PART FIVE:
ANALYSIS OF ALL SUBMISSIONS AGAINST THE NATIONAL STANDARDS FOR MENTAL HEALTH SERVICES

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It was agreed by the MHCA, BMRI and HREOC, that the most useful framework for organising the vast amount of written and verbal data collected through the consultation process, was the *National Standards for Mental Health Services* (the Standards; see Appendix 8.7).

The information in this Part 5, and in Part 6, comes from the submissions and public consultations. The information represents a persuasive cumulation of personal experiences but it is not intended to suggest definitive proof or disproof of the implementation of the Standards. The data is analysed according to State and Territory (Parts 6.1-6.8), and then nationally (Part 6.9) for submissions received from national organisations.

In this section (Part 5), we summarise those common themes and provide a small sample of quotes that highlight personal experiences relevant to each Standard. The volume and consistency of the information gathered through this process demonstrates the gaps and the difficulties governments have had across Australia in meeting these Standards.

5.1 STANDARD 1: RIGHTS

The rights of people affected by mental disorders and/or mental health problems are upheld by the Mental Health Service (MHS).

Standard 1 is designed to generally promote and protect the rights of people with mental illness. The Standard is broken down into specific components which set out the criteria for meeting this principle in more detail (see Appendix 8.7).

There was universal concern about the implementation of this Standard across Australia. The concerns (see list below) indicate the continuing vulnerability of people with mental illness, continued exposure to abuse and a lack of access to complaints procedures to identify systemic failures and provide personal redress.

Carers and service providers noted flaws with complaints procedures that resulted in consumers and carers being afraid to lodge complaints. They described fears of retribution and withdrawal of services. Carers who had lodged complaints also felt that they were being ‘fobbed off’.

There were also reports that mental health consumers were not being treated with dignity or respect. Experiences ranged from humiliating and degrading treatment in hospital settings to forced interactions with the police. Consumers and carers said that they were not being provided with information about their illness and treatment choices. They also complained that they were frequently denied the right to have others, such as carers and advocates, involved in their care.

Consumers from a Non-English Speaking Background (NESB) reported a denial of access to interpreters by services, which led to difficulties in accessing appropriate treatment and support services.

Another key area of concern was the protection of the rights of one of the most vulnerable groups of consumers - people with mental illness in the criminal justice system. This is a critical issue, given the rising rate of incarceration of people with mental illness (often due to the inability of consumers to access treatment and support services when needed).

In summary, the key issues relating to this Standard, across Australia, include:

- Consumers and their carers are not being provided with information about their rights (Standards 1.2, 1.3, 1.4)
- Consumers and their carers are not being provided with information about available mental health services, mental illness and available treatment and support services (Standard 1.8)
- Consumers from a NESB and their carers are not being provided with accessible information about available mental health services, mental illness and available treatment and support services and how to access them (Standards 1.7 and 1.8)
- Consumers are not being treated with dignity and respect (Standards 1.1 and 1.4)
- Lack of access to interpreters (Standard 1.7)
- Lack of access to advocates (Standard 1.6)
- Problems with complaints procedures (Standard 1.10)
- General failure to protect consumers rights (Standard 1.1)
- Denial of a consumer's right to have others involved in their care (Standards 1.5 and 1.6)
- Staff and services are not complying with relevant legislation, regulations and instruments protecting the rights of people with mental illness (Standard 1.1)
- Concern about the rights of people with mental illness in the criminal justice system (Standards 1.1 and 1.4)
- Concern about Ministerial discretion and the rights of people with mental illness (Standard 1.1)

The following selected quotes from community forums and submissions describe people's recent experiences of mental health services in the context of Standard 1. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Consumers and their carers not being provided with information about their rights

Failure to inform consumers of their rights. The recent review of the Mental Health Act 1996 revealed continued resistance amongst mental health workers to the philosophy and practice of informing mental health consumers of their rights, including review of orders, involuntary treatment second opinions, use of advocates. The provision of pamphlets listing consumers' rights is the most routine means of meeting the duty to inform. This is a minimum standard and considerable pressure needs to be applied to encourage verbal communication by staff about rights, at levels appropriate to consumer needs, at various times during hospitalisation or care in the community.

(Health Consumers' Council WA, Western Australia, Submission #29)

[X] was not informed of his rights as a Voluntary Patient and was not made aware that he had been made an 'Involuntary Patient'. This had been done without notification, oral or written. This was witnessed by us prior to [X] being placed in a drug induced sleep. He has not obtained or received copies of associated Forms relevant to this admission…. Management of [X]'s case, have violated his rights as a person with a mental illness.

(Carers, Western Australia, Submission #177)

Consumers not being treated with dignity and respect

A lack of dignity and respect in care received from mental health services are reported generally but in particular, forensic patients, young people and Aboriginal patients are reported to be treated poorly.

(Mental Health Community Coalition Consumer and Carer Caucus,
Australian Capital Territory, Submission #342)

Why in 2004 are our loved ones still suffering after policy documents from fancy government watchdogs have been released? Why aren't our loved receiving the same quality of care as people with physical illnesses? Are they not worthy of treatment? Where is the concern? There are huge problems with the system and some of the staff within the system. There is physical and sexual abuse still occurring. Why do we still use seclusion where there are no toilets, no water?

(Carer, New South Wales, Parramatta Forum #1)

I stayed in the Psychiatric Intensive Care Unit at the Royal Derwent Hospital – human rights regarding seclusion. There was no access to a toilet so I had to urinate in the corner of the room.

(Consumer, Tasmania, Hobart Forum #3)

By 15 December 2001, our daughter had developed severe oral thrush, her tongue being swollen preventing her from swallowing and talking without great distress. Unbelievably, her meals still comprised solid food (which she could not eat); this situation led to her subsequent malnutrition and severe dehydration which resulted in her losing 12 kilograms and being transferred to medical ward 2 East on 4 January 2002 for prompt life-saving intravenous and naso-gastric treatment… my wife saw our daughter drinking the toilet water to help relieve her dry and thickly-coated tongue, mouth and throat.

(Carers, Parents, New South Wales, Submission #106)

We are often required to transport these people but they are not criminals, they are ill.

(Police officer, Western Australia, Bunbury Forum #9)

Concern about protection of the rights of the mentally ill in the criminal justice system

Prison is an expensive housing option for the mentally ill: it is also a grave abuse of their human rights.

(Anonymous, Queensland, Submission #67)

In May 2001, as a consequence of that inadequate treatment, he was charged with malicious damage by arson and in April 2002 was found not guilty by reason of mental illness. From May 2001 until June 2003 our son was incarcerated in appalling conditions at Long Bay Prison Hospital. His behaviour throughout that period was exemplary. During all of that time, he was locked for at least 11 hours a day, and often longer, in solitary confinement in a prison cell and was not allowed to have a TV in his cell. He was frequently hungry, due to the poor quality of the food provided.

(Carers, Parents, New South Wales, Submission #75)

[Prisoners] are in a highly restricted environment, have no choice in provision of service, have far reduced access to their support network, have even greater problems in accessing any complaint or oversight body and in allowing such bodies to examine information that they request to be examined.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA),
New South Wales, Submission #349)

Problems with complaints procedures

95% of the reason why you don't get complaints – because they are exhausted and afraid of victimisation.

(Anonymous, Northern Territory, Darwin Forum #27)

I want to talk about what happens to patients if you complain about staff. If you complain you go from the frying pan to the fire! …You still need the treatment and the service so you don't complain.

(Consumer, Victoria, Morwell Forum #10)

People are afraid to complain. There's a fear of impact if they complain. Even when the evidence is overwhelming, there is still a real fear. The more serious the complaint, the more "they" will try to discredit the consumer. The culture is such that "they" never want to help the consumer.

(Consumer Advocate, Victoria, VMIAC Forum # 9)

A protocol needs to be developed for the dealing with complaints on a prompt basis whether it be from official agencies such as OCA or others including family, friends and carers. A responsible accountable system for dealing with complaints may well assist morale and confidence in the safe care provided by PSU. (Excerpt from Report of findings by the Chief Coroner)

(Carer, Partner, Australian Capital Territory, Submission #305)

…even numerous complaints to the WA Medical Board have been dismissed with such statements as 'time lessens the memory'.......... sure, after they kept fobbing off meetings with them and letting time lapse. I went to every viable person in Perth only to crash into brick wall after brick wall. [Y], Head Psych for the state, told me I was just an emotive mother... too right I am!

(Carer, Mother, Western Australia, Submission #103)

Staff and services not complying with relevant legislation, regulations and instruments protecting the rights of people with mental illness

The hospital has reduced the Ward Clerk hours, which leaves her unable to provide the time needed to do the paperwork to comply with the Mental Health Act. Often when a patient is to have a review by the Mental Health Review Board, there is no paperwork ready, no psychiatrist in attendance and no report by the treating psychiatrist.

(Nurse, Western Australia, Submission #55)

Mental Health Review Board (MHRB) fails to uphold human rights of mental health consumers. The MHRB has consistently failed to work to the reasonable extent of the scope of its powers, by testing the attitudes and practices that lead to detention and forced treatment of consumers. The MHRB is widely regarded by mental health consumers with experience of the system as not being worth the effort of contacting. Reviews are routinely limited to 20 minutes, psychiatrists' reports are taken on face value and rarely challenged, procedural fairness is seen by most consumers and advocates as completely absent.

(Health Consumers' Council WA, Western Australia, Submission #29)

Lack of access to advocates

We have also found problems with the system's recognition of independent advocates, who having been specifically requested to act of behalf of a patient regarding a certain matter, are denied the ability to do so. This even occurs when the request has been in writing - demands are made for the request to be rewritten in a standardised format. This causes frustration in the patient and delay in resolving a problem.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA),
New South Wales, Submission #349)

To offset the abuse of human rights occurring on a daily basis, the need for advocacy services is stronger than ever before, and yet funding for these services has steadily diminished. Without access to independent, fully funded, fully trained advocates, human rights will continue to be breached and the effects will continue to be long lasting and impede the recovery of so many consumers. Independent advocacy can be very effective when used pro-actively in mental health service provision.

(Centre for Psychiatric Nursing Research and Practice, Victoria, Submission #323)

Lack of access to interpreters

The lack of interpreters is a real issue. Many of our people don't have carers, they are socially isolated and they have problems with the language. But they are told by many practitioners that they don't work with interpreters so they can't access adequate care.

(Service Provider, Western Australia, West Perth Forum #36)

Interpreter use of people with limited English. The Health Consumers' Council has assisted a Macedonian mental health consumer who was challenging the actions of mental health services to require him to submit to medication and involuntary hospitalisation. The clinical consultation during which the decision was made to place the consumer on an involuntary order occurred without an interpreter. We include an Advocacy report produced at the time of this consultation that highlights our concerns about the failure of mental health service clinicians to engage interpreters. Specific comment: The engagement of an interpreter should not be optional where action under the Mental Health Act is likely or possible.

(Health Consumers' Council WA, Western Australia, Submission #29)

Concern about Ministerial discretion and the rights of people with mental illness

The Minister is sitting on a request for a consumer to go home even after the Mental Health Tribunal has approved his release.

(Carer, New South Wales, Parramatta Forum #1)

During the period of our son's Forensic Order, we have not been satisfied with the 'due process' of administration of conditions of that order. The requirement that the NSW Minister for Health approve these conditions means that the process is inappropriately politicised. Decisions about transfer and leave for patients, seem to be made to appease community attitudes about mental illness and violence, which are steeped in stigma, rather than in the best interest of the patient.

(Carers, Parents, New South Wales, Submission #75)

5.2 STANDARD 2: SAFETY

The activities and environment of the MHS are safe for consumers, carers, families, staff and the community.

There was serious concern that mental health services are not providing treatment and support to ensure the safety of consumers, their families and the community. The lack of services to assist youth, in particular, was noted. Submissions indicated that many consumers are unable to access emergency services even when at risk of self-harm or harm to others.

Families and carers reported fear for their own safety and the safety of their family member, with no or little response from mental health services. Some consumers shared experiences where they were afraid in hospital treatment settings and provided examples where their safety was not adequately provided for.

Submissions and presentations provided examples of consumers dying while in hospital care, or soon after discharge. Some services responded to safety issues by employing security guards and limiting the freedom of inpatients. However, submissions indicate that this response did not improve safety and security, rather it exacerbated stigma issues and feelings that people with mental illness were criminals or "animals".

Fears for personal safety were also expressed by staff. The expressed a need for additional resources and staff support and training in order for mental health services to respond appropriately and ensure the safety of consumers, carers, staff and the community.

Nationally, the key issues raised regarding this Standard include:

- lack of response to family concerns of danger (Standard 2.3);
- excessive use of physical restraint, sedation and armed escort (Standard 2.3);
- excessive focus on security (Standards 2.1 and 2.3);
- problems with the use of security guards with inpatients (Standard 2.3);
- Consumers are not kept safe or protected from abuse in hospital and treatment settings (Standard 2.2);
- inappropriate staff responses to aggressive and difficult behaviour (Standard 2.4);
- need for staff training to respond appropriately to aggressive and difficult behaviour (Standard 2.4);
- safety concerns for children with mental illness (Standard 2.2);
- lack of services for children and youth with behaviour problems (Standard 2.2);
- lack of procedures in hospitals to ensure safety of consumers, carers and the community upon discharge (Standards 2.1 and 2.3);
- inadequate treatment and support services to ensure the safety of consumers, carers and the community (Standard 2.3);
- lack of support and services in the community to protect consumers from abuse (Standard 2.2);
- lack of trust in MHS to ensure safety for the community (Standard 2.3);
- occupational health and safety issues (Standard 2.3);
- safety concerns of staff (Standards 2.3 and 2.5);
- safety not ensured in supported accommodation environments (Standards 2.2 and 2.3);
- the MHS is not communicating vital information with other accommodation service providers to ensure the safety of staff and other residents (Standard 2.3);
- transport of consumers in a manner which is not 'safe and dignified' (Standard 2.3); and
- safety issues due to lack of resources (Standard 2.3).

The following selected quotes from community forums and submissions describe people's recent experiences of mental health services and their areas of concern under Standard 2. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Safety of people with mental illness not ensured

The only way the people I have mentioned will receive help is if they harm themselves severely or someone else which is more than likely and why should carers have to wait for such a result.

(Carer, Queensland, Submission #109)

Two consumers died at Xmas one who self harmed and took it too far – we referred him to the service as he was very distressed and out of control he was assessed by a case manager as OK but died within the following week; The second went to the service begging to go into the unit as he knew that when he got this depressed he was at risk – this was our experience in the past and he was hospitalised and kept safe; they refused on this occasion – he took his own life a couple of days later.

(Anonymous, Queensland, Submission #113)

Safety of families and carers not ensured

More than half of the time within 48 hours, to a week, of her release we would be back at the emergency room when the medication had worn off and the delusions had returned full force and often she had lashed out at myself or my grandparents.

(Anonymous, Queensland, Submission #82)

[X] subsequently stayed with us for 10 days even though he was clearly very unwell and should not have been released from hospital. He seemed to be getting worse staying with us and constantly paced through the house day and night. [X] became very aggressive towards his family and had problems with his thought processes. His condition was obviously deteriorating rapidly and we were very worried about safety issues, both his and our own.

(Carers, Parents, New South Wales, Submission #198)

Lack of services for children and youth with behaviour problems

I have staff using the expulsion / suspension guidelines to exclude these kids. I have staff being attacked by kids who are on drugs. Because of a lack of services there's nothing left but to exclude these kids. Actually they really need care.

(Teacher, South Australia, Murray Bridge Forum #17)

Safety not ensured in supported accommodation environments

Hostels like St. Bartholomew's House can no longer afford the risk of injury to staff and/or other residents from people who are not having adequate treatment and support from mental health services.

(St Bartholomew's House Inc, Western Australia, Submission #37)

Safety concerns of staff

As well as the serious implications this crisis has for patients, there are very real and unacceptable consequences for staff. In addition to the obvious risks associated with safety and aggression, there is the deleterious psychological impact on staff constantly frustrated in their attempts to deal humanely with these people in a system that is patently incapable of responding adequately to demand.

(Mental Health Workers Alliance, New South Wales, Submission #325)

Excessive focus on security

Some of these security measures convey to the public that the people behind the wire are animals that need to be constrained.

(Carer, New South Wales, Parramatta Forum #4)

Excessive use of physical restraint, sedation and armed escort

…it goes against the grain to see people being made to stay on a trolley, in a cubicle, usually sedated, occasionally mechanically restrained, just because the mental health system is overloaded and poorly resourced. This situation is chronic and untenable.

(Clinician, Victoria, Submission #201)

Generally if a person's level of distress is of such concern to the clinic staff, themselves, family and / or community, the person will be evacuated, generally by air, to Alice Springs for assessment. The distances involved and the use of planes mean that evacuation to the acute service often requires chemical and / or physical restraint. Clearly there are significant safety issues that are evaluated in each case, however it does mean that Anangu are more likely to be chemically and physically restrained during an acute episode.

(Anonymous, Northern Territory, Submission #271)

Problems with using security guards with inpatients

One of the most disturbing practices for me is the use of security guards from a private security firm to facilitate the care of inpatients, due to lack of proper facilities and staffing levels in Bunbury. The hospital regularly employs guards to "special" patients who are considered at risk of either self-harm or absconding. They often use the guards to boost the staffing levels in the unit to try and make the environment safe. This can often mean an untrained person, usually male, following around a very ill or deeply disturbed person in the medical ward of the hospital as well as the psychiatric unit, or is sitting around in full uniform in the psychiatric unit. This has a couple of very major concerns. Firstly, the patient often self discloses to the security guard their personal history… Secondly, it also gives the patient, visitors and other patients, the impression that the person with the guard is "trouble", i.e. violent, bad, etc.

(Clinician, Western Australia, Submission #55)

Consumers not kept safe or protected from abuse in hospital and treatment settings

I'm a patient in the hospital at the moment under an involuntary order and it was very difficult for me to get here to this forum today… It's a place where you can get away from the world but there's not much else. The situation is terrible and I can't even have a shower in private. I'm scared and I have no privacy.

(Consumer, Western Australia, Bunbury Forum #17)

In my last admission (one year ago) to a public hospital I was assaulted and many of my things were stolen and some jewellery was flushed down the toilet. I do not blame the other patient because she was very unwell but I expect to be safe when I get admitted to hospital.

(Consumer, Queensland, Submission #204)

I am writing to you in order to express how appalled I am to hear that, eighteen months after the release of the Bunbury Health Task Force Report major problems with clinical safety at the Bunbury Hospital Psychiatric Inpatient Unit still continue… I can only hope that now, with the release of yet another report, your Office and that of the State Wide Office of Mental Health will be able to insist upon change – before someone is seriously injured, killed or otherwise jeopardised… (extract from a letter to the Office of the Chief Psychiatrist)

(Clinician, Western Australia, Submission #24)

Need for staff training to respond appropriately to aggressive and difficult behaviour

As a nurse academic and educator, I am aware that it seems that nurses often adopt or are directed to adopt a zero tolerance to aggression and violence, creating an often adversarial stance with patients and thus increasing the possibility of an aggressive episode... This is avoidable and unacceptable workplace practice. Patients deserve better care, nurses deserve high quality ongoing education and support to provide them with the skills and knowledge to care for people with difficult behaviours.

(Academic, South Australia, Submission #142)

Safety issues due to lack of resources

…the increasing service resource crisis presents significant threats to the rights of mentally ill people. This occurs through compromising safety and increasing the risk of sub-standard treatment, undermining centres of clinical academic excellence, increasingly marginalising those with mental illnesses, and through a tendency when addressing clinical problems to rely increasingly on administrative and legal solutions rather than clinically led solutions.

(Public Sector Psychiatrists, New South Wales, Submission #297)

> *There is a crisis in attracting all disciplines to work in Mental Health due to lack of support/ training and poor working conditions and a lack of attractive career paths. This impacts on comprehensive care and there are recurrent safety issues due to staff dealing with potentially violent and dangerous situations, sometimes without any back up.*
>
> (Anonymous, Tasmania, Submission #254)

5.3 STANDARD 3: CONSUMER AND CARER PARTICIPATION

Consumers and carers are involved in the planning, implementation and evaluation of the MHS.

Across Australia there were concerns about the diminishing level, or complete abandonment, of consultation and engagement with consumers and carers in the planning, implementation and evaluation of service delivery. There were reports that critical service delivery decisions were being made without any consultation with consumers and carers. Nor were there attempts to communicate the ramifications of such decisions to this group.

Where such processes were still operating, they were frequently described as ‘tokenistic’ and consumers and carers did not feel valued. Continued withdrawal of funding and lack of resources to support consumer and carer participation programs was also reported. Consumers and carers described feelings of weariness and ‘consultation fatigue.’ They are sick of being ignored and frustrated by the futility of participation and lack of progress.

Concern was also expressed that representation is not inclusive of all consumers and carers; for example, the representation of people with Borderline Personality Disorder was noted as lacking.

Nationally, the key issues relating to this Standard include:

- abandonment of participation by consumers and carers in planning, implementation and evaluation processes by the MHS (Standards 3.1 and 3.2);
- lack of meaningful consultation (Standard 3.1);
- ‘tokenistic’ approach to consumer and carer participation (Standard 3.1);
- views of consumers and carers are not being heard (Standard 3.1);
- views of youth with mental illness and mental health problems are not being heard (Standards 3.1, 3.2 and 3.6);
- consumers with borderline personality disorder, in particular, are not being heard (Standard 3.6);
- lack of funding and resources to support consumer and carer participation (Standards 3.2, 3.3 and 3.4);
- concerns about lack of progress and ‘consultation fatigue’ (Standard 3.1); and
- need to address barriers to effective participation by consumers and carers (Standard 3.7).

The following selected quotes from community forums and submissions describe people’s recent experiences of mental health services and areas of concern under Standard 3. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Concerns about lack of progress and 'consultation fatigue'

The other thing the NSW government is good at is holding inquiry after inquiry, establishing one task force or select committee after each other – and all it is, is a big talk fest and we go around the same circle for the next 2-3 years or in Australia's case for the next 10 years.

(Consumer and Consumer Advocate, New South Wales, Submission #8)

My son and I have been involved with the Mental Health Association and been on lots of committees and attended many forums and consultations and where are we?

(Carer, Mother, Northern Territory, Alice Springs Forum #13)

Too many times over the years have many other people and I given information, been part of a consultation group, spoken up when asked to do so. Too many times have we been promised that something would be done? Too many times we have been let down. I am certain that somewhere in archives there is a plethora of information that has been collected and not activated on. I like many of my colleagues in the Mental Health System am sick and tired of being told that we have a voice only to find out that we have been fooled once again.

(Consumer, Victoria, Submission #112)

Lack of meaningful consultation

There is a rhetoric of inclusion of the consumer voice in mental health debates but the consumer-survivor experience of this, virtually unanimously, is that this rhetoric is lip-service not matched by any real commitment and certainly not by any meaningful resources to promote the inclusion of the consumer perspective…

(Insane Australia, Victoria, Submission #232)

Other Consumers Consultants, an apparently smaller group – who measured their situations in various different ways – said that the local Area Mental health Services where they worked remained apparently "resistant and entrenched" toward consumer perspectives, maintaining attitude barriers and "us and them" thinking, and sometimes taking a "pathologising" view of issues. A more subtle but still difficult situation was where consumers perceived that services seemed to be "saying all the right things" but were short on meaningful action – sometimes opting for quick fixes, tick-the-box checklists and "tokenistic" displays of consumer participation through Public Relations exercises, and ever more pamphlets.

(Consumer Advocate, Victoria, Submission #253)

Views of consumers and carers are not being heard

We're at no risk of being threatened for speaking out because we're not being heard at all!

(Advocate, South Australia, Adelaide Forum #15)

Unless people are heard then the government of the day whether it be State or Federal will do nothing.

(Carer, Wife, Australian Capital Territory, Submission #149)

Abandonment of participation by consumers and carers in planning, implementation and evaluation processes by the MHS

Only recently in July, Carers at a Carer Advocacy & Issues Forum in Bunbury met and expressed their frustration regarding the sudden closure of mental health services in their community. Specific concerns regarding the closure of services include: …The complete lack of consultation with carers, consumers and health professionals regarding the closure.

(Carers WA, Western Australia, Submission #277)

The Health Consumers' Council operated a Mental Health Consumer Advocacy Program for six years until this was de-funded in late 2003. This program supported consumer participation in service decision-making, trained consumers as public speakers on service standards and provided a Participation Payment scheme to assist consumer participation. The most promising feature of this program was the employment of mental health consumers as advocates for service reform. Consumers worked on a part-time basis in a team supporting a wide network of peers involved in service reform work. The cost to the state of this program was in the order of $130K per year – 4 workers, 200 consumer reps, 100 committees. The loss of this program was catastrophic for the emerging mental health consumer movement. Almost all progress against the National Mental Health Plan in respect to consumer participation in mental health services has stopped in Western Australia.

(Health Consumers' Council, Western Australia, Submission #29)

Lack of funding and resources to support consumer and carer participation

Let's talk about consumers being employed within the mental health system. Yes, I'm a consumer employee and I get paid for 30 hours and work close on 48 hours each week… What my gripe is that we have such minimal hours, that we simply cannot do half the stuff we're capable of and try to put into effect. More often than not we're not acknowledged as having any expertise, definitely expected (in my situation) to perform as a manger yet not paid accordingly. In other areas we're the most under utilised resource within a mental health service – and forget the voluntary crap – we deserve to be paid for a good day's work like any other person in the community.

(Consumer and Consumer Advocate, New South Wales, Submission #8)

To remove barriers to participation more resources need to be dedicated for consultation, organisational commitment and leadership and consumer participation.

(Anonymous, Tasmania, Submission #290)

Views of youth with mental illness and mental health problems are not being heard

While consumer participation has fixed some of the worst bits of the adult mental health system, it is virtually non-existent in youth and adolescent services.

(Youth Participation Worker, Victoria, Submission #255)

For a number of years, YACSA has recommended that the State Government establish and resource a youth health advisory mechanism to provide advice to the Department of Human Services on policy and strategic issues aimed at maximising health outcomes. With issues of mental health, sexual health, drug and alcohol abuse and access to services (particularly for young people in rural, regional and outer metropolitan South Australia), there is an urgent need to act on the implementation of an appropriate advisory structure to the Minister for Health. Given the Generational Health Review emphasis on regionalisation and community participation, YACSA recommends that the Department of Human Services establish a number of regional Youth Health Advisory Committees in key, strategic locations as determined through the process of decentralising the existing health system. YACSA envisages that the Committees would comprise relevant departmental officers and non-government stakeholders in the youth, community and mental health sectors, as well as representation from young people / consumers. YACSA further recommends that the structure of the Committees be based on the previously successful Youth Views young consumer participation model, with executive support to be provided by existing staff.

(Youth Affairs Council of South Australia, South Australia, Submission #38)

5.4 STANDARD 4: PROMOTING COMMUNITY ACCEPTANCE

The MHS promotes community acceptance and the reduction of stigma for people affected by mental disorders and / or mental health problems.

The submissions and consultations reveal ongoing concerns about the high level of stigma associated with mental illness in the community, the workplace and in treatment settings. These concerns indicate that stigma reduction activities and campaigns to-date have had little real impact.

Consumers and families report feeling completely isolated, lonely and ashamed. They feel like they have no support from anyone. Of particular note is the documentation relating to children of parents with mental illness.

There were submissions describing discrimination in the workplace and exclusion of people in social and community settings. Some of those experiences included people losing their job after they disclosed their illness and people physically distancing themselves from them in public social places (e.g. in pubs and cafes). Some described negative behaviour and remarks from mental health workers, police and accident and emergency staff.

It was highlighted that a lack of access to treatment and support services often results in deteriorating mental health, and this serves to exacerbate stigma-related issues for the community. Thus there is a vicious cycle that perpetuates myths, stereotypes and unnecessary fear. Many pointed out the role of the media in maintaining these myths and stereotypes, and urged for rapid changes in this area.

Nationally, the key issues relating to this Standard include:

- high levels of stigma still prevalent within the community (Standard 4.1);
- high levels of stigma still being experienced by people with mental illness and their children (Standard 4.1);
- social isolation experienced by consumers and their family (Standard 4.1);
- rejection by the community (Standard 4.1);
- offensive remarks by police and accident and emergency staff (Standard 4.2);
- discrimination in the workplace and the need to educate employers (Standard 4.2);
- lack of community acceptance and support (Standard 4.1);
- need for community education (Standard 4.2);
- non-acceptance by mental health workers (Standard 4.2);
- non-acceptance by family members (Standard 4.2);
- discrimination by real estate agents (Standard 4.2);
- problems with terminology and stigma for people with personality disorders (Standard 4.3);
- the impact of lack of access to services on stigma and stereotypes (Standard 4.3);
- stigma associated with ‘therapy’ as opposed to treatment by medication (Standard 4.1);
- stigma and stereotypes being perpetuated by the media (Standard 4.2); and
- diminishing use of the radio as a medium to promote community acceptance (Standard 4.1).

