PART FOUR:
ANALYSIS OF ALL SUBMISSIONS AGAINST THE TOP TEN NATIONAL COMMUNITY PRIORITIES IN MENTAL HEALTH

In April 2003, the Mental Health Council of Australia released its national review of mental health services in Australia '*Out of Hospital, Out of Mind!'* (Groom et al, 2003). This report highlighted deficiencies in care and developed a set of community priorities for further action.

The community priorities were derived through a national consultation process with individuals and organisations including consumers, carers, clinicians, service providers and administrators (for a description of this process see Hickie & Groom, 2004). The consultation process identified 26 potential areas for further action. A survey was developed and individuals and organisations were then asked to rank their top ten preferences 'for focussing activity over the next five years in mental health planning'.

The top ten priorities that emerged through this process were:

1. Implementation of early intervention services nationally;
2. Development of innovative services for persons with mental heath and alcohol or substance abuse disorders;
3. Development of a wider-spectrum of acute and community-based care settings;
4. Support for service development in rural and regional areas;
5. Implementation of national standards for mental health services;
6. Support for service development in poorly resourced areas;
7. Support for programs that promote attitudinal change among mental health workers;
8. Increased support for stigma reduction campaigns;
9. Development of specific inter-governmental service agreements (e.g. between health, education, housing, employment and social security); and
10. More genuine consumer participation at regional and local service levels.

The extent to which these priorities have been met provides a useful indication of the real impact of national mental health reform on the lives of those people who seek mental health care.

The surveys described in Part 3 suggest that people were generally of the view that the priorities were not being implemented.

The following extracts from the submissions and community consultations measure the experiences of those who use or provide care against these priorities.

> *I'm sick to death of inquiries, committees and the like who simply write and report, have a bit of fan fare and absolutely nothing changes. Oh let's write another policy. We don't need more policies. We need the one's we've got actually taken seriously and implanted and consequences for MHS and Staff and Directors who actually don't implant them.*
>
> (Consumer and Consumer Advocate, New South Wales, Submission #8)

4.1 PRIORITY 1: IMPLEMENTATION OF EARLY INTERVENTION STRATEGIES NATIONALLY

The submissions and presentations suggest that access to early intervention services is limited and that the community clearly recognises the need to extend access to these services. The comments relate to: (a) some of the highly regarded services specialising in the early stages of psychotic disorders and (b) the wider spectrum of services catering to depression, anxiety and substance-abuse related problems.

Mental health consumers and their families have commented on the contrast between mental health care, with its relative lack of provision of early intervention services, and the physical health care system. Providers of mental health care expressed frustration at the lack of administrative and financial support to develop early intervention services.

From the perspective of many of those who made submissions, the mental health care system seems to provide a palliative care rather than early intervention model of service. They suggest that only those who have reached the most severe or the most chronic forms of illness are prioritised for specialised or ongoing care.

> *What is acceptable about refusing to carry out early intervention until the person is 'acutely' unwell, which leads to a very distressing forceful intervention, then having to administer extremely strong dosages of medication which induce obvious physical side effects which take months to subside? …What is acceptable about not keeping people with a mental illness as well as they can possibly be, thus reaching and maintaining their full potential within the illness?*
>
> (Carer, Mother, Victoria, Submission #178)

> *Early intervention should focus on maintaining life skills and personality – trying to keep family supportive and involved – explaining to the patient exactly what their condition is, what treatments are to be tried and what side effects / benefits can be expected.*
>
> (Anonymous, Queensland, Submission #49)

> *Both consumers and carers reported that in the ACT it is almost impossible to get intervention or be listened to at an early stage when warning signs are initially beginning to appear.*
>
> (Mental Health Community Coalition Consumer and Carer Caucus, Australian Capital Territory, Submission #342)

> *Youth mental health services are disconnected and often staffed by people with limited or no experience in working with these client groups. 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. We can't get staff with the right skills to this area. The situation is very poor and we rarely receive information about what's happening with services.*
>
> (Anonymous, Western Australia, Bunbury Forum #8)

> *All we are talking about now is more beds. We don't want more beds – we want a system of community based care. We want early intervention in the community. We have to move from talking to doing.*
>
> (Consumer Consultant, New South Wales, Parramatta Forum #9)

> *In our region people have the choice of living in the community and only have access to public hospitals when they become critically unwell. This leads to increased strain on family members who are coping with little support. Critical incidents can follow which feeds into community perceptions of people with a mental illness and setbacks the person with a mental illness. The alternative of earlier and timely interventions are desirable but seemingly not possible under the current funding and care model.*
>
> (Service Provider, Victoria, Submission #266)

> *We support a population health model, with its emphasis on promotion, prevention and early intervention in mental health. Many of our organisations believe that the Eastern Suburbs Mental Health Program is falling far short of achieving systematic and strategic approaches to early intervention, often failing to respond effectively or provide any service at all, on many occasions when consumers in our services are in need of proper assessment and timely intervention… We request the implementation of National Standards as they relate to early intervention and continuity of care.*
>
> (Eastern Area Interagency NSW, New South Wales, Submission #100)

There is a lack of resources to ensure good quality mental health care in NSW. Our son was unable to access early intervention and rehabilitation. Instead his condition was left to deteriorate, resulting in gross violations of his human rights on his imprisonment at Long Bay Hospital. His future prognosis has been compromised by the years of neglect by the system and his level of disability is worse that it would have been, had he received the treatment he required.

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

Depending on the nature, severity and urgency of the problem, other barriers may then come into play, such as "closed books", waiting lists, reluctance of specialist services to get involved (a mix of work practice and funding barriers) or the frightening and uninviting nature of such environments. This means that people typically present late in their illness course, and may be much less personally accessible and responsive to treatment. Treatment often gets off on the wrong foot and there is much collateral damage to repair.

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

A new model of integrated care linking adolescent and young adult psychiatry resources with substance abuse services and primary care for young people should be engineered and mainstreamed with educational, vocational, sports and leisure programs in key locations across all capital cities and regional centres.

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

National Mental Health Plan 2003-2008… Page 20 – "Outcome 9: Improved access to early intervention services." As discussed above, the reality is 'the system' does nothing unless the consumer is either psychotic, suicidal, or in some other emergency.

(Carer Advocate, Western Australia, Submission #339)

"To invest in the effective treatment of young people where mental health issues are a concern is of paramount importance. It can and does change the entire trajectory of an illness over a lifetime as so many studies have indicated. I'm sure this needs no debate." (Consumer contribution to Mental Health Coalition Council On-line forum).

(Consumer Advocate, Western Australia, Submission #338)

With regard to remote communities in Central and North West Queensland, further inadequacies become evident with the local mental health system insisting that an individual must present with a clinical diagnosis in order to receive any type of service intervention. This policy flies in the face of research and the National Mental Health Strategy which emphasis the need to provide interventions early and to prevent the actual incidence of mental illness. I have personally found it very difficult to make referrals to Queensland Mental Health service due to barriers within the system. Employees within state mental health cite lack of resources and difficulties attracting staff to remote areas for their inability to accept referrals.

