CHAPTER 3

MENTAL HEALTH AND HUMAN RIGHTS

Introduction

3.1 Mental illness raises many human rights issues. People with mental illness experience discrimination within society, and even within the health care system; mental illness can cause significant social disadvantage that under-resourced services may fail to adequately address; during episodes of acute illness, a person with mental illness may be unable to assert their rights at the very time when those rights may be most vulnerable to being breached; people experiencing acute mental illness may be treated against their will, or confined against their will, which can be a serious threat to their rights.

3.2 Human rights have been central to discussion about mental health care reform in Australia and overseas. Australia's 1991 *Mental Health statements of rights and responsibilities* focused on consumers' and carers' human rights. The intention was 'to promote social justice, equity, access and a compassionate society with metal health as a primary goal'.[1]

3.3 In the early 1990s, the National Inquiry into the Human Rights of People with Mental Illness sought to assess how well the human rights of the mentally ill in Australia were being honoured. The findings were not encouraging. That inquiry was conducted by reference to human rights instruments developed through the United Nations system and to which Australian governments are committed either as a matter of legal obligation or as a matter of policy.[2]

3.4 The Human Rights and Equal Opportunity Commission (HREOC) summarised the findings of the Burdekin Report:

> … people affected by mental illness suffered from widespread systemic discrimination and were consistently denied the rights and services to which they are entitled.
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> Families and carers were found to be badly overstretched and insufficiently supported. As well as improved crisis facilities and other community mental health services the Burdekin Inquiry recommended better information for carers and greater provision for involvement in decisions.
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> … recommended consistent accountability mechanisms and service standards.[3]

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[1] The Mental Health Consumers Outcomes Task Force, *Mental Health statements of rights and responsibilities*. AGPS, 2000, Foreword.

[2] Human Rights and Equal Opportunities Commission, *Submission 368*, p. 1.

[3] *Submission 368*, pp. 2–3.

3.5 The National Mental Health Strategy (NMHS) has been significantly influenced by the Burdekin Report and the *Statements of rights and responsibilities*. This has included the development of national standards for services. In 1996 the Australian Health Ministers' Advisory Council's National Mental Health Working group endorsed *National Standards for Mental Health Services* (the *Standards*) which signified 'an important milestone in the achievement of the 1992 agreement by Australian Health Ministers to the development of national standards for mental health services under the Mental Health Strategy'.[5]

3.6 The *Standards* demand that the rights of people affected by mental disorders or mental health problems be upheld by mental health services. They include twelve criteria regarding consumers' and carers' rights. The criteria state, among other things, that: mental health services staff should comply with relevant legislation and instruments protecting the rights of people with a mental illness; consumers should be informed of their rights and responsibilities; consumers should have access to independent advocates and to accredited interpreters; and consumers and carers should have easy access to a responsive and fair complaints procedure.[6]

Consumers' rights

3.7 The Burdekin Report made the obvious points that people with mental illness are human beings with human rights, and that they are entitled without discrimination to the full range of human rights.[7] The report concluded that:

> … our current neglect in terms of violations of the most fundamental rights of Australians affected by mental illness … demand an urgent, concerned and effective response.[8]

3.8 People with mental health issues are protected by the anti-discrimination provisions of the *Disability Discrimination Act 1992*:

> The DDA was enacted to eliminate, as far as possible, discrimination against people on the grounds of disability, and to ensure that people with

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[5] *National Standards for Mental Health Services,* Commonwealth of Australia, January 1997, Foreword.

[6] *National Standards for Mental Health Services*, Commonwealth of Australia, January 1997, pp 7–8.

[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*, AGPS, Canberra, 1993, p. 15.

[8] 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. 15.

> disability have the same rights to equality before the law as the rest of the community.[9]

3.9 HREOC informed the committee that all states and territories, except for South Australia, now also cover disabilities from mental illness with their equal opportunity or anti-discrimination laws in broadly similar terms to those contained in the Commonwealth Act.[10]

3.10 HREOC also submitted that a 2000 evaluation of Australian mental health legislation found that there had been significant progress in reform of that legislation since the adoption of the NMHS:

> Every state and territory has amended or is amending its mental health legislation to move away from an emphasis on detention to a model based more properly on human rights – although the same evaluation showed that no Australian jurisdiction had achieved full compliance with the UN Mental Health Principles.[11]

3.11 Reforms made under the NMHS have been beneficial for consumers:

> We acknowledge the extent to which some of the changes driven by the National Mental Health Strategy have influenced mental health services. Apparent among these is the consumer involvement in auditing services and the development of the National Mental Health Practice Standards and the National Mental Health Service Standards.[12]

3.12 Not all consumers do believe, however, that current policies adequately reflect their human rights:

> There is a growing worldwide social movement of mental health consumer-survivors that sees itself in the tradition of the civil rights movements, women's liberation and feminism, Gay Pride movement, and also the physical disabilities movements that are now recognised as communities with their own cultures, needs and rights. The rights of these other movements to speak – and be heard – in their own voices, from their own direct experience, and from within their own communities and cultures, is now generally recognised, accepted and respected in Australian society. This is not yet the case for mental health consumers and survivors.[13]

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[9] Australian Government, *Submission 476,* p. 6.

