

Chapter 6 Privacy, confidentiality and information

The moment Reno cancelled his authority for me as his Nominee meant that he had no-one that cared about him or had access to any information to help him. Had I known who his psychiatrist was and had I been able to get information, in order that there was a support team in place, maybe Reno would still be here.³³⁹

[Mr Robert Wirth]

In evidence presented to the Committee, carers, families and advocates for people with serious mental illnesses raised questions about whether or not upholding a person's right to privacy was always compatible with delivering appropriate care. Privacy and confidentiality laws shape the delivery of mental health services in NSW, from individual primary care through to statewide data collection. This chapter considers the legal and practical dimensions of mental health information exchange in NSW, and presents the different viewpoints of stakeholders in privacy and mental health information.

Confidentiality and consent

6.1 The right of people with a mental illness to privacy and confidentiality was acknowledged throughout the inquiry. The anguish families and carers experience due to mental health information disclosure restrictions, however, was encapsulated in many personal accounts related to the Committee by witnesses and in submissions. The Hon Frank Walker QC, President of the Schizophrenia Fellowship NSW described his own experience as follows:

If you are a parent you may have a different view, and I was twice. I found myself totally frustrated and very angry about the total lack of information. I never managed to get any explanation out of a psychiatrist ever about the nature of the disease. I had to find out for myself. I had to educate myself. I got no support at all at any stage over a long period of time, and nor did my family. Of course the families are often in just as much crisis. It is a very terrible thing, this schizophrenia disease. It has a massive impact upon family relationships and to be left in a vacuum is a very frightening thing for a family.

The disease, of course, presents with symptomatology that is delusional, often extremely delusional; these people live in an unreal world and you could get no information at the time when my son was in terrible delusions. He had five voices talking to him constantly year in, year out, and he had a total lack of sense of reality for large periods of time, but never once was I able to persuade a medical practitioner to assist me as to what the nature of the problem was or what should be done about it. Not only that, he was extremely paranoid and he feared any part of his medical record getting out because he knew that the CIA would get it and he knew that aliens with laser beams were likely to use that information to hurt him. Yet that was the excuse used to keep my family in the dark.³⁴⁰

³³⁹ Submission 303, Mr Robert Wirth, p 6

³⁴⁰ The Hon Frank Walker QC, President, Schizophrenia Fellowship NSW, Evidence, 8 August 2002, p 29

- 6.2 The mother of a man who had suffered schizophrenia for seven years described her own situation as follows:

As a carer I have felt in the ‘dark’. No-one sat down with me and explained the system, or how to get help and so on. When I visit my son in hospital no-one comes up to say how he is going, what the diagnosis is, what medication he has to have, when he is going home etc. I have had to be very ‘pushy’ and ‘demanding’ otherwise I would not have got any information. This all causes extra stress on the carer.³⁴¹

- 6.3 Another carer for a mentally ill relative commented at the Committee’s Public Forum on 7 August 2002:

We take on all the responsibilities of seeing them take medication, keep appointments, pay bills, but when we ring the doctors to see if they have arrived for an appointment we are so often told ‘I cannot tell you unless the patient gives his permission’. Our hands are tied in so many unnecessary ways.³⁴²

- 6.4 The laws and principles of confidentiality and privacy are complex. The following sections describe how they apply in NSW and the impact they have on mental health services and their clients, as well as on carers and families.

Confidentiality and privacy in mental health settings

- 6.5 The common law notion of patient-doctor ‘confidentiality’ outlines a clinician’s duty of confidence to his or her patient, and relies on the clinician’s ‘obligations of conscience’ on what information is disclosed, and how it is disclosed.³⁴³ An obligation of conscience may not only prevent the disclosure of information, but also the unauthorised use of that information. Confidentiality at common law does not mean that the patient-confider owns the information they disclose.³⁴⁴

- 6.6 Privacy NSW has described ‘privacy’ as meaning:

the right to be let alone, the right to personal space or autonomy, the right of people to exercise control over their personal information or the degree of interference with their personal life.³⁴⁵

- 6.7 Since 1988, a number of Commonwealth and NSW Acts have been enacted to protect the right to privacy of individuals. The *Commonwealth Privacy Act 1988*,³⁴⁶ the *NSW Privacy and Personal Information Protection Act 1998* (PPIP), and the recent *NSW Health Records and Information Privacy Act 2002* (HRIP), serve to protect individuals’ rights to privacy by defining the responsibilities of health service providers to their clients in dealing with

³⁴¹ Submission 177, Mrs Dorothy Ridley, p 2

³⁴² Mrs Jean Cooper, Speaker public forum, 7 August 2002

³⁴³ R Magnusson, *Data Linkage, Health Research and Privacy: Regulating Data Flows in Australia’s Health Care System*, Sydney Law Review, Vol 24, no 1, 2002, p 21

³⁴⁴ See *Breen v. Williams* (1996) 186 CLR 71 at 81.90. 128-29

³⁴⁵ Privacy NSW, *Submission to the ALRC/AHEC Issues Paper on Genetic Information and Privacy*, 2002, p 1

³⁴⁶ Amended by the *Privacy Amendment (Private Sector) Act 2000*

personal information. The *Commonwealth Privacy Act 1998* sets out ten National Privacy Principles (NPPs) that represent the minimum privacy standards for handling personal information. The HRIP has fifteen Health Privacy Principles (HPPs) which will be discussed later in this chapter.

- 6.8** The *National Standards for Mental Health Services* were first published in 1997. These standards are a ‘blueprint’ for services and quality improvement, and underpin National Mental Health Care Plans.³⁴⁷ National Standard Number 5 deals with privacy and confidentiality, where Mental Health Services must “ensure the privacy and confidentiality of consumers and carers”.³⁴⁸
- 6.9** In NSW, Section 289 of the *Mental Health Act 1990* prohibits disclosure of any information “obtained in connection with the administration or execution” of the Act or the regulations unless the person “about who the information was obtained” gives consent.

Consent and guardianship

- 6.10** Consent to any medical treatment must be obtained prior to the treatment commencing. If patients are to give consent to any medical treatment, they must be deemed capable of understanding the nature of the treatment or action proposed, possible outcomes and what will happen if they refuse to give consent.
- 6.11** Under the *Mental Health Act 1990*, and now the *Health Records and Information Privacy Act 2002*, a patient’s consent must also be sought to permit the disclosure of information about him or her to other parties. The HRIP allows for disclosure of information to an immediate family member of the individual for ‘compassionate reasons’ (see HPP 11 [g]). Where a person is incapable of giving consent, an ‘authorised representative’ may act on their behalf. Under Part 1, Clause 8 of the HRIP, the person may be:
- an attorney for the individual (under an enduring power of attorney)
 - a guardian within the meaning of the *Guardianship Act 1987* or a person responsible within the meaning of Part 5 of the Act
 - a person with parental responsibility if the person is a child
 - a person otherwise empowered under the law to act in the best interests of the individual.
- 6.12** The NSW *Guardianship Act 1987* permits decisions to be made for a person where they are incapable of giving consent and a Guardianship Order does not exist. Under Part 5 of the Act, a guardian, relative, friend, unpaid carer or other ‘person responsible’ may give consent where medical treatment is required. Currently, this provision for substitute decision-making in the *Guardianship Act* does not appear to be widely applied in the mental

³⁴⁷ Submission 226, Commonwealth Department of Health and Ageing, Attachment: *National Standards for Mental Health Services*, p i

³⁴⁸ Commonwealth of Australia, *National Standards for Mental Health Services* (1997), pp 7-12

health system. Mr Robert Ramjan, Executive Officer of the Schizophrenia Fellowship of NSW commented:

There is the legislation in the Guardianship Act that says there is a person responsible and that person responsible can be involved in medical decisions and medical information...You do not need a guardianship order if there is a person responsible who can make the consents and who can deal with the information... It just means the health authorities do not understand the concept of 'person responsible'. But the Act actually provides for a person responsible who can hear the information and make the decisions if the subject person is not competent to do it themselves.³⁴⁹

6.13 Mr Walker also commented that mental health care professionals appeared to be concerned they might offend under the *Mental Health Act 1990* if they sought decisions from a 'person responsible' even when a mentally ill person is clearly incapable and in need of treatment:

They will not tell you he is on the streets in King's Cross anyway, even though they know it. They will not tell you that... That is their duty under the Mental Health Act. That is the doctor's duty. District Court judges complain to me all the time that they make orders saying people are incompetent, they say they are a danger to themselves or are a danger to the general public; they then send them into the health system who will immediately discharge them into the community where they kill someone or they do some damage or they kill themselves. That is something that happens every day of the week. They are prepared to make that decision to overrule a judge's decision, a seriously taken judicial decision, they are prepared to do that, yet they are not prepared to say "This person is incompetent. He is delusional. He is suicidal. We are going to ring the parent and tell them that he is up the Cross trying to sell his body".³⁵⁰

6.14 The Office of the Public Guardian NSW commented in its submission that, even where formal Guardianship Orders exist, some mental health practitioners are nevertheless unaware of their obligations to obtain consent under Part 5 of the *Guardianship Act 1987*:

Often planning for a person is undertaken without the input of the person's appointed guardian. Consent to decisions made concerning discharge and follow up treatment may be required under the functions of the guardianship order. In some circumstances mental health professionals contact the guardian to 'inform' them of a decision rather than seek the consent of the legally appointed guardian. Greater discussion and inclusion of the guardian in the planning phase would avoid this.³⁵¹

6.15 This indicates that in some cases consent has not been properly obtained prior to decisions regarding treatment being taken. The Committee is concerned that this is contrary to both the *Guardianship Act 1987* and the *Mental Health Act 1990*.

6.16 The Committee acknowledges that in mental health settings, assessing a person's ability to make an informed decision can be difficult. Where an illness is episodic, obtaining and retaining consent can also be highly challenging. The family of a person who suffered

³⁴⁹ R Ramjan, Evidence, 8 August 2002, p 28-29

³⁵⁰ F Walker, Evidence, 8 August 2002, p 29

³⁵¹ Submission 255, Office of the Public Guardian NSW, pp 6-7

frequent and lengthy episodes of psychosis suggested a system of ‘secondary guardianship’ for those suffering episodic illnesses. The model was envisaged as follows:

A secondary guardian [would be] chosen by the mentally ill/disordered person to represent their personal interests and to make relevant decisions on the behalf of that person while under a mental health schedule. Secondary Guardians can only be chosen by the mentally ill/disordered person when they are not under schedule, agreed to in a signed legal contract.³⁵²

- 6.17** This model is similar to the existing provision for Enduring Guardianship in the NSW *Guardianship Act 1987*. Enduring Guardianship enables a person to choose another person or persons to make personal or lifestyle decisions for them only if they become incapable of doing it themselves. The authority to override a mentally ill person’s objections to medical treatment cannot be given to the Enduring Guardian. Only the Guardianship Tribunal can do this.³⁵³
- 6.18** The Committee notes that decisions relating to the appointment of guardians (including enduring guardians) can now be reviewed by the Administrative Appeals Tribunal under the *Guardianship and Protected Estates Legislation Amendment Act 2002*. This legislation would further protect the rights of people with a mental illness wishing to appoint guardians as per the Committee’s recommendations.
- 6.19** The complexities of establishing competence during an episode of severe mental illness mean that Enduring Guardianship in its current form may not be suitable for the ‘secondary guardianship’ model proposed above. A specific adaptation of the Enduring Guardianship system is worthy of further consideration. Under such a model, people with episodic mental illnesses, while they are capable, could nominate people of their choice to be secondary guardians. When the person is scheduled or deemed incapable of making informed consent, the secondary guardianship order would commence. The order would cease to apply as soon as:
- pre-agreed recovery milestones are met or
 - the person is no longer under schedule or
 - the person is deemed capable of giving informed consent, either by their psychiatrist or the Guardianship Tribunal.
- 6.20** Such a system would need to contain safeguards and frequent dates for review. Nominated secondary guardians would need to demonstrate to the Guardianship Tribunal their understanding of and commitment to secondary guardianship, and the principles of protecting patients’ rights.
- 6.21** Given the Public Guardian’s evidence that medical officers currently do not routinely seek the permission of appointed guardians for consent to treatment, it would appear that substitute decision making in NSW needs to be better understood in the mental health system.

³⁵² Submission 223, Mr Patrick Connoley and Ms Elizabeth Brennan, p 13

³⁵³ Guardianship Tribunal of NSW, ‘Enduring Guardianship’ Factsheet, p 1

Recommendation 30

That the Minister for Health and the Attorney General review the *Guardianship Act 1987* with respect to people who suffer severe and/or episodic mental illnesses during which they are not capable of making informed consent. This review should include the possibility of enduring guardianship.

Recommendation 31

That the Centre for Mental Health and the Office of the Public Guardian work together to develop an information package for mental health professionals that:

- outlines their obligations as well as the rights of families and carers under relevant mental health, privacy and guardianship legislation, and
- clarifies the existing definitions of ‘consent’ and ‘substitute decision-making’ in mental health settings and communicate this clarification to mental health professionals.

Recommendation 32

That the Minister for Health prepare a proposal for consideration by the Minister for Education to ensure that students in undergraduate and postgraduate health programs receive training regarding:

- their obligations to seek information from and disclose information to consumers, families, guardians, carers and other service providers, and
- the rights of consumers, families and carers under the relevant mental health, privacy and guardianship legislation.

Families’ and carers’ rights

6.22 Although evidence from carers, families and rehabilitation services endorsed the right of mental health service users to confidentiality and privacy, where a serious mental illness was involved, many families, carers and NGOs expressed frustration with the inconsistent application of privacy and confidentiality principles.

6.23 The NSW Consumer Advisory Group (NSW CAG) identified the ‘underlying tension’ between consumer, carer and health care providers in regard to the use of information:

rights to information about admission, treatment, and discharge planning (including the location to which the consumer will be discharged, and the date, time etc of planned discharge) currently either do not exist for carers, or are granted informally by hospitals/agencies, at their discretion and without a formal legal basis, or are subject to the consent of the consumer. While it is the right of the consumer to deny consent (a right which may not always be in the best

interest of the consumer) nevertheless situations where consumer consent is not sought, or given and not acted upon, give rise to considerable distress and danger. A consistent approach across the state, with a firm legal basis, could address this.³⁵⁴

6.24 Carers NSW reported that information withheld by mental health service providers could hinder rehabilitation:

They do not discuss their relative's care with them, do not ask the carer's opinion and do not tell them about medication changes. This makes it extremely difficult for some carers to manage their caring responsibilities effectively. The carers often feel as though they learn by trial and error...A major complaint of carers is often that confidentiality requirements are used to exclude them...However as the major people responsible for their relatives when they are unable to care for themselves, carers need information – both for effective management and their own safety.³⁵⁵

6.25 The Parents and Carers Mental Health Group, North Casino, also suggested that excessive application of confidentiality principles impeded appropriate treatment:

It is our view that the Mental Health Act does not provide for adequate input by carers/relatives/significant others. It is realised that confidentiality is extremely important. However, each family involved with mental health services in this area, who are members of the Parents and Carers Group, has experienced frustrating and dangerous situations caring for their family, due to the restrictions placed on them by the problems associated with confidentiality and the refusal by many mental health staff to acknowledge the validity and indeed, the importance of input into that person's care, appropriate intervention and ongoing treatment plan.³⁵⁶

6.26 Ms Cathy Heyes emphasised the need to include families in assessment procedures:

Clinicians must avail themselves of all available sources of information if they are to do comprehensive information gathering. Thus the family needs to be involved in the suicide assessment procedure...Unfortunately my experiences show that family are not taken seriously or included in the assessment yet they know the person better than any psychiatrist can through a one hour interview.³⁵⁷

6.27 Submissions such as that from Ms Heyes emphasised that not only do carers require information from mental health services to provide ongoing care, but they also need the opportunity to provide information when acute care may be required. At present, carers do not appear to have opportunities to either provide input or receive basic medical advice regarding the person they care for. In the case of people suffering from episodic illnesses, carers and families expressed the view that their ability to detect 'warning signs' or rapid deterioration needed be taken into consideration by health professionals, if early intervention is to work. Carers NSW stated:

³⁵⁴ Submission 162, NSW Consumer Advisory Group, pp 30-31

³⁵⁵ Submission 196, Carers NSW, p 6

³⁵⁶ Submission 49, Parents and Carers Mental Health Group, North Casino, p 2

³⁵⁷ Submission 150, Ms Cathy Heyes, p 10

The mental health system would do well to listen to carers' knowledge of the person they support. This will minimise the chances of a person becoming less manageable because they have not been adequately assisted with either medication or support.³⁵⁸

6.28 This observation is consistent with the findings of the *International Mid-Term Review of the Second National Mental Health Plan for Australia*. Despite the desired outcome in the Strategy of “increased consumer and carer satisfaction with clinicians’ response to early warning signs”³⁵⁹, the reviewers found:

It was commonly reported by consumers and carers that crisis services were not responsive to those who were beginning a period of relapse.³⁶⁰

6.29 The NSW CAG argued for the right of carers and advocates to provide relevant information to mental health professionals. The submission states:

While we note that the Mental Health Act precludes the giving of information to carers by mental health professionals without consumer consent, the Act does not preclude the right of carers to give information. The rationale for adding this right for carers and advocates flows from the Mental Health Statement of Rights and Responsibilities (Australian Health Ministers 1991, p 18, para 1-3). This states very clearly that carers/advocates have rights to initiate contact and give relevant information to service providers. This request should not contravene issues of confidentiality but is often denied carers on that ground.³⁶¹

6.30 Like carers and families, NGOs outlined that, as providers of services for people with a mental illness, they require information about clients in order to provide appropriate care. In its submission, UnitingCare reported:

UnitingCare services also have problems getting information from mental health services – information which would be important in identifying how the welfare service can assist the client. In one case, a woman who has psychotic episodes was referred to UnitingCare Burnside from the Department of Community Services. Burnside was concerned about being able to support the woman properly, but mental health services would give it no information about the woman’s condition.³⁶²

6.31 UnitingCare’s submission also made the point that “while the mental system is supposed to be multidisciplinary”, the model is still “very medically based”. UnitingCare staff felt that their insights went unheard by psychiatrists.³⁶³

³⁵⁸ Submission 196, Carers NSW, p 8

³⁵⁹ Australian Health Ministers, *Second National Mental Health Plan*, Mental Health Branch, Commonwealth Department of Health and Family Services, 1998, p 14

³⁶⁰ V Betts and G Thornicroft, *International Mid-Term Review of the Second National Mental Health Plan for Australia*, 2001, p 11

³⁶¹ Submission 162, NSW Consumer Advisory Group, p 31

³⁶² Submission 78, UnitingCare, p 29

³⁶³ Sr M Harris, Evidence, 23 May 2002, p 28

Limited disclosures of confidential information

6.32 The Hon Frank Walker QC and Mr Robert Ramjan from the Schizophrenia Fellowship suggested an information disclosure model to involve families and carers while still observing privacy and confidentiality principles. The model would provide for an ‘interim order’ for substitute decision-making. Mr Walker explained how an interim order would be administered:

You would think that it would be easy to get an interim order situation the same as you can get a warrant from a judge; if there were someone in the health care system you could contact and say: “I think we really ought to tell the parents in this case”, and you have an interim order. If the person wants to challenge it there is a judicial challenge to it later but at least at that time the parents are advised and may be able to save the life of their child.³⁶⁴

6.33 In July 2002, Victoria amended Section 120A of its *Mental Health Act 1986* to allow limited disclosure of confidential information about clients of mental health services, without the consent of the client. The following circumstances are exceptions to confidentiality requirements that will allow information to be disclosed:

- to guardians, family and primary carers if the information is reasonably required for the ongoing care of a client and the person who is receiving the information will be involved in providing the care
- where it is required in connection with the further treatment of a client.³⁶⁵

6.34 Section 120A of the Victorian *Mental Health Act 1986* also allows disclosure:

- for management purposes (HPP 2.2 [f])
- to prevent risk to a person or the public (2.2 [h]), or
- when a person is missing or dead.³⁶⁶

6.35 In NSW, Health Privacy Principle 11 (g) of the *Health Records Information Privacy Act 2002* allows for disclosure of information without consent to immediate family members for ‘compassionate reasons’ when a person is incapable of giving consent. This is restricted on the basis:

the disclosure is not contrary to any wish expressed by the individual (and not withdrawn) of which the organisation was aware or could make itself aware by taking reasonable steps.

6.36 In view of the current inconsistent application of privacy and confidentiality principles in the NSW mental health system in relation to patients, guardians, families, carers, and other service providers, the provision for disclosure for ‘compassionate reasons’ is ambiguous

³⁶⁴ F Walker, Evidence, 8 August 2002, p 30

³⁶⁵ Department of Human Services, Victoria, *Confidentiality: Amendments to Section 120A of the Mental Health Act 1986*, p 1

³⁶⁶ *ibid*, p 2

and open to interpretation. Specifically, it does not provide for disclosure to assist in the ongoing treatment and care of the client, as in Section 120A of the Victorian *Mental Health Act 1986*.

Recommendation 33

That the Minister for Health seek to amend the NSW *Mental Health Act 1990* to allow limited disclosure of confidential information about clients of mental health services without the consent of the client. These exceptions to confidentiality would allow information to be disclosed in the following circumstances:

- to guardians, family and primary carers if the information is reasonably required for the ongoing care of a client and the person who is receiving the information will be involved in providing the care and
- where it is required in connection with the further treatment of a client.

Recommendation 34

That, prior to the operation of the *Health Records Information Privacy Act 2002* in 2003, NSW Health and the NSW Privacy Commission ensure that public and non-public health care service providers, be provided with adequate information and training about consent and substitute decision-making laws in NSW.

Recommendation 35

That the Minister for Health allocate funds for the training of public health employees on the requirements of the *Health Records Information Privacy Act 2002*.

Police access to information in crisis situations

- 6.37** NSW Health and the NSW Police Service are co-parties to a Memorandum of Understanding (MOU) for the management of situations involving persons who may have mental illness.³⁶⁷ Despite this agreement, both the Police Association of NSW and NSW Police submissions argued that police information requirements were not being satisfied.
- 6.38** NSW Police submission noted the importance of mental health workers attending crisis situations. This was seen as crucial not only for early intervention in the situation, but also because specialists could provide background information on the person that might be crucial in assessing the current situation and determining an appropriate response.³⁶⁸
- 6.39** NSW Police is concerned that: “Police access to crisis teams is not available on a 24 hour basis statewide” and that the 24-hour general advice line did not provide operational support in attending scenes.³⁶⁹ The NSW Police submission recommended that mental

³⁶⁷ For a detailed understanding of the Memorandum of Understanding, refer to Chapter 14 of this report.

