸⁷*Ibid.*

⁸⁸Champ, 'Interview', 01:50.

⁸⁹*Ibid.*, 02:41.

⁹⁰*Ibid.*

⁹¹*Ibid.*

⁹²*Ibid.*, 17:34. For a research paper Champ wrote for his course see: Simon Champ, 'The Colour of Dinosaurs and the Flight of a UFO' (Graduate Diploma Research Paper, Sydney College of the Arts, University of Sydney, 1993). Personal collection of Simon Champ.



Image 2. Simon Champ's creative re-definition of schizophrenia. Photo courtesy of One Door Mental Health.

originally conceived during his time at Rozelle Hospital, Champ redefined an individual with schizophrenia as a 'Special, Creatively Heightened Individual, Zanily, Overly Perceptive, Humorous, Really Emotional, Needing Insight and Care' (see [Image 2](#)).

In 2021, Champ reflected on the experience of having schizophrenia and his hospitalisation, stating that this condition ‘severely ruptured the relationship that I had enjoyed with myself prior to my illness’.⁹³ His treating psychiatrist told him that ‘I could not trust my thoughts and senses. I felt that my mind had betrayed me’.⁹⁴ The medication he received dulled his senses and made his world appear colourless and flat. It was hard to make sense of his own experiences: ‘To try to decide what was normal or sane was like negotiating a foreign city without a map. I felt like a stranger to myself’.⁹⁵ Champ later realised that there was no such thing as a normal state, although broadly shared perspectives on normality were abundant. In his art and through psychotherapy, he attempted to integrate the strange and alienating views he had experienced during the most acute phases of his condition into his personal identity. In addition to the effects of schizophrenia, Champ found the experience of hospitalisation deeply troubling. Only through his participation in various civic associations and by supporting other individuals who had experienced severe mental illness did he regain his dignity.

The New South Wales branch of the Schizophrenia Fellowship, an advocacy group for individuals with schizophrenia and their caregivers, was established in 1985.⁹⁶ At the founding meeting in Sydney, Champ stood up and said: ‘My name is Simon Champ and I have schizophrenia. I need an organisation like this’.⁹⁷ The newly established organisation mandated that consumers were represented at all levels; Champ was duly elected as Deputy Chairman of the Board. At this time, few people with a severe mental illness had spoken out publicly, and Champ’s statements made a deep impression. In 1983, when New South Wales’ new mental health legislation had been proposed, Champ had appeared with Meg Smith on the ABC television show *Compass*, each openly discussing their experience of severe mental illness. In 1986, he also appeared on the popular Mike Willesee current affairs television show. By publicly speaking out about his mental illness, he aimed to reduce the stigma associated with the condition. It also empowered individuals who had been diagnosed with mental illness, because it demonstrated that living with mental distress outside of psychiatric hospitals was possible and that they could confidently discuss their condition. Champ later appeared in Anne Deveson’s documentary about schizophrenia (*Spinning Out*), which was broadcast by the ABC.⁹⁸

In 1987, through the Schizophrenia Fellowship and the New South Wales Association for Mental Health, Champ participated in activities which aimed to destigmatise schizophrenia by visiting high schools and having discussions with students about mental illness. Champ visited many high schools and discussed the challenges of

⁹³Simon Champ, ‘A Most Precious Thread’, *Australian and New Zealand Journal of Mental Health Nursing* 7, no. 2 (1998): 54.

⁹⁴Champ, ‘Most Precious Thread’, 54.

⁹⁵Champ, ‘Most Precious Thread’, 55.

⁹⁶The Victorian association had been established in 1978. See Catherine Waterhouse, *The Schizophrenia Fellowship of Victoria, 1978-1999: A Brief History* (Melbourne: SFV, 1999). For the New South Wales counterpart, see Virginia Macleod, *From Seed to Sunflower: A History of the Schizophrenia Fellowship of New South Wales, 1985-2010* (Sydney: Schizophrenia Fellowship of NSW, 2010).

⁹⁷Robert Ramjan, ‘Interview 2’, by Anthony Harris, Tina Kenny and Hans Pols, *Oral History Project on the History of Community Mental Health in Australia*, 4 September 2020, 00:51.