[10] Human Rights and Equal Opportunities Commission, *Submission 368*, pp. 4–5.

[11] *Submission 368*, p. 4.

[12] Mental Health Legal Centre, *Submission 314*, pp. 6–7. (The Australian Government stated that by June 2003 the National Standards for Mental Health Services were being used by 90 percent of all public sector mental health services. See Australian Government, *Submission 476*, p. 2.)

[13] insane australia, *Submission 2*, p.2.

[15] *Submission 2*, pp. 3–4. The submission lists a third category – discharge from services – which, while not discussed further here, is addressed in Chapter 8.

3.13 Consumers' rights may be compromised in other ways. Two of the most critical are denial of services and abuses within services.[15]

Denial of services

3.14 The *Statements of rights and responsibilities* states that 'the consumer has the right to a co-ordinated and ongoing range of adequately resourced …treatment'.[16] Many consumers, however, are denied proper treatment because insufficient resources are allocated to mental health services. In the words of the HREOC submission, 'Governments have not matched their words with resources'.[17]

3.15 According to insane australia:

> The current, limited public debate on mental health in Australia today focuses largely on the appalling lack of resources for mental health services. At insane we agree that mental health services are grossly neglected in this country and that many people are dying, mostly through suicide, from this neglect. This neglect needs to be seen as not just a failure to resource an essential service but as a violation of our fundamental human rights.[18]

3.16 However, insane australia submitted that lack of resources is a second-order issue. It argued that people in desperate need are denied access to services not only because of lack of resources but also because they do not meet diagnostic criteria.[19] It also argued that the real cause of human rights violations is the stigma surrounding mental health. This stigma results in discriminatory practices which are intrinsic to the system. Insane australia claimed that without a changed approach the allocation of more resources would only entrench the current human rights abuses of mental health consumers and survivors.[20]

3.17 The committee has discussed issues surrounding the allocation of resources to mental health services, stigma attaching to mental illness and problems regarding diagnosis. These matters are examined in Chapter 4, Chapter 7 and Chapter 5, respectively.

Abuses within services

3.18 Abuses within services are said to include hostile environments, mental health staff ignoring or dismissing consumers' personal feelings, physical abuse and forced treatment. Graphic examples are included in Chapter 8. The evidence suggests that if

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[16] The Mental Health Consumers Outcomes Task Force, *Mental Health statements of rights and responsibilities*. AGPS, 2000, p. 7.

[17] Human Rights and Equal Opportunities Commission, *Submission 368*, p. 5.

[18] insane australia, *Submission 2*, pp. 2–3.

[19] *Submission 2*, p. 3.

[20] *Submission 2*, p. 3.

there were greater levels of consumer participation in their own treatment and in the provision of mental heath services this might alleviate at least some of those concerns.

Consumer participation

3.19 The Burdekin Report and the various documents that comprise the NMHS endorse consumers' participation in the mental health system. One consumer commented on the findings contained in the Burdekin Report:

> For the first time in the history of mental health policy in this country we were perceived outside the sick role. This was a very significant change in policy direction and one of the key platforms of the First National Mental Health Strategy. There was a new vision for consumers to start playing vital roles in 'the system'; as peer supporters, educators of the mental health workforce, as consultants to the system, advocates and other paid roles in service delivery; consumer evaluators and decision makers; service auditors; researchers; orators and visionaries.[21]

3.20 A number of witnesses stated, however, that the promise of substantial consumer participation in the delivery of mental health care had not been met:

> Although National and State Mental Health Plans emphasise the importance of consumer participation, particularly in the planning, monitoring and review of mental health services, there is little evidence that consumers are meaningfully and substantially involved in the development of the methods and procedures used in the monitoring and review of services.[22]

3.21 Another witness submitted that:

> Consumer involvement in mental health programs and services is largely tokenistic, minimal and inadequate. Consumers need to be involved in their own treatment and in remaining well, and in the design of appropriate services and programs. There is currently very little funding and support for consumer driven services and recovery focussed services.[23]

3.22 The National Mental Health Plan 2003-2008 has identified the need for greater consumer participation at all levels, including the development of policy, planning, implementation and evaluation of services, and research.[24]

Extent of participation

3.23 The Australian Government submitted that at the national level consumers are now integral participants in policy forums and committees and are members of project

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[21] Ms Merinda Epstein, *Submission 207*, p. 6.

[22] Centre for Psychiatric Nursing and Practice, *Submission 217*, p. 4.

[23] South Australian Division of General Practice Inc., *Submission 88*, p. 11.