³⁶⁸ Submission 286, NSW Police Service, p 8

³⁶⁹ *ibid*, p 7

health teams be adequately funded to provide an operational 24-hour crisis team response to police and the community in all areas of the state.³⁷⁰

6.40 The Police Association recommended that police be allowed to access information about individuals in crisis situations:

This could take the form of a national health database for identification purposes in relation to the storing and updating of an individual's name and medical history. Access by hospitals to this information would in turn enable police to be better informed and more aware of how to best approach and interact with these individuals when they come in contact with them.³⁷¹

6.41 Mr Ian Ball, President of the Police Association, told the Committee that he recognised such a register would involve “quite considerable legislative change”,³⁷² but that:

We are not asking that we know the ins and outs of their illness. What we are asking is just tell us that these people have some problems so our members can be a little aware.³⁷³

6.42 The Committee asked the NSW Privacy Commissioner, Mr Chris Puplick, about the implications of enabling police access to information stored on a national mental health database. Mr Puplick responded:

I do not object to people, whether it is the police or others, having access to information which is held by a department like the Health Department if it can be demonstrated that it is to the positive benefit of the individual about whom the information is being sought or if it is to prevent imminent threat to life or health, or danger or security of other persons, and provided—and I think this is the important thing—that there is a proper audit trail and a proper degree of accountability.³⁷⁴

6.43 Instead of allowing police greater access to confidential information, the Privacy Commissioner emphasised the importance of establishing universal precautions, meaning that police would act the same in all crisis situations whether or not they knew a mental health issue existed.³⁷⁵

6.44 The Privacy Commissioner also highlighted the need for police training, keeping them informed about mental health, and ensuring mental health professionals were available to officers to provide advice in crisis situations:

My difficulty with all of this is exactly the same as the arguments we get about knowing people's HIV status, that is, if I knew X I would have dealt with it differently. The question is: Why would you have dealt with it differently? I understand; I have a great deal of sympathy for the fact that we are constantly

³⁷⁰ Submission 286, NSW Police Service, p 25

³⁷¹ Submission 254, NSW Police Association, p 14

³⁷² I Ball, President, Police Association of NSW, Evidence, 14 June 2002, p 13

³⁷³ *ibid*, p 3

³⁷⁴ Mr Chris Puplick, NSW Privacy Commissioner, Evidence, 8 August 2002, pp 2-3

³⁷⁵ *ibid*

putting on the Police Service and on individual police officers a degree of responsibility and pressure for doing welfare work of one sort or another for which they are not being properly trained or adequately equipped. But that does not mean that in fact you should change the health system or the privacy issues, rather than address the question about recognising situations where it would be appropriate to seek advice from a mental health professional.³⁷⁶

6.45 The role of police in the mental health sector is examined in Chapter 14.

6.46 Prof Beverley Raphael, Director of the Centre for Mental Health, informed the Committee that under the revised MOU between NSW Police and NSW Health, clinicians would now be able to advise police on a strictly ‘need to know’ basis.³⁷⁷ NSW Health will need to ensure that procedures regarding disclosure of health information comply with HPP 10 (c) ‘Limits on use of health information’ of the *Health Records and Information Privacy Act 2002*. HPP 10 (c) states that an organisation that holds health information must not use the information for a purpose (a ‘secondary purpose’) other than that for which it was collected (the ‘primary purpose’), unless there is a “serious threat to health or welfare”. Such situations would be where:

the use of the information for the secondary purpose is reasonably believed by the organisation to be necessary to lessen or prevent:

- (i) a serious and imminent threat to the life, health or safety of the individual or another person, or
- (ii) a serious threat to public health or public safety.

Recommendation 36

That the Centre for Mental Health prepare guidelines on limited disclosures under the *Health Records and Information Privacy Act 2002* and ensure these guidelines are:

- incorporated into a privacy protocol within the Memorandum of Understanding between NSW Health and the NSW Police Service and
- communicated to all mental health workers and police across NSW.

Recommendation 37

That NSW Health ensure that the NSW Police Service has access to mental health services on a 24 hour basis for support and urgent advice.

³⁷⁶ C Puplick, Evidence, 8 August 2002, p 3

³⁷⁷ B Raphael, Evidence, 12 August 2002, p 29

Recommendation 38

That the Minister for Health seek a further amendment to the NSW *Mental Health Act 1990* to enable guardians, family and primary carers to obtain an interim court order for:

- the release of confidential information from a health care provider or
- an urgent assessment of an individual's mental health, where it can be established there is a reasonable belief that there is:
 - a serious and imminent threat to the life, health or safety of the individual or another person or
 - a serious threat to public health or public safety.

NSW data collection and compliance with health privacy principles

- 6.47** The Commonwealth *Privacy Act 1988*³⁷⁸ applies nationally to both Commonwealth public sector agencies and the private health care providers. The ten National Privacy Principles set out in the Act do not apply to de-identified or statistical data. The *Privacy Act 1988* does not bind State or Territory agencies or authorities, including the NSW State public sector.³⁷⁹
- 6.48** Until recently, all NSW public sector agencies were subject to the NSW *Privacy and Personal Information Protection Act 1998* (PPIP). The NSW *Health Records Information Privacy Act 2002* (HRIP), passed by NSW Parliament on 25 September 2002, introduces a comprehensive system for the regulation of privacy in health information in NSW, including both the private and public sectors. The PPIP will no longer apply to health information. According to Privacy NSW, the HRIP will require holders of health information to comply with 15 Health Privacy Principles (HPPs). These principles are consistent with the Commonwealth National Privacy Principles and establish obligations in relation to the collection, retention, storage, use and disclosure of health information.³⁸⁰
- 6.49** The Commonwealth *Privacy Act* allows for 'implied' consent for personal information to be used for other purposes, however, Health Privacy Principle 15 of the HRIP prevents the creation of linked electronic health records without the express consent of the individual to whom the information relates.³⁸¹
- 6.50** Section 3 of the Commonwealth *Privacy Act* states that the Act is not to affect the operation of a law of a State or Territory that makes provision with respect to the collection, holding, use, correction, disclosure or transfer of personal information. As a result, if a privacy

³⁷⁸ Amended by the *Privacy Amendment (Private Sector) Act 2000*.

³⁷⁹ A Flannigan, *Health Records and Information Privacy Bill (NSW) 2001 – Release of Exposure Draft*, Australian Health Law Bulletin, Vol 10, No 8, 2002, p 88

³⁸⁰ Submission 239, Privacy NSW, p 3

³⁸¹ *ibid*

standard is the same or higher than the Commonwealth Act, that standard can operate concurrently.³⁸²

- 6.51** By calling for express rather than implied consent, the HRIP has introduced a different standard to the Commonwealth *Privacy Act*. Recognising the difference in Commonwealth and State standards, Privacy NSW noted:

Federal government agencies and private sector agencies outside NSW that are not covered by similar state legislation will, however, be able to use the principle of 'implied consent' as defined in the Privacy Act 1988.³⁸³

Unique Patient Identifiers

- 6.52** As part of NSW Health's Mental Health Information Development Project, Unique Patient Identifiers (UPI) will be attached to records, with data available through area and state Health Information Exchanges³⁸⁴. Data will be stored at Area Health Information Exchanges but few individuals will have access to names and only when it is necessary to their work³⁸⁵. Data at state level will be de-identified, in accordance with privacy requirements. NSW Health advised the Committee that:

The only level at which names and complete clinical data are available at present is the local services level, usually the hospital or community clinic. The legally permissible level is, however, the Area Health Services, which can maintain a complete and identified record.³⁸⁶

- 6.53** NSW Health has liaised extensively with Privacy NSW to ensure privacy principles are upheld in the UPI System. During 2001-2002 the UPI technical support processes were tested, the strategy evaluated, and approved by Privacy NSW.³⁸⁷ In its submission, Privacy NSW explained the need for strict protocols to limit access to data:

A UPI raises privacy issues because it allows information to be linked, and potentially accessed by a range of third parties who have no right to that information. An administrative system relying on a UPI in the health field will need to limit the scope of its use, and have the backing of a strong legislative regime.³⁸⁸

- 6.54** The Committee asked the NSW Privacy Commissioner, Mr Chris Puplick, whether a patient could exclude information being recorded on the register and avoid the UPI system by presenting to services under different names. Mr Puplick stated:

³⁸² A Flannigan, *Health Records and Information Privacy Bill (NSW) 2001 – Release of Exposure Draft*, Australian Health Law Bulletin, Vol 10, No 8, 2002, p 92

³⁸³ Submission 239, Privacy NSW, p 4

³⁸⁴ Submission 267, NSW Health, H 2

³⁸⁵ Correspondence from NSW Health to Committee, 23 September 2002, p 2

³⁸⁶ *ibid*

³⁸⁷ *ibid*

³⁸⁸ Submission 239, Privacy NSW, p 3

people operate in this community, and in particular in the health system, under a variety of different names. In some areas—community health areas and sexual health areas—we have gone to great lengths to preserve the right of anonymity of accessing health services, and if we had not done that, the capacity to intervene in areas like community mental health, trauma services and sexual health services would have been grossly compromised.³⁸⁹

- 6.55** The Privacy Commissioner cited considerable evidence from HIV and Hepatitis C research indicating that, if practitioners cannot guarantee that data will be protected from unauthorised third-party access, clients will disclose less information about themselves, give false names or not access services at all:

It is a balance, not just of community good, but also a balance of education that we are prepared to put into persuading people that the safeguards in place are sufficient and that they ought not to be overly concerned about co-operating with the system and helping to make the system work. It is a trust question.³⁹⁰

- 6.56** Mr Doug Holmes, Executive Officer of the NSW Consumer Advisory Group (NSW CAG) referred positively to NSW CAG's recent involvement in the development of electronic health records for NSW:

We have had quite a lot of input into electronic health records and we believe that that will overcome some of the problems you are talking about, because in time as people start to trust the system and to realise that there are safeguards in there where they will not be abused, I think some of those things you are suggesting will be able to take place.³⁹¹

- 6.57** NSW Health has agreed with the Commonwealth to meet its data collection requirements from 2000-2001 with 'interim' systems that will then migrate to a new strategic system, which was released for field testing in August 2002 in the Hunter Area Health Service.

- 6.58** Under National Mental Health Reform and Incentive Funding, NSW received \$90 million to develop and deliver data sets between 1998 and 2003. NSW received an additional \$12.5 million under an Information Development Agreement with the Commonwealth to move forward with its information infrastructure.³⁹² It was the first state to sign such an agreement, and is ahead of other jurisdictions in training programs and development of infrastructure to support the introduction of routine outcome measures.³⁹³ This was confirmed by Prof Beverley Raphael when she appeared as a witness before the Committee on 12 August 2002.³⁹⁴

³⁸⁹ C Puplick Evidence, 8 August 2002, p 6

³⁹⁰ *ibid*; see also United States Surgeon General (1999), *Mental Health: A Report of the Surgeon General*, Chapter 7, Section 2

³⁹¹ Mr Doug Holmes, Executive Officer, NSW Consumer Advisory Group, Evidence, 23 May 2002, p 32

³⁹² Commonwealth of Australia, *National Mental Health Report* (2002), p 54

³⁹³ *ibid*

³⁹⁴ B Raphael, Evidence, 12 August 2002, pp 26-27, 28

6.59 All services in NSW are expected to be reporting outcomes data by June 2003.³⁹⁵ The Committee congratulates NSW Health on its success in implementing a set of large-scale, complex reforms that have the necessary privacy safeguards in place.

Mental Health Outcomes and Assessment Tools (MH-OAT)

6.60 Many submissions to the inquiry commented on the NSW Health Mental Health Outcomes and Assessment Tools initiative (MH-OAT), which commenced in July 2001.³⁹⁶ The initiative aims to standardise the way in which clinical mental health records are kept in all public health providers in NSW. In this regard it is a ‘clinical tool’ to enable better diagnosis and record keeping. MH-OAT also aims to collect outcome measures on mental health clients in public health services in NSW.³⁹⁷ MH-OAT is significant because it is the first system of its kind in NSW, and its development has meant that NSW is ahead of other jurisdictions in training and developing infrastructure to support the introduction of routine outcomes measures.³⁹⁸

6.61 NSW Health describes MH-OAT as “fundamentally an initiative to improve quality of assessment and build the evaluation of service effectiveness at the individual, service, and system level.”³⁹⁹ It aims to achieve this by:

- ensuring documentation is consistent with National Standards for Mental Health Services
- ensuring service units or area health services all use the same processes
- strengthening mental health assessment skills of workers
- ensuring reliability and validity of standard clinical ratings used as outcome and case mix measures.⁴⁰⁰

6.62 At the end of June 2002, 4,191 of a targeted 6,000 NSW public sector mental health staff had been trained in MH-OAT.⁴⁰¹ Currently, MH-OAT is designed for use in public health settings, with private and NGO service providers continuing to use their own existing systems.

³⁹⁵ Commonwealth of Australia, *National Mental Health Report* (2002), p 54

³⁹⁶ Submission 267, NSW Health, H.3

³⁹⁷ Correspondence from NSW Health to Committee, 23 September 2002, p 5

³⁹⁸ Commonwealth Department of Health and Ageing, *National Mental Health Report 2002*, p 54

³⁹⁹ Correspondence from NSW Health to Committee, 23 September 2002, p 4

⁴⁰⁰ *ibid*

⁴⁰¹ *ibid*, p 1

The impact of MH-OAT on service delivery

- 6.63** In evidence to the Committee, clinicians tended to support the principles and aims of MH-OAT but expressed frustration with the time-consuming nature of compiling MH-OAT records. Some submissions expressed doubts about MH-OAT's effectiveness as a clinical tool. The Australian Salaried Medical Officers' Federation (NSW) remarked in its submission that:

MH-OAT is widely considered a burden on clinical time and the data it produces cannot be relied on. Psychiatrists are happy to participate in practical quality assurance activities that do not place an unreasonable burden on clinical time.⁴⁰²

- 6.64** The NSW Nurses' Association was involved in the development of the MH-OAT and is supportive of the project. The submission, however, noted that MH-OAT is not without its problems:

In this climate of extreme nursing shortages our members are finding it exceedingly difficult to complete all the necessary data collection and information gathering associated with MH-OAT. The nurses feel that the time taken for data collection and entry is time away from providing direct services to the client/patient. The Centre for Mental Health estimates that the time taken to complete the paperwork is equivalent to the time taken to complete the interview. In actual fact it is taking up to three times as long to complete the paperwork as opposed to the interview.⁴⁰³

- 6.65** Mr John Lyons, a Clinical Nurse Consultant, and member of the NSW Nurses' Association, stated that filling out the standard MH-OAT assessment took up to 140 minutes to fill out 34 to 36 pages. This took up a substantial amount of time that he felt could be spent in clinical work instead:

There is no question about getting outcomes later. No-one is complaining about that. No-one is complaining about the fact that there is a formalised assessment tool across the State. What clinicians are complaining about is the amount of time it is taking, and in a rural area when you are spending 140 minutes filling out one assessment, you have to do either one of two things: reduce the number of clients you see or do the paperwork haphazardly.⁴⁰⁴

- 6.66** The Comprehensive Area Service Psychiatrists Special Interest Groups made a similar point about the reduction in face-to-face hours, and further argued that this 'devalued' clinical workers:

The focus on promotion and prevention has often been translated into funding for special projects or project officers rather than more clinical services. More worryingly, the demand for increasing data-collection has often translated into reports, guidelines, audits and assessment formats, making further demands on frontline staff providing them with less support for their clinical interventions.⁴⁰⁵

⁴⁰² Submission 91, Australian Salaried Medical Officers' Federation (NSW), p 2

⁴⁰³ Submission 212, NSW Nurses' Association, p 14

⁴⁰⁴ Mr John Lyons, Clinical Nurse Consultant, Evidence, 30 July 2002, pp 44-45

⁴⁰⁵ Submission 209, Comprehensive Area Service Psychiatrists Special Interest Groups, p 5

6.67 With the growing number of GPs involved in mental health service provision, Port Macquarie Division of General Practice noted that:

GPs will need to be made cognisant of the content of the MH-OAT in order for them to be able to understand the reports on their patients that will originate in the Mental Health Services.⁴⁰⁶

6.68 NGOs have not been involved in the MH-OAT initiative, a point made by a number of submissions to the inquiry.⁴⁰⁷ NSW Health has advised that a national project to develop a minimum data set for NGOs is underway, with Victoria acting as the lead agency. A report on the project is due by 30 June 2003.⁴⁰⁸

Recommendation 39

That the Minister for Health ensure, through a process of monitoring and review, that the Mental Health Outcomes Assessment Tools do not have an adverse impact on clinical service provision.

⁴⁰⁶ Submission 149, Port Macquarie Division of General Practice, p 6

⁴⁰⁷ Submission 78, UnitingCare NSW; Submission 162, NSW Consumer Advisory Group; Submission 218, Mental Health Co-ordinating Council, p 19

⁴⁰⁸ Correspondence from NSW Health to Committee, 23 September 2002, p 1

Chapter 7 Housing and homelessness

Housing alone is not enough. It must be appropriately supported housing.
[Mission Australia]⁴⁰⁹

Research and anecdotal evidence indicates a high correlation between homelessness and mental illness.⁴¹⁰ Deinstitutionalisation has been blamed for increasing numbers of homeless people with mental illness. Poverty, lack of family and social support, and a shortage of affordable housing are however, important factors contributing to the incidence of homelessness among people with a mental illness.

The role of housing in recovery

7.1 Stable, secure and safe housing is the most important component of rehabilitation and recovery for people with a mental illness. This is acknowledged in the NSW Government *Framework for Housing and Accommodation for People with Mental Health Problems and Disorders* (2002).⁴¹¹ The Northern Rivers Area Mental Health Council noted that:

on a scale of one (one being the most crucial) to ten, poverty and accommodation show up in Australian and American studies as the most important problems facing people with a chronic mental illness.⁴¹²

7.2 The Richmond Report proposed that most people with mental health problems and illnesses can be cared for in the community.⁴¹³ Submissions to the Committee endorsed the community care model while emphasising that people with chronic and episodic mental illnesses will require adequate support to live successfully in the community.⁴¹⁴ Depending on the client's needs, 'support' can range from 24-hour high-level supported accommodation to a visit from a mental health worker once a month.

7.3 Evidence to the Committee overwhelmingly stated that support services for people with a mental illness living in the community are underfunded and in critically short supply in NSW. The Council of Social Service of New South Wales (NCOSS) stated that there is still a "serious lack of commitment" to provide affordable, secure, and appropriate housing for people with a mental illness.⁴¹⁵ Submissions have argued that the agencies that fund and deliver housing to people with a mental illness, including the Commonwealth and State

⁴⁰⁹ Submission 188, Mission Australia, p 7

⁴¹⁰ Submission 245, Schizophrenia Fellowship of NSW, pp 5-6; Submission 85, Parramatta City Council, p 2; Society of St Vincent de Paul, *Down and Out in Sydney* (1998).

⁴¹¹ NSW Health, *Framework for Housing and Accommodation Support for People with Mental Health Problems and Disorders Report*, NSW Government Action Plan for Health, August 2002, p 5

⁴¹² Submission 76, Northern Rivers Area Mental Health Council, p 1

⁴¹³ D. Richmond (1983), *Inquiry into Health Services for the Psychiatrically Ill and Developmentally Disabled* ("The Richmond Report").

⁴¹⁴ Submission 255, Office of the Public Guardian NSW, p 3; Submission 218, Mental Health Co-ordinating Council, p 2; Submission 209, Comprehensive Area Service Psychiatrists, p 2; Submission 198, Shelter NSW, p 3; Submission 238, The Salvation Army, p 3; Submission 159, The Richmond Fellowship of NSW, p 1; Submission 78, UnitingCare, p iii; Submission 178, Society of St Vincent de Paul – Wollongong Diocesan Council, p 3

⁴¹⁵ Submission 192, NCOSS, p 17

governments, non-government and private sector, do not effectively work together to deliver a range of supported accommodation options.

Housing options in NSW

7.4 NSW Health outlined the following accommodation options for people with a mental illness:

- public housing – secure, long term and affordable rental housing assistance
- supported housing – NGOs and then allocated to clients in need of specialist services and
- boarding houses – generally operated by the private sector and licensed by the NSW Department of Ageing, Disability and Home Care (DADHC). The licence stipulates that a boarding house cannot have more than two people with high support needs unless there is 24-hour supervision.⁴¹⁶

7.5 Evidence presented to the Committee identified five additional tiers of housing options for people with a mental illness:

- crisis and short-term accommodation
- private rental market
- unlicensed lodging houses⁴¹⁷
- psychiatric facilities⁴¹⁸ and
- gaols.⁴¹⁹

7.6 In May 2000, the Centre for Mental Health completed a survey of housing and accommodation support services for people with mental health problems in NSW.⁴²⁰ Some key findings of the survey were:

- half of the properties were share accommodation with three or more residents, one third had two residents and the remainder were single residency properties
- two thirds of the programs were for people aged between 19 and 65, one fifth targeted 17 and 18 year olds, with the remainder catering for persons aged over 65 years

⁴¹⁶ Submission 267, NSW Health, G 24

⁴¹⁷ Ms Leonie Manns, Evidence, 23 May 2002, p 37

⁴¹⁸ Submission 255, The Office of the Public Guardian, p 4; M Giuffrida, Evidence, 8 August 2002, p 51

⁴¹⁹ Submission 162, NSW Consumer and Advisory Group, p 25

⁴²⁰ Submission 267, NSW Health, p G 24, citing Centre for Mental Health, *Housing and Accommodation Survey*, May 2000

- 87% of the programs had an identified entry and exit policy
- 80% provided a service based on the person's prior residency in the Area Health Service and in some cases specific sector catchment area and
- 92% of programs had exclusion criteria – history of violence, criminal record, comorbid mental illness and substance abuse.⁴²¹

Crisis and short-term accommodation

7.7 The Salvation Army provides crisis contact centres, crisis accommodation facilities, night shelters, women's refuges, community houses, youth refuges and targeted programs.⁴²² Its key concerns about people presenting at crisis facilities included:

- difficulty accessing acute adult inpatient mental health services via crisis assessment and treatment teams, particularly for people who are homeless or have a mental illness and a substance abuse disorder (MISA)
- inadequate discharge planning and lack of support immediately post-discharge from hospital and
- after-hours mental health crises for individuals are more likely when staff levels are lowest.⁴²³

7.8 The Salvation Army expressed concern that the ability of crisis centres and night shelters to meet the needs of people with mental illness is limited. Staff in these facilities are usually welfare officers and not trained to give care to mentally ill clients. Low staff to client ratios may at times require that a mentally ill person be turned away.⁴²⁴ People who are 'truly homeless' are not served well by crisis care because they require 'long term, high support and accommodation'. The Salvation Army described these people as:

- not suitable for crisis admission to hospital as their illness is chronic
- not sufficiently insightful to attend properly to their own needs
- at potential risk of exploitation, emotional and mental abuse from other people in the community and
- a potential risk to staff and other persons in homeless persons' facilities.⁴²⁵

7.9 Without long-term accommodation, the Salvation Army stated that these people are cycled between the police, the courts, mental health workers and hostel and refuge workers. The

⁴²¹ Submission 267, NSW Health, G 24

⁴²² Submission 238, The Salvation Army, Australia Eastern Territory, p 2

⁴²³ *ibid*, p 5

⁴²⁴ *ibid*, p 5

⁴²⁵ *ibid*, p 3

submission urged that this group in particular receive supportive and therapeutic hostel and group home accommodation, as was recommended in the Richmond Report.⁴²⁶

7.10 Ms Elsworthy noted her own experiences in the community sector following the release of the Richmond Report:

Before this job I worked as the Co-ordinator at Randwick Information and Community Centre for five years, which was the community centre for the lower end of the eastern suburbs... A number of people came to see me in my position there, people living on housing estates who were pulling their hair out because of disputes, complaints, threats and violence. It all happened post Richmond. It was all a consequence of the Richmond Report... I went there in the late 1980s and I was there for five years. It was all because people were being shunted out.⁴²⁷

7.11 B. Miles also highlighted the lack of crisis accommodation for people with mental health issues, including accommodation for consumers who do not manage their medication. The submission further commented:

Entering crisis accommodation does not ensure consumers will be able to move into stable housing. This results in many women moving from one crisis accommodation services to another, further draining resources and exacerbating the individual's mental health problems.⁴²⁸

7.12 The Coalition for Appropriate Supported Accommodation (CASA) indicated that people with coexisting mental illnesses and substance abuse disorders were particularly disadvantaged in crisis accommodation services:

The type and intensity of support that is required by this group is almost totally unavailable. Between 20% and 30% of those residing in the inner city crisis hostels for men have [MISA].⁴²⁹

The Supported Accommodation Assistance Program (SAAP)

7.13 The Supported Accommodation Assistance Program (SAAP) is a joint Commonwealth-State-Territory support program, coordinated by the NSW Department of Housing, which aims to provide secure accommodation and support for people who are homeless or at risk of homelessness.⁴³⁰ NSW Health describes the goals of SAAP as being to:

Resolve crisis, re-establish family links where appropriate, and re-establish the capacity of clients to live independently of SAAP.⁴³¹

⁴²⁶ *ibid*, p 3

⁴²⁷ L. Elsworthy, Evidence, 29 May 2002, p 12

⁴²⁸ Submission 98, B. Miles Women's Housing Scheme, p 9

⁴²⁹ Submission 172, CASA, p 5

⁴³⁰ Submission 192, NCOSS, p 18

⁴³¹ NSW Health, *Framework for Housing and Accommodation Support for People with Mental Health Problems and Disorders Report*, NSW Government Action Plan for Health, August 2002, p 7

