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HEALTH CONSUMERS' COUNCIL WA (INC)

YOUR VOICE ON HEALTH

Senate Select Committee on Mental Health
Department of the Senate
Parliament House
CANBERRA ACT 2600

Dear Committee Secretary

Please accept this submission to the Senate Select Committee on Mental Health.

A representative of this organisation would be available at any time to provide further information or elaboration of any issue contained within the submission.

Yours sincerely

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18 May 2005

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Health Consumers' Council

Submission to Select Committee on Mental Health

May 2005

Introductory comments

The Health Consumers' Council is an independent community based organisation representing the consumers' 'voice' on health policy, research and service delivery. The Council provides an advocacy service to individuals experiencing problems in the health system. At any time, 50% of advocacy cases at the Council's advocacy service are mental health consumers. This is disproportionate to the ratio of mental health to medical health services and indicates a high incidence of problems faced by mental health consumers.

This submission will make particular comment in reference to the Terms of Reference number referenced below. These comments are based upon observation and analysis formed over ten years of advocacy service provision in the Western Australian mental health system.

(a) Divisions of responsibility

A significant barrier to progress for mental health consumers lies in the artificial demarcation between disability and health in Western Australia. Mental health consumers are caught between eligibility for services in either the health or disability sectors due to the exclusion of mental illness from the mandate of the state's Disability Services Commission. This exclusion is discriminatory and prejudicial for mental health consumers as it limits access to disability support, housing funding and a range of other forms of disability-related assistance.

(b) Adequacy of various modes of care

Mental health consumers experience the biomedical model of care in mental health services as limiting and inadequate to address the complexity of the human experience of mental illness. Medication is the primary modality of treatment that dictates and constrains the interactions of mental health workers with consumers, whether in hospital or in the community. There is a predominance of acute care treatment and a lack of investment in services that would keep people out of hospital. Counselling or 'talking therapy' is scarce. Mental health community teams are either under-resourced or fail to give priority to early intervention, leading to unnecessary hospitalisation. It is a familiar experience for consumers to seek to speak with a case worker, or arrange an appointment when they are experiencing early signs of relapse, only to be told they will need to wait for their referral to be processed or weeks for an appointment.

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(c) Non-government sector and private providers

The non-government sector in mental health represents a stable, flexible and consumer focussed resource that provides necessary, cost-effective care to mental health consumers. Many consumers engage with state mental health services where there is significant staff turn-over and limited opportunity to develop relationships with practitioners and to become known as a person. Non-government services are able to develop programs that meet the needs of their constituency in response to changing circumstances and service delivery ideas, including specialist employment, living skills, therapies in arts and other areas.

The community sector provides an ideal setting for the provision of psychological and counselling services due to the continuity NGO's can provide, and the separation of these services form the state authorities that can order and supervise involuntary treatment.

Private providers (not-for-profit and for profit) of disability support and home care services perform an important role in the network of assistance for mental health consumers in the community. Private support agencies also provide an avenue of employment for mental health consumers as workers, as the work can be sessional and draw on the consumers' own experiences of managing mental illness in daily life.

(f) Special needs groups

Mental health services are primarily geared towards a patient group that is English-speaking, non-indigenous, metropolitan based, of a fixed address, not young and not dependent on drugs or self-medicating with illicit substances. Mental health services need to be mandated to provide more flexible and responsive services.

Indigenous Australians
Mental health services and the broader community fail to acknowledge the catastrophic impact of dispossession and genocide inflicted on the Indigenous populations and the consequent harm that this has caused to individuals and communities in respect to mental health. There is a need for special provision to be made for assisting Indigenous people to deal with the mental health, psychological and social wellbeing issues that arise from the impact of European settlement of Australia. Currently Indigenous people are dealt with in the same way as other mental health consumers, in a 'one size fits all' system.

People with drug and alcohol dependence
People who use illicit drugs and develop mental health problems such as drug induced psychosis are frequently turned away form mental health services. A common scenario to illustrate this is where police are called to a disturbance and determine that a person has a mental health problem and needs psychiatric assessment. The behaviour of the person may be antisocial, aggressive, destructive or harmful, but police determine that their mental state is at issue, not criminality. If the person is then taken or sent to an emergency department or mental health service and found to be under the influence of drugs, the person will most likely be

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sent back out into the community. In this case police identify there is no action appropriate from them, but mental health services do not accept any duty to respond medically to the person's condition.

One young man in Perth in 2002 experienced this cycle of aggressive behaviour due to drug use, police attendance and referral to Emergency Departments then discharge without intervention, many times. His attempts to seek help, and his family's efforts, were unsuccessful. He was told on one discharge that he would not be accepted back at the hospital Emergency Department if he returned. He took his life under a train near his family home. There were no services available to help him with his drug use and consequent disturbed behaviour.