(Clinician, Queensland, Submission #285)

During this time of trying to obtain help for my son, I received a phone call from someone from the clinic informing me that my son was discharged from the service. When I asked how this could be when it was on record that my son was most unwell and that I had been reporting this for some time, his answer was "That's how it is, there is nothing that you can do about it, but of course we will do something if and when he comes to our attention". In other words my bringing it to their attention was worthless, once again it would require my son behaving in such a way that would bring him to the attention of the police or perhaps something far worse happening.

(Carer, Mother, Victoria, Submission #178)

4.2 PRIORITY 2: DEVELOPMENT OF INNOVATIVE SERVICES FOR PERSONS WITH MENTAL HEALTH AND ALCOHOL OR SUBSTANCE ABUSE DISORDERS

In the submissions and consultations, the community clearly recognised that many people with mental health problems are at great risk of developing alcohol or other substance abuse disorders. The extent to which mental health services refuse to deal effectively with these common presentations of illness is seen as nonsensical and anachronistic. The impact of this system seems to fall disproportionately on young people.

Reports indicate that persons with comorbid mental health and substance abuse problems are commonly picked up by the criminal justice rather than the mental health system. Many feel that the chances of achieving reasonable personal, social or economic outcomes once young people have entered the criminal justice systems become markedly decreased.

Despite ongoing recommendations about co-management of these problems by both mental health and alcohol and drug services, there do not seem to be sufficient or effective service structures. Not only are inadequate resources devoted to the task but the negative attitudes of health care providers to such persons seems to have created further problems.

> *As the incidence of substance misuse is so high it is essential that mental health issues are addressed within this context. According to NT / SA Remote Mental Health team in 2002 half of their referrals also involved substance misuse.*
>
> (Anonymous, Northern Territory, Submission #271)

> *The key issues as I see them are the lack of support services available to young people with comorbid mental health and drug and alcohol problems … There is a lot of buck passing that goes on between mental health, justice and welfare departments. Ultimately these young people are primarily dealt with by the justice system. The other departments have failed them and they end up in trouble.*
>
> (Youth Advocacy worker, Queensland, Brisbane Forum #6)

> *I've been banging on doors and writing letters. My son became ill at 15, he's now 18 and in the justice system. They're not about rehabilitation, just containment. There are no facilities for people with mental health and drug and alcohol problems….you get worn out. You get fobbed off. There's like a blanket discrimination.*
>
> (Carer, Father, Northern Territory, Darwin Forum #3)

> *Where are the services for people suffering form a dual diagnosis (mental patients who use drugs / alcohol)? The drug services want mental health to assist these people. Mental health want the courts and prison system to deal with these people. And the Courts consider the issue to rest with Mental Health. Inevitably these people end up in prison, which seems to be the dumping ground for anyone with mental health issues and obviously this is not an appropriate place for them. There are not enough beds for mental health patients which means that the few beds available go to the "deserving few" – whatever that means, presumably it means those people who do not have a drug / alcohol problem.*
>
> (Anonymous, Western Australia, Submission #145)

> *Due to a lack of appropriate facilities for persons with mental health issues and substance abuse issues, many emergency accommodation hostels find themselves in the position of having to accommodate people with disabilities they are not resourced to care for appropriately. A large percentage of homeless persons have nowhere to go if not accommodated by hostels such as St. Bartholomew's.* (excerpt from Coroners Report, 2004)
>
> (St Bartholomew's House Inc, Western Australia, Submission #37)

We're also really concerned for those young people with comorbid mental health and drug and alcohol problems. Who picks them up? Nobody really, they get shifted back and forth because nobody wants to deal with them.

(Accommodation Service Provider, South Australia, Adelaide Forum #4)

When these individuals are refused to be scheduled on the basis of being affected by drugs or alcohol or if they are deemed to have behavioural disorders, they are being let down by the health system. Police then have only one avenue available to them in their duty of care, and that is to proceed by charge when inappropriate… In order to provide protection to the mentally ill person and the community, for example to stop further criminal acts, breaches of the peace and self-harming, police feel they have no alternative but to go around the mental health system who are currently not doing their job.

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

My son [X] committed suicide 2 years ago – he was 26. He was extremely intelligent, creative and a good athlete. His story started when he was 17 and started smoking marijuana and became quite depressed. My husband and I encouraged him to go to the local mental health service - where he saw [Y] and was encouraged by [Y] not to "prostitute" his ideals or lifestyle choices. I also went to see [Y] separately (as did my husband) who more or less said it was none of my business - he's 17… Anyway – [my son] started drinking and smoking at the age of 21 (before that he didn't like alcohol) then of course problems began - with psychotic episodes where [my son] would become violent (have no recall of what happened and then have deep remorse) and we had to call the police - of course this was no use - it only made the spiral deeper and his self esteem lower.

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

My son is 19 and he has chronic schizophrenia and a drug abuse problem – he's been in the locked ward at Graylands for quite a while and I'm glad he's been locked up for that long because he can't cope outside the hospital. He lives with me and I worry about what will happen to him if he is released – he can't be accommodated anywhere and this is a human rights issue – there's unreasonable pressure on the family to provide care for really sick people like my son. But one of the big problems is how much people are charged to be in supported accommodation - 80% of a person's income for supported accommodation is too much because it just leaves enough for cigarettes. My son can't even get supported accommodation... These kids with comorbid problems like my son are becoming the new generation of homeless people.

(Carer, Mother, Western Australia, West Perth Forum #31)

Services are lacking to help consumers, of all ages, with combined drug addiction and mental illness. Drug and alcohol services and psychiatric services still work in isolation. This causes additional trauma to the sick person and families.

(ARAFMI Tasmania, Tasmania, Submission #245)

We believe that there should have been somewhere for [X] to be cared for ***safely and securely*** *while he was* ***stabilised*** *on the new drug regimen prescribed for his profoundly-depressed and suicidal condition.* ***Then*** *the Valium dependency could have been addressed. (author's emphasis)*

(Carer, Mother, Australian Capital Territory, Submission #288)

In all hospitals (four), supported accommodation facilities, and drug/alcohol services, there was failure to address the complex interaction between mental illness and substance abuse, with disastrous consequences. Integration of training, services, and philosophy between Mental Health and Drug & Alcohol Services should be a high priority!

(Carer, Mother, Victoria Submission #320)

Individuals who have a mental illness as well as a drug and alcohol problem are even more limited in their access to services. They face discrimination on both sides of the system. Drug and alcohol agencies are not set up to deal with issues of mental illness, and mental health agencies declare their work sites to be drug and alcohol free. People with a dual disability find themselves in a bind. There are services available that cater for them, but like most other organisations, they are under resourced and over burdened.