7.14 SAAP services are delivered by non-government organisations across NSW. The main models in 2000-2001 were crisis and short term supported accommodation and medium to long-term supported accommodation.⁴³²

7.15 Submissions received by the Committee indicated that crisis services funded under SAAP are finding it difficult to meet the needs of clients with mental illnesses. CASA commented that:

SAAP services are generally unable to offer the type of intensive support required by those with a mental illness. As a result some people become trapped in SAAP crisis accommodation meant only for short-term stays. Too often people are discharged from inpatient wards to the street or crisis homeless services.⁴³³

7.16 NCOSS was concerned that SAAP services in NSW have not received any growth funding for the past eight years. It was also concerned about:

the high proportion of people with a mental illness who are clients of SAAP services...this is indicative of a breakdown of the system of support services for people with a mental illness.⁴³⁴

7.17 UnitingCare described the situation facing the Hope Hostel, a SAAP-funded generic facility for homeless men operated by Parramatta Mission:

At any one time 20% of its 36 residents could have mental health issues. The hostel employs one worker on duty and worker on sleepover, each night. The Mission describes the situation as 'an occupational health and safety time bomb'. Generic homeless men's facilities are the wrong place for people with psychiatric disabilities who are chronically homeless and the Mission believes that there needs to be a number (say three) of special facilities with no more than six beds each for those people.⁴³⁵

Supported accommodation

7.18 NSW Health describes mental health rehabilitation services as consisting of a clinical rehabilitation component as well as an accommodation and disability support component. The latter interventions are aimed at the maintenance of role functioning, skills and independence.⁴³⁶

7.19 In NSW, clinical rehabilitation is the responsibility of the public mental health sector, with supported accommodation and rehabilitation services largely delivered by the NGO sector.⁴³⁷ NSW Health describes the purposes of accommodation support services as:

⁴³² Commonwealth of Australia (2002), *SAAP Annual National Performance Report 2000-2001*, p 7

⁴³³ Submission 172, CASA, p 5

⁴³⁴ Submission 192, NCOSS, p 18

⁴³⁵ Submission 78, UnitingCare, p 25

⁴³⁶ Submission 267, NSW Health, G 40

⁴³⁷ *ibid*; Submission 218, Mental Health Co-ordinating Council, p 16

maximising the independence of the consumers receiving services. Interventions based on individualised assessment may target activities of daily living including domestic chores such as shopping, cooking and cleaning; personal care tasks, such as showering and taking medication as prescribed; health care, including identification of general health and mental health treatment, and rehabilitation needs, and seeking assistance when required. Interventions may also focus on income support issues such as the identification of a source of income, maintenance of budget, and rent payment.⁴³⁸

7.20 More than half of disability support services are provided by NGOs (53%), followed by AHS (11%), volunteers (12%) and other organisations (18%).⁴³⁹

7.21 The Mental Health Co-ordinating Council (MHCC) commented that there are overlaps between the public mental health sector and the NGO mental health sector in the areas of supported residential and psychosocial rehabilitation programs.⁴⁴⁰ The submission notes:

Historically, most of the rehabilitation services and some of the supported residential programs were managed by public health services. In the past decade supported residential services have been established mainly by the non-government sector.⁴⁴¹

7.22 This observation by the MHCC is supported in evidence provided by the Commonwealth Department of Health and Ageing. Since 1993, under the National Mental Health Strategy, the Australian non-government sector has increased its overall share of mental health funding from 2% to 5%. This shift has been accompanied by a 65% national increase in the number of beds in 24-hour staffed community residential units, “designed to replace the former role of psychiatric institutions”.⁴⁴² This trend has not occurred in NSW. According to the *National Mental Health Report 2002*, the number of psychiatric beds in NSW declined from 2,652 in 1992-1993 to 2,032 in 1999-2000. The number of 24-hour staffed community beds declined slightly from 283 in 1992-1993 to 276 in 1999-2000.⁴⁴³

7.23 The MHCC outlined three main models of supported residential services in the mental health NGO Sector:

- Outreach or continuous ‘on site’ support in high, medium or low support houses. As residents’ support needs change they move to a house with a different level of support or to independent housing. The more disabled clients often become long-term residents of the service. In this situation, the NGO leases or owns the property but may contract the landlord responsibilities for the property to a Housing Association (a housing NGO).
- partnership between health, housing and NGO services houses are owned by the NSW Department of Housing, and the Area Health Service contracts out the

⁴³⁸ *ibid*, p G.40

⁴³⁹ *ibid*, p G 25

⁴⁴⁰ Submission 218, Mental Health Co-ordinating Council, p 15

⁴⁴¹ *ibid*, p 15

⁴⁴² Submission 226, Commonwealth Department of Health and Ageing, p 22

⁴⁴³ Commonwealth of Australia (2002), *National Mental Health Report*, p 50

support services to a local NGO. In some services the NGO also provides the landlord function and in others a Housing Association is the landlord. The housing, health and NGO services involved in the partnership are coordinated by a committee that meets regularly to accept and discharge clients to and from the service. Houses in this model are also categorised as high, medium or low support houses.

- clients may live in public housing, a rental property or a privately owned property and NGO staff provide outreach support to assist clients in maintaining their accommodation and successfully live in the community.⁴⁴⁴

7.24 NSW Health explained how accommodation support services and mental health services work together:

Strong links are developed locally between accommodation support services and mental health services. Accommodation service staff and mental health staff work collaboratively with each individual to plan care, rehabilitation and support and identify the role of the individual, the accommodation support staff and the mental health staff.⁴⁴⁵

7.25 NSW Health also stated that care coordinators are responsible for the coordination of clinical care, rehabilitation and disability support services for people in supported accommodation.⁴⁴⁶

7.26 In contrast to the coordinated care described by NSW Health, the MHCC commented:

the public mental health services, in theory, provide the residents with case management or clinical care services. In practice, however, mental health NGOs report that case managers or similar staff rarely see clients living in supported residential services and that NGO key workers provide the case management service.⁴⁴⁷

7.27 The MHCC's observations about the inadequacy of clinical care services were supported by comments in the B. Miles submission:

The support workers at B. Miles are often expected to carry out the duties of the case manager as [community health] do not have the time to do so...Bondi Junction Community Health psychiatrists only provide episodic case management and will refer clients to private psychiatrists. This is not always a viable solution as women who access have limited financial reserves and are always in receipt of some form of benefit.⁴⁴⁸

⁴⁴⁴ Submission 218, Mental Health Co-ordinating Council, pp 16-17

⁴⁴⁵ Submission 267, NSW Health, p G 40

⁴⁴⁶ *ibid*

⁴⁴⁷ Submission 218, Mental Health Co-ordinating Council, p 17

⁴⁴⁸ Submission 98, B. Miles Women's Housing Scheme, pp 7-8

7.28 NCOSS also commented in its submission:

NCOSS has received regular reports that supported accommodation providers are consistently unable to obtain necessary support services from mental health teams, including crisis response services, to assess and manage clients with mental disorders.⁴⁴⁹

7.29 Charmian Clift Cottages, which provides a residential program for women with mental illness and their dependent children, explained how it was responding to a lack of case management services:

Charmian Clift Cottages has established its own community integration worker, in an attempt to support families and ease their transition back into independent living on completion of the program. This was as a direct result of a reduction in case management support for families.⁴⁵⁰

7.30 The reduction in case management support has increased pressure on existing mental health teams. UnitingCare commented on the heavy workload facing community mental health teams:

Several staff who work as part of community teams commented to our chaplains that their workload for the supported accommodation teams is so heavy (100 to 150 clients) that they can do nothing more than attend to the medical and/or pharmaceutical aspects of mental health. The focus seems to be on quantity rather than quality. Staff are burning out and dissatisfied.⁴⁵¹

7.31 The Hornsby Ku-ring-gai Association Action for Mental Health and the Schizophrenia Fellowship collaborated to establish the Hornsby New Housing Group. This initiative has established a family-style, independent living housing model that is integrated with the community. It highlights the importance of local level partnerships and high quality care. As the Committee has noted repeatedly of such projects, it is an isolated example that needs to be replicated in communities across NSW.⁴⁵²**Waiting lists for supported accommodation****7.32** As well as limited case management support, the Committee was concerned that there is grossly insufficient accommodation to meet current needs. The B. Miles Housing Scheme provides secure, affordable medium term (up to 18 months) housing for women (without dependent children) who are affected by mental illness. It also runs an after care program once tenants have left the service. The organisation advised that the success of the program is demonstrated by the very low readmission rate to the B. Miles scheme, averaging about one client per year.⁴⁵³

⁴⁴⁹ Submission 192, NCOSS, p 19

⁴⁵⁰ Submission 30, Charmian Clift Cottages, p 2

⁴⁵¹ Submission 78, UnitingCare, p 16

⁴⁵² Correspondence from Jane Woodall, Joint Coordinator, Hornsby New Housing Group, p 1

⁴⁵³ L. Elsworthy, Evidence, 29 May 2002, p 3

7.33 B. Miles houses up to 26 women at one time.⁴⁵⁴ With 70 women currently on the waiting list, the submission described the situation as ‘untenable’ and attributed it to the growing numbers of people with mental health problems living on the streets, coupled with a lack of secure long term housing to which it can refer its clients.⁴⁵⁵ Ms Leanne Elsworthy, Coordinator of B. Miles, informed the Committee that those on the waiting list would be currently located in a range of settings:

Some [are] in refuges, some are literally homeless and floating out there, some [are] in boarding houses, and some are living with their family but in highly stressful situations with the family at breaking point. Some are living in domestic violence situations...[others]...go into departmental accommodation, but it is not working for them, because there is no support there.⁴⁵⁶

7.34 Ms Elsworthy explained that, as the waiting periods with the NSW Department of Housing have increased, the average time of stay at B. Miles has also increased from 18 months to two years.⁴⁵⁷ This is because they are reluctant to take the ‘retrograde step’ of placing tenants back on the homelessness circuit,⁴⁵⁸ or ‘dumping’ them into inappropriate services.⁴⁵⁹

7.35 The Richmond Fellowship provides supported accommodation to people with mental illness.⁴⁶⁰ It supports 181 residents in 68 properties across NSW, providing varying levels of support, from 24 hour to drop in support on a needs basis. It is funded by NSW Health and DADHC, but funding has not kept up with increases in running costs over the past ten years, meaning that it can only provide ‘decreasing hours of service to the same number of people’. The accompanying increased need for community based supported accommodation has led to a waiting list in the organisation’s Central Sydney area of over 40 people, with some on the waiting list for more than five years.⁴⁶¹ The Richmond Fellowship confirmed that waiting lists were a feature of supported accommodation services:

The situation is mirrored in all other supported accommodation services across the state, resulting in people remaining in hospital simply because there is nowhere else to go or living in unsuitable accommodation where the support needs are not met and rehospitalisation, incarceration or homelessness are the end results.⁴⁶²

7.36 The Guardianship Tribunal also noted in its submission:

There is a lack of adequate discharge planning for people leaving psychiatric facilities. This is compounded by the lack of suitable supported accommodation

⁴⁵⁴ Submission 98, B. Miles Women’s Housing Scheme, p 4

⁴⁵⁵ *ibid*, pp 5-6, 8

⁴⁵⁶ L Elsworthy, Evidence, 29 May 2002, p 8

⁴⁵⁷ Submission 98, B. Miles Women’s Housing Scheme, p 6

⁴⁵⁸ L Elsworthy, Evidence, 29 May 2002, p 2

⁴⁵⁹ Submission 98, B. Miles Women’s Housing Scheme, p 6

⁴⁶⁰ The Richmond Fellowship is not connected to the 1983 *Richmond Report*. It is part of an international organisation that began in the suburb of Richmond in the UK

⁴⁶¹ Submission 159, The Richmond Fellowship of NSW, pp 2-3

⁴⁶² *ibid*, p 2

options available in the community...Waiting lists are long and there is often insufficient funding to enable the necessary level of support to be provided. As a result, people with mental illness are often forced to live in inappropriate boarding house or rooming accommodation.⁴⁶³

7.37 The Richmond Fellowship stated that the greatest unmet need in accommodation for people with mental illness is in the following three areas:

- high support (12 to 24 hour a day support)
- short to medium term (2 to 12 months) and
- supported accommodation for people with mental illness and substance addiction.⁴⁶⁴

7.38 The Richmond Fellowship highlighted an imbalance of funding structures from different government departments in NSW. The Committee was concerned that service users with similar needs are funded very differently depending on the funding source. For example, the Richmond Fellowship is unable to provide 24 hour supported accommodation to anyone who has not been identified for a 24 hour funding package from DADHC.⁴⁶⁵ Mr Fred Kong, Chief Executive Officer of the Richmond Fellowship, further explained to the Committee:

Health funding up to 1998 was \$8,000 to \$10,000 average per bed. DADHC allocates an average of about \$50,000 per bed. There is a huge difference. Therefore the level of support is quite different.⁴⁶⁶

7.39 The Society of St Vincent de Paul (Wollongong Diocesan Council) urged for the creation of more supported accommodation places to meet growing demand:

Our contact with public and community housing organisations suggests to us that the problem is not necessarily a lack of suitable accommodation but a dire shortage of funding for support programs. In most situations, existing public and community housing can be adapted for supported accommodation programs but housing organisations cannot find partners with sufficient funding to meet even a small proportion of the need for support programs.⁴⁶⁷

7.40 NSW Health advised the Committee that there will be 1,635 supported accommodation beds for people with mental disorders across NSW by early 2003. Of these, 100 new places will provide high-level support. The beds will be provided by non-government organisations in partnership with AHS and housing providers.⁴⁶⁸ Although NSW Health has committed to increasing supported accommodation beds, it is apparent from even the small volume of evidence cited here that this is still insufficient to meet to current needs.

⁴⁶³ Submission 106, The Guardianship Tribunal of NSW, pp 3-4

⁴⁶⁴ Submission 159, The Richmond Fellowship of NSW, p 3

⁴⁶⁵ *ibid*, p 4

⁴⁶⁶ Mr Fred Kong, Chief Executive Officer, Richmond Fellowship, Evidence, 29 May 2002, p 30

⁴⁶⁷ Submission 178, Society of St Vincent de Paul (Wollongong Diocesan Council), p 5

⁴⁶⁸ Correspondence from NSW Health to Committee, 19 September 2002, p 1

Bed numbers must accordingly increase to not only satisfy present requirements but also to accommodate future demands.

Recommendation 40

That the Minister for Health increase the number of supported accommodation places for people with mental disorders in NSW from 1,635 to 2,635 over the next two years, and that an average of 12 adult beds per 100,000 are available for 24-hour per day high level supported residential services.

Recommendation 41

That NSW Health match the level of funding provided by the NSW Department of Ageing, Disability and Home Care for 24 hour supported accommodation packages for people with psychiatric disabilities.

Psychiatric facilities and nursing homes

- 7.41** The post-Richmond Report policy to deinstitutionalise long-term care arrangements has not resulted in closure of all psychiatric facilities. Submissions recognised that there are still people in NSW who are institutionalised in large psychiatric facilities. Dr Michael Giuffrida, Director of Forensic Psychiatry, Westmead-Cumberland Hospital, explained to the Committee that patients waiting for a rehabilitation bed can wait in acute units for months on end. Dr Giuffrida stated that an acute unit may have up to four or five such people.⁴⁶⁹
- 7.42** UnitingCare observed in its submission that the ‘least restrictive environment’ requirement of the *Mental Health Act 1990*⁴⁷⁰ has decreased the incidence of abuse and destructive custodial care. People considered however, ‘indigent, less articulate and marginalised’ have become residents in the old state psychiatric hospitals,⁴⁷¹ with some unable to be discharged because of a lack of supported facilities to which the hospital can discharge them. The Richmond Fellowship commented in its submission:

Unfortunately, people often remain in hospital unnecessarily due to the lack of appropriate accommodation options. This is despite the obvious advantages of discharging people from hospital when ready – from the perspective of both cost and the individual’s mental health... our own research (conducted in May 1998) shows that the cost of a hospital rehabilitation bed is approximately \$232.00 per person per day. The funding to the Richmond Fellowship from Central Sydney Area Health Services is \$22.00 per person per day, or less than one-tenth of the cost of a hospital bed. This is significant when a person no longer requires a hospital bed but remains there simply because there is no alternative.⁴⁷²

⁴⁶⁹ M Giuffrida, Evidence, 8 August 2002, p 51

⁴⁷⁰ Section 4 (2a) of the *Mental Health Act 1990* states that the Act is to be performed or exercised so that persons who are mentally ill or mentally disordered receive the ‘best possible care and treatment in the least restrictive environment’.

⁴⁷¹ Submission 78, UnitingCare, p 10

⁴⁷² Submission 159, The Richmond Fellowship of NSW, p 2

7.43 UnitingCare described stand-alone psychiatric hospitals as ‘relaxed environments’, although ‘depersonalising and restrictive’.⁴⁷³ The Public Guardian raised a number of concerns about large psychiatric hospitals:

- these institutions remain separate and largely isolated from the community
- there is limited transitional planning or funding for people who have resided in institutions over a number of years and who need to be able to return to the community
- a number of people with mental illness under the guardianship of the Public Guardian have stated that they feel significantly at risk when residing in these facilities and
- discharge planning is often inadequate with the person often moving to a poorly supported housing arrangement that in turn places the person at risk of readmission.⁴⁷⁴

7.44 The Schizophrenia Fellowship emphasised that while long stay beds may be necessary for those with acute and prolonged episodes:

the moot point is where that care should be provided and whether what is required is a hospital or community environment.⁴⁷⁵

Public Housing

7.45 For the 2000-2001 year, there were 96,075 households on the NSW Department of Housing waiting list.⁴⁷⁶ This may reflect the general lack of affordable housing in NSW. Mission Australia commented that the Sydney housing market is:

characterised by high rents, low vacancy rates and very high cost of home purchase. There is also an historical mismatch between housing supply and demand. The relatively high supply of 3-4 bedroom housing located in the outer suburb housing estates is not suitable for people with mental illness. Many of those placed on estates find themselves being ‘cycled’ back through short-term crisis housing and refuges because they are unable to cope without the appropriate support.⁴⁷⁷

7.46 Shelter NSW informed the Committee that the NSW Department of Housing did not have access to statistics about the number of its tenants who indicated they were receiving treatment for a mental illness.⁴⁷⁸ NCOSS expressed a similar view that:

⁴⁷³ Submission 78, UnitingCare, p 10

⁴⁷⁴ Submission 255, Office of the Public Guardian NSW, p 4

⁴⁷⁵ Submission 245, Schizophrenia Fellowship of NSW, p 4

⁴⁷⁶ Department of Housing, *Annual Report 2000-01*, p 15

⁴⁷⁷ Submission 188, Mission Australia, p 6

⁴⁷⁸ Submission 198, Shelter NSW, p 4

there is little information about the housing support needs of public housing tenants and how these needs are being met.⁴⁷⁹

7.47 The B. Miles submission highlighted the limitations of the NSW Department of Housing in providing accommodation for people with mental illness:

The Department of Housing is limited in the housing choices it can make available to tenants. Allocations are often made on the basis of what house is available rather than what house is needed. Inappropriate allocations cause neighbourhood disputes and can place consumers at risk. This situation is compounded by a lack of services to support behavioural issues as they arise.⁴⁸⁰

7.48 Shelter NSW elaborated on the problems in providing public housing support to people with complex needs:

The policy of tightly targeting public housing support to only the most needy has meant that additional strain has been placed on the housing estates due to disadvantaged people being concentrated in these estates without adequate support... Those living with mental illness may engage in anti-social behaviour or become forgetful from time to time and fall into rent arrears. Ideally, they should receive support during times of episodic illness or hospitalisation and assistance in meeting their obligations to the Department of Housing. But all too often these supports are not available or are dependent on the understanding of a particular client service officer or mental health professional.⁴⁸¹

7.49 NSW Health and the NSW Department of Housing signed a Joint Guarantee of Service for People with a Mental Illness (JGOS) in 1997.⁴⁸² The JGOS was developed in response to concerns about the lack of coordination between health and housing services. It defines the roles and responsibilities of both departments and outlines the processes and procedures for the departments to follow to enable them to work together cooperatively.⁴⁸³

7.50 Shelter NSW stated in its submission that the NSW Department of Housing was unable to provide statistics on the number of its clients covered by Joint Service Agreements.⁴⁸⁴ Shelter NSW also made the following remarks about JGOS:

These work well in some areas, depending on local circumstances, and often, the commitment or competency of key individuals. However, application of these policies is patchy across NSW. Shelter NSW's constituents who work in the field continually tell us that although policies exist on paper, the situation as it really is does not match up with the rhetoric of integrated support, because the level of support required is either not available in some areas, or in poor supply.⁴⁸⁵

⁴⁷⁹ Submission 192, NCOSS, p 17

⁴⁸⁰ Submission 98, B. Miles Women's Housing Scheme, p 12

⁴⁸¹ Submission 198, Shelter NSW, p 3

⁴⁸² Submission 267, NSW Health, p G.41 *Joint Guarantee of Service for People with a Mental Illness* available at: www.health.nsw.gov.au

⁴⁸³ Submission 267, NSW Health, G.41

⁴⁸⁴ *ibid*, p 4

⁴⁸⁵ Submission 198, Shelter NSW, p 4

7.51 NCOSS similarly noted in its submission:

NCOSS understands that some [Joint Service Agreements between the Department of Housing and other agencies] are working well, but they are highly variable in their use and effectiveness across the state. A major barrier to effective work across agencies is the shortage of support services.⁴⁸⁶

7.52 The Northern Rivers Area Mental Health Council noted the limited scope of the JGOS as:

only aimed at maintaining accommodation for those already in public accommodation. So instability of accommodation remains a major health and security risk for people living with a mental illness.⁴⁸⁷

7.53 To address the inconsistency in application of the JGOS, NCOSS suggested:

NSW Health and the Department of Housing should explore models for effective integration, including outreach services in public housing and housing support workers. This integration should also provide effective support to clients exiting SAAP services, given the increasing number of SAAP clients with high and complex needs.⁴⁸⁸

7.54 The St Agnes Support Service, Port Macquarie, which conducts a volunteer visiting service for people with mental illness, informed the Committee that some people with mental illness are placed in public housing despite an inability to cope without adequate support:

A great number of people with mental illness live in Department of Housing homes but they lack the ability to do this. They have problems organising their money, they go without healthy food, have problems looking after their medication, and some cases their personal hygiene and state of their homes leave much to be desired.⁴⁸⁹

7.55 This was graphically illustrated by Ms Joyce Said, Chair of the MHCC and Executive Director of AfterCare:

[The] person was living at Merrylands in a public housing place. When my staff went there at the behest of the Public Guardian they found all the doors boarded up. The man had got rid of all his furniture, and the refrigerator and electricity had been disconnected because he was afraid of the power coming into his place. He was living on the floor of the kitchen, with cockroaches everywhere. The whole place was absolutely filthy. This man had not received any meals and was half starving.

Our staff could not get entry. All they could do was talk to the person through the door. After a period of time they got an agreement to arrange for Meals on Wheels for this person. So that opened the door, and he started to eat. The mental health team had not been to see him. He had gone off the books of the mental health team. That person eventually was relinked to the mental health system and

⁴⁸⁶ Submission 192, NCOSS, pp 17-18

⁴⁸⁷ Submission 76, Northern Rivers Area Mental Health Council, p 1

⁴⁸⁸ Submission 192, NCOSS, p 18

⁴⁸⁹ Submission 71, St Agnes Support Service, p 1

started receiving assistance. But if another NGO or another type of organisation had maintained contact with that person, he would not have got into that state.⁴⁹⁰

7.56 Several submissions raised the problem of people with mental illness losing their NSW Department of Housing home while hospitalised for acute episodes. Illawarra Legal Centre Tenants' Service gave an example of this from their case files:

The tenant is a woman in her early thirties. She has lived in a two bedroom Department of Housing flat for three years. She is separated from her partner and has her children stay on weekends. She had a psychiatric episode that resulted in hospitalisation. The initial medical assessment suggested she could be in hospital for two to three months. The departmental workers wanted the woman to relinquish her government housing and be placed on a priority list for housing after being discharged. They would also provide bond and rent assistance so she could take up a private rental premises until priority housing was available.