The following selected quotes from community forums and submissions describe people’s recent experiences of mental health services and areas of concern under Standard 4. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

High levels of stigma still prevalent within the community

I have 2 sons who have schizophrenia. [X] (eldest son) had a bad breakdown so we decided we would move to a small community to give him a better chance at life but the stigma here was very bad – when our sons went to the pub for a drink the locals would move away from them.

(Carer, South Australia, Murray Bridge Forum #10)

Stigma is also high in small communities like Broken Hill as people fear what they can't see. In discussions with legal advisors they have encouraged people not to disclose their illness. In addition, community attitudes are often dismissive of people with a mental illness.

(Consumer, Carer & Family Worker, New South Wales, Broken Hill Forum #23)

Admission to mental health facilities or contact with mental health professionals results in fear of consequences for community and professional standing and this fear has a realistic base.

(Support and Equity Services, Charles Darwin University, Northern Territory, Submission #269)

No one understands what is like to have a mental health problem in your family unless they are in the situation themselves. We live a silent pain. Ashamed. Embarrassed. In fear of our lives. Family destroyed. No one wants to help.

(Carer, Mother, New South Wales, Submission #90)

In every discussion held to date, stigma and discrimination have been raised as issues of concern. Unfortunately, the experience of stigma and discrimination is endemic, ranging from the common media portrayal of people with a psychiatric illness being violent and aggressive to discrimination in employment and even to how people are treated in mainstream medical services.

(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

Social isolation experienced by people with mental illness and their families

…three members of my family who have been diagnosed with Schizophrenia. This has had a devastating effect on not only the immediate family but also on extended family relationships, namely the isolation we have suffered since the diagnoses were made.

(Carer, Anonymous, Submission #224)

[X] finally lost all hope and on the 29th of May 1999 he laid himself on a train track… Because of the myths and stigma associated with mental illness his condition became worse. He had nobody to turn to about his problem, as mental illness is something that is not discussed in our society. I also did not have anyone to turn to. It was like something very shameful had hit our family.

(Carer, Mother, Queensland, Submission #81)

My son had schizophrenia and he's now dead as well - he committed suicide. The community didn't understand and when people found out he had a mental illness they dropped him like a hot potato.

(Carer, Mother, Queensland, Rockhampton Forum #9)

I think for those who are severely ill and are isolated in the community due to their illness they often have no form of support even from family or friends. For people like that they are in the community living like ghosts – they are dying alone.

(Consumer, Victoria, Footscray Forum #11)

My son had so many friends, his photo in the local paper every week, and captain of every team he was in, and as soon as the diagnosis came, he'd say "Any mail, mum?", "Any phone calls?", but there weren't any.

(Carer, Mother, Victoria, Submission #211).

Mental illness is a 'hidden' disability for families who are labelled and marginalised along with their unwell relative. Their predominant theme is loss - of the 'well' relative, a lifestyle, a rightful place in their community and their identity as spouse, parent, child or sibling.

(Carer, Wife & Mother, Queensland, Submission #157)

Lack of community acceptance and support

In Western Australia mental health problems are shrouded in ignorance. Few people ever think about the mental health needs of our communities and even less people think about the needs of mothers with mental illness and their children. The cost to our community is only counted in fiscal terms for the Health Department…

(Health Consumers' Council WA, Western Australia, Submission #29)

The impact of lack of access to services on stereotypes

When my son and others like him are unwell, their behaviour is their stigmata... this policy requires them to be different enough to draw attention to themselves in a totally negative way... thus under this policy the stigma of mental illness is propagated rather than alleviated. And let us not forget that this behaviour, not chosen behaviour, but behaviour dictated by the illness, is that which can cause them to lose accommodation, employment, friends and perhaps even family, thereby having their lives fall apart time and time again.

(Carer, Mother, Victoria, Submission #178)

Because my kids don't get any support, in fact they get teased about having a father who is mentally ill, they then come home and take it out on me; tell me I'm nuts or I'm a loony.

(Consumer, South Australia, Murray Bridge Forum #1)

Discrimination in the workplace

One client did eventually disclose her medical history three months after she got a job and then promptly lost that job.

(NGO Worker, New South Wales, Broken Hill Forum #21)

I am a nurse but I have been told that I will never get a job in this area because of my previous mental health condition.

(Consumer, Nurse, Western Australia, Bunbury Forum #2)

I also have a lot of contact with people who have had bad workplace and insurance issues. Also people who have been working and then need time off work and try to get income support have great difficulty. I also have many clients who have had depression and have lost their jobs because of their illness.

(Clinician, Queensland, Brisbane Forum #20)

There is discrimination in employment. You become ill, get the treatment on sick leave, get well again and are asked to leave.

(Carer, Mother, Northern Territory, Darwin Forum #5)

I took 3 months off from work on personal leave to recover from suicidal thoughts. When I came back, I had to deal with new management and new thinking. Previously, I had a supportive supervisor. I asked for a transfer to another section. The new management sought a psychiatric assessment of my illness. Their solution to the problem was to pension me off rather than look to work with me around the illness.

(Consumer, Australian Capital Territory, Canberra Forum #19)

A female client hospitalised with major depressive episode and a high suicide risk took sick leave from her job, only to be eventually fired due to her illness. This occurred despite the fact that she was planning on returning to work and was progressing well. She later returned to work with another company (she didn't disclose her history).

(Clinician, Queensland, Submission #105)

I advise clients not to disclose to their employer if they currently have or have had depression or any other mental health condition, as ignorance and stigma remain high in the general community and they are likely to be penalised for their honesty.

(Clinician, Queensland, Submission #105)

Stigma and stereotypes being perpetuated by the media

I'm from the bush and I have bipolar disorder. I agree with the previous speaker that there are many shocking articles in the media that shape the community's attitudes. Stigma is the biggest thing to fight.

(Anonymous, Queensland, Brisbane Forum #12)

While there has been some improvement in media coverage of mental illness, this is not sufficient to counter systemic stigma. Some newspapers and TV dramas also continue to portray mental illness in an inaccurate, sensationalised and disrespectful way. This can suit political leaders, as it displaces blame for the consequences of poor service delivery onto the mentally ill themselves.

(SANE Australia, National, Submission #302)

Discrimination by real estate agents

Housing is difficult – if you present to a real estate agency and declare that you are on a disability support pension you aren't assisted – you'll be rejected!

(Consumer, Queensland, Brisbane Forum #11)

…an eviction notice as he had not been paying his rent… I then contacted the rental agent from the Real Estate Agency and arranged to meet with her at my son's unit for an inspection and to arrange removal of his belongings. She arrived, followed by two police officers. There was no damage to the unit. I apologised for what had happened and was strongly rebuked by the agent for not having informed her that my son suffered from schizophrenia and added that she would have to inform all other rental agencies that he was an evictee along with my name as his next of kin. (Obviously this would make acquiring further accommodation for him very difficult).

(Carer, Mother, Victoria, Submission #178)

Problems with terminology and stigma for people with personality disorders

…the term, personality disorder, makes people sick… personality disorder implies that a person's problems are all that person's fault and responsibility… some clinicians use the term personality disorder indiscriminately as short hand for everything that presents as difficult to diagnose or socially construed.

(Consumers, Victoria, Submission #194)

Stigma associated with 'therapy' as opposed to treatment by medication

Intensive psychotherapy is extremely hard on everybody. The public image that it is somehow what privileged, overindulged, middle class women do to fill in the time needs challenging. I am very concerned that the efforts that have been made by SANE and other organisations to de-stigmatise mental illness have not even tried to do anything about de-stigmatising therapy in Australia

(Consumer, Victoria, Submission #203)

Non-acceptance by mental health workers

SANE Stigma Survey 2004:… Analysis of over 300 responses suggests that being treated unfairly and disrespectfully – by health professionals as well as the general community – is a regular occurrence for many Australians whose lives are affected by mental illness.

(SANE Australia, National, Submission #302)

5.5 STANDARD 5: PRIVACY AND CONFIDENTIALITY

The MHS ensures the privacy and confidentiality of consumers and carers.

Concerns were strongly expressed across all States and Territories regarding the misuse and incorrect application of policies and procedures designed to protect the privacy and confidentiality of consumers. The complexity of, and misunderstandings about, privacy laws and policies has hindered communication between consumers, carers and clinicians and has led to obstructions in the provision of treatment and support to consumers.

There many examples where mental health professionals have refused to communicate with carers and family even when consumers have expressed a desire, and provided specific authorisation, for others to be involved in their care.

Some carers report a ‘double whammy’ wherein the mental health care system expects them to assume and accept the responsibility of care but fails to involve them in the development of treatment plans or provide them with the information necessary to fulfil this role. Similarly, carers reported that clinicians were often not prepared to even ‘listen’ to their notifications regarding signs of relapse or fears for the personal safety of consumers or themselves under the pretext of ‘privacy and confidentiality’.

There was also concern that often clinicians mistakenly assume that consumers lack the capacity to give informed consent and for this reason do not discuss these issues with consumers.

The need for culturally sensitive approaches to dealing with information, for Indigenous cultures in particular, was raised as an area of concern.

The privacy and confidentiality of information relating to consumers who are subject to the criminal justice system was also raised as a critical area of concern.

‘Privacy’, ‘private space’, control over that space and adequacy of physical care environments are also covered under this Standard. The diminishing importance of consumers having adequate privacy in residential and inpatient settings (both indoor and outdoor spaces) and control over their personal effects was noted. The generally poor condition of mental health inpatient and residential settings was described as being of a standard that would not be acceptable for those receiving care for physical health problems.

Nationally, the key issues relating to this Standard include:

- concerns about policies and procedures to protect confidentiality (Standards 5.1 and 5.2);
- concerns about privacy and confidentiality policies hindering communication with carers (Standards 5.1 and 5.2);

- staff applying privacy and confidentiality rule without authority, ignoring or not requesting permission from consumers to share information or involve carers (Standards 5.1, 5.2 and 5.4);
- the MHS denying consumers their right to have others involved in their care (Standard 5.3);
- reluctance by services to involve carers, even when permission is given by consumers (Standard 5.3);
- problems with access to databases and confidentiality (Standards 5.1 and 5.4);
- indigenous issues (Standards 5.3 and 5.4);
- prisoners and problems with information sharing between agencies (Standards 5.1 and 5.4);
- information sharing with the police (Standard 5.4);
- privacy laws and assisting youth to access care (Standards 5.1 and 5.3);
- rights of carers (carers not informed of discharge) (Standards 5.1, 5.2, 5.3 and 5.4);
- consequences that may follow for consumers and their relationship with carers or significant others if policies and procedures to protect the confidentiality and privacy of consumers are misunderstood (Standard 5.3);
- lack of privacy and outdoor physical space (Standards 5.5 and 5.7);
- concerns about lack of privacy and control over personal space (Standards 5.7 and 5.8);
- inadequate indoor physical care environment (Standards 5.7 and 5.9); and
- loss of personal effects (Standard 5.8).

The following limited selection of quotes from community consultations and submissions describe people's recent experiences of mental health services and areas of concern under Standard 5. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Concerns about policies and procedures to protect confidentiality

> *Family, friends and carers could provide information valuable for such a plan and they need to be involved on discharge of patients to be treated within the community. Information from family, friends and carers is important for treatment planning and risk assessment and for the continuation of treatment upon discharge. The problem of patient resistance to the involvement of family, friends and carers and privacy issues needs to be contended with. Best practice does involve this question. It did not happen here at an appropriate level… (Excerpt from Report of findings by the Chief Coroner)*
>
> (Carer, Partner, Australian Capital Territory, Submission #305)

> *…the laws are often given as an easy way to avoid talking about issues with people involved with the patient regardless of the appropriateness or otherwise of the request, and c) privacy laws are often attacked because they are inaccurately blamed for lack of social support, and general medical information about psychiatric disability comprehensible to the general public that people close to a patient might need… Generally, no matter what laws are enacted regarding them, the problems of information / privacy issues will always come down to the attitudes of all parties in the practical application of any such laws. These are complex relationship and social issues that have to be dealt with at the grass roots level and through three way learning between professionals, patients and people connected to patients.*
>
> (Indigenous Social Justice Association (ISJA) and Justice Action (JA),
> New South Wales, Submission #349)

> *'What is wrong with the CATT [Crisis Assessment Treatment Team] and the emergency processes? It's getting worse. They tell us they are short staffed. They tell us they can't talk to us that it's a matter of privacy and confidentiality, but surely when our lives and our safety are at risk, they must listen to us'.*
>
> (Mental Health Community Coalition Consumer and Carer Caucus,
> Australian Capital Territory, Submission #342)

Staff applying privacy and confidentiality rule without authority, ignoring or not requesting permission from consumer to share information or involve carers

Family members reported that some clinicians are receptive to speaking with and listening to them but that others are not and will cite 'confidentiality' as a reason for not engaging with family members.

(Mental Health Community Coalition Consumer and Carer Caucus,
Australian Capital Territory, Submission #342)

Doctrines of confidentiality and privacy of adult patient information are often interpreted by some professionals and adhered to so strongly within that Carers are intentionally not provided with information about medication, treatment and progress. Also, they are frequently denied linkages with those treating the consumer, even though Carers are expected to support and manage the care of the consumer in the community. The reality is that care provided in the community by family members frequently occurs without recognition from the mental health system, the professionals, or the general health care and primary health care sectors.

(Carers Association of SA, South Australia, Submission #30)

Respondent F. spoke of her husband's in-patient psychiatrist as "abrupt, arrogant…I was supposed to defer to his 'expert' knowledge". Due to privacy legislation, most respondents felt they had not been given a full description of their relative's diagnosis. Respondent C. stated, "even my family doctor would not discuss my son's condition with me… how could I continue to care for him if I did not know what to expect?" Confidentiality considerations can be an excuse for lack of family members' inclusion in care planning.

(Carer, Wife & Mother, Queensland, Submission #157)

Concerns about privacy and confidentiality policies hindering communication with carers

The mental health system failed [X] in so many ways. In summary the key failings were: … the role of family members as carers was ignored: they would not listen to our input and apparently valued privacy requirements above everything else, including [X]'s welfare and even his life.

(Carer, Sister, Australian Capital Territory, Canberra Forum #9)

A common problem for carers is the impact of privacy laws and recognition of their role. Each State and Territory has different legislation governing rights of carers and the release of information to carers so that a three-tier system must be overcome prior to information being shared with the mental health service or recognition of their role being granted. This tiered system is comprised of the relevant State or Territory mental health legislation, State or Territory privacy or health legislation and the Federal privacy laws.

(Carers Australia, National, Submission #276)

We as a family were not allowed to be involved with my son's treatment ***because of the confidentiality law.*** *The law states, that my 19-year-old son - suffering mental illness and living at home - was deemed an adult so we were excluded from his treatment. This was thrown at me –* ***his mother*** *– in every direction and I tried extremely hard trying to contact my son's Doctor's, Psychiatrist and various organisations, but to no avail. (author's emphasis)*

(Carer, Mother, Queensland, Submission #81)

Carers continue to report that they feel there is minimal recognition of them by mental health services and minimal efforts to consider their views and/or involve them. Whilst Carers respect the need for confidentiality the lack of possible involvement of carers is a significant barrier to carers in providing care and support for their family members/friends with mental illness.

(Carers WA, Western Australia, Submission #277)

MHS reluctant to have others involved in the care of patients

I have power of attorney over my wife but when I ask for information about my wife they tell me they can't give it to me – until I slap the POA(Power of Attorney) in their hands.

(Carer, Husband, Victoria, Melbourne Forum #3)

Consequences of exclusion of carers and families

I was married to a paranoid schizophrenic and did not know… No Dr. would tell me – ethics, the result was, this "man" totally destroyed my life, and there was not a thing I could do about that legally… I am still trying to "pick myself up off the floor", but sadly never will.

(Carer, Wife, South Australia, Submission #148)

Capacity to provide consent

It should never be assumed that the person is incapable of considering a matter, forming an opinion and giving direction regarding the matter. This includes who is privy to information and who may be involved in admission, treatment, and discharge, in terms of Health and non-Health persons and the interaction of the two. There is generally a presumption that any patient with psychiatric disability lacks capacity. This is untrue.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA),
New South Wales, Submission #349)

Rights of carers

…two issues which can cause enormous problems for carers and which I believe can create the greatest divisions in understanding between mental health professionals and carers. The first is 'confidentiality'… from personal experience and anecdotally, this has proved on many occasions to have the potential to put either the carer or the person with the illness at risk - even if that risk is simply to their personal health and well being, apart from the distinct possibility of far more serious consequences. It is small wonder that carers can often feel used and abused by the mental health system - it appears that there has been little thought given to the rights of carers, or rather their lack of rights; we are expected to accept responsibility for the continuity of care without even the right to be informed of hospital discharges without the patient's consent, and with currently minimal time spent in hospital, the matter of the person with the illness being able to make such important decisions in regard to their own welfare has proven to be highly questionable.

(Carer, Mother, Victoria, Submission #178)

Family carers indicate they have all responsibility but no rights. They are key players in caring for sick family members. The confidentiality / privacy act is an aberration. Carers observe a loved one's illness daily and can warn when episodes/relapses are imminent. Professionals deny themselves access to the wisdom of carers and hinder early diagnosis and accurate diagnosis.

(ARAFMI Tasmania, Tasmania, Submission #245)

The CONFIDENTIALTY LAW needs to be amended. There is no other illness in society that the medical profession do not involve the families or carers. However once a person has been diagnosed with mental illness the confidentiality law is used and abused to the detriment of the family and carers. An example of this abuse is if a person has been diagnosed with cancer, heart attacks, diabetes etc the whole family is involved however if a person who has been diagnosed with some form of mental illness the confidentiality/privacy act comes into play. SO WITH OR WITHOUT THE CONSENT of the person who has been diagnosed with mental illness we the families and carers who are the community care givers and providers MUST be involved, consulted and our opinions respected in determining the health and happiness of our loved ones. Exactly in the same way other illnesses are treated. (author's emphasis)

(White Wreath Association Inc, Queensland, Submission #81)

Indigenous issues

It is a necessity to recognise formally the Indigenous concepts of family, kinship and community, and to allow communities and individuals within the Indigenous communities to work out appropriate ways of dealing with information that affects the relationships within the Indigenous communities. Indigenous Cultures must be respected and Indigenous people must not be forced or pressured to reveal Cultural information. There are arrangements already existing that are supposed to be respected, such as the AHRC / NSW Health Partnership, to look into these issues and ensure that matters affecting Indigenous people(s) are dealt with at all law, policy and service levels in the appropriate and culturally respectful manner. It cannot be allowed to be done in ignorance of the rights and concerns of Indigenous peoples and without self determination. As these issues are already known to government and departments, a choice to ignore the issue and deny rights amounts to a deliberate decision which we contend must be examined with regard to the International Convention on Genocide. We also argue that these issues be examined in the light of the 2003 WHO guidelines on Mental Health Law and Human Rights regarding the protection of Indigenous ethnic groups and minorities.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA),
New South Wales, Submission #349)

Prisoners and problems with information sharing between agencies

We wish to express here our absolute objection that prisoners, as an entire class of people, have by law no right to privacy due to recently passed laws. This discrimination is offensive in and of itself. It is also highly damaging to prisoners' wellbeing and relationships with medical staff and others. Prisoners' patient records have been given to the media, for example the X-rays of the hand of Ivan Milat. (We note that forensic patients' mental state and therapeutic relationship has also been released and discussed in the media, and that this is a nation-wide problem. Forensicare of Victoria is often considered exemplary in debates around forensic standards, but they are in no way immune from problems and have also revealed such personal information in an inappropriate and political manner.)

(Indigenous Social Justice Association (ISJA) and Justice Action (JA),
New South Wales, Submission #349)

Problems with access to databases and confidentiality

We also completely object to NGO / Police access to databases and information sharing regarding the mental state and medical records of patients as suggested in submissions and hearings at the NSW Parliamentary Inquiry into Mental Health Services. This is an abuse of patient's private information and must not occur. NGO's and Police can contact Mental Health Teams if really necessary.

(Indigenous Social Justice Association (ISJA) and Justice Action (JA),
New South Wales, Submission #349)

Inadequate indoor physical care environment

Many people fear that ultimately Graylands Hospital will be closed down, as was Heathcote Hospital. It should always be born in mind that to replace beds in a facility like Graylands Hospital with its peaceful surrounds with extra beds in a general hospital like Royal Perth or SCGH [Sir Charles Gairdner Hospital] with their locked wards and lack of personal space is absolutely a huge step backward!

(Carers, Parents, Western Australia, Submission #76)

There have been complaints made to St Vincent's but nothing has been done about it. I think it's there to stay. The nurses lobbied for it and said they had it built to protect their patients and themselves from people coming in off the street. I'm not opposed to secure units at all. That's not what I mean. What I mean is that we need to give more thought about how we build secure units. They shouldn't look like cheap prisons. People, even high security people have a right to privacy and respect.

(Consumer Advocate, New South Wales, Parramatta Forum #3)

> *The James Fletcher Hospital is also frequently "dirty"… cleanliness could be upgraded to hospital standard. For example, the carpets are very dirty, which leaves patients with black feet. There was an example of food smeared on a window which was left for more than 3 weeks. A dead cockroach was left lying in a corridor for several days. There are frequently coffee stains left on the garden furniture. Overall, it is a very dirty environment, not what you would expect from a hospital. There is also no air-conditioning or fans and so no fresh air. The fans were removed after a patient attempted to hang themself. A plan for installation of air conditioning was developed 12 months ago, but no action has occurred yet. Furthermore, there is only one meal option available to patients, regardless of the individual's tastes or beliefs. There is often no privacy for patients using the telephone because if there is a staff meeting being held in the room housing the phone it is placed in the hallway… patients are treated as 2nd class citizens. They do not receive the same level of care you would receive in other health facilities.*
>
> (Anonymous, New South Wales, Submission #156)

5.6 STANDARD 6: PREVENTION AND MENTAL HEALTH PROMOTION

The MHS works with the defined community in prevention, early detection, early intervention and mental health promotion.

A recurrent theme at the community forums and in submissions received from consumers, carers, clinicians, academics, advocates and service providers was the concern about lack of resources and plans to support early intervention and prevention. Participants noted the serious negative consequences this has for consumers, carers and the community.

Submissions and representations described a failure to provide early intervention and implement prevention programs. Consumers, carers and providers also said access to care was practically impossible when people were becoming seriously unwell. Consumers are regularly told they can not access services until their health has deteriorated further. For example, one consumer was told he was 'not psychotic enough'.

For some consumers an inability to access timely services led to deteriorating mental health which, in turn, led to behaviour resulting in entry into the criminal justice system. Others entered a 'revolving door' pattern of admission for acute care due to a lack of rehabilitation programs and ongoing support.

Carers reported that clinicians need to engage with consumers and, with consent, their family members to develop plans to identify early warning signs of relapse. Family members then need to be heard and the information acted upon.

The lack of services for youth, and the implication this has for attempts to avert long-term negative life consequences, was highlighted as a particularly significant deficiency. Similar concerns were expressed about the lack of early intervention and prevention programs to deal concurrently with mental illness and substance abuse problems.

Reports were also received regarding the lack of effective mental health promotion strategies, particularly for children at school, for people who are hearing impaired and for those who come from a Non-English Speaking Background. A better promotion strategy would help consumers, carers and the community at large to identify early warning signs and assist in seeking the appropriate care. On the other hand, service providers noted that it is unfair to promote early intervention and prevention to the community when services do not have sufficient resources to respond to crises.

Nationally, the key issues relating to this Standard include:

- due to lack of access to services, no prevention or early intervention is happening (Standard 6.1);
- no attempts at and lack of focus on early intervention or prevention - reactive, crisis driven approach to service delivery (Standard 6.1 and Standards 6.4 – 6.8);
- lack of services for youth – no early intervention or mental health promotion possible (Standards 6.2 and 6.5);
- early intervention – families need to be heard (Standard 6.1 and 6.7);
- early intervention – involvement and role of GPs (Standard 6.5);
- early intervention - importance of open discussion and acceptance (Standards 6.2 and 6.3);
- more promotional strategies needed (Standards 6.2 and 6.3);
- lack of rehabilitation programs (Standard 6.8);
- social needs are not being met through the use of mainstream agencies (Standard 6.9);
- prevention – substance abuse and mental illness need to be tackled jointly (Standards 6.4, 6.5 and 6.6);
- preventing depression in older men (Standard 6.4);
- need for education campaigns in schools (Standard 6.2);
- lack of support for children of parents with mental illness (Standard 6.4);
- unfair to promote early intervention when services are failing to cope with current demand (Standards 6.1 and 6.10);
- need for more programs to promote mental health and prevent mental disorders in the deaf community (Standards 6.2 and 6.3); and
- need for more programs to promote mental health and early intervention to people from a non-English speaking background (Standard 6.3).

The following selected quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 6. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Due to lack of access to services, no prevention or early intervention is happening

Consumer relapse knowledge ignored. Consumers who feel themselves to be becoming unwell have little or no access to assistance from their treating team. It is not uncommon to contact a clinic on behalf of a consumer who feels the need for immediate intervention and be told that the referral will be placed on a list to be discussed at an 'intake' meeting at a later date… It is the experience of mental health consumers with early signs of relapse or episodes of need that the inability of services to respond to their needs pushes them towards crisis, disruption of their life and greater need to call on those same mental health services.

(Health Consumers' Council WA, Western Australia, Submission #29)

No attempts at and lack of focus on early intervention or prevention - reactive, crisis driven approach to service delivery

Despite the seriousness of the disorders, there is no philosophical or legal framework supporting a more assertive or early intervention approach, nor the funding capacity to support such a model. Indeed such an endeavour is still impeded by a residual moral dimension to understanding these disorders. The clinical focus is typically on advanced phases of disorder (even in young people) where treatment can no longer be withheld, yet when it may be much less effective.

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

Crisis Assessment and Treatment Services are variable in their response. Family carers seeking early intervention can find it difficult to get an assessment from the CAT service until their relative has deteriorated to a point where inpatient admission may be the only solution.

(ARAFEMI Victoria, Victoria, Submission #230)

In Canberra, I tried to get access to mental health care when I was becoming unwell. The doctor estimated that I wasn't psychotic enough. The doctor told me they couldn't help as they didn't have the resources, but if I was becoming more unwell and reached a point where I couldn't leave my apartment then I should "give him a call". If people are that unwell these things are beyond them!

(Consumer, Australian Capital Territory, Canberra Forum #21)

On 4 December 2001, my wife discussed our daughter's condition with her treating psychiatrist, the MHU [Mental Health Unit] Psychiatric Registrar and MHU nursing staff, who agreed that the MHU did not cater for our daughter's then current mental state – she was not psychotic. At the request of my wife, and our daughter's clinical psychologist, our daughter was placed in the MHU lock-up ward for her physical protection. It was not until four weeks later, when our daughter's condition had significantly deteriorated, that she was "specialled". We later discovered by accident that "specialling" is normal procedure for vulnerable patients. It seems reasonable that early "specialling" for our daughter would have significantly reduced the severity, duration and cost of her confinement and prevented her ongoing loss of hair and teeth problems from unnecessary malnutrition.

(Carers, Parents, New South Wales, Submission #106)

I would like to comment on the fact that people with a mental illness are being arrested because often it's the only way they can get any help. They have a right to get care, not be arrested. We've got to get access to early intervention programs but it doesn't happen – now my brother is in the court system, not because he's bad but because he's got a mental illness.

(Carer, Sister, Western Australia, Bunbury Forum #24)

Lack of services for youth – no early intervention or mental health promotion possible

Youth mental heath services… At the moment there's no access to services at all – previously there was a 6-months waiting list – so the notion of early intervention or prevention doesn't exist for this community.

(Western Australia, Bunbury Forum #8)

Early intervention – families need to be heard

What is acceptable about a clinician making an assessment in a 15 minute appointment whilst ignoring the information of these same carers who are in the position of being far more sensitive to the signs of deterioration in the person for whom they care?