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

4.3 PRIORITY 3: DEVELOPMENT OF A WIDER SPECTRUM OF ACUTE AND COMMUNITY-BASED CARE SETTINGS

As demand for acute care services increases and the cost of providing hospital services also rises, there is an urgent need to develop a range of service environments that provide appropriate alternatives to the most intensive forms of hospitalisation. Where there are insufficient alternatives, like stable housing or community-based clinical support, the pressure on acute hospital beds is exacerbated.

Over the last decade there has been a marked decline in hospital-based medium length stay and rehabilitation beds (National Mental Health Report 2004, Commonwealth Department of Health and Ageing, 2005). This has also contributed to increased pressure to discharge persons back to community-based care after relatively short periods in hospital.

A variety of complications may arise from premature discharge and inadequate community care, including early relapse, increased self-harm and increased pressure for readmission. The sense of a 'revolving door' system of care, rather than a coordinated spectrum of care was expressed strongly in many of the submissions.

There has been little or no realistic attempt to correct the lowering in the levels of acute beds across the state. In Victoria we not only closed the institutions but also substantially reduced the number of beds available for short term and acute admissions.

(Clinician, Victoria, Submission #123)

The move to community based services, while positive, has not been matched by attention to stratified and good quality accommodation options for persons with chronic mental illness who rarely can access supervised community accommodation. Disabled and disorganised patients flounder in unsupervised single accommodation, are cast onto the streets, or are involved in "revolving door" admissions to acute units, which are the only "accommodation" facilities remaining for them. A distressingly high number kill themselves.

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

Supported and step down accommodation is desperately needed for clients requiring support after leaving acute care and for those people who have difficulty living by themselves or are too big a burden on their family members (often aged parents).

(ARAFMI Tasmania, Tasmania, Submission #245)

Consumers need a whole range of support systems not just 2 weeks or less in an inpatient service to then be dumped back into the community experiencing symptoms.

(Consumer Activist, New South Wales, Submission #257)

My son had schizophrenia… I'm a nurse and I understand why he wasn't kept in hospital – you can't just keep people like him in hospital. What he needed was a halfway house. We need more money spent on after care and pre care – something staged that people can access when they don't necessarily need to be in hospital.

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

Currently there is no interim or step down facility in Alice Springs, although apparently there are plans to develop such a service. Currently the options are the acute ward in the hospital or being flown back to the community.

(Anonymous, Northern Territory, Submission #271)

The really sad thing is that people like my sister feel they are a burden on their families. There needs to be a place where they can go when they become unwell where they can get the care they need and the support they need. It's too late to wait until she is in a crisis for the system to respond to her – it's too late then! The support services that are in the community don't get the necessary increases in funding they need so they can't respond appropriately either.

(Carer, Victoria, Melbourne Forum #16)

Supported accommodation is in short supply. The Boarding House Reform program instigated by the NSW Government in 1996 has seemingly failed in its objectives. The standard care in those boarding houses remaining open is still poor and the number of beds available greatly reduced – where have all the previous residents gone? A lucky few were rehoused under the boarding house reform program into NGO run group homes. The bulk have possibly added to the majority of people accessing homeless shelters who have mental health problems, live on the streets or in unsupported private rental ghettoes. Seemingly no government department feels it is their responsibility to provide disability support and / or housing for people experiencing mental health problems…

(Clinician, New South Wales, Submission #197)

There is a consensus across human service agencies working with homeless young people with high and complex needs that the capacity of agencies to retain and work constructively with these clients needs to be developed. There is also a consensus that there is a need for a residential service that can manage and support these young people in extreme circumstances, as an alternative to hospitalisation or worse.

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

It is recognised that there is a need for sub-acute care services to be developed in the Northern Territory, to provide an alternative to hospitalisation and improve transition between inpatient and community care.

(Mental Health Program, Department of Health and Community Services, Northern Territory, Submission #259)

It is easier to recover from mental illness in hospital than at home. However, the average is about 3 days, and discharge from mental health care occurs far too early. Consumers have no option but to rely on hostels for accommodation, which cannot provide proper care or suitable environments for recovery.

(Consumer, South Australia, Submission #41)

When a patient is on a Community Treatment Order which has to be revoked because the patient has become unwell and in the absence of any intermediary facility requires hospitalisation. There is again often no bed available for them…

(Carer Advocate, Western Australia, Submission #339)

Lack of suitable accommodation (i.e. lower level care) following a stay in hospital is urgently needed to help the consumer adjust back to a normal life. The gap between hospital and normal life can be difficult to handle, and is of critical concern given that many patients are discharged prematurely.

(Peninsula Carers Council, Victoria, Submission #321)

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: people unable to access community mental health services unless they are in crisis and are a threat to themselves or others; people presenting at hospital emergency departments requiring treatment for mental illness waiting in corridors as beds are not available in psychiatric hospitals; the 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)

4.4 PRIORITY 4: SUPPORT FOR SERVICE DEVELOPMENT IN RURAL AND REGIONAL AREAS

Despite recognition by Commonwealth and State governments of the general difficulties faced by persons residing in rural and regional Australia, there was little sense that substantial improvements in mental health services were being achieved. There was, however, a sense that new services, or new policies or procedures, are being developed to give an impression that a service exists rather than to provide a real improvement in actual services. Submissions suggested that the emphasis was on providing an accessible point of contact, such as a new telephone triage service, rather than a real increase in access to actual services.

The submissions and consultations also suggest that the development of telepsychiatry services has had a marginal impact on access to specialist services. Neither government nor relevant professional bodies seem to be serious about addressing the tough issues of access to primary care and specialist services. On the other hand, increased emphasis appears to have been placed on securing appropriate transport to metropolitan services and ensuring the safety of staff, as opposed to consumers during this process. Consumers and carers continue to report inappropriate use of sedation and restraint for the purposes of transportation. It also seems that there has been greater use of police rather than ambulance services for transport of persons with mental illness.

We live in Devonport, 30,000 population. We have 1 psychiatrist at the service 1 day a week. It's not enough! They are beautiful people but they are under-resourced.

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

Of great concern is the attitude of Perth Metro area hospitals regarding the patients from the South West. Often the statements are we have "one of yours", our hospital is full of "your" patients and I was even told by a senior clinician that our patients were using up the beds in Perth funded by her tax money! There is a perception in the community and by the community mental health team that patients from the South West are discharged prematurely and without follow-up being arranged.

(Clinician, Western Australia, Submission #55)

The majority of medical services provided to these patients are provided by general practitioners. The provision of these services are largely unsupported and despite recent changes in the schedule are largely under funded for the time and resources needed to manage patients with long term mental health problems.

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

The high levels of unemployment in Rockhampton contribute to the development of mental health problems. These people keep coming back and back but you see the deterioration – no support and no families – living in hostels.