The tenant's father unsuccessfully sought to act on his daughter's behalf and prevent her from giving up the flat. The tenant's father was hindered in his efforts by the Department of Housing, who believed they could act in the tenant's best interest. However, a hospital social worker facilitated the signing over to the flat to the Department believing it would be in the tenant's interest.⁴⁹¹

7.57 Unsupported accommodation in public housing impacts not only on the mental health of the tenant, but also affects other vulnerable tenants. Submissions from public housing tenants described the difficulties of living in close proximity to people with untreated or unstable mental health problems.

7.58 Mr David Jobling, a member of the Public Housing Customer Council, commented that the most common reported problem is that no support is provided to ensure tenants are 'okay'.⁴⁹² The submission described the consequences for all tenants in a housing estate when an individual experiences an acute episode without proper care and attention:

An individual with (say) bipolar disorder who is on a heavy amount of prescribed medication will fail to comply with his/her medication routine and start to behave in a disruptive or damaging way towards him/herself, property, other people. The most regular response will be that someone calls the police and the police delivers the individual to a mental health unit. After a stay in a mental health unit, the individual is released, or to put it plainly, deposited back on the estate.

The nuisance and annoyance they may have caused while on an 'off medication bender' impacts on the Department of Housing estate community and creates friction amongst many tenants.⁴⁹³

7.59 Another public housing tenant described the anxiety vulnerable older people experienced as a result of intimidation and harassment while living in close proximity to people with acute mental illnesses.⁴⁹⁴ The Committee was also advised that:

⁴⁹⁰ Ms Joyce Said, Chair, MHCC, Evidence, 28 May 2002, p 39

⁴⁹¹ Submission 175, Illawarra Legal Centre Tenants' Service, pp 3-4

⁴⁹² Submission 13, Mr David Jobling, p 2

⁴⁹³ *ibid*, p 2

⁴⁹⁴ Supplementary Submission 44, Mr James Qusted, p 1

Putting mentally ill people among aged pensioners is very unsettling for both...It is very hard for the mentally ill people when they are not getting the support they need.⁴⁹⁵

7.60 CASA similarly advocated for helping public housing tenants with mental illnesses ‘make their tenancy work’ through adequate support rather than evicting them:

People with a mental illness can experience episodes of psychotic behaviour if they do not receive the right treatment and ongoing support. This can make them difficult to live near, but CASA does not believe they should be evicted from public housing as a result. Far better to ensure adequate support is available to assist them in making their tenancy work than contributing to the growing number of homeless.⁴⁹⁶

7.61 CASA, together with several other submissions, emphasised the importance of support services in helping people maintain tenancies and integrate more into their local community.⁴⁹⁷ UnitingCare also commented:

UnitingCare supports the public policy objective of supporting people with mental health issues, including those with psychotic illnesses, to live in a ‘normal community environment’. We note that for people without psychotic illnesses, living in the community is not just about a house of their own (a building) – it is about relationships with other people: at work, at leisure, etc...Integration of people with psychotic illnesses in the ‘community’ involves a careful consideration of appropriate housing situation (for example, cluster housing rather than isolated, individual units) and broader social supports that counter stigmatisation and the reinforcement of inferiority.⁴⁹⁸

7.62 NCOSS raised concerns that the recently announced social housing package for public housing tenants, which includes rental bonds and renewable tenancies may have a disproportionate and unfair impact on people with mental illness and mental disorders. Without adequate support services for these tenants, NCOSS is concerned that:

people with mental illness and other highly marginalised communities are more likely to face homelessness as a result of this policy change.⁴⁹⁹

Recommendation 42

That NSW Health inquire into and report publicly on the shortfall in support and case management services for people with a mental illness who are accommodated in public housing, and allocate adequate resources to meet the identified shortfalls.

⁴⁹⁵ Submission 39, Mrs Edna Crossingham, pp 1-2

⁴⁹⁶ Submission 172, CASA, p 8

⁴⁹⁷ *ibid*, p 5

⁴⁹⁸ Submission 78, UnitingCare, pp 14-15

⁴⁹⁹ Submission 192, NCOSS, p 18

Recommendation 43

That the proposed Office of Mental Health oversee the implementation of effective, coordinated support services for people with a mental illness living in public housing. This will require monitoring service agreements at state and local level between the NSW Departments of Housing, Health, Community Services and Ageing, Disability and Home Care.

Recommendation 44

That NSW Health and the NSW Department of Housing establish a clustered housing (intensive, managed) project for people with a mental illness who have had difficulty maintaining public housing tenancies.

Boarding houses

- 7.63** It is estimated that over 40% of people in licensed boarding houses have a mental illness.⁵⁰⁰ From submissions received by the Committee, it appears that boarding houses are considered an undesirable accommodation option, but at times are the only facilities available for people with complex needs. The Public Guardian stated:

There is limited ability of appropriate and safe community based accommodation to meet an individual's immediate and long-term needs. Referral to boarding house accommodation for people with mental illness is often the only option.⁵⁰¹

- 7.64** UnitingCare commented on the quality of life of those living in boarding houses:

While the residents of [government-licensed] boarding houses are not living in mental hospitals, they still largely have an institutionalised life. They lack privacy, because they might share rooms with from 1 to 6 people. They might have to move rooms when/if a reshuffle occurs after any resident changes, either through exit or intake of new residents.⁵⁰²

- 7.65** A number of submissions stated that people living in boarding houses or other group arrangements did not receive adequate treatment and follow-up from community mental health teams. CASA argued in its submission that this was because community mental health teams are understaffed and under-resourced and can only attend the 'direst' emergencies.⁵⁰³

- 7.66** Several submissions highlighted the problems that emerge when the homeless and people in single-room accommodation "experience day to day lives which are bereft of meaningful activity".⁵⁰⁴ Without employment and training opportunities, and limited recreational

⁵⁰⁰ Submission 172, Coalition for Appropriate Supported Accommodation (CASA), p 7

⁵⁰¹ Submission 255, Office of the Public Guardian NSW, p 3

⁵⁰² Submission 78, UnitingCare, p 26

⁵⁰³ Submission 172, CASA, p 6

⁵⁰⁴ Submission 238, The Salvation Army Australia Eastern Territory, p 4

activities, people in boarding house style accommodation frequently have limited scope for recovery and rehabilitation. The Salvation Army commented that these people are, as a result, unable to contribute to the community, and more likely to be caught up in antisocial and illegal activities.⁵⁰⁵ CASA commented that existing rehabilitation programs tend to be 'treatment focussed within the medical model', when studies have shown that social activities are of significant benefit to people with a mental illness. It cited the Mary MacKillop Outreach Program in Lewisham, Sydney, as a successful program run on limited resources.⁵⁰⁶

7.67 Shelter NSW, CASA and NSW CAG also pointed to the lack of legislative protection for tenants of boarding houses. Boarding houses are not covered by the *NSW Residential Tenancies Act 1986*. As a result boarders and lodgers are not classified as 'tenants' and regardless of whether or not boarding houses are licensed, tenants have no access to the rights afforded to ordinary tenants.⁵⁰⁷ CASA stated that Victoria, South Australia and Queensland resolved this problem when they introduced boarders and rooming house legislation.⁵⁰⁸

7.68 Shelter NSW commented that boarding houses could provide sustainable accommodation if adequate support is provided:

For some people group homes or boarding house style accommodation, combined with support services, can result in sustainable tenancies. However, this should be a genuine choice people make freely make rather than a cheap 'solution' which fits all circumstances and creates 'ghettos'.⁵⁰⁹

7.69 Ms Leanne Elsworthy, Coordinator, B. Miles Women's Housing Scheme, described to the Committee the concept of 'clustered housing', in which people with a mental illness could live in supported arrangements but in their own apartment and with separate staff facilities. Such arrangements, though costly, would avoid the 'institutional feeling' of boarding houses and enable individuals to become as independent as possible.⁵¹⁰

7.70 The Salvation Army advised that there was a closure of unlicensed boarding houses and other group homes due partly to the lack of community mental health support. The submission argues that these closures have increased the likelihood of mentally ill people needing to seek accommodation in crisis centres.⁵¹¹ The submission further argued that:

sufficient funding should be allocated for the provision of adequate services to tenants and landlords so that those people whose mental illness does not require high levels of care, can be sustained in low cost accommodation options. We understand that the lack of adequately trained staff in these services can be

⁵⁰⁵ Submission 238, The Salvation Army Australia Eastern Territory, p 4

⁵⁰⁶ Submission 172, CASA, p 7

⁵⁰⁷ Submission 198, Shelter NSW, p 6; Submission 172, CASA, p 7; Submission 162, NSW Consumer Advisory Group, p 26

⁵⁰⁸ Submission 172, CASA, p 7

⁵⁰⁹ Submission 198, Shelter NSW, pp 4-5

⁵¹⁰ L. Elsworthy, Evidence, 29 May 2002, p 13

⁵¹¹ Submission 238, The Salvation Army Australia Eastern Territory, p 3

addressed by the allocation of sufficient funding. This should include adequate provision and training of staff.⁵¹²

- 7.71** The NSW Government has sought to improve the quality of boarding houses in NSW through its \$66 million Boarding House Reform Strategy.⁵¹³ The Public Guardian commented favourably regarding its effect on services to boarding houses:

The Government's Boarding House Reform Strategy has significantly opened the boarding house sector to mental health and other services. NSW Health and the NSW Department of Ageing, Disability and Home Care (DADHC) have worked in close partnership to increase the access that people in boarding houses have to appropriate mental health and other services. It will be important that this continues.⁵¹⁴

- 7.72** The Coalition for Appropriate Supported Accommodation for People with Disabilities (CASA) argued in its submission that there was still much to be done for those with mental illness residing in low cost, congregate living arrangements and other 'marginal housing'.⁵¹⁵

Recommendation 45

That NSW Health, the NSW Department of Community Services, the NSW Department of Ageing, Disability and Home Care and the NSW Department of Housing, cooperate to conduct an assertive outreach campaign that includes raising the awareness of boarding house residents and landlords about residents' rights to health care, mental health care, legal services and other services relevant to their needs.

Recommendation 46

That the NSW Government fund the continuation and expansion of the Boarding House Reform Strategy.

The private rental market

- 7.73** The private rental market includes conventional housing as well as bedsits, hotels and caravans. People with a mental illness can experience difficulties in the private rental market. They can be vulnerable to exploitation by landlords, and unaware of their rights under the *Residential Tenancies Act 1986*.
- 7.74** The Illawarra Legal Centre 'Tenants' Service described two situations in which people with a mental illness had difficulties with private rentals. In one situation, a private landlord repeatedly visited the property of a man with a mental illness. The man decided to move, but relinquished his bond rather than taking formal action against the landlord, because he

⁵¹² Submission 238, The Salvation Army Australia Eastern Territory, p 4

⁵¹³ Submission 172, Coalition for Appropriate Supported Accommodation (CASA), p 5

⁵¹⁴ Submission 255, The Office of the Public Guardian, p 5

⁵¹⁵ Submission 172, Coalition for Appropriate Supported Accommodation (CASA), p 5

wished to avoid psychological distress. In another situation, a family of five could not find premises to rent because the father was listed on a private industry database of 'unsuitable' tenants. The father had experienced bouts of depression and had been late in paying rent at times, leading to a poor relationship with a real estate agent.⁵¹⁶

7.75 The Illawarra Legal Centre 'Tenants' Service commented that people 'blacklisted' in this fashion are often forced to live in caravan and residential parks, boarding houses, hostels and cramped arrangements with families and friends, because they cannot secure rental housing.⁵¹⁷

7.76 The Society of St Vincent de Paul (Wollongong Diocesan Council) commented:

It is common experience for our members to find people with mental illness living in caravans, sub-standard rooms in hotels or boarding houses or living alone in bedsits without apparent support.⁵¹⁸

7.77 The Tweed River Valley Fellowship found during its local consultations that due to a lack of supported accommodation facilities, brokerage funds are used to house people in caravan parks and motels:

This is proving to be problematic for consumers and the community, it is difficult for follow-up by acute care teams and often people are need of intensive supported accommodation...It is extremely difficult to convince caravan park [or] motel owners to tenant a person directly after discharge from inpatient stays nor is it appropriate for consumers with high disability support needs.⁵¹⁹

Coordination of housing service provision

The present situation

7.78 The analysis of accommodation options for people with a mental illness revealed a system that is under resourced and understaffed. In the view of Mission Australia:

The current environment of service provision is considered to be uncoordinated, fragmented and confusing for both those it is intended to help and those providing support services.⁵²⁰

7.79 Ms Joyce Said, Chair of the MHCC, told the Committee in May 2002 that NGOs were still an 'afterthought' in the area level planning and delivery of mental health services:

There is no direction from the Centre of Mental Health to the [Area Health Services] telling them how to fit the NGO sector, in a partnership way, into the services that are being provided. It would have been useful...to see the NGOs as

⁵¹⁶ Submission 175, Illawarra Legal Centre Tenants' Service, pp 4-6

⁵¹⁷ *ibid*, p 6

⁵¹⁸ Submission 178, Society of St Vincent de Paul (Wollongong Diocesan Council), p 5

⁵¹⁹ Submission 100, Tweed River Valley Fellowship, Appendix p 2

⁵²⁰ Submission 188, Mission Australia, p 5

true partners in the service provision and have us made part of a system of management for the people so that there is a seamless system for them to use...I think the lack of NGO inclusion in the planning is the same across the state. It is starting to happen in a small way in some of the metropolitan areas. There is a little bit of it happening but in the main there are insufficient numbers of NGOs. Northern NSW is quite good at working with NGOs but it is very patchy.⁵²¹

7.80 Ms Leanne Elsworthy from B. Miles stated to the Committee:

There needs to be someone keeping track of people, an organisation that is keeping an eye on how somebody is going, not tied up to case managers. Ideally case managers should be doing that but they cannot because their workloads are too high. Ideally there needs to be agencies responsible for overseeing how the person is going and someone to bring in the services as they are needed. People are episodic and unpredictable.⁵²²

7.81 UnitingCare observed in its submission:

It is clear that many of the most effective interventions follow from a collaborative approach in which non-profit organisations not deemed by the Department of Health to be psychiatric disability support services, or funded by that Department, play a key role.⁵²³

7.82 UnitingCare proposed that there be a greater focus on post-acute care:

We would like to see the mental health system in New South Wales recognised as a 'system', in which the Department of Health has a *lead agency* role. That system has three legs:

- promotion, prevention and early intervention
- acute care of people with mental disorders and
- post-acute care of people with chronic disabilities in community residential settings.

The government's focus has been on acute care. Greater attention is now being given to promotion, prevention and early intervention. Post-acute care of people with chronic disabilities in community residential settings is a public policy vacuum.⁵²⁴

7.83 NSW Health has acknowledged its responsibility to ensure access to appropriate accommodation:

The fundamental need for people to be housed to maintain health highlights the responsibility for NSW Health to work in close partnership with public, non-

⁵²¹ J Said, Evidence, 28 May 2002, p 30

⁵²² L Elsworthy, Evidence, 29 May 2002, p 23

⁵²³ Submission 78, UnitingCare, p iv

⁵²⁴ *ibid*, p iii

government and private housing providers to ensure access to safe, secure and affordable housing for people with mental health problems and disorders.⁵²⁵

7.84 During the inquiry, the Committee was informed about several good practice examples for housing people with a mental illness in Australia. These included the South Australian Special Needs Housing Unit and the Victorian Rooming House Program.⁵²⁶ In each initiative, there was an emphasis on encouraging innovation at local area level in order to best meet the needs of client groups. Mission Australia stated in its submission:

striking the correct balance between the provision of health service support and other forms of social support, through innovative models of service delivery, remains the critical question for integration of people with a mental illness into the community.⁵²⁷

NSW Health – Government Action Plan

7.85 In recognising the need to address the shortcomings of accommodation and support, NSW Health published the *Framework for Housing and Accommodation Support for People with Mental Health Problems and Disorders Report* (Framework) in August 2002, as part of the NSW Government Action Plan for Health Framework.⁵²⁸ The Director General of NSW Health stated the Framework:

provides a template to assist NSW Mental Health Services, social housing providers, mental health NGOs and the mainstream NGO sector with service planning, development and evaluation.⁵²⁹

7.86 In the Framework document, NSW Health advises that it has developed new strategies that are related to the accommodation, support and wellbeing of people with a mental illness. These include increased funding, a comprehensive plan to address issues in boarding houses, an interdepartmental committee on challenging behaviours, interdepartmental Partnership against Homelessness and an interdepartmental agreement between NSW Health and the NSW Department of Housing to address the public housing needs of people with mental illness.⁵³⁰

7.87 The Framework specifies that each AHS will develop a Housing and Accommodation support plan that:

identifies key partners, resources and strategies for the development of housing and accommodation support options for people with mental health problems and disorders. They key partners will be the Department of Housing, the Office of Community Housing, community housing associations, non-government

⁵²⁵ NSW Health (2002), *Framework for Housing and Accommodation Support for People with Mental Health Problems and Disorders Report*, p 3

⁵²⁶ Submission 78, UnitingCare, p 26

⁵²⁷ Submission 188, Mission Australia, p 6

⁵²⁸ NSW Health (2002), *Framework for Housing and Accommodation Support for People with Mental Health Problems and Disorders Report*, p 2

⁵²⁹ *ibid*

⁵³⁰ *ibid*, p 8

providers of both disability services and services for homeless people, the Department of Ageing, Disability and Homecare and other community organisations. Area Health Services will identify their role as the providers of clinical support.⁵³¹

- 7.88** The Framework also indicates that the JGOS will be developed further at local levels, incorporating other ‘key partners’, designed to facilitate the availability of a range of housing and accommodation support options to meet local population needs.⁵³² The Centre for Mental Health has engaged in consultation with a range of other government departments including the NSW Department of Housing, the Office of Community Housing and the Commonwealth Department of Family and Community Services. This is to promote the development of strategies to evaluate innovative housing and accommodation support models for service delivery.⁵³³
- 7.89** Under the Framework, NGOs will participate at “systems, service provision and individual levels,”⁵³⁴ but their role at the strategic planning and policy level is left unstated.
- 7.90** It is important that the *Framework for Housing Accommodation Support for People with Mental Health Problems and Disorders* is seen to deliver against its objectives. One way of achieving this is to ensure that NSW Health publicly reports on the outcomes and achievements of the Framework.

Recommendation 47

That NSW Health publish a report on the outcomes of the *Framework for Housing Accommodation Support for People with Mental Health Problems and Disorders* within 6 months and then annually. The reports should include information from Area Health Services on:

- consumer satisfaction indicators
 - waiting list numbers for supported accommodation places and public housing and
 - indicators of unmet need at all local area levels.
-

⁵³¹ NSW Health (2002), *Framework for Housing and Accommodation Support for People with Mental Health Problems and Disorders Report*, p 3

⁵³² *ibid*, p 20

⁵³³ *ibid*, p 8

⁵³⁴ *ibid*, p 20

Homelessness

- 7.91** In Australia, homelessness is growing and its causes are increasingly complex.⁵³⁵ Homelessness of people with a mental illness is a serious problem for most Western industrialised countries.⁵³⁶ Under the *Supported Accommodation Assistance Program Act 1994*, a person is defined as homeless “if he or she has inadequate access to safe and secure housing”.⁵³⁷ The 1996 census found that 29,608 people in NSW were homeless under this definition,⁵³⁸ and that number is anticipated to rise when the corresponding 2001 census data is available.
- 7.92** A number of studies have estimated the number of homeless people that also have a mental illness ranges between 10% and 50%.⁵³⁹ In the 1996 census, this meant that between 2,960 and 14,804 people in NSW who were homeless on census night had a mental illness. A much-cited study from 1998, *Down and Out in Sydney*, estimated that 75% of homeless people in inner Sydney had at least one mental disorder.⁵⁴⁰
- 7.93** Of some concern to the Committee is a report from Parramatta City Council that, in its area, the number of homeless people with mental illness is rising rapidly:
- the number of people with mental illness admitted to Cumberland Hospital with no fixed abode has doubled since 1995.⁵⁴¹
- 7.94** NSW Health noted that the homeless population now includes a significantly high proportion of young people with a range of complex problems, including mental illness.⁵⁴² The Society of St Vincent de Paul (Wollongong Diocesan Council) commented:
- People with dual diagnosis [MISA] who are homeless are triply disadvantaged, as many homeless persons services do not have the capacity to assist people with mental illness or people who have a current substance abuse problem. The neat division of services into mental health, drug and alcohol or homeless persons services fails to take into account that many of the most vulnerable people in our state are people who are homeless and suffering mental illness and substance abuse problems.⁵⁴³

⁵³⁵ Commonwealth Department of Family and Community Services (2000), *National Homelessness Strategy: A Discussion Paper*, p 4

⁵³⁶ L. Craze, Discussion Paper, ‘SAAP Linkages with Mental Health: Improving Outcomes for Homeless People with a Mental Illness’, 2000, p 3

⁵³⁷ Commonwealth of Australia, *Supported Accommodation Assistance Program Act 1994*, Section 4. (1)

⁵³⁸ C Chamberlain, *Counting the Homeless: Implications for Policy Development 1996*, 1999, p 44

⁵³⁹ Submission 245, Schizophrenia Fellowship of NSW, pp 5-6; Submission 85, Parramatta City Council, p 2

⁵⁴⁰ St Vincent de Paul Society, Sydney City Mission, the Salvation Army, Wesley Mission and the Haymarket Foundation (1998), *Down and Out in Sydney*.

⁵⁴¹ Submission 85, Parramatta City Council, p 2

⁵⁴² NSW Health, *Framework for Housing and Accommodation Support for People with Mental Health Problems and Disorders Report*, NSW Government Action Plan for Health, August 2002, p 4

⁵⁴³ Submission 178, Society of St Vincent de Paul (Wollongong Diocesan Council), pp 5-6

7.95 People who are discharged from psychiatric institutions do not necessarily become homeless.⁵⁴⁴ A range of factors, including available support networks upon discharge, determine whether someone becomes homeless.⁵⁴⁵ The Mental Health Co-ordinating Council (MHCC) noted that in the case of the Richmond Report, many people had erroneously associated the Report with deinstitutionalisation and increasing levels of homelessness among people with mental illness.⁵⁴⁶ The submission stated that:

Only relatively few patients were discharged from long stay wards to the community following the Richmond Report. The number of people residing in psychiatric hospitals in NSW in 1985 was 55 per 100,000 population and the total population was 5.6 million. Between October 1984 and October 1987, 208 long-term patients were discharged from hospitals and placed in supported group homes. As a follow up review, Andrews et al (1990) found that the majority was successfully living in the community, while 22 patients had been rehospitallised. At the time of the study, the residents had been living in the community for varying lengths of time, ranging from three to 40 months post discharge.⁵⁴⁷

7.96 Prof Ian Webster also addressed the misconception about the correlation of homelessness with the Richmond Report:

It is wrong to suggest that the increasing number of homeless people who are mentally ill is because of the closure of beds in psychiatric hospitals. It is especially wrong to ascribe the current situation to the Richmond Report. The situation is due to a 'pincer movement' in which the most vulnerable are squeezed out of secure housing. These pressures come from income disparities, lack of affordable housing, lack of opportunities for gainful employment or activities, problems with income support, difficulties in accessing health services and other support.

This is not because previously institutionalised patients are being discharged to the community, but due to a range of factors operating across many western countries such as the UK, Australia and US. The homeless mentally ill are those who might have been admitted in the past to institutions but now have reduced access to a declining number of institutional beds.⁵⁴⁸

7.97 Mental illness itself may not be the direct cause of homelessness, with other factors related to the mental illness having a significant influence such as poverty⁵⁴⁹, and discrimination in housing and employment markets.⁵⁵⁰ Research shows that among people with mental illness, those most at risk of becoming homeless:

⁵⁴⁴ Submission 218, Mental Health Co-ordinating Council, p 3

⁵⁴⁵ L. Craze, Discussion Paper, 'SAAP Linkages with Mental Health: Improving Outcomes for Homeless People with a Mental Illness', 2000, p 4

⁵⁴⁶ Submission 218, Mental Health Co-ordinating Council, p 1

⁵⁴⁷ *ibid*, p 1

⁵⁴⁸ Submission 193, Prof Ian Webster, p 3

⁵⁴⁹ Sydney City Mission, Society of St Vincent de Paul, the Salvation Army, Wesley Mission, and the Haymarket Foundation (1997), *Shifting the Deckchairs: Homeless People and Mental Health Services in Inner City Sydney*.

