

SELECT COMMITTEE ON MENTAL HEALTH

MENTAL HEALTH LEGAL CENTRE SUBMISSION

May 2005

A Select Committee to be known as the Senate Select Committee on Mental Health was appointed on 8 March 2005 to enquire into and report by 6 October 2005 on the provision of mental health services in Australia. The Mental Health Legal Centre is very keen to not only put in this submission to the enquiry but also to have an audience with the Select Committee in Melbourne. We believe that our input will be of interest as one of only two Mental Health Legal Centres in Australia, with extensive experience and knowledge of the mental health system and its impact on individual human rights.

The Mental Health Legal Centre Inc is a Community Legal Centre specialising in legal advice, policy and law reform, advocacy and promotion of the rights of people experiencing mental illness. We have 18 years experience working with and representing people with mental illness in all areas of the law which impact on our clients' lives. This submission is based on our own clients experiences, in particular those who have experienced incarceration in the prisons and at Thomas Embling Hospital, the Victorian Forensic Mental Health facility. We have had some opportunity to consult with women in these facilities and will attempt to incorporate their views in our submission.

Establishment of this enquiry stems from the shocking events surrounded the treatment and detention of Cornelia Rau. As mental health advocates we wish to make particular observations about these events:

- What about the mental health system is so abhorrent to Ms Rau and many of our clients that they flee, abscond from acute hospital settings, choosing homelessness and isolation rather than seeking assistance?
- Why, when to some people treatment is so horrendous that given the choice they would prefer the distress and perhaps torture of symptoms rather than debilitating side effects of medication, do we insist on detaining and treating rather than explore other modalities and engage them in developing treatment options?
- Why does the mental health system discriminate between the availability of services and supports according to a diagnosis? Cornelia Rau was ejected from a system that diagnosed her with a personality disorder but treated when the label shifted and she became a person with schizophrenia. Her symptoms remain the same.
- This is the first public outcry about the failure of the mental health system to provide for a person with a mental illness. Had she not been detained in a detention centre where extremely active advocates, concerned about the plight of asylum seekers, have acted on her behalf, Cornelia Rau's experience would have remained out of the public eye. Indeed there is nothing remarkable about her mental health treatment - the awfulness of this system is the daily experience of many people with mental illness.
- Having been removed from the awfulness of detention at Baxter Ms Rau was transferred to an acute psychiatric facility, where her treatment has probably remained consistent – seclusion, being forced to take treatment, punishment and discipline for non-compliance, limited activities and exercise. The awfulness of detention in this facility is little known and of little concern to the public, but to Ms Rau and many of our clients it is bleak.

A client in a forensic facility stated:

“ I’d rather be in jail than here...in jail they take you seriously, here everything you say is ignored, they reckon you don’t know what you’re talking about because you're sick, nothing you say they believe”

Why do we accept that it is OK to treat people with mental illness in a way that it is deemed appalling to other members of our community?

- Cornelia Rau was silent in this story, what are her views and wishes? Her family were appropriately protective of her however, carers cannot be assumed to act as advocates. Clients and mental health professionals are frequently opposed to carers in their views of allowing the person to resume control of their lives to move towards autonomy and well-being, yet carers continue to have the loudest voice in determining the direction of services and the amount of consultation allowed to consumers.

In general we are concerned that the Australian Government considers all rights are protected in articulated treaties and does not support the development of an International Convention on the Rights of People with Disabilities. A Convention which realises the rights for people with disabilities serves a vital purpose: it articulates rights not in other instruments and appropriately tailors the specific rights entitlements of people with disabilities. The Rau case is a stark manifestation of the fact that the human rights instruments, legislative regimes and procedural safeguards which exist in Australia are not adequate.

We respond as follows to the specific terms of reference provide by the select committee:

Terms of Reference A

The extent to which the National Mental Health Strategy, the resources committed to it and the division of responsibility for policy and funding between all levels of Government, has achieved its aims and objectives, and the barriers to progress.

In the early 1990s the Commonwealth became increasingly more involved in mental health policy. The first instrument developed by the Commonwealth to try and engage States in re-shaping mental health delivery and practice was the First National Mental Health Strategy. This was launched at about the same time as the Burdekin Report¹ was released to the public. The MHLG, many consumers and others were encouraged by both of these documents that appeared to offer hope for a system of healthcare that was haemorrhaging. The Commonwealth Mental Health Branch grew very quickly over the 1990s as efforts were made to influence policy and service delivery. Over a period of almost fifteen years the Commonwealth has maintained a much more active role in policy determination.

To realise the principles outlined in United Nation Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care ("UN Principles") we must develop a cohesive national model. One of the greatest barriers to achieving optimum delivery of mental health services nationwide may be the federal/state division itself.

Standards (such as those articulated in the National Standards for Mental Health Services) are monitored by the Commonwealth but services are funded and run by the states and territories. Despite the National Strategy and the Standards, we have a situation where funding for mental health services is at less than half the level it should be if level of services are to meet level of need. Of course, simply injecting more funding is not enough - there must be sufficient accountability and appropriate minimum standards to ensure that funding is directed away from older, stigmatising, side-effect

¹ Burdekin Report

inducing treatments to a range of optimally therapeutic treatments which will enhance people's engagement with services.

Particularly relevant to our work, each state and territory has its own legislative scheme governing provision of mental health services and the important rights involved. The aspiration of achieving consistency with the UN Principles seems risible, however, given the huge disparity between Australian jurisdictions. For example at present, depending on where a person lives they may have their involuntary detention reviewed anywhere between 2 and 8 weeks. They may or may not have a right to legal representation; to challenge the use of ECT; to ask a tribunal to vary their treatment, or to obtain a statement of reasons or a transcript of their review hearing. The appeal bodies and processes are inconsistent as are the practices and cultures that have evolved around compulsory treatment of people with mental illness.² Whilst there has been some reduction in the gap between state and territory regimes and the UN Principles, there is a long way to go, and this process appears to have lost priority in the third National Mental Health Plan. Processes around the UN Principles and National Strategy, such as the Rights Analysis Instrument process, have been called into question³.

Advocacy

In the years of orthodox economic rationalism the voices of people who had little economic power were rarely heard in the political life of Victoria. Government minimised advocacy support for people who have a disability. Many people's rights were neglected or abused for want of decent, independent advocacy services.

Advocacy services are crucial to ensure the protection of individual rights. For people with disabilities they are even more crucial, to assist in the power imbalance pitted against those with diminished capacity and lack of experience in a system with the power to oblige them to treatment and involuntarily detain them. It is likely that, had Ms Rau had more extensive advocacy support this inquiry would not be taking place. We are concerned that there is no specific term of reference around the adequacy of advocacy services for people with mental illness, and other disenfranchised people such as asylum seekers, and hope the Committee will nonetheless address advocacy as a central issue in this Inquiry.

Based on our own work we believe that advocacy is essential in its aims to work towards empowerment, equality, and justice for people with a psychiatric disability. There is often an assumption when talking about advocacy that there is a shared understanding of what it means and a common ideological framework. This is not the case.

Advocacy is premised on empowerment – standing up for the rights of people who are treated unfairly to ensure they have a voice, that represents their wishes and not necessarily those of the advocate.⁴ Advocacy can manifest itself in many different ways, which respond to different needs and outcomes sought. It can include standing with someone to support them to advocate for their own wants and needs, the central tenet remains adherence to basic international human rights principles and principles of social justice.

Advocacy with people with disabilities as “dynamic”, operating to:

² Delaney, S. “An Optimally Rights Recognising Mental Health Tribunal – What Can be Learned from Australian Jurisdictions” ANZAPPL Vol 10 No.1 2003

³ N., Rees “Does the Victorian Mental health Act 1986 comply with the United Nations Principles for the Protection of Persons with Mental Illness and Improvement of Mental Health Care”. (2003) 10 *Psychiatry, Psychology and Law*.