(i) Iatrogenesis, Recovery, consumer involvement

Harm caused by mental health care

One of the most significant iatrogenic injuries caused to mental health consumers in the mental health system is the stigmatisation and damage to personhood and sense of self from deprivation of liberty through repressive use of involuntary orders, police transportation for assessment, compulsory detention and treatment. Mental health consumers experience these aspects of treatment as a severe affront based on the tendency of mental health services to use these means as a first resort and for extended periods. The review mechanisms put in place in WA through the *Mental Health Act 1996* have not been effective in limiting the culture of control and abuse of power seen in mental health services. Police are used routinely when mental health workers attend a home with the expectation of taking a person in for assessment. This use of police can precipitate confrontation, as well as characterise a person as dangerous and stigmatise them in their own neighbourhood and community.

The culture of mental health services needs to change to one where the exercise of control of individuals through repressive measures is less the norm. Consumers rarely experience acts of kindness or any gentleness or caring in mental health services. If the legislation that permits use of force and containment allows for abuses of power and lacks the capacity to protect people, the legislation needs to be strengthened. WA legislation does not contain the United Nations principles on the protection of the rights of the mentally ill. The inclusion of these principles in the Mental Health Act is seen to be important by mental health consumers.

Consumer involvement

The Terms of Reference of the Senate Select Committee omit one area of consumer involvement that has an important part to play in mental health service reform. Mental health consumer participation in health service policy, planning, research and service delivery has the potential to assist mental health service reform in a positive and constructive way. Consumer representatives on committees, boards, advisory groups and as consultants provide a means of influencing the way services operate and policy decisions are made. Consumer representation also provides a tremendous avenue to assist mental health consumers to return to participation in community life, by validating their expertise and knowledge about mental health

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services and providing an area of activity that is not rehabilitation focussed but contributes significantly to recovery and well-being.

Mental health consumer participation was progressing well until September 2003 when the central program supporting this work was de-funded by the state government. This program was a victim of a brutal cost-cutting regime at the time and its loss was catastrophic for the emerging mental health consumer movement. The level of activity before the funding cut was considerable, with over 150 mental health consumers actively participating in a range of decision-making settings. With the loss of the support structures and the participation payment scheme, this movement has never recovered and there are very few consumers involved in this work currently. The Minister has committed to the re-instatement of the program, but the state mental health administration has not supported the re-establishment of consumer participation.

(k) The practice of detention and seclusion within mental health facilities

The use of seclusion can reflect an abuse of power when the grounds for the seclusion are inappropriate. The WA mental health legislation allows for the use of seclusion as a management tool within wards where the safety of other patients may be at risk. The experience of the Health Consumers' Council advocacy service is that seclusion is used punitively and unjustly for some patients who are disruptive and challenging, but not necessarily a threat to other patients. Accountability for the use of seclusion rests with the Office of the Chief Psychiatrist, however the analysis of usage rates never enters the public arena. There is no way for the community to know whether the incidence of seclusion use is appropriate or otherwise. It is our concern that in the absence of any robust system of accountability for the use of seclusion, there is enormous scope for abuse.

> ***Case example***
> *A locked ward has a policy that all patient cigarettes are retained by the nursing staff and patients must request a cigarette each time they want one. A young patient asks for a cigarette in the early hours (5am or so) and is refused. He argues and is restrained by 3 staff and taken to the 'side room'. He asks to be allowed to walk there himself but is instead dragged to and detained in the room for 3 hours. He later calls an advocate who visits the ward and has the account verified by other patients. The staff, when questioned, acknowledge that the previous shift detained him but defended the need to do so as justified.*

Removal of a person's liberty by paid servants of the state is a serious action. Many people who are subjected to seclusion are already in secure wards. The nursing staff are the agents employed to engage in therapeutic relationships that will assist the person's recovery from mental illness. The action of detaining a person against their will can be profoundly anti-therapeutic and undermine any other good work done to treat the person's mental health condition. Consumers report their first approach to mental health services to be based on a naïve impression that they will be cared for and helped in their recovery. Many of these consumers then experience

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repressive treatment and a lack of kindness and actively resist further engagement with the mental health system. The use of seclusion must be strictly circumscribed by policy and standards in order to protect this vulnerable group of people from the abuse of this management strategy.