⁵⁵⁰ L. Craze, Discussion Paper, 'SAAP Linkages with Mental Health: Improving Outcomes for Homeless People with a Mental Illness', 2000, p 4

have higher rates of hospitalisation and arrest, are more likely to abuse alcohol and drugs than other patients, have higher psychiatric symptom levels, and are less likely to comply with medication.⁵⁵¹

7.98 The MHCC also commented in its submission that people with mental illness can become homeless if suitable accommodation and support is not provided in the community.⁵⁵² A six-year study of clients following deinstitutionalisation submitted by the Comprehensive Area Service Psychiatrists indicated that adequate community resources and continuity of care provides individuals with much greater life satisfaction, community tenure, clinical stability and social integration.⁵⁵³

7.99 CASA reported that in some areas, community based mental health teams will not attend if a person is homeless. It cited cases of this occurring in Parramatta and the City of Sydney.⁵⁵⁴

7.100 Carers Lodge, a drop-in centre at Young, illustrated in its submission that some people with mental health problems only require minimal support in order to avoid homelessness. While NSW Health funds the lease on the building, the Carer's Lodge is staffed solely by volunteers, providing a free, accessible service for its clients:

In providing this service we assist the client in locating more permanent accommodation so that accommodation is no longer an issue. We also ensure that the client is receiving all social security benefits that they are entitled to receive...Where appropriate the client is also referred to other agencies... Furthermore, as some of the clients are homeless and may have previously been unable to pay their rent, we encourage them to have Centrelink deduct the rent from their pension and pay it directly to their landlord, this in turns assists in providing security of tenancy.⁵⁵⁵

7.101 Prof Ian Webster stated that despite the suffering homelessness caused, some people with mental illness who are homeless prefer to be on the streets than in a psychiatric institution:

I have asked many homeless men with mental illness where they would prefer to be: in a mental hospital, or say, at the Matthew Talbot Hostel in Wolloomooloo. Almost all without exception say they prefer not to be in a psychiatric hospital. They value their freedom. It is important to them...The people who are homeless and mentally ill value the medical clinic (at the Matthew Talbot Hostel) because general nurses and doctors who are not part of the mental health system work there.⁵⁵⁶

7.102 In his submission, Prof Webster referred to the 'three week rule' of homelessness, a term used in the United Kingdom. The 'three week rule' is the amount of time it takes for a newly homeless person to become acclimatised to life on the street, after which they

⁵⁵¹ ibid

⁵⁵² Submission 218, Mental Health Co-ordinating Council, p 3

⁵⁵³ Submission 209, Comprehensive Area Service Psychiatrists Special Interest Groups, Attachments I and II.

⁵⁵⁴ Submission 172, CASA, p 6

⁵⁵⁵ Submission 8, Carers Lodge (Young Community Caring Group), p 2

⁵⁵⁶ Submission 193, Prof Ian Webster, p 3

become entrenched and it becomes more difficult to move back into mainstream society.⁵⁵⁷ Prof Webster was concerned that:

The event of homelessness has a powerful downward effect on a person's ability of function normally. A person quickly adapts and accepts their circumstances. They soon give up and sink into a state of hopelessness and helplessness... This means that early intervention, especially those with mental disorders, is an area in which innovation is required.⁵⁵⁸

7.103 Early discharge from psychiatric care without housing support liaison can trigger an episode of homelessness. UnitingCare commented:

UnitingCare Burnside services have worked with people who have come out of the local psychiatric unit (such as Waratah House in the Macarthur region) to inappropriate housing or no housing at all.⁵⁵⁹

7.104 CASA gave a case study of one woman's path to homelessness, which highlighted the 'marginal' nature of boarding house accommodation:

[A] Boarder with a psychiatric disability lived in a boarding house for 1 year. Her illness was managed and she was working. She got involved in an altercation with another resident, as a result the caretaker summarily locked her out of the premises.

She sought emergency accommodation, but it was not appropriate and [she] was homeless. As a result of the homelessness she developed severe psychiatric symptoms and is currently in and out of a psychiatric hospital.⁵⁶⁰

7.105 In view of this evidence, the Committee supports the initiative in the 2002 NSW *Framework for Housing and Accommodation Support for People with Mental Health Problems and Disorders* that calls for the development of:

discharge planning protocols [to] inform the transition from acute hospital settings to home, housing and accommodation support programs.⁵⁶¹

7.106 In February 2002, the NSW Department of Housing announced that the NSW government would be introducing a protocol for all government agencies that come into contact with homeless people.⁵⁶² NCOSS strongly supported the development of a homelessness protocol, similar to the one developed for the Sydney Olympic Games. NCOSS emphasised in its submission that such a protocol must address the particular needs of homeless people with mental illness.⁵⁶³

⁵⁵⁷ *ibid*, p 7

⁵⁵⁸ Submission 193, Prof Ian Webster, p 7

⁵⁵⁹ Submission 78, UnitingCare, p 25

⁵⁶⁰ Submission 172, CASA, p 7

⁵⁶¹ NSW Health, *Framework for Housing and Accommodation Support for People with Mental Health Problems and Disorders Report*, NSW Government Action Plan for Health, August 2002, p 21

⁵⁶² Submission 192, NCOSS, p 20

⁵⁶³ *ibid*

Bail hostels

7.107 The *NSW Bail Act 1978* was recently amended through the *Bail Amendment (Repeat Offenders) Act 2002* to allow the courts to consider additional options in granting bail.⁵⁶⁴ Section 32 of the *Bail Act* now allows the courts to consider the interests of a person with a mental illness when considering a bail application. In considering conditions of bail, the courts may consider whether placement “in accommodation for persons on bail” is available and suitable for the accused person. During the second reading speech on the *Bail Amendment (Repeat Offenders) Bill*, the Attorney General noted:

Often the lack of employment or appropriate residence will be a debilitating factor in deciding whether to grant bail. The availability of supervised bail accommodation and the suitability of the accused person to be bailed to this type of accommodation allows the court to both strengthen existing requirements of bail and divert offenders who might otherwise be incarcerated. This is particularly important for vulnerable accused persons such as juveniles, intellectually or disabled persons, or persons of an Aboriginal or Torres Strait Islander background.⁵⁶⁵

7.108 During the Second Reading debate on the *Bail Amendment (Repeat Offenders) Bill* in the Legislative Council, the House was informed that there is no accommodation in NSW for adult offenders and only one bail hostel for juvenile offenders.⁵⁶⁶ In order for homeless people with mental illness to meet bail requirements there appears to be a strong need for supervised accommodation with mental health service support, so that homeless mentally ill people can obtain bail and meet bail conditions. The Government must be committed to funding sufficient services for the provision of bail hostels or alternative accommodation to incarceration. The Committee is concerned that unless this commitment is made, homeless people who are mentally ill will continue to be denied bail.

Recommendation 48

That the NSW Departments for Housing, Community Services, Health, Ageing Disability and Home Care and Attorney General, coordinate to immediately initiate a specialist supervised and supported accommodation or ‘bail hostel’ program across NSW, for homeless people with a mental illness who have been charged with an offence.

Recommendation 49

That the Attorney General propose amendments to the *NSW Bail Act 1978* to legislate for the provision of supervised and supported bail hostels for people with a mental illness.

⁵⁶⁴ NSW Legislative Assembly, *Hansard*, 20 March 2002, p 818

⁵⁶⁵ NSW Legislative Assembly, *Hansard*, 20 March 2002, p 818

⁵⁶⁶ For example, the Hon John Ryan MLC referring to a letter from the Law Society of NSW: NSW Legislative Council, *Hansard*, 9 May 2002, p 1888

Initiatives to prevent homelessness in NSW

- 7.109** The Crisis Accommodation Program (CAP) is a program under the Commonwealth State Housing Agreement administered by the Office of Community Housing (an agency of the NSW Department of Housing). CAP provides funds to community-based providers to acquire, lease, renovate, convert or build accommodation specifically for homeless people and those at risk of homelessness.⁵⁶⁷
- 7.110** In 1999, the NSW Government established the Partnership Against Homelessness to coordinate and improve a wide range of housing and support services for homeless people in NSW. The participating agencies are the NSW Department of Housing (lead agency), Aboriginal Housing Office, Department of Community Services, NSW Health, The Cabinet Office and the Departments of Ageing, Disability and Home Care, Fair Trading, Women, Corrective Services, and Juvenile Justice. The key aims of the partnership are to:
- help homeless people access services
 - coordinate support services
 - provide accommodation in a crisis
 - make the move to long term housing.⁵⁶⁸
- 7.111** Projects initiated under the Partnership Against Homelessness include:
- *Homeless Action Team in Sydney*, to help long-term residents of accommodation find more suitable housing
 - *Providing Extra Support*, in which the NSW Department of Community Services coordinates support services that homeless or recently housed people need
 - *Broadening the Range of Accommodation Models*, with the NSW Department of Housing trialling two different supported housing arrangements to provide alternative housing models for people disabilities and low to moderate support needs
 - *Meeting Indigenous Needs*, developing services that meet the needs of the indigenous community for more accessible crisis and transitional accommodation
 - *Making a Smooth Transition*, which provides additional transitional accommodation to free up crisis services and
 - *Working together in Inner Sydney*, to assist people sleeping in public places.⁵⁶⁹

⁵⁶⁷ NSW Department of Housing, *Crisis Accommodation Program Delivery Plan 2002-03*, 2002 p 1

⁵⁶⁸ NSW Department of Housing, Fact Sheet, 'Partnership Against Homelessness', 2002, p 1

⁵⁶⁹ *ibid*

7.112 The submission from NSW Health described the Inner Sydney project in more detail:

The Woolloomooloo Homeless Project, coordinated by the Department of Housing is a Partnership Against Homelessness Project. The Steering Committee has been developing and monitoring strategies to reduce the number of people rough sleeping in the Woolloomooloo area and related issues...

A Partnership Against Homeless Working Party is developing a Draft Action Plan for Inner City Homeless. The development of the Action Plan has been identified as a desirable outcome of the Woolloomooloo Homelessness Project Steering Committee.

...The Action Plan aims to improve the quality of services rough sleepers receive from agencies, while at the same time increase the options available to meet their individual needs. The Plan also aims to enhance collaboration in service delivery and service management to target hotspots of rough sleepers in the inner city and move people into permanent housing options with support as necessary. Discussions have been taking place with inner city mental health service providers to map out the strategies...⁵⁷⁰

7.113 While there are a significant number of projects to address homelessness in NSW, frustration was expressed by NGO service providers regarding their lack of inclusion in an overall state strategy and area planning to combat homelessness:

[There are a] high amount of referrals to the NGO sector from government agencies especially in regard to accommodation support. Consumers who have long term psychiatric disability and are not acknowledged as having long term support needs...are being discharged to homelessness, however there is no recognition from the Centre for Mental Health of the responsibility of NSW Health providing housing (refer to Government Action Plan documents), only clinical treatment.⁵⁷¹

7.114 There also appeared to be dissatisfaction with the high number of pilot and one-off projects, as evidenced in the following comment:

What we are getting now is a whole lot of pilot programs, one-offs, and it just feels like flicking coins into a fountain.⁵⁷²

⁵⁷⁰ Submission 267, NSW Health, G.42

⁵⁷¹ Submission 100, Tweed River Valley Fellowship, p 1

⁵⁷² L. Elsworthy, Evidence, 29 May 2002, p 25

Recommendation 50

That NSW Health evaluate the success of existing pilot programs for homeless people with a mental illness and:

- discontinue programs shown not to be effectively and efficiently achieving their planned outcomes
 - expand funding to programs identified as effectively and efficiently achieving planned outcomes.
-

Victorian strategies to assist people with a mental illness who are homeless or at risk of homelessness

7.115 Since 1997, initiatives for people with mental illness in Victoria include:

- residential rehabilitation services for young people with mental illness
- mental health funding of outreach services for people in marginalised housing.⁵⁷³

7.116 The Victorian Housing Strategy has a 'Joined Up Initiatives' Program which works with government and non-government agencies. The 2002-2003 Plan is highly detailed and targets identified areas for property acquisition across the state, staffing and funding levels for each service, and support staff ratios. The Program is coordinated with the SAAP and a range of specialist support providers. The Transitional Housing Management Program (THM) is coordinated with SAAP and delivered through 19 THM agencies throughout the state. Properties, either owned or leased by the Director of Housing, are allocated to THM agencies.⁵⁷⁴

7.117 Major initiatives under the Victorian strategy include:

- *The THM/Mental Health Housing Pathways Initiative 1.* This initiative targets people identified by mental health or homelessness services who are living on the streets or in crisis accommodation. The project aims to provide pathways out of homelessness for people with a serious mental illness and complex needs through the provision of specialist support packages and allocation of Transitional Housing Management housing stock. Twelve support providers are located across Victoria for the project, and support is intensive at a 1:5 to 1:10 ratio. The Office of Housing has supplied 68 THM properties over two years, and the Mental Health Branch of Department of Human Services has funded approximately 112 support packages.
- *The THM/Mental Health Housing Pathways Initiative 2* expands on Initiative 1. The Office of Housing has supplied a further 50 THM properties to this initiative, and Mental Health has funded 10 additional Psychiatric Disability Support Services.

⁵⁷³ Correspondence from Department of Human Services Victoria to the Committee, 19 November 2002, p 1

⁵⁷⁴ Department of Human Services, Victoria, Victorian Homelessness Strategy: Joined Up Initiatives 2002-2003, p 3

- *The Victorian Homelessness Strategy/Mental Health Discharge Planning Initiative* is an 18-month pilot that aims to reduce the risk of homelessness for people with a mental illness when leaving hospital, by improving discharge and access to appropriate housing and support options. It is being undertaken in two metropolitan regions and one rural region. Six THM properties have been allocated to this initiative.⁵⁷⁵

7.118 Agencies in Victoria work closely to support these initiatives. Properties are provided through THM agencies under nomination rights, with housing stock matched in capacity to support at the program/planning level. Locally negotiated protocol agreements between the housing and support provider assist the linkages. The Department of Human Services Victoria noted:

A key element of these initiatives has been the capacity for the Office of Housing and the Mental Health Branch to work closely in developing and coordinating resources. Colocation in a single department has greatly facilitated this work.⁵⁷⁶

7.119 The Intensive Home Based Outreach Psychiatry Disability Support Program in Victoria aims to assist people with a mental illness, complex needs and who are homeless to stabilise accommodation and improve their health and wellbeing. Individual support works within a framework of psychosocial rehabilitation, with individual program plans reflecting the consumer's goals. A key feature of the program is that relies on assertive outreach rather than referrals from other agencies.⁵⁷⁷

Improving access and service coordination in NSW

7.120 As detailed by submissions from the NGO sector, NSW needs to work harder on a 'joined up' strategy to deal with people with a mental illness who are homeless and those in housing crisis. Of particular concern is the lack of strategies to prevent people with a mental illness becoming homeless in the first place. Evidence provided to the Committee has demonstrated that people with a mental illness become homeless because they:

- live in marginal housing situations such as boarding houses, where they have no support in maintaining their tenancies and no protection under residential law⁵⁷⁸
- are unable to maintain public housing tenancies because they have no support services⁵⁷⁹
- are unable to afford or maintain tenancies in the private rental market⁵⁸⁰ and

⁵⁷⁵ Correspondence from Department of Human Services Victoria to the Committee, 19 November 2002, p 1-2

⁵⁷⁶ Department of Human Services Victoria, Correspondence to the Committee, 19 November 2002, p 3

⁵⁷⁷ Mental Health Branch, Department of Human Services Victoria, *Mental Health Homelessness Program: Intensive Home Based Outreach Psychiatric Disability Support*. 2002

⁵⁷⁸ Submission 172, CASA, p 8

⁵⁷⁹ *ibid*; Submission 78, UnitingCare, p 15; Submission 71, St Agnes Support Service, p 1; Submission 98, B. Miles Housing Scheme, p 13; Submission 192, NCOSS, p 18

⁵⁸⁰ Submission 175, Illawarra Tenants' Legal Service, pp 4-6; Submission 178, Society of St Vincent de Paul (Wollongong Diocesan Council), p 5

- are discharged from hospital with nowhere to go.⁵⁸¹

7.121 Once people with a mental illness are homeless and seek crisis accommodation, they once more ‘fall through the net’ because crisis services such as SAAP are generic and not designed to meet the complex needs of clients with mental illness. It is important to recognise that the SAAP sector was never mandated nor resourced to provide support to homeless people with a mental illness.⁵⁸²

7.122 People with serious mental illnesses require a specialist set of services if they are to sustain secure accommodation. Rather than expanding SAAP itself, a specialised supported housing program to which intake-level clients of SAAP can be referred is required. This point was emphasised by Mission Australia. Mission Australia included the following comment by Ms Jennifer Westacott, former Deputy Director General of the NSW Department of Housing, in its submission:

It is important that we understand that housing is not in and of itself one thing that can change people’s lives. In our business it is always something else: housing and support, housing and health, housing and community facilities. Many tenancies often fail because we have not been able to get that support coordinated effectively. We are housing people with very complex support needs as well as their housing needs. The access points to housing and support services are often unclear and often uncoordinated. People will have to access their needs from a number of services and multiple points and that can be quite confusing for people.⁵⁸³

7.123 The *NSW Framework for Housing and Accommodation Support for People with Mental Health Problems and Disorders* proposes that:

clinical care, rehabilitation, accommodation support and other required services be delivered to people in their homes wherever they may be.⁵⁸⁴

7.124 The Committee recognises a critical flaw in this statement. Without clinical care, rehabilitation and accommodation support, people will not have homes that can be visited. Early intervention before homelessness occurs is critical if the *Framework for Housing and Accommodation Support for People with Mental Health Problems and Disorders* is to have an effect on the lives of people with mental illness.

Recommendation 51

That the Partnerships Against Homeless initiative be expanded to include key non-government agencies that deliver services to homeless people.

⁵⁸¹ Submission 78, UnitingCare, p 25; Submission 172, CASA, p 5

⁵⁸² L Craze, Discussion Paper, ‘SAAP Linkages with Mental Health: Improving Outcomes for Homeless People with a Mental Illness’, 2000, p 6. See also Section Five of the *Supported Accommodation Assistance Program Act 1994*.

⁵⁸³ Submission 188, Mission Australia, p 7

⁵⁸⁴ NSW Health, *NSW Framework for Housing and Accommodation Support for People with Mental Health Problems and Disorders*, p 11

Recommendation 52

That the participating agencies in Partnerships Against Homelessness, in collaboration with Supported Accommodation Assistance Program services, establish coordinated referral systems between participating agencies.

Recommendation 53

That the participating agencies in Partnerships Against Homelessness, fund assertive outreach services among homeless people in areas where the incidence of homelessness is identified as particularly high.

Recommendation 54

That the NSW Department for Housing and NSW Health develop a simple Housing Risk Identification Tool, which can serve as a proactive measure for managing an individual's housing risks. This should be incorporated into an 'Early Intervention Manual for People with Mental Illnesses at Risk of Homelessness'.

Recommendation 55

That NSW Health and the NSW Department of Housing adopt a housing strategy for people with a mental illness similar to the 'Joined Up Initiatives' program in Victoria where:

- the NSW Department of Housing allocates suitable housing stock for mentally ill people with complex needs and
- NSW Health funds non-government organisations to manage residential rehabilitation programs using the allocated housing stock.

This strategy should be developed and implemented within 6 months and allocation of housing stock commenced within 12 months of the strategy implementation.

Chapter 8 Multicultural issues

The large and diverse multicultural population in NSW poses many challenges for the provision of health services. This challenge increases where cultural and language barriers coincide with mental illness. This chapter will highlight various issues facing people from culturally and linguistically diverse (CALD) backgrounds.

Context

- 8.1** Cultural practices, religious beliefs and the language of a person affected by mental illness greatly influence the level of access to mental health services and the benefits they may receive. People from CALD backgrounds are less likely to use mental health services and less likely to be admitted voluntarily to inpatient hospital services. They are however, more likely to seek assistance from bilingual general practitioners (GPs) and may rely heavily on family members and other traditional methods for support and healing.⁵⁸⁵
- 8.2** The percentage of the NSW population born overseas rose from 27.2% in 1996 to 30.1% in 2001. The total proportion of the 2001 population who spoke a language other than English at home was 25%, compared with 21.8% in 1996.⁵⁸⁶

Recent policy initiatives

- 8.3** In 1998, NSW Health released *Caring for Mental Health in a Multicultural Society – A Strategy for the Mental Health Care of People from Culturally and Linguistically Diverse Backgrounds in NSW*. The strategy aims to improve the access to and effectiveness of the mental health system in meeting the needs of people from CALD backgrounds. Some of the goals outlined in the strategy aim to:
- provide information on mental health services in a manner sensitive to cultural values, practices and language
 - facilitate better coordination between mental health services and multicultural services to improve access and care
 - enhance and support the role of GPs and primary mental health carers to increase effectiveness of health care and
 - enhance the skills and capacity of mental health professionals to provide appropriate assessments, diagnosis and treatment.⁵⁸⁷

⁵⁸⁵ NSW Health, *Caring for Mental Health in a Multicultural Society – A Strategy for the Mental Health Care of People from Culturally and Linguistically Diverse Backgrounds in NSW*, 1998, p 1

⁵⁸⁶ NSW Health, *Report of the NSW Chief Officer*, 2002 p 99-100

⁵⁸⁷ NSW Health, *Caring for Mental Health in a Multicultural Society – A Strategy for the Mental Health Care of People from Culturally and Linguistically Diverse Backgrounds in NSW*, 1998 p 1

Factors influencing access to mental health services

8.4 The Transcultural Mental Health Centre (TMHC) has worked in partnership since 1993 with mental health services, consumers, carers and the community to improve the mental health of people from non-English speaking backgrounds in NSW.⁵⁸⁸ In its submission to the inquiry, the TMHC described the number of complex factors that influence or inhibit access to mental health services by people of CALD backgrounds.⁵⁸⁹ The *Caring for Mental Health in a Multicultural Society* policy strategy outlined the following factors as reasons for developing the strategy:

- People from particular cultural backgrounds utilise mental health services less frequently than the general community. When they access mental health services it is most often at a later stage in their illness and they are often hospitalised as involuntary patients
- Many people from culturally diverse backgrounds are unfamiliar with the mental health system and do not sufficiently understand the role of mental health services. Combined with different cultural concepts of mental health as well as English language difficulties, their access to appropriate diagnostic and treatment services may become limited
- Many mental health service professionals do not have culturally specific knowledge and the skills to identify psychiatric symptoms accurately in people from particular cultural backgrounds
- Some ethnic communities prefer to use traditional networks of support such as family members and traditional healers
- Bilingual and bicultural staff employed in mental health services are underutilised by mental health services
- People from particular cultural and linguistic backgrounds are overrepresented among the forensic patient population
- Some ethnic communities experience high levels of stigma and shame associated with mental illness.⁵⁹⁰

8.5 Ms Diana Qian, Acting Deputy Chairperson, Disability Council of NSW, explained to the Committee that the problem of stigma associated with mental illness and intellectual disability was still prevalent in some CALD communities:

Some ethnic communities have a very negative view about people with disabilities. People with disabilities and, in particular, people with mental illness, are regarded as bringing shame on a family. Of all the disabilities, mental illness is seen as a huge embarrassment to the family. So a lot of those people would have been hidden away, although they would have been well cared for by their families.⁵⁹¹

⁵⁸⁸ Submission 228, Transcultural Mental Health Centre, p 2

⁵⁸⁹ *ibid*, pp 7, 9

⁵⁹⁰ NSW Health, *Caring for Mental Health in a Multicultural Society – A Strategy for the Mental Health care of People from Culturally and Linguistically Diverse Backgrounds in NSW*, 1998, p 2

⁵⁹¹ Ms Diana Qian, Acting Deputy Chairperson, Disability Council of NSW, Evidence, 28 May 2002, p 11