(Carer, Mother, Victoria, Submission #178)

Early intervention – involvement and role of GPs

At the Forum in the Melbourne Town Hall on Monday, I picked up a card saying "Mental Health-GP Business", and I'd just like to be sure that GPs now can pick up mental illness symptoms in young people. When my son was suddenly diagnosed at 21 with chronic paranoid schizophrenia, which was such a shock, we heard from him later that at 15 he'd been seeing our GP, because he knew there was something wrong. (he always had great insight), the Doctor felt he looked so well and fit, he sent him off.

(Carer, Mother, Victoria, Submission #211)

Prevention – substance abuse and mental illness need to be tackled jointly

Significant substance abuse problems exist in Aboriginal remote communities, resulting in significant mental health problems. .

(Anonymous, Northern Territory Submission #188)

Most participants reported taking drugs at early ages (12-14 years) and experiencing psychotic episodes some years later. Commonly, they did not seek help or recognise that they needed help. They reported having a vague understanding of what schizophrenia is but they failed to associate their own experiences with such a mental illness. In most cases, the first episode of their mental illness was diagnosed when they were brought into hospital by police and assessed and hospitalised in the psychiatric ward.

(NSW Association for Adolescent Health, New South Wales, Submission #98)

Preventing depression in older men

Men need more support – because they don't ask for help. There's nothing in this town for men – no support. My partner phoned his parole officer to ask for help because there was nothing else for him.

(Consumer, New South Wales, Broken Hill Forum #24)

More promotional strategies needed

There is a general lack of awareness and information about mental illness, so that those affected and their friends and family members may not realise that they are becoming unwell.

(Health and Community Services Network, Murray Mallee Strategic Task Force,
South Australia Submission #115)

Need for education campaigns in schools

[Y] added there needs to be more education about mental and physical illness and disabilities in schools. They have sex education and drug awareness and healthy eating education at his school but he hasn't been to a school that talks about mental illness.

(14 year old Consumer and Carer (Son), Young Carers Forum Canberra #2)

Lack of rehabilitation programs

The lack of ongoing rehabilitation programs also means that we see a lot of young people, especially, being discharged after treatment but then without the necessary support, quickly becoming unwell again and the cycle constantly being repeated.

(Carer, Mother, Tasmania Submission #315)

This means that as there is no follow up people return to their previous bad state and so these clients have to repeat the whole the process.

(NGO Worker, New South Wales, Broken Hill Forum #5)

He had support through Eureka. He looked forward to it – he did it for 2 years then they told him he had to stop because there wasn't enough funding and someone else had to have a go. He got very depressed, very ill and became very violent. He broke someone's arm and was arrested and taken to the hospital.

(Carer, Tasmania, Hobart Forum #22)

There's a real lack of services to help people get back into society to rehabilitate.

(Clinician, Queensland, Brisbane Forum #7)

> *We have a son... with a mild intellectual disability… 22 years of age and remained in that job for ten years feeling a 'normal' part of the community… Due to all this floundering over the past two years our son now 34 has regressed to a point where he is now in a community care unit seeming as though he has lost all hope of getting anywhere, his hygiene medication and budgeting skills at an all time low. My husband and I both 70 are no experts in mental health but feel had there been positive intervention in the beginning instead of lying about home he would be less reliant on the medical system now, plus the government spending good money into these job agencies which are totally dysfunctional.*
>
> (Carers, Queensland, Submission #150)

> *The Health System's main approach to people with Mental Illness is to get them medicated and then very little else. There are no serious rehabilitation facilities.*
>
> (Carer, Father, Victoria, Submission #231)

5.7 STANDARD 7: CULTURAL AWARENESS

The MHS delivers non-discriminatory treatment and support which are sensitive to the social and cultural values of the consumer and the consumer's family and community.

Concern was expressed regarding the lack of culturally sensitive treatment and support for Indigenous people and people from a Non-English Speaking Background (NESB). For Indigenous people, access to care was reported to be complicated by discriminatory attitudes by some clinicians who often refuse treatment on the basis of prevailing stereotypes (for example belief in intoxication or drug misuse as the only cause of the behaviour). There were also reports by clinicians and carers that some staff impose their own spiritual and cultural beliefs on consumers by ridiculing consumers or passing judgment. Further there seems to be a failure to consider service delivery in the context of global Indigenous disadvantage and community needs

The need for specific training and employment of mental health workers with relevant experience appears to be an essential missing ingredient.

Nationally, the key issues relating to this Standard include:

- lack of culturally appropriate practices for NESB consumers (Standards 7.2 and 7.3);
- lack of culturally appropriate treatment and support services for Indigenous consumers and their families (Standards 7.2 and 7.3);
- lack of treatment and support services for older immigrants and newly arrived young people (Standard 7.1);
- problems with treatment due to cultural barriers and intellectual disability (Standard 7.3);
- social and cultural prejudice by staff towards Indigenous people with mental illness (Standard 7.5);
- need for cultural competency training (Standard 7.5);
- need for training of interpreters on mental health issues (Standard 7.3);
- utilisation of staff and services with expertise to provide services to consumers from a NESB (Standard 7.4);
- staff imposing their own religious and cultural attitudes on consumers (Standard 7.5);
- cultural background not being respected and considered in the delivery of treatment and support (Standards 7.1- 7.4);
- lack of sensitivity to spiritual beliefs (Standard 7.3); and
- the need to understand issues associated with recent immigration (Standards 7.1 – 7.4).

The following selected quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 7. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Lack of culturally appropriate treatment and support services for Indigenous consumers and their families

My son committed suicide 2 years ago. There are a lot of deaths here amongst Indigenous youth. Before he killed himself my son went to the mental health unit and they told me he was suffering from behaviour problems – the perception was that because he was an Indigenous young man that he was 'sloshed out'. We were told that he wasn't suicidal.

(Carer, Mother, Queensland, Rockhampton Forum #3)

When Indigenous people become unwell they are all put in baskets, they either have a mental illness or a drug and alcohol problem. There's no holistic care. There have been 20 close deaths in my family.

(Anonymous, South Australia, Murray Bridge Forum #15)

If the current mental health system works at its optimum level, there are still critical and serious service provision gaps. Anangu do not have access to a spectrum of interventions that are culturally appropriate and responsive to individual and / or community need. There is no access to counselling, grief and trauma support, early intervention programmes or ongoing rehabilitation programmes if someone has been diagnosed with an ongoing disability.

(Anonymous, Northern Territory, Submission #271)

Underlying this submission are several assumptions of knowledge:

- *Indigenous Australians have significantly worse health outcomes than the general population, including higher rates of mental health concerns*
- *The mental health concerns of indigenous Australians need to be viewed in the context of global disadvantage including poverty, reduced life expectancy and chronic ill health, as well as issues of cultural dislocation, trauma and grief.*
- *Anangu view mental health issues as part of a general concept that includes the health of the individual, family, community and land in a cyclic view of past, present and future.*

(Anonymous, Northern Territory, Submission #271)

By far and away the most prominent mental health concern facing the communities to which I travel [remote communities in Central and North West Queensland] are those of accumulated grief and loss and the intergenerational consequences of such losses. The history of colonization and cultural oppression represents over and over as symptoms of trauma, depression, drug and alcohol abuse, relationship breakdown and self harm. Tragically, the current, mental health system seems ill-equipped to deal, in culturally appropriate ways, with the complexities of Indigenous health.

(Clinician, Queensland, Submission #285)

Lack of culturally appropriate practices for NESB consumers

People who do not speak English as their first language have very limited access and their linguistic and cultural needs are not met.

(NESB Consumer Advocate, New South Wales, Parramatta Forum #8)

Anecdotal evidence further suggests a disregard within the system for the cultural and religious beliefs of people in patient psychiatric settings. Such anecdotes include no attempts to meet the dietary requirements of religious and cultural groups, and a complete lack of sensitivity to exposure of parts of the body and / or nakedness.

(Australian Nursing Federation (Vic Branch), Victoria, Submission #322)

Need for cultural competency training

Cultural competence doesn't exist at the level it's needed. No cultural competence is taught. Unless we make it as a core competency, it won't happen.

(Anonymous, New South Wales, NESB Parramatta Forum #14)

Staff imposing their own religious and cultural attitudes on consumers

[I] attended the hospital with a friend who had attempted suicide. This was after hours. When I took her to the A and E she was initially checked over for any physical effects of the overdose she had taken. She also reported that she had been abused as a child. The consulting doctor then talked to her at length about religion indicating to her that people who commit suicide "go to hell". This greatly upset my friend who was already very upset. She said later it made her feel guilty about what she had done…An understanding and non-judgmental attitude would also have helped.

(Clinician, Western Australia, Submission #333)

Lack of sensitivity to spiritual beliefs of consumers

Also it's insulting to not believe the spirituality of the consumer. My daughter has been ridiculed about her belief in God and how prayer helps her. This occurred in our Psychiatric Hospital here in Bendigo.

(Carer, Victoria, Submission #199)

Need for training of interpreters on mental health issues

Language and cultural barriers are often not overcome because skilled and experienced interpreters are not available. Also interpreters will often have to play a role as a bi-cultural worker, to bridge the gap in cultural understanding.

(Melaleuca Refugee Centre, Northern Territory, Submission #191)

5.8 STANDARD 8: INTEGRATION

5.8.1 STANDARD 8.1: SERVICE INTEGRATION

The MHS is integrated and coordinated to provide a balanced mix of services which ensure continuity of care for the consumer.

Concerns were expressed across Australia from consumers, carers and clinicians alike that mental health services are not integrated and coordinated due to a lack of resources, staff and planning. There is a perception that the situation is progressively becoming worse.

Reports also suggest that the mental health system is unable to provide a mix of services to respond to consumer needs, even during a crisis. This results in a reliance on the police for a response. Even with police intervention and assistance in taking people to appropriate care facilities, consumers were often sent home again without any arrangements for treatment or follow-up.

Treatment and support services for children and youth with mental illness across Australia seem to be almost non-existent. Submissions suggest that there are either no services at all or extremely long waitlists (for example, a nine to ten month waiting list for children with mental illness to get into care). Thus the need for integrated and coordinated care for this group is particularly pressing.

Many General Practitioners spoke of their willingness to be involved in the provision of mental health treatment and support, but noted difficulties in doing this without the necessary professional support.

High staff turnover and frequent staff rotations between programs and sites was also mentioned as a difficulty in providing continuous and coordinated care. Consumers report that they are tired of repeating their story and frustrated at being passed from one doctor to another. Fragmented service delivery and breakdown of links with NGO service providers seems to be another consequence of the scarcity of resources.

Nationally, the key issues relating to this Standard include:

- MHS not integrated to provide the mix of services required to respond to consumer needs (Standard 8.1.1);
- MHS not providing continuity of care for consumers (Standard 8.1.5);
- more staff and resources are required for integrated service to respond effectively to crises (Standard 8.1.1);
- chronic under-resourcing of MHS resulting in inability to deliver integrated and coordinated care (Standards 8.1.1 and Standard 8.1.2);
- difficulties in organising integrated and coordinated care with components of the MHS (Standards 8.1.2 and 8.1.3);
- lack of staff and resources to provide integrated care to rural and remote communities (Standard 8.1.1);
- shortage of mental health staff to provide integrated care across settings and programs (Standards 8.1.2 and 8.1.3);
- difficulties accessing case managers (Standard 8.1.1);
- inability to provide coordinated continuous care due to high staff turnover and staff rotations, especially in rural and regional areas (Standard 8.1.4);
- no continuity of care leads to lack of communication (Standards 8.1.3 and 8.1.6);
- lack of cooperation within MHS leads to poor attitudes towards rural and regional patients and providers (Standards 8.1.1 and 8.1.6);
- lack of mental health services for children and youth (Standard 8.1.5);
- problems with continuity between adolescent and adult mental health services (Standard 8.1.5);
- problems with link between General Practitioners and mental health services (Standard 8.1.6);
- problems with integration with NGO services (Standard 8.1.5);
- general Practitioners lack the skills to treat people with mental illness or mental health problems. (Standard 8.1.5);
- inability of MHS to deliver coordinated and integrated services to consumers from a non-English speaking background (Standard 8.1.1);
- inability of mental health teams to provide services resulting in reliance on police force (Standard 8.1.1); and
- problems with Schedule II procedures and integrated and coordinated care (Standard 8.1.6).

The following limited selection of quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 8.1. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

MHS not integrated to provide the mix of services required to respond to consumer needs

[X]… is escorted to the emergency department of the local hospital… [Y]… assessed [X] to be at high risk of suicide. No admission and no follow-up is arranged. Additionally, no contact was made with the referring agency and according to [X], no request of discussion with the referring agency was sought by mental health services.

(Support and Equity Services, Charles Darwin University, Northern Territory, Submission #269)

Lack of communication and co-operative case management between inpatient and outpatient hospital staff can cause serious errors in treatment. At one time [X] was in hospital for 4-5 days before the inpatient staff knew what the treatment orders were!

(Carer, Mother, Victoria Submission #320)

Chronic under-resourcing of MHS resulting in inability to deliver integrated and coordinated care

This support is not being provided and has been progressively withdrawn over the last several years. The patients are constantly disappointed by the diminished level and duration of service as provided by the state funded public psychiatric system.

(Clinician, Victoria, Submission #123)

Some of the issues that matter are poor accessibility, lack of access to private practitioners, lack of bulk-billing GPs and lack of accessibility to counselling services particularly for people with high prevalence disorders.

(NGO worker, Victoria, Morwell Forum #7)

Lack of staff and resources to provide integrated care to rural and remote communities

I have been advocating for improved psychiatric services in this region for 8 years now. Over 1/3 of our GPs have undertaken additional training. But there's no psychiatrists East of Dandenong! As GPs we have little to no support from the specialist sector.

(Clinician, Victoria, Morwell Forum #8)

More staff and resources are required for integrated service to respond effectively to crises

4 weeks ago a young man came to see me. He was suicidal, he had several crises in his life he was trying to deal with and he had been self-medicating. I see many people like him – they are not bad people but people who need assistance from society. I managed to get him assessed by a crisis assessment service – that in itself was a really big win! But the crisis service was going to send him home with some phone numbers. Fortunately I had organised to see him and got irate and asked them how they would feel if this young man was dead in the morning.

(Clinician, Queensland, Brisbane Forum #7)

I have a friend who had a mental breakdown… I rang the mental health team and they couldn't see her for 5 days no appointment for 3 to 4 weeks. The GP tried to cope. Good clinicians took details but 3-4 weeks later was asked the same questions again. There is a lack of staff – the team in community and lack of coordinated services.

(Anonymous, Western Australia, Geraldton Forum #65)

The community staff are stretched to the maximum and their resort is to tell people to go to their GP or access an emergency service (was one very recent answering machine message I happen to hear when I was trying to contact a community health worker. Mind you, no information about how to contact the emergency service was part of the message.)

(Consumer and Consumer Advocate, New South Wales, Submission #8)

MATT (mobile assertive treatment team) – work with severely sick psychotic people to keep them out of hospital – only one team with 7 staff who see 70 clients for the Central Sydney area which has 5000 consumers, 500 of whom would benefit from seeing the MATT team, which provides intensive case management, support, counselling and supervision

*(*Consumer and Consumer Advocate, New South Wales, Submission #169*)*

Shortage of mental health staff to provide integrated care across settings and programs

[[X] went] to a psychologist just 2 months before he died - who referred [X] to a psychiatrist - but unfortunately the psychiatrist was away on holidays - so he couldn't get an appointment - in the detailed referral it was obvious to blind Harry that [X] was screaming out for help he had in a one hour session with the psychologist relayed every vital piece of information in regard to his condition. [X] should never have been allowed to leave that psychologist's office - in the referral it said he had a (suicide) plan - it wasn't the first time etc etc.

(Carer, Mother, New South Wales, Submission #122)

Lack of mental health services for children and youth

I've been on a few committees and it's not the service providers who are the problems; they are on our side. It's the politicians and our government that are negligent… There's a 9-10 month waiting list for mentally ill children to get into care.

(Consumer, Western Australia, West Perth Forum #41)

Problems with continuity between adolescent and adult mental health services

Young people 16-17 come and see us but we do some transitioning to the adult mental health service also. There is a period when there's nothing for young people during this transition.

(Clinician, South Australia, Murray Bridge Forum #14)

Inability to provide coordinated continuous care due to high staff turnover and staff rotations, especially in rural and regional areas

He has a different social worker every three months and suffers from psychotic episodes. He finds it difficult to trust people and the constant changes to the social worker assigned to his case are not helpful.

(17 year old Carer, Sister, Australian Capital Territory, Young Carers Forum Canberra #1)

The lack of consistency with being passed from one trainee doctor to another. Where we are the doctors change every three months

(Carer, Victoria, Submission #199)

More than once the police local have said that it is not their problem and we should call her mental health worker, who is 100kms away and never able to take our call because she is so busy she is rarely in the office. More often also, the mental health worker who is in charge of my mother's care, changes twice a year, and she is periodically moved between the West End Mental Health Clinic to the one at Ashgrove (I can never remember if it is Ashmore or Ashgrove).

(Anonymous, Queensland, Submission #82)

[Y] has depression and no longer accesses counsellors through ACT government services. [Y] explained the counsellors in the government system change a lot so he had to keep starting from the beginning and moving to a point in his story, when the counsellor would be replaced with another, and he would have to start again. [Y] said he found this really frustrating. [Y] said the counsellors in the government services didn't know why they were swapped around.

(14 year old Consumer and Carer (Son), Australian Capital Territory, Young Carers Forum Canberra #2)

Problems with link between general practitioners and mental health services

There were a number of GPs in Bunbury who wanted to be involved with the mental health unit but only if there was adequate support. We don't have that support anymore.

(Clinician, Western Australia, Bunbury Forum #19)

One can usually find a specialist physician or surgeon to follow up difficult cases, offering whatever support they can. As a GP, I find it frustrating when psychiatrists will not do likewise. It appears that psychiatry operates in a comfort zone that conveniently defines the most troublesome and least lucrative cases as outside their concern. I often diagnose a life-threatening personality disorder but can't arrange any specialist support.

(Clinician, Queensland, Submission #49)

MHS not providing continuity of care for consumers

The attempts to shore up the interfaces between GPs and specialist care are appropriate however most of their work is with so-called high prevalence or non-psychotic disorders, and sadly there is no longer expertise in the specialist system to help them to manage the more challenging of these disorders. In fact a team approach rather than a solo GP or even a solo private psychiatrist is needed for many of these cases.

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

However, GPs have limitations on the time they can spend with patients and the level of service that they can provide. Both of these areas are aspects of the system where GPs need support to provide home care and follow up services to patients being treated by the GP. This area has in the past been one where local public mental health services have been utilized.

(Clinician, Victoria, Submission #123)

Problems with integration with NGO services

The sector is currently very fragmented. Continuity of care between Government services and NGOs is difficult to maintain given the current restrictions of time and scarce resources.

(Anonymous, Tasmania, Submission #254)

There's a real breakdown between NGO and public services. The Government is happy to treat NGOs as extensions of services but not fund them accordingly. In fact the Government has cut funding to NGOs and still expects that the NGOs will carry the load. I have had to put a ban on all referrals from services. We're now in a position where we are rationalising our services. We don't like it but we have to run our service within the resources we have to work with… My service has a budget of $400,000 / year but our funding hasn't increased since early 1990s.

(Clinician, New South Wales, Sydney Forum #3)

Difficulties in organising integrated and coordinated care with components of the MHS

The mental health system failed [X] in so many ways. In summary the key failings were: Third, was lack of integration across the various mental health areas, such as the hospitals and the mental health crisis team, and related areas such as Drug and Alcohol services and accommodation facilities: we are a very "bureaucracy-literate" family and we had immense difficulty navigating the system.

(Carer, Sister, Australian Capital Territory, Canberra Forum #9)

> *I do not refer to Mental Health Services because of past experiences, particularly as they will not see people who have a drug problem. I use GRAMS [Geraldton Regional Aboriginal Medical Service] where possible.*
> (Anonymous, Western Australia, Geraldton Forum #94)

5.8.2 STANDARD 8.2: INTEGRATION WITH THE HEALTH SYSTEM

The MHS develops and maintains links with other health service providers at local, state and national levels to ensure specialised coordinated care and promote community integration for people with mental disorders and / or mental health problems.

Across Australia, there were concerns about the neglect of the physical health of people with mental illness. A focus solely on the mental health of many consumers resulted in holistic care being ignored, including in inpatient settings where patients are often required to be transferred to general hospital wards to address their deteriorating physical health conditions. Difficulties in obtaining physical health assessments and access to general practice were also noted.

Research identifying elevated death rates in all main causes of death for people with mental illness, compared with the general population, was noted as a critical indicator of this neglect.

There have been suggestions that comprehensive care is only available to those who can afford to 'purchase care' in the private sector.

It was also reported that for Indigenous people with mental illness and / or mental health problems, poor physical health meant that mental health care was not being addressed as a priority or at all.

Problems with access to General Practitioners (GPs), barriers between GPs and psychiatrists and interagency collaboration are all complicating the provision of comprehensive care.

Nationally, the key issues relating to this Standard include:

- physical health care neglected (Standard 8.2.1 and 8.2.5);
- physical health care neglected in inpatient settings (Standard 8.2.1 and 8.2.5);
- problems with integrated and continuous care when consumers are admitted to hospital for physical illnesses (Standards 8.2.1, 8.2.3 and 8.2.4);
- comprehensive care only obtainable from the private sector (Standard 8.2.1 and 8.2.5);
- comprehensive health care not promoted (Standard 8.2.1 – 8.2.4);
- inability of consumers to afford basic heath care (Standard 8.2.1 and 8.2.5);
- For Indigenous people, mental health care is neglected due to poor physical health (Standard 8.2.1 - 8.2.5);
- lack of access to services to meet physical health needs (Standard 8.2.1, 8.2.2 and 8.2.3);
- problems with accessing General Practice (Standard 8.2.4);
- the need to improve arrangements with Psychiatrists and General Practitioners (Standard 8.2.4); and
- problems with interagency collaboration (Standard 8.2.4).

The following limited selection of quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 8.2. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Physical health care neglected in inpatient settings

However on 4 January 2002 (following our threats to involve the media), she was transferred to a medical ward, having become psychotic and also because she had acquired dehydration, malnutrition, severe carpet thrush and split and bleeding heels. These four new conditions had developed in the MHU whilst she was under the "care" of staff. We believe that our daughter's mental and physical states are inseparable as regards duty of care, and we vigorously question the therapeutic efficacy of the Liverpool Hospital Mental Health Unit.

(Carers, Parents, New South Wales, Submission #106)

On three occasions my son [X] has been admitted with physical problems which either had not been noted on admission or were ignored even when they had been noted. On one occasion he went three days before the symptoms were properly addressed. The end result was an emergency operation for the removal of a salivary gland with embedded calcium stones.

(Carer, Wife and Mother, Queensland, Submission #52)

Physical health care neglected

Because [X] my wife was having active mental health problems with her schizophrenia and that she was poorly controlled while under the CTO [Community Treatment Order] a decision was made not to treat her with either chemotherapy or radiation to me that is a Human Rights issue, even the HSC [Health Services Commissioner] office told me that there 15 to 18 other such cases in Victoria like our case.

(Carer, Husband, Victoria, Submission #179)

Access to services will also be discussed below but it seems appropriate to raise the issue of general medical treatment here. It is reported, by people who have a psychiatric illness, that it can be very difficult to have physical illness concerns taken seriously by main stream health providers—too often their concerns are dismissed as 'just the symptoms of their mental illness'. One young woman who participated in the consultations spoke of the difficulty she had convincing her general practitioner that she was unwell—after a number of months she sought other advice and was diagnosed as having diabetes. Other consumers spoke of the difficulties they had experienced in emergency departments—as soon as doctors saw their file and read 'mental illness' consumers felt they were dismissed and some even reported having been sent home without speaking to a doctor. Discrimination is not something that is only experienced among the 'uneducated' broader community; it clearly even exists within the health and welfare community.

(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

Comprehensive care not promoted

Among a series of similar studies internationally, the crucial Duty to Care study from Western Australia (Coghlan et al 2001) showed that people with serious mental disorders, especially schizophrenia, had considerably elevated death rates from all main causes of death, with heart disease topping the list of causes ahead of suicide. Not only is the prevalence of these disorders increased, but they are diagnosed late and treated inadequately. This pattern of premature death and substandard medical care is characteristic of marginalised and disadvantaged sections of the community and demands urgent action.

(Patrick McGorry, Professor of Psychiatry, Victoria, Submission #180)

Inability of consumers to afford basic heath care

Consumers and carers reported that the most basic of health care is often out of the reach of people experiencing mental illness and sometimes also out of the reach of members of their families. In particular, greater and free access to the following services and professionals is required: GPs; Specialists; Non-urgent, non-life threatening or elective procedures; Dental care; Foot care; Skin care; Optometrists, physiotherapists and psychologists etc.

(Mental Health Community Coalition Consumer and Carer Caucus,
Australian Capital Territory, Submission #342)

Lack of access to services to meet physical health needs

Since the closure of the institutions there has been a large influx of people into this community. But these people need access to other health services for their physical and mental health needs – they often get sent on buses and taxis to Adelaide for care.

(Police Officer, South Australia, Murray Bridge Forum #16)

There's also very poor access to physical health assessments for people with a mental illness.

(Clinician, Queensland, Brisbane Forum #7)

Problems with interagency collaboration

In defence of mental health services, there has been a big effort to liaise with NGOs – there have been significant efforts made in the last few years to get better community integration of mental health services. But the high turnover of staff it makes it very hard to establish those relationships and collaborations and hard to get the protocols right.

(NGO, New South Wales, Broken Hill Forum #10)

The need to improve arrangements with general practitioners

If people do attend for help for anxiety disorders or depression it is usually to the GP where the response is usually to offer medication only. GP's are generally unaware of other services that are available. People need to know the range of treatment options for their condition as one would expect with any physical illness. GP training in CBT [Cognitive Behavioural Therapy] is also useful and hopefully will mean earlier intervention for many people, however significant numbers of people with anxiety disorders and depression have complex histories and require longer and more specialised help.

(Clinical Service Provider, Victoria, Submission #268)

5.8.3 STANDARD 8.3: INTEGRATION WITH OTHER SECTORS

The MHS develops and maintains links with other sectors at local, state and national levels to ensure specialised coordinated care and promote community integration for people with mental disorders and / or mental health problems.

Concerns were expressed nationally that in order for the rights of people with mental illness to be protected and promoted, a whole-of-government approach was needed to tackle the myriad of problems facing consumers and their families.

Collaborative arrangements were identified as vital to enable consumers and their carers to participate socially, economically and politically in society. Many consumers required assistance beyond mental health care in a hospital. For example many mentally ill persons need financial support, access to home and community care (for those choosing to live independently, or with their family at home), or access to a range of short and long-term housing and supported accommodation options.

The large deficit in available housing and supported accommodation was cited as a critical barrier to successful rehabilitation and integration into community life for consumers and a critical burden on families who are not being compensated or supported to provide interim support.

The nexus between poverty and mental illness for consumers and their families was also cited repeatedly. Many consumers reported that they and their families living were below the poverty line and had insufficient money to pay for medication and food.

Consumers noted the scarce number of bulkbilling clinicians. They also highlighted the problems caused by an absence of Medicare rebates for psychologists.

For consumers, financial hardship was also often due to interrupted ability to work or difficulties in gaining and maintaining employment. Some of the barriers to employment include high levels of stigma and discrimination in the workplace and lack of workplace supports. To address this, the need for a whole-of-government approach to tackle employment and education-related issues was cited as an area requiring urgent attention.

For carers, the high burden of caring for a family member as a result of lack of access to treatment and support services also disrupted their ability to gain and maintain employment.

Intersectoral links and collaboration with police, court liaison and prison services were also cited as critical to provide appropriate alternatives for the increasing number of people with mental illness who are coming into contact with the police. Without better coordination there will be little success in diverting those who would otherwise enter the criminal justice system.

Youth, wards of the State, people requiring guardianship and people with disability are all disproportionately impacted by the failure to provide holistic care and integrated services for people with a mental illness.

The need for cross-border agreements was also raised to improve service delivery for consumers in rural and remote areas.