[24] Australian Government, *Submission 476*, p. 72.

reference groups.[25] Consumers and carers account for 25 percent of the membership of the Mental Health Council of Australia (MHCA), the peak body representing groups and individuals concerned with mental health.[26]

3.24 A witness who has been a consumer representative on a number of government advisory boards argued that the representation of consumer organisations on MHCA, on which other interested parties were also represented, was not sufficient for the views of consumers to influence decision making:

> Having responsibility for drafting a constitution [for the MHCA] we tried to build in clauses that would ensure that the consumer voice did not get swamped by all the professional and other voices which we knew would now demand to be part of this new and potentially influential body. It was obvious right from the beginning however that the MHCA could not be for the consumer voice the strong articulation that NCAG[27] had been. Put simply, we would never have the numbers … Having the numbers is essential because we don't have the power derived from professional authority.[28]

3.25 The Australian Mental Health Consumer Network made a similar point:

> Because of differences in assumed and real power between consumers and other players in the mental health industry the Australian Mental Health Consumer Network policy is that consumers should work together in at least pairs.[29]

3.26 The MHCA agreed that consumers are not sufficiently involved in mental health services:

> The [National Mental Health] Strategy has established consumer and carer participation in service planning and delivery as a desirable goal, though there is little evidence it has progressed into a practical reality. It has established consumer rights as an accepted part of service delivery, though again there is considerable evidence that the exercise of such rights is weakened by a lack of support for consumers and carers. There is inadequate and patchy funding to train and support carers and consumers to enable them to participate fully in this role, and what is available often does not address mental health issues specifically. As importantly, a change in service culture and practice by the mental health workforce is required so that they recognise the rights of and work effectively with consumers and

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[25] *Submission 476*, p. 2.

[26] Australian Government, *Submission 476*, p. 19.

[27] The National Community Advisory Group on Mental Health (NCAG), comprising consumers and carers, was established under the first National Mental Health Plan and reported directly to the Minister for Health.

[28] Ms Merinda Epstein, *Submission 207*, p. 8.

[29] Australian Mental Health Consumer Network, *Submission 322*, p. 33.

> carers. This is a fundamental and urgently needed element of workforce training and service.[30]

3.27 The involvement of consumers needs to respect the diversity of mental illnesses, but also the diversity of treatment outcomes and experiences. The unpaid nature of many consumer advocacy roles, the stigma that still attaches to having experienced mental illness, and the organisation of consultative meetings during the working day are factors that work against consumer representatives being people who have fully recovered from an illness or are successfully managing it while engaged in full-time work.

3.28 If people with a mental illness who are living and working in the community are involved as consumer representatives, this would provide a greater range of viewpoints, with several advantages:

> (a) they are an excellent resource that comes into play; and (b) the community begins to understand that good outcomes are highly possible. To do that we need to think about when we hold meetings and have funding to cover costs.[31]

3.29 The National Mental Health Reports (NMHRs) compiled by the Commonwealth Department of Health and Ageing contain data on the progress of mental health reform under the NMHS.[32] The latest report found that:

> Overall, the results suggest that the involvement of consumers and carers in mental health service development is increasing when assessed against these 'coarse' criteria.[33]

3.30 These 'coarse' criteria relate to the structural arrangements made by service delivery organisations for involving consumers and carers, with the data being assigned to one of four levels. A Level 1 arrangement is one in which consumers and carers are given a formal place in the local decision making structures or a specific consumer and carer group is established to advise on all aspects of service delivery. A Level 4 arrangement is one in which agencies have made no specific arrangements for consumer and carer participation.[34]

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[30] Mental Health Council of Australia, *Submission 262*, p. 10.

[31] Dr Simon Bridge, *Committee Hansard*, 5 August 2005, p. 76.

[32] Department of Health and Ageing, *National Mental Health Report 2005: Summary of Ten Years of Reform in Australia's Mental Health Services under the National Mental Health Strategy 1993-2003*, Commonwealth of Australia, Canberra, 2005, p. i.

[33] Department of Health and Ageing, *National Mental Health Report 2005: Summary of Ten Years of Reform in Australia's Mental Health Services under the National Mental Health Strategy 1993-2003*, Commonwealth of Australia, Canberra, 2005, p. 60.

[34] Department of Health and Ageing, *National Mental Health Report 2005: Summary of Ten Years of Reform in Australia's Mental Health Services under the National Mental Health Strategy 1993-2003*, Commonwealth of Australia, Canberra, 2005, pp. 59–60.

3.31 The 2005 NMHR found that the proportion of organisations with some type of formal mechanism for consumer participation had increased from a 53 percent 'baseline' in 1994 to 82 percent in 2003. Ten years into national mental health reform, however, 18 percent of mental health service organisations remained without a basic structural arrangement for consumer and carer participation.[35]

3.32 Taken at face value, these data indicate that, throughout Australia, arrangements have been made by most organisations to enable consumers to have input to the delivery of mental health services. The 2005 NMHR states, however, that consumers and carer representatives had suggested that the progress reported by the states and territories in the previous NMHRs did not match consumers' and carers' perceptions. In particular, consumers and carers considered that the measures used in the survey did not provide information on the extent of the commitment of an organisation to employing consultants.

