

CHAPTER 1

THE CHALLENGE OF MENTAL HEALTH

Introduction

1.1 Millions of Australians experience mental illness at some stage in their lives, survive that experience, and continue to live and work happily. The committee heard from many people in that situation. Mr John Olsen described his experience with acute schizophrenia:

I am one of the lucky ones... When I take medication, the period from being [too] sick to becoming well and being discharged from hospital may take as little as one or two weeks. Then I am ready and quite happy to go. Within the next few months I get back to more or less 100 per cent of my previous functioning. I am very lucky in that the medications work very well for me; they suit me. I have not been as well in my life as I am now that I am taking Risperdal. I do not mean that as an advertisement for the drug itself, but it means that I am the lucky type of person with the genotype that the treatment works for. That is how I can be a consumer advocate and maintain a three-day-a-week job. I also do voluntary work on a community housing board.¹

1.2 Dr Simon Bridge is a doctor in the Cairns area, who came and gave valuable evidence to the committee from his experience as a general practitioner (GP) with an interest in mental health. He has produced a pamphlet aimed at helping reduce suicide, and is an advocate for the role of GPs in mental health. He works as a doctor, but also suffers from bipolar disorder.²

1.3 Ms Leanne Pethick gave evidence in Melbourne. A former Telstra executive and Chief Executive Officer of depressioNet, Ms Pethick has suffered with depression. She described the struggle to continue working while coming to grips with a diagnosis of a mental illness. However she also talked about her happy and successful working life that has continued since recognising and learning to manage her depression.³

1.4 Despite the many examples of people who successfully recover from, or manage, their illness, no one can be involved in the field of mental health and remain unaware of the tragic loss of life that can befall people who experience a serious mental illness. As former Victorian Premier and Chair of beyondblue Jeff Kennett remarked in evidence in Melbourne, each day around 'eight or nine Australians take

1 Mr John Olsen, *Committee Hansard* 27 July 2005, p. 76.

2 Dr Simon Bridge, *Committee Hansard* 5 August 2005, p. 76.

3 Ms Leanne Pethick, *Committee Hansard* 5 July 2005, pp. 82–86.

their life—suicide—as a result of depressive illnesses'.⁴ As the committee undertook its work, it was informed by submitter Ms Dianne Gaddin that her daughter Tracy, for whom Dianne had cared for years, finally took her own life in November 2005. Many individual submissions to the committee came from parents and siblings of people who had experienced mental illness, and all too often lives had ended in suicide, accidents or fatal confrontations with police.

1.5 The high levels of stigma, high rates of death, low levels of access to services, and poor employment outcomes for people with mental illness are amongst the many indicators that show that there must be reforms in mental health if these tragic statistics are to be improved. This inquiry is one part of the process of securing those reforms.

Terms of Reference

1.6 On the 8 March 2005, the Senate created a Select Committee on Mental Health, to conduct a wide-ranging inquiry into:

- (a) the extent to which the National Mental Health Strategy, the resources committed to it and the division of responsibility for policy and funding between all levels of government have achieved its aims and objectives, and the barriers to progress;
- (b) the adequacy of various modes of care for people with a mental illness, in particular, prevention, early intervention, acute care, community care, after hours crisis services and respite care;
- (c) opportunities for improving coordination and delivery of funding and services at all levels of government to ensure appropriate and comprehensive care is provided throughout the episode of care;
- (d) the appropriate role of the private and non-government sectors;
- (e) the extent to which unmet need in supported accommodation, employment, family and social support services, is a barrier to better mental health outcomes;
- (f) the special needs of groups such as children, adolescents, the aged, Indigenous Australians, the socially and geographically isolated and of people with complex and co-morbid conditions and drug and alcohol dependence;
- (g) the role and adequacy of training and support for primary carers in the treatment, recovery and support of people with a mental illness;
- (h) the role of primary health care in promotion, prevention, early detection and chronic care management;

