
PART ONE: METHODOLOGY

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

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

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1.1 OVERVIEW

1.1.1 Background

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

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

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

1.1.2 Overview of methods

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

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

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

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

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

1.2 COMMUNITY CONSULTATIONS

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

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

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

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

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

1.3 CALL FOR SUBMISSIONS

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

1.4 ANALYSIS OF SUBMISSIONS AND INFORMATION PRESENTED AT FORUMS

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

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

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

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

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

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

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

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

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

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

1.5 SURVEYS

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

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

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

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

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