(Anonymous, Queensland, Rockhampton Forum #17)

There is a lack of community outreach to rural areas and for specific programs such as child and adolescent, forensic. The focus is on inpatient care rather than community support.

(Anonymous, Tasmania, Submission #254)

…there has been ongoing debate regarding the mal-distribution of medical services in Australia… The majority of medical services have been concentrated in capital cities and major regional centres and have been quite limited in rural and remote areas. It has become increasingly difficult to recruit and retain general practitioners (GPs) in country areas and there is a long history of difficulties in the provision of specialist services outside large population centres. It is a fact that there are relatively few medical specialists living and working outside major regional centres… For example, in South Australia in 1997, only 1.1% of psychiatrists lived outside Adelaide.

(Clinician, South Australia, Submission #274)

There is a real need in Broken Hill for after hours care as there is not even a 1800 number that people can call to get assistance.

(Consumer, New South Wales, Broken Hill Forum #7)

Triage is a real problem in Broken Hill as there is constant confusion over who is responsible for assessment. This confusion makes it hard for consumers if they require immediate assistance… I have always presented to the hospital or to the mental health service but there seems to be no clear protocol amongst the staff about how to conduct an assessment when I am unwell. I have never been assessed by a psychiatrist and am normally assessed by the registrar on duty.

(Consumer, New South Wales, Broken Hill Forum #8)

You can't get care in the country. I travel 3.5 hours from the country to here (Melbourne) because I can get care… now I can't work because I need to travel down to here for care.

(Consumer Advocate, Victoria, VMIAC Forum #8)

In order to get an appointment with a psychiatrist I send my patients to Melbourne – but even this means about a 3 month wait.

(Clinician, Victoria, Morwell Forum #8)

The need is both dire and urgent, particularly on the South Coast of New South Wales. For persons with a mental illness the main issues are hospitalisation, rehabilitation places for persons leaving psychiatric hospital and not enough case workers. The closest hospital for acute treatment is at Chisholm Ross Hospital in Goulburn, a four to five hour trip from parts of the South Coast. Beds there are like hens teeth, accepting only the most acute cases; so with a degree of improvement, patients are discharged back into the community… Community resources are stretched to the maximum when a patient is required to be transported to Goulburn. This is costly in both money and workers time: such as police, local emergency hospital staff and community mental health workers. The South Coast is in desperate need. Money injected for projects now would both save lives, and save money in the long run.

(South Coast Mental Health Community Consultative Committee, New South Wales, Submission #244)

In the country you don't have a choice of psychiatrist, and there are no alternatives when it comes to what is available to help you. There is no therapy, little in the way of counselling and no choice but to do your own rehabilitation.

(Consumer, South Australia, Submission #77)

Human rights in regional and especially remote areas, are often infringed upon, because of lack of resources and very poor (if any) government funding. In fact in many areas services are being drastically reduced because of dramatic cuts in both Federal and State funding.

(Consumer Advocate, Queensland, Submission #16)

The Child and Adolescent Mental Health service in both Geraldton and Carnarvon has not been running for substantial periods of time over the past three years. This has left many children and adolescents at high risk of suicide. In Carnarvon a number of aboriginal adolescents have committed suicide.

(Clinician, Western Australia, Submission #333)

It is intended to fill the position with a person qualified in mental health. But one person doesn't make a team.
(Anonymous, Western Australia, Geraldton Forum #105)

4.5 PRIORITY 5: IMPLEMENTATION OF NATIONAL STANDARDS FOR MENTAL HEALTH SERVICES

The implementation of national standards for mental health services has been a top priority for the Mental Health Council of Australia and for most of the major national mental health non-government organisations. The most recent National Mental Health Report (2004) reported that less than half of the services had actually implemented the standards by the agreed date of June 2003. That date was some seven years after governments from all jurisdictions endorsed the National Standards for Mental Health Services (The Standards).

The key issue for users of services is whether the spirit of The Standards has translated to real effects on daily practices within the services. In the view of most mental health consumers, there are clear and ongoing examples of complete disregard for The Standards. While we have addressed these issues in detail elsewhere in the report, it is important to emphasise that this represents one of the major areas of non-compliance with the agreed implementation strategies of the second National Mental Health Plan (1998-2003). Universal implementation of The Standards, and ongoing monitoring of compliance, should be among the first steps towards any genuine commitment to improved quality and safety of specialist mental health services.

A major concern is the unwillingness of the hospital to initiate changes to organisational and clinical practices to meet standards set out by the National Standards for Mental Health (1996) based on the National Mental Health Policy (1992). (Excerpt from: Shanley (2001), Management of change in a psychiatric hospital using a 'bottom up'approach)
(Eamon Shanley, Professor of Mental Health Nursing, Western Australia, Submission #33)

At the same time the constant struggle to achieve best practice has been fraught with difficulties against a backdrop of increased accountability and devolution of administrative duties to clinical Staff. We have wonderful policies but no resources to implement them.
(Anonymous, Tasmania, Submission #254)

Mental health services are not implementing the National Standards for Mental Health Services and the Third Plan, despite government beliefs.
(Advocate, Australian Capital Territory, Canberra Forum #11)

There has been a failure to address issues identified by current Mental Health reporting. There has been no commitment to instigate long-term change when gaps have been identified. Lots of ideas – very little action.
(Anonymous, Tasmania, Submission #254)

The meeting agreed that an independent review of mental health services in the ACT against national service and workforce standards would be timely and merited.
(Mental Health Community Coalition Consumer and Carer Caucus,
Australian Capital Territory, Submission #342)

Australia's National Mental Health Strategy is in disarray and in urgent need of reform: in leadership, additional funding and delivery of services.
(SANE Australia, National, Submission #302)

Unfortunately, in more recent years positive change does not seem to have continued, and if anything, deterioration has taken place. Now, at least in Western Australia, there is a crisis in regard to provision of Mental Health Care within the community. (extract from a letter to Communications Manager, Mental Health Council of Australia)

(Clinician, Western Australia, Submission #24)

It is an unhealthy system that allows even a minority of its parts to operate in ways that are so hostile to its service users and against its own mandate.

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

The WA Office of Mental Health has established a Branch solely to examine reform and redesign issues, based on WA's Mental Health Strategic Plan 2004-08. Any action, however, will depend on the Gallop government which has been defensive and reluctant to commit itself seriously in this area.

(SANE Australia, National, Submission #302)

There are continuing problems in regard to the integration of the APU [Acute Psychiatric Unit] into the management structure of the Bunbury Regional Hospital. It is by no means clear that senior management staff have a good grasp of issues to do with mental health and psychiatric clinical service delivery. Despite principles of integration and mainstreaming there still is a tendency for psychiatry to be treated differently to other medical specialities… (extract from a letter to the Office of the Chief Psychiatrist)

(Clinician, Western Australia, Submission #24)

More money into mental health services will not make the difference without some changes to the fundamental assumptions that direct the current treatment paradigm.