⁴ Parsons, I., *Oliver Twist has Asked for More – The Politics and practice of getting justice for people with disabilities*, p ix, 11

- Clarify and focus the opportunities for people with disabilities to participate fully in society;
- To inform and develop public debate around the position of people with disabilities; and
- To grow and maintain that debate within, and for the benefit of, the broad community.⁵

Advocacy itself also comes in different forms with each form having different but related functions and a common ideological framework.

The objects of the *Disability Discrimination Act 1992* (Cth), include:

"to ensure, as far as practicable, that persons with disabilities have the same rights to equality before the law as the rest of the community; and to promote recognition and acceptance within the community of the principle that persons with disabilities have the same fundamental rights as the rest of the community."⁶

As a legal advocacy service the MHLC's key objectives are as follows:

1. To provide legal services of advice, representation, advocacy and referral to people having or labelled as having a psychiatric disability who otherwise would not have access to those services.
2. Through community legal education to achieve knowledge of and attainment of rights for people having or labelled as having a psychiatric disability.
3. To advocate with and for people having or labelled as having a psychiatric disability on policy and law reform issues, facilitating Consumer participation and basing Centre position on Consumer views.

The Victorian Mental Health Legal Centre was established in 1987 with 4 staff positions, now nearly 20 years later, with deinstitutionalisation completed, with people with psychiatric disabilities living in the community and experiencing a whole range of daily legal issues to address, to say nothing of the increase of population, there has only been funding for one additional position at the Centre, which services the whole State. We have 1.7 EFT paid lawyers, the other paid hours being divided between crucial policy and law reform, community legal education, administration and management roles.

The MHLC applies about half its advocacy resources to involuntary patients under the Victorian Mental Health Act. However there are many other legal concerns to clients which demand our specialist advocacy services including access to health records, privacy, complaints about health service providers, discrimination, guardianship and advocacy matters, support for parenting and the interface between the criminal justice sector and mental health. There are significant legal problems facing people with psychiatric disability we are unable to assist in due to limited resources, such as debt and credit matters and civil litigation. Although Victoria is fortunate to have a Community Legal Centre specifically geared for working with people with mental illness we cannot meet demand. Because of this many very disempowered and disenfranchised consumers supporting themselves only on disability pensions are forced to represent themselves in many jurisdictions. We recommend targeted funding for specialist legal services to assist and represent people with psychiatric disabilities in areas where their legal problems relate to their disability.

The MHLC, the VMIAC (Victorian Mental Illness Awareness Council - a non-legal advocacy organisation) and the mental health lawyers employed by Victoria Legal Aid find themselves overwhelmed by people urgently needing advocacy support. Not only does this leave us constantly trying to create transparent rules for who we can and who we can not advocate for but it also too often

⁵ Women with Disabilities Australia, "Submission to the National Disability Advocacy Program Review", 1998, available at <http://www.wwda.org.au/advoc.htm> at p3

⁶ *Disability Discrimination Act 1992* (Cth), Section 3(b) and (c).

robs us of time to undertake the essential systemic advocacy which we hope will in the end lead us to less destructive mental health systems and practices.

And given that our Centre and the Mental Health Law Centre in Perth are the only specialist mental health community legal centres in Australia, the situation nationwide is grim.

Legal Representation before Mental Health Review Tribunals

There are significant respects in which Victoria's Mental Health Act 1986 does not provide optimal safeguards in comparison with other Australian jurisdictions and the United Nations Principles. One of these is representation of clients before the Mental Health Review Board. Within Australia there is great variation between jurisdictions as to levels of representation.

There is no representation in Tasmania in 2000/2001, less than 10% in Victoria, and over 90% in the Northern Territory. In NT the legislation mandates the Tribunal to appoint a lawyer unless satisfied it is not necessary. It also empowers it to order the State to cover the costs. In contrast the Victorian *Mental Health Act* merely provides a person has a right to be represented but makes no provision for the payment of representatives. South Australia's health department funds representation for some appeals, though advocates are concerned that funding comes from the department responsible for service provision and this conflict may hamper access to these resources. UN Principles provide that people should always have access to representation, funded by the state if necessary.⁷

As well as discharge, representation can increase the prospect of positive outcome from the hearing process at a number of levels, whether in terms of some sort of variation to the person's situation, the opportunity to have their views and wishes fully and clearly articulated, or otherwise. As advocates acting for clients we are aware that they highly value representation even with no change to their situation. If representation increases the extent to which patients experience the process as fair and participatory, in our view, will have a therapeutic impact and increase level of engagement with treatment.

Of course, issues around involuntary treatment are just one area where advocacy is crucial. One of advocacy's most valuable outcomes is to facilitate people's access to optimum mental health treatment which is as consistent as possible with their wishes, least aversive and least likely to lead to treatment avoidance, isolation and homelessness

A study of personal advocacy for involuntarily hospitalised patients had some extraordinary results. The experimental advocacy maintained throughout involuntary admission significantly improved patients' and staff members experience and produced a better compliance with after care and reduced rehospitalisation.⁸

Advocacy does not rate in the first or any of the subsequent national strategies. As previously stated Victoria and Western Australia are the only States with specialist Mental Health Legal Centres. The significant differences between all States and Territories in terms of access to legal representation, can also vary in terms of the type of advocacy offered or available. It is the person's right to have an advocate to act on instructions and not in the assumed 'best interest' of the person. One of the most striking features of Ms Rau's situation is the complete absence of her own voice in the process. Rights based advocacy ensures, crucially, that a person's own perspective is put. Advocacy resources need to

⁷ Delaney, S "An Optimally Rights Recognising Mental Health Tribunal – What Can be Learned from Australian Jurisdictions" ANZAPPL Vol 10 No.1 2003.

⁸ Rosenman S Korten K Newman L "Efficacy Of Continuing Advocacy in Involuntary Treatment" Psychiatric Services August 2000 Vol 51 No 8

be directed towards specialist mental health lawyers with a high level of skill and experience in mental health law matters.

Debate may rage about the extent to which legal representation of itself significantly increases chances of discharge. In British Columbia the move to introduce representation at all hearings was driven by a recognition that it did substantially increase discharge likelihood, and that effect has been acknowledged in other studies. In a jurisdiction such as that, with discharge rates of approximately 25%, discharge is not the primary objective, representation can increase the prospect of positive outcome from the hearing process at a number of levels, whether in terms of some sort of variation to the person's situation (the scope for that in jurisdictions such as Victoria is relatively limited given the limited jurisdiction of the Board as regards decisions about treatment discussed above), the opportunity to have their position fully and clearly articulated, or otherwise. It is a very common experience as an advocate for clients to indicate having highly valued representation even where there has been no change in their situation. It can reasonably be assumed that, if representation increases the extent to which patients experience the process as fair and participatory, it will have a therapeutic impact and might increase level of engagement with treatment.

Whilst increasing representation clearly has resource implications both for state funded legal services and tribunals in terms of increased length of hearings, these are costs which can clearly be met in other jurisdictions such as the Northern Territory and British Columbia.

We recommend targeted funding for specialist legal services to assist and represent people with psychiatric disabilities in areas where their legal problems relate to their disability. We are dismayed at the insufficient funding in Victoria for advocacy services. More services are urgently needed. It is about respecting the fundamental human rights and right to full citizenship of some of Australia's most disadvantaged people.

Effective and Co-ordinated Complaints Mechanisms

The National Mental Health Strategies have been silent about model co-ordinated complaints systems. Consumers have fought for better complaint procedures in all States. The MHLC has been advocating for a review of the disparate complaints mechanisms in Victoria with a view towards the establishment of an independent, co-ordinated and accessible body for complaints handling and with a monitoring and audit function.