⁹⁸Anne Deveson, *Spinning Out* (Australia: National Film and Sound Archive, 1991), <https://video-alexanderstreet-com.ezproxy.sl.nsw.gov.au/watch/spinning-out>.

living with schizophrenia with the students. Most importantly, by doing so, he demonstrated that individuals diagnosed with this condition were able to live meaningful and fulfilling lives if they received proper medical care and other forms of support. Champ also participated in police training sessions, as the police force regularly received poor press coverage for the way it dealt with mentally ill individuals. Champ considers these training sessions a high point in this activist career: 'They all had glasses of beer at the end of the day. And if you've done a good job, the circle [of police officers] would break, and you would be able to stand in the circle and that'd be about 30 cops there'.⁹⁹

One of the Schizophrenia Fellowship's activities was organising support groups for clients and carers. The Fellowship and other organisations active in mental health were convinced that it was important to listen to the voices of consumers of mental health. When the state government announced an inquiry into services for the psychiatrically ill and developmentally disabled (which resulted in what became known as the Richmond Report, published in 1983), the newly established Mental Health Coordinating Council organised a call centre to survey opinions of service users and carers; the call centre was run with the Redfern Legal Service. The phone line allowed 'people with direct experience of psychiatric services in New South Wales to express their opinions about the quality and availability of services'.¹⁰⁰ Through this initiative, it was possible to submit an overview of the experiences and opinions of consumers of mental health care and their carers in a more or less systematic way to the inquiry. This submission was a significant milestone in the official recognition of the authority of people with experience of psychiatric services.

The MAD self-help group

Around the same time that the members of the Schizophrenia Self Help group started meeting, Meg Smith set up a similar group for individuals who had been diagnosed with bipolar disorder (at the time named manic-depressive disorder). In an interview, Smith remembered that she had 'always had mood swings'.¹⁰¹ She had her first depressive episode as a high school student in Casino, northern NSW. She was dux one year and the bottom of the class the next. There were no psychiatrists or other mental health professionals in Casino at the time. Her general practitioner (GP) prescribed anti-depressants, which did not help. After she graduated from high school, Smith enrolled at the University of New England to study English and History. In 1969, 'after my first year of university, I had a pretty serious depressive episode'.¹⁰² Seeking answers, she switched to study psychology, but found it did not offer anything about 'counselling or how to talk to people'.¹⁰³ 'This was in the 1970s', she relates, when 'Valium and

⁹⁹Champ, 'Interview', 32:21.

¹⁰⁰'Interim Report on Phone-in Survey on Psychiatric Services', *New South Wales Association for Mental Health Newsletter*, no. 1 (Jan 1983): 2-3. See also David T. Richmond, 'Interview', by ARC research group on the History of Community Mental Health in Australia, *Oral History Project on the History of Community Mental Health in Australia*, 12 November 2020; David T. Richmond, *Inquiry into Health Services for the Psychiatrically Ill and Developmentally Disabled [Richmond Report]*, 4 vols. (Sydney: Department of Health, NSW, 1983).

¹⁰¹Meg Smith in Re/Minding Histories, 'Mental Health from the Ground Up', 12:17.

¹⁰²*Ibid.*

¹⁰³Smith, 'Interview', 05:51.

antidepressants were the treatments of choice. And I bumbled along for a couple of years, finally ended up in the [Shortland] Clinic in Newcastle'.¹⁰⁴ The Shortland Clinic was a psychiatric unit run as a modified therapeutic community and provided treatment on a voluntary basis. It ran day programs, had a limited in-patient facility, and was attached to a general hospital. However, after a three-month stay, Smith had left 'angry'.

Smith continued her Honours at the University of Newcastle, majoring in psychology, and wrote a thesis on women and feminism. She also joined the local women's liberation group. After being depressed for two years, she thought she 'might as well accept the fact that I was going to be depressed for the rest of my life, and it was probably my faulty personality!' Like many others, it was many years before she was diagnosed with bipolar disorder and received appropriate treatment. She nonetheless went on to do a Master's in clinical psychology at the University of New South Wales with Robin Winkler. It was 'the radical anti-psychiatry kind of time in the '70s', she explained, 'along the lines of, "there's no such things as mental illness"'. Critics who viewed psychiatry as a repressive and dehumanising force were discussed in social science disciplines in some Australian universities. Smith recalled the discussions about Winkler's pseudo-patient experiments. Her recollection of the discussions during that class are mentioned above.

After graduating, Smith was employed by Leichhardt Women's Community Health Centre. It was run with a 'feminist philosophy, "the personal is political" ... your personal experience is important in a political context'.¹⁰⁵ In 1980, while working there, she had her 'first serious, psychotic episode', which challenged her radical views on the nature of mental illness.