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

Re-institutionalisation. The National Mental Health Strategy was launched in 1992 to transfer services from an institutional to a community setting. After 12 years, four of the five mainland States still have standalone psychiatric hospitals! These institutions continue to soak up around $420 million a year – 14% of the entire cost of mental health services of around $3 billion per annum. In several States, community-based services are being withdrawn onto hospital grounds to make short-term savings. Prisons are also becoming de facto psychiatric institutions – in NSW, for example, 46% of inmates at reception have a mental disorder, and the prevalence of psychosis is 30 times greater than the norm.

(SANE Australia, National, Submission #302)

[Report recommendation] Establishment of a National Mental Health Commission to monitor and report on effectiveness of mental health services.

(SANE Australia, National, Submission #302)

Despite welcoming the policy efforts and designated funding commitment of both state and federal governments, consumer agencies and community organisations are critical of their performance. It is argued that the failure of government to adequately resource its policy initiatives has lead to a chronic deterioration of care and support for mental health consumers. There is significant concern that because of the inability of services to provide preventative care this leads to delays and neglect in treatment, some of which creates irreversible damage in the mental health status of consumers. It also leads to an increased demand on an already overstretched mental health system.

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

Both State and Federal Governments put considerable energy into devising lengthy and detailed mental health plans. Of what use are they if there is no funding with which to implement their recommendations? Human rights are not adequately addressed in these plans; there is no detailed documentation on accountability measures where rights are not upheld.

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

t may be timely to review the system – for many, it is complicated, convoluted and un-navigable with people seeking help being turned away, and falling through its cracks. There may be more effective, efficient, and user friendly ways of designing a mental health system.

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

4.6 PRIORITY 6: SUPPORT FOR SERVICE DEVELOPMENT IN POORLY RESOURCED AREAS

On the basis of the submissions and presentations, it would appear that major areas of Australia have poorly resourced mental health services. This problem is commonly assumed to be confined to rural, remote or indigenous communities. In reality, many of the poorly resourced areas also lie in the outer suburbs of our major metropolitan or regional centres. Such areas typically have poor access to non-hospital based medical services, private hospital services and non-government service providers. Access to mental health specialists is often restricted in both the public and private sectors.

Difficulties in the distribution of specialist services have been long recognised by all levels of government and the relevant professional bodies but little substantial progress has been achieved. The under-resourcing spreads well beyond shortages in traditional hospital-based services and is particularly acute for many of the other community-based systems of clinical care or housing or welfare support.

Secondly in Australia, and notably in Melbourne, the distribution of public mental health services, private psychiatrists and high levels of quality primary care, is almost the direct inverse of the need for care. The affluent inner city areas have high levels of services of all kinds, while the growing or deprived outer suburban regions have minimal resources with inevitable consequences. The funding model was never valid and is now obsolete as well.

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

There's no crisis team in the area… There is differential access depending on which area you live in. For example, Fairfield, Camperdown and Bowral have no crisis assessment teams.

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

The distribution of private psychiatrists … the practices of large numbers of private psychiatrists are concentrated in the capital cities. In Melbourne this situation is extreme. Within a fifteen kilometre radius of the Melbourne GPO can be found the highest concentration of private, practicing psychiatrists in the southern hemisphere and the second highest concentration in the world - second only to Manhattan, New York. The allowance of these capital city concentrations means that vast areas of Australia and thousands of people have virtually no access to psychiatry. This has to be seen as a demonstration of gross inequity given the fact medical undergraduate education and post-graduate psychiatric training are subsidized to such a high degree by tax payers.

(Anonymous, Victoria, Submission #318)

We only have one inpatient facility for the region – people of a low socio economic background find it very difficult to travel long distances to get care.

(Clinician, Victoria, Morwell Forum #11)

We have discovered that often the only way to access good mental health treatment in NSW is by constant hard lobbying by family or carers. The consequence of this is that adequate mental health care is frequently out of the reach of people from aboriginal and ethnic backgrounds, and those from lower socioeconomic areas.

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

There are not enough nurses, social workers and psychiatrists in the country where as in the city there are more. However, even in the city staffing in the mental illness field is less than satisfactory.

(Consumer, South Australia, Submission #77)

My son (33) has severe schizophrenia. We are from the North West Coast and we have a real lack of services, accommodation. There is nowhere that my son can go apart from home. There is a lack of rehab and recreational services. I see people going into hospital and then coming out but no support in community so they end up back in hospital. There is nothing for him to do to keep him occupied.

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

The resources need to be outsourced from the hospital. We need respite care, prevention education for the communities, it's too chemical.

(Anonymous, Northern Territory, Alice Springs Forum #21)

Follow up is then provided by a visiting psychiatrist and two community case managers who are funded to cover the entire southern area of NT and SA. This means that the focus of the service can only be crisis management at best. The ability for workers to provide ongoing support or any meaningful individual case planning is significantly impaired. Generally the workers will average a trip once a month to the region, which means even the larger communities may not see a worker for several months. The level of service is purely resource, rather than need, driven.

(Anonymous, Northern Territory, Submission #271)

The issues relevant to indigenous physical health outcomes are well documented. With the ongoing critical physical health needs of the community, staff are already at full capacity. In this context issues of mental health cannot be prioritised, unless there is an acute need for treatment.

(Anonymous, Northern Territory, Submission #271)

People have to drive 5 hours to get counselling. There are some acute fly-in services but these are highly medicalised. Access to acute services requires either a flight into Alice or to Perth. Often if they are taken they are then sent out – that's it.

(Anonymous, Northern Territory, Alice Springs Forum #10)

As people are often evacuated, without the support of family, relatives may have no contact with the treating team. They may not be given information or able to provide information to the treating team. If a person is admitted to hospital for a period of time the costs associated with family visits are prohibitive. In communities diesel can be up to $1.60 / litre, which means that doing 1000km round trips is beyond the capabilities of most. There is no public transport available on NPY Lands. This leads to extreme distress within families and communities. It also needs to be noted that due to the high level of chronic ill health within communities the burden on carers within families is often very high. Therefore it is important that health professional do not make assumptions about the level of family support available when making discharge plans.

(Anonymous, Northern Territory, Submission #271)

Our area has 12% of the population but receives 6% of the funding. We don't have anywhere near enough resources, enough staff or enough beds! We don't even have enough basic services!

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

If the metro is $118 and Geraldton is $70 per capita, I would think that Dongara would be about $1.50 / capita… There is a lack of support for carers and acute clients.