We endorse the rights outlined by the UN - the right for "access to mechanisms for complaint and redress" – this must be elevated to a key priority if the crucial objective of adequate service quality and accountability is to be met. Moreover, the establishment of an adequately empowered and independent national complaints and accountability mechanism may well be the only way to address the serious deficiencies in terms of both "civil libertarian" and service access and quality rights which endure, Burdekin Report and National Mental Health Strategy notwithstanding.

Crucial to addressing underlying impediments to realization of these rights, such as disproportionately low mental health service funding and priority from a whole-of-government perspective is the development of a mechanism to ensure transparent service delivery and proper accountability of mental health providers. Lack of accountability and secrecy systemically undermine the legitimacy of complaints of people who have mental illness and the confidence the community can have in the complaints systems and services themselves.

Changes in State policy driven by the National Mental Health Strategy

We acknowledge the extent to which some of the changes driven by the National Mental Health Strategy have influenced mental health services. Apparent among these is the consumer involvement

in auditing services and the development of the National Mental Health Practice Standards and the National Mental Health Service Standards.

The push towards consumer participation has come, we believe in part at least, from the thrust of national policy. Consumers indicate this was a significant policy directional change in the First National Mental Health Strategy (1992). The MHLC has maintained the inclusion of consumers as a fundamental strategy for many years preceding the First National Mental Health Strategy. Two thirds of the people on our Management Committee are consumers. The chair of our Management Committee is also a consumer and he speaks for and on behalf of the MHLC when we are presenting policy publicly.

Terms of Reference B

The adequacy of various modes of care for people with mental illness in particular, prevention, early intervention, acute care and community care after hours services and respite care.

Prevention and Early Intervention

Anecdotally we know from clients of the many occasions where people when unwell have themselves requested support and treatment from community or by hospital admission, only to be rejected. Clients inform us that it is not sufficient to report suicidal thoughts and fear of self-harm, it is only when there is a perceived risk of harm to another that admission and intervention is assured. We are advised that identifying the early symptoms, developing risk management strategies and seeking support – ie managing a mental illness is the optimal way for the person to move towards well being. This demands a compassionate, active and responsive mental health system not the present system that requires the person to plummet into a severe state of illness before treatment is offered.

We are also aware of mental health experts who advocate identifying the first signs of ‘illness’ in children from three months to six years old. Concerningly these illnesses are amongst the most damaging in terms of labelling for example with anxiety disorders and Borderline Personality Disorder. Labelling children as early as three months old and reacting to them principally as potential mental illnesses is extremely dangerous and destructive to any child development. In our submission if there is anything to be gained from diagnosing a child like this it is manifestly undone by labelling that person at such a young age.

Cornelia Rau was upon one assessment, diagnosed with a personality disorder, which meant she was deemed not deserving of mental health services. The public outrage in her case was attached largely to a finding that she had a psychotic diagnosis. It is manifestly unacceptable that diagnosis (which many clients explain changes frequently) should be the vital indicator of whether that person is worthy of public outrage. It is also manifestly unacceptable that people with personality disorders and abuse and neglect histories are refused services because they are deemed not to have a ‘proper’ mental illness. We know of many women who describe experiences of abuse and neglect, childhood and current, as a major part of their distress who are ignored if they have a psychotic diagnosis, their claims are dismissed as psychotic ramblings. This is a gender issue, that women struggle the hardest to get services and have their experiences and fears for safety treated seriously and respectfully.

Many of our clients have childhood abuse and neglect histories. There appears to be a political blind spot in relation to childhood abuse in terms both of State policy and everyday practice, the National Mental Health Strategies are silent about it. People who have early experiences of child abuse and neglect often end up in the mental health system particularly but not exclusively with diagnosis of dissociative identity disorder, borderline personality disorder and other forms of personality disorders;

there are many people who have the diagnosis of psychotic illness who have early experiences of abuse and neglect.

Psychiatric disability is extremely diverse, as are its implications for many people. There are great differences in impact from disability to disability, and time to time in the case of an individual's disability. Furthermore, there is the need to avoid discrimination and stigmatisation which impose assumptions, deny people their autonomy and treat them unfavourably because they have a psychiatric disability, diagnoses such as personality disorder are deserving of treatment, they are serious debilitating and stigmatising psychiatric disabilities.

Government agencies are quick to assess and label, as a means of denying services. This is evident in the increasing priority given to "serious" mental illness. Many people with diagnoses such as depression, anxiety and obsessive compulsive disorder find it difficult, if not impossible, to get adequate access to public health services because their conditions are not considered as serious as, say, psychotic illnesses or bipolar affective disorder. Mental illness related substance abuse is another condition to which there has been inadequate response from mental health services, though this may be starting to change in Victoria. People with dual diagnosis of mental illness and substance abuse have tended to fall between conventional mental health and substance abuse services. One high profile tragedy resulted from services failure to respond appropriately to this type of co-morbidity - the killing of a Queensland teenager by Victorian Claude Gabriel. The young man who recently shot dead a police officer and himself experienced both obsessive compulsive disorder and substance abuse. There is a significant likelihood his combination of problems did not attract a sufficient response from the public mental health system⁹.

A range of negative and discriminatory consequences can flow from labelling by government agencies which is not matched by appropriate service provision. In Victoria we have a push for antenatal notifications against parents the Department of Human Services perceive may have trouble parenting, there is nothing more offered, no parenting support or guidance, these parents continue with a pregnancy under surveillance, knowing that the child may be whipped away upon delivery.

Acute Care

UN PRINCIPLE 4

1. DETERMINATION OF MENTAL ILLNESS

- 1. A determination that a person has a mental illness shall be made in accordance with internationally accepted medical standards.*
- 2. A determination of mental illness shall never be made on the basis of political, economic or social status, or membership of a cultural, racial or religious group, or any other reason not directly relevant to mental health status.*
- 3. Family or professional conflict, or non-conformity with moral, social, cultural or political values or religious beliefs prevailing in a person's community, shall never be a determining factor in diagnosing mental illness.*
- 4. A background of past treatment or hospitalisation as a patient shall not of itself justify any present or future determination of mental illness.*

⁹ "The last call: Mum, I shot a policeman." Sunday Age May 1 2005.

5. *No person or authority shall classify a person as having, or otherwise indicate that a person has a mental illness except for purposes directly relating to mental illness or the consequences of mental illness.*

The UN Principles require that, if treatment is to be given to someone who cannot consent on the basis that it is in their best interests an “independent authority” must be satisfied it is appropriate. Again this is an area where there is a huge inconsistency between States, under the Victorian Mental Health Act involuntary treatment can be imposed as a clinician's decision, and there may be no independent review of that decision for up to eight weeks – if at all.¹⁰

Something which must be understood about involuntary psychiatric treatment, is that it usually involves a strongly felt and expressed resistance to the treatment, as opposed to an inability to express or make a decision due to an impairment relating to communication or cognition. And there will often be good reason for a person's resistance quite apart from the restriction on their autonomy. Treatments provided for mental illness often have serious, debilitating and stigmatising side effects.

From our daily experience people are failed by acute hospital services. More acute beds will not resolve these issues. Cornelia Rau may well have been one of the many people who find acute inpatient treatment so aversive they will risk increasingly desperate lifestyles to avoid it. The emphasis needs to be towards support of people who are experiencing mental illness in ways that preserve liberty unless there is absolutely no other way of keeping a person safe. The only way that this can be done is to work with people who have experienced acute admissions first hand and to take advice on workable alternatives.

Central to services are resources dedicated to exploring ways that people can maximise the autonomy and power that they have over their own lives. People with a psychiatric disabilities experience discrimination in all aspects of their lives. In the design of services it is crucial to consider the negative effects of institutions that remain in effect long after people are discharged¹¹. In the Understanding & Involvement Project¹² researchers heard that experiences of acute services were where the most lasting damage was incurred. Places of asylum and refuge must be safe and do no further harm of people in crisis. This must be the first priority of governments. Pouring more money into manifestly inappropriate hospital acute units is a waste of precious resources.