3.33 In the 2003 National Survey, on which the 2005 NMHR was based, additional data were sought on the employment of consumers and carers as an indication of the commitment of organisations to consumer participation. These data showed what was described in the 2005 NMHR as 'a more realistic picture':

> Nationally, a total of only 53.6 fulltime equivalent consumer consultants and 8.6 carer consultants were employed across the 251 mental health service organisations funded by state and territory governments. Total expenditure on consumer and carer consultants in 2002-03 was $2.5 million, or 0.2 per cent of total spending on salaries and wages.
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> Consumer and carer consultants are not employed in all states and territories. Three jurisdictions (Western Australia, Tasmania and the Northern Territory) reported neither category within their 2002-03 workforces.[36]

Rationale for consumer participation

3.34 There was no real dissent from the widely-held view that consumers have a major role to play in mental health care. One witness summarised that role:

> Consumers can and should play a core role in monitoring service quality and ensuring that services are responsive to consumer needs. This includes employing consumers as consultants within services as well as ensuring they contribute to pre-service and in-service training for mental health professionals. Statewide consumer advocacy organisations are another important component as they can identify and seek redress for systemic

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[35] Department of Health and Ageing, *National Mental Health Report 2005: Summary of Ten Years of Reform in Australia's Mental Health Services under the National Mental Health Strategy 1993-2003*, Commonwealth of Australia, Canberra, 2005, pp. 59–60.

[36] Department of Health and Ageing, *National Mental Health Report 2005: Summary of Ten Years of Reform in Australia's Mental Health Services under the National Mental Health Strategy 1993-2003*, Commonwealth of Australia, Canberra, 2005, p. 61.

> problems as well as resourcing and supporting consumers taking on consultancy roles in services.[37]

3.35 The Victorian Mental Illness Awareness Council informed the committee that:

> It has been our observation and experience that the knowledge and skill gained through the "lived experience" is invaluable with regard to assisting other consumers not only when people are quite unwell, but also in the recovery and rehabilitation phases of their illness.[38]

3.36 Consumers play a useful role in the treatment even of forensic patients.[39] At the Thomas Embling Hospital in Melbourne, which treats forensic patients, consumers perform valuable functions:

> One of the things that has been a remarkable success—to me, at least—has been the development of consumer representatives within the hospital and within the community service … when this started seven or eight years ago I was somewhat sceptical about whether this could work, given the nature of our system and the nature of our patient population. In fact, it has been an extraordinary success. Every unit has its own consumer rep. We employ consumer representatives who have been patients in the hospital and are now in the community. They make a very important contribution to the running of the hospital and to the whole way in which we manage treatment.[40]

3.37 While there is clear support for consumer participation, its extent seems still to be too limited. This limited role afforded to consumers is even more clear when it comes to the absence of consumer-run services.

Services delivered by consumers

3.38 The committee heard evidence suggesting that twelve years after the adoption of first *National Mental Health Plan* there are no consumer-run mental health services in Australia, and that resources have not been put into exploring successful consumer-run services despite ample evidence from overseas that these work:[41]

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[37] Public Health Association of Australia Inc., *Submission 212*, p. 5.

[38] Victorian Mental Illness Awareness Council, *Submission 267*, p. 8.

[39] Forensic patients are persons charged with an indictable offence who have been found not fit for trial or who have been acquitted on grounds of mental impairment. People in mainstream mental health services who are a significant danger to others and who require the involvement of a specialist mental health service may also be considered forensic patients.

[40] Professor Paul Mullen, Clinical Director, Victorian Institute of Forensic Mental Health, *Committee Hansard*, 6 July 2005, p. 44.

[41] Ms Merinda Epstein, *Submission 207*, p. 10.

> Where is the money to investigate whether consumer-run crisis services are less damaging than professionally run ones, or peer counselling is more effective than drugs once every two weeks and so on.[42]

3.39 The Australian Mental Health Consumer Network submitted examples of publicly-funded, consumer-run services that had apparently achieved success in other countries. These were: safe houses that provide 24 hour crisis respite; sub-acute 'peaceful places'; and 'warm lines' that consumers can ring to speak to people who have experienced mental health issues first hand.[43] The SOAR Consumer Case Management in Madison, Wisconsin, and the employment of consumer case workers in Hawaii were also cited as examples of successful consumer-run services.[44] AMHCN pointed out that the only consumer-run recovery service in Sydney was achieving success but completely lacked government support:

> Pitane Recovery Centre is the only consumer run recovery centre for consumers in metropolitan Sydney. This centre has no funding whatsoever from mental health services and relies on small community grants, membership fees, and fundraising efforts of consumers. Yet this centre is gaining an international reputation due to providing a unique range of recovery activities which consumers not only enjoy but have given very positive feedback.[45]

3.40 Not everyone was supportive of consumer-run services. As regards the provision of treatment by consumers, one professional service provider observed:

> That consumers feel they could do better is important and is another indictment of service failure. … During the sixties we had consumer groups taking responsibility for the treatment of early psychosis. This experiment failed – people with psychosis do need medication. There is professional knowledge, and for all disorders evidence-based care is better than compassionate care…[46]

3.41 A community-based, volunteer, non-profit support and advocacy organisation submitted that:

> In theory the provision of services for consumers by consumers is laudable. However, to what extent this is feasible given the level of debilitation is unknown.
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> Having said that, only consumers can give a consumer perspective on what is and is not perceived by them to be a positive approach. However, because of the many different illnesses that make up mental illness, the vast variation in levels of severity of episodes from time to time for the

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[42] *Submission 207*, p. 17.