Nationally, the key issues relating to this Standard include:

- the need for a whole-of government response for consumers and families (Standards 8.3.1 and 8.3.3);
- the lack of housing and accommodation options for people with mental illness and mental health problems (Standards 8.3.2 and 8.3.3);
- the need for a whole-of government response for youth (Standard 8.3.1 – 8.3.3);
- lack of coordinated care across sectors for older people with mental illness (Standard 8.3.1 – 8.3.3);
- integration with police services and the criminal justice system (Standards 8.3.2 and 8.3.3);
- the need for a whole-of government response to tackle employment (Standard 8.3.3);
- whole-of-government approach needed to tackle poverty and mental illness (Standards 8.3.1 – 8.3.3);
- lack of support from Centrelink (Standard 8.3.3);
- Welfare support – problems with carer allowance and disability support pensions (Standards 8.3.1 – 8.3.3);
- lack of support for families (Standards 8.3.1 – 8.3.3);
- lack of access to home and community services (Standard 8.3.3);
- whole-of-government approach to specifically care for children who have become Wards of the State (Standards 8.3.1 – 8.3.3);
- the lack of cross border agreements (Standard 8.3.3);
- need to integrate mental health strategy with drug strategy (Standard 8.3.3);
- lack of support from departments dealing with disability (Standards 8.3.2 and 8.3.3);

- lack of support from departments dealing with community services (Standards 8.3.2 and 8.3.3);
- whole of government approaches needed to improve mental health outcomes for Indigenous communities (Standards 8.3.1 – 8.3.3);
- transport (Standard 8.3.3);
- education (Standards 8.3.1 – 8.3.3);
- higher education (Standards 8.3.1 – 8.3.3);
- guardianship (Standards 8.3.1 – 8.3.3);
- emergency services (Standards 8.3.1 – 8.3.3);
- medicare rebates (Standard 8.3.3);
- affordability of care – lack of bulk billing clinicians, cost of psychiatrists and psychologists, private health insurance and medication costs (Standard 8.3.3);
- national strategies to increase the number of mental health professionals (Standards 8.3.3);
- need to address training and support issues for mental health nurses and general practitioners (Standard 8.3.3); and
- national legislative reform of anti-discrimination legislation to cover vilification and harassment (Standard 8.3.3).

The following limited selection of quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 8.3. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

The need for a whole-of government response for consumers and families

People with a mental illness and long term disability resulting from such illness impact heavily on the justice, drug and alcohol, housing and welfare systems as well as the health system. The failure to provide adequate support services has resulted in an overrepresentation of people with a mental illness among the homeless and in the criminal justice system. MIFA calls for structural reform of services, which incorporates a whole of government approach to address the structural impediments and the failure to provide sufficient support systems to address the overrepresentation.

(Mental Illness Fellowship of Australia, National Submission #331)

My concern arises from the criminalisation of mental illness. Some people with a mental illness are being punished over and over again. Housing and support for these people has been so neglected that approximately 400 are now housed in mainstream prisons in south-east Queensland.

(Anonymous, Queensland, Submission #67)

NCOSS is extremely concerned about the poor coordination of mental health issues, which is occurring across Government agencies in NSW, including poor linkages between specialist mental health services and other Government services. Health consumers and community organisations participating in NCOSS forums have repeatedly raised the need for closer and more consistent integration between mental health services and other Government services.

(NCOSS, New South Wales, Submission #47)

I have also long advocated the need for Mental Health Impact Statements (analogous to Environmental Impact Statements) to be prepared as a component of planning services / projects. The purpose being to draw attention / make conscious the contribution (or lack thereof) of matters under consideration and to educate us all as to how pervasive is our neglect (or otherwise). Whether it be housing, fostering programs, recreational facilities / programs, religion based plans, setting up a business, claimed therapeutic practice, governmental proposals, or whatever. This may well get up a few noses, including our own, with benefit!

(Clinician, New South Wales, Submission #154)

Where is it? The organisation I work for has tried for the last decade to supply appropriate, affordable **supported** *accommodation for people with a mental illness / disability. We are exhausted, frustrated and generally confused by the inflexible poorly coordinated Government Departments that should be providing service to people with a mental illness. It seems to me that no single Department has the ability or inclination to play the lead role in the provision of service to this client group. (author's emphasis)*

(NGO Service Provider, Queensland, Submission #40)

People with mental health problems and their families do not go away if the government does not provide services for them. Instead they go or are brought to other service systems. This phenomenon is most obvious as people with mental health problems are stranded in the emergency departments of hospitals. However General Practitioners, Police, Schools, the Correctional system and Community Groups all report increasing numbers of people with mental health problems they encounter who cannot get adequate assistance.

(Health and Community Services Union, Victoria, Submission #220)

The lack of housing and accommodation options for people with mental illness and mental health problems

There's a high level of homelessness. People ring up and say I've got $35 left to last me for the week and my medications will cost me $38. I've got no food and I won't get my pension until next week. What should I do? How can I survive?

(Consumer Advocate, Victoria, VMIAC Forum #3)

Living on the street further complicates matters by making it difficult for mentally ill person to receive follow-up services. Without this and ongoing care, these individuals stop taking their medication and sooner or later, end up having a run in with law enforcement. It is at this point that, what was once the institution's mental health problem, now becomes a police problem.

(Police Association of New South Wales, New South Wales, Submission #59)

There's a real revolving door syndrome – people get admitted, they get treatment and then they get discharged but because there's no supported accommodation for them they keep coming back into the hospital.

(Clinician, South Australia, Murray Bridge Forum #5)

We have 12 houses and a boarding house for single men so we can take in 18 men. I have worked in human services for the last 16 years and I can tell you that we are now on a path to disaster – people are being 'dumped' on our service and on the streets because other people don't know what to do with them. They are sent here by the service or the hospital with no consultation with us – they are just told where to go, how to find us.

(Service Provider, Western Australia, Bunbury Forum #12)

In the inner suburbs of Melbourne some 'unofficial' rooming houses operate, offering sub-standard accommodation to vulnerable people living with a mental illness. The BSL provides services to some consumers who do not have access to reasonable bathroom or kitchen facilities, a situation that should not continue to exist today. Without access to stable, safe and affordable housing it makes it extremely difficult to treat people for their psychiatric illness. The Victorian Homeless Strategy 2002 reported that long term housing and support for people with a mental illness drastically reduces inpatient stays (VHS 2002,p.7) —providing this housing must be a government priority.

(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

People on a Disability Pension for Mental Illness, are paid an allowance and left to their own devices. There isn't enough funding for supported accommodation or even subsidized housing. If you want a Minister of Housing accommodation, it's a 12-18 YEAR! wait. What are people supposed to do in the meantime?

(Carer, Mother, Victoria, Submission #352)

Whole-of-government approach needed to tackle poverty and mental illness

This nexus between poverty and serious mental illness extended to the lives of the carers. The task of caring for people with serious mental illness tends to fall heavily on their families, usually parents. This research highlights the high toll taken in terms of their health in addition to their social, emotional and financial wellbeing. The dollar cost of care is no measure of the real price of anxiety and grief expressed by carers, yet it is a significant and largely unmeasured impost on families. This report documents the real cost for carers of providing accommodation, food, clothing and support to people with serious mental illness. This significant cost remains largely hidden, picked up by carers, who, if they are themselves on a low fixed income, may be forced on to income support, emergency relief services, charities, and crisis accommodation services. In addition to the financial impost of caring, carers report a critical lack of support in the form of community-based ser vices, clinical, counselling, information and respite options. In particular they identified the lack of appropriate supported accommodation which denied their adult son or daughter the chance to live a meaningful independent life.

(Anglicare Tasmania, "Thin Ice: Living with Serious Mental Illness and Poverty in Tasmania", Tasmania, Submission #144)

Lack of access to home and community services

Some support services such as some Home and Community Care programmes still discriminate against people with mental illnesses by denying them access to needed services for a range of reasons i.e. 1) lack of knowledge about mental illness and how to care for those effected 2) lack of understanding of their needs and the way in which certain conditions affect their ability to care for themselves, i.e. an attitude that a person is lazy when they lack the motivation to clean their home.

(Anonymous, Tasmania, Submission #254)

Lack of support for families

…plight of children who have one or both parents who suffer a mental illness. I would like to see more attention and assistance for these children, many of who have a very heavy load to bear, and are often quite isolated. There is great shortage of any help or accommodation for children when parents are unwell, or in hospital.

(Carer, Victoria, Submission #185)

Some programs require that carers pay for their own education and support. Families have in effect been told that they are part of the mental health workforce and indeed they save the federal government billions of dollars per year. Yet lack of direct funding for carers of people with a mental illness including for education programs, support services and carer consultants sends the message that carers' requirements are not valid in their own right and that it is up to them to deal with the fallout from de-institutionalisation.

(The Network for Carers Of People With A Mental Illness, Victoria, Submission #319)

Education sector

Our core business is education – we identify children with intellectual disability but not psychiatric disability. We are not funded to support these kids. We can provide inclusive resources but we can't really do it properly. Generally they are just piece meal packages. I have staff using the expulsion / suspension guidelines to exclude these kids… Because of a lack of services there's nothing left but to exclude these kids. Actually they really need care.

(Teacher, South Australia, Murray Bridge Forum #17)

Welfare support – problems with the Carer Allowance and Disability Support Pension

As a carer, I cope reasonably well, but being retired and on a pension, our income is limited, so I work part-time. At times I am stretched mentally and physically, and often feel depressed myself.

(Carer, Husband, Victoria, Submission #247)

They pay us an inadequate amount a fortnight to do a job they know we are unqualified and ill-equipped for, when they are the ones who should be providing us with the people and services to care for our families properly.

(Carer, Mother, Victoria, Submission #352)

Whole-of-government approach to specifically care for children who have become Wards of the State

…children were displaced into the adult mental health system and are still suffering from our incarceration, many of us were under the care and protection of the state, But unfortunately we were overlooked by the Forde inquiry because although we originated in children's homes and suffered there, we were thrown to the wolves! ,adult institutions were not part of the ford inquiry, which sucks because at thirteen wasn't I still a child with the right to be protected from rape, vicious attacks, exposure to violence and the incredible suffering of others, forced drug addiction, inhumane and degrading punishment, emotional and mental torture, terrifying treatment such as ECT chemical torture (servier dystonic reaction with bronchial collapse) what does this mean EXCRUCIATING PAIN AND MENTAL ANGUISH." (author's emphasis)

(Anonymous, Consumer, Queensland, Submission #300)

Lack of cross-border agreements

Lack of co-ordination between State Governments can lead to services gap and duplication. With the exception of the South Australian & Northern Territory agreement there is no coordination of services, increasing the risk of service duplication. It also means that more cost effective, co-ordinated, innovative service options are not explored.

(Anonymous, Northern Territory Submission #271)

The need for a whole-of government response to tackle employment

The Commonwealth should be seriously committed in assisting people with psychiatric disabilities in gaining employment and as a matter of urgency should consider: (1) new employment policies for people with psychiatric disabilities; (2) alternate employment models as a way of providing more appropriate assistance and choices; and (3) new measures to increase labourforce participation.

(Disability Employment Action Centre, Victorian Submission #209)

Integration with police services and the criminal justice system

The public mental health system and the criminal justice system must collaborate so that police officers have several alternatives, not just arrest or hospitalisation, when handling mentally ill persons in the community…

(Police Association of New South Wales, New South Wales, Submission #59)

Despite the existence of an official Memorandum Of Understanding between police and mental health services in the ACT, consumers and families reported that there appears to be a need for clarification of responsibilities on a daily basis and at 'ground zero'. It is reported that mental health services frequently refuse to act and families report they are told by mental health services to phone the police.

(Mental Health Community Coalition Consumer and Carer Caucus,
Australian Capital Territory, Submission #342)

Solicitors may have poor knowledge of mental health issues. A court liaison officer works at the Brisbane courts but mental health clients appearing at other courts have no access to this service.

(Anonymous, Queensland, Submission #67)

National legislative reform of anti-discrimination legislation to cover vilification and harassment

In most parts of Australia it is unlawful under anti-discrimination Acts to vilify people on the grounds of race, religion, sexuality or gender identity. In NSW it is also unlawful to vilify people with HIV / AIDS. Under current Australian legislation, however (apart from Tasmania), people with a psychiatric or other disability do not enjoy this protection. It is totally unacceptable that vilifying the mentally ill remains a legal activity in mainland Australia.

(SANE Australia, National, Submission #302)

Need to address training and support issues for mental health nurses and general practitioners

In 1993 in Victoria, the separate psychiatric nurse degree was abolished, and merged with the comprehensive nurse training degree. This has meant that the mental health component of undergraduate nurse training is as little as 3% in some courses… This has a direct impact on the quality of care offered to consumers, and the capacity of services to meet care needs with appropriately trained staff.

(Centre for Psychiatric Nursing Research and Practice, Victoria, Submission #323)

Affordability of care

There are noticeable differences between the private and parts of the public mental health systems with respect to attitudes to treatment. Money appears to be a major driver here although workforce culture and age profiles, differing financial controls and the evolution of new patterns of illness and new opportunities for treatment all play their part. We have reached a situation in this country where the public in-patient services are geared to short term, crisis management. These services are also restricted in the sense that by the population of patients that is receives treatment is essentially made up of persons with psychotic disorders and persons who are considered to be at risk of suicide. For too many this access to specialist treatment and care is also transient and upon discharge to private GPs enter the process. Issues like bulk billing, surgery hours, GP interest, geographic location of residency etc. then take their toll.

(Anonymous, Victoria, Submission #318)

5.9 STANDARD 9: SERVICE DEVELOPMENT

The MHS is managed effectively and efficiently to facilitate the delivery of coordinated and integrated services.

Problems with accountability and declining levels of consultation with consumers, carers, staff and service providers in the planning and delivery of care were noted as serious areas of concern across Australia. Sudden closure of community services and decisions to relocate community services back to hospital settings, without consultation, were cited as examples of this trend.

The lack of funding and resources and problems with the distribution of resources across metropolitan, regional and rural areas were described as critical factors in the inability of mental health services to deliver quality care. Consumers, carers and clinicians alike described services which were struggling to cope with increasing workloads without parallel increases in funding, staffing levels and resource allocation. Instead, reports were received that services were non-existent, inaccessible or declining in quality.

A significant number of carers reported increasing reliance on them as 'cheap resources' and 'slaves', there to provide the support to consumers that is not being provided by mental health services.

Many staff reported feelings of 'burnout'. High staff turnover and inability to recruit and retain staff were seen as indicators of the stress being experienced by staff due to lack of resources, funding and support to deliver services. This was acutely evident in rural and remote areas. The lack of community-based services and the model of care underpinning service delivery were also reported as factors inhibiting improved service delivery. The current model was described as overly emphasising the medical model of care, as focusing on crisis intervention and 'custody and control'. The perceived trend towards requiring consumers to pay for care was also noted by some as a key area of concern to be addressed.

Nationally, the key issues relating to this Standard include:

- the poor quality of existing services and the lack of appropriate services (Standards 9.22, 9.24, 9.28, 9.29, 9.30, 9.33 and 9.34);
- distribution of resources (Standard 9.14-9.16, 9.33. 9.34);
- service development issues in rural and regional areas (Standard 9.33 and 9.34);
- lack of resources, treatment and support services in rural, regional and remote areas (Standard 9.7-9.11, 9.14-9.16, 9.33, 9.34);
- services ever diminishing in rural and regional areas (Standard 9.7-9.11, 9.14-16, 9.29, 9.33 and 9.34);
- consumers, carers, staff and service providers not involved in planning and delivery of services (Standard 9.8);
- lack of planning to provide continuous care (Standards 9.4. 9.5, 9.7-11);
- lack of resources to deliver quality mental health care (Standards 9.14-9.16, 9.33, 9.34);
- lack of resources to support community-based care following deinstitutionalisation (Standards 9.14-9.16, 9.33, 9.34);
- a greater focus needed to meet the needs of Indigenous people with mental illness and mental health problems (Standards 9.4, 9.5, 9.14-9.16, 9.33, 9.34);
- low regard for psychogeriatric planning, policy development and funding (Standards 9.7-9.11, 9.14-9.16);
- lack of funding and services to meet the needs of young people (Standards 9.7-9.11, 9.14-9.16)
- more services required to support young carers (Standards 9.7-9.11);
- staffing issues including supply, education and training (Standards 9.16-9.21);
- low quality of services associated with staff shortage (Standard 9.4, 9.16, 9.17-9.21, 9.28, 9.29, 9.30, 9.33, 9.34);
- lack of resources and staff and the impact this has on staff and their work practices (Standard 9.8, 9.15, 9.16-9.21, 9.29);
- recruitment and retention of staff in rural and regional areas (Standards 9.6, 9.14-9.16, 9.29);
- staff recruitment and retention issues in general (Standards 9.6, 9.14-9.16, 9.29);
- lack of funding (Standards 9.14 and 9.15);
- funding model needs to change (Standards 9.14 and 9.15);
- lack of funding and support for critical services provided by NGO's (Standard 9.8, 9.14-9.16, 9.29);
- problems with funding arrangements for service providers (Standards 9.14-9.15);
- loss of clinical leadership (Standards 9.1-9.3 and 9.5);
- problems identified with the loss of a coherent vision and direction (Standard 9.1-9.5, 9.14, 9.15, 9.33, 9.34);

- the model of mental health care needs to change as there is an inappropriate focus on inpatient and crisis care (Standards 9.14, 9.15, 9.22, 9.24, 9.29, 9.30, 9.33, 9.34);
- lack of resources and services is resulting in reinstitutionalisation of people with mental illness (Standards 9.14 – 9.15);
- problem with 'custody and control' model of care (Standard 9.14 and 9.15);
- an inappropriate focus on the medical model for service delivery including concerns about the relocation of community based services back to hospital sites (Standards 9.7-9.10, 9.14-9.16, 9.29, 9.30);
- lack of community based support or prevention focus (crisis model of care) (Standards 9.7-9.10, 9.14-9.16, 9.29, 9.30);
- carers are shouldering the burden of services which should be provided by the MHS (Standard 9.15);
- staff attitudes (Standards 9.17-20);
- lack of skilled staff (Standards 9.16-20);
- staff training and development needed (Standards 9.17-9.20);
- lack of education and training of workforce (Standards 9.16 and 9.18);
- training programs for GPs (Standard 9.16 and 9.18);
- need for more graduate programs and supervision for mental health nurses (Standards 9.17-9.20);
- education and training of mental health staff (Standards 9.16-9.20);
- the dismantling and subsequent "imploding" of working services (Standards 9.1-9.3, 9.5, 9.8, 9.10, 9.14, 9.24, 9.29, 9.33, 9.34);
- lack of mechanisms to improve service delivery and accountability (Standards 9.1-9.6, 9.7-9.11, 9.14-9.15, 9.17-9.18, 9.24, 9.28, 9.29, 9.33, 9.34);
- problems with management, planning and accountability (Standards 9.1-9.6, 9.7-9.11, 9.14-9.15, 9.17-9.18, 9.24, 9.28, 9.29, 9.33, 9.34);
- the need for a national audit and an independent review to ensure strategic plan and services conform to national mental health policies (Standards 9.10, 9.11, 9.14, 9.25, 9.28, 9.29, 9.30, 9.33);
- lack of progress and quality improvement despite inquiries being conducted, reports released and recommendations being made (Standards 9.7-9.11, 9.14, 9.15, 9.30, 9.31, 9.33, 9.34);
- concerns about government and health bureaucracy (Standard 9.1-9.6);
- fear of repercussions for 'speaking out' on mental health issues (Standards 9.8-9.9, 9.29);
- affordability of care and access to psychiatrists and psychologists (Standard 9.4, 9.15, 9.29, 9.30);
- private versus public mental health services (Standard 9.22, 9.24, 9.30);
- the lack of support for research (Standard 9.31); and
- the need for more research (Standard 9.28-9.32).

The following selected quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 9. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Lack of resources to support community based care following deinstitutionalisation

> *Since the National Mental Health Policy was signed by the Australian Health Ministers in 1992 to deinstitutionalise mental health care and move treatment of mental illness to a community based system, the community has had to attempt to establish some system of care with insufficient funding resulting in a system lacking the basic ability to meet the needs of people with mental illness. In an interview between the Hon Peter Costello MP and Alan Jones on 23 September 2004, the Treasurer openly admitted in relation to this policy of moving treatment into the community 'I don't think that policy has been a great success'.*
>
> (Carers Australia, National, Submission #276)

Thin Ice is an examination of the failure of systems to support people with serious mental illness. It outlines how this systems failure ultimately makes people sick and forces them into the costly acute care sector. The conclusion of the report is the urgent need for an increased range and supply of support services in the community to support people and assist recovery.

(Anglicare Tasmania, Tasmania, Submission #144)

Lack of funding

…the issue of inadequate funding to mental health services is a major concern. Compared to other OECD [Organisation for Economic Co-operation and Development] countries Australia is falling behind in the level of funds to mental health and the distribution of those funds. As an example New Zealand has increased their overall funding to mental health by 174% in nominal terms over the last decade and by 6.8% in the year 2002 / 2003. 28% of funds go to services provided by NGOs and 69% of funds are spent on community services with only 31% spent on in-patient services. Australia urgently needs to increase the overall funding to mental health in line with best practice in OECD countries and to avoid being classed as having a 'banana republic mental health system'.

(Mental Illness Fellowship of Australia, National Submission #331)

Unless Australia increases its mental health budget from 5-7% to at least 17%; as recommended by the WHO [World Health Organisation], inadequacies will continue to plague the Mental Health System in years to come.

(Carer, Anonymous Submission #224)

Consumers, carers and staff not involved in planning and delivery of services

Until we erase the current culture of poor Health governance in W.A., unfortunately we will not move forward. For example, local doctors were excluded from participating on the local Hospital Board from the mid 1990's, and the Hospital and Health Department have ignored, or been unwilling to accept our advice on all matters medical, for many years… Government cannot continue to blame lack of staff for our current Mental Health care problems. Any money thrown at the current system without a fundamental change, as outlined, will not work.

(GP, Western Australia, Submission #326)

It is evident to clinical staff that contributions to policy formulation or micro-reform suggestions aimed at service improvement are not welcome. In the rare instances where consultation processes exist they are tokenistic, without power and their outcomes are not acted on. When suggestions / proposals are submitted they are ignored as a rule. If the person making suggestions, raising issues insists, s/he will be increasingly ignored, and should s/he persist, s/he will be marginalised, described as having a 'bee in his / her bonnet' or 'a chip on his / her shoulder'. This may gradually degenerate in outright denigration of his / her work or person on the part of managers, team leaders, including character assassination which outside of the Public Service would be subject to slander and libel laws.

(Clinician, South Australia, Submission #56)

Problems with management, planning and accountability

Those who wield the power need to take responsibility for their decisions and the outcomes of those decisions. They need to stop trying to silence those who complain and to engage in open and honest dialogue and shared projects identified by those who have an interest in developing them.

(Anonymous, Tasmania, Submission #254)

Unfortunately, no matter what clinicians say or do, it is managers within the various systems that control budgets and therefore the important resource requirements. The system in Western Australia now is such that it is as though a divide exists between managers on the one hand and clinicians on the other.

(extract from a letter to Communications Manager, Mental Health Council of Australia)
(Clinician, Western Australia, Submission #24)

The system doesn't reflect the clients' needs – the system is more interested in reflecting KPI's [Key Performance Indicators] / good outcomes / indicators so they don't deal with the difficult ones. These are the ones that are given the bus tickets from other places and they end up here in our community. I know this happens.

(Police Officer, South Australia, Murray Bridge Forum #16)

Concerns about government and health bureaucracy

It is unfortunate but a culture exists which places the protection of government, Ministers, bureaucrats, organisations, managements, clinicians, and service providers above the protection of patients, in particular those with a mental illness.

(VMIAC, Victoria, Submission #332)

...issues that are regularly presented to our offices… One of the dilemmas is the culture of the mental health system – "toxic" culture of the mental health system.

(Office of the Public Advocate, Queensland, Brisbane Forum #14)

Carers are shouldering the burden of services which should be provided by the MHS

Carers consistently report that mental health services are inadequate and their family members can't get access to services when needed. On these occasions the responsibility for care and management is transferred onto the family carer who tries their best to manage and provide the care and support that is not available through mental health and community services. Without this sustained contribution from carers, the mental health system which is already under extreme pressure would be placed in greater jeopardy.

(Carers WA, Western Australia, Submission #277)

Carers carry the burden of this system. They are used as cheap resources – this is wrong!

(Carer, Mother, New South Wales, Parramatta Forum #1)

Lack of resources and staff and the impact this has on staff and their work practices

Case managers are burned out and/or distressed by their inability to provide a quality service or simply join the fold and deliver a sub standard service.

(Anonymous, Queensland, Submission #113)

Mental health services in this State have been in crisis for a long time and the chronic under-resourcing of this sector is responsible for an unacceptable decline in working conditions for the police, ambulance officers, nurses, doctors, allied health staff and security officers who are attempting to provide safe care and humane treatment for this vulnerable group.

(Mental Health Workers Alliance, New South Wales, Submission #325)

I am a clinical psychologist and I left the mental health system because of burnout and the feeling that in my previous role I felt like I was perpetuating the abuse because I didn't have the resources I needed to do my job properly.

(Anonymous, South Australia, Adelaide Forum #12)

Public mental health services for in-patients operate exclusively on a crisis- management basis. This fact is contributing to very high levels of staff burn out, low levels of job satisfaction and an inability of public mental health services to attract young nurses. These services are chronically under-funded and the experiences of many medical staff, who spend time in the public system gaining training to become qualified psychiatrists, drives them into private practice as soon as they gain accreditation.

(Anonymous, Victoria, Submission #318)

Staff recruitment and retention issues in general

There is a crisis in attracting all disciplines to work in Mental Health due to lack of support/ training and poor working conditions and a lack of attractive career paths.

(Anonymous, Tasmania, Submission #254)

There are also real problems with the workforce. Medical graduates are just not going into mental health. Who can blame them if they see this as the model?

(Anonymous, New South Wales, Submission #303)

As I said before, the administrative burden has increased significantly at the same time as bed numbers have been reduced. It's a vicious circle, a negative feedback loop – the more people (clinicians etc) who leave the more the increased workloads fall on those who are left behind. Then of course, they leave! This is happening at a consultant and registrar level and it is compounded by the declining entry into psychiatry of trainees.

(Anonymous, New South Wales, Submission #303)

Junior nurses and doctors are discouraged from pursuing careers in mental health due to the disgraceful working conditions that staff are forced to endure. This only compounds the problems of staff shortages.

(Clinician, Western Australia, Submission #4)

Junior medical staff are voting with their feet, we've seen a dramatic reduction in the number of applicants psychiatry training. Also an increased drop-out rate once in and a massive shift towards immediate private practice post Fellowship…

(Consumer Advocate, Western Australia, Submission #338)

The shortage of psychiatric nurses and other mental health professionals is a major issue. Low recruitment and retention is due in part to perceived low status, inadequate training and extreme workloads.

- *Average age of a psychiatric nurse (2004) 46 years*
- *% of nursing graduates entering mental health system 4%*

The SANE Mental Health Report recommends that this workforce issue be urgently addressed at a national level.

(SANE Australia, National, Submission #302)

Lack of resources to deliver quality mental health care

Victoria provides dramatic proof that having a good model, good intentions and committed, innovative health professionals is still not enough to provide adequate mental health services…. if there is insufficient funding to implement services properly.

(SANE Australia, National, Submission #302)

We now have access to the lowest cost health service! Not only do we have to tolerate the closure of our mental health service but ever diminishing resources. My experience is that we have extremely diligent staff and GPs but there simply isn't enough money or resources to support them in delivering quality mental health care.

(Carer, Western Australia, Bunbury Forum #14)

As a result of our enquiries into this area, we were made increasingly aware of the incredible reduction in the amount of care in almost every area which affects mental health treatment. Doctors and nursing staff are struggling with ever mounting burdens of care, while working with continually decreasing resources in Graylands Hospital and the mental health clinics. When our son was first admitted to Graylands Hospital in 1990, there were approximately 300 beds available. Now, after several wards have been closed, there are only 197 beds, of which 30 are in a separate locked forensic ward (built in about 1995), and hence are not available to the general public!! As Perth has grown in leaps and bounds with an ever increasing population, and therefore by extension, ever increasing numbers of mentally ill people of all ages, the amount of available care has been significantly reduced by successive governments, and particularly so in the past few years.

(Carers, Parents, Western Australia, Submission #76)

Lack of resources to support community-based care following deinstitutionalisation

There was never enough funding to support the move from institutions to community based care. Very little funding for ongoing support followed the clients into the community. Mostly their needs were expected to be absorbed by the existing community resources. This placed enormous stress on the community sector in terms of accommodation, support services and Staff. While the policy, undoubtedly, had its merits, some people with mental illness and their families were left unsupported in the community, and without a range of meaningful activities to occupy their time. Some clients preferred the asylum that the old facilities had to offer. With the exit from the hospitals also went much of the State's responsibility to care for those most vulnerable. There is nowhere to go if a safe place is needed for any length of time.