(Anonymous, Western Australia, Geraldton Forum #108)

[Z], the other psychiatrist also contributing to the current roster, is reluctant to continue feeling that the role is not well supported and lacks parity with metropolitan arrangements. (extract from a letter to the Office of the Chief Psychiatrist)

(Clinician, Western Australia, Submission #24)

Transportation in regional areas is a real problem as many seriously ill patients have to go to Orange with the Royal Flying Doctors Service but then they have to make their own way home. Some people in Bourke have even been sent from Bourke to Orange in police cars.

(NGO worker, New South Wales, Broken Hill Forum #26)

4.7 PRIORITY 7: SUPPORT FOR PROGRAMS THAT PROMOTE ATTITUDINAL CHANGE AMONG MENTAL HEALTH WORKERS

Issues related to stigma and discrimination are still evident in many submissions and presentations and hence high on the community agenda. Within that broad agenda, however, the need for changes in the attitudes of health care providers are a high priority for users of the services. Accounts of highly negative, dismissive or stigmatising remarks by health staff towards persons with mental illness are still too common. Additionally, family members often feel discounted or ignored by health workers, even though they are expected to contribute greatly to ongoing care. Thus, while some attention has been directed to this issue in the past, it seems that there is little evidence now of a systematic response to inappropriate behaviour by mental health professionals.

It has been the experience of the VMIAC [Victorian Mental Illness Awareness Council] that more often than not, if you ask consumers if they could wave a magic wand and change something about the mental health system what would they change? The attitude of health professionals is the most frequent answer followed by access to services.

(Victorian Mental Illness Awareness Council, Victoria, Submission #332)

Many young people in the focus groups described their first experiences with health professionals and authority figures as unpleasant, frightening, coercive and humiliating, which subsequently had a profound effect on their attitudes to future dealings with health professionals. Young people said: …It broke my spirit… Humiliation… It took away my rights…

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

Prosperity and pleasantness are common causalities of severe mental illness. One would hope that psychiatrists, of all people, could accept this but like most doctors, psychiatrists rarely show enthusiasm for, or understanding of, patients who are neither cashed up nor personable.

(Clinician, Queensland, Submission #49)

Apart from the crucial issue of ease of local communal access, appropriate crisis and community care depends more on team attitudes than the site of services. But there is a widespread international consensus that it is much easier to generate and maintain the appropriate attitudes on a community site, rather than a hospital based site.

(Clinician, New South Wales, Submission #351)

The staff treating depressed inpatients should be educated about the potential adverse effect of negative comments on the patient's mental state. Education to staff that persons who attempt suicide can and do later succeed in suicide should be undertaken. (excerpt from a report prepared by an independent external reviewer)

(Carers, Parents, Australian Capital Territory, Submission #354)

In many settings there appears to be no multi-disciplinary approach to care, and in some cases, the seeking of care can be further stigmatised by the attitudes of the treating mental health care professionals.

(blueVoices, National, Submission #355)

Money alone can't buy service improvement… service provider "attitudes" can be a make or break factor. It emerged that many of these Consumer Consultants were often more immediately concerned and affected by the many ways that the cultures and environments of mental health services could be a supporting factor for consumer participation efforts, or the source of difficult and frustrating barriers. ***"Attitudes"*** *of service provider staff and managers towards consumers and receptivity to change were seen by some stakeholders as an important factor influencing outcomes. Consumer consultants spoke about a wide range of experiences at their local Area Mental health Services. (author's emphasis)*

(Consumer Advocate, Victoria, Submission #253)

Feedback we receive from people with a diagnosis of Personality Disorder suggest that they are being treated badly by staff (e.g., staff are irritable towards them, their concerns being dismissed as part of their illness, they are characterised as manipulative)… We request that the MHS considers conducting an evaluation to determine how people with a diagnosis of Personality Disorder experience ESMHP [Eastern Suburbs Mental Health Program] services, and address staff attitudes towards these consumers.

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

One day I asked [my psychiatrist] whether he had any patients with Borderline. He said he didn't like using that label because it brought such terrible consequences for people but, yes, he did see quite a lot of people who would fit into that category. I asked him what the treatment was and his immediate answer was to say, "the first thing I do is treat them nicely! This is a new experience for most of them".

(Consumer, New South Wales, Submission #327)

People, who doctors have decided have a 'personality disorder' are treated in the public system like [they] are not even human half the time – like dirt. My friend calls us ground feeders – we just pick up scraps of services that everyone else has discarded. How do we stop professionals judging us so badly?

(Consumer, New South Wales, Submission #205)

Better training for people working in mental health so there is not the "patronising put down" attitude that I have witnessed… An inclusive attitude for carers and families - where they are listened to and really heard and consulted more closely.

(Carers, Parents, Victoria, Submission #241)

Police need to have more MH [mental health] education / training. Ditto for Accident & Emergency staff including medical heads of dept about personality disordered people in crisis. I was told personally by a medical head of DEM [Department of Emergency Medicine] that 'they're arseholes' . So imagine the working culture if that view is held at the top.

(ARAFMI Hobart, Tasmania Submission #214)

At best, the mental health professionals we dealt with were genuinely concerned but were seemingly powerless within the system. At worst they were arrogant, inconsistent, disrespectful and uncaring. Above all, the mental health system failed to provide [X] with hope. Mental illness should not be terminal, and he wasn't beyond help.

(Anonymous, Australian Capital Territory, Submission #288)

I can understand how there are so many suicides in our community. Any hope for a normal life is minimal. Not only is the welfare of these people ignored there is positive discrimination against any progress they might want to make. More understanding and education is needed. The last government (and only) education campaign fell far below the mark required. Mental health sufferers need long term care and understanding. Not only by the general population but also (and more so) by the health industry and government.

(Carer, Western Australia, Submission #163)

4.8 PRIORITY 8: INCREASED SUPPORT FOR STIGMA REDUCTION CAMPAIGNS

General community attitudes towards persons with mental illness are difficult to change. Daily experiences of stigma and discrimination were reported repeatedly in the submissions and consultations. There was recognition that some progress had been made, particularly with regard to the non-psychotic disorders of depression and anxiety. However, consumers, carers and community groups reported that community attitudes towards persons with psychosis or substance abuse were still very negative. More importantly, it was also reported that little had been done in terms of planned and well-resourced community education programs. Community groups have argued for renewed efforts in this area as they are considered critical to achieving genuine social and vocational opportunity and recovery from mental illness.

Need to be aiming at inclusion not exclusion – I know of people who are banned from coming into shops because they have a mental illness. The stigma in our communities is still very bad. People are treated differently, badly because they have a mental illness.

(Carer, New South Wales, Sydney Forum #13)

A cousin who worked for the blue nurses in NSW was looking for work. She couldn't get work any more because of her mental illness and she ended up killing herself.

(Anonymous, Queensland, Rockhampton Forum #5)

[A] young man went off to have a cappuccino, and came back so quickly that [Y] asked him why and he told her that they'd said "Come back when there's no one here." That wouldn't happen there now, as a result of the Kew Regional Outreach Ministry.