4 Mr Jeff Kennett, Chairman, *beyondblue*, *Committee Hansard* 4 July 2005, p. 4.

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- (i) opportunities for reducing the effects of iatrogenesis and promoting recovery-focused care through consumer involvement, peer support and education of the mental health workforce, and for services to be consumer-operated;
 - (j) the overrepresentation of people with a mental illness in the criminal justice system and in custody, the extent to which these environments give rise to mental illness, the adequacy of legislation and processes in protecting their human rights and the use of diversion programs for such people;
 - (k) the practice of detention and seclusion within mental health facilities and the extent to which it is compatible with human rights instruments, humane treatment and care standards, and proven practice in promoting engagement and minimising treatment refusal and coercion;
 - (l) the adequacy of education in de-stigmatising mental illness and disorders and in providing support service information to people affected by mental illness and their families and carers;
 - (m) the proficiency and accountability of agencies, such as housing, employment, law enforcement and general health services, in dealing appropriately with people affected by mental illness;
 - (n) the current state of mental health research, the adequacy of its funding and the extent to which best practice is disseminated;
 - (o) the adequacy of data collection, outcome measures and quality control for monitoring and evaluating mental health services at all levels of government and opportunities to link funding with compliance with national standards; and
 - (p) the potential for new modes of delivery of mental health care, including e-technology.

1.7 The committee was initially asked to report to the Senate by 6 October 2005. However a strong public response to the committee's work led the Senate on 18 August 2005 to extend the committee's reporting deadline to 30 March 2006. A further extension was granted on 1 March 2006, allowing the Committee to report at any time prior to 28 April 2006. In view of the importance of the issue and the desire to have a significant impact on the CoAG reform process, the Committee decided to report on March 30.

Conduct of the inquiry

1.8 Reflecting a high level of community interest in mental health issues, the committee received over 600 submissions from individuals and organisations. It also received a further 200 submissions from people who spent time in institutional and foster care during childhood. Many submitters provided other reports and publications, for which the committee was grateful. Overall, the committee received in excess of ten thousand pages of written material.

1.9 Many submissions told personal stories of living with mental illness, and of living with or caring for someone suffering from mental illness. Many of these people found it painful to come forward and speak about their experiences, and the committee was grateful for their willingness to do so. Special thanks should go to the young people from ORYGEN Youth Health who met with the committee and gave evidence at the Melbourne hearings, and the young people who gave evidence as part of a confidential submission on DVD, put together by Australian Infant Child Adolescent Family Mental Health Association. The committee wishes also to thank several consumers and carers who came to hearings to give confidential evidence to the committee.

1.10 The committee was concerned, when receiving such submissions, to balance the desire to publish as much of the material submitted to it as possible, with the desire to protect the privacy of individuals. These same issues were faced by the National Inquiry into the Human Rights of People with Mental Illness (the Burdekin Report) in 1993.⁵ There is still significant stigma associated with having a mental illness. The committee did not want to create any additional difficulties for people with such an illness by publicising their identity, particularly when the person with the illness was often not the person making the submission. For these reasons, the committee decided to keep many submissions confidential, or to publish them with the name or other identifying details of the submitter withheld. In other cases, the committee published material only after submitters supplied written consent from third parties mentioned in their submissions.

1.11 The committee accepts that not every individual or organisation was able to be satisfied by the committee's resolution of these competing needs. It is hoped that all individuals and organisations understand the difficulty of balancing publication with privacy. Everyone participating in the inquiry should be assured that the committee takes every submission and every case very seriously. Whether or not individual cases were publicly published or quoted in the report, they were all considered by the committee, giving it a great many insights into the difficult path faced by consumers, carers and workers in addressing mental illness.

1.12 The committee held one of the most extensive series of public hearings organised by a Senate Committee, totalling seventeen days of hearings, across every capital city, as well as in Cairns and the Gold Coast. It took over 1500 pages of oral evidence from 302 witnesses, some of whom travelled long distances to participate in the hearings, from locations as remote as Alice Springs and the Gulf of Carpentaria. During the course of hearings, committee members often asked individuals and organisations to provide answers on notice to numerous questions. Witnesses were extremely helpful in responding to these requests, and the list of material provided is shown at Appendix 4.

5 Human Rights and Equal Opportunity Commission, *Human Rights and Mental Illness: Report of the National Inquiry into the Human Rights of People with Mental Illness*, AGPS, Canberra, 1993, p. 7.

1.13 The committee also made visits to various mental health facilities and programs around the country. These included

- At Port Hedland:
 - Port Hedland Mental Health Unit
 - Port Hedland Regional Hospital
 - Gemini Medical Services
 - Ms Pauline Robinson, psychologist in private practice
 - Wirraka Maya Health Service
- At Port Augusta:
 - Baxter Immigration Detention Facility
 - Pika Wiya Clinic
 - Community members and Aboriginal health workers
- At Melbourne:
 - ORYGEN Youth Health
 - Thomas Embling Hospital
- At Shepparton:
 - Two joint projects of the Goulburn Valley Area Mental Health Services and the Mental Illness Fellowship Victoria: the Specialist Residential Rehabilitation Service; and Prevention and Recovery Care.