(Anonymous, Tasmania, Submission #254)

Carers… [t]hey express frustration with the crisis driven care at the expense of community support and rehabilitation.

(Anonymous, Northern Territory, Submission #188)

The model of mental health care needs to change as there is an inappropriate focus on inpatient and crisis care

Quite interesting is that 95% of the resources go to 5% of the burden. If we looked at the date we only look at hospital admissions not where the real burden is. We need the resources to support the people in the communities who are doing the work anyway. I am actually encouraged by the strength of the response here but we don't support people well enough.

(Anonymous, Northern Territory, Alice Springs Forum #23)

Prior to the meeting I gave a lot of thought to the pattern of the previous ten years... lack of consultation about treatment plans or changes to treatment plans resulting in persistent relapses, not being given information and not having my information or concerns heeded, the Mental Health System not accepting the responsibility of maintaining my son's 'wellness' and then repeatedly expecting me to accept the responsibility for his care and rehabilitation.

(Carer, Mother, Victoria, Submission #178)

Our community could benefit from a return to the program of social health visitors initiated by Dr Brain Hennessy... Those selected received substantial training, were given a car, were at the call of, and assisted, psychiatrists, psychologists, doctors and social workers. [They] were mainly the first involved in crisis intervention and the main contact following up patients after their stay in psychiatric ward of the hospital. The difference in [their] position as compared with the other professionals was that [they] we were considered more as a friend to [consumers] and their family, someone on their side. Thus [they] were able to persuade clients to cooperate more fully with treatment plans. Gone are the social health visitors; the service has become more clinically oriented, replacing the human / personal involvement. This makes it more difficult for people to develop a good self image and experience hope for the future. In our endeavour to improve mental health we could do no better that re-examine Dr Brian Hennessy's approach and implement again the strategies that worked effectively in the past.

(Anonymous, Australian Capital Territory, Submission #132)

Lack of resources and services is resulting in reinstitutionalisation of people with mental illness

It is becoming obvious, that persons who previously were treated within the mental health system are increasingly being shunted into the criminal justice system. People with mental illness must not be criminalised as a result of inadequate funding for the mental health system.

(Police Association of New South Wales, New South Wales, Submission #59)

This institutional model extends into the prison system. The Chair of the SA Parole Board has drawn attention to the high number of people with a mental illness in the State's prisons, saying the government was using them as a 'sump' for people who should be cared for by mental health services.

(SANE Australia, National, Submission #302)

Lack of funding and support for critical services provided by NGO's

There has been a rapid devolution to NGOs in NSW but the degree of funding is very poor. In fact, what governments have devolved to NGOs is the problem! Such devolution is unacceptable if NGOs do not have the capacity nor the resources to deliver the necessary services. There are huge gaps in clinical services, case management.

(Consumer Advocate, New South Wales, Parramatta Forum #3)

Rather than calling for a return to hospital and institutional care, the Alliance calls for real investment in the community and in community-governed organisations. People with mental illness want to live in the community – not in hospitals. They have a right to housing, employment and to flexible treatment and support. Queensland has an urgent need to exploit the potential of the non-government sector in providing recovery-focused services, which are cost effective and respect the rights of people affected by mental illness.

(Queensland Alliance of Mental Illness and Psychiatric Disability Groups, Queensland, Submission #218)

Distribution of resources

…(people making decisions about the distribution of resources) need to ask challenging questions such as 'serious to whom?' and 'serious through whose eyes?'

(Consumers, Victoria, Submission #194)

Need for more graduate programs and supervision for mental health nurses

The situation with regards to training of mental health nurses is also of grave concern… There are too few new and younger graduates coming through the generic nursing degree streams, who either interested in, or have enough training for mental health nursing. As the population of mental health clients seems to be escalating, concurrently the population of trained and experienced staff to deal with them seems to be falling. If this situation continues the welfare of patients will be at risk and consequently, the community also.

(Clinician, Victoria, Submission #201)

Problem with 'custody and control' model of care

Culture of control, not therapeutic engagement. The WA mental health system has evolved within the treatment model, excessive use of medication and routine use of police in dealing with patients. There is room for debate on the attitudes and practices of mental health service workers and whether these social norms support punitive handling of mental health consumers.

(Health Consumers' Council WA, Western Australia, Submission #29)

Affordability of care and access to psychiatrists and psychologists

Another factor in mental health consumers 'missing out' on appropriate services and timely treatment is the users pays system. Many simply cannot afford the cost of luxury 'private' services and many cannot afford the cost of private health insurance. Health insurance is becoming more and more out of reach for the 'average' Australian, let alone for someone who tries to exist on a disability support pension.

(Clinician, Queensland, Submission #105)

Fear of repercussions for 'speaking out' on mental health issues

HACSU members, although acutely aware of the issues, are often unable to articulate the problems they confront on a daily basis as they attempt to provide mental health services. Government policy, conditions of employment and fear of negative repercussions often prevent workers speaking publicly about the difficulties they face.

(Health and Community Services Union, Victoria, Submission #220

5.10 STANDARD 10: DOCUMENTATION

Clinical activities and service development activities are documented to assist in the delivery of care and in the management of services.

Concern was expressed that documentation systems to assist in the delivery of care or in the improvement of service delivery are not being adhered to. Some consumers, carers, clinicians and service providers reported that sometimes clinical records and individual care plans are not comprehensive or reliable and that documentation systems are not accessible to allow continuity of care across settings, programs and time.

Furthermore, it was suggested that the information that is available is not used to inform decisions related to treatment and support. Instead decisions are made for 'economic reasons' rather than having a clinical basis.

Submissions also suggest that data collection is time consuming and that the administrative burden is increasing at the same time as staffing and resource levels are diminishing. This as appears to create further barriers to the completion of documentation as required by the Standard.

Consumers were frustrated that they were asked to continuously repeat their stories. This suggests that documentation is not being accessed to provide continuity of care, and therefore essential information is not being relayed back to clinicians.

Some submissions suggested that treatment plans are not being followed because they are not being recorded. Others reported that community treatment orders are being abandoned due to the amount of time to complete paperwork associated with such treatment plans.

Concern was raised with regard to inferences drawn from data collected to assist with the management and planning of service delivery. It was suggested that different indicators and outcomes need to be utilised as markers of improved service delivery and outcomes for consumers.

Nationally, the key issues relating to this Standard include:

- Lack of coordinated, comprehensive and accessible documentation systems (Standard 10.2 - 10.5);
- Lack of comprehensiveness of documentation (Standard 10.2, 10.3 and 0.6);
- Clinical documentation failing to provide a comprehensive, factual and sequential record of treatment and support (Standard 10.5 and 10.6);
- Problems with the management of documentation (Standard 10.1 and 10.2);
- Concerns about the type and quantity of data collected to assist in the delivery of care and management of services (Standard 10.9);
- Documentation systems not being utilised to corroborate carers' pleas for access (Standard 10.4);
- The system does not allow continuity of care across settings (Standard 10.2); and
- Lack of communication between services and programs to ensure continuity of care (Standard 10.8).

The following selected quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 10. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

> **Concerns about the type and quantity of data collected to assist in the delivery of care and management of services**
>
> *There is no reliable data collection program as yet, despite the time spent by clinicians collecting information. Decisions appear to be made based on economic rather than clinical reasons.*
>
> (Anonymous, Tasmania, Submission #254)
>
> *The administrative burden is ever increasing. I have worked for 30 years in the public system and there has been a steady creep of administrative duties but now it's out of control and on top of that there are fewer administrative staff to assist us.*
>
> (Anonymous, New South Wales, Submission #303)
>
> *My daughter recently left hospital and we had no contact from the hospital to inform us that our daughter had actually been discharged. I had no idea where she was or when she had been released. The authorities had placed a community treatment order on her for the next 12 months which we thought was a good thing because at least she would get some care however the psychiatrist took her off that order after 2.5 months complaining about the level of paperwork required as part of the process.*
>
> (Carer, Mother, Victoria, Footscray Forum #10)

Clinical documentation failing to provide a comprehensive, factual and sequential record of treatment and support

Treatments discussed were not acted because proper treatment notes were not recorded.

(Carers, Parents, New South Wales, Submission #106)

…there did not appear to be an updated, clear and continuous treatment plan for [X] in the period of admission prior to his death. …the availability of a continuously updated care and treatment plan with a multidisciplinary input is important. It must be clear, unequivocal and available to all persons who need access to it. (Excerpt from Report of findings by the Chief Coroner)

(Carer, Partner, Australian Capital Territory, Submission #305)

In one instance, a patient was on 15-minute sightings, which were noted in the file from 0900 to 1050. The problem was that the patient jumped in front of a train at 0910. No accountability occurred or fault was found. The parents were devastated especially after the police contacted them, they phoned the hospital and were told he was okay when in fact he was dead.

(VMIAC, Victoria, Submission #332)

Several months following the creation of the Coordination Committee there was an audit of the activities of the ward by a senior nurse manager and the professor of mental health nursing. It found that although some of the changes introduced have been maintained a number had been modified or abandoned… Hand-over sheets, information sheets to patients, allocation files, medication sheets, information boards were rarely used and not fully replenished or when used were not completed systematically or consistently.

(Professor of Mental Health Nursing, Western Australia, Submission #33)

Lack of coordinated, comprehensive and accessible documentation systems

My brother has done the hospital shopping in Perth looking for help. What this means is that his current case notes are not available, the person (Me) who supports and follows his medical care and history, has been until now unable to speak with doctors to share valuable, timesaving, costsaving information that would support my brother more effectively with his care.

(Carer, Sister, Western Australia, Submission #101)

The system does not allow continuity of care across settings

The system is stuffed and so difficult for consumers to navigate. People have to tell the stories over and over again to a range of different people. They should only have to tell their story once.

(NGO Worker, South Australia, Adelaide Forum #24)

The after hours psych services number in this region is switched through to a town 100km away, and then the consumer's issue is not referred back to the local nurses;

(Coordinator, Grampians disAbility Advocacy Association, Victoria, Submission #212)

Problems with the management of documentation

I do not like people keeping records about me behind my back that they share with absolutely everyone but me and the people I designate as my supporters. These things make recovery SO MUCH harder. (author's emphasis)

(Consumer, Australian Capital Territory, Submission #287)

Documentation systems not being utilised to corroborate carers' pleas for access

> *In the past I have gone to see CAT [Crisis Assessment and Triage] team Triage in hospital ER room where my file has not been available, when I know that this particular hospital Mental Health Triage was set up with access to a key in the ER to make files available as people are seen in crisis there.*
>
> (Consumer, Victoria, Submission #112)

5.11 STANDARD 11: DELIVERY OF CARE

Principles guiding the delivery of care: The care, treatment and support delivered by the mental health service is guided by: choice; social, cultural and developmental context; continuous and coordinated care; comprehensive care; individual care; least restriction.

Information received via submissions and via presentations at forums suggests that treatment and support services are not being delivered according to the six principles of care outlined under this Standard. Reports of lack of treatment and support services (see Standards 11.1-11.6) and limited access effectively meant that for many consumers there were no options to consider and hence no choice.

Additionally, options were further restricted due to lack of available clinicians, long waitlists and lack of bulkbilling clinicians. The scarcity or inability to afford to pay for psychologists also limited treatment and support options. Lack of supported accommodation and housing options also limited choices. These difficulties suggest that care is not comprehensive (i.e. not available throughout the lifespan and not available during onset, acute, rehabilitation, consolidation and recovery phases) and is not tailor-made to reflect each individual's needs. An inability to access services prior to the need for acute care also meant that many consumers were not able to select the most appropriate option in the most empowering setting.

Deteriorating mental health and the need for acute care often resulted in the need for sedation, restraint and seclusion; the maximum restriction of rights. Some consumers entered the criminal justice system due to an inability to access treatment and support services, also reflecting a maximum restriction of rights.

Lack of appropriate treatment and support services for youth, the elderly and the lack of culturally appropriate services for Indigenous people and people from a Non-English Speaking Background also suggests that some services are not being guided by the 'social, cultural and developmental context'.

Nationally, the key issues under this universal Standard outlining the principles underlying care, submissions and presentations indicate concerns about:

- lack of access to any care (and therefore no choice);
- the lack of individualised and continuous care in mental health services;
- lack of coordinated care (due to problems of services, limited resources and crisis response-driven access);
- lack of services for youth, the elderly, people from a non-English speaking background and Indigenous people;
- social and cultural needs of Indigenous communities are not guiding the delivery of care to Indigenous consumers and their families ;
- services unable to respond in a flexible manner to changing need or diverse needs for individuals;

- lack of comprehensive care (due to an inability for consumers to access services during the onset phase, lack of access to rehabilitation services, and an overall inability to access mental health services);
- reports of a focus on containment and control (treatment and support is not the least restrictive)
- restriction of rights;
- restrictive approaches in the least empowering settings; and
- the fragility of the 'whole package of treatment and support' needed to promote and protect the rights of people with mental illness to participate socially and economically in the community.

The following selected quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 11. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

The lack of individualised and continuous care in mental health services

I am writing to say how difficult it is as a carer to source appropriate and continuous support mechanisms within the public health system for the recovery of a mentally ill patient. That is to say that the medical and psychosocial models have to operate in parallel, not serially, and that the psychosocial rehabilitation infrastructure has to offer a level of service which provides continuity so that planned rehabilitation activities can be sustained instead of a scattergun approach.

(Carer, Mother, Victoria, Submission #280)

More funding to make it possible for programs to be developed and tailored to individualised needs to make it possible for suffers to become worthwhile participants in the community.

(Carers, Parents, Victoria, Submission #241)

We are a group of community workers with a vast experience in their area of mental health and mental health and the ageing… Since deinstitutionalisation occurred in the 1980s, we believe that the pendulum has swung to far in the other direction whereby a number of sufferers do not have options open to them if their illness is so severe that they are unable to sustain living in the community with medication only.

(Social Worker and Team Leader, Victoria, Submission #236)

Services unable to respond in a flexible manner to changing need or diverse needs for individuals

It seems that the decision of treatment is entirely taken out of the hands of the family or carer and left to the sufferer. In most cases to find their own cure. The Public Mental Health System at present - processes people – they do not treat patients individually with the good will and respect that they deserve. The system we have is only too willing to allow this process to continue. In my opinion no other method of treatment is considered, or recommended in the Public Health System. The exception being pharmaceutical methods where there is limited explanation of how much and how often to take the prescribed medication and their possible side affects. The message to us was that you can't help those who won't help themselves. Yet people suffering mental illness are less able to help themselves.

(Carer, Mother, Queensland, Submission #81)

Restrictive approaches in the least empowering settings

Restraint practices across the state appear to be often cruel harsh and in many cases, in breach of the WHO guidelines re least restrictive environment.

(Academic, South Australia, Submission #142)

Social and cultural needs of Indigenous communities are not guiding the delivery of care to Indigenous consumers and their families

Extreme stress on the resources available, allowing very little capacity to develop culturally appropriate and meaningful services, which are Anangu driven.

(Anonymous, Northern Territory, Submission #271)

Lack of coordinated care (due to problems of services, limited resources and crisis response-driven access)

They must be [an] emergency to be admitted, if not the already overburdened and underfunded / resourced community teams have to try and maintain them, but in reality it is more likely to be the family / carer and the GP. There is no room for innovation, just relentless grind: the culture of therapeutic nihilism is now deeply ingrained. Staff fight with staff, barriers to service access are getting higher and higher.

(Consumer Advocate, Western Australia, Submission #338)

Surely it would be better to keep mental health people here in this town where they are close to their family and support. This doesn't happen because there is not the facility for their care therefore they are sectioned and sent off.

(Anonymous, Western Australia, Geraldton Forum #96)

Lack of access to any care

Another unsatisfactory situation that exists is when someone 'phones the AC Team for advice regarding a psychotic patient, invariable the advice is 'phone the police'.

(Carer, Wife and Mother, Queensland, Submission #52)

I am concerned that I, who see my role as my daughter's protector and nurturer, had to call the police on my daughter, because she could not be treated by the mental health system. I am concerned that the Eastern Area Mental Health Service was totally inadequate in dealing with the situation and left the police and emergency services and casualty departments to deal with a mental health problem. I am amazed at the amount and cost of public resources that were consumer in 'managing' her behaviour while she was untreated – police, ambulances, lawyers, courts, accident and emergency rooms. You can add to this the resources used in supporting her family – private counselling, Victims of Crime, the court system. This is in stark contrast to the negligible resources used in addressing the situation and in treating her.

(Carer, Mother, Victoria, Submission #307)

Lack of comprehensive care (due to an inability for consumers to access services during the onset phase, lack of access to rehabilitation services, and an overall inability to access mental health services)

The standards of service vary from adequate to excellent in the major cities around this country, to almost nothing existing in rural Australia. When services can be accessed, the issue of the quality of the service offered has caused us some concern.

(blueVoices, National, Submission #355)

I have had session times allocated which were constantly being changed from 1/2 hour appt that were made to a 10 min. session… When I would say "you and I both have a copy of the letter stating duration of sessions" I was told "we don't care, we don't have the time"?

(Consumer, Victoria, Submission #112)

> *Like all health care, we have serious concerns about the adequacy of the mental health workforce and its ability to treat people in a timely and appropriate manner. The shortened length of stay all too often results in people being discharged, with referrals to all over stretched community mental health services. The burden on the individual and their family is huge, as the individual may not receive the type and quality of treatment required. Conditions remain untreated and the severity of the illness increased – at times with disastrous consequences.*
>
> (Australian Nursing Federation (Vic Branch), Victoria, Submission #322)

> *We are fortunate that she becomes a danger to herself and others when acutely unwell otherwise she would probably receive no treatment at all.*
>
> (Carer, Mother, Victoria, Submission #299)

Lack of services for youth, the elderly, people from a non-English speaking background and Indigenous people

> *Considering the high rate of suicide amongst young people in Australia I find it absolutely appalling that when people do seek treatment and assistance they are refused, given minimal attention or are treated poorly by being labelled as being malingerers*
>
> (Clinician, Queensland, Submission #105)

5.11.1 STANDARD 11.1: ACCESS

The MHS is accessible to the defined community.

Serious concerns were expressed in every State and Territory about the increasing inability of consumers to access mental health services when needed. It seems to be necessary to wait for a crisis to occur before treatment and support can be accessed. Of particular concern were reports of difficulties in obtaining assistance when consumers were at risk of self harm or injuring others. Often, a police response was the only response available. To this extent, the police were frequently referred to as the ‘de facto mental health service’.

In rural and regional areas, reports described access difficulties of enormous proportions and reliance on the police was even higher due to diminishing services and increasing reliance on telephone triage. The combined factors of deteriorating mental health (due to the inability of consumers to access treatment and support) and increasing reliance on police was also reported to be contributing to the increasing representation of people with mental illness in the criminal justice system.

Access to services was reported to be limited, and in some cases non-existent, for certain consumers. For example, consumers with: intellectual disability; personality disorders; drug and alcohol problems; complex needs; dual disability; a history of past sexual abuse; or a past forensic status. Appropriate services were also reported to be limited for Indigenous consumers, consumers from a Non-English Speaking Background and consumers who were elderly. Access to psychiatrists, psychologists and rehabilitation services were also noted to be difficult.

Nationally, the key issues relating to this Standard include:

- inability to access services when needed (Standards 11.1.1-11.5, 11.1.8, 11.1.9);
- a crisis is required before services can be accessed (Standards 11.1.1-11.1.5);
- concerns about inability to access services during a crisis (Standard 11.1.4);
- access being limited to those with ‘serious mental illness’ (Standards 11.1.1 and 11.1.5);
- no or limited access to services in regional and rural areas (Standard 11.1.1-11.1.5);

- access problems in remote areas (Standard 11.1.2, 11.1.3 and 11.1.4);
- lack of access to care in regional areas – transportation issues (Standards 11.1.2-11.1.5);
- problems when phone service is the only contact with mental health services (including problems with telephone triage) (Standard 11.1.1 and 11.1.3-11.1.5);
- operational policies which limit access (opening hours and mode of contact) (Standard 11.1.4, 11.1.8 and 11.1.9);
- problems with access after hours (Standard 11.1.4);
- police response is the only response – police are the de facto mental health service (Standard 11.1.4, 11.1.8 and 11.1.9);
- lack of access to care - "right to get care, not be arrested" (Standard 11.1.1-11.1.5);
- lack of access to treatment resulting in entry into the criminal justice system (Standard 11.1.8 and 11.1.9) ;
- access denied due to past forensic status (Standard 11.1.1);
- access denied due to history of sexual abuse (Standard 11.1.1);
- access denied for consumers with intellectual disability (Standard 11.1.1);
- access denied if consumer has dual disability (Standard 11.1.1);
- access difficulties for people in detention centres (Standard 11.1.1, 11.1.2, 11.1.3 and 11.1.5);
- lack of access to treatment and support services for people with personality disorders (Standard 11.1.1);
- lack of services for people with mental illness and complex needs (Standard 11.1.1);
- concerns about attitudes towards Indigenous people (Standard 11.1.1, 11.1.2, 11.1.3 and 11.1.5);
- carers concerns are being ignored (Standard 11.1.2);
- long waitlists or no clinicians available at all (Standard 11.1.4 and 11.1.8 and 11.1.9);
- problems with access through emergency departments (Standard 11.1.2, 11.1.3, 11.1.4, 11.1.8, 11.1.9);
- lack of services for youth with drug and alcohol problems (Standard 11.1.1, 11.1.2, 11.1.5);
- general difficulties in accessing care if new to the system (Standard 11.1.1, 11.1.6, 11.1.8 and 11.1.9);
- accessing services 'out of area' (Standard 11.1.3);
- problems for consumers from a non-English speaking background (Standards 11.1.1 and 11.1.5);
- no access to treatment and support for consumers who are elderly (Standards 11.1.1 and 11.1.5);
- limited access to people from low socio-economic backgrounds (Standards 11.1.1 and 11.1.5);
- difficulty accessing psychiatrists and psychologists (Standard 11.1.1, 11.1.2, 11.1.3, 11.1.5 and 11.1.9);
- lack of access to psychologists for those who can not afford to purchase care in the private sector (Standard 11.1.1, 11.1.5, 11.1.8 and 11.1.9); and
- lack of access to private psychiatrists, GPs, counsellors and rehabilitation services (Standard 11.1.2 and 11.1.3).

The following selected quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 11.1. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

A crisis is required before services can be accessed

We do not know how many patients have committed suicide as a result of being denied a service, but we have heard reports of individuals who have successfully suicided shortly after being refused hospitalisation and being left to fend for themselves. Additionally, we have had quite a number of patients tell us that they took an overdose or slashed their wrists as a means of gaining hospitalisation. Our feedback also indicates that many patients are just left to deteriorate until such time as they finally get admitted in a much worse state than was necessary.

(VMIAC, Victoria, Submission #332)

Whenever I contact the CAT [Crisis Assessment and Treatment] team for one of our clients the response is always "are they at risk of harming themselves or someone else" and the answer is no. You can't get help then. If they aren't in crisis they don't get help.

(Carer and Disability Accommodation Service Provider, Victoria, Melbourne Forum #9)

I know of no other illness where we wait until the person needs the intensive care ward and their family is in chaos before we address it.

(Carer, Mother, Victoria, Submission #307)

Concerns about inability to access services during a crisis

…daughter-in-law who was seriously mentally ill but had difficulty accessing care. She attempted to jump off a moving ferry, she said the voices told her to jump off. She was finally transported to hospital at 10am and assessed by the mental health assessment team. She was then sent home in a taxi and murdered her nephew.

(Family Member, Queensland, Rockhampton Forum #2)

I was once a very depressed, suicidal individual and the government hospitals and health care systems did absolutely nothing to help me when I was screaming out for help at the time!

(Consumer, Queensland, Submission #73)

Inability to access services when needed

Throughout our consultations people have spoke of the difficulties they have accessing the mental health services they feel they need, both in acute and community care. In acute care, consumers have spoken of being refused hospital beds even though they were at a crisis point, only to be admitted a few days later in an acute psychotic state. They tell stories of fronting at emergency departments of hospitals, only to be turned away without being properly assessed by a doctor and without being given any advice or assistance. They speak of their general practitioners refusing to believe they were hearing voices and of CAT teams visiting and quickly leaving because they determined 'you're not going to hurt yourself or someone else'. There is a clear picture that emerges—help is reserved for the most psychotic episodes only and that prevention or early intervention is of a low priority. Acute psychiatric services are under-funded, rationing access to a point where people have to beg for assistance.

(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

Recently a friend of mine went to hospital willingly and was turned away. So out of sheer frustration with not being able to get help she picked up an ashtray and threw it at the window and smashed it. They called the police. They took her to the police station and called the Crisis Assessment Team (CAT) who then admitted her! It's a joke that someone has to do something like that to get care.

(Consumer Advocate, Victoria, VMIAC Forum #5)

Staff also describe a "Revolving Door Syndrome" where only short-term crises are dealt with and long-term structured support for clients is not obtainable.

(Anonymous, Tasmania, Submission #254)

Challenging behaviours – people are often turned away from the system and don't get care because of the 'behaviour problem' but often the behaviour is a result of the frustration of the consumer not getting care.
(Service Provider, Northern Territory, Alice Springs Forum #16)

A lot of my clients I see come to me with bad experiences they have had when trying to access care. It's a sad reflection on the system if it is making people more traumatised!
(Clinician, Queensland, Brisbane Forum #20)

Psych disability rehab support sector – our services are funded to provide support to a group of people – the demands on our services always exceed the target but in the past we have worked hard to deliver as much as we can. We have continually raised this with the mental health branch as a problem that needs addressing but we've had no success. So we have been left with no other option but to make the decision to work to target only. This is very difficult because now there are people who need our service and now can't access it. To not be able to access services is a breach of people's human rights.
(Anonymous, Victoria, Morwell Forum #4)

Police response is the only response – police are the de facto mental health service

The fact remains that police, being the 24 hour, 7 day a week, mobile and free public service that they are, usually means that the residual problems of the community are left for them to handle when they have neither the resources nor the knowledge to adequately do so.
(Police Association of New South Wales, New South Wales, Submission #59)

'On one occasion we were told to by the CATT to phone the police, the police came, two officers spent almost a day with my family members, gradually got him to cooperate and to agree to going to the PSU [Psychiatric Support Unit]. But at no stage during this day as far we know, did mental health services assist the police.'
(Mental Health Community Coalition Consumer and Carer Caucus,
Australian Capital Territory, Submission #342)

A contradiction arises, however, because the police feel that their job is to step in only when action is deemed necessary, usually when someone is in danger or breaking the law. Police do not feel, and rightly so, that it is their role to provide psychotherapy, counselling or aid and comfort for the lonely and confused. This is the job of mental health professionals, a group whom police see to some extent, as abdicating their responsibilities. Police see the responsibilities thrust upon them as they are – they are being asked to shoulder duties no one else wants or can manage.
(Police Association of New South Wales, New South Wales, Submission #59)

As a carer of a daughter with a mental illness my husband and I were forced to call police for help because we couldn't get any other response. The police were wonderful but after an 8 hour wait to be assessed the local hospital said they couldn't deal with her and she was sent to Perth to a secure ward. She was very quickly discharged and now we are dealing with the same situation again. Where do we go for help when there is no help?
(Carer, Mother, Western Australia, Bunbury Forum #10)

Problems with access after hours

As to crisis services – what crisis services – consumers are usually told to have a cuppa and go to bed. The service closes at 10pm and consumers simply cannot revolve their crisis around mental health service timeframes, which we are continually expected to do. I've even had staff tell me the consumer can go to Life Line if they're in crisis, who happen to be volunteers are not clinicians and cannot make mental health assessments. If Life Line counsellors refer consumers back to the MHS the consumer within a couple of hours are back onto the phone with Life Line – because at least a Life Line counsellor will try and listen to what is actually happening to the consumer.
(Consumer and Consumer Advocate, New South Wales, Submission #8)

No or limited access to services in regional and rural areas

I took someone who was suicidal up to the mental health service and they didn't do anything – there didn't appear to be any protocols in place. Where are we supposed to take someone when they need care?

(Carer, New South Wales, Broken Hill Forum #11)

How much does it cost to transport a patient by Ambulance to Perth? There are no doctors available here in Bunbury on nights or weekends so they send us to Perth! What have we got for a MH system? Nothing, absolutely nothing!