[43] Australian Mental Health Consumer Network, *Submission 322*, p. 21.

[44] Mental Health Association NSW Inc., *Submission 230,* p. 10.

[45] *Submission 322*, p. 56.

[46] Professor Gavin Andrews, *Submission 176*, p. 11.

> individual, and the vast differences between people it has to be recognised that this is a very complex question with no straightforward answer.[47]

Involuntary treatment

3.42 In an environment in which human rights are clearly tenuously maintained and sometimes breached, the forced treatment of individuals is a difficult and controversial practice. Involuntary admissions and treatment are common, and can be the norm in acute inpatient settings. For example, 83 per cent of patients admitted to St Vincents Acute Inpatient Unit in Sydney are involuntary admissions.[48] The actual level of people being treated against their will is probably higher than figures alone suggest. In addition to involuntary admissions, some patients are threatened with being made involuntary if they attempt to leave hospital.[49] In practical terms, these too might be considered 'involuntary' patients.

3.43 Involuntary and coerced 'voluntary' treatment give rise to questions regarding human rights, especially when the person being treated has not been charged with a crime:

> …for 5 months I was imprisoned in Mental Institutions and injected and forced to swallow tranquilisers against my will, without any proven wrong doing or transgression. I am completely innocent and seek full justice...[50]

3.44 Some took the view that the philosophical and practical problems with involuntary treatment were so great that it should never occur.[51] Most people with a mental illness are entitled to refuse treatment. In the words of one carer:

> Frustrating as it may seem to bystanders, especially families, individuals who are ill do have a right to refuse treatment. Some do so through lack of insight or misinformation; some for very sound reasons and good understanding of the effects of treatments.[52]

3.45 Some persons, however, do not have the legal right to refuse treatment. Mental health laws in all Australian jurisdictions make provision, in certain circumstances, for the detention of people with mental illness and for involuntary treatment. The relevant provisions in the different Mental Health Acts vary among the different jurisdictions, but generally they provide that if persons appear to suffer from a mental illness, if their health or safety is at risk, or if they pose a threat to members of the public, they may be 'scheduled' or 'sectioned' as involuntary patients.

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[47] Canberra Schizophrenia Fellowship, *Submission 103*, p. 10.

[48] St Vincents & Mater Health, *Submission 390*, p. 2.

[49] Australian Mental Health Consumer Network, *Submission 322,* p. 41.

[50] Mr Glen Minahan, *Submission 477*, p. 1.

[51] Ms Catherine Roper, Mr David Webb, *Committee Hansard*, 5 July 2005, pp. 24–30.

[52] Name withheld, *Submission 113*, p. 4.

3.46 The Mental Health Commission of New Zealand recently published a paper, *No-Force Advocacy by Users and Survivors of Psychiatry*, prepared by Tina Minkowitz, an American human rights lawyer and a self-described survivor of psychiatry. Also published in the document are commentaries on the paper from lawyers and consultant psychiatrists.[53] The introduction to that paper states:

> Minkowitz advocates for psychiatry without compulsion. Two principal grounds underlie her advocacy: force is a breach of human rights, and secondly that force is counter-productive, doing more harm than good. She examines a range of relevant human rights and human rights instruments, including the UN Convention Against Torture.[54]

3.47 The lawyers' commentaries on the Minkowitz paper focus on the limits of a human rights approach, especially when the courts are unwilling to uphold those rights, and on difficulties involved in relying on the UN Convention Against Torture. It is argued that allegations of mistreatment may provide a more effective route for challenging forced incarceration and compulsory treatment than reliance on the Convention.[55]

3.48 Two consultant psychiatrists who commented on the Minkowitz paper and the Mental Health Commission itself did not entirely agree with the 'no force' proposal. They considered that, in the words of Dr Codyre, an Auckland-based psychiatrist, the use of compulsion needs to become the rare and temporary exception rather than the rule for engaging people with serious mental illness in care and treatment.[56] There was agreement also that compulsion was overused. Dr Curtis, an Australian psychiatrist, stated that not all involuntary examinations are necessary,[57] and the Mental health Commission considered:

> … we believe that those emergencies [occasions when compulsion is necessary to protect people from immediate danger to themselves or others] are far less frequent for people who have not committed a crime than New Zealand's compulsory treatment rates suggest.[58]

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[53] Minkowitz, T. (2006) *No-Force Advocacy by Users and Survivors of Psychiatry.* Wellington: Mental Health Commission.

[54] Minkowitz, T. (2006) *No-Force Advocacy by Users and Survivors of Psychiatry.* Wellington: Mental Health Commission, pp 7-8.

[55] Minkowitz, T. (2006) *No-Force Advocacy by Users and Survivors of Psychiatry.* Wellington: Mental Health Commission, p. 8.

[56] Minkowitz, T. (2006) *No-Force Advocacy by Users and Survivors of Psychiatry.* Wellington: Mental Health Commission, p. 43.

[57] Minkowitz, T. (2006) *No-Force Advocacy by Users and Survivors of Psychiatry.* Wellington: Mental Health Commission, p. 38.

