Mental Health Community Coalition of the ACT
Consumer and Carer Caucus

Submission to:
The Senate Select Committee on Mental Health

Introduction

The Mental Health Community Coalition of the ACT Consumer and Carer Caucus prepared this submission for the review of mental health treatment and care conducted by the Mental Health Council of Australia and HREOC. Eighteen consumers and carers attended a Consultation Workshop, held on 18th October 2004. A further 10 people contributed to this submission either orally or in writing. As the contents of this submission seem relevant to the Senate's current inquiry, the MHCC Consumer and Carer Caucus is making the information available to he Senate Select Committee.

Better in-patient facilities, treatment and care

Consumers and carers reported that the standard of care and treatment in in-patient facilities can be very unsatisfactory. Most present, suggested that the reasons for this, included a shortage of staff and difficulty in keeping sufficient numbers of skilled and experienced staff in the public system.

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. There is little to do, and little assistance is said to be given to preparing for discharge or for ongoing recovery in the community.

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.

Young people were reported to fair poorly in the PSU. The need for a specialised and a purpose built unit for children and young people was emphasized.

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.

Longer or long-enough in-patient care

Consumers and family members and other carers reported that discharge occurs frequently too soon and that people are discharged despite being too ill to care for themselves.

> *'It is just not possible to stay long enough. Maybe you can if you have private insurance but if you are a public patient your stay will be brief if you can get admitted in the first place.'*

Sufficient numbers of case-managers and other clinical and non-clinical staff

Consumers and carers called for an independent review of staffing levels and levels of experience and expertise. It was reported that MHACT (Mental Health ACT) including PSU (Psychiatric Services Unit at Royal Canberra Hospital), CATT (Crisis Assessment Treatment Team) and regional Mental Health teams are critically understaffed and have difficulty in maintaining staff with appropriate skills and experience. New graduates are reported to not receive the professional support and supervision they require to 'survive in the job'.

> *'I have recently noticed a deterioration in the care my son receives, apparently because there is a shortage of psychiatrists and clinical managers in public mental health services. Appointments are infrequent and very short. Little effort is made to explore the current state of my son's symptoms. His appointed clinical case-manager is most helpful, but, when he is on leave, there is insufficient back up.'*

Sufficient and appropriate support in the community

Consumers and carers in the ACT reported that there is insufficient, appropriate support in the community including:

- Sufficient numbers of paid consumer and carer advocates;
- Peer support;
- Support that can be accessed in a person's home not just from a center;
- Affordable and appropriate accommodation linked to support;
- Recovery and rehabilitation programs that are individually tailored;
- Training and work options.

> *'There is no organised rehabilitation program which suits my son's needs. There are programs, but they do not suit him as he needs an individually tailored program…. He was doing well, organizing his own activities, but a change in his condition undid all of that and he has not had any strong encouragement to resume activities. A mother is not always the best person for an adult son to hear telling him what to do.'*

> *'There is no supported employment program that meets the criteria of best overseas practice. My son would dearly love to work pat-time, but in a field in which he has experience.'*

Greater access to free healthcare, dental care and psychological services

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.

There is little access to bulk-billing GPs in the ACT. People with mental illness quickly acquire a backlog of health complaints that remain largely undiagnosed and/or untreated. Dental care is beyond the reach of most people with mental illness as well as their families unless they are able to afford private health insurance.

> *'There is little recognition of the need for special programs to take care of other medical problems which occur for people experiencing mental illness, often, at least partially the result of side effects of medication. Diabetes, other metabolic problems and cardiovascular conditions affect people with schizophrenia particularly, leading to a life expectancy variously estimated at between 12 and 20 years less than the average of a given population.'*

> *'You don't have to be mentally ill for long, before you can't afford basic health care. Add in becoming homeless and you soon gather a number of health complaints.'*

More support for families and carers

Though staff members of Mental Health ACT 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 understanding their role and the difficult nature of that role.

> *'I do many things for my son that would normally be done by professional people. I do this for two main reasons. Firstly because it leaves more time for overworked professional people to attend to the needs of those whose families do not or cannot help them. Secondly because, even in a perfect world, I think families can do more than professional people and can do it in a way that allows people to feel more a part of the mainstream. I am more likely to be immediately available when my son needs treatment or reassurance. I can better judge when he can cope with appointments etc by himself and when he needs reminders or even accompanying etc. Sometimes he needs me to hear and remember what he has been told by doctors because he forgets so easily. I am here to judge whether symptoms are psychotic or medical, minor or potentially life threatening. I also provide some mainstream company for him and provide education in cooking and*

housekeeping. However, if and when I am no longer available, I have no confidence whatsoever that my son will receive what he needs.'