(Consumer, Western Australia, Bunbury Forum #1)

I can support what the police office said earlier about people who have been transported by the police to Graylands hospital often beating the police back to Bunbury!

(Mother, Western Australia, Bunbury Forum #22)

Lack of access to care - "right to get care, not be arrested"

My brother suffers from bipolar disorder… But I would like to comment on the fact that people with a mental illness are being arrested because often it's the only way they can get any help. They have a right to get care, not be arrested. We've got to get access to early intervention programs but it doesn't happen – now my brother is in the court system, not because he's bad but because he's got a mental illness.

(Carer, Sister, Western Australia, Bunbury Forum #24)

He tried cutting down on his antidepressant tablets when he was living in Salisbury about five years ago. He was bed ridden and physically ill in his attempt. He was crying out for help. He rang Glenside a few times and tried to convey to them by phone his desperate situation. His frustration in being dismissed combined with his lack of verbal and social skills resulted in the opposite from obtaining help. Again [X] faced court and was charged with abusive language. The system that should have protected [X], failed him.

(Carer, Mother, South Australia, Submission #195)

Problems when phone service is the only contact with mental health services (including problems with telephone triage)

Carers in some of these remote rural areas have reported having a crisis at midnight on a Friday. When attempting to contact SW24 they have told me the service has advised them that their problem will be forwarded to the clinicians who they know will not be in the office until the following Tuesday. When they explain this they are often asked to take the person they are concerned about to the nearest health facility which will handle psychiatric emergencies. Again for many this may be Bunbury which is located over two hundred kilometres away, further should they be able to get to Bunbury they are often told they can not be seen and are sent onto Perth a further two hundred and forty kilometres. Should this not be possible their alternative is to contact the local police, who are for most at least fifty kilometres away and usually only have one officer on duty, who then has to choose between leaving a town with out a service for what may turn out to be a ten hour round trip to Perth or advise the family they can not attend and this leaves them to fend for themselves. Although on the surface a 24 hour call services appears to be an effective means of offering support to people it is in fact only able to offer information which in most cases the person is already aware of, but it has very limited if not non existent ability to offer "hands on" or "face to face" practical assistance."

(NGO Service Provider, Western Australia, Submission #45)

Problems with access through emergency departments

At the beginning of this year, I began to suffer debilitating depression and eating disorder symptoms. I sought help in the Emergency department of Flinders Medical Centre three times. The first time I sought help there, I waited well over 3 hours to be seen, then was admitted and left in "Extended Emergency Care Unit" for 3 days, then discharged because there were no beds available in the Psychiatric Ward. The second time I presented, I gave up after a day in the EECU. I was on the waiting list for a bed, and after a number of weeks and another presentation to FMC Emergency, I finally got admitted.

(Consumer, South Australia, Submission #158)

No access to treatment and support for consumers who are elderly

It is harder for older people to gain admission to a system which is responsive to danger and acute suicidality. If you are an older person at home quietly depressed and not eating and just fading away it's much harder to get an urgent admission.

(Anonymous, New South Wales, Submission #303)

Lack of access to treatment and support services for people with personality disorders

Assessment, treatment, engagement, case management and care for people diagnosed with borderline or thought to have personality disorder continues to be a failing of mental health services in the ACT. People with personality disorder are reported to be still frequently denied service. They are reported to be another group that frequently ends up in the criminal justice system.

(Mental Health Community Coalition Consumer and Carer Caucus,
Australian Capital Territory, Submission #342)

…people with Borderline Personality Disorder who have been chased, sometimes in seriously undignified and persecutory ways, out of the public mental health system that they are as entitled as anyone else to use.

(Consumer, Victoria, Submission #203)

Carers concerns are being ignored

In this regard it is a reactive system, whereby consumer's rights take precedence over their welfare to an utterly illogical extent and something bad has to happen before something can be done. It fails them, it fails carers and it fails the community. For my son and others, who, like him do not recognise when they are unwell it means that by the very nature of their illness, when they are unwell, they are unable to access, accept and use voluntarily available treatment. This leads me to the belief that a mentally ill person's fundamental right to treatment and care should transcend all other considerations even when they are not well enough to seek treatment themselves.

(Carer, Mother, Victoria, Submission #178)

Carers are often best placed to notice subtle changes in the person for whom they care, and usually the first to notice the early warning signs of a relapse. However health professionals usually do not recognize the value of this information, and in fact when carers try to pass on this information it is often ignored. This can lead to additional problems for carers and a full blown episode for the consumer often with devastating consequences. Unfortunately it is the carers who usually bear with the consequences of a relapse not the health professionals.

(Peninsula Carers Council, Victoria, Submission #321)

Access being limited to those with 'serious mental illness'

There are concerns that the Mental Health Act is often used as a convenient excuse to provide no service to a person in need of treatment, simply because they don't meet the criteria for coercive treatment.

(Eastern Area Interagency NSW, New South Wales, Submission #100)

Lack of services for people with mental illness and complex needs

> *People with more complex issues such as homelessness, drug and alcohol issues, being diagnosed with Borderline Personality Disorder or have aggressive behaviour find it more difficult to access support and clinical services. This difficulty can be due to services wanting to transfer the responsibility to other sectors, stating that the diagnosis does not fit their criteria (particularly BPD), or stating they do not have the capacity/flexibility to work with this population.*
>
> (Western Region Health Centre, Victoria, Submission #292)

5.11.2 STANDARD 11.2: ENTRY

The process of entry to the MHS meets the needs of the defined community and facilitates timely and ongoing assessment.

Concerns were expressed nationally about the increasingly difficult procedures associated with entry to mental health services. The result has been delays in assessment and assessments occurring in inappropriate settings. Reports were received that in some areas there are now only two real options for entry into the system: (1) entry via emergency departments or (2) telephone triage. Both options were described as problematic.

For entry via emergency departments, problems include: long wait times; the absence of appropriately qualified mental health professionals; and an inappropriate setting in which to conduct assessments.

For entry via a phone service (especially when this was the single point of entry), problems included: difficulties for people without phones or where mobile phone coverage did not exist; calls not being free of charge; forwarding of information to offices where clinicians would not be attendance for long periods of time (sometimes several days); and suggestions to callers to contact the police or to go to the closest emergency department.

Excessive wait times were also reported between time of referral and assessment, and assessment and diagnosis. Submissions indicated that initial assessments of urgent referrals are not commenced within one hour of initial contact as specified by this Standard.

Nationally, the key issues relating to this Standard include:

- problems with entry via Emergency Departments and triage services (Standard 11.2.4, 11.2.6, 11.2.7-11.2.12);
- concerns about long waits with entry via emergency departments (Standard 11.2.12);
- problems when a phone service is the only entry point to the system (Standard 11.2.3, 11.2.4, 11.2.5, 11.2.6, 11.2.7, 11.2.8, 11.2.9, 11.2.11, 11.2.12);
- excessive amount of time between time of referral and time of assessment (Standard 11.2.12);
- concerns about the amount of time between the assessment being undertaken and a diagnosis being made (Standard 11.2.11); and
- lack of appropriately qualified mental health professionals to assist with entry (Standard 11.2.6).

The following selected quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 11.2. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Problems with entry via Emergency Departments and triage services

People with a mental illness also have to go through the accident and emergency department – they have difficulty in getting assessed.

(Anonymous, Queensland, Rockhampton Forum #13)

When clients come through triage the client has to tell their story 5 or 6 times before they get to see a psychiatrist. I cannot, as a worker in the community, leave the client – they'll leave if I don't stay with them through the process – they have no other continuity.

(Clinician, Queensland, Rockhampton Forum #15)

Can you imagine going to emergency department with a Paranoid Psychotic patient who is being admitted involuntary, having to sit with open doors, [and the] TV is always on in the ED [Emergency Department] waiting room (my loved one receives messages via the TV; e.g. he's dead, he has killed someone, run over someone)? [He is] paranoid and suspicious of other people. He has lots of enemies. Isn't the trauma and stress great enough without this not being a safe place for both them and the other people in emergency?

(Carer, Mother, Victoria, Submission #242)

Concerns about the amount of time between the assessment being undertaken and a diagnosis being made

There is a single point of entry through the acute care team – they have an initial assessment and then a decision is made within a period of 4-5 weeks.

(Clinician, Queensland, Rockhampton Forum #7)

Problems when a phone service is the only entry point to the system

SouthWest 24 has been around for quite a while as a private company – it used to work reasonably well but the problems occurred earlier this year when it became the single point of entry into the system!

(Clinician, Western Australia, Bunbury Forum #19)

Lack of appropriately qualified mental health professionals to assist with entry

For an emergency you'd go to the hospital at Burnie and sit there for however long it takes. You've always got to go through casualty before you get into the service – even though he has a long history of mental illness. Then he sees a registrar who knows nothing about mental illness.

(Carer, Mother, Tasmania, Hobart Forum #15)

Concerns about long waits with entry via emergency departments

We knew by his symptoms and after talking with the staff in Monash Psychiatric Ward that there was nothing else that could be done except take him to Monash Hospital through the Emergency Department. The waiting room was packed with sick people and quite a few young children. After I had explained my son's problem we were told to take a seat and wait - we waited nearly five hours! Can you imagine waiting all that time with an acutely psychotic patient, who, for the first time in eighteen years recognised that he was very unwell and was making an attempt to 'hold himself together'? I'll never forget the experience. My son was so agitated. Several times he wheeled out the Emergency Entrance and tried to get in the Psychiatric Ward himself, with me in hot pursuit trying to tell him that he had to go through 'the right channels'… Whilst the doctor went off to arrange a trolley, my son made a frantic escape attempt and pulled the emergency ambulance door off it's hinges and was only saved from escaping and possibly harming himself by a very strong security guard… I believe that people with a psychiatric illness should be seen in a special emergency section reserved for them only - this could be attached (or very near) to the psychiatric ward of the particular public hospital. This would make it easier for the admitting psychiatrist to see the prospective patient in a quieter and less threatening environment and, hopefully, create a much smoother and quicker transition to the admittance procedure.

(Carer, Mother, Victoria, Submission #176)

> *The trend towards generalisation is such that now consumers have to wait for anything up to 4 days plus in the Emergency Department which is a totally inappropriate environment for consumers in an acute phase of illness, especially if suicidal or aggressive, to be in. There is simply not the space; the noise factor is high, lights continually on, plenty of instruments to harm oneself or another in Emergency Departments. God help you if you actually want to talk to a mental health clinician in an emergency department if it happens to be out of hours of the CNC [Clinical Nurse Consultant] who happens to work business hours and a five day week.*
>
> (Consumer and Consumer Advocate, New South Wales, Submission #8)

5.11.3 STANDARD 11.3: ASSESSMENT AND REVIEW

Consumers and their carers receive a comprehensive, timely and accurate assessment and a regular review of progress.

Concerns were expressed in all jurisdictions regarding the difficulties in obtaining comprehensive, timely and accurate assessments. Problems included the location of assessments (increasingly limited to emergency departments where the Standards specify a preference for home visits or a setting chosen by the consumer), excessive delays in organising assessments (up to 12 weeks), lack of appropriately qualified and experienced mental health professionals, and the disregard of information offered by carers and service providers.

Concerns were also expressed about assessments conducted over the phone and assessment procedures in rural and regional areas.

For consumers who were young, Indigenous or from a Non-English Speaking Background, concerns were raised about the appropriateness of the assessment tools used and the manner in which the assessments were conducted.

Reports were also received that assessments were continuously being conducted but accompanying treatment plans were not being developed and some assessments were focussing exclusively on “risk”.

Concerns were also raised with regard to the review process and that assessments were not being continually reviewed and that reviews were not occurring prior to discharge.

Nationally, the key issues relating to this Standard include:

- no notification of arrival for assessment and use of force (Standard 11.3.3);
- concerns about the quality of the assessment and review process (11.3.1, 11.3.2, 11.3.5, 11.3.6, 11.3.11, 11.3.12, 11.3.14, 11.3.17, 11.3.18, 11.3.19, Standard 11.3.20 and 11.3.21);
- problems with assessments in emergency departments (Standard 11.3.1 and 11.3.2);
- assessments focussing on risk only (Standard 11.3.5);
- problems with the review process (Standards 11.3.14-11.3.18);
- concerns about assessments conducted over the phone (Standard 11.3.1, 11.3.2, 11.3.5, 11.3.6, 11.3.13);
- assessment, admission, and immediate discharge (Standard 11.3.5, 11.3.8, 11.3.12);
- continuous assessments without any treatment (Standard 11.3.5 and 11.3.12);
- extended police involvement once at hospital for assessment (Standard 11.3.2, 11.3.20, 11.3.21);
- assessment problems in rural and regional areas (Standard 11.3.1, 11.3.2, 11.3.5, 11.3.6, 11.3.13, 11.3.20, 11.3.21);

- assessment problems for children and youth under the age of 18 with mental illness or and/mental health problems (Standard 11.3.1, 11.3.5, 11.3.6, 11.3.7);
- lack of opportunity to obtain a second opinion (11.3.18);
- the exclusion of people with complex needs (Standard 11.3.1, 11.3.5, 11.3.6, 11.3.7, 11.3.20, 11.3.21);
- carers and service providers not being involved or listened to during the assessment process (Standard 11.3.5);
- assessment problems for Indigenous people with mental illness or and/mental health problems (Standard 11.3.1, 11.3.6, 11.3.7, 11.3.9, 11.3.10);
- assessment concerns for people from a non-English speaking background (Standard 11.3.1, 11.3.6, 11.3.7, 11.3.9, 11.3.10);
- the need for consumers to have an advocate (Standard 11.3.5);
- long periods of time between reviews of involuntary orders (Standard 11.3.14, 11.3.17, 11.3.18);
- problems with staff workload and management of work (Standard 11.3.19); and
- large staff caseloads (Standard 11.3.19).

The following selected quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 11.3. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Concerns about the quality of the assessment and review process

As a GP who does a lot of mental health work and knows a lot of people in the system, I can get an assessment in 2 weeks if I pull strings – otherwise it is 12 weeks to get someone assessed.

(Clinician, Queensland, Brisbane Forum #7)

We question the practice of conducting minimal assessments, (those conducted in a few minutes) - it is our view that assessments must be thorough, and that unwell consumers can manage to hold it together during short assessments when it is harder to do so if an assessment is conducted with more time devoted to speaking with the person.

(Eastern Area Interagency NSW, New South Wales, Submission #100)

When our son did finally get to see Dr [Z], within one hour of entering the clinic he was pronounced miraculously cured, his diagnosis was changed to a behavioural disorder, he was given a three month supply of anti psychotic medication, told to go for a C.T. [Computed Tomography] scan and advised that he would be managed by his local GP from there. This despite the fact his local GP had absolutely no experience with him. However after spending seven years dragging our son to a clinic and dealing with his frequent episodes unassisted, to be told he has no condition other than a behavioural problem, lowers the science of psychiatry into the realm of the black arts… At the time of writing this letter we have still not been able to get our son to the C.T. scan clinic. He is so agitated and not well. I rang Armadale Hospital and asked them what to do (they said they would speak to Dr [Z]) this was four weeks ago no one rang back.

(Carer, Mother, Western Australia, Submission #13)

Carers and service providers not being involved or listened to during the assessment process

We know of 5-6 cases over the past few months. We don't wish to target Logan but we do wish to ensure that all Psychiatric Services including Logan lift their game to prevent further deaths. We point out that there has been a number of murders, police shootings / deaths in custody as a result of the initial assessment services not listening to the patient, patient's family and the police attempting in good faith to get help for the patient.

(White Wreath Association Inc, Queensland, Submission #81)

I was horrified to see my DSM [Diagnostic and Statistical Manual] classification that my stress-induced disorder was classified as Bipolar… The psychiatrist would not listen to me, would not read my diaries. I saw the psychiatrist several times but he wouldn't listen. My GP rang the hospital 5 times about my work-related stress. My psychiatrist would not see through the public system, and I was paying $275 to be put on Lithium. I was put on medication after only 1 episode, but this should not occur before adequate assessment.

(Consumer, Australian Capital Territory, Canberra Forum #3)

Problems with assessments in emergency departments

Now the PET [Psychiatric Emergency Treatment] unit asks you to bring the [unwell] person to the hospital. Previously the mental health nurses would come to the person's home to provide assessment and assistance. If a person is acutely unwell, it can be impossible to convince them to go to hospital. This leaves the police as the only resort, which is embarrassing and inappropriate. When you get to the hospital, there is only a junior doctor [i.e. registrar] on duty, as there is no senior doctor at the hospital anymore.

(Anonymous, New South Wales, Submission #156)

Ultimately, OH&S and economy-of-scale arguments can be extended to banning all community health centres and all home visits. The appropriate path is to make community work as safe as possible, to screen and divert most assessments and initiation of treatment away from Emergency Departments, and then use Emergency Departments in exceptional, highly ambiguous or emergency circumstances only, or to assess mixed medical/psychiatric emergencies.

(Clinician, New South Wales, Submission #351)

Some Emergency Department medical practitioners rely on Level 2 nursing staff for mental health and psychiatric assessments. To the best of my knowledge this is not the case for medical or surgical emergency presentations. In my opinion, credentialing may need to be reviewed in the case of any medical practitioner unable to undertake a bio-psycho-social assessment including mental state examination, risk assessment and management plan development. All of these issues, really, raise important questions in regard to strong clinical governance… (extract from a letter to the Office of the Chief Psychiatrist)

(Clinician, Western Australia, Submission #24)

The need for consumers to have an advocate

Patients should not have to find an advocate before they are believed.

(Carers, Parents, Victoria, Submission #275)

5.11.4 STANDARD 11.4: TREATMENT AND SUPPORT

The defined community has access to a range of high quality mental health treatment and support services.

Across Australia, consumers, carers, clinicians, service providers and advocates alike expressed serious concerns about the lack of treatment and support services available to consumers (a) in the community and (b) when acute care was required.

Submissions indicate that mental health services have not ensured access to a comprehensive range of treatment and support services that are specialised in regard to a person's age and stage of development, the consumer's stage in the recovery process, dual diagnosis and other disability, or for those subject to the criminal justice system.

Submissions suggest that either no services at all, or a limited number of services, catered to the needs of the following groups of consumers: people with intellectual disability; people with drug and alcohol problems;

people with physical disability; people with hearing impairment; people with Acquired Brain Injury; people with personality disorders; people with eating disorders; people who were homeless; children and adolescents; the elderly; and refugees.

Many barriers and difficulties were also reported for Indigenous people and people from a Non-English Speaking Background.

For consumers and carers living in remote, rural and regional areas, services were reported to be diminishing and deteriorating (due to lack of resources and staff and overburdened services) rather than expanding and improving.

For people with mental illness in the criminal justice system, there were problems with access to appropriate treatment and support services at entry (for court diversion purposes), when incarcerated or under community treatment orders, and when in the community post release. However, a submission was received providing an analysis of the outcomes and benefits of a court diversion program in South Australia.

Due to an inability generally to access treatment and support services during the onset, rehabilitation and recovery phases, and descriptions that treatment was often only available for acute emergency care, suggests that some mental health services are not providing the least restrictive and least intrusive treatment and support possible as outlined under Standard 11.4. Reports were also received indicating that often treatment and support is not developed collaboratively with consumers and other persons nominated by consumers.

Nationally, the key issues relating to this Standard include:

- lack of treatment and support services - only available when in a crisis (Standard 11.4.1);
- lack of treatment and support services generally (Standards 11.4.3 - 11.4.8, 11.4.12 and 11.4.13);
- lack of services for people living in rural and regional areas (Standard 11.4.1, 11.4.3 - 11.4.8);
- lack of support services for consumers to live in the community (Standards 11.4.3 - 11.4.8);
- lack of treatment and support services for Indigenous consumers and their families living in remote communities (Standard 11.4.1, Standards 11.4.3 - 11.4.8);
- lack of services for people with dual diagnosis - intellectual disability (Standard 11.4.7);
- lack of services for consumers with dual diagnosis - drug and alcohol (Standard 11.4.7);
- lack of services for consumers with hearing impairment (Standard 11.4.x);
- lack of treatment and support services for consumers who are homeless (Standard 11.4.6);
- lack of treatment and support services for consumers who are elderly and homeless (Standard 11.4.3 and 11.4.6);
- lack of treatment and support services for people with eating disorders (Standards 11.4.1 and 11.4.7);
- lack of appropriate treatment and support services for consumers subject to the criminal justice system (Standards 11.4.7);
- lack of appropriate treatment and support services for consumers after release from prison (Standards 11.4.1, 11.4.6, 11.4.7);
- lack of treatment and support services for children and youth (Standard 11.4.3);
- lack of mental health services for the elderly (Standard 11.4.3);
- lack of services for people with Personality Disorders (Standards 11.4.1, 11.4.6 and 11.4.7);
- lack of services for people with Acquired Brain Injury (Standard 11.4.7);
- lack of services for people with mental illness and physical disability (Standards 11.4.6 and 11.4.7);

- lack of services for consumers with hearing or both hearing and vision impairment (Standard 11.4.7);
- lack of services for people with complex needs (Standards 11.4.1, 11.4.3, 11.4.6 and 11.4.7);
- lack of services for refugees (Standard 11.4.4, 11.4.6 and11.4.8);
- difficulties in accessing treatment and support for consumers from a non-English speaking background (NESB) (Standards 11.4.6 and 11.4.8);
- limiting access to treatment and support by diagnosis (Standards 11.4.1, 11.4.4);
- difficulties for community-based offenders with mental health problems (Standard 11.4.7);
- problems for consumers subject to the criminal justice system (Standard 11.4.7);
- problems with forensic care and new forensic units (Standard 11.4.1, 11.4.7 and 11.4.10);
- concerns about relocating the provision of community treatment and support services to hospital settings (Standards 11.4.5 and 11.4.10);
- concerns about restrictive and intrusive practices (Standards 11.4.5 and 11.4.10);
- carers not involved or informed with the development or review of the individual care plan (Standard 11.4.9);
- resistance to involving consumers and carers in the planning of treatment and care (Standard 11.4.9, 11.4.11-11.4.13); and
- individual care plans not discussed with consumers and carers (Standard 11.4.9 and 11.4.11).

The following selected quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 11.4. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Lack of treatment and support services - only available when in a crisis

Clinical services leave clients till they are so unwell that they have to been hospitalised.

(Anonymous, Northern Territory, Submission #188)

Lack of treatment and support services generally

The thing that concerns me most is that moral judgements are made about our illness and used to exclude us from treatments, yet we are told that our illnesses are like diabetes, but no one with diabetes is told to just convince themselves to fix their insulin levels.

(Consumer, Tasmania, Hobart Forum #21)

On three occasions I have been taken by ambulance to a hospital in Melbourne, Victoria, after taking an overdose of medication. On all three occasions I was discharged after recovery in the accident and emergency unit. I was still feeling suicidal, I live alone without family and with no available support. I can only supply you with these skeleton details now, as I am feeling too distressed to write more about the incidents in depth.

(Consumer, Victoria, Submission #84)

Please, if you are aware of any services I could access for my daughter or myself, could you let me know, as I cannot accept the answer I have been given by a number of health care professionals - that if my daughter survives into her twenties, I will have done well !

(Carer, Mother, New South Wales, Submission #92)

We're in a crisis here in NT, particularly indigenous suicides.

(Service Provider, Northern Territory, Darwin Forum #1)

For the 35 days that our daughter was in the MHU, we often experienced poor internal communication in the ward. We were given incorrect information about our daughter's medications and levels; the Psychiatric Registrars, Doctors [Y] and [Z], were reluctant to contribute to our twice-weekly case meetings, and items that were to be noted for our daughter's treatments were not actioned.

(Carers, Parents, New South Wales, Submission #106)

Lack of support services for consumers to live in the community

My brother suicided in a hospital… My brother is just an example of what will happen to others who are failed by the system. People are placing too much faith in institutions – people need access to good quality community care without having their human rights abused. My brother had care at Rozelle but he didn't really qualify for that catchment area so he then had to go back to St George but there wasn't anything for him to do there.

(Carer, Sister, New South Wales, Sydney Forum #7)

I live in fear for my life most days. But, I won't turn him on the streets to be homeless. I am not sure what the answer is, the prison system seems to be were they all end up. There is no help there for them. Actually it is the worse place they can go as they are treated like animals.

(Carer, Mother, New South Wales, Submission #90)

Effectively, CTOs extend involuntary status into the community, and yet in many instances community supports are fractured and insufficient to assist the consumer.

(Centre for Psychiatric Nursing Research and Practice, Victoria, Submission #323)

Sure staff are busy but service isn't there – particularly when there is a dual diagnosis. He's referred back and forth.

(Carer, Mother, Northern Territory, Darwin Forum #2)

Lack of treatment and support services for children and youth

Parents have difficulty accessing limited child psychiatrists and psychologists for their disturbed youngsters. Adult facilities are inappropriate, overburdened and inaccessible. Early intervention and accurate diagnosis, stressed as priorities in the National Mental Health Plan 2003 – 2008, remain as rhetoric instead of reality.

(ARAFMI Tasmania, Tasmania, Submission #245)

I work with young people aged 13-18 years, but this is getting pushed out to work with people as old as 25. I provided 24 hour support to a 21 year old recently who couldn't get care anywhere.

(Service Provider, Australian Capital Territory, Canberra Forum #20)

We are letting young people down by not dealing with them properly. We need to provide services in the prison system if that is where they are going to end up.

(Service Provider, Australian Capital Territory, Canberra Forum #20)

Lack of services for people with Personality Disorders

People who have a personality disorder are rarely treated by mental health services due to this condition not being identified as a mental illness. People with a personality disorder/s often fall between service delivery gaps and due to their behaviour, at times their housing and mental health / well being needs are not met.

(Colony 47, Tasmania, Submission #227)

Borderline Personality Disorder is not untreatable. This is a myth and one we should get rid of. … Resources need to be fed into providing services for people with Borderline.

(Consumer, Victoria, Submission #203)

Lack of mental health services for the elderly

Another problem is the lack of dedicated facilities for older people with psychiatric disorders requiring admission. Older people don't mix well with younger people, particularly those younger violent patients who are taking illicit drugs and are psychotic. There are strong arguments for separate for separate facilities.

(Anonymous, New South Wales, Submission #303)

Lack of services for consumers with dual diagnosis – drug and alcohol

There are real problems with the lack of partnerships in dual diagnosis. Because I have a mental illness and use drugs I can't get care from anywhere.

(Consumer, NGO member, Victoria, Footscray Forum #6)

It is ORYGEN's experience that the lack of integration between drug and alcohol and mental health services in Australia has significantly contributed to the poor detection and treatment of mental illness amongst young people with substance abuse. This results in waste of resources and long-term psychiatric and substance use problems for individuals who could otherwise be helped.

(ORYGEN Research Centre, Victoria, Submission #258)

Failure to address issues raised by a Dual Diagnosis has left thousands of young people with mental illness floundering, unemployed, uneducated, unskilled and many of them in gaol or homeless. As a group they seem to have been thrown on the Mental Health scrap heap, regarded as having developed an illness which easily becomes too entrenched to treat. A number of our younger daughter's friends have suicided which has added to her distress. And now the 'law of diminishing returns' applies - this being the way one senior clinician put it to me. He was discharging our schizophrenic daughter from HDU in an Acute Inpatient Unit directly onto the street after her sixth hospitalisation.

(Carer, Mother, Victoria, Submission #299)

Lack of services for people with dual diagnosis - Intellectual disability

In recent years, OPA (Office of the Public Advocate), and other support organisations and service providers have raised concerns about the failure of the existing service system to meet the needs of people with dual/multiple disabilities… OPA observes the following continuing difficulties:

- *Despite the existence of substantial research data to indicate that people with intellectual disabilities are more at risk of developing mental illness than the general population (Hudson & Chan, 2002); gaps in service provision for people with intellectual disability and mental illness remain. People who have an intellectual disability are less likely to receive assistance from mental health services because they are considered to have behavioural problems attributed to their intellectual disability rather than to their co-existing mental illness.*
- *Service boundary issues; people with dual intellectual disability/psychiatric disability have difficulty accessing the mental health system, and intellectual disability services are often left to support people with dual/multiple disabilities without funding and with non-specialist staff.*
- *People with presentations that cross behavioural, psychiatric and intellectual disability boundaries are often the subjects of service boundary disputes about which service should provide 'the' service to these clients.*

(Victorian Office of the Public Advocate, Victoria, Submission #284)

Lack of appropriate treatment and support services for consumers subject to the criminal justice system

As psychiatric services struggle to respond to the needs of the mentally ill the criminal justice system becomes a substitute. Prisons are now accommodation for more mentally ill people. How many will remain incorrectly diagnosed and return to the community without psychiatric treatment? Adolescents detained in Ashley detention centre present with mental health issues. The criminal justice system is a bleak future for their young lives.