The most basic human rights are often denied to people in acute hospital settings – wards are open with both men and women in the same unit, there may be shared bathrooms and toilets, there may be no places to take visitors, no where private to have a conversation; telephone access is available only by public phone usually situated in a central corridor, there is no choice of treatment, choice of visitors, choice of food, choice of programs (indeed there are generally no programs at all on weekends), choice of follow up treatment and support.

Seclusion and restraint are used inappropriately and without proper regard to the person. A client of our service was stripped naked and thrown in seclusion for 12 hours when she had a known history as a victim of sexual abuse. Clients report experiences of seclusion, terrified and left alone for long periods of time with frightening psychotic symptoms. Seclusion is used far more on weekends when

¹⁰ Victoria's Auditor General has identified that 70% of Victoria's involuntary patients do not have their status reviewed by the Mental Health Review Board at all because they have been discharged before the hearing takes place.

¹¹ Victorian Mental Illness Awareness Council, Understanding and Involvement (U&I) – Consumer Evaluation of Acute Psychiatric Hospital 1994

¹² A very intensive five year consumer evaluation of acute psychiatric hospital practice.

no programs are available. Staff and clients agree that it is used inappropriately as a treatment when proper engagement and even boredom is the issue.¹³

Safety in Psychiatric settings

The MHLC knows of many instances of abuse in psychiatric settings, however these are seldom acted upon. We provide legal advice to people who have experienced abuse and feel threatened and frightened in acute care, from both staff and other residents. It ought be noted that the Victorian Health Services Commission has only investigated 6 matters of sexual abuse since 1987, 5 of these were against staff.¹⁴ Anecdotally we know that women clients may suffer sexual harassment and abuse as part of any inpatient admission.

We must also be aware of safety issues and proper delivery of services to people in private psychiatric settings. There is a vexed issue of informed consent in private settings that cannot use the involuntary detention provisions of mental health legislation.

Units are also experienced as being psychically unsafe, where people are contained by threats and taunts from staff. Clients advise they are told that they won't be discharged unless or until they comply, others report fear of being discharged too early. Clients may experience violence for example being held by clinicians, brought to the floor and forcibly injected before being slammed into seclusion. Those who have experienced physical violation such as a rape experience forced injections as re-rapes.¹⁵

We are informed this is acceptable practice of how to manage behaviour, 'management' in itself is indicative of the acute hospital culture.

We are concerned about the use of hearsay evidence, there is evidence on clinical files of diagnosis made by clinicians after speaking to family friends carers neighbours co-workers but not the person subject to involuntary detention. We appreciate there are some occasions when a person is unwell that it may be difficult to get a complete medical history from them but emphasise the importance of consulting with them and considering their wishes. Clinical reports are too often soiled by defamatory statements and bias - race, religion, gender, sexual preference and age may be portrayed negatively. Negative language is used in verbal interactions and especially in writing medical histories for example - B presented as non-malodorous.

Alternatives to involuntary detention and treatment

UN PRINCIPLE 9

TREATMENT

1. *Every patient shall have the right to be treated in the least restrictive environment and with the least restrictive or intrusive treatment appropriate to the patient's health needs and the need to protect the physical safety of others.*

¹³ 2004 Study at St Vincents Hospital in Victoria incorporating interviews with staff and consumers of their views on the use of seclusion

¹⁴ FOI request to Office of the Health Services Commissioner, 2005

¹⁵ See Sara Clarke's paper "What do consumers want to tell new clinicians?" unpublished

2. *The treatment and care of every patient shall be based on an individually prescribed plan, discussed with the patient, reviewed regularly, revised as necessary and provided by qualified professional staff.*
3. *Mental health care shall always be provided in accordance with applicable standards of ethics for mental health practitioners, including internationally accepted standards such as the Principles of Medical Ethics adopted by the United Nations General Assembly. Mental health knowledge and skills shall never be abused.*
4. *The treatment of every patient shall be directed towards preserving and enhancing personal autonomy*

It is our experiences that services do not explore less restrictive options, do not consult fully and properly with the person with a psychiatric disability, take heed of their interests, wishes and respect their autonomy in decision making. Clients of our service are keen for us to develop a legal framework that allows this to happen and demands respect from mental health service providers. Interference with people's decision-making capacity should only be limited to what is necessary in that persons particular circumstances.

One way of encompassing this is with the use of instruments such as an "advance directive" or "living will".

Living Wills

The MHLC has been working with consumers on developing Living Wills which contain a person's instructions in relation to any aspects of their lives they wish to direct. These documents enable people with psychiatric disabilities to identify a plan including strategies to preserve and enhance autonomy, articulate their wishes and implement less restrictive options to assist recovery. We believe this is crucial for people who know there is some likelihood that they might be involuntarily detained against their wishes. They can include areas such as treatment eg. what drugs to avoid, views on ECT, activities or therapies of preference, nominated contacts and people to be consulted or not; employment and study, role of family; what will happen to the children, this is especially important if the consumer is a single mother – no medical intervention will have any salutary effect unless mothers know their children are safe.¹⁶; the bills are paid etc.

There are enormous gains that can be made simply by consumers having appropriate templates to guide conversations with significant others and clinical staff **before** they are detained involuntarily. There is also value for the documents to be used by consumers for training clinicians about their needs during times of crisis.

We promote the idea of developing Living Wills as an essential tool to protect the human rights of people with episodic illness, however we are limited by resources and urge a National approach to pursue this initiative. In 1996 HEREOC showed some interest in the development of a rights based document and prepared and circulated a discussion paper to which we and other advocacy organisations enthusiastically responded however HREOC's interest has waned. Client enthusiasm for this instrument however has not.

¹⁶ One story involved a consumer who was forcibly taken away by the crisis team and the police and her children, who were under ten, were left unsupervised in her flat. Every time she tried to tell medical staff that she needed to know where her children were she was ignored and given more psychotropic medication and her anxiety and anger escalated to the point where she was destroying hospital property. At this point she was grabbed, forcibly injected and locked in seclusion "till she calmed down".

Complaints Procedures

UN PRINCIPLE 21

COMPLAINTS

Every patient and former patient shall have the right to make a complaint through procedures as specified by domestic law.

The MHLC acts frequently for clients where they have experienced unsatisfactory treatment of varying proportions. However to register a complaint most experience poor satisfaction, the system is complex it assumes and needs assertiveness, knowledge, persistence and savvy. There is an endemic lack of transparency, accountability and reporting. In Victoria there is a lack of independence which expose the inadequacy of complaints procedures. Furthermore, the conciliation function of the Health Services Commission is not backed up by determinative/arbitrative capability, limited powers to implement systemic change. In our experience repeat players (services, service providers) advantaged as against first time users/complainants, especially in conciliation with Health Services Commissioner, who seems to value primarily the maintenance of happy relationships with these providers.

And the behaviour leading to complaints continues. In acute units people suffer shocking degrading and humiliating experiences that fail to be heard or taken seriously.

“how do you complain when you are under lock and key in a high dependency unit, no access to private telephone, no money for calls, you complain and they increase your medication “

There is an urgent need for exploration about proper resolution of complaints.¹⁷ It is very difficult to prove the link between the staff behaviour and the consumer's future distress. As people with mental illness obviously already have psychological pain, complaints -even formal complaints to the Health Complaints Commissioner, are too often dismissed as just ‘problems in communication’. Events that are experienced by clients as cruel, inhuman and outrageous are often described by staff as ‘an incident’, ‘usual practice’ or just the ‘illness speaking’. Events that cause ‘inconsolable pain’, or staff behaviour that re-triggers black nightmares for people are seen by staff as routine requirements of practice.