(Carer, Mother, Victoria, Submission #211)

The belief exists that people with mental illness are inferior citizens who are best confined to certain areas, if not buildings, because they "would be happier there" and other citizens have a right not to be even mildly bothered by them. In fact people want them out of sight so that they do not have to deal with the reality of their existence.

(Carer, Australian Capital Territory, Submission #173)

Social isolation & loneliness are guaranteed triggers of episodes of mental illness, substance abuse, self harm & suicide. This happens, and it happens all the time. And in rural and isolated communities, where resources are even more scarce, the problems are much worse.

(Consumer Advocate, New South Wales, Submission #153)

It is scandalous and a national disgrace that there is no significant commitment by governments and the prevalence of community unawareness and apathy. There has to be a national campaign similar to that for AIDS if mental health is to successfully obtain government support etc.

(Carer, Son, New South Wales, Submission #120)

On one occasion when my son was ill he frightened some people in the town and when he was in hospital I put an advertisement in the paper to thank the police for their help but also to try to educate the community that he had received treatment and was not a threat to them. It didn't really help.

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

Finally I have lost some friends because they could not accept or cope with my mental illness. My new friends have their own mental illness and we meet to socialise and support each other but not in an integrated community way.

(Consumer, South Australia, Submission #77)

In respect to employment a person can have extended sick leave for a physical ailment or condition but if mentally ill it may be impossible to return to work. A period of mental illness is not looked on favourably by an employer. Applying for work knowing one has been mentally ill for ten years as is the case for me is exceedingly difficult because of stigma. It is assumed I cannot cope with daily life but if I had a broken leg or a bad heart no one would judge me in relation to coping with daily life let alone work. I don't have the right of a job or the right to suffer an illness without bias.

(Consumer, South Australia, Submission #77)

In my opinion there is considerable stigma attached to being mentally ill. The media often reports on certain mentally ill people as being dangerous and frightening. My mentally ill friends and myself are nether dangerous or frightening. Our society expects that people get physically sick but if a person becomes mentally ill for a time they are told unkindly to pull their self together. No understanding is entered into.

(Consumer, South Australia, Submission #77)

Stigma is a persistent issue in the NT. Some of the local media have repeatedly reported on anti-social behaviour by Aboriginal and Torres Strait Island people with mental illness in a way which blames those affected, rather than relate this to symptoms and lack of treatment, as they would with any other illness.

(SANE Australia, National, Submission #302)

There is a complete lack of understanding in the community that people may be able to function in some parts of their lives and not in others, or they may well for some part of the day / week / year and not others. This lack of understanding leads to unjustified criticism and discrimination.

(Carer, ACT, Submission #173)

The family never rings, or visit even though he has asked them to do so. Their excuse is that they are frightened.

(Carer, Father, Australian Capital Territory, Submission #208)

Community attitudes need to change, to move away from a fear of 'madness' and accept that mental illness is a common and serious condition, which has the capacity to ruin many lives if unacknowledged and untreated.

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

Our research has proven to us that the root cause of inequity and social injustice is stigma. Therefore, as a society we need to continue with public awareness and education and to demonstrate our intolerance of stigma and discrimination in the workplace, the schoolyard and our health care system.

(blueVoices, National, Submission #355)

Human rights violations in mental health in Australia occur not just because of a few rotten apples in the barrel, or because of inadequate resources. Human rights violations are systemic and deeply embedded in how Australia responds to mental health. First, in the broader community, the stigma that surrounds mental health has to be seen as a deeply entrenched discrimination against madness that requires sustained, constructive measures to overcome. A clear and strong voice from consumer-survivors, in their own language, will be essential to this task. Second, within existing mental health services, this stigma and other discriminatory prejudices and practices are intrinsic to these services and central to the systemic human rights violations. Without a major overhaul of how we approach mental health, more resources will only further entrench and possibly worsen the current human rights abuses of mental health consumer and survivors.

(Insane Australia, Victoria, Submission #232)

At a public level, the association of violence and aggression with mental illness must be challenged whenever it appears. The public must be made aware that such violence is an exception, and that people who do have a psychiatric illness are much more likely to be on the receiving end of it rather than to be the perpetrators. All people with a psychiatric illness suffer at some level by the misperception that is created by sensationalist media reporting.

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

4.9 PRIORITY 9: DEVELOPMENT OF SPECIFIC INTER-GOVERNMENTAL SERVICE AGREEMENTS (E.G. BETWEEN HEALTH, EDUCATION, HOUSING, EMPLOYMENT AND SOCIAL SECURITY)

Many submissions and presentations suggest that inter-government service coordination is poor. Mental health consumers report that the system is chaotic, disorganised and unresponsive to their wide range of needs.

To achieve a genuine improvement in health, social, welfare and emergency services, there is a clear need to identify the role and responsibilities of multiple government agencies. Unless clear inter-government agreements are in place and acted upon, there is little chance of on-the-ground service cooperation or coordination.

People living with a mental health problem are one of the most acutely disadvantaged groups in Australia. They are more likely to be living in poverty, with limited access to affordable and secure accommodation, to have low education and to be without employment. The ability of consumers to access service systems across the spectrum of care demands that government urgently increase their investment into services.

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

The overwhelming conclusion from this research is the urgent need for an increased range and supply of support services to assist people with serious mental illness and their families to live successfully in the community. Deinstitutionalisation has not failed. What has failed is the political will to fund essential support services in the community… Ultimately, it is a failure of systems which is making people sick and forcing them into the costly acute care sector.

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

In viewing health as indigenous people do, in holistic terms, it is impossible to overlook the enormous influence social factors have on the mental health of the people of Western Queensland. Poverty, inadequate housing and isolation rank high in the list of challenges to people's general health and well-being… Mental Health services which insist on providing individualized, clinical services cannot hope to be effective without also addressing the collective, environmental influences on mental health.

(Clinician, Queensland, Submission #285)

Many problems arise from the systems stasis of Mental Health, Social Security, Corrections, and Social Services, i.e. they serve the system, not the community, and as such constrain the development of appropriate, diverse, flexible and voluntary services and the growth of good relationships between staff, patients and people close to patients. Policy, political and societal will is as important as legislation here.

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

We just don't have the resources to support these kids so the schools call the police. Yes we have other avenues, other services but how do we access these – the waiting lists are sometimes 18 months. These kids do not complete their education and they end up in a life of trouble – a horrendous situation – we have the mandate to keep the schools safe – but it's too hard.

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

There are more fundamental issues that bear on mental health and mental health problems; there are issues around the priority given to mental health by all the human service and related systems. For example, look at the training of general nurses, and of the many of the specialities in medicine. In many of the latter mental health is critically important yet mental health does not feature in the training programmes, I am thinking especially of physicians and paediatricians. But there are others. The same could be said of lawyers and

police. Some of the most intractable problems I have found in caring for some young adults with mental illness are the way the justice system and police have treated them, and other systems like housing and income support.