One carer described what happens when the case-manager goes on leave:

'I also need support to do what I do. I have fantasist support from my son's clinical manner, but when he has been on leave I am left very much unsupported.'

Another said

'…each time the case-manager changes, we, the family, start all over again. Sometimes the case-manager is receptive sometimes not.'

Intervention prior to crisis, self harm, violence and/or significant deterioration

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.

'We have to fight for treatment every time a crisis occurs and the fight seems to be getting harder each time.'

'My son deteriorates, he is then in and out of goal, only ends up in hospital after he has harmed himself.'

'The CATT said my relative was too dangerous and that we were to call the police. We then spent several weeks trying to get our relative mental health treatment. Our relative became sicker, hungrier, more mal nourished and more dangerous to himself. In the end he got I after seriously harming himself. He could have died from self inflicted injuries but a member of the family found him.'

'What is wrong with the CATT 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.'

Because intervention comes so late, consumers and families report that once the police are involved and no matter how the police are, there is still a sense of not being treated with dignity. One consumer explained the situation:

'I know when I get sick that I quickly lose insight and will resist treatment but I am sick and there I am being handcuffed by police. No other groups of people with an illness are treated like this. Why are we? Surely there can be a better way. I think it starts with me being able to say, I'm becoming unwell and clinicians taking me seriously.'

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 metal health services to phone the police.

> *'… 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. But at no stage during this day as far we know did mental health services assist the police.'*

Families report that mental health services often do not listen to them when they try to get help in a crisis:

> *'People are just fobbed off in a crisis no matter how ell our relative's case is known. The CATT tells us to phone the police.'*

> *'The mental health emergency and crisis processes are simply not working and are frequently failing.'*

> *'It is always the same, getting help in a crisis means the family has to pit itself against the mentally ill member. Authorities need to understand just what this does to relationships and how long it takes, if ever, for the harm to mend.'*

Consumers and carers both reported that to get help in a crisis generally means getting the police involved. Carers told of the consequences of police involvement and its impact on relationships.

> *'Once this occurs the person is carted off in handcuffs by police and we are never forgiven.'*

> *'We don't want to be seen as the enemy but we are put in this position all because we try to get help before something bad happens.'*

Those present at the meeting, urged Mental Health to compare the rates of people presenting at the PSU who are not admitted with the non-admission rates of similar inter-state admission units.

Discharge and follow up

It was reported that people are frequently discharged too early from inpatient units and are discharged apparently without firm plans in place. Families report frequently not being informed about discharge or about what they are required to do. Consumers and carers also report that the practice of being 'discharged as a client' can have disastrous affects as it results in people being cut-off from follow up and having to start all over again if their condition deteriorates or if warning signs appear. Consumers argued that whilst they often welcome being discharged as a client or as an active client', there are times when follow-up for a further period might assist to prevent relapse following a major episode.

Appropriate care and treatment for people with dual disabilities

People with mental illness and drug and alcohol problems or brain injury are reported to be frequently denied service. Both groups frequently do not receive treatment unless an advocate becomes involved. It was reported that when denied psychiatric assessment, treatment and case management, people with dual disability are at risk of offending and coming to the attention of the criminal justice system.

Appropriate affordable accommodation with support if necessary

Those in attendance reported that a critical short fall in services in the ACT is absence of a system of person centred, flexible, community based housing and support options that respond to a person's changing needs in a timely manner. Bed-sits available through public housing were thought to be of a poor standard, inappropriate to the needs of people with mental illness and difficult to access. There is reported to be very little public accommodation for young people and single adults. Waiting lists are reported to be high. Accommodation in a crisis other than at Ainslie Village is difficult to obtain. Crisis accommodation funded the SAAP are reported to be frequently full and also have difficulty in accommodating a person who has been either discharged from a psychiatric inpatient unit or who has been refused inpatient care.

People in attendance reported that in their experience the Housing ACT either hasn't taken notice of reports from psychologists and psychiatrist concerning the accommodation needs of people with mental illness or has been unable to act on the recommendations contained in these reports.

Satisfactory income support

People experiencing mental illness as well as their families frequently experience financial problems. For the people with the illness themselves, the longer they are sick or the more episodes they experience the more likely it is that their only income is Centrelink payments. It is very difficult to subsist on Centrelink payments. A Centrelink payment barely covers board or rent and people are often left with little for food, transport, clothing and other necessities. People with mental illness frequently have difficulty in affording health care and medications as well.