The second major problem is that many consumers believe that they are so unworthy that the way they are being treated is acceptable. ‘Mental illness’ often destroys self esteem and most people need belief in themselves and their rights, and to be encouraged to complain. Because many clients do not believe they have a right to complain, despite the circulation of glossy pamphlets that tell them they do, the service must take on some of the responsibility for advocating for patients who have been wronged by other staff. This is an extremely difficult thing to do within a closed culture and especially for relatively low status professionals such as nurses and junior practitioners. An increase in the number of complaints should be encouraged, it demands accountability and openness and advances best practice. It suggests that there is an unbinding of the prison-like culture with ‘inmates’ acknowledging that they have rights. This is a major step forward for any psychiatric service.

It is our experience that in order to access any complaint mechanisms properly people need advocacy support.

¹⁷ The work of the Australian Council For Safety And Quality In Health Care (ACSQHC) (chaired by Professor Bruce Barraclough) on Open Disclosure¹⁷

As stated by a person in an acute hospital setting, admitted following a serious suicide attempt:

“I didn’t complain because... the mechanism for formal complaints is really, really inappropriate in that context. I mean, I don’t know what other mechanism you can have but, at a time like this your world is upside down. You have done something that you are really ashamed about...you try to say sorry but no one will listen... it’s a terrible part of your life, its something you want to run away from... you know, it has all these consequences. Wanting to prolong the pain by putting through a formal complaint thing or actually even feeling empowered to do it is very difficult...[and] I didn’t know at that time that I didn’t deserve to be spoken to like that.”¹⁸

The burden is on consumers to seek to understand the similarities and differences between the different remedies and actions for their complaint in the hope of finding someone who might take their complaint seriously, to identify a harm caused to them.

In a Victorian context we know that the formal mechanisms that have been put in place to hear consumer complaints are grossly inadequate. There is the Office of the Chief Psychiatrist, the Health Complaints Commissioner and individual Area Mental Health Services have their own complaints mechanisms. Clients advise us that they are either intimidated or treated dismissively by these institutions. It is a priority that we get complaints systems right. The urgency stems from the fact that citizenship and basic human rights are under threat by an institution that has been through history manifestly bad at protecting those it is supposed to ‘care’ for.

As stated above we support the recommendation of the Mental Health Council of Australia¹⁹ for the establishment of a permanent independent commission with responsibility to monitor and influence funding and service delivery issues, investigate and act on abuse and neglect and, importantly, investigate and act on complaints about mental health services generally.

Community Care

UN Principle 15

1. ADMISSION PRINCIPLES

1. *Where a person needs treatment in a mental health facility, every effort shall be made to avoid involuntary admission.*

We are concerned about the increasing number of people who are routinely placed on Community Treatment Orders (CTOs). They are an insidious form of control, deceitful in presentation. It seems people are free and ‘out there in the community’ when it is apparent they are not. It is a very serious thing indeed to force people who have committed no crime to live a life of only partial citizenship. At least in a public mental health unit the locks are obvious and the wire cages and huge brick walls are sufficiently confrontational to give an honest indication of the reality. However, the ‘prison in the home’ of CTOs is deceptive.

¹⁸ Quote from a consumer in; Victorian Mental Illness Awareness Council (VMIAC) Understanding & Involvement (U&I) – A Project’s Beginnings, VMIAC 1994 p. 73

¹⁹ Mental Health Council of Australia *Out of Hospital Out of Mind – A Review of Mental Health Services in Australia*, April 2003, Executive Summary, Page 1.

One reason there is a desperate need to significantly increase funding of mental health services is to ensure people have access to a range of treatments, pharmacological and otherwise, to optimise their engagement with services and minimise the need for involuntary outpatient treatment such as on CTOs.

Term of Reference C

Opportunities for improving coordination and delivery of funding and services at all levels of Government to ensure appropriate and comprehensive care is provided throughout the episode of care.

One significant problem that comes with attempts to better coordinate medical and general community services is that people may not want it known to other services that they have a mental illness.²⁰ It is imperative that we respect this. Clients tell us that from their perspective this discrimination travels through medical systems and culture as quickly and as insidiously as it travels through the rest of society. Many of the consumers we deal with complain that the very worst discrimination comes from General Practitioners, Accident and Emergency Departments, specialist medical services and private and public mainstream hospitals.²¹ Comprehensive care is a double edged sword for many consumers who have argued to us that they do not want everyone who happens to work in a health setting to get information about their diagnosis from which they are fearful discrimination will emanate. They also want to be as in control as possible of who knows what about them. This is a basic human right. Some argue that the mental illness label has jeopardised their physical health care²² as well as their human rights.

We have a particular interest in the coordination of systems between the police, the Department of Human Services and CAT teams. We are concerned that police are the first to arrive at a crisis situation when it is apparent that the person is in mental health crisis and should be assessed and treated immediately by a skilled mental health professional. Clients report the humiliation, terror and ongoing stigma of being apprehended and transported by police. Situations of crisis quickly escalate and place the person and others at risk of serious harm. Too often they also result in in-appropriate criminal charges.

Medical Records

Pursuit of comprehensive services introduces the dilemma of medical records. Privacy, confidentiality and integrity of these documents must be respected together with the client as right to access records, amend them and control their release.

We are concerned about the language of reports. Extravagant use of terms like “manipulative”, “attention seeking” or “acting out” are generously dotted through most people’s files. All of these are devaluing and dubiously helpful for staff. We seriously question what this sort of labelling. However we worry especially around concepts that we know will have an enormous and nasty influence on the future service experiences of the consumer. Perhaps one of the most graphic examples would be the inclusion of the word, “violent” or “aggressive” in someone’s records. We are concerned that clinicians have a poor grasp of ethical reporting and that as we have gone through consumers’ files and

²⁰ Heather Moore, a postgraduate Social Work Student, has found in her work towards her thesis that when asked whether they use general community services and programs the vast majority of her sample (of consumers) did but stated categorically that they very often did not tell people working in such services that they had a mental illness. Heather was using this material to argue that some of the impression that consumers are not linked in across a comprehensive range of services is illusionary.

²¹ Moore (unpublished)

²² Marina Gloster who is now dead wrote about a stay in a general hospital orthopaedic ward where the hospital placed a security guard beside her bed.

spoken with people we find these so called acts of violence melt down to one act. As we talk further with clients we sometimes find that such acts actually occurred many years before²³. This information has been reiterated and copied from record to record for years and years after any violence was witnessed but the written word continues to influence clinical behaviour and Mental Health Tribunal hearings. It is diabolical for consumers to have something about 'dangerous' or 'violent' embossed in their medical histories. It is also diabolical for this to be given out to other services, which form part of this so-called comprehensive network of 'supports'. Significantly this is amplified by the fact that even after viewing their file clients are only able to put things in and not take inaccuracies out. The MHLC, because of its frequent access to client files, is very critical of many of the histories that are made. Often files are written without including personal pronouns. We support open charting where consumers and staff can co-write medical histories.

Term of Reference D

The appropriate role of the private and non government sectors

Services provided by the private sector are not exposed to the scrutiny and monitoring of the public sector, for example the processes of review and appeal against involuntary treatment are not available to those in the private system. Without the ability to apply involuntary treatment this sector coerce their patients into treatment, anecdotally we know of situations where informed consent was not obtained and in many situations people are not offered a range of choice to treatment.

Psychiatric Disability Rehabilitation Support Services (PDRSS's) are non government funded agencies which in Victoria provide a range of services primarily residential; they offer a vital source of alternative/holistic treatments and must be supported with adequate funding and scope to develop new and creative treatments, to assist and support people to move to less restrictive options.

Term of Reference E

The extent to which unmet need in supported accommodation employment, family and social support services is a barrier to better mental health outcomes.

Many employment opportunities for people with psychiatric disabilities are insulting. We are aware that clients get offered jobs that are greatly below their level of education and expectations, purely on the basis that they have a psychiatric disability.