- 8.6 Ms Qian and other members of the Disability Council of NSW supported the work of the TMHC but agreed there was still more to be done to raise awareness of available services for CALD communities:

About 15 or 16 per cent of the disability population are people from a non-English speaking background and the services access rate is about 3 per cent. So it is only a very few of them who actually access the services. The majority of them are hidden in the community not knowing that they have a right to access services and not fully aware of what is happening to them because there is a huge gap in terms of promoting community awareness about mental health issues in different communities. Usually you will have information in English about educational and mental health issues but they are not available, they are not penetrating the ethnic communities.⁵⁹²

- 8.7 Ms Leonie Manns, former Chairperson of the Disability Council NSW, commented that some community mental health teams seemed unaware of the existence of the TMHC.⁵⁹³

Access to mental health services

- 8.8 To inform this Committee on the effectiveness of access to mental health services by people of CALD backgrounds, the TMHC conducted a consultation with consumers and carers. Various major concerns emerged from the consultation:

- lack of consumer information about the mix of available mental health services such as multidisciplinary care, case management, community support and rehabilitation services
- need for mental health services to be more consumer responsive – professional staff are often rigid and clinically focused rather than focused on consumer needs⁵⁹⁴
- gaps in access to crisis services – 24 hour crisis services to people from CALD backgrounds are perceived as available only in certain areas of NSW and not operating on a 24 hour basis due to lack of resources
- gaps in inpatient services – focus on containment and not on discharge planning involving family and friends
- need to improve service linkages between GPs, the private sector and the public mental health system
- need to enhance the cultural and linguistic appropriateness of services.⁵⁹⁵

⁵⁹² D Qian, Evidence, 28 May 2002, p 10

⁵⁹³ L Manns, Evidence, 28 May 2002, p 10

⁵⁹⁴ Submission 228, Transcultural Mental Health Centre, p 15

⁵⁹⁵ *ibid*, p 14

- 8.9** With regard to consumer and carer information about services, there was a feeling that information was not easy to obtain and had to be directly requested from mental health professionals. The TMHC advocated that more information about different models of care needed to be made available, such as the ‘case management model’ and the ‘multidisciplinary team’ approach. It was recommended that ‘care kits’ be developed for consumers, which would outline information on mental health problems and services and rehabilitation options available, in addition to existing pamphlets and booklets.⁵⁹⁶ The Committee suggests that existing information for CALD consumers be reviewed and new packages be developed that are suitable for facilitating self-care.
- 8.10** The TMHC also reported a general perception that there were not enough bilingual mental health professionals available to meet the need. The TMHC submission highlighted research findings indicating that interpreters were generally underutilised and that there was a lack of compliance with NSW Health guidelines regarding interpreter use.⁵⁹⁷ A submission provided to the TMHC from a carer expressed concern that there is a general lack of knowledge about the availability of the Health Care Interpreter Service (HCIS) and the Telephone Interpreter Service by both consumers and mental health professionals. The submission stated that there was a:
- lack of training for health staff about the effective use of interpreters in clinical settings (even though all HCIS offer comprehensive training for health staff)
 - lack of skills in identifying whether a consumer or carer needs an interpreter.⁵⁹⁸
- 8.11** The TMHC informed the Committee that one of the dominant strategies under the *Caring for Mental Health in a Multicultural Society* policy, has been an attempt to increase the availability of bicultural/bilingual mental health professionals. Initiatives include the Bilingual Counsellor Program, which employs approximately 28 bilingual mental health professionals and the TMHC’s Brokerage Program, which employs approximately 97 bilingual sessional workers. These workers speak about 45 languages to assist mainstream mental health workers to clarify diagnostic issues and to provide short-term specific intervention as required.⁵⁹⁹
- 8.12** A submission to the TMHC expressed concern that there are still insufficient bilingual mental health positions created under the Bilingual Counsellor Program. It argued that:
- much of the work related to access has been left to generalist multicultural health workers...who do not have the skills to effectively promote access to mental health services.⁶⁰⁰
- 8.13** Similarly, the Multicultural Disability Advocacy Association of NSW (MDAA) submitted that there was an overall low level of cultural competencies among mental health professionals and that “a significant shift towards understanding of cultural diversity needs

⁵⁹⁶ Submission 228, Transcultural Mental Health Centre, p 15

⁵⁹⁷ *ibid*, p 11

⁵⁹⁸ *ibid*, p 20

⁵⁹⁹ *ibid*, p 12

⁶⁰⁰ *ibid*, p 20

to occur”.⁶⁰¹ All mental health professionals should be required to undertake cross-cultural training to increase sensitivity and awareness during service delivery.

- 8.14** The shortage of dedicated transcultural mental health service workers was particularly evident for rural and regional areas as outlined by Mr Jem Masters, President of the NSW branch of the Australian-New Zealand College of Mental Health Nurses. Mr Masters highlighted problems in obtaining transcultural mental health services outside Sydney:

I know the multicultural mental health service, [but] it is really hard to get resources to access different area health services other than in western Sydney, where they are based, and it could take two or three weeks to get a person from the multicultural centre to come out to a regional area. Even if it is crossing from western Sydney to south-western Sydney it is a problem. I think that is not just within mental health but across the board.⁶⁰²

- 8.15** The TMHC and MDAA submissions outlined the findings of various studies which highlighted that consultation with GPs tended to be the first point of contact for people of various CALD backgrounds seeking help. GPs consequently have a powerful role in mediating contact with mental health services within various cultural groups. Despite this, overall it appears that few GPs use interpreters or have established links with mental health professionals.⁶⁰³

- 8.16** The TMHC emphasised that the bulk of support for mental health consumers from CALD backgrounds tends to be provided by family and a significant portion of community care is provided by carers. This support often incurs a high personal cost.⁶⁰⁴ Carers NSW advised the Committee that coordinators of support groups for carers from non-English speaking backgrounds have reported that carers have difficulty accessing counselling provided by bilingual workers and that mainstream services do not use interpreters. NSW Carers stated that, consequently:

carers do not receive any support from the mental health service in coping with their caring situation.⁶⁰⁵

- 8.17** The Committee considers that due to the vital importance of the role of carers, appropriate carer support initiatives should be provided.

⁶⁰¹ Submission 265, Multicultural Disability Advocacy Association of NSW, p 9

⁶⁰² Mr Jem Masters, President, NSW branch of the Australian-New Zealand College of Mental Health Nurses, Evidence, 30 July 2002, p 63

⁶⁰³ Submission 265, Multicultural Disability Advocacy Association of NSW, p11; Submission 228, Transcultural Mental Health Centre, p 10

⁶⁰⁴ Submission 228, Transcultural Mental Health Centre, p 19

⁶⁰⁵ Submission 196, Carers NSW, p 13

Conclusion

8.18 NSW Health advised the Committee that *Caring for Mental Health in a Multicultural Society* will be reviewed through 2002-2003 and that further policy development processes will be set in place.⁶⁰⁶ The TMHC reported that in terms of the changes that have taken place since the Richmond Report:

all the consumer representatives felt that while there has been some fulfilment of the recommendations of the Report...opportunities for improvement still remained.⁶⁰⁷

8.19 It is apparent that more initiatives and enhanced funding are required to improve access to appropriate mental health care by people from CALD backgrounds, and to ensure equity in service provision. Accordingly, the Committee advocates a series of initiatives to be considered and implemented by NSW Health.

Recommendation 56

That NSW Health and the Centre for Mental Health develop information packages or 'care kits' for consumers that will enhance access to information facilitating self-care. Kits should contain information such as:

- contact details from the Health Care Interpreter Service and the Telephone Interpreter Service
- contact details and locations of 24 hour crisis services and
- rehabilitation options available, such as case management and multidisciplinary care as well as contact details for access to such services.

Recommendation 57

That NSW Health develop and conduct a consumer and carer perception survey for people from culturally and linguistically diverse backgrounds to:

- identify satisfaction with the manner and attitudes of mental health professionals in delivering services, and
 - assist in development of staff training programs designed to improve focus on individual care and flexibility in providing treatment suitable to the patient's needs.
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⁶⁰⁶ Submission 167, NSW Health, p G 23

⁶⁰⁷ Submission 228, Transcultural Mental Health Centre, p 14

Recommendation 58

That NSW Health provide, in accordance with its *Caring for Mental Health in a Multicultural Society* policy, a strategy to improve access to appropriately trained health care interpreters and services for people from culturally and linguistically diverse backgrounds, including:

- adequate funding so that bilingual crisis services are provided 24 hours per day
- recruitment of more interpreters and bilingual mental health workers in a broad range of language groups and
- education for mental health professionals about effective use of interpreters in clinical settings and referral of consumers and carers to the Health Care Interpreter Service and the Telephone Interpreter Service.

Recommendation 59

That NSW Health work with the Transcultural Mental Health Centre to develop and implement a cultural training program that requires:

- the participation of all mental health professionals and staff and
- ongoing cultural sensitivity training relative to the client group they support.

Recommendation 60

That NSW Health develop and initiate a program tailored for General Practitioners to inform them of the full range of public mental health service options available to people from culturally and linguistically diverse backgrounds.

Recommendation 61

That NSW Health investigate and implement support initiatives for carers of mental health consumers from culturally and linguistically diverse backgrounds, including counselling services with bilingual interpreters.

Chapter 9 Indigenous issues

Aboriginal Mental Health Services are at a disadvantage relative to the mainstream mental health system. It is of concern that there is still little coordination of mental health services for Aboriginal people and consequently there is a great deal of variability in the performance of different Area Health Services.⁶⁰⁸

[Council of Social Service of NSW]

Context

9.1 Aboriginal and Torres Strait Islander (ATSI) people have a holistic view of health. The National Aboriginal Health Strategy Working Party (1989) defines health as:

not just the physical well-being of the individual but the social, emotional and cultural well-being of the whole community. This is a whole-of-life view and it also includes the cyclical concept of life-death-life.⁶⁰⁹

9.2 The NSW Health *Aboriginal Mental Health Policy*, stated that Aboriginal people have adopted a holistic view of mental health which means that mental health is part of full health as defined above in the Aboriginal definition of health.⁶¹⁰ A major concern raised by groups representing Aboriginal and Torres Strait Islander (ATSI) people is the lack of cultural sensitivity in mainstream mental health services.

9.3 At the 2001 Census, 119,895 people living in NSW, or 1.9% of the population, identified as Aboriginal or Torres Strait Islander.⁶¹¹

Recent policy initiatives

9.4 The 1997 NSW *Aboriginal Mental Health Policy* was released after extensive consultation and development. Its strategic directions were:

- respect for the Aboriginal person as an individual, within a family, community, nation and society
- consultation with Aboriginal people, communities and community controlled organisations in all aspects of health programs and services
- recruitment of Aboriginal people into the public health system to be conducted in partnership with Aboriginal community controlled organisations and

⁶⁰⁸ Submission 192, Council of Social Services NSW, p 16

⁶⁰⁹ National Aboriginal Health Strategy Working Party (1989) cited in NSW Health, *NSW Aboriginal Mental Health Policy – A Strategy for the Delivery of Mental Health Services for Aboriginal People in New South Wales*, 1997, p 8

⁶¹⁰ NSW Health, *NSW Aboriginal Mental Health Policy – A Strategy for the Delivery of Mental Health Services for Aboriginal People in New South Wales*, 1997, p 8

⁶¹¹ Australian Bureau of Statistics (2001), *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples*. Catalogue no 4704.0.

- education in the workplace for Aboriginal and non-Aboriginal people.⁶¹²

9.5 NSW Health stated in its submission that the major components of the policy are in place. A review process is underway and will produce the basis for the new Aboriginal Mental Health Policy for NSW.⁶¹³

Factors influencing access to mental health services

9.6 The *NSW Aboriginal Mental Health Policy* advised that there are a range of barriers unique to ATSI people accessing mental health services, including:

- inadequate assessment of Aboriginal persons presenting to accident and emergency departments of hospitals and in some instances to departments of surgery and medicine
- culturally inappropriate services or an absence of services that address the issues that are important to Aboriginal people
- lack of understanding of Aboriginal issues amongst mental health staff and lack of staff with training in mental health in Aboriginal Medical Services
- fragmentation of service delivery
- difficulties in accessing transport to mental health services
- lack of Aboriginal staff in mental health services and lack of training for Aboriginal people in mental health
- fear of mental health services and staff attitudes and behaviours and
- the role and functioning of police in relation to mental health services.⁶¹⁴

9.7 A submission from the Mid-North Coast Area Action Group for Addressing Mental Health Issues in the Justice System (a group of carers, supporters and mental health staff) indicated additional indigenous health issues that faced the Port Macquarie and Kempsey areas:

- pure psychiatric models disregard social and emotional wellbeing
- focus on centre based services rather than community delivered services
- lack of resources to provide community education relating to mental health in Aboriginal communities

⁶¹² NSW Health, *NSW Aboriginal Mental Health Policy – A Strategy for the Delivery of Mental Health Services for Aboriginal People in New South Wales*, 1997, p 13

⁶¹³ Submission 267, NSW Health, p G 22

⁶¹⁴ NSW Health, *NSW Aboriginal Mental Health Policy – A Strategy for the Delivery of Mental Health Services for Aboriginal People in New South Wales*, 1997, p12

- large burnout rates for Aboriginal mental health staff
- cultural awareness training for non-Aboriginal staff no longer conducted and
- families not involved in the assessment process.⁶¹⁵

9.8 The Health Care Complaints Commission drew attention to a number of serious concerns about mental health services for rural and remote Aboriginal communities. These concerns included:

- feelings of isolation and alienation when admitted to public psychiatric facilities
- numbers of suicides and unauthorised departures from care and
- variable levels of discharge planning and follow-up services.⁶¹⁶

9.9 The Commission's submission included the following comments from Aboriginal community members:

One community member advised that, when she rang the community mental health team for assistance, she was told, 'We can only do something if you are going to kill yourself. Another community member was told, 'We can't do anything – call the police'. Some people were advised to consult their general medical practitioner despite their need for mental health services. In summary, most community members agreed with the statement that "Community mental health services only help you if you hit rock bottom".⁶¹⁷

Delivery of mental health services

9.10 On the issue of access to mental health services by ATSI people, the Council of Social Service of NSW (NCOSS) noted:

In certain areas Aboriginal mental health workers are placed in mainstream health services (or an Aboriginal staff member is designated that role), giving rise to problems of access and appropriateness when Aboriginal people won't utilise services for cultural and historical reasons.⁶¹⁸

9.11 NCOSS further commented in its submission that there had been progress in the treatment of the mental health of Aboriginal people with the development of the *Aboriginal Mental Health Strategy* and Aboriginal Mental Health Services. Despite this, however:

Aboriginal Mental Health Services are at a disadvantage relative to the mainstream mental health system. It is of concern that there is still little coordination of

⁶¹⁵ Submission 67, Mid-North Coast Area Action Group for Addressing Mental Health Issues in the Justice System, pp 7-8

⁶¹⁶ Submission 120, Health Care Complaints Commission, p 4

⁶¹⁷ *ibid*, p 4

⁶¹⁸ Submission 192, Council of Social Services NSW, p 16

mental health services for Aboriginal people and consequently there is a great deal of variability in the performance of different Area Health Services.⁶¹⁹

- 9.12** Mr Michael Roberts, Chief Executive Officer, Dharah Gibinj, Aboriginal Medical Service Aboriginal Corporation (Casino), explained to the Committee that Aboriginal people prefer to care for the sick, even the very frail and elderly, in the home.⁶²⁰ Where there is violence or acute mental illness however, both Mr Roberts and Ms Lexie Lord, Vice-President of the Parents and Carers' Mental Health Group, North Casino, told the Committee that the burden of full-time care could be overwhelming.⁶²¹ Carers NSW stated in its submission:

In certain Aboriginal communities, the prevalence of mental disorders is now starting to exceed illnesses such as diabetes. The needs of carers in these communities are even less likely to be met, as mainstream services often do not understand the cultural needs of Aborigines and therefore do not deliver services appropriately.⁶²²

- 9.13** Mr Roberts, Ms Lord and Carers NSW all believed that the burden on carers in Aboriginal communities could be alleviated by the introduction of greater numbers of Aboriginal mental health workers to look not only after the needs of the client, but the carer as well.⁶²³

- 9.14** NCOSS strongly supported the placement of Aboriginal mental health workers in Aboriginal community-controlled organisations. From there, they would work in conjunction with mainstream services to provide mental health services to the Aboriginal community.⁶²⁴

- 9.15** Dharah Gibinj expressed the need for Aboriginal health workers to be appointed to mainstream services and decision-making process committees as well as Aboriginal community controlled health services. While mainstream mental health services have received training in the holistic view of Aboriginal health, Dharah Gibinj's submission suggested that in reality, little attention was paid to the holistic model:

Aboriginal people usually hold strong cultural/spiritual belief systems that are not adequately dealt with in mainstream services. This is a compelling reason to employ ATSI people at every level of planning, implementing and evaluating mental health programs. It is imperative that ATSI people keep in touch with the land, their kin and their spiritual and cultural beliefs.⁶²⁵

- 9.16** Dharah Gibinj called in its submission for cultural awareness training for all health professionals, not just mental health workers.⁶²⁶

⁶¹⁹ Submission 192, Council of Social Services NSW, p 16

⁶²⁰ Mr Michael Roberts, Chief Executive Officer, Dharah Gibinj, Aboriginal Medical Service, Aboriginal Corporation (Casino), Evidence, 31 July 2002, p 5

⁶²¹ Ms Lexie Lord, Vice-President, Parents and Carers' Mental Health Group, North Casino, Evidence, 31 July 2002, p 15

⁶²² Submission 196, Carers NSW, p 13

⁶²³ M Roberts, Evidence, 31 July 2002, p 3; Lord Evidence, 31 July 2002, p 14; Submission 196, Carers NSW, p 13

⁶²⁴ Submission 192, Council of Social Services NSW, p 17

⁶²⁵ Submission 119, Dharah Gibinj Aboriginal Medical Service, p 2

⁶²⁶ *ibid*

9.17 A number of submissions focused in particular on mental health problems faced by ATSI males. The Men's Health Information and Resource Centre (MHIRC) raised concerns about the impact on communities of mental health problems in ATSI men.⁶²⁷ In 2001, the *NSW Public Health Bulletin* noted that many of the mental health problems identified in Aboriginal males are linked to historical factors such as disruption at colonisation, institutionalisation and separation from natural family. Mental health problems of Aboriginal men include alcohol abuse, violence, destructive behaviours, and the loss of a sense of personal worth. Indigenous people also have higher levels of psychosocial distress compared with non-indigenous people.⁶²⁸ Mental health problems among Aboriginal males may be related to other factors such as:

- an historical fear of hospitals
- 'lack of closure' and unresolved conflict due to past government policy and practice and the past separation of mothers and children
- the reduction of authority and status within families and sociological changes to the male role model in society and
- the intervention of family courts and government departments.⁶²⁹

9.18 NSW Health has initiated an *Aboriginal Men's Health Implementation Plan*, which includes mental health issues as a focus area.⁶³⁰ Mr Phillip Scott, Court Liaison Clinician for the Mid North Coast Area Health Service, cited the importance of establishing coordinated local area support for Aboriginal men, particularly in view of the high number of Aboriginal men who come into contact with the criminal justice system:

I have been concerned over the last 12 months also about the actual effect of Aboriginal males coming into contact with the courts. They are coming into contact with the court on charges such as domestic violence orientated types of crimes associated with alcohol and with low self-esteem and a very poor opinion of themselves. As a result of that the community is setting up a men's group to look at these types of issues within the Kempsey area. It is utilising the existing resources within that area to start to mobilise those types of areas to work for the best outcome.⁶³¹

9.19 The general shortage of mental health professionals, particularly in rural and regional areas, is magnified in the corresponding shortage in Aboriginal mental health workers. In its submission, Dharah Gibinj Aboriginal Medical Service cited a "dearth of psychiatrists" in the Northern Rivers Area Health Service. Considering the large ATSI population in the area, Dharah Gibinj stated that ways of obtaining the services of, and keeping, suitable staff needed to be examined.⁶³²

⁶²⁷ Submission 251, Mens' Health Information and Resource Centre, p 7

⁶²⁸ B Nielsen, E Katrakis and B Raphael, *Males and Mental Health: A Public Health Approach*, NSW Public Health Bulletin, vol 12 no 12, 2001, p 330. Also noted in Submission 267, NSW Health, p G 21

⁶²⁹ *ibid*, p 330

⁶³⁰ *ibid*, p 331

⁶³¹ P Scott, Evidence, 1 August 2002, p 11

⁶³² Submission 119, Dharah Gibinj Aboriginal Medical Service, p 3

9.20 Dharah Gibinj made the following suggestions to attract more psychiatric staff and Aboriginal health workers:

- offer attractive packages to attract and retain the right workers
- explore partnerships with local general practitioners and
- provide more training and professional development opportunities for Aboriginal health workers, including scholarships, tutoring, and paid study leave.⁶³³

9.21 Mr Phillip Scott explained to the Committee the importance of having Aboriginal mental health workers, particularly in his court liaison work. He related his own experience in court liaison in Northern NSW:

In communication with that group professionally I need to recognise that possibly coming from a white background is not the most therapeutic in getting people talking on a truthful level. As a result of that, the use of Aboriginal liaison people or consumers has been utilised in a way to break that communication down, especially when we are communicating with people who have committed a crime...when they are in the cells they sometimes do not want to talk to me, but if I get a fellow like an Aboriginal mental health worker to come with me, he or she is able to communicate much better.⁶³⁴

9.22 Mr Michael Roberts suggested a diploma in Aboriginal mental health should be available to indigenous people living in NSW. Currently, only general Aboriginal health diplomas are available through TAFE NSW. Mr Roberts envisaged the diploma as not only providing clinical understanding of mental illness, but also skills in assessment, administration of medication and referral if required.⁶³⁵

Recommendation 62

That as part of its review of any Aboriginal Mental Health Policy, NSW Health should:

- review Aboriginal Mental Health Worker numbers and their distribution in NSW
 - assess obstacles and incentives to recruit and retain Aboriginal Mental Health Workers in NSW and
 - integrate review findings into the new Aboriginal Mental Health Policy.
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⁶³³ Submission 119, Dharah Gibinj Aboriginal Medical Service, p 3

⁶³⁴ P Scott, Evidence, 1 August 2002, pp 10-11

⁶³⁵ M Roberts, Evidence, 31 July 2002, p 2 and p 6

Recommendation 63

That NSW Health, as part of any new Aboriginal Mental Health Policy, develop a strategy for recruiting and adequately resourcing Aboriginal Mental Health Workers throughout NSW.

Recommendation 64

That NSW Health continue to work towards partnerships between mainstream mental health services and Aboriginal community-based mental health services, including trial partnerships between local general practitioners and Aboriginal Mental Health Teams.

Recommendation 65

That the Minister for Health develop a proposal to the Commonwealth Ministers for Health and Education to initiate a post-graduate module in Aboriginal Mental Health for nursing and health related courses.

Recommendation 66

That the Minister for Health provide at least three fully funded scholarships for psychiatric nurses undertaking the proposed post-graduate module in Aboriginal Mental Health on an annual basis.