[58] Minkowitz, T. (2006) *No-Force Advocacy by Users and Survivors of Psychiatry.* Wellington: Mental Health Commission, p. 7.

3.49 Involuntary treatment, usually administered in the form of drugs, may be provided in an institution or in the community. Insane australia submitted that outside of the hospital setting forced treatments and coercion are found in the widespread and growing use of Community Treatment Orders.[59] Insane australia submitted that voluntary patients are often coerced into treatment by the threat of being made involuntary patients, or are deceived, tricked or bullied into taking potent psychotropic drugs with harmful side effects.[60] At the same time, the Committee heard from families who had tried to ensure that someone was admitted to or kept in hospital, and who felt that discharge was often neglectful, and sometimes tragic in its consequences.[61]

Consumers versus carers

3.50 Involuntary treatment also raises issues for carers, and is an area in the treatment of mental illness where there is at least the potential for tensions between the rights of carers and those of consumers. The *Statements of rights and responsibilities* states that:

> Carers and advocates have a right to comprehensive information, education, training and support to facilitate the understanding, advocacy and care of those consumers they care for.[62]

3.51 However, some consumers and their advocates consider that consumers and medical personnel should have absolute discretion not to provide information to carers:

> Crucially also, governments and service providers must resist the ongoing pressure from carers to facilitate greater access to confidential information about consumers. Privacy of information concerning mental health is a fundamental right protected at every level - from the International Covenant on Civil and Political Rights down to domestic legislative regimes and professional codes of ethics. And it has vital therapeutic importance. It is essential for consumers' trust and rapport with therapists that they are confident their privacy will be respected. Periodically in Victoria there is pressure to broaden the capacity of services to disclose information to carers beyond the provision of the Mental Health Act 1986. As it is that provision discriminates against consumers in that the comparable provision which applies to users of general health services under the Health Services Act 1988 contain no such exception. Facilitating greater access to personal information for carers than already exists is likely to lead to further distrust of and disengagement and alienation from mental health services.[63]

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[59] insane australia, *Submission 2*, p. 4.

[60] *Submission 2*, p. 4.

[61] Names withheld, Submissions 27, 31, 49, 367; Sharon Ponder, Submission 84.

[62] The Mental Health Consumers Outcomes Task Force, *Mental Health statements of rights and responsibilities*. AGPS, 2000, p. 17.

[63] The Mental Health Legal Centre, *Submission 314*, p. 19.

3.52 Some carers see things in a different light. A father of a son who experienced mental illness and who committed suicide and husband of a wife who requires care, including occasional hospitalisation, for bi-polar disorder, informed the committee that:

> In the case of my son, no information was ever provided to those who were expected to care for him after each of his 3 discharges. Family were not even informed that he was to be discharged despite the assumption that they would care for him. He was in effect discharged onto the street.
>
> I now have a much more aggressive approach and will demand, with whatever threats are necessary, information about my wife and how to care for her. This should not be necessary, but all too often is.[64]

3.53 Parents who lost a daughter to suicide submitted:

> We would rather have our daughter alive with some of her rights set aside than dead with her rights (uselessly) preserved intact.
>
> The most important 'right' that a mentally ill person (or an outside person coming into contact with a violent patient) has is the right to life…[65]

3.54 The committee is concerned that consumer rights, including the right to privacy, should be respected, but this should not become an excuse for failure to engage with the families of those with mental illness, inadequate discharge planning or failure to implement appropriate community care.

Accountability issues

3.55 Providers of mental health services, in common with providers of all public services, should be accountable to the people for the efficiency and effectiveness of those services. This requires that:

> Accountability mechanisms should be developed and implemented across the mental health system at both a Federal and state level to ensure that the progressive policies and philosophies contained in plans such as the National Mental Health Plan (NMHP) 2003-08 are actually delivered in practice.[66]

3.56 One measure of effectiveness is whether every person with a mental illness who requires care receives care. In the absence of an accurate assessment of needs, it is not possible to know if this has been the case. An indication of needs is provided by an Australian Bureau of Statistics study that found that in 1997 approximately 18 percent of Australian adults (2.4 million) had experienced a mental disorder at some

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[64] Mr Graeme Bond, *Submission 484*, p. 4.

[65] Name withheld, *Submission 28*, p. 4.

[66] Office of the Public Advocate Victoria, *Submission 172*, p. 3.

time during the previous 12 months.[67] The committee heard estimates that perhaps only 40 percent of people who should be treated are treated,[68] and that:

> Mental health consumers are less likely to be diagnosed with health problems, less likely to complete treatment, and less likely to receive state of the art treatment.[69]

3.57 There were concerns expressed about the level of accountability at a systemic level:

> … blaming the victim and shooting the messenger is very much alive and well in the mental health care system. Thus, accountability is only limited to the few things governments, organisations, managements and staff cannot get away with.[70]

3.58 Another witness contended that:

> … one of the reasons there are gaps in services generally and why certain groups continue to fall through the cracks is because both levels of government are not really held accountable for the mental health status of their communities. Governments should be aiming towards marked percentage improvements in the health status and quality of life in the population generally and in particular for vulnerable groups.[71]