One person described how he was looking for work and attended a specialist employment agency for people with psychiatric disabilities. He explained that he was a qualified librarian and that he also had a science degree majoring in chemistry. They asked him whether he would like to 'work' (unpaid of course to 'get him work ready' whatever this means) in the library. He had previously told them he was a librarian. They allocated him the job of putting dust covers on books under the supervision of a carer, who of course, had no qualifications whatsoever.

The MHLC is very concerned that when we talk about a mental health system, we are talking about a mental health system and not a mental illness system. Good mental health is about life realities and how we live in the community and support each other. This is fundamental to understanding better mental health outcomes for everyone and covers every area of life experience including work. All organisations, particularly organisations in the mental health field, have a duty of responsibility to their employees to have work practices that are consistent with enabling the best mental health possible in their workforce. It is absolutely unacceptable that organisations working in any area of mental health

²³ Example might have occurred when a teenage boy walloped his mother who was giving him the irate.

should have employees who end up distressed and psychiatrically damaged by their workplace experiences. Discrimination in the workplace and work place bullying, are of major concern.

Terms of Reference F

The special needs of groups such as children, adolescents, the aged, indigenous Australians the socially and geographically isolated and of people with complex needs and drug and alcohol dependence, parents with disability etc.

One of the problems with naming special needs groups is that inevitably some groups are left out. In some ways everyone has special needs and the pitting of one group against another is unfortunate. This is a particular problem in a political situation where 'selling' your interest's greater worth to the mass media, philanthropists, influential politicians and mental health decision makers is the norm.²⁴ This is exemplified when some organisations have the resources and capacity to employ professional submission writers and others can't even communicate to each other in different States because several of the delegates have neither phone nor email.²⁵ As advocates we are finely attuned to this reality. Mental Illness is not and has traditionally not been trendy or seductive to the philanthropy dollar.

We are nevertheless concerned that the following special needs are addresses:

People using mental health services who are parents

The Centre has witnessed many examples of prejudicial practices in the assessment of skills and relationships of parents with a mental illness. Frequently, parental ability has been based on discriminatory assumptions derived solely from a psychiatric diagnosis. While the presence of a mental illness alone cannot constitute grounds for intervention, on many occasions these parents have been subjected to intense scrutiny and expected to perform to excessive standards.

A fundamental principle to emerge from our work is that mental illness is extremely diverse, and its impact alters from time to time. Caution must be exercised to avoid rigid application of one set of rules to a non-homogenous group. It is necessary to avoid stigmatizing parents with a psychiatric disability in a manner that is patronising or denies individual autonomy.

Professional responses must be respectful, informed, flexible and tailored to individual needs, and workers educated to see beyond the mental illness and focus on ways of enriching familial relationships. Fundamental to this process is training on the impact of mental illness on parenting responsibilities, to ensure that families receive appropriate understanding and dignity.

Discriminatory responses imposed by protective services, police and Family Court personnel act as a major deterrent to parents with a mental illness initiating any form of contact with support systems. While they may require assistance during intermittent periods of ill-health, the climate of fear created by regulatory procedures prevents them from independently engaging services. The perceived potential for children to be removed causes an unwillingness to request support even when the parent recognizes a compromised coping capacity.

²⁴ This is demonstrated in some of the feelings that have been accentuated by the huge amount of money that has been found to fund Beyond Blue. Other groups are now feeling miffed that people who they sometimes cruelly describe as "just people with depression" are getting all the money which should be going to the people "who have the real mental illness (like Schizophrenia)" This is unfortunate and divisive. Attacking other groups in an effort to claim public attention and money is a sad reflection on our incapacity as a sector to listen to the complex needs of many.

²⁵ As is the case for the National Mental Health Consumer Network

One case example which exemplifies this:

SD was diagnosed as having a borderline personality disorder. She had a period of not coping with life and was feeling particularly anxious about parenting her son. She stated to her doctor that she was concerned that she might smack him. Mandatory reporting required the doctor to report the incident. The Department assessed the situation and placed him with his grandmother and restricted SD's contact to monthly visits. An Interim Accommodation Order was granted to the grandmother but after 6 months, a Custody to Secretary Order was made in favour of the grandmother.

SD self referred to a number of support agencies and established for herself a support network. No assistance had been provided by DHS although this is one of their roles. SD's mental health had also significantly improved. DHS took no account of SD's improvement in mental health and were proceeding on a case plan for permanent care of the child to the grandmother. Child Protection told SD and her mother that overnight contact had to be supervised - this was not in the Order. SD resided in Melbourne while her son was placed with his grandmother at the end of a 3 hour \$30 train journey.

Where can a parent go for support without intervention? We know anecdotally that many parents with disabilities are totally isolated, have no family supports, friends or neighbourhood contacts. Support funding is tagged to parents who are identified as needing support through DHS - clearly these parents are then placed in a glass bowl for ongoing assessment, and the stakes are high, and the expectations distorted by often inexperienced child protection workers.

We are concerned too that over the past decade there has been an escalation in the money that is spent on programs designed to support, 'the children of the mentally ill'²⁶. As these groups have penetrated conventional thinking in relation to service provision they have resorted to public campaigns, which too often discriminate against parents who live with mental illnesses. The corollary to this is that this type of talk and this type of image making then gives community justification to the increasing number of cases where parents have to legally defend their rights to keep custody of their children.

Later this year the MHLC will be running a workshop, which will honour the extraordinary parenting skills that many women who use mental health services bring to our society. It is designed as a celebration. One of the greatest needs in this area is to provide resources to women parenting under very difficult conditions, but to do so in an atmosphere of admiration and celebration rather than patronism and admonishment. This will never happen if the allocation of resources continues to be based on which group can put up the greatest public plea of hardship.

Complex and co-morbid conditions

Complex and co-morbid conditions and drug and alcohol dependence, affects many of our clients. Like many people with multiple needs this may mean being on the waiting list for a number of different specialist services, though never being a priority for any, each service expecting another 'more appropriate' service to act. These clients fall between the gaps between service silos. The Victorian Department of Human Services was perplexed by the plight of such clients and established new legislation for some such complex clients. It is envisaged that the complex care list will provide a range of services to those people deemed to be some of Victoria's most difficult clients.

²⁶ Consumers do not use this term, "the mentally ill" because it removes the personhood from the person. Consumers use what they call, "person first language" so instead of describing a group as 'the mentally ill' they will rather describe people as "people who live with mental illness" or "people who have been labelled mentally ill".

In examining this group of people it is not at all surprising to note that most have had a history of interaction with many services who have consistently failed to engage them and provide stability, housing, support or offer engagement to the person. It would be true to say that most have been failed by the state from a very young age. What is good about the scheme is that it is not compulsory which means that it is up to the services to genuinely engage people in their treatment and care.

The range of services however offered is not new, the clients are not new and we are concerned that all that will emerge from this experiment is further alienation of this client group. It is crucial in such a program that participants are genuinely engaged in planning and directing their own treatment, that they are making informed decisions and that they have access to independent advocacy to support them to negotiate their case plan. We have clients who have complex problems and who would willingly self refer to this program, however they don't fit the 'cohorts' defined by the DHS.

There is a high correlation between drug and alcohol use and mental health, many consumers seeking their own methods of dealing with their mental illness. We hypothesise that again this is as the mental health system is not a service where people wish to go to for support. We know of many young people with mental illness who find drugs give them a peer group and a life style accepting of their mental illness.

Many consumers argue that the drug and alcohol sector provides services more generous to the consumer than mental health services and where they are treated like adults and treated respectfully. Service agencies must address this problem by engaging with clients, allowing them to take responsibility, to support them in the development of treatment plans and engage all appropriate services in this process.