[I]t was interesting because, at the feminist women's health centre – nobody lived with mental illness, it was all oppression by the patriarchy and stuff like that. So they were kind of pretty confronted by the fact that I ... had to go to hospital and ... had to take medication. So there was a kind of struggle for me in the 1980s about ... how do I describe and understand what's happened to me? And how do I communicate that to our people?¹⁰⁶

During her involuntary stay at Rozelle Hospital, Smith was diagnosed with bipolar disorder.¹⁰⁷ 'In some ways', she recalled, 'it was a great relief to be diagnosed with something that was neurochemical, because I could do something about that. I didn't have a faulty personality. It was neurobiological: there was treatment available, so it was pretty liberating, actually'.¹⁰⁸ Despite the relief of being diagnosed, Smith found the experience of hospitalisation deeply traumatising. As she recalled: she had left the hospital after she had been assaulted by another patient, which was not noted on her patient file. She was subsequently forcibly readmitted: 'I was made an involuntary patient after

¹⁰⁴Smith in *Re/Minding Histories*, 'Mental Health from the Ground Up', 12:17.

¹⁰⁵*Ibid.*, 31:30.

¹⁰⁶*Ibid.*, 25:01.

¹⁰⁷Smith, 'Interview', 03:42.

¹⁰⁸*Ibid.*, 36:49.

I walked out because I didn't understand what the hospital was, how it could help me, and why I had to stay there'.¹⁰⁹

Smith became involved with the Mental Health Association of NSW around the same time as Janet Meagher. Until then, this Association had been dominated by psychiatrists, social workers, psychologists, and concerned citizens. The involvement of Smith, Meagher and others signalled that a new era of consumer involvement and representation in mental health had begun. Inspired by the philosophy of wellness and social action of the feminist movement and the consciousness-raising groups organised at the women's health centre, Smith started to think about founding a self-help group for individuals diagnosed with bipolar disorder. Her plans solidified during conversations at the Festival of Madness held in September 1980. The festival was organised by PALA, a group focused on providing alternatives to psychiatric hospitalisation and at that time associated with the Bondi Junction Community Health Centre.¹¹⁰ Soon after, Smith founded the Manic and Depressive Self Help Group (MAD).¹¹¹ Initially, the group met in the living rooms and kitchens of interested individuals; somewhat later 'we started putting out the newsletter, basically, to let people know where the next meeting was'. It was called the 'MAD newsletter ... Manic and Depressive', after the group had spent hours 'agonising' over the name:

[I]t became sort of symbolic of who we were, [what] we were struggling with: were we MDPs – manic depressive psychotics – who'd have to take medication for the rest of our lives? And no professionals were really interested in who we were as people. ... So we were kind of struggling with this kind of secrecy and stigma, but also kind of also trying to sort of be out and open.¹¹²

The struggle with stigma and self-stigma on the one hand, and the desire to destigmatise bipolar disorder and advocate for better treatment by physicians and psychiatrists on the other, suggested different names to call the group. The early groups also started to collect information, articles, poetry, and other writings that were published as the *MD Papers*.¹¹³ In the 1990s, a newsletter (*MANDA; Newsletter of the Depressive and Manic Depressive Association of NSW*) commenced publication.

The self-help groups set up in the early 1980s operated independently from the mental health care system. They addressed the practical and non-medical challenges of living with diagnosed mental distress. Relevant information, peer education, support, and art dominated the material these groups published. Those who wanted to do so could share their experiences of managing their distress, living outside mental hospitals, and interacting with physicians. Providing information about psychiatric diagnoses, medications, and treatment options was useful for members, their friends and

¹⁰⁹Meg Smith, 'Detained, Diagnosed, and Discharged: Human Rights and the Lived Experience of Mental Illness in New South Wales, Australia', in *Mental Health and Human Rights: Vision, Praxis, and Courage*, ed. Michael Dudley, Derrick Silove and Fran Gale (Oxford: Oxford University Press, 2012), 12.

¹¹⁰Meg Smith, 'Community Development and Self Help Groups for People with Serious Mental Illness', *Network: Newsletter of the Board of Community Psychologists* 8, no. 2 (1993): 1–12.

¹¹¹Meg Smith, 'MAD: Manic and Depressive Sufferers Group', *New South Wales Association for Mental Health Newsletter* 1 (Jan 1981): 7.

¹¹²Smith in Re/Minding Histories, 'Mental Health from the Ground Up', 25:01.