Accountability to consumers

3.59 For the individual who does receive treatment the most significant measure of the effectiveness of mental health services is the outcome for that individual. Some consumers and service providers hold different views about what constitutes a successful outcome. According to the Victorian Mental Illness Awareness Council:

> The failure to either understand or respect the principles of consumer participation is perhaps best demonstrated by the introduction of consumer outcomes.
>
> Consumer outcomes have been introduced in some clinical and non-clinical services. Consumers in the psychiatric and disability rehabilitation sector were given a choice of measures. What the services failed to do was provide consumers with the education necessary to make an informed decision. Thus, services got the measure they preferred.[72]

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[67] Australian Bureau of Statistics, *Mental Health and Wellbeing: Profile of Adults, Australia*, 1997, AGPS, Canberra, p. 5.

[68] See for example, Professor Gavin Andrews, *Submission 176*, p. 11.

[69] The Richmond Fellowships of Australia, *Submission 234*, p. 7.

[70] Victorian Mental Illness Awareness Council, *Submission 267*, p. 12.

[71] Catholic Health Australia, *Submission 276*, p. 16.

[72] *Submission 267*, pp. 13–14.

3.60 Successful outcomes include the concept of recovery from illness, but recovery from mental illness may not have the same connotation as recovery from a physical ailment:

> Recovery is a myth; promulgated by over-optimistic therapists … Recovery is a very positive and uplifting word. It has been linked into a limited medical model where it does not fit. 'Personal recovery' may be a better term as it stresses the individual …[73]

3.61 The Centre for Psychiatric Nursing and Practice submitted that consumers should define recovery and what approaches should be used to facilitate recovery.[74] Desirable outcomes therefore may have a significant element of subjectivity:

> Outcome measures need to be consumer driven, if they aren't then their validity and reliability is highly questionable. We need to stop the pretence that experts know best and it is they who know what indicates a good outcome. The person receiving the service can only determine what constitutes a good outcome. Therefore measures need to be developed in collaboration with them.[75]

Advance directives – A way forward?

3.62 Consumers are likely to achieve successful outcomes if they participate in their own treatment, but this may not be possible at those times when they are extremely unwell. This has led to suggestions that when consumers are experiencing good health they could give advance directives (also known as 'living wills') about matters that may affect them later, during episodes of illness, including directives about their treatment.

3.63 HREOC produced a discussion paper on 'living wills' ten years ago. The Commission defined a 'living will' as:

> … a voluntary statement outlining the types and conditions of medical care that a person would prefer in a given situation prior to requiring care. A person may also nominate one or a number of substitute decision-makers (Power of Attorney) to make decisions of their own behalf. A living will sets out a consumer's wishes in relation to treatment decisions in advance … A living will may also cover financial, personal and medical decisions concurrently.[76]

3.64 The discussion paper addressed several issues surrounding the making and implementation of advance directives, including their legal status, invocation and

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[73] The Richmond Fellowships of Australia, *Submission 234*, p. 2.

[74] Centre for Psychiatric Nursing Research and Practice, *Submission 217*, p. 6.

[75] Dr Barbara Tooth, *Submission 453*, p. 7.

[76] Human Rights and Equal Opportunity Commission, *Discussion Paper: Living Wills*, http://www.hreoc.gov.au/disability_rights/hr_disab/Wills_DP/wills_dp.html (accessed March 2006).

advocacy implications. HREOC invited comment from interested parties, and received several submissions in response, but appears not to have proceeded to making a report.[77]

3.65 The submissions made in response to HREOC's invitation canvassed many matters of a legal, medical and practical nature. The committee has noted these matters, but has not been able to consider them in detail. It is of interest, however, that provision has already been made in Canada for agreements similar to the proposed advance directives.

3.66 The committee was told that if consumers with episodic illnesses were able to prepare advance directives regarding their treatment and other matters of importance this could somewhat alleviate their situation if they are involuntarily detained. A witness gave the following example of what might be included in an advance directive on treatment:

> 'I do not want ECT unless' or, 'I have been tried on Mellaril and I have really bad side effects from it. Please don't put me on Mellaril, but I have had this other drug before and that has been okay.'[78]

3.67 The committee was also given an example of another important matter that could be included in an advance directive:

> … one woman was taken by the police from her flat. They left two children under 10 in the flat. This woman became very upset. They saw that as part of her psychotic illness so they just kept medicating her more and more. It turned into a crescendo in the acute setting. This woman said to us that she wanted to have an advance directive that said: 'If I get taken away by the police, this is my sister's number. Please ring her. She needs to come straightaway and look after the kids.' That does not seem to be too difficult a request. If it is all written down beforehand, it is very empowering for people to have.[79]

3.68 Other witnesses similarly advocated the making of advance directives. The Mental Health Legal Centre (MHLC) informed the committee that it considered the introduction of 'living wills':

> … is crucial for people who know there is some likelihood that they might be involuntarily detained against their wishes. They can include areas such as treatment eg. what drugs to avoid, views on ECT, activities or therapies of preference, nominated contacts and people to be consulted or not; employment and study, role of family; what will happen to the children, this is especially important if the consumer is a single mother – no medical

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[77] HREOC submitted that in the time since the release of the *Burdekin Report* it has not had sufficient resources to continue a detailed monitoring role on mental health issues. See Human Rights and Equal Opportunity Commission, *Submission 368*, p. 4.

