
EXECUTIVE SUMMARY

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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