Family members and other carers are faced with having to cover the unmet costs of living for their loved one. These costs can be considerable – ranging, it is reported, not uncommonly from $60 to over $100 per week. Families also find themselves with unpaid bills, fines and unpaid rent when the loved one is hospitalized or is experiencing and episode of acute illness. Many families due to the burden of caring for a loved one with mental illness have not been able to maintain employment and hence are forced to rely on Centrelink payments. This results in many carers themselves not being able to afford health care and other necessities for themselves. One respondent wrote:

> *'We just become poorer and poorer. I cannot get dental care; I'm on the waiting list for that. You name it; I'm on the waiting list for a number of things ranging from health care through to accommodation. I probably won't be able to keep the car going after this year. The payment I get is just not enough to live on. I can't remember our last holiday. I shop at St*

Vinnies, haven't had new clothes for ages. It is just so tiring trying to make ends meet. It can come down to, do I buy milk and food or go to the doctors.'

Service providers present reported that it is not uncommon for families to be unaware of the carer payment available through Centrelink.

Adequate forensic mental health treatment and care

A matter of concern raised by several in attendance was the lack of appropriateness of the care received by forensic patients and other people with mental illness or disturbance who become subject to the criminal justice system. Reported short fallings included:

- People not being treated with dignity e.g., cases where management plans involve no clothing or night shirts;
- Behaviour being controlled by high medication dosages;
- Some prisoners having been apparently 'black listed' by mental health services including the forensic service;
- Aboriginal prisoners doing poorly in the forensic mental health system.

The need for appropriate treatment facilities rather than goal was emphasized. Some in attendance pleaded that the ACT should learn from the difficulties experienced by NSW when the forensic mental health inpatient facility was built within the grounds of Long Bay Goal. It is hoped that all possible steps are taken to prevent the forensic hospital planned to be built adjacent to the new prison from being antithetical to the therapeutic needs and to the recovery of inmates with mental illness.

Treatment, care and support for people personality disorder

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.

Ongoing education, training and support for police, ambulance officers and other emergency services personnel

Those in attendance pointed to the apparently increasing role of emergency services personnel in responding to people with mental illness who are in crisis. The need for ongoing education, training and support for emergency services personnel from mental health services was stressed. Consumer and carer advocates and the Mental Health Consumer and Carer Caucus stated that it was important that they assist in such training.

Information for consumers and carers

'Loss of hope that things will ever get better'

…was how several in attendance reported to view the current state of mental health services in the ACT. Other important comments made by consumers and carers included the following.

> *'I have lost a lot of hope, I have suffered a lot of stress as there has not been much improvement in my husband's treatment over the last 30 years – the cycle still comes and goes – the high – psychosis – depressions – normal. There have been many backward steps in this time including not being able to get help early or in a crisis and not being able to stay long enough in hospital.'*

> *'I have a young soon in his early 20s. He has schizophrenia and lives with me. He is unmedicated … He is impossible to live with, and only lives with me because he has nowhere else to go. There is no mental health vacancy anywhere in the ACT and he is incapable of living independently. There is just nowhere for him.'*

> *'There is a lack of therapy in the ACT other than medical treatment available through public mental health services. My son could benefit from CBT or other similar therapies, but such therapy is not offered. This is one of the reasons why he refuses medication, nothing else is offered and he believes rightly or wrongly that other therapies could help him.'*

Address cross-border difficulties

Cross-border recognition of orders, transfers and admissions despite formal agreement and legislative base remain problematic.

Privacy and confidentiality issues

Family members reported that confidentiality is often used as reason as to why they cannot told anything by mental health clinicians. Family members argued:

> *'Surely when my safety is at risk, I have a right to know certain, if not prescribed, information.'*

Those in attendance discussed the National Statement of Rights and Responsibilities that states:

> *'There may be circumstances where the consumer is unable to give consent or may refuse consent because of their disturbed mental state. In such cases it may be appropriate for service providers, carers and/or advocates to initiate contact and involve those who may be able to assist with the contact and involve those who may be able to assist with the consumer's diagnosis and care.'*

'Carers and advocates have the right to put information concerning family relationships and any matters relating to the mental state of the consumer to health service providers.'[1]

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.

[1] Australian Health Ministers Council 1991, *Mental Health Statement of Rights and Responsibilities*, National Mental Health Strategy, Commonwealth Department of Human Services and Health, Canberra, p. 18.