(ARAFMI Tasmania, Tasmania, Submission #245)

My primary concerns in relation to mental health, are the extremely high rates of incarcerated women (and men) with both diagnosed and undiagnosed mental illness, and furthermore the treatment they receive from health services whilst in prison. There are also serious issues relating to treatment post release from community mental health services…I know I do not have to outline the issues related to dual diagnosis, which this client group exemplify. Particular problems also arise for this client group when a Borderline Personality diagnosis is given, which is very often.

(Service provider, Western Australia, Submission #14)

About 8 weeks ago my son was arrested and put in prison for 8 weeks for breaking a court order. He had been taking medication for years. While he was there he was not permitted to see a doctor or take his medication. While there he was bashed. He was released on strict conditions that he sees a psych. Again we are having difficulty as he does not work and can not afford a psychiatrist. There have been times when I have been to the hospital and spoken with the mental health teams and they have turned us away.

(Carer, Mother, New South Wales, Submission #90)

…if the incarceration of people with mental health disorders is to be reduced, the assessment, treatment and support services for offenders with mental illness/mental health issues (including intellectual disability) are not only required pre sentence and upon transition from gaol to the community, but additionally and predominantly for those who serve their entire sentence in the community.

(Community Offender Services, Probation and Parole Service, Department of Corrective Services, New South Wales, Submission #317)

Difficulties for community-based offenders with mental health problems

All offenders supervised by COS [Community Offender Services] are members of the community. While they may form a sub-group within the community, offenders should remain entitled to services from mainstream agencies that are funded to provide services to the community.

(Community Offender Services, Probation and Parole Service, Department of Corrective Services, New South Wales, Submission #317)

Resistance to involving consumers and carers in the planning of treatment and care

My other concern is for the carers they are told not to get involved but there's no one else to get involved. If the service doesn't want to involve carers then who do they think will provide the care once someone is discharged from a hospital? Who else is there?

(Clinician, Western Australia, Bunbury Forum #19)

… attitudes towards families generally within the system are very mixed. The impression one gets is that senior management are unsympathetic and find input from carers a nuisance - and too time consuming. The attitude seems to be that, if you are lucky enough to actually have a family, you are so far ahead of most consumers that you can look after yourself.

(Carer, Mother, Victoria, Submission #299)

5.11.4.A STANDARD 11.4.A: COMMUNITY LIVING

The MHS provides consumers with access to a range of treatment and support programs which maximise the consumer's quality of community living.

A consistent theme throughout many submissions and forums across Australia was the paucity of treatment and support services to enable consumers to maximise their quality of living and level of social and economic participation whilst living in the community. In particular, the lack of support for the family was described with access to family-centred approaches and support services being rarely offered. Without such support valued relationships were generally not strengthened and families took considerable strain. Some families wanting to be involved reported being "fobbed off" by mental health services. Children of parents with mental illness and young carers were also reported to be poorly supported and their needs ignored or not met. The decreasing availability of programs teaching self-care skills to enable consumers a choice to live independently was reported and consumers spoke of their desire to learn or relearn such skills.

Also reported to be diminishing were leisure, recreation and rehabilitation programs. These were described to be of critical importance in the reintegration process and rehabilitation phase. Withdrawal from such programs due to service reduction was reported to have catastrophic effects on some consumers and precipitated deteriorating events. Access to employment opportunities and education, training and work programs was also reported to be scarce.

Nationally, the key issues relating to this Standard include:

- lack of treatment and support services to maximise consumers' quality of living in the community without their health deteriorating (Standard 11.4.A.2, 11.4.A.4, 11.4.A.10, 11.4.A.11, 11.4.A.12);
- lack of community support services to maximise opportunities to live independently (Standard 11.4.A.13);
- lack of support services in community (Standard 11.4.A.2, 11.4.A.4, 11.4.A.10, 11.4.A.12, 11.4.A.13);
- difficulties accessing community based services (Standard 11.4.A.14 and 11.4.A.15);
- lack of support for consumers and their families in the community (Standard 11.4.A.2, 11.4.A.4, 11.4.A.10, 11.4.A.12, 11.4.A.13);
- Withdrawal of support from community mental health clinics (Standard 11.4.A.15);
- lack of education, training, work and employment programs (Standard 11.4.A.4 and 11.4.A.9);
- lack of vocational programs and employment opportunities (Standard 11.4.A.4, 11.4.A.6-11.4.A.8);
- lack of leisure, recreational, social and rehabilitation programs (Standards 11.4.A.4, 11.4.A.5, 11.4.A.10);
- lack of self care and living skills programs (Standards 11.4.A.1 and 11.4.A.2);
- access to leisure and recreation programs is being reduced (Standards 11.4.A.4, 11.4.A.5, 11.4.A.10, 11.4.A.14 and 11.4.A.15);
- more support needed to strengthen valued relationships (Standard 11.4.A.11);
- lack of family-centred approaches and support services (Standard 11.4.A.12);
- lack of support for children of parents with mental illness (Standard 11.4.A.12);
- lack of support for carers (Standard 11.4.A.12); and
- lack of recognition and support for young carers (Standard 11.4.A.12).

The following selected quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 11.4.A. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Lack of treatment and support services to maximise consumers' quality of living in the community without their health deteriorating

The impact of the erosion of community based rehabilitation services has been underestimated; as the networks of support so critical for the maintenance of stable mental health are removed, the burden upon the health system grows even larger. This again typifies a lack of understanding indeed an ignorance of the issues of those living with mental health conditions, as these programmes that offer social networks, education and recreation play a key role in the maintenance of mental health, community and social cohesion, and significantly contribute towards decreased admission rates, and burden upon the health care system.

(Clinician, New South Wales, Submission #197)

*MHCC's [*Mental Health Coordinating Council*] major concerns are related to the inadequate levels of community mental health services provided by the public health system and the shortage of psychosocial rehabilitation services. The latter services respond to a person's 'whole of life' needs in a community setting and include supported residential services, day centres which provide social and recreational activities and link clients to other such services in the community, outreach support services, vocational and employment services, and information and education services. Even though NSW Health has recently acknowledged in its draft document, NGOs and Mental Health: a Framework for Partnership, that these services are most appropriately provided by the non-government sector (NSW Health, 2002), there has been no indication that new funds will be allocated for this purpose.*

(Mental Health Coordinating Council, New South Wales, Submission #298)

There is no follow-up of medication or therapy to help people with a disability get back into society or become independent.

(Carer, Mother, Victoria, Submission #352)

Lack of self care and living skills programs

I came from the institution. I lived there from 7-21. I wasn't trained how to dress or how to wash. I am now 39 and I'm still trying to get over all my fears and anxieties. You need a lot of care and support and there is not a lot of that around.

(Consumer, Victoria, Morwell Forum #9)

We need a service here in Bunbury that teaches living skills. It is my understanding that there was someone here doing that once but not anymore. It seems that living skills are the last thing on the agenda for mental health services.

(Support Worker, Western Australia, Bunbury Forum #13)

Programs like living skills have been dropped out of NSW.

(Consumer Advocate, New South Wales, Parramatta Forum #3)

Lack of support for consumers and their families in the community

Single parents with a mental illness have very little help (if any) to care for their children and are usually forced to put them into state care. Sometimes the children are split up causing further trauma to both the parent and the children.

(Anonymous, Tasmania, Submission #254)

To obtain a comprehensive narrative, the author conducted a small research project focusing on the impact on nine family members of persons living with mental illness. The project identified a significant number of traumatic physical, mental and emotional impacts, which had a disabling effect on these relatives. Listening to the stories of spouses, parents, children and siblings it became obvious that all respondents felt the mental health 'system' had failed them and their relative living and/or dying with mental illness.

(Carer, Wife & Mother, Queensland, Submission #157)

Difficulties accessing community based services

We provide a comprehensive service. It is difficult to link mental health clients to get community based services… It seems to be a big problem with links to mental health clinicians linking in with the discharge planning. Mental health patients are not linked in to home help.

(Social worker, Western Australia, Geraldton Forum #84)

Lack of community support services to maximise opportunities to live independently

We are now seeing houses that are nothing short of disgusting! These houses are occupied by people who have been discharged from psychiatric institutions and they live like dogs because there's no follow-up care for them, they are not taught any basic living skills and most don't even know how to cook for themselves.

(NGO Employment Service Provider, Adelaide Forum #19)

Our families want a life, a job, accommodation. We can't get home care or meals on wheels for our loved ones. Why is this? When our children come out of hospital they are often severeley disabled, they can't remember how to cook or clean up after themselves. So why can't they get home help in these situations?

(Carer, Mother, New South Wales, Parramatta Forum #1)

We need more housing, accommodation and day programs to support people in the community. But there's a real lack of willingness to provide these services.

(Consumer, NGO member, Victoria, Footscray Forum #6)

Lack of leisure, recreational, social and rehabilitation programs

Apart from accommodation our biggest problem is the lack of recreation and rehabilitation programs available. [X] struggles at the best of times with no real motivation to do much at all and this coupled with constant tiredness leaves him incredibly bored for most of the time… There have been a couple of programs run over the last year by the Richmond Fellowship of Tasmania Inc. During these [X] would get to go out with the group twice a week. Not only did he really enjoy it and looked forward to it, but it was beneficial for him… the 'Kicking Goals Program' …the rapport he has built up with the coordinator has made such a difference to his behaviour and to our family unit.

(Carer, Mother, Tasmania, Submission #315)

I would like to know why mental health funding is dominated by the medical model when funding could be better used to develop mechanisms to provide assistance for when people are well. We need to give people an opportunity of a life worth living... The medical model is about risk management. We neglect people when we leave them out to rot – in front of a TV all day! I lost all my social skills… We need case workers who have no more than 8-10 clients and who can give due attention to people's long-term needs.

(Consumer, Victoria, Footscray Forum #3)

There are inadequate rehabilitation services for consumers who are trying to rebuild their lives. People recovering from heart surgery are automatically given a place on a rehabilitation program and access to professional assistance such as dieticians. Unfortunately the same cannot be said of psychiatric rehabilitation. In Frankston, Impact Services provide a quality Psycho-social rehabilitation service but due to long waiting lists, many consumers are unable to access this much needed type of service. At best the PDRS (Psychiatric Disability & Rehabilitation Service) offers a few hours of rehab per week leaving the carer with the responsibility for over 100 hours for the rest of the week to the carer. Rehabilitation services and support programs are essential for people with a mental illness many of whom have become socially isolated.

(Peninsula Carers Council, Victoria, Submission #321)

Lack of vocational programs and employment opportunities

My son has paranoid schizophrenia. He's on new medication and he's the best he has been for 20 years. He wants to work but we can't get any help.

(Carer, Mother, Ballarat, Melbourne Forum #11)

Lack of education, training, work and employment programs

There need to be more community based treatments available for mental health consumers (especially job placements), voluntary work, educational achievements (at TAFEs) (anything to keep the self-esteem of a mental health consumer as this will develop positive outcomes).

(Anonymous, Western Australia, Submission #243)

Lack of family-centred approaches and support services

Though the ACT Mental Health Services receive training in family sensitive practice, families report that they are frequently told by the clinical case-manager that they can't be involved or that the case-manager can't talk to them or tell them anything. Families reported feeling 'fobbed off'. Families and other carers pleaded to be taken seriously and for clinicians to understand their role and the difficult nature of that role.

(Mental Health Community Coalition Consumer and Carer Caucus,,
Australian Capital Territory, Submission #342)

Families not supported – we know entire families who are adrift.

(Consumer, Carer & Family Worker, New South Wales, Broken Hill Forum #23)

When we expressed our fear and worry about [X]'s premature discharge from the psychiatric unit after his first suicide attempt, we were told, "Family dynamics are not our concern."

(Carer, Sister, Australian Capital Territory, Canberra Forum #9)

Lack of support for carers

I coordinate family carer services. I focus mostly on urban carers. One of our carers has been a carer for a long time and I now advise carers to develop their own support because it's too frustrating to try and get anything from the system.

(Service Provider, Northern Territory, Alice Springs Forum #12)

I have no family or children so have had to cope on my own. Some good sound advice and suggestions from a mentor would be wonderful, but where can I go without it costing me an 'arm and a leg'.

(Carer, Wife, Australian Capital Territory, Submission #149)

Secondly, government policy states that carers have a right to appropriate education and training in order to fulfil their role, and yet our research indicates that carer support, education and training lacks the funding to administer comprehensive, timely and targeted support for carers in all regions .

(The Network for Carers Of People With A Mental Illness, Victoria, Submission #319)

5.11.4.B STANDARD 11.4.B: SUPPORTED ACCOMMODATION

Supported accommodation is provided and / or supported in a manner which promotes choice, safety, and maximum possible quality of life for the consumer.

Serious concerns were expressed across Australia about the decreasing level of available supported accommodation, especially in rural and regional areas. The lack of supported accommodation options in rural and regional areas effectively means that these consumers are forced to live away from their social and cultural supports.

Long wait lists (up to 3-4 years) were also reported by many service providers. Service providers also described the increasing number of consumers with complex needs who were requesting admission. Some NGO service providers described the increasing trend for their services to be used as "quasi-psychiatric" by mental health services without the requisite resources, funding and expertise.

Both these factors (lack of resources and increasing pressure to admit people with complex needs) are reportedly creating serious safety risks for consumers and staff. The need for a range of options was also voiced; in particular, the need for step-up and step-down facilities and facilities for consumers with drug and alcohol problems.

Access to a range of treatment and support for consumers living in supported accommodation was also reported to be limited and problematic. Support for accommodation service providers was also reported to be difficult to access, for example, after hours crisis support and medication supervision. The lack of respite options was also noted as a critical gap.

Nationally, the key issues relating to this Standard include:

- lack of housing and supported accommodation (Standards 11.4.B.1, 11.4.B.5, 11.4.B.6, 11.4.B.8-11.4.B.115);
- a necessary range of accommodation options is lacking (Standard 11.4.B.8);
- need for interim and step-down accommodations options (Standard 11.4.B.8);
- the need for step-up and step-down accommodation facilities for consumers with dual diagnosis (drug and alcohol) (Standards 11.4.B.6 and 11.4.B.8);
- lack of support for consumers and providers of supported accommodation (Standards 11.4.B.2-11.4.B.18);
- lack of supported accommodation options for people in rural and regional areas (Standards 11.4.B.8 and 11.4.B.9);
- lack of supported accommodation for people with complex needs (mental illness, drug and alcohol, homeless, elderly) (Standards 11.4.B.3, 11.4.B.5, 11.4.B.6 and 11.4.B.12);
- lack of supported accommodation options for young people (Standards 11.4.B.5, 11.4.B.9, 11.4.B.12);
- lack of support for homeless people with mental illness (Standards 11.4.B.5, 11.4.B.6, 11.4.B.8-11.4.B.12);
- lack of supported accommodation for offenders with mental illness or mental health problems (Standard 11.4.B.5);
- lack of supported accommodation options for consumers form a non-English speaking background (NESB) (Standards 11.4.B.5, 11.4.B.6, 11.4.B.9, 11.4.B.10, 11.4.B.12);

- lack of respite options (Standard 11.4.B.8);
- lack of respite options for parents with mental illness who have children (Standard 11.4.B.6 and 11.4.B.8);
- lack of funding and support for supported accommodation services (Standards 11.4.B.17 and 11.4.B.18); and
- lack of resources and support for NGO accommodation service providers (Standards 11.4.B.14-11.4.B.18).

The following selected quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 11.4.B. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Lack of housing and supported accommodation

St Bartholomew's [accommodation provider for homeless men] had found in 2001 in a situation where over 60% of its clients were potentially involved with mental health issues. It was utilised as a quasi-psychiatric service without any resources with respect to this aspect of care. Mental Health Services all over the area were discharging clients directly to St Bartholomew's… (excerpt from Coroner's Report, 2004)

(St Bartholomew's House Inc, Western Australia, Submission #37)

Homeless shelters, refuges and boarding houses are now functioning, defacto, as a major component of the accommodation provided by our society for thousands of Australians affected by Mental illness. This is completely unacceptable. It must have been acceptable because it has not changed. Homeless shelters are receiving more referrals from Acute Psychiatric Units to supply accommodation for their patients then ever before.

(NGO Service Provider, Queensland, Submission #40)

Brian Burdekin's 1993 report is just as valid today as it was eleven years ago and in some instances the situation is worse, e.g. with psychiatric clients losing case management support; and the decrease in housing stocks.

(Anonymous, Queensland, Submission #67)

The provision of suitable housing and accommodation available within Australia is appalling… When the large institutions were closed and patients moved into community care settings it allowed the Governments at all levels to neglect the accommodation for the mentally ill. They have taken this opportunity to neglect the provision of accommodation for the mentally ill with a zeal that they display in no other area of health care! We regret that this same level of enthusiasm is not evident in the area of service provision." Which level of government is responsible for housing?

(Clinician in rural Victoria, Victoria, Submission #123)

In addition to the financial impost of caring, carers report a critical lack of support in the form of community-based services, clinical, counselling, information and respite options. In particular they identified the lack of appropriate supported accommodation which denied their adult son or daughter the chance to live a meaningful independent life.

(Anglicare Tasmania, "Thin Ice: Living with Serious Mental Illness and Poverty in Tasmania",
Tasmania, Submission #144)

I had a lady staying with me and she had a mental illness and I took her home and she had nowhere to go. I went on a holiday and when I came back she had killed herself. Her case worker and I tried to get someone – but no one would take her.

(Anonymous, Queensland, Rockhampton Forum #10)

We are still trying to find suitable accommodation for [X] after his release from hospital. It is very obvious to all that [X] needs to go into supported accommodation to help with his rehabilitation. He has shown that he can be very well, given the right set of circumstances, which include support of his family, psychiatrist and suitable supported accommodation. It is our greatest wish that [X] be well enough so that he may enjoy a useful and happy independent life.

(Carers, Parents, New South Wales, Submission #198)

I'm [X]'s carer and I feel for myself to cope so soon is very scary, walking on egg shells, mentally and physically very draining experience. I feel I can no longer cope with him living at home due to this illness. Bit there is nowhere for him to live. It's all unavailable. I would <u>not</u> want him locked away in an institution. But where can people with a mental illness live.

(Carer, Mother, Victoria, Submission #310)

There is a critical lack of suitable accommodation for suffers of mental illness. Large numbers are homeless or living with family who struggle to cope with the burden.

(Carer, Mother, Victoria, Submission #299)

Lack of support for consumers and providers of supported accommodation

NCOSS has received 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.

(NCOSS, New South Wales, Submission #47)

…is a non government organisation which provides housing and support to people with psychiatric disabilities in the Swan Region of Perth. We have been providing these services for 8 years now and have a waitlist for housing of between 40 and 50 people. It is almost an embarrassment to do an assessment for housing and then have to inform applicants that the waitlist is 3 to 4 years long… We are also now in the position where we are housing people when properties become available, without the capacity to support them in their housing.

(NGO Service Provider, Western Australia, Submission #18)

The closure of long term residential care beds in institutions has not been accompanied by the development of properly resourced and supported community accommodation. Sub-standard conditions in boarding houses are of great concern. In addition, placing consumers (people with mental illness) into public housing without ongoing supervision and support has lead to a deterioration in health of consumers and serious problems for other tenants in public housing.

(NSWCAG, New South Wales, Submission #273)

Lack of support for homeless people with mental illness

Tragically, the homeless people are the forgotten people. You won't hear from the homeless people even in a meeting like this.

(NGO Nurse Unit Manager, New South Wales, Sydney Forum #3)

A necessary range of accommodation options is lacking

Huge deficit in supported accommodation options: People who have recently been discharged after an acute episode usually require intensive support from both clinical care and social support services. However, the reality is that upon discharge, many people with a mental illness enter crisis accommodation services, or end up in police lock-ups or on the street. The alternative of being housed by their family often leaves the family vulnerable to emotional, physical and financial disruptions. Pressure on resources in hospitals means that patients have been discharged from hospital too early, placing a further strain on the family. Sometimes violence, financial demands and other factors associated with people with a mental illness prevent families from accepting their relative into the home.

(The Network for Carers Of People With A Mental Illness, Victoria, Submission #319)

Carers report that the current funding and provision of mental health care in WA is clearly inadequate to meet the level of need. This is demonstrated by: … [a] lack of independent accommodation options for people with mental illness. There should be a range of options available and flexible to the individual needs of people with mental illness.

(Carers WA, Western Australia, Submission #277)

Critical to the stabilisation and recovery of consumers is the availability of a flexible range of accommodation options. There are currently an inadequate number and range of residential rehabilitation programs offered to people with a mental illness in Victoria. Most of these offer psychosocial rehabilitation to people usually over 1-2 years. Yet longer-term residential rehabilitation programs lasting up to 6 or 7 years are needed to properly address the issues of clients with complex and chronic issues.

(The Network for Carers Of People With A Mental Illness, Victoria, Submission #319)

We go the extra mile in trying to provide accommodation for Mental Health Clients but are continually frustrated and concerned for both the client and ourselves at the lack of services and funding available. These are the same clients who cannot be accommodated more appropriately anywhere else.

(Darwin Red Shield Hostel, Northern Territory, Submission #217)

The mental health system failed [X] in so many ways. In summary the key failings were: … safe, secure accommodation was non-existent: there is nothing between the psychiatric unit and the charity-run refuges, which often have waiting lists and seem to pick up the pieces falling from the mental health system.

(Carer, Sister, Australian Capital Territory, Canberra Forum #9)

Many families, particularly elderly parents / carers, are being placed under a lot of stress because of the severe shortage of suitable assisted accommodation for their mentally ill adult children who are unable to manage on their own. Most of them are worried sick about what will happen to their children when the carer dies. Will the consumer end up on the streets? This is the biggest fear for the parents of these consumers. Many of these consumers COULD manage their own home IF they had the ongoing support of a case manager. And I mean a case manager who visits a minimum of once per week. So the problem of eliminating case managers also affects the ability of consumers to live in society independently of their family. (author's emphasis)

(Carer, Mother, Queensland, Submission #10)

This young man now has two fines which he will not pay. He needs a 'sheltered living hostel', a mentor, some work under supervision, like the Work for the Dole project. It is my contention that a program such as this is not more expensive than the present cost to the community and it may be good for him. He is a walking advertisement for the failure of Mental Health Services to support vulnerable people like him.

(Consumer Advocate, Western Australia, Submission #35

There is a lack of government funded long term supported housing for people who may not be able to live independently, or for people who may require supported housing long term before being able to sustain independent living

(Western Region Health Centre, Victoria, Submission #292)

Need for interim and step-down accommodations options

A huge area lacking in the mental health system overall is the lack of some form of interim accommodation like houses or hostels for patients who have recovered to the extent that they no longer require hospitalisation, but still require some overall supervision in a secure environment to give them their medication regularly and help to prepare them for release into the community. We have come across patients in Graylands hospital who have been there for many months, and have really nowhere to go where they can still be supervised and helped to rehabilitate.

(Carers, Parents, Western Australia, Submission #76)

Short term fully supported accommodation is needed to enable the development of living skills and rehabilitation back into the community. Families are often not best placed to provide such support - they are working to try to make ends meet.

(Carer, Mother, Victoria, Submission #299)

Lack of supported accommodation for offenders with mental illness or mental health problems

Undoubtedly, homelessness is a major issue for offenders with mental health issues… homeless mentally ill people are up to 40 times more likely to be arrested and 20 times more likely to be imprisoned than those with stable, suitable accommodation. While statistics are not available, there would appear to be no compelling reason why the situation would be different for mentally ill offenders in NSW. Incarceration appears to worsen post release accommodation issues… Further, offenders released with no stable accommodation were three times more likely to re-offend than those who had accommodation.

(Community Offender Services, Probation and Parole Service, Department of Corrective Services,
New South Wales, Submission #317)

Lack of respite options

There is no available respite for families/carers of those people with mental health issues. However, for a carer of someone with an intellectual disability resources are available for respite. This raises another concern which is for that of the mental and physical health of the carer. (I have seen the health of carers and their families – including young children – deteriorate as they struggle to cope with their loved one).

(Anonymous, Western Australia, Submission #145)

5.11.4.C STANDARD 11.4.C: MEDICATION AND OTHER TECHNOLOGIES

Medication and other medical technologies are provided in a manner which promotes choice, safety and maximum possible quality of life for the consumer.

Across Australia, concern was expressed that there is an over-reliance and emphasis on medication as the only treatment option. There is a perception that therapies are omitted as a choice or are not available due to lack of services and clinicians. Concerns were also raised about the increasing use of Electro Convulsive Therapy (ECT) in both public and private hospitals and that consumers are not being given sufficient information to provide informed consent. The lack of opportunity to obtain a second opinion was also noted under this Standard.

Nationally, the key issues relating to this Standard include:

- concerns about the over reliance and emphasis on medication and medication as the only treatment option (Standard 11.4.C.1-11.4.C.4, 11.4.C.10-11.4.C.112);
- concern about the use of antidepressants for children (Standard 11.4.C.1, 11.4.C.2, 11.4.C.4 and 11.4.C.10);
- unsafe practices during treatment using Electro Convulsive Therapy (Standard 11.4.C.1, 11.4.C.2, 11.4.C.6, 11.4.C.9, 11.4.C.10, 11.4.C.11, 11.4.C.15 and 11.4.C.16);
- difficulties in accessing maintenance ECT (Electro Convulsive Therapy) treatment (Standard 11.4.C.1, 11.4.C.15 and 11.4.C.16); and
- the lack of opportunity to get a second opinion (Standard 11.4.C.12).

The following selected quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 11.4.C. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Concerns about the over-reliance and emphasis on medication and medication as the only treatment option

I'm also concerned that many people are treated for mental illness when the main treatment seems to be to whack them on large doses of medication – there is a lack of review of medication.

(Consumer, Queensland, Brisbane Forum #11)

By this time, [X] seemed as if he felt he didn't really need to attend the unit as Dr [Y] had provided him with a script with seven repeats! I didn't even think this was possible. Dr [Y] apparently also increased the dosage. This meant that [X] was not being seen by anyone at Mental Health so his deterioration was going undetected.

(Carer, Wife and Mother, Queensland, Submission #52)

Our son felt that the Psychiatrists and doctors in the Public Health System were not helping him. Either they don't know, don't want to know or their hands are tied because of government guide-lines. In fact their treatment was to heavily medicate our son and send him home, without any follow up treatment.

(Carer, Mother, Queensland, Submission #81)

Medication as the only treatment modality. Consumers of public mental health services, as in patients or in the community, rarely have an opportunity to 'talk through' the contents of their thoughts, their ideas about the causation of their illness, or the progressive processing or understanding they are developing about their condition. The structure of mental health services means that frequent turnover of staff leads to discontinuous relationships between consumers and doctors. Medication has become the primary treatment modality. Most consultations centre around negotiations on dose, medication type, combinations, side-effects, and consumer concerns about being on chemical treatments…

(Health Consumers' Council WA, Western Australia, Submission #29)

The ever-increasing reliance on medication to manage mental illness means there is an ever-increasing reliance on forcing people to take medication. As a result, involuntary orders have increased at the same time as people are crying out for treatment.

(Mental Health Legal Centre, Victoria, Submission #330)

Currently the focus of treatment is predominantly on medication. People who suffer from a mental illness, not only need medication but assistance and support to help deal with their situation. As well as medication they need counselling to help them deal with the difficulties of having a mental illness.

(Peninsula Carers Council, Victoria, Submission #321)

Medication is often inappropriately tailored to the individual's needs and poorly monitored with distressing results. Mental Health Workers do not take sufficient notice of consumers in this regard. I have seen my daughter faint onto a thinly carpeted concrete floor as a result of low blood pressure induced by medication whilst a psychiatric nurse looked on impassively as if she was 'putting it on'. She was once medicated so heavily that her voice sank to an almost inaudible whisper for 36 hours. She has suffered severe involuntary protrusions of the tongue and I have seen her endure a 10 minute wait at the nurses station in full view of all the other patients before Cogentin was administered. Such experiences are frightening, especially given that her medication is administered involuntarily.