1.14 The committee is grateful to the many individuals and organisations in each location who worked hard to make these visits possible and very informative.

1.15 In addition, individual members of the committee visited other facilities or organisations including Deer Park Women's Prison in Victoria and Brisbane Women's Correctional Centre in Queensland, as well as visiting a world-leading mental health program in Trieste, Italy. It met with representatives of the New Zealand Mental Health Commission. The committee thanks these and many other groups for their assistance and cooperation.

1.16 The committee benefited from the expertise of staff of the Parliamentary Library, and the devoted assistance of Hansard and broadcasting staff at every hearing. The committee was assisted by secretary Ian Holland, and secretariat staff Terry Brown, Robyn Clough, Tim Davies, Lisa Fenn, Eleesa Hodgkinson, Lisa Hornsby, Jill Manning, Kelly Paxman and Loes Slattery.

An inquiry in a time of rapid change

1.17 During the course of the inquiry, there were significant events in the area of mental health policy. These included:

- The release on 14 July 2005 of the 'Palmer Report': the Inquiry into the Circumstances of the Immigration Detention of Cornelia Rau, which raised concerns about mental health care in prisons and in immigration detention
- The release on 19 October 2005 of the *Not for Service* report, a joint project of the Mental Health Council of Australia, the Human Rights and Equal Opportunity Commission and the Brain and Mind Research Institute
- The release on 21 December 2005 of the National Mental Health Report 2005, which provided a ten year view of trends across the First and Second National Mental Health Plans
- Discussion of mental health reform at the Council of Australian Governments (CoAG) meeting in Canberra on 10 February 2006
- Announcement on 1 March 2006 of reforms to immigration services, particularly in the area of mental health.⁶

1.18 During the same period some states and territories also announced new initiatives in the area of mental health. Some of these are discussed in Chapter 2 and in the final chapter of the report. The many recent developments serve to highlight the attention that is currently being devoted to mental health, and to underline the need for change. The CoAG meeting resulted in a commitment for officials to develop a plan of action on mental health by June 2006. The committee expects that this report, together with the evidence assembled during the inquiry will have a significant bearing on the form taken by that action plan.

1.19 The committee hopes that the current level of concern will be translated into action by everyone responsible for mental health in Australia.

The committee's approach to this report

1.20 This report is structured around major issues in mental health, and major groupings affected by mental health policy. Had the committee attempted to write a chapter on each and every individual element of the terms of reference, the report would have been excessively long, and would have diverted attention from key issues. Drawing on the experience of the Burdekin Report⁷, the *Not for Service* report,⁸ and the committee's own evidence, this report focuses on key issues in mental health, key relationships, and key groups for which special concerns were raised during the course of the inquiry.

6 Department of Immigration and Multicultural Affairs, *On the move to improve – DIMA's progress on Palmer*, http://www.immi.gov.au/departments/dima_improvements/index.htm (accessed March 2006).

7 Human Rights and Equal Opportunity Commission, *Human Rights and Mental Illness – Report of the National Inquiry into the Human Rights of People with Mental Illness*, Canberra 1993.

8 Mental Health Council of Australia and the Brain and Mind Research Institute, *Not For Service: Experiences of Injustice and Despair in Mental Health Care in Australia*, Mental Health Council of Australia, Canberra, 2005.

What is mental health?

1.21 The National Mental Health Plan 2003-2008 (the Plan) defines mental health as a:

state of emotional and social wellbeing in which the individual can cope with the normal stresses of life and achieve his or her potential

and that:

Mental health describes the capacity of individuals and groups to interact, inclusively and equitably, with one another and with their environment in ways that promote subjective wellbeing, and optimise opportunities for development and the use of mental abilities.⁹

Mental illness (or mental disorder) is described in the Plan as:

a clinically diagnosable disorder that significantly interferes with an individuals cognitive, emotional or social abilities.¹⁰

1.22 The diagnosis of mental illness is defined in terms of classifications listed within two professional publications, the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, and, the International Classification of Diseases, Tenth Edition. However, these manuals include as mental illness things generally excluded in Australian health care planning, particularly drug and alcohol disorders, and dementia. Indeed, this exclusion typifies one of the recurrent themes of this report: barriers between services provided for different illnesses and different population groups.