¹¹³*The Third MD Papers: A Collection of Personal Accounts, Information and Sundry Items About Living with Mania and Depression* (Sydney: Depressive and Manic Depressive Association of NSW, 1986). The *Fourth MD Papers* appeared in 1992.

relatives, and their general physicians. Many members of the MAD support groups had been living with their condition for years before they were diagnosed. The groups created opportunities 'to regain the dignity and self-worth lost in an episode of serious mental illness by providing opportunities to help others and share experiences'.¹¹⁴ One of the most stimulating experiences of participating in these groups was 'the joy of discovering that other people have survived it and become stronger and more aware'.¹¹⁵ Self-help groups allowed members to meet potential role models: 'people see others who have recovered, who are leading valuable, productive lives and who can talk about the benefits as well as the costs of treatment and rehabilitation'.¹¹⁶

In addition, these self-help groups had political dimensions: they empowered their members to take charge of their own lives and to engage in advocacy.¹¹⁷ Smith explained her own involvement from recognising that she 'could not believe that I would survive another serious episode of mental illness in a poorly managed, underfunded and run-down state psychiatric hospital'.¹¹⁸ She continued: 'If I don't say anything ... the mentally ill will always be some other invisible group to be kicked rather than me or my friend or a neighbour or a workmate'.¹¹⁹ The MAD support groups demonstrate that opinions about the medical treatment of mental illness within the consumer movement at the time were divided. Many individuals who had been diagnosed with bipolar disorder appreciated receiving medications that would help them to live with this condition. Most consumers, however, were united in demanding better mental health services and hoped that the severely degrading treatments within mental hospitals would be abolished.

Making alliances and forming coalitions: consumers and community mental health organisations

In 1980, the state of New South Wales found itself in an ambiguous position regarding the provision of mental health services. At that time, most mental health services were still being provided in mental hospitals, even though mental hospital treatment had come under continuous and severe critique and the number of beds in these institutions had already decreased significantly. Unfortunately, community mental health services were only available on a very modest scale, leaving most individuals who had been discharged from mental hospitals fending for themselves. Many were homeless or living in boarding houses and nursing homes. Several civic associations (now generally called non-government organisations) had established some services with funds made available by the Whitlam government in the mid-1970s. These associations introduced novel practices in mental health support and provided new opportunities for individuals discharged from mental hospitals to find their voice, speak out, and be heard. By

¹¹⁴Smith, 'Community Development', 4.

¹¹⁵Meg Smith, 'How it All Started', in *The Fourth MD Papers* (Sydney: DMDA, 1992), 3.

¹¹⁶Smith, 'Community Development', 7. See also Ingrid Weddell and Meg Smith, 'Running a Support Group: Some Ideas for Starting a Group for People Who Have a Mood Disorder', in *The Fourth MD Papers* (Sydney: DMDA, 1992), 34–7.

¹¹⁷Alan Owen, 'Self Help Approaches in Health Care', *Social Alternatives* 1, no. 2 (1978): 5–7.

¹¹⁸Smith, 'How it All Started', 2.

¹¹⁹Smith, 'How it All Started', 3.

forming alliances and coalitions with consumers of mental health services, the critique of mental health services articulated by these associations gained in persuasiveness and authority.

Going beyond strictly medical interpretations of mental illness and mental disorder, these associations focused on the needs of individuals recently discharged from mental hospitals and others experiencing severe mental distress, including housing, employment, and places to meet. Rather than focusing on strictly medical definitions of treatment and cure, their services focused on agency, recovery, well-being, and peer support, before these ideals found acceptance in regular mental health services. Individuals recently discharged from mental hospitals were invited to participate in decision-making and play meaningful roles in these initiatives. Some were hired as peer workers, and many of these new organisations had consumers of mental health services as board members over time. Consequently, the highly asymmetrical relationships between physicians and patients common in mental health hospitals were gradually replaced with more egalitarian ones. Over time, the innovative practices introduced by these non-government organisations became standard in mental health services, many of which now employ peer workers and have consumer advisory groups.

Attending to the narratives of individuals with lived experience of mental distress reveals the active roles these individuals have played in mental health history, promoting changes in services and advocating for meaningful involvement in decisions about mental health systems. By making more democratic and recovery-oriented services available, the early community mental health initiatives contributed to the emergence of the voices of individuals previously dismissed as mere patients unable to take charge of their own affairs. Simon Champ, Meg Smith, and Janet Meagher, three pioneering Australian consumer advocates, started to speak out publicly and make their opinions heard, thereby breaking down stigmas associated with severe and persistent forms of mental illness as well as creating new opportunities for individuals who were similarly affected. To investigate these histories, historians should abandon their common asymmetric stance towards the individuals they are investigating, which is still present in Porter's admonition to do medical history 'from below'. Instead, they should place themselves on the same level and engage in meaningful dialogues about the meanings of recent history.

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