People with Borderline (and other) Personality Disorders

Mental Health services provide primarily for people experiencing psychotic illnesses and systematically discriminate against people with personality and other disorders. These people are often in desperate need and have usually been failed by mental health systems and services. They are often refused treatment and forced into very destructive cycles of self-harm. In Victoria the plight of people labelled as having Borderline Personality Disorder is ameliorated somewhat because of the existence of Spectrum – the Statewide Borderline Personality Disorder Service.

Unfortunately the lack of services for people who have “just behavioural problems” is not the end of it. The Cornelia Rau story exemplified the problems that are happening on a daily basis in services across the country. Whilst she was seen to have “just behavioural problems” abusive treatment and social neglect were not seen to be outrageous. The outrage only came when the diagnosis was changed to Schizophrenia. After speaking to many consumers we have learnt that this is an insidious trend that infiltrates hospital, detention centre, prisons and community mental health services. Unfortunately this tendency towards exclusion and abusive practice is complimented by the fact that some of the wealthiest lobby groups (eg SANE Australia) have been very tardy to take up the cause of people diagnosed as having a Borderline Personality Disorder for fear of tarnishing the pristine message that all mental illness is biological and medical. Whilst medical model messages are the only ones going out to the public we know that people experiencing Borderline Personality Disorder, for example, will continue to be shunned by services.

Service systems must become committed and resourced to respond to personality disorders as the disabilities that they are - that is, as conditions that require and are responsive to appropriate supports and treatment. Moreover, as for all psychiatric disabilities, every effort must be made to provide treatments which are least aversive and will accordingly promote optimum engagement, There is very

good reason for the legislature's refusal over many years to sanction involuntary treatment for personality disorders, and this position should be maintained.

Term of Reference G

The role and adequacy of training and support for primary carers is in the treatment of recovery and support of people with mental illness.

It is a fundamental tenet of MHLC practice that we take instructions from clients only, not carers or families, unless we have the client's full consent and are confident on an ongoing basis that the carer's position is consistent with that of the client. We generally direct carers to carer organisations or other legal services. One of the reasons for the Centre's establishment was an acknowledgment that people with mental illness themselves are seldom heard and need support to protect their rights and advocate on their own behalf. And as the carer voice has grown louder over recent years the consumer perspective is in increasing danger of being overwhelmed.

It is impossible to generalise, but in very many instances consumers and carers have very different agendas. These agendas are played out in various debates; they become particularly obvious around issues to do with confidentiality and forced treatment, both central areas of practice and concern for the MHLC.

Whilst many carers undeniably play a crucial role in the care, support and rehabilitation of consumers, and must be adequately resourced, there is a danger that resources will be directed their way rather than to services which directly assist consumers because the carer lobby is so much more vocal, visible and better resourced than that of consumers. Resources for carers must not be at the expense of adequate services for consumers. Furthermore, one of the most crucial features of carer training and support is that consumers be key planners and providers of such programs. One of the most effective ways of increasing respect, trust and understanding between these groups is for consumers to communicate their own experience, needs and expectations.

Crucially also, governments and service providers must resist the ongoing pressure from carers to facilitate greater access to confidential information about consumers. Privacy of information concerning mental health is a fundamental right protected at every level - from the International Covenant on Civil and Political rights down to domestic legislative regimes and professional codes of ethics. And it has vital therapeutic importance. It is essential for consumers' trust and rapport with therapists that they are confident their privacy will be respected. Periodically in Victoria there is pressure to broaden the capacity of services to disclose information to carers beyond the provision of the Mental Health Act 1986.²⁷ As it is that provision discriminates against consumers in that the comparable provision which applies to users of general health services under the Health Services Act 1988 contain no such exception. Facilitating greater access to personal information for carers than already exists is likely to lead to further distrust of and disengagement and alienation from mental health services.

Term of Reference H

The role of primary health care in promotion, prevention, early detection and chronic care management

Clients often prefer their mental health to be managed by local GPs who can provide a much more holistic, more dignified and less patronising and restrictive services than that provided by government

²⁷ Section 120A of the Mental Health Act 1986 provides that information can be disclosed to primary carers involved in the ongoing care of someone where disclosure is reasonably necessary.

clinics and case managers. Such an approach may well be incidentally more cost effective, also. The Commonwealth government has funded an initiative to upgrade General Practice in providing mental health services, particularly short (six weeks) courses in Cognitive Behavioural Management ("CBM").

Some GP's are trying to access these opportunities but struggle because their training in how to do such complex therapy is insufficient. It is important that these practitioners remain prepared to refer on, and, crucially, have adequate services to which people requiring longer term therapy can be referred. It may be that GPs can adequately address some people's issues with therapy such CBM, but for many people more lengthy, specialist "talking" or psychological therapies may be required. The introduction of some Medicare funding for psychological therapies is a welcome step in the right direction. Many of our clients are desperate for those kinds of therapies as alternatives to side effect producing or largely ineffective medication therapies.

Terms of Reference I

Opportunities for reducing the effects of the iatrogenesis and promoting recovery through consumer involvement, peer supported, consumer education of mental health workforce and services to be consumer operated.

Many clients fear admission to mental health facilities as they have experienced them as dangerous places. Many abuses, with associated trauma occur within psychiatric services including hostile intimidating environments. Clients say that their feelings are ignored and they are only viewed through their symptoms. Seeking explanation or making complaints is seen often as difficult behaviour and dismissed as symptomatic of illness. The main form of treatment is forced treatment used to control and subdue the person. Despite legislative exhortations to the contrary, it is also used as punishment. There is a frequent failure to obtain genuine informed consent and people are coerced into treatment, even bullied or deceived. In such environments people become unwell.

A feature of both inpatient and outpatient public mental health services which compounds their ill-health making for many consumers is their "one-size-fits-all-approach". People have access to services based on geographic considerations, not their particular mental health needs. This means that people with a range of very diverse conditions and needs are treated together by the same team of workers. There are some exceptions in Victoria - mother baby units, specialist forensic services and child and adolescent services exist, for example. But access to those services is limited, and there are many other specific conditions and needs for which there are no specialist services. The lack of specialist services for women for instance may exacerbate problems for individual women and is far from optimally therapeutic.

The provision of least aversive, most appropriate treatments is essential for overcoming iatrogenesis and maximising recovery. We are please this inquiry's terms of reference have identified the pivotal role of consumer involvement in and operation of services.

We must as a society and as a matter of urgency work out how we can provide acute mental health services that are actually therapeutic for people rather than just places of internment for very distressed people whose distress then further distresses others. The most important aspect of this is to ask those who have used the services, had services imposed on them or been unable to access services.

The first step we need to take is to enter discussions with consumers from a position of, "professional humility". Safe places need to be designed by those who have not felt safe in the past. Healthy places need to be designed also by consumers. Consumers don't always agree with each other. Some individuals have the need to escape more constantly in their world view than others. One very

insightful nurse in a public mental health service ran a program called 'the escape program' and inpatient consumers brainstormed all the best ways to escape, tried some of them together, and in a totally upfront way eventually talked themselves around to staying put for a little while longer to give the place a bit of a chance. The amazing candidness of this exercise is particularly impressive because public acute psychiatric units where so many people are there unwillingly are not usually candid places. It's more often in the collective consumer interest to keep important escape plans and other information amongst themselves²⁸.

It is our view that the iatrogenic tendency has now spread out from the acute unit to community clinics and 'carers'. If adults are constantly ignored, if there is a conspiracy between family and the mental health professionals, people will continue to get sick. This sickness will manifestly be caused by the extended reach of an unhealthy culture of containment, control, compliance and hopelessness. Unlike acute surgical units or acute medical hospitals iatrogenic proof cannot be found in the spread of an infection or the finding of a surgical instrument in someone's abdomen. Perhaps the best indicators of iatrogenic events are symptoms of post-traumatic and flashbacks or hopelessness and inertia.