1.23 There are many different mental illnesses, just as there are many different physical diseases. Mental illnesses can be classified in different ways. One of the commonest is the reference to *high prevalence* and *low prevalence* disorders. The most widely known high prevalence disorders are depression and anxiety disorders. Around 20 percent of people may experience depression at some stage in their lives, while about 10 percent of people may experience an anxiety disorder. These high prevalence disorders can be extremely serious, but often go unnoticed and untreated, particularly if a sufferer is not acutely ill. The most widely known low prevalence disorders are schizophrenia and bipolar disorder, which at some stage in their lives may affect about one percent and two percent of the population respectively.¹¹ More information about mental illnesses is included in Appendix 1.

9 Australian Health Ministers, *National Mental Health Plan 2003-2008*, 2003, p. 5.

10 Australian Health Ministers, *National Mental Health Plan 2003-2008*, 2003, p. 5.

11 Data about mental illness is available from numerous sources, including SANE Australia, *Facts and Figures about Mental Illness*, fact sheet, 2005, http://www.sane.org/images/assets/Factsheets-PDF/fs13_facts&figures.pdf (accessed February 2006).

1.24 Beyond these relatively well known illnesses, however, are many others including eating disorders, drug and alcohol disorders and personality disorders. It is also not uncommon for people to experience more than one condition. The interactions between them can be complex, and are not always well understood. Managing the interactions between disorders can be very important to effective treatment, and evidence about some of these interactions, such as between drug use and other mental illnesses, or between dementia and other mental illnesses, featured prominently in evidence to the committee.

Talking about mental illness

1.25 The committee would like to comment briefly on the language used in this report.¹² It is a measure of how traumatic some people find their experience of mental illness, and of attempts to manage it, that they speak of being 'survivors'.¹³ The term is a reference to surviving their illness, which is understandable, given that people with mental illnesses such as depression, schizophrenia, and borderline personality disorder face a far higher risk of death and disablement than the rest of the community. For some, however, describing themselves as survivors is also a reference to surviving their treatment, which can sometimes be experienced as confronting, violent, painful or a breach of their human rights. In this sense of the term individuals can refer to themselves as 'survivors of psychiatry'.

1.26 Most commonly in Australia, people speak of being 'consumers': that is, consumers of mental health services. This language arose out of a desire to entrench the idea that people with a mental illness use health care services and as such have expectations and rights in relation to those services. It was an important step in recognising that mental health services should meet consumer needs, just as other services attempt to give consumers what they want.

1.27 At the same time, the committee recognises that talking of 'consumers' has its limitations. Most of the time, the idea of being a consumer is a positive one: it is linked to the idea of wanting the thing that is consumed, whether it is whitegoods or holidays. In contrast, to *want* mental health services generally means to experience mental illness, something most people want to *avoid*. In this context, some people find use of the term 'consumer' inappropriate. More troublingly, evidence suggests that the majority of Australians who experience mental illness get no help. How can one be a consumer, when one does not get any help in the first place? Use of the term 'consumer' can hide the fact that most people with mental illness in fact never become 'consumers' of services they may desperately need.

1.28 On the other hand, in an environment where – as the Mental Health Council of Australia has highlighted – just getting some service can be a challenge, being a

12 There is a useful discussion of the terminology used in discussing mental illness in J. Meagher, *Partnership or Pretence*, Psychiatric Rehabilitation Association, NSW, 2002.

13 See for example, insane australia, *Submission 2*, p. 2.

consumer of mental health services still serves as a positive reminder that those services should be there, available for all who need them.

1.29 The committee has accepted the prevalent use of the term 'consumer' and uses it throughout this report. Two other terms are also used. The report refers to 'people experiencing mental illness' or 'people with a mental illness', partly to acknowledge that not all people who face mental illness ever receive help (in contrast to the implication of the term 'consumer'). The terms also remind us that people *experience* mental illness, they are not 'the mentally ill'. Many of us will experience an episode of mental illness at some time, but we will also be free of that illness for most of our lives.

1.30 Finally, in those contexts where it seems clearly appropriate, the report refers to 'patients', particularly when talking about clinical relationships with medical professionals.