(Carer, Mother, Victoria, Submission #299)

Unsafe practices during treatment using Electro Convulsive Therapy

ECT [Electro Convulsive Therapy] use is increasing in WA, in both public and private hospitals. There was a marked 25% increase in ECT hospitalisations in the financial year 2000 / 01 (618), compared with the previous year 1999 / 00 (495). 63% of these hospitalisations were in private hospitals. Why is this the case? …The majority of hospitalisations for ECT treatment in 2001 were female (70%)… There is no standard protocol for the administering of ECT over all hospitals. Individual hospitals have their own clinical protocols, including voltage, area of administration and number of treatments. While a standard protocol for public hospitals is being addressed, the private hospitals adhere to their own individual policies. Elderly patients (24% of ECT patients were over 65 years) are being given "maintenance ECT" with no other treatment, and no treatment plan. Patients are not fully informed of the multitude of side effects associated with ECT. There has been a move away from unilateral ECT (which was thought to minimise side effects) to bilateral ECT. A review of the literature indicates there is little agreement amongst ECT "Experts" about ECT procedures. Issues such as current, electrode placement, and number of treatments remain controversial. I do not believe the public are aware of the extent of ECT use. In my opinion, ECT is an unacceptable treatment. If it is used at all, ECT should be given as an absolute last resort, under the most stringent guidelines. Currently ECT is being given in an ad hoc manner.

(Giz Watson MLC, Western Australia, Submission #171)

Difficulties in accessing maintenance ECT

For this treatment to continue being successful it is essential that [X] receive regular maintenance ECTs. Although this was previously done at Dandenong for out patients, it is no longer the case. This means that [X] must book as an inpatient, taking a bed that could otherwise be used for someone else, or if no bed available, then her treatment is cancelled, as has happened with her last four sessions, which I am sure you would understand has had a negative affect on the benefits initially gained from her ongoing treatment. It is my understanding that outpatient maintenance ECTs are available at surrounding hospitals but we are "out of area", we and the many others who could benefit from this program are missing out.

(Carer, Husband, Victoria, Submission #348)

5.11.4.D STANDARD 11.4.D: THERAPIES

The consumer and consumer's family / carer have access to a range of safe and effective therapies

Concerns were expressed about the extremely limited availability of therapies throughout mental health services in Australia. Reports were received that non-pharmaceutical therapies are often not offered as a choice and there is an emphasis on medication as the only treatment option. Lack of access to psychologists in the public sector meant that only those who could afford to pay for such services in the private sector were able to access this form of treatment option. This situation was described as 'immoral' and 'incompatible with human rights'.

Nationally, the key issues relating to this Standard include:

- lack of access to a range of therapies – emphasis on medication (Standards 11.4.D.1 – 11.4.D.4);
- lack of access to Psychologists (Standards 11.4.D.1 – 11.4.D.4);
- lack of access to treatment programs for people with Borderline Personality Disorder (Standards 11.4.D.1 – 11.4.D.4); and
- concerns about the costs associated with therapies making this a limited option for many consumers (Standard 11.4.D.5).

The following selected quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 11.4.D. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Lack of access to a range of therapies – emphasis on medication

My husband was diagnosed with bipolar 40 years ago. On and off with depression. Treated every time with drugs, no cognitive behaviour therapy (CBT).

(Carer, Wife, Northern Territory, Darwin Forum #13)

Both consumers and carers reported that whilst a person is in hospital, very little 'therapy' or 'treatment', other then medication and injections, are available or provided.

(Mental Health Community Coalition Consumer and Carer Caucus,
Australian Capital Territory, Submission #342)

During the years I have been involved with the Rockhamptom Mental Health Unit the only option offered to consumers seems to be by way of medication. There is a real need for other options to be available instead of / or in conjunction with the use of medications.

(Carer, Wife and Mother, Queensland, Submission #52)

A predominant finding in our experience has been the difficulty in seeking non-pharmacological treatments for persons who experience Anxiety and Depression.

(blueVoices, National, Submission #355)

People with anxiety disorders and depression often have no idea how to access the services that are available. The majority of the people coming to see the psychologists at PADA (Panic, Anxiety and Depression Assistance) have had their anxiety disorder for many years – usually between four and ten years. This is outrageous for conditions that respond well to CBT (Cognitive Behaviour Therapy).

(Clinical Service Provider, Victoria, Submission #268)

Lack of access to psychologists

Psychologists are not available in the public health system. It's inaccessible and it's impossible to ask people to do that themselves. People with a mental illness don't get help to deal with normal life stress - they get their meds increased.

(Carer, Mother and NGO Service Provider, Tasmania, Hobart Forum #14)

The Burdekin report stated that "restriction to access to psychologists results in important treatment options being denied to many individuals affected by mental illness and that the lack of access is incompatible with human rights and is economically unsound". It seems immoral that in 2004 clinical psychologists are not routinely available to people suffering mental disorders.

(ARAFMI Tasmania, Tasmania, Submission #245)

Concerns about the costs associated with therapies making this a limited option for many consumers

It is almost impossible to see a psychologist or psychotherapist in the public mental health sector these days. This is a disaster. Where have they all gone and why? Why do those of us who desperately need counselling and other talking therapies always seem to come last?

(Consumer, Queensland, Submission #204)

Access to the combination of pharmacological prescription and therapeutic counselling is not available to people who cannot afford to pay full private price and for those who can, remains extremely limited.

(Support and Equity Services, Charles Darwin University, Northern Territory, Submission #269)

While living with a mental illness is hard, the fact is that if you have money you can get help. For example, with money you can access other forms of therapy (non-drug), which can help greatly but we can't access this care through Medicare.

(Carer , New South Wales, Sydney Forum #9)

For our members access to low cost counselling would be invaluable to assist with their recovery. Anecdotally we have worked with members who report the benefits of using local community counselling services to resolve the underlying causes of issues.

(Service Provider, Victoria, Submission #266)

My wife suffers from depression and I took her to the regional mental health unit in Wodonga. An initial interview was conducted with 2 people from this unit and their only advice was 'go and see a private psychologist, we don't have the resources here to help'. This news was devastating as we cannot afford the treatment required in private practice, and this has now tainted my wife's view of any help possible.

(Carer, Husband, Victoria, Submission #119)

5.11.4.E STANDARD 11.4.E: INPATIENT CARE

The MHS ensures access to high quality, safe and comfortable inpatient care for consumers.

Serious concerns were expressed about the quality of treatment and support currently being delivered in inpatient units in every Australian State and Territory. Reports of excessive use of sedation, restraint and seclusion and the increasing inappropriate use of security guards due to a shortage of secure beds were cited as areas of critical concern.

A chronic shortage of beds was also described as one of the main reasons for non-admission of consumers where acute care was urgently required. The pressure to vacate beds is also the cause of premature discharge.

Reports were received that a chronic shortage of resources and staff resulted in occasions when the safety of consumers was not ensured and when consumers harmed themselves or died while in care. Reports were also received of many consumers absconding from care and staff not adhering to protocols. There have also been illustrations of occasions when voluntary admissions were not promoted.

Also of serious concern were reports from consumers that they were frequently not involved in the development of their own treatment plans. Many inpatient units were described to be in very poor condition with minimum regard for privacy and increasingly inpatient units were being renovated to resemble prison enclosures.

Consumers also reported feeling scared and having nothing to do within inpatient facilities and that they were being treated as ‘second class citizens’ and receiving services of an inferior standard compared to other health facilities.

Transport to and between hospital settings with police vehicles also raised concerns that that this was not the most respectful mode of transport possible and suggests that people with mental illness are criminals.

Concern was also expressed that the impact of admission on the consumer’s family is not minimised and that children of parents with mental illness are not always notified of admission and their needs may not be considered while their parent is in hospital.

Nationally, the key issues relating to this Standard include:

- care not being provided in the least restrictive environment (Standard 11.4.E.1);
- excessive use of restraint (chemical and physical) and seclusion (Standard 11.4.E.1);
- death while an inpatient (Standards 11.4.E.1, 11.4.E.14 - 11.4.E.16);
- concerns about consumers suiciding in hospital settings (Standards 11.4.E.1, 11.4.E.14 - 11.4.E.16);
- protection from harm not ensured (Standards 11.4.E.1, 11.4.E.14 - 11.4.E.16);
- patients absconding from hospitals and involvement of police (Standards 11.4.E.1 and 11.4.E.14 - 11.4.E.16);
- lack of beds (Standard 11.4.E.1, 11.4.E.2, 11.4.E.14 - 11.4.E.16);
- problems with increasing use of security guards in hospital settings due to a shortage of secure beds (Standards 11.4.E.1, 11.4.E.14 - 11.4.E.16);
- lack of access to professional mental health staff (Standard 11.4.E.5, 11.4.E.15-11.4.E.16);
- appropriate treatment and support not being provided in inpatient units (Standard 11.4.E.1, 11.4.E.4 and 11.4.E.5);
- voluntary admission not supported (Standard 11.4.E.2);
- transport to hospital is not occurring in the most respectful manner possible (Standard 11.4.E.3);
- use of police to transport consumers to and between hospitals (Standard 11.4.E.3);
- lack of supervision and adherence to protocols (Standards 11.4.E.15 and 11.4.E.16);
- consumers and carers are not being informed or involved in treatment plans (Standards 11.4.E.6, 11.4.E.11);
- impact of admission on consumers’ family not minimised (Standard 11.4.E.7);
- lack of continuity of care and extreme distress for consumers and their families and carers when admission is required (Standard 11.4.E.5 and 11.4.E.7);
- children of parents with mental illness are not being notified of admission of parent or their needs considered while their parent is receiving inpatient treatment and support (Standard 11.4.E.7);
- need for separate psychogeriatric facilities (Standards 11.4.E.1, 11.4.E.11 and 11.4.E.16);
- inpatient units in poor condition (Standard 11.4.E.14); and
- lack of privacy and lack of choice (Standard 11.4.E.14).

The following selected quotes from community forums and submissions describe people’s recent experiences of mental health services and areas of concern under Standard 11.4.E. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Death while an inpatient

Attempts were made to locate a facility to meet the needs of my sister. It is my understanding that of all the hospitals with closed wards, there were no beds available that evening. Eventually after a long delay, she was transferred to the psychiatric unit at Royal Perth Hospital in the Perth CBD. She stayed there the night but was not in a locked ward. In the morning she walked out of the hospital. She walked less than 500m to a multilevel carpark on the corner of Wellington and Pier Streets. She went to the top floor and jumped to her death... It was unnecessary tragedy that could and should have been averted. There are many questions unanswered for my family: How can this happen? Who is accountable? Why are there insufficient resources when the problem is so evident? ...the system failed my sister and her family. It is unacceptable and these issues need to be voiced and addressed… I was unable to return to [my] job after my loss.

(Brother, Western Australia, Submission #89)

[Graylands Hospital[is a nightmare of mammoth proportions and at the moment I am writing a book showing such facts along with the death of my daughter there, along with other young adults. It is usual to go to a hospital to improve one's health... these young people are dying through neglect by hospital staff and not being listened to. Certainly no fault of their own. I have searched long and hard and if I honestly believed that my daughter and the others I know of had died through their own doing and with compassion behind them I would leave well alone. They didn't - they died in strange circumstances.

(Carer, Mother, Western Australia, Submission #103)

15 March, 2002. She said [X] was being sent out on unaccompanied leave that night. When asked had she read my letter, she said "yes" and made no further comment. I told her, at some length, that [X] was acutely paranoid and believed that stalkers were at her flat. She listened, made no reply, and noted these serious matters in the file as "allowed to ventilate"… When asked six weeks later if she had informed Dr [Y] of my fears and [X]'s paranoia, [she] said no. I called the ward at 2pm to say that [X] might kill herself if sent out without me. [X] was sent out. We stayed in contact by phone. She got through Friday night. 16 March. We were in contact by phone. [X] was not happy, but said she would stay. We spoke last at 8.30pm. At 11pm [X] jumped in front of a train and was killed instantly.

(Carer, Mother, Victoria, Submission #206)

Excessive use of restraint (chemical and physical) and seclusion

I am extremely concerned about the use of restraint and seclusion in SA hospitals. There have been frequent recent stories of psychiatric patients being shackled in the ED [Emergency Department] at central city hospitals, inappropriate use of seclusion (for staff convenience not patient care), the use of outmoded and banned restraint holds by nurses and patients not being treated with the care and respect they deserve.

(Academic, South Australia, Submission #142)

More extreme forms of physical abuse include being strip-searched, locked up and isolated, physically restrained by ward staff or restraining devices such as shackles.

(Insane Australia, Victoria, Submission #232)

I also want to talk about a story that was reported in the Penrith Press – the story is about patients being sedated for up to 5 days and being strapped to beds – they have no access to any therapeutic services - only TV or smoking.

(Advocate, New South Wales, Sydney Forum # 8).

When I asked patients in a research study about what they thought of seclusion, their answers were largely negative, they feel punished humiliated, bored and scared when in seclusion. This is not quality nursing care.

(Academic, South Australia, Submission #142)

The use of Seclusion Rooms and involuntary restraint is still continuing in NSW. Seclusion Rooms and involuntary restraint, which are often, degrading, inhumane and traumatic, are a normal form of 'treatment' in NSW Public hospitals. Why is it that in other parts of the World including the U.S., Prevention Programmes have greatly reduced the need for these abuses, yet in NSW this form of treatment is still seen as legitimate?

(Consumer Activist, New South Wales, Submission #257)

Further, nurses report that the workload results in their having no option but to adopt a custodial approach to patient care, rather than that of the development of therapeutic relationships. We learn of instances where restraint is used, with security guards and the police being called to emergency departments to restrain people who are acutely and severely unwell.

(Australian Nursing Federation (Vic Branch), Victoria, Submission #322)

Appropriate treatment and support not being provided in inpatient units

I was admitted to hospital one night. I had a serious overdose on drugs, trying to commit suicide, I explained this to the nurses in the Logan Hospital, they left me in a room by myself all night and released me at 6am the following morning and told me I was fine.

(Consumer, Queensland, Submission #73)

Treatment is typically brief and often people are released the next day; they are just kept in over night. This type of care is no good – it creates a revolving door – people just get sick again because they have been discharged early so the figures look good and someone else can have their bed. This is not good care.

(NGO worker, Queensland, Brisbane Forum #3)

I believe the public have a right to know about the dangerously inadequate psychiatric services currently available in Gippsland. As previously reported, people who are deemed in need of admission, & thus 24 hour care, are being cared for during the day in a highly stressed environment, where Nurses are often General Nurses, inexperienced in psychiatric care. At times there has only been one Psychiatric Nurse on duty, responsible for supervising a nursing team, comprising some for whom it was their first experience in an acute psychiatric ward. It is not surprising that some of these nurses have refused to return. Because the number of patients being admitted is higher than the number of available beds, it is correct that patients are sent to motels and caravan parks to sleep. As you can imagine any psychiatric ward can be and often is a place where highly charged emotions are expressed. Imagine the added effect of overcrowding and at times fearful inexperienced staff. This is a recipe for tragedy waiting to occur.

(Anonymous, Victoria, Submission #312)

[X] believes that patients are treated as 2nd class citizens. They do not receive the same level of care you would receive in other health facilities.

(Anonymous, New South Wales, Submission #156)

Lack of beds

… it is also worth noting that the Consultant Psychiatrist who admitted her had to almost beg for the last bed on the ward, otherwise the client, who was suicidal, would have been sent home with no support. The doctor informed me that on the previous day, he had wasted 3 hours of his clinic time chasing a bed for an extremely unwell patient. His other patients could not be seen due to this.

(Clinician, Western Australia, Submission #15)

Early discharge – people are moved from wards to overnight rehab beds so another patient can have their bed. This type of system is not in favour of patients or their family or staff. We have 56 patients in a 33 bed ward. Patients are often put on leave for a week because we have a bed shortage. Their clinical care is being determined not by their need but by the availability of resources! The ones who have families are the ones who are discharged more quickly.

(Service Provider, New South Wales, NESB Parramatta Forum #21)

There is a real shortage of beds and this results in a crisis occurring every weekend with respect to beds and community based care… What happens is that they get lined up in emergency departments, which are overfull in any case and ED staff are stressed and unhappy. Alternatively other patients are moved from the psych unit to general wards to make room for new admissions or people are sent home earlier than desirable clinically, with fingers crossed! This is really a system problem, not a clinician problem.

(Anonymous, New South Wales Submission #303)

Currently there is a catastrophic and cruel shortage of acute mental health beds in the state. I work in psychiatric triage, based in an Emergency Department and almost on a daily basis, my colleagues and I search for beds for people who have become acutely unwell and require hospitalisation. It is not uncommon for these people to have to wait 48 to 60 hours in the emergency department, amidst the noise and chaos of emergency, for a suitable bed. They are even unluckier if they require a High Dependency bed.

(Clinician, Victoria, Submission #201)

Nurses told me when a patient is in emergency needing a bed, they do "eenie, meenie, miny, mo" around the ward and decide who can be discharged – whether or not they are well. . On one occasion during the 6 month period my son was ill he was discharged and threatening staff while we were still standing in the ward waiting for his medication.

(Carer, Mother, Queensland, Submission #168)

The few who make it to an inpatient unit face the risk of premature discharge in order to 'free up' more beds for those in crisis awaiting admission. People are often discharged on the basis of who is the least risk rather than who is ready to return to their home.

(Health and Community Services Union, Victoria, Submission #220)

There are extended waiting times in Emergency Departments for Mental Health patients/clients, because there are limited beds; inpatient mental health services run above capacity most of the time. Deinstitutionalisation and mainstreaming have resulted in general hospitals having more contact with Mental Health patients/clients; Emergency Departments are the main access point for mental health emergencies. There is clear evidence that general hospital staff and systems are poorly equipped and resourced to provide mental health care to patients/clients with mental health concerns. The availability of meaningful assistance to general hospitals from mental health services varies dramatically. Psychiatric Emergency and Consultation-Liaison Psychiatry Services are inequitably distributed across the state and in many cases, virtually non-existent in country regions.

(ANZCMH Nurses Victorian Branch, Victoria, Submission #316)

Voluntary admission not supported

[X] was kept heavily sedated: [X] was in and out of drug induced sleep for approximately 18 hours until admission at Graylands Hospital. Surely this is way too long and unnecessary considering the fact that [X] was voluntarily seeking treatment! During the assessment stage at the Emergency Department of Bunbury Regional Hospital, [X] had been calm and fully compliant. No grounds were shown for involuntary admission witnessed by parents, security and nursing staff.

(Carers, Western Australia, Submission #177)

Transport to hospital is not occurring in the most respectful manner possible

The fact remains that these individuals should not be treated as offenders and as such it is inappropriate to be transporting them in police vehicles. Police have received complaints regarding this very point by concerned family members of these patients.

(Police Association of New South Wales, New South Wales, Submission #59)

Impact of admission on consumers' family not minimised

> *When admitted to an Adelaide hospital you become distant from your family and visiting is less affordable. Again no communication from the hospital to help families adjust and understand what is happening occurs.*
>
> (Consumer, South Australia, Submission #77)

5.11.5 STANDARD 11.5: PLANNING FOR EXIT

Consumers are assisted to plan for their exit from the MHS to ensure that ongoing follow-up is available if required.

Under this Standard, the prevailing concern at the national level was that discharge decisions are made according to the need to vacate beds rather than the health status of consumers. As such, reports were received of discharge frequently occurring with very little notice, without the review of individual care plans, without proper assessments and without adequate discharge plans being in place. Where attempts had been made to plan for exit, it seems that the lack of treatment and support services in the community and long wait lists, means there were few real options. Reports were also received of occasions when services were identified in plans but contact had not been established prior to exit, and arrangements for ongoing follow-up had not been made.

Nationally, the key issues relating to this Standard include:

- discharge occurring suddenly while consumer still unwell due to lack of resources (Standards 11.5.1 and 11.5.2);
- planning for exit on the basis of need to vacate beds (Standards 11.5.7 - 11.5.9);
- discharge being used as a threat with consumers (Standard 11.5.7);
- discharge without proper assessment (Standards 11.5.1 and 11.5. 2);
- individual care plans not being reviewed properly prior to exit (Standard 11.5. 2);
- discharge occurring without adequate planning (Standards 11.5.1 – 11.5.6);
- inadequate discharge plans (Standards 11.5.1 – 11.5.3);
- exit plans not authorised by medical staff (Standards 11.5.8 and 11.5.9);
- difficulty in coordinating community-based services when exiting mental health services (Standards 11.5.5 and 11.5.6);
- lack of services and options available to assist with delivery of treatment and support after discharge (Standards 11.5.4 – 11.5.6); and
- other service providers nominated on exit plan not informed prior to exit (Standards 11.5.5 and 11.5.6).

The following quotes from community forums and submissions describe some people's recent experiences of mental health services and areas of concern under Standard 11.5. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

Planning for exit on the basis of need to vacate beds

> *It should be noted that discharge is largely driven by the assessment that another incoming client has a greater need rather than the client is ready for discharge.*
>
> (Anonymous, Tasmania, Submission #254)

Patients admitted with a mental illness are often discharged before they have sufficiently recovered, due to pressure on hospital beds. This can place an unnecessary burden on carers, who are untrained but are forced to care for someone who is still unwell. This can also put the consumer at risk, and in particular risk of suicide.

(Peninsula Carers Council, Victoria, Submission #321)

Discharge occurring without adequate planning

"The first time I was in hospital—on the day I was to be discharged and I didn't know it was going to be that day—I was given a sheet of paper with a list of boarding houses on it and told to find myself a place to stay because I was going to be discharged that afternoon. I lived under a train station for 2 weeks until I found somewhere to stay. I had just spent 8 weeks in hospital getting better and then they say you have to get out and they don't care where you go. They told me I could come back on Monday if I needed to". (BSL 2004 Focus groups with mental health consumers)

(Brotherhood of St. Laurence and Catholic Social Services Victoria, Victoria, Submission #324)

But then they sedated him even though I told them I would transport him to Graylands. 20 hours later after being in a drug induced state in Graylands he was discharged (the next morning) without any explanation to him or to us.

(Mother, Western Australia, Bunbury Forum #22)

Patients admitted with a mental illness are often discharged without establishing whether they have appropriate accommodation arranged. This can mean that carers are unprepared for their loved one to return home, or that their loved one literally has nowhere to go.

(Peninsula Carers Council, Victoria, Submission #321)

Inadequate discharge plans

Psychiatric disability is ongoing, not fixed on release from hospital. There needs to be an adequate discharge plan available for people discharged from hospital. These plans don't always occur. Many plans are not adequate enough.

(Carer, Father, Australian Capital Territory, Canberra Forum #18)

Difficulty in coordinating community based services when exiting mental health services

We provide a comprehensive service. It is difficult to link mental health clients to get community based services. We have difficulty getting mental health staff to work in with discharge of patients. It seems to be a big problem with links to mental health clinicians linking in with the discharge planning. Mental health patients are not linked in to home help.

(Social Worker, Western Australia, Geraldton Forum #84)

The Hospital (eg RHH {Royal Hobart Hospital]) is outside the community mental health structure and therefore has no commitment to the care of clients once it perceives them as ready for discharge. Despite frequent attempts to establish coordinated discharge planning ("discharge planning begins on admission") the community services are still often left out of the loop and find the client has been discharged without proper arrangements for continued support.

(Anonymous, Tasmania, Submission #254)

5.11.6 STANDARD 11.6: EXIT AND RE-ENTRY

The MHS assists consumers to exit the service and ensures re-entry according to the consumer's needs.

Concerns were expressed across Australia that treatment, support and ongoing follow-up are not being arranged or reviewed prior to exit for many consumers. A result of this was that some consumers and carers felt that once they "walked out the door of the mental health service no one cared".

There were many reports of consumers committing suicide soon after discharge. Other reports illustrated and absence of follow-up arrangements or, if they were made, appointments were not kept by the mental health service.

The stories illustrate that discharge protocols are not in place in some mental health services or are inconsistently applied. There are seems to be insufficient procedures ensuring provision of adequate information to consumers and their carers about treatment and support, how to gain entry to the mental health service at a later date, how to identify early warning signs and who to contact.

Nationally, the key issues relating to this Standard include:

- consumers being discharged while still very ill with no arrangements for ongoing treatment and support (Standard 11.6.1);
- suicide soon after discharge (Standards 11.6.1 - 11.6.5);
- lack of involvement of carers on exit (Standards 11.6.3 and 11.6.5);
- no review of arrangements prior to exit (Standard 11.6.1); and
- inadequate or no follow-up (Standards 11.6.2 – 11.6.5).

The following selected quotes from community forums and submissions describe people's recent experiences of mental health services and areas of concern under Standard 11.6. More detailed descriptions of experiences relevant to this Standard can be found in Part 6:

> **Suicide soon after discharge (consumers being discharged while still very ill with no arrangements for ongoing treatment and support)**
>
> *On leaving the hospital with her son, the only information given to his mother was a copy of the discharge summary and four pages of "better sleep tips". Dr [Y], the discharging doctor, was asked if there was a discharge protocol. She replied that she did not use one and was unaware if one existed. Dr [Z] later agreed that there should have been a conference with the family before discharge… The standard of care provided for [X] left much to be desired. After considerable questioning, this was reluctantly conceded by some of the doctors who gave evidence at this inquest… [X] was discharged with a minimum of formality and no guidance or assistance to them or their son… (*excerpt from the Coroner's Report*)*
>
> (Carers, Parents, New South Wales, Submission #137)
>
> *The thing I found is that once he walked out the door of the mental health service no one cared about him or what happened to him… They said he was okay and released him with no shoes, no where to go and blood all over him. I spoke to the Dr and [X] died 10 days later – he jumped. There are so many suiciding. Nobody to help me. I should have had more help, I couldn't do it… Everybody like that needs someone to care for them.*
>
> (Carer, Tasmania, Hobart Forum #22)

I saw my husband rapidly lose weight, lose sleep, lose more interest in things he loved to do and withdraw from me, and yet it never occurred to me that he would attempt suicide again. I had no idea on the high statistics of that happening. No-one told me anything. Especially the fact that a Mobile Crisis Team was available if I needed them to be at my beck and call. I didn't know of their existence until they came to see me after [X] died and they said to me, "your husband has fallen through the cracks. If you wanted to take further action I wouldn't blame you." My heart just sank. Apparently in the clinic they asked [X] if he thought he needed acute care????? What sort of a question is that to ask a suicidal patient? How in the hell would he know? During the whole 9 days after [X]'s discharge from the clinic he did not receive one follow up phone call or anything to check on his condition. That I find is appalling.

(Carer, Wife, New South Wales, Submission #126)

Consumers being discharged while still very ill with no arrangements for ongoing treatment and support

Then he was discharged while still obviously very psychotic, and 14 hours later his brother sat in an emergency room at the hospital for another 5 hours to have him re-admitted.

(Carer, Mother, Queensland, Submission #168)

Inadequate or no follow-up

After his discharge from hospital [X] had a couple of appointments with the psychiatrist at Swan Valley Centre, then was discharged form there and told to go his GP for his medication. So far [X] has gone twice to be issued with 6 month repeat prescriptions. There has been no other contact – not even a phone call to ask how he is doing.

(Carer, Mother, Western Australia, Submission #99).

I feel my main concerns are that there is: NO FOLLOW UP ON DISCHARGE, NO REHABILITATION ON DISCHARGE. [X] said to me when he came out of hospital 'Mum what am I going to do with my life? I didn't know what to say. (author's emphasis)

(Carer, Mother, Western Australia, Submission #99).

It is very difficult to be admitted to the facility and in many cases there is no follow up and / or case management is kept to a minimum. But this is not always the case, some people are taken up or case managed long-term that are far less ill than others.

(Anonymous, Queensland, Submission #113)

After I took the overdose I was admitted to hospital. I only saw the doctor on the day I was being discharged and he told me I would be assigned a case worker but still 4 weeks later I have had no contact.

(Consumer, New South Wales, Broken Hill Forum #3)

Lack of involvement of carers on exit

My son was discharged from hospital and we didn't even know he had been discharged until he turned up on our doorstep. No one tried to inform us even though they knew he would come back to us because we are his carers.

(Mother, Western Australia, Bunbury Forum #22)

My other concern is for the carers they are told not to get involved but there's no one else to get involved. If the service doesn't want to involve carers then who do they think will provide the care once someone is discharged from a hospital? Who else is there?

(GP, Western Australia, Bunbury Forum #19)

On discharge there is no discharge plan and the support received by the patient from the hospital ends with not even a phone call to see how you are.

(Consumer, South Australia, Submission #77)

Each time I have been hospitalised "no" follow-ups have occurred. You have to wait until you can "acquire" an appointment at the clinic. This can be 2-4 weeks later.

(Consumer, Victoria, Submission #112)