Treatment and care of Aboriginal patients who are acutely unwell

- 9.23** The Legal Aid Commission reported in its submission that some Aboriginal patients were receiving poor quality service, or no services, while acutely unwell:

The Commission's solicitors have observed that, for a variety of reasons, some Aboriginal clients act out more aggressively when unwell. Because of this, some hospitals are reluctant to hold them for longer than a few weeks. As a result, Aboriginal clients are routinely released before they are well, and are often released without a Community Treatment Order because they are considered to be too difficult to manage. This results in a high number of Aboriginal patients re-offending because of lack of inpatient and community based services. When the person comes back into custody the hospital will often refuse to accept them because they are too aggressive.⁶³⁶

- 9.24** The Commission provided a case study in which a hospital failed to provide duty of care to an Aboriginal client who was very unwell:

KL, a young Aboriginal man, was held in hospital under section 33 of the *Mental Health (Criminal Procedure) Act 1990*. An Aboriginal legal service dealt with his matters and he was referred to the hospital for further treatment. The hospital contacted the police alleging that KL had become aggressive. The police took him into custody. No charges were laid. The hospital was aware that there were no

⁶³⁶ Submission 216, Legal Aid Commission, p 6

charges current. It appears that the hospital discharged KL into police custody because they were afraid to discharge him into the community when he was still very unwell. Police contacted the Legal Aid Commission after KL had been held in police custody for 24 hours without charge. A Commission solicitor advised the police to release him. KL was released into the community with no medication. The medication he was on was a type which should not be discontinued suddenly, as this carries an increased risk of psychosis. There is a possibility that this young man will re-offend as he is currently receiving no treatment.⁶³⁷

9.25 In another case given by the Legal Aid Commission, a young Aboriginal woman with a chronic mental illness received no ongoing care and eventually committed a serious offence:

MN...becomes aggressive and highly distressed, making allegations of sexual assault against her father. Despite being extremely unwell she was consistently released under a Community Treatment Order after about one week without proper follow up. She would then assault her father with whom she was placed, and be returned to the hospital, where she was represented by a Legal Aid Commission solicitor. She eventually committed a serious offence while unwell and was placed in custody. ⁶³⁸

Recommendation 67

That NSW Health implement a policy that requires the Aboriginal and Torres Strait Islander Medical Service be involved, with the consent of the patient, once an Aboriginal and Torres Strait Islander person is admitted to hospital for psychiatric care and later when discharged.

9.26 While the Committee did not receive specific evidence regarding the mental health of ATSI people in prison, the Committee notes with concern recent Australian Bureau of Statistics figures indicating an 8% increase in the number of indigenous prisoners in the total prison population in NSW. ⁶³⁹ The Committee is well aware that the issue of suicide in custody was comprehensively covered in the Royal Commission on Aboriginal Deaths in Custody.⁶⁴⁰ Preventing ATSI people with mental health problems coming into contact with the criminal justice system is vital. Court diversionary programs for people with a mental illness are considered in Chapter 14.

⁶³⁷ Submission 216, Legal Aid Commission, p 6

⁶³⁸ *ibid*, p 6

⁶³⁹ Australia Bureau of Statistics (2002), Cat 4512.0, 'Corrective Services, Australia'.

⁶⁴⁰ Royal Commission on Aboriginal Deaths in Custody, 1991, National Report, Vol. 3

Chapter 10 Mental illness and substance abuse

One of the dilemmas being faced in hospitals and environments where people present with acute illness is how to manage the acutely disturbed person, the person who is psychotic, and there has in the past been the tendency to say, well, I am not prepared to look after that person unless you fix up their mental problem first or, if they have entered the drug and alcohol system, I am not prepared to look after that person unless their psychosis is managed. Clearly those things have to be better managed together. Hospital systems have to be better organised so that it happens.⁶⁴¹

[Prof Ian Webster, Emeritus Professor]

Throughout the course of the Committee's inquiry, the comorbidity of mental illness and drug and alcohol abuse was a recurring issue. The Committee notes the term 'dual diagnosis' is often used to describe this comorbidity, but that this term is also used interchangeably to describe intellectual disability and mental illness. To avoid confusion the Committee has adopted the term 'mental illness and substance abuse' (MISA), as referred to in the Burdekin Report.⁶⁴²

While the term 'abuse' may be considered politically incorrect in current health terminology, the term accurately conveys its historical meaning. Dr Richard Matthews, Chief Executive Officer, Corrections Health Service, succinctly distinguished between 'use' and 'abuse':

Alcohol is probably a good way of helping people to understand. If we all have a glass or two of wine with the evening meal, that is use. If we have more than the standard four drinks a day or we go to the pub on Friday night and have 12 schooners, that is abuse. In terms of opioids, it is a little bit more difficult to define, but the tool has a way of doing it. If I have been to a party once or twice in the past year and have snorted some cocaine, that would be use, and not abuse. If, on the other hand, I was doing that every day and missing time from work and my social functioning was disintegrating, that would be abuse or dependence.⁶⁴³

Incidence of comorbidity – mental illness and substance abuse

10.1 The 1997 *National Survey of Mental Health and Wellbeing* identified a considerable degree of coincidence of mental health disorders with substance use problems (comorbidity). The survey found that among men with a current anxiety disorder, 31% also had a current substance use disorder, while the rate of substance abuse and comorbidity with affective disorders, such as depression, was 34%.⁶⁴⁴

⁶⁴¹ I Webster, Evidence, 31 May 2002, p 4

⁶⁴² Human Rights and Equal Opportunity Commission, *Report of the National Inquiry into Human Rights of People with a Mental Illness*, 1993 [Burdekin Report] p 664

⁶⁴³ R Matthews, Chief Executive Officer, Corrections Health Service Evidence, 30 May 2002, p 25. Due to the variety of expressions for MISA in quoted material, the phrase 'use disorder' is used interchangeably with abuse for the purposes of this report.

⁶⁴⁴ G Andrews, W Hall, M Teeson, & S Henderson, *National Survey of Mental Health and Wellbeing, Report 2 – The mental health of Australians*, (Canberra, Commonwealth Department of Health and Aged Care), 1999, p 34

- 10.2** NSW Health stated that, depending on the population sample, 30% to 80% of people with a mental illness have a co-existing substance use disorder.⁶⁴⁵ A recent study of inpatients with an early episode of psychosis conducted in Queensland suggests that the incidence is probably more towards the higher end of the percentage range. The study found that 70% of young people admitted also had a current substance use disorder.⁶⁴⁶
- 10.3** In a submission to the House of Representatives Standing Committee on Family and Community Affairs Inquiry into substance abuse in Australian communities, the Australian National Council on Drugs (ANCD) further confirmed the high percentage of comorbidity:
- Although it is difficult to accurately measure the prevalence of this problem, recent figures have suggested that as many as three quarters of all clients with drug and alcohol problems have a dual diagnosis. Similarly it is asserted that there is an equally high percentage of people with mental illness misuse who misuse alcohol and other drugs.⁶⁴⁷
- 10.4** The Committee notes that in 1993 the Burdekin Report determined that the prevalence of MISA in Australia would be comparable to that found in the United States of America.⁶⁴⁸ The National Co-morbidity Survey undertaken in the United States between 1990-1992.⁶⁴⁹ The study found that rates of such dual disorders were particularly high among those with alcohol dependence, with 78% of men and 86% of women having alcohol dependence and a co-existing mental disorder.⁶⁵⁰
- 10.5** More recently, the Hunter Health Service investigated the prevalence of substance abuse in a community outpatient clinic for people with schizophrenia. Of the 194 outpatients assessed the study found lifetime prevalence rates for schizophrenia and substance abuse to be 59.8% and six-month prevalence was 26.8%.⁶⁵¹
- 10.6** The Victorian Institute of Forensic Mental Health highlighted the correlation of MISA with violent offences. The Institute stated that for people with schizophrenia who did not have a problem with substance abuse, there was only a modest increase in committing a violent offence. The level of violent offences increases significantly with substance abuse:

⁶⁴⁵ NSW Health, *The Management of People with a co-existing Mental Health and Substance Use Disorder – Service Delivery Guidelines* 2000, p 2

⁶⁴⁶ D J Kavanagh, *Social and Economic Costs of Comorbid Substance Abuse and Mental Disorder*, p 4 - submission to the House of Representatives Standing Committee on Family and Community Affairs, Inquiry into substance abuse in Australian communities, 2002

⁶⁴⁷ Australian National Council on Drugs, submission to the House of Representatives Standing Committee on Family and Community Affairs, Inquiry into substance abuse in Australian communities, 2002 cited at www.ancd.org.au/publications/parlinquiry.htm (accessed 11/11/02)

⁶⁴⁸ Burdekin Report, p 664

⁶⁴⁹ R C Kessler, et al, Lifetime and 12 month prevalence of DSM-11-R psychiatric disorders in the United States. *Archives of General Psychiatry*, 51, p 8-9 cited in NSW Health, *The Management of People with a co-existing Mental Health and Substance Use Disorder – Discussion Paper* (2000), p 4

⁶⁵⁰ NSW Health, *The Management of People with a co-existing Mental Health and Substance Use Disorder – Discussion Paper*, 2000, p 4

⁶⁵¹ I L Fowler, et al (1998), Patterns of current and lifetime substance use in schizophrenia, *Schizophrenia Bulletin*, cited in NSW Health, *The Management of People with a co-existing Mental Health and Substance Use Disorder – Discussion Paper* 2000, p 4

People with schizophrenia however, who also had problems with substance abuse, were over 18 times more likely to have received a conviction for violent offending, and over 28 times more likely to be convicted of homicide. People with severe depression or bipolar illness showed a similar pattern with the risk of offending as that of the general population. Violent offending though skyrocketed when there was co-existing substance abuse. Among people with an affective disorder without substance abuse, violent offences were 2.9 times higher, but the incidence of violent offending was 19 times higher in those with substance abuse.⁶⁵²

- 10.7** The Institute also reported on general offences committed by those with schizophrenia and substance abuse problems:

There was a dramatic increase in offending if the patients also abused alcohol or drugs. In those with schizophrenia who did not abuse substances, their rates of offending were less than half of those who did abuse alcohol or drugs. In those with substance abuse and schizophrenia, their rates of violent offending were nearly 10 times higher than the general population.⁶⁵³

- 10.8** The *National Survey of Mental Health and Wellbeing* outlined the importance of examining MISA in this report:

The high rates of comorbidity have a number of implications for treatment and management. Mental disorders complicated by alcohol and other drug use disorders, and vice versa, have been recognised as having a poorer diagnosis than those without such comorbid disorders.⁶⁵⁴

The impact of the Richmond Report on drug and alcohol services

- 10.9** At the time of the Richmond Report, a number of drug and alcohol services, including detoxification programs, were provided within 5th Schedule⁶⁵⁵ psychiatric hospitals in NSW. The Richmond Report noted that a ‘significant proportion’ of psychiatric admissions to these hospitals had a drug or alcohol related association with the mental illness.⁶⁵⁶ The Report stated, however, that there is an:

important distinction between the actual taking of drugs, including alcohol, and the physiological, biochemical or psychological effects of drug taking. A person who takes drugs is not necessarily mentally ill and requires different assistance to one who is affected by drugs in a manner which manifests itself as mental illness.⁶⁵⁷

⁶⁵² Submission 302, Victorian Institute of Forensic Mental Health, p 4

⁶⁵³ *ibid*, p 4

⁶⁵⁴ G Andrews, W Hall, M Teeson, & S Henderson, *National Survey of Mental Health and Wellbeing, Report 2 – The mental health of Australians*, (Canberra, Commonwealth Department of Health and Aged Care), 1999, p 9

⁶⁵⁵ ‘5th Schedule hospitals’ were created under schedule 5 of the *Public Hospitals Act 1929*, repealed by the *Health Service Act 1997*

⁶⁵⁶ Richmond Report, Part 5, 7.2 (a) p 72

⁶⁵⁷ *ibid*

10.10 The Richmond inquiry heard evidence, based on this distinction, which argued that drug and alcohol services should not be provided within specialised psychiatric hospital services. It was decided that such hospitals should concentrate on providing services for “the longer term effects of drug and alcohol intake such as the management and rehabilitation of brain damaged persons”.⁶⁵⁸

10.11 The Richmond Report admitted that this area had not been investigated extensively; and this is reflected through the four paragraphs dedicated to drug and alcohol services.⁶⁵⁹ The report nevertheless supported the proposal to remove substance abuse treatment and care from psychiatric hospitals:

drug detoxification programmes including those for acute alcoholic states should be phased out of specialised psychiatric hospital services and provided for in general hospital and in appropriate community based services.⁶⁶⁰

10.12 The Report also stated:

Within health services it is considered that drug abuse programmes should be integrated with other health care activities within hospitals and community health programmes. These in turn should be linked at local level with a network of services involving other service providers outside the health system.⁶⁶¹

Illicit drugs, post-Richmond

10.13 The Richmond Report was compiled prior to the increasing potency of illicit drugs, and more significantly the heroin drought of the 1990s. Subsequently, that inquiry could not have foreseen the impact that amphetamines and similar drugs would have on people with MISA. Dr Richard Matthews, Chief Executive Officer, Corrections Health Service, outlined this issue:

Some evidence has been presented by Don Weatherburn that during the so-called heroin drought, those who were heavy injectors of heroin tended to switch to injecting amphetamines and cocaine. Those who were lighter users of heroin tended to switch to much heavier marijuana consumption. In some senses, a heroin drought is bad news.⁶⁶²

10.14 Dr Jennifer Gray, Director, NSW Health Drugs Program Bureau, informed the Committee of the difficulties the increase in amphetamine use has caused the health system:

The whole issue of amphetamines and amphetamine-related psychosis, as opposed to a person having a pre-existing psychosis...is new, it has occurred within the past few years. There were pockets of it but it is something that the system as a whole has to learn to respond to very quickly. For the very skilled and able staff and medical practitioners with years of experience, it is not such a tall

⁶⁵⁸ Richmond Report, Part 5, 7.2 (a) p 72

⁶⁵⁹ *ibid*

⁶⁶⁰ *ibid*

⁶⁶¹ *ibid*

⁶⁶² R Matthews, Evidence, 30 May 2002, p 27

order. For an NGO worker who is there because they themselves used to be substance dependent, learning new skills for how to manage more complex issues is quite problematic and complex so we need to spend a lot of time in assisting them to get to there.⁶⁶³

- 10.15** Given the increasing prevalence and complexity of MISA, there are clear implications for the provision of mental health and drug and alcohol services. The NSW Health document, *The Management of People with a co-existing Mental Health and Substance Use Disorder – Discussion Paper*, has acknowledged the pressure MISA imposes on mainstream health services:

access to drug and alcohol services is limited on weekends and outside regular working hours, consequently the care and treatment of people with comorbid disorders is largely provided by mental health and mainstream health services. This clearly indicates the need for mainstream health staff to have up to date skills on the assessment and management of substance use disorders. Furthermore, attempts to develop collaborative partnerships with drug and alcohol professionals, in government and non-government sectors, are required for people with disorders which are complicated by substance use.⁶⁶⁴

MISA - NSW Government response

- 10.16** In 1993, the Burdekin Report found that the ability of the system to identify and manage people with MISA was diminished by the lack of an inclusive model of care. The Report identified that these people were often referred to one service or another, or had no access to services at all.⁶⁶⁵

- 10.17** In 1998 NSW Health published *Caring for Mental Health – A Framework for Mental Health Care in NSW*, which aimed ‘to improve coordination of mental health and drug and alcohol services’.⁶⁶⁶ A joint initiative between the Centre for Mental Health and the Drug Programs Bureau of NSW Health was subsequently developed to identify and address the gaps in service delivery, and:

to promote a model of collaborative partnerships and specifically, to develop service delivery guidelines to improve the health care and health outcomes for people affected by dual disorders.⁶⁶⁷

- 10.18** In 2000, the joint initiative produced two documents:

- *The Management of People with a co-existing Mental Health and Substance Use Disorder – Service Delivery Guidelines* and
- *The Management of People with a co-existing Mental Health and Substance Use Disorder – Discussion Paper*.

⁶⁶³ Dr J Gray, Director, Drug Programs Bureau NSW Health, Evidence, 8 October 2002, p 25

⁶⁶⁴ NSW Health, *The Management of People with a co-existing Mental Health and Substance Use Disorder – Discussion Paper* 2000, p 8

⁶⁶⁵ Burdekin Report, pp 665-667

⁶⁶⁶ NSW Health, *Caring for Mental Health – A Framework for Mental Health Care in NSW* (1998), p 36

⁶⁶⁷ NSW Health, *The Management of People with a co-existing Mental Health and Substance Use Disorder – Discussion Paper*, NSW Health 2000, p 8

10.19 The *Discussion Paper* acknowledged that there remain barriers to service provision in NSW and that the system of care lacked the necessary philosophy of inclusive and comprehensive health care.⁶⁶⁸ The *Discussion Paper* found that service provision relied more on the interest and expertise of individual clinicians than on a consistent, inclusive or comprehensive system of care. The review concluded, ‘a cultural shift in attitudes, from exclusion to one of holistic care is required’.⁶⁶⁹

NSW Health MISA Service Delivery Guidelines – general principles and models

10.20 The *Service Delivery Guidelines* placed responsibility for service provision with the AHS, primarily the Chief Executive Officers and service directors.⁶⁷⁰ The *Service Delivery Guidelines* also outlined NSW Health’s general principles for the management of people with MISA:

- harm minimisation
- health promotion, prevention and early intervention
- comprehensive and inclusive health care
- interagency links and partnerships
- evidence based good practise
- health outcomes and
- building self-efficacy.⁶⁷¹

10.21 The *Service Delivery Guidelines* included general service delivery models designed to fit within the primary role and functions of separate services. The models outline how services can meet the needs of people by identifying the severity and treatment needs of the individual.⁶⁷² MISA presentations, according to the model, should be handled individually or by a combination of mental health services, drug and alcohol services and general practitioners, as depicted in the following table:

⁶⁶⁸ NSW Health, *The Management of People with a co-existing Mental Health and Substance Use Disorder –Discussion Paper*, NSW Health, 2000, pp 9-10

⁶⁶⁹ *ibid*, p 9

⁶⁷⁰ *ibid*, p 21

⁶⁷¹ *ibid*, p 4

⁶⁷² *ibid*, pp 5-6

Table 10.1 MISA Presentations (Service Delivery Guidelines)

<p>Mental Health Services</p> <p>Primarily responsible for people severely disabled by current mental health problems and disorders and adversely affected by substance use disorders.</p>	<p>Drug and Alcohol Services</p> <p>Primarily responsible for people severely disabled by current substance use disorders and adversely affected by mental health problems and disorders.</p>
<p>Mental Health and Drug and Alcohol Services</p> <p>Shared responsibility for people severely disabled by comorbid disorders where both disorders are treated concurrently in the service best placed to meet the client needs.</p>	<p>General Practitioner</p> <p>Primarily responsible for people with mild to moderate comorbid disorders but with access to expertise from specialist mental health and drug and alcohol services as required.</p>

Source: NSW Health, *The Management of People with a co-existing Mental Health and Substance Use Disorder – Service Delivery Guidelines*, NSW Health (2000), p 6

- 10.22** NSW Health acknowledges that the model outlined in the table must be supported by “flexibility and collaboration between service providers”⁶⁷³ to ensure services are accessible.

Screening and Assessment

- 10.23** The *Service Delivery Guidelines* advocated that engagement is the first step in developing a trusting alliance between client and service provider:

Successful engagement is critical to effective intervention or treatment and is dependent on a number of factors including a clear delineation of the interventions that can be offered and their potential value.⁶⁷⁴

- 10.24** Assessment tools are recommended by NSW Health to improve the ability of clinicians to detect comorbid conditions and assist the assessment process. For mental health clinicians, tools such as the Alcohol Use Disorders Identification Test (AUDIT) would provide the framework for taking a drug and alcohol history. For drug and alcohol staff, the incorporation of a mental state exam and psychological screening instruments with their regular assessments would increase the identification of a range of mental health problems.⁶⁷⁵

Integrated care

- 10.25** The *Service Delivery Guidelines* noted the importance of links between specialist and mainstream services and formal and informal collaborative partnerships across health and related care systems:

These may involve links between specialist services such as mental health and drug and alcohol with a Memoranda of Understanding or service agreement. They may also involve shared-care arrangements – for instance between these specialist

⁶⁷³ ibid, p 6

⁶⁷⁴ ibid, p 8

⁶⁷⁵ ibid, pp 8-9

services and general practitioners or between health services and non-government organisations and so forth. Understanding how and who to contact in other health and related organisations should be established as core, every day business.⁶⁷⁶

- 10.26** It was suggested that AHS should ensure that better identification, treatment and care coordination is achieved through sharing of expertise, such as joint assessment and co-management:

Collaborating in joint approaches should be two-way, mutually beneficial and focused on delivering comprehensive health care.⁶⁷⁷

- 10.27** AHS, according to the *Service Delivery Guidelines*, should facilitate the establishment of formal networks and regular liaison between primary care providers across service sectors, in order to better integrate the delivery of services and reduce the incidence of people falling through the gaps.⁶⁷⁸

- 10.28** In its submission to the Committee, NSW Health stated that the *Service Delivery Guidelines*, aimed at addressing issues in the *Discussion Paper*, have been implemented and that all AHS “should provide integrated services or collaborate as clinically appropriate”.⁶⁷⁹ According to Dr Jennifer Gray, Director of the Drug Programs Bureau within NSW Health, an integrated service system currently exists in NSW, and furthermore, that it is growing rapidly and positively.⁶⁸⁰

- 10.29** Dr Gray informed the Committee that it is necessary for drug and alcohol services to differentiate where, and which clients to treat:

In drug and alcohol very careful determinations and decisions are made about what the status of the person is. We must be careful about putting people into particular services where it is not good for them or for the other clients. Therefore, we find other ways of managing that person...It is not appropriate to have a severely mentally ill person in a regular detoxification unit because those units are not set up in terms of security or staffing to manage people with extreme mental health problems. The far better option is for that person to receive drug and alcohol treatment in the setting to which they are most suited. It is what I mean by ambulatory: We bring those services to those people at that particular point in time.⁶⁸¹

- 10.30** Evidence presented to the Committee suggests that a situation continues to exist where neither mental health services nor drug and alcohol services will accept responsibility for MISA patients. Consequently, the best-designed health care models remain inaccessible to a person with a mental illness and substance use disorder.

⁶⁷⁶ NSW Health, *The Management of People with a co-existing Mental Health and Substance Use Disorder – Discussion Paper*, 2000, p 15

⁶⁷⁷ *ibid*

⁶⁷⁸ *ibid*

⁶⁷⁹ Submission 267, NSW Health, p G.30

⁶⁸⁰ J Gray, Evidence, 8 October 2002, p 29

⁶⁸¹ *ibid*, pp 43-44

Access to mental health and drug and alcohol services

10.31 The primary difficulty people with a MISA problem have accessing health services was identified in the Burdekin Report:

If someone with a psychiatric disability has a drug problem and is on medication, to try and get them into a detoxification centre is impossible because detox centres will not take anyone on medication...[and] try to get anyone with a drug problem into an accommodation service designed for psychiatrically disabled people, is almost impossible.⁶⁸²

10.32 The *Discussion Paper* published in 2000 by the Centre for Mental Health and the Drug Programs Bureau acknowledged comments in the Burdekin Report which indicated that, despite the high prevalence of MISA:

a severe lack of communication existed between mental health and drug and alcohol services. A result of this, the Inquiry was told that people with a dual diagnosis tend to “fall through” the gaps in the health care system.⁶⁸³

10.33 Evidence presented to the Committee indicates that the gaps continue to exist. In February 2000, the Australian National Council on Drugs (ANCD) conducted a NSW Local Agency Consultation Forum for over 100 people from the NSW drug and alcohol field. A major theme raised during the forum was MISA, including:

- the continuity of care between treatment for alcohol and other drug problems and treatment for mental illness
- funding for mental health services and the difficulty in attracting and retaining skilled professionals and
- problems placing people who are psychiatrically affected in detoxification or treatment services.⁶⁸⁴

10.34 Two years later in March 2002, ANCD conducted a similar forum on mental health and drug and alcohol services, which concluded:

The gap between mental health services and drug and alcohol services has existed for many years, and is not getting better. Integrated program delivery was seen as the most obvious way to improve the situation.⁶⁸⁵

10.35 The Mental Health Review Tribunal also informed the Committee that the lack of a coordinated approach to service delivery still exists:

[Issues] reported and discussed by tribunal members around Australia relate to the lack of expertise in treating and working with people with dual or multiple

⁶⁸² Burdekin Report, 1993, p 665

⁶⁸³ NSW Health, *The Management of People with a co-existing Mental Health and Substance Use Disorder –Discussion Paper*, NSW Health (2000), p 10

⁶⁸⁴ Australian National Council on Drugs, NSW Local Agencies Consultation Forum Report, February 2000

⁶⁸⁵ Australian National Council on Drugs, Sydney Local Agencies Consultation Forum Report, February 2002

diagnosis (including drug and alcohol). In the absence of clear service pathways and "buy-in" by clinical services, people with dual diagnosis are frequently passed from one department to another.⁶⁸⁶

10.36 UnitingCare stated that people with a mental illness and co-existing substance use problem are victims of 'buck-passing' between health services:

For example, Burnside youth services in the Macarthur region report that if a young person has a dual diagnosis, for example alcohol or other drug abuse and a mental health issue, the mental health services say that it is a matter for alcohol and other drug services, while alcohol and other drug services say it is a mental health service problem. Alcohol and other drug usage (particularly prolonged usage) can be the catalyst for serious psychosis and suicide ideation, even with marihuana smoking. It is ludicrous that there is a difficulty in gaining access to services. This is an ongoing concern for all services in Macarthur, which, given the region has no after-hours mental health crisis team, is exacerbated considerably.⁶⁸⁷

10.37 Ms Patricia Zabaks made a submission to the Committee and spoke at the Committee's public forum. Ms Zabaks' daughter was diagnosed with schizoaffective disorder and has a co-existing drug problem. Ms Zabaks highlighted that mental health services would not recognise their duty of care, citing her daughter's substance abuse as the rationale for not treating her mental illness:

opinions from numerous psychiatrists, counsellors and the local mental health team were sought. Because of co-morbidity with drug use her father, my daughter and myself were frequently sent away to deal with the drug problem first. No advice or referral to an appropriate professional was ever given. Our observation that the mental illness persisted in the absence of illicit drug taking was ignored.⁶⁸⁸

10.38 Ms Colleen Deane also made a submission to the Committee and spoke at the public forum. Ms Deane's son Joseph had a mental illness and a co-existing drug and alcohol problem. Joseph committed suicide after absconding from the psychiatric unit of a general hospital. Ms Deane expressed her frustration at the barriers to treatment and care for her son:

The hospital did not want Joseph – he was a difficult patient with his drug and alcohol addictions and his violent psychotic episodes – so I was left to deal with Joseph.