[78] Ms Merinda Epstein, *Committee Hansard*, 6 July 2005, p. 28.

[79] Ms Merinda Epstein, *Committee Hansard*, 6 July 2005, p. 28.

> intervention will have any salutary effect unless mothers know their children are safe; the bills are paid etc. [80]

3.69 Dr Meg Smith OAM, speaking at a national conference on mental health services at the University of Newcastle in 1997, discussed what could be included in advance directives, making similar points to those of Ms Epstein and others. She identified 'treatments to which one objects' as being appropriate for inclusion in an advance directive. She reported that in her case haloperidol had dreadful side effects, while another medication, clonazepam, was much more pleasant, had fewer side effects and worked just as quickly as haloperidol.[81]

3.70 From her experience as a member of the New South Wales Guardianship Board Dr Smith suggested that guardianship legislation, or the principles of guardianship, may be an appropriate vehicle for the making of advance directives.[82] She also offered practical advice to people thinking of making a living will:

- Research the current service system. Choose a couple of hospitals, asylums or places where you can be cared for.
- Pick some good friends or carers to carry out your wishes; who do you know who is strong, determined, articulate, persistent? …
- Find out about new treatments and services. Talk to other consumers. Ask your health care workers…
- Educate your health care workers. What are their attitudes and values?[83]

3.71 According to Dr Smith:

> Living wills and, more importantly, the process of making one, can be a powerful way of accepting disability in your life and putting it into some context. I don't think very much now about impending illness or worry about what is going to happen if or when I become ill. Like my other will it is tucked away to be activated when necessary.[84]

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[80] The Mental Health Legal Centre, *Submission 314*, p. 11.

[81] Dr M Smith, *Living Wills for People with a Psychiatric Disability*, Proceedings of the Conference, *Mental Health for All: What's the Vision*, the University of Newcastle, 13-15 February 1997, p. 127.

[82] Dr M Smith, *Living Wills for People with a Psychiatric Disability*, Proceedings of the Conference, *Mental Health for All: What's the Vision*, the University of Newcastle, 13-15 February 1997, pp 127-128.

[83] Dr M Smith, *Living Wills for People with a Psychiatric Disability*, Proceedings of the Conference, *Mental Health for All: What's the Vision*, the University of Newcastle, 13-15 February 1997, p. 128.

[84] Dr M Smith, *Living Wills for People with a Psychiatric Disability*, Proceedings of the Conference, *Mental Health for All: What's the Vision*, the University of Newcastle, 13-15 February 1997, p. 127.

3.72 However, Dr Peter Bartlett, Nottinghamshire Healthcare NHS Trust Professor of Mental Health Law at the University of Nottingham, UK, observed that, based on the judgements of British courts, there may be difficulties in the application of advance directives:

> The courts have no stomach for taking rights seriously in this area, [involuntary treatment] particularly when the contest is between a psychiatric patient and doctors or other well-intentioned professionals. The precisely similar problem occurs, by the way, for advance directives: the experience is that the courts will bend over backwards to find reasons why they don't apply.[85]

3.73 Despite some possible legal problems, MHLC stated that the development of 'living wills' is 'an essential tool to protect the human rights of people with episodic illness'.[86] It recommended to the committee that there should be a national approach to pursue the initiative.[87]

Conclusion

3.74 Since the release of the *Burdekin Report* there have been significant advances in the official acknowledgment of consumers' human rights and the incorporation of those rights in legislation. Nevertheless, there is evidence that, in practice, the rights of consumers may be denied by a lack of adequate services, and there is anecdotal evidence that consumers have sometimes suffered abuse within services.

3.75 Consumers also do not participate in their treatment to the extent that the NMHS demands that they should. Witnesses made many suggestions as to how consumer participation could be increased. These suggestions may be found in the submissions made to the committee, and should be explored further by service providers.

3.76 A suggestion of particular interest, which should be explored as a matter of priority, is that people who have episodic illness should have the right to make advance directives regarding their treatment and other matters of importance. If these directives were followed by service providers, there could be many advantages. Consumers would have a greater voice regarding their own treatment, within a legally recognised framework, however sick they might occasionally be. Service providers could be more efficiently guided toward successful treatment strategies, which would reduce the time consumers spend in care, reduce the pain and suffering they endure, and reduce the costs. Transitions into and out of acute care could be smoother, and less traumatic for family members. Finally, many of the serious concerns surrounding

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[85] Dr P Bartlett, *Human Rights? Of course ... but what does that mean?* in *No-Force Advocacy by Users and Survivors of Psychiatry*, Wellington: Mental Health Commission, p. 26.

[86] *Submission 314*, p. 11.

[87] *Submission 314*, p. 11.

inappropriate treatment and unnecessary curtailment of consumers' rights could be addressed.