(Anonymous, New South Wales, Submission #125)

The research uncovered a disturbing cycle of poverty and ill-health for many people with serious mental illness in Tasmania. Participants reported patterns of unstable housing, food insecurity, with a heavy reliance on emergency relief agencies, inadequate clothing, and regular disconnections from essentials such as telephones and electricity. Access to services such as general practitioners, the public dental service and public transport is made difficult by issues of cost. Without adequate support in the community to manage their accommodation, their finances and the tasks of everyday living, many found the stress of trying to survive alone exacerbated the symptoms of their illness, often resulting in relapse and re-hospitalisation.

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

Collaborative service agreements between sectors that respond to the needs of people with dual diagnosis are required.

(Brain Injury Association of Queensland, Queensland, Submission #60)

Another thing I want to raise is the trauma and violence inflicted on carers and negotiating the systems such as Centrelink is extremely hard. This is not being recognised in the system. I have just been working with a Grandma who has been fighting for custody of her grandchild. She has no money and no support. We need a system to support these people who provide the care.

(Consumer, Victoria, Footscray Forum #6)

The closure of long term residential care beds in institutions, and the transfer of responsibility for care to families, has not been accompanied by the development and implementation of appropriate legislation and support for families to enable them to continue to care without severe emotional and financial distress.

(NSWCAG, New South Wales, Submission #273)

A new system of vocational recovery programs within public sector mental health / substance use services should be developed in conjunction with the Commonwealth and the business sector.

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

People with a psychiatric disability are on of the most disadvantaged groups in the labour market with an unemployment rate of 72% compared to a national rate of 5.7% (Australian Bureau of Statistics, 2001). These statistics reflect the enormous barriers people with a psychiatric disability face in gaining and keeping work. It also demonstrates that existing workplaces and employment agencies are clearly struggling to provide adequate support for this group.

(Disability Employment Action Centre, Victoria, Submission #209)

People with mental health concerns, or maybe dilemmas, who attempt to recreate or regain their lives through training and study are currently not given the support they need to do this adequately. Student support services are not able to adequately meet student's needs independently…

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

One of the richest sources of expertise, in many districts helping with the recognition of depression and psychosis, the Aged Care Assessment Services, cannot intervene past the point of assessment. They are also poorly integrated with State-funded agencies in many instances.

(Clinician, Queensland, Submission #140)

4.10 PRIORITY 10: MORE GENUINE CONSUMER PARTICIPATION AT REGIONAL AND LOCAL SERVICE LEVELS

While the National Mental Health Policy places strong emphasis on the key roles of consumer and carer participation, it seems there is still a long way to go before such participation actually influences patterns of local service delivery. The impediments to this process appear to be both attitudinal as well as resource constraints. Traditional medical services appear to struggle to develop genuine service provider-consumer partnerships.

Mental health consumers are the great hope for the reform of mental health services in this state and no doubt elsewhere. … [U]ntil the users of mental health services are brought into the centre of the service delivery culture, there will be no change for the better. Consumer participation in meaningful and robust ways, will be the singlemost important accountability mechanism that will improve the safety and quality of mental health services in this state…

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

Many of these volunteers report that their time on these bodies was, at best, a complete waste but, more often, that they felt cheated and ripped-off – their contributions were rarely heard and virtually never acted upon.

(Insane Australia, Victoria, Submission #232)

It is still the case that dominant groups decide for consumers what kind of services should be provided, if any, without any meaningful consultations and when consumers are quite able to speak for themselves. This leads to a situation such as we have in Tasmania where consumers feel excluded and their different needs are overlooked or even worse dismissed. The anger and grief that results from such indifference then surfaces and very often labelling of those who complain then occurs.

(Anonymous, Tasmania, Submission #254)

There is a perception among consumers that more time and opportunities are given to consumers who are well, literate and not experiencing co-occurring disorders. Another concern is that consultation tends to focus on surveys, suggestion boxes and complaint forms.

(Anonymous, Tasmania, Submission #290)

Families are fed up. They've told their stories over and over again. What assurance can I give them that this will be any different. We simply tell our stories yet again and nothing gets done to address the problem.

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

One of the problems with consumer employment and consumer advocates is the vast dearth of an actual skills base. As a trainer in consumer advocacy for a state organisation, I constantly talk to consumers whose only criteria for having been employed in a consumer position is the fact they're a consumer. Even though some consumers are more sensitive to the situations that many consumers find themselves in – training is a must and understanding the very, very specific role of consumer advocacy is imperative.

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

There's a need for a rural consultation in areas like Port Augusta… There's also a need for consumers, carers etc to be heard and to be supported with funding.

(Advocate, South Australia, Adelaide Forum #15)

There are many consumer advocates employed here in WA but the attitude is one of extreme paternalism by the office for mental health - when consumer advocates speak up and their position is in any way critical of the Government or the system, they are classed as being unwell.

(Consumer advocate, Western Australia, West Perth Forum #28)

Perhaps the greatest disconnection has occurred between the consumers, the providers and the decision makers. Consumers are no longer being consulted about their needs here.

(Clinician, Western Australia, Bunbury Forum #15)

I am constantly amazed at how many people in the community have experienced difficulties with the service over the years and it continues unabated, theirs and my constant frustration that nothing changes and that the treatment of consumers and carers remains poor. We have brought many issues up and were tired of our own voices and frustrations; we each have our own stories it just goes on…

(Anonymous, Queensland, Submission #113)

Consumers and carers continue to be largely denied effective participation in both their personal treatment and in the development of effective service delivery systems.

(Clinician, South Australia, Submission #56)

There is considerable support and some would say a growing "critical mass" of support, commitment and goodwill toward consumer participation among many service provider managers and staff and some genuine attempts to work in partnership and collaboration with consumers – as well as some quite entrenched pockets of doubts, resistance and "hangovers" from the institutional attitudes and approaches in some areas.

(Consumer Advocate, Victoria, Submission #253*)*

While some organisations appear to be genuinely committed to consumer participation, anecdotal reports from consumer consultants and consumer representatives persistently and consistently indicate that the attitudes of many service providers, managers and bureaucrats are that consumer participation exists because it has to rather than it needs to.

(VMIAC, Victoria, Submission #332)

This is the 4th community forum / report for mental health services in the NT – we are exposing ourselves.

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

I have had an ongoing discussion with SANE about what I see as the invisibility of BPD [Borderline Personality Disorder] on their website and in their publications… on the Fact Sheet for BPD there is no emphasis on distress; rather, the whole emphasis is on people learning to manage their behaviour successfully. I hate this. The behaviour is as a result of something. It doesn't just jump out from nowhere. This is grossly unfair and judgemental.

(Consumer, Advocate, Victoria, Submission #166)