(m) Other government agencies

The link between police and mental health services is far too strong. Funding to mental health services should provide for transportation and for greater funding for Psychiatric Emergency Services so that the police do not have contact with the mentally ill unless there is compelling need. The Health Consumers' Council has anecdotal story of mental health consumer walking in the middle of the road outside a dedicated mental health service, and a nurse calling the local police to bring the consumer into the hospital. We believe such instances should not involve the police and doing so unnecessarily exacerbates consumer distress. Especially in rural settings police are used instead of trained mental health practitioners to transport mental health consumers to mental health service facilities. The police service must be accountable to the community for its involvement in mental health transportation, by only engaging in this activity when it is absolutely necessary. The Police service should advocate strongly for alternative transportation arrangements that do not include police officers and police cars.

(n) Mental health research

There is significant investment in neuropsychiatry research which looks for biological explanations for mental illness. This research is costly and painfully slow at revealing meaningful insights into the operation of the brain in both well and mentally ill people. The prospect of any of this research yielding treatments for consumers in the near to medium term is limited. This highly technical and scientific research is focussed on the low prevalence, high severity illnesses such as schizophrenia and bi-polar disorder. An audit of the costs of this research should be carried out, taking into account the relative progress being made towards any effective understanding of these conditions. A cost-benefit analysis may reveal that the beneficiaries of this research are pharmaceutical companies and the researchers themselves, more than the mental health consumers about which the research is conducted.

Research that makes greater sense to consumers is that which examines the links between mental illness and experiences of a person throughout their lifespan. Traumatic events in childhood, particularly sexual and physical abuse, are profoundly linked to mental illness in later life. The other factors in childhood that foster or undermine resilience to trauma are of interest to consumers. Many consumers find their own explanations for their illness in examination of the conditions of their lives and their reactions to the events they encounter. There is a distinct lack of qualitative research that examines and makes some sense of the collective narratives of consumers. This form of research is less expensive, more immediate and more comprehensible to consumers and the community than pure science research conducted in neuropsychiatry units throughout the country.

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Research into the adverse effects of pharmaceutical treatments
Breggin and Cohen demonstrate that *"all ...(neuroleptics) can cause toxic psychosis with delirium, confusion, disorientation, hallucinations and delusions"* [1] Psychiatrists who compel people to take medications against their will also routinely withhold Consumer Medicine Information from their patients. These medications can have life threatening and life altering side effects but patients are rarely given adequate information to allow for a reasoned refusal or debate on dosage. For example, Breggin and Cohen also content that neuroleptics carry a 25 – 35% risk of causing Tardive Dyskinesia after 5 years of use. [2]

Research into incidents of poisoning with psychotropic medications
Research needs to be conducted by an independent Non Government researcher into **A&E admissions and Intensive Care admissions of patients referred directly from mental health units**. Three such incidents have come to the attention of the Health Consumers' Council over the past four months. One of these people required intensive care for over three weeks as a result of being overmedicated by a mental health practitioner. In one case, a patient was transferred from the country through two mental health units before reaching the metropolitan A&E. In that time, medications were administered that cumulatively placed the consumer's life at risk. Overdosing of patients, where PRN (as needed) medication is added to routine medications, is a serious problem.

National research is needed into the incidence of deaths and suicides of current patients of mental health services, and people who had recent contact with mental health services or Emergency Departments who may not have been accepted as patients. Death by despair and loss of hope is reported by carers and friends of mental health consumers who succeed in taking their life. These people may have been defined by mental health services in pejorative terms as 'attention seekers' and dismissed from the service to their own resources in the community. Consumers who are not able to gain help from the institutions established to provide that help, are left with nowhere to go and no hope for recovery or treatment. The Health Consumers' Council defines these people as help seekers who are trying to save their own lives. When the help is withheld, the person loses hope and surrenders. The consistency of the stories of family and partners of people who have been through this process is chilling. It is a matter of the culture of mental health and emergency services lacking in sympathy, humanity and capacity to respond to the distress of the person concerned who are in great need.

In direct contrast, there is a tendency for mental health services to become overly involved in other peoples lives who may not require such intervention. The Health Consumers' Council believes that there are people over-treated by the mental health system, and many others go under-treated.

[1] Peter Breggin and David Cohen Your Drug May be Your Problem: How and Why to Stop Taking Psychiatric Medications. (1999) p 80.
[2] Ibid. p78.

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Closing statement

The National Mental Health Plans of the last decade have had a powerful and positive influence on the profile of mental health as an issue and on the scrutiny of mental health services. The culture of mental health services has been resistant to change. It is difficult to identify positive improvement for consumers at the patient care level. The standards of respect, privacy and consent that apply in mainstream health services are not evident in mental health services. It is critical that the profile of mental health as an issue remains high and that efforts are not stopped prematurely. Consumer involvement in driving improvement in mental health services is the ingredient for reform that has not been fully explored and will lead to the greatest advancement in the quality of care that mental health service users receive.

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