...I called the crisis team so many times, only to be told it was a drug and alcohol problem, police problem or I was too emotional. I pleaded with them to help – but to no avail.⁶⁸⁹

10.39 Ms Diane Oakes's son suicided while in the psychiatric wing of a public hospital, after a history of drug induced psychosis and depression.⁶⁹⁰ Ms Oakes was critical of the diagnosis

⁶⁸⁶ Submission 266, Mental Health Review Tribunal, p 11

⁶⁸⁷ Submission 78, UnitingCare, p 24

⁶⁸⁸ Submission 205, Ms Patricia Zabaks, p 1

⁶⁸⁹ Submission 17, Ms Colleen Deane, p 1

⁶⁹⁰ NSW Police Service, Crime Agencies, Coroners Support Section, Investigation Report, p 2 cited in Submission 220, Ms Diane Oakes

and assessment of her son by health services, and stressed that health services must recognise their duty of care. In relation to mental health and drug and alcohol services, Ms Oakes expressed anger over the division of responsibility:

Mental Health and Drug and Alcohol Services must be seen as part of the same Service. Too many people with both mental health problems and drug and alcohol induced mental health are being shunted backwards and forwards between these two services with neither being willing or able to take responsibility for the complete and complex care required by these patients. This shirking of responsibility for the care of these patients in crisis must STOP.⁶⁹¹

10.40 Nine years after publication of the Burdekin Report, Sister Myree Harris RSJ and Mr Colin Robinson, Society of St Vincent de Paul, informed that Committee that:

People who are doubly disabled this way, are poorly served and tend to “fall through the cracks” of our mental health and drug and alcohol services. They are often shuffled back and forth between services which take responsibility for treatment of only half the condition.

Drug and alcohol services often refuse to treat people who have been prescribed psychotropic medication. Mental health services address only the mental illness component of the condition.⁶⁹²

10.41 Prof Ian Webster, Emeritus Professor, commented that the specialisation of services may actually hinder access to treatment and care:

Possessing dual diagnosis is not a problem of the affected person as such but a problem created by the specialisation of services. Specialisation arises for two main reasons. One is to deal with an area of need and the other is to cope with evolving new technologies.

...In mental health and drug and alcohol some of the specialised responses have developed around institutions and facilities...This has led to exclusiveness, as the facilities are designed around a culture for one problem exclusively so that other problems are unwelcome.⁶⁹³

10.42 The Legal Aid Commission referred to "tragic results" when the seriousness of MISA is not recognised:

The tendency to refuse service to people with dual problems of mental illness and drug usage has, in our view, been the cause of some tragic incidents.⁶⁹⁴

10.43 The Commission concluded:

For patients with a dual diagnosis of drug addiction and mental illness, there appears to be little assistance for the drug addiction while the patient is in hospital,

⁶⁹¹ Submission 220, Ms Diane Oakes, p 6

⁶⁹² Sr M Harris, Evidence, 23 May 2002, Tabled document no.7, p 2

⁶⁹³ Submission 193, Prof Ian Webster, p11

⁶⁹⁴ Submission 216, Legal Aid Commission, p 4

and when patients are discharged from hospital it is into hit and miss arrangements with drug rehabilitation services.⁶⁹⁵

10.44 An example of such tragic results was illustrated in the Society of St Vincent de Paul publication *A Long Road to Recovery*:

Annette suffers from anorexia as well as severe anxiety and depression, which have led her to become entrenched in chronically compulsive patterns of thought and behaviour. Her thoughts prevent her from standing still, literally, or caring for her physical well being and have led in the last four years to drug abuse as her latest way to escape her condition.

She is now a heroin addict and is homeless. Her body weight regularly plummets. Periodically, she is taken to the emergency room of a hospital where she is promptly discharged, if admitted at all, on the grounds that hers is a drug problem and that she needs to address that before hospitals will address her psychiatric condition.

However, even the most sophisticated and long-term drug rehabilitation programs admit that she needs help with her mental health at the same time as her drug rehabilitation. And so it is back to the public health system for more 'rejection therapy'.

With severely disordered thought patterns, life-threatening body weight, and a manifest inability to make basic choices to keep herself alive, the main public hospitals in inner-city Sydney have nonetheless discharged or not admitted her on several occasions over the last three years.

Recently her weight plummeted to 29 kilograms. Unable to stand, Annette was taken to St Vincent's public hospitals, Darlinghurst, and was discharged the same day. A lack of beds and the protection of Annette's freedom are two of the most frequently given reasons by the hospitals for their decision to discontinue her care. On one occasion, the phrase used by a young psychiatrist was 'we must not be paternalistic'. Sadly however, when a person is dying, what good is this to them?...The dual nature of Annette's problem effectively means she is in 'no-man's land'.⁶⁹⁶

10.45 Despite best practice models and the *Service Delivery Guidelines* developed by NSW Health, people with MISA are not necessarily receiving adequate treatment and care.

⁶⁹⁵ Submission 216, Legal Aid Commission, p 13

⁶⁹⁶ Submission 143, Society of St Vincent de Paul, *A Long Road to Recovery: a social justice statement on mental health*, July 2001 p 14

NSW Health - drug and alcohol responsibilities and funding

Table 10.2 Total drug and alcohol funding by year from State and Commonwealth

	1998-1999		1999-2000		2000-2001	
	\$	%	\$	%	\$	%
Commonwealth	13,100,000	17%	15,400,000	18%	21,400,000	20%
State	64,700,000	83%	72,000,000	82%	85,700,000	80%
Total	77,800,000	100%	87,400,000	100%	107,100,000	100%

Source: NSW Health, 14 November 2002

10.46 Considering the high prevalence of substance abuse by people with MISA, the Committee was interested in the allocation of funding and responsibility for drug and alcohol services in NSW. The Director of the Drug Programs Bureau, Dr Jennifer Gray and the Chief Health Officer of NSW, Dr Greg Stewart, informed the Committee of the complex system of drug and alcohol services funded and provided by the Commonwealth, NSW Health, and the Office of Drug Policy in the Cabinet Office.

10.47 Dr Stewart highlighted the division of responsibility between these agencies. In response to a question from the Committee regarding whether or not NSW Health is the principal agency in relation to drug and alcohol, Dr Stewart stated that:

In relation to drug treatment, yes. In relation to a broad range of services about drug and alcohol—drink-driving, for example—the answer is no.⁶⁹⁷

10.48 Dr Stewart later explained that NSW Health has a clear role in terms of services provided for drug and alcohol, though added:

I think it is important, though, to talk about how the Government has responded to drug and alcohol in general, not just the Drug Summit because the Health Department is not the leading agency.

...The lead Minister is the Special Minister of State. The lead agency—and they remind us of this from time to time—is the Cabinet Office.⁶⁹⁸

10.49 The complicated allocation of responsibility within drug and alcohol services in NSW was further highlighted by the Director of the Drug Programs Bureau, NSW Health:

We are no longer the lead agency. We were, prior to the repeal of the Drug Offensive, but that was stripped away from us. As a post-Drug Summit process the Office of Drug Policy was established in the Cabinet Office. They have the coordinating role of policy of all types across government to do with drug and alcohol.⁶⁹⁹

⁶⁹⁷ Dr G Stewart, Chief Health Officer, NSW Health, Evidence, 8 October 2002, p 40

⁶⁹⁸ *ibid*, p 41

⁶⁹⁹ J Gray, Evidence, 8 October 2002, p 41

10.50 As the Committee attempted to ascertain the roles and responsibilities within drug and alcohol services with respect to coordination with mental health services, Dr Stewart stated that the Committee was confusing drug and alcohol services and drug and alcohol treatment services. Dr Stewart explained:

Of course the Health Department is the lead agency in relation to drug and alcohol treatment services. We provide those services. It is our responsibility to provide them. After the Drug Summit, reconsideration was given to which government department will be the lead agency in relation to drug and alcohol services because they involve things that are much greater than just treatment services. They involve a whole lot of things that I have just talked about, such as training, police response, the response in youth, DOCS, so on and so forth.⁷⁰⁰

10.51 The Committee was interested to understand the allocation and accountability for drug and alcohol funding in NSW, particularly that which would be utilised by a significant percentage of people with a co-existing mental illness. Under the Commonwealth National Drug Strategy, the funding allocated to NSW stipulates that 10% must be expended on 'law enforcement' programs. NSW Health has historically directed this money to the NSW Department of Corrective Services. In response to a question from the Committee regarding the accountability of Corrective Services for this funding, Dr Stewart stated:

The important point here is that we are required to provide, out of this component of Commonwealth funds, 10 per cent for law enforcement. We provide it to Corrections, and they tell us they spend the \$1.3 million on counsellors.

...we are just a post box for that. You will have to ask Corrections how they spend the money.⁷⁰¹

10.52 The Committee then asked Dr Stewart how NSW Health evaluated that utilisation of funding to the NSW Department of Corrective Services. Dr Stewart responded:

surely, it is a matter for the Commonwealth what reporting it requires from an agency that is not NSW Health. I am quite happy to answer questions on what NSW Health reports. But I cannot possibly answer on how Corrective Services responds.

...It is the Commonwealth that provides the funds. It is the Commonwealth that should ask the additional questions.⁷⁰²

10.53 Dr Stewart was later asked whether or not he thought the \$1.3 million is "well spent on drug and alcohol issues by Corrections, in cooperation with Corrections Health". Dr Stewart responded:

in the end, surely it is the Commonwealth's responsibility, since it is the body to whom we report, to ask those kinds of questions. It is Commonwealth money.

⁷⁰⁰ G Stewart, Evidence, 8 October 2002, p 41

⁷⁰¹ *ibid*, p 34

⁷⁰² *ibid*, p 35

The Commonwealth has been satisfied for 10 years. It apparently has asked us no more questions.⁷⁰³

...I am not unconcerned but it is difficult for me as the Chief Health Officer or anyone within NSW Health when there is a mandate of 10 per cent to go to [Corrective Services] to have any powerful levers in relation to our money.⁷⁰⁴

10.54 As noted, the 10% component of the Commonwealth's funding for drug and alcohol services is allocated for 'law enforcement'. The distribution of this funding to the NSW Department of Corrective Services is at the discretion of NSW Health. The Committee expressed concern over the allocation of this funding to Corrective Services, and it is concerned by the Chief Health Officer's confusing response regarding allocation and accountability, in terms of coordinated service delivery.

10.55 Early in 1997-1998 the Centre for Mental Health was transferred from the Public Health division of NSW Health to the Policy division to integrate the various health policy components within the Department. As stated earlier, *The Management of People with a co-existing Mental Health and Substance Use Disorder - Service Delivery Guidelines* and the *The Management of People with a co-existing Mental Health and Substance Use Disorder - Discussion Paper* were a joint initiative between the Centre for Mental Health and the Drug Programs Bureau of NSW Health. Consequently, the Committee was concerned that Dr Stewart was unable to comment on mental health and substance abuse:

We cannot comment on what happens to a patient with predominantly a mental health problem, because we came along to talk about drug and alcohol. It does not fall within the public health division. But we can talk about drug and alcohol services.⁷⁰⁵

10.56 Prof Webster expressed concern over the perceived division of responsibility in health care between mental health and substance abuse:

Everyone working in primary health care needs upskilling in mental health and addiction. The illusion that these are rare problems and not the business of primary health care, must be set aside. Mental health and drug and alcohol problems are principal areas of focus for all human services but especially primary health care.⁷⁰⁶

10.57 The Committee considers that the division of responsibility within drug and alcohol services may be a barrier to the continuity of care for people with MISA. The Committee is concerned that a mental health service provider, especially an NGO, would have great difficulty in evaluating funding streams for MISA patients in order to determine the equity and accessibility of available programs.

⁷⁰³ *ibid*, p 37

⁷⁰⁴ *ibid*, p 38

⁷⁰⁵ *ibid*, p 47

⁷⁰⁶ Submission 193, Prof Ian Webster, p 15

- 10.58** Considering the evidence presented to the Committee, including that by the Legal Aid Commission, Mental Health Tribunal, the Society of St Vincent de Paul, and the Chief Health Officer, the Committee considers that effective integration of mental health and drug and alcohol services is required in NSW as a matter of urgency.

MISA – the need for service integration

There needs to be more communication between drug and alcohol services and mental health teams...In the case of dual diagnosis – they don't need to be further fragmented by being pushed between the services – they need to be treated holistically.⁷⁰⁷

[Ms Colleen Deane]

- 10.59** A 1999 study suggested that treatment for both drug problems and mental health disorders improves prognosis, whereas continued illicit drug use intensifies mental health problems.⁷⁰⁸ The *International Mid-Term Review of the Second National Mental Health Plan for Australia, November 2001*, stated however, that providing adequate services for people with mental health and substance use problems was consistently raised as “one of the greatest services limitations throughout Australia”.⁷⁰⁹

- 10.60** Dr David Kavanagh, Department of Psychiatry, University of Queensland, referred to a recent survey of professional staff across Queensland which found that:

the separation of services produced a range of problems in co-ordination of treatment, information exchange and access to specialist services for people with comorbidity...We know from outcome trials that integrated treatment for comorbid disorders is more effective than parallel or sequential treatment (Drake, Mercer-McFadden, Mueser, McHugo, & Bond, 1998), so these service delivery problems are of significant importance in terms of maximising effectiveness and minimizing delivery costs.⁷¹⁰

- 10.61** The Australian National Council on Drugs submission to the Commonwealth House of Representative *Inquiry into substance abuse in Australian communities*, also highlighted the need for effective integrated service provision:

The Council is concerned about the lack of integration between mental health and alcohol and other drug services. Putting it very simply, clients with a dual diagnosis of a mental disorder and substance use, usually have to access different treatment services for their substance use and mental illness. Some have reported being referred to one service to treat one disorder/disease before being accepted for treatment at another.

⁷⁰⁷ Submission 17, Ms Colleen Deane, p 2

⁷⁰⁸ I B Crome, Substance misuse and psychiatric comorbidity: towards improved service provision. *Drugs: Education, Prevention and Policy*, 6 (2), 1999, p 149 – 174

⁷⁰⁹ Prof V T Betts, Prof G Thornicroft, *International Mid-Term Review of the Second national Mental Health Plan for Australia*, November 2001, Commonwealth Department of Health and Ageing, 2002 Canberra, p 16

⁷¹⁰ Dr D Kavanagh, Department of Psychiatry, University of Queensland, submission to the House of Representatives Standing Committee on Family and Community Affairs, *Inquiry into substance abuse in Australian communities*, 2002

Other problems include the difficulty in accurate diagnosis, comparative lack of skilled professionals in dealing with dual diagnosis patients and the statistical suggestion that people with dual diagnosis are more likely to experience negative outcomes (eg: increased levels of medication, suicidal behaviour, higher family burden, etc) and generally respond less-well to treatment than those with mental disorders alone.⁷¹¹

10.62 The need to treat and care for both substance abuse and mental illness problems concurrently is recognised by the Triple Care Farm (TCF). This is a youth project operated by Mission Australia, targeting young people with complex histories including substance abuse and mental illness issues.⁷¹² TCF receives only 9% of its funding base from government departments, and is supported primarily by the private sector. TCF made a submission to the inquiry to highlight “the growing number of young people with dual disorders, and specifically mental health and substance use”.⁷¹³

10.63 Mr Warren Holt, Manager of TCF, expressed that while the program was established to accept young people with a mental illness who were stabilised and had been through a detoxification program, in practice:

Often Triple Care Farm has been the first program to recognise the young person’s mental health problem, which had previously been seen as purely a drug problem by other services.

...On occasion, young people are withdrawing when they first come to the farm...Triple Care Farm ensures that the underlying factors contributing to the young person’s substance use problem are also addressed.⁷¹⁴

10.64 The *Service Delivery Guidelines* published by NSW Health acknowledged the need for service integration in NSW. The Guidelines advocate how suitable service delivery that meets the specific needs of various services and geographical areas across NSW could be developed by implementing a number of options, including:

- integrated service provision under one umbrella organisation
- establishing links between identified key staff in local services
- initiating a formal process of collaboration and networks in joint meetings, journal clubs and case reviews by service providers in mental health, drug and alcohol, general practice and non-government organisations
- employment of staff with drug and alcohol expertise in mental health services
- employment of staff with mental health expertise in drug and alcohol services.⁷¹⁵

⁷¹¹ Australian National Council on Drugs, submission to the House of Representatives Standing Committee on Family and Community Affairs, *Inquiry into substance abuse in Australian communities*, 2002

⁷¹² Submission 302, Triple Care Farm, p 1

⁷¹³ *ibid*, p 1

⁷¹⁴ *ibid*, p 2

⁷¹⁵ NSW Health, *The Management of People with a co-existing Mental Health and Substance Use Disorder –Service Delivery Guidelines*, NSW Health, 2000, p 20

10.65 The Committee is concerned however, that the mental health policy and service review arm of NSW Health has little control over the implementation and monitoring of policy programs for mental health and drug and alcohol services. Implementation of service delivery guidelines is reliant upon the AHS. The Office of the Protective Commissioner highlighted this absence of control in its submission to the Committee:

Whilst the Centre for Mental Health offers some opportunity for state-wide overview of the strategic issues pertaining to mental health services, the provision and management of services through Area Health Services can sometimes be experienced as disjointed, if not inconsistent or absent.⁷¹⁶

10.66 Prof Raphael confirmed this observation when she informed the Committee that the Centre for Mental Health, the NSW Government's primary mental health policy and service development agency, has no control over the delivery of mental health services in NSW by AHS.⁷¹⁷

10.67 The division of responsibility exists despite the concerted efforts of NSW Health in developing interagency policies and protocols to provide continuity of care. The Office of the Protective Commissioner informed the Committee that:

While policies and protocols are in place an operational evaluation is required at the practice level of the NSW Health [system]...

While some interagency protocols have existed in the past it has been the experience of the OPC that its frontline staff are unaware of the existence of these protocols.⁷¹⁸

10.68 Based on the evidence received by the Committee, the health care system for people with MISA lacks integration. Clearly, there are gaps between policy development and implementation. The initiatives outlined in the *Service Delivery Guidelines* provided a foundation for bridging gaps in the delivery of mental health and drug and alcohol services. Nine years after the Burdekin Report highlighted the gaps in service provision for people with MISA, the 'links', 'collaborations' and skill sharing required to address this issue are still largely absent.

10.69 The Gethsemane Community reinforced this view:

The Mental Health system and the Drug and Alcohol system often work against each other. There is a desperate need for a combined approach to the treatment of people with both conditions⁷¹⁹.

10.70 Prof Webster succinctly outlined the fundamental change required in delivery of services to people with MISA:

The old idea of sequential treatment – get them off the drugs first, or treat their madness before we start rehabilitation – should go out the window.⁷²⁰

⁷¹⁶ Submission 219, The Office of the Protective Commissioner, p 9

⁷¹⁷ B Raphael, Evidence, 12 August 2002, p 18

⁷¹⁸ Submission 219, The Office of the Protective Commissioner, p 9

⁷¹⁹ Submission 75, Gethsemane Community, p 1

Re-integrating mental health and drug and alcohol services

10.71 The *International Mid-Term Review of the Second National Mental Health Plan for Australia* reported that the ‘way forward’ for MISA was to eliminate the barriers between mental health and substance use agencies, leading towards full integration of these two health services.⁷²¹ This approach was supported by Prof Webster:

Mental health promotion and prevention must be linked with a comprehensive approach to prevention that will deal with underlying causes and by virtue of this approach deal concurrently with risks for substance use disorders...⁷²²

10.72 The Western Australian Health Department recognised the lack of continuity of care between mental health and drug and alcohol services, and subsequently established the Joint Services Development Unit (JSDU). The JSDU was an initiative of the mental health division that aimed to combine the delivery of mental health and drug and alcohol services. Staffed by workers experienced in both mental health and drug and alcohol, the JSDU offers its services to both mental health and drug and alcohol services, including the provision of treatment, education and training services. In relation to this initiative the *International Mid-Term Review of the Second National Mental Health Plan for Australia* stated that:

WA considers that this is a necessary step to offer better integrated services for the dually diagnosed at the operational level, since they estimate that about 70% of specialist mental health service consumers also have substance use problems.⁷²³

10.73 The Committee acknowledges the achievements of the Drug Summit in NSW, and the subsequent establishment of the Office of Drug Policy within the Cabinet Office. While not recommending a change in this policy initiative, the Committee considers that an adequate component of the NSW drug and alcohol budget should be allocated to the Centre for Mental Health in order to reintroduce an integrated service program for people with a mental illness and a substance use disorder.

10.74 The process in NSW would be one of reintegration. As the NSW Health *Discussion Paper* noted, mental health and drug and alcohol services were not always segregated in NSW:

It should be noted however that these services were once part of an integrated service framework dealing with both types of disorders in one organisational system.⁷²⁴

⁷²⁰ Submission 193, Prof Webster, p11

⁷²¹ Prof V T Betts, Prof G Thornicroft, *International Mid-Term Review of the Second National Mental Health Plan for Australia*, November 2001, Commonwealth Department of Health and Ageing, 2002, p 7

⁷²² Submission 193, Prof Ian Webster, p14

⁷²³ Prof V T Betts, Prof G Thornicroft, *International Mid-Term Review of the Second national Mental Health Plan for Australia*, November 2001, Commonwealth Department of Health and Ageing, 2002, p 18

⁷²⁴ NSW Health, *The Management of People with a co-existing Mental Health and Substance Use Disorder –Discussion Paper*, NSW Health, 2000, p 10

- 10.75** The Committee supports the integration of service provision under the one organisation.⁷²⁵ This proposal is supported in-principle by a number of submissions to the Committee, including the Mental Health Association,⁷²⁶ the Gethsemane Community,⁷²⁷ the Office of the Protective Commissioner,⁷²⁸ and Prof Ian Webster,⁷²⁹ to name but a few.

Recommendation 68

That the Minister for Health provide additional funding to the Centre for Mental Health for the purposes of reintroducing an integrated service program for people with a mental illness and substance use disorder.

Recommendation 69

That the Centre for Mental Health develop and conduct a training program for drug and alcohol workers designed to increase the awareness and knowledge of mental illnesses and mental health practices.

⁷²⁵ *ibid*, p 20

⁷²⁶ Submission 171, Mental Health Association NSW, p 19

⁷²⁷ Submission 75, Gethsemane Community, p 1

⁷²⁸ Submission 219, The Office of the Protective Commissioner, p 1011

⁷²⁹ Submission 193, Prof Ian Webster, p 11