
FOREWORD

Dr Sev Ozdowski OAM

Human Rights Commissioner and Acting Disability Discrimination Commissioner
Human Rights and Equal Opportunity Commission

The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

International Covenant on Economic Social and Cultural Rights, Article 12

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

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

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

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

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

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

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

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

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

FOREWORD

Keith Wilson

Chair, Mental Health Council of Australia

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

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

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

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

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

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

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

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

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

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

FOREWORD

Ian Hickie

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

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

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

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

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

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

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

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