We are concerned about the totally inadequate funding for the recovery focussed care that can be provided through advocacy; both consumer advocacy and legal advocacy; individual advocacy and particularly systemic advocacy. We are aware that there are very few consumer initiatives in Victoria that are not funded to fail. The National Mental Health Consumer Network is in exactly the same position.

There is appalling tokenism towards consumer involvement initiatives and many consumers are working in shocking conditions in mental health services across the State. These jobs are often inadequately supported, inadequately funded, inflexible and, potentially dangerous.

To properly reform mental health services there needs to be some attention paid on the education of the mental health workforce. Properly resourced legal and other advocacy services ought provide legal education to workers. Clients and mental health professionals need to understand the law as it relates to the Mental Health Act, consumer rights, discrimination, and privacy. Clients who lack information will fail to realise that the things that are being done to them that are making them 'sick' are against the law. Without access to information about the law some providers will continue to behave in ways that disempower, institutionalise, re-victimise and generally make people 'sick'.

The MHLC involves people with psychiatric disabilities as employees, consultants, through networks and on the Committee of Management. This is crucial. It is particularly important that they hold senior positions on the Committee of Management. At present the chair of the Committee of Management and two-thirds of the committee members are consumers. Even in a progressive organisation such as the MHLC this would not have happened fifteen years ago (before the Burdekin Report and the First National Mental Health Strategy). And even now it is precarious - we are certainly not resourced to provide the optimum support to consumer participants. We make it a priority to provide reasonable remuneration to consumer speakers (more so than the vastly better funded mental health bureaucracy - recently a high profile consumer expert was asked to present the consumer perspective at a major departmental conference and, after some pressure was applied, received payment of \$20 for their participation!).

It is through consumer partnerships within organizations such as ours and through the symbolism of authority and power that consumers can create an alternative vision of recovery, potency, mental prosperity, hope and power. It is through recovery understanding your own potency and power, maintaining both individual and collective hopefulness and empowering each other that the insidious

²⁸ Wadsworth, Y The Essential U&I – Victorian Mental Illness Awareness Council, Melbourne 2001

pressure of iatrogenic illness will be retarded and maybe even reversed. This is manifestly not tokenism but we know we must be always vigilant because one of the realities of true consumer participation is that it will sometimes hurt and under these conditions there is in all organisations a cultural drag back towards institutional safety.

Terms of Reference J

The overrepresentation of people with a mental illness in the criminal justice system and in custody, the extent to which these environments give rise to mental illness, the adequacy of legislation and processes in protecting their human rights and the use of diversion programs for such people.

Any guess as to the numbers of this population can only be conservative. We know anecdotally of many clients who have never been assessed by the criminal justice system as having special needs, although known to mental health services, and in receipt of treatment. Often people will not disclose their illness because of shame or a real fear of victimisation and discrimination. In encounters with the criminal justice system we know that this discrimination may manifest as humiliation, ridicule or cruelty. It is of great concern to us that we don't create a system that involves a higher level of commitment and surveillance of people with disability, indeed a discriminatory system.

With more than a quarter of the prison population diagnosed with a psychiatric disability at some point in their lives, and the figure being much higher, around 70%, if mental disorder more generally is taken into account, psychiatric disability must have a reasonably high prevalence amongst those who are charged.

It is our view that diverting people from inappropriate encounters with the criminal justice should be the ultimate goal. No useful purpose is served by charging people with summary offences when they were clearly unwell.

In the alternative in Victoria there is opportunity to have the matter dealt with in a Diversion Scheme. This scheme is only available if recommended by the police informant and the approved by the Court. Police and Courts are also often reluctant to approve it if the person has prior offences. Also, it is not always a good option however, as it also requires an admission of guilt by the offender when they may well not be guilty according to the law. It is our view that in situations where the offender was unwell then they ought access a complete defence and get the charges withdrawn. Any diversion system must not be subject to the agreement of police or prosecuting authorities, but in the full discretion of the Court. As they do in some Australian jurisdictions, Courts must have discretion to dismiss charges completely in appropriate cases, without requiring police or prosecution approval. And diversion schemes must not exclude people with prior offences - generally the offending acts of a person with a psychiatric disability are all connected to the disability and the lack of appropriate support in the community.

If the matter proceeds a defence of mental impairment under the *Crimes Mental Impairment and Unfitness to be Tried Act 1997* may be heard in the Magistrates Court, it is an absolute defence, resulting in the charges being discharged, for this reason the prosecution generally oppose believing that people should be obliged to treatment. Both the prosecution and informant in most situations have an extremely poor knowledge of psychiatric disability, the availability of treatment and rehabilitation.

It is clearly not the role of the Court to oblige people to mental health treatment, Mental Health Acts offer compulsory treatment to persons deemed to be at risk to themselves or others. In most of these

situations it is clear to police that the person was unwell at the time of the offence, when charged. On many occasions after investigating the incident the police transport the person to an acute psychiatric setting.

In the higher Courts the *Crimes Mental Impairment and Unfitness to be Tried Act 1997*, a person can enter the same defence which allows the Court to impose treatment conditions. In essence this Act is designed to divert people from the criminal justice system. The dispositions available and treatment conditions may look like a soft option though in reality they bind a person to the Court for treatment far beyond usual sentencing. They also bind a person to treatment when mental health services believe they would not fit the criteria of involuntary treatment.

The overarching concern in these matters is the protection of the community at large at a huge cost to the individual and a diminution of their rights. Media hype dictates the cautionary approach of the Courts in these matters stories of 'psycho killers' and 'feral psychotics' which are splashed in the tabloid press harm all people with mental illness and hamper the rehabilitation of offenders with mental illness.

There needs to be a challenge to the myths and fears attached to mental illness. This involves considerable training of magistrates and judges. It requires active involvement of consumers and mental health professionals into police training as well as their commitment to respond with police and divert people immediately into the health care system and away from the criminal justice system.

Prisons

Both men and women in prisons with mental health issues report that they are reluctant and even frightened to reveal that they have such issues. There is little offered in the way of support and lots in terms of discrimination, abuse and bullying. Men in the Victorian prison system can be referred to an assessment unit or to the Thomas Embling Forensic Hospital, remand also provides a psychiatric support service.

Women in prison have less access to specialist services, more barriers to accessing tertiary health care and less availability of intensive mental health care than men in prison. Women at Deer Park inform us that they can access 6 counselling sessions, they may also be referred to the visiting psychiatrist who may review their treatment on a monthly basis. We were advised that these sessions are brief and that there is only one visiting psychiatrist.

Women distressed and agitated, or at risk of suicide or self-harm are placed in Muirhead cells, known as 'wet cells' (there are similar facilities in male prisons). They are strip searched and then issued with a canvas gown, under which they wear nothing.

Muirhead cells contain no furniture except for very rudimentary bedding. They incorporate one entire glass wall for ease of observation. This also limits privacy. Depending on the observation regime, inmates' movements will be observed and documented between every 15 to 60 minutes. The observation log contains very intimate details of what women do including masturbating, changing sanitary pads, scratching, talking etc. While we understand the requirement to keep a watchful eye on people who are suicidal or having self-harm tendencies, this method of managing suicide and self harm risks exacerbates any existing mental health problems. Clients have such sentiments as, 'If I wasn't suicidal when I went in, I sure as hell was when I came out.'²⁹

²⁹ Federation of Community Legal Centres submission to the Vic EOC

Evidence from the most recent comprehensive assessment of prisoner health, the *Victorian Prisoner Health Survey*,³⁰ reveals that women are 1.7 times more likely to have a mental illness than men and are more likely to have attempted suicide.

A study conducted on the mental health needs of women prisoners in Victoria found that:³¹

- 84.5% of women in prison had a mental disorder (including a drug and alcohol related disorder) compared with 19.1% of women in the community;
- 66% of women had a mental disorder (excluding a drug and alcohol disorder) compared with 16.5% of women in the community;
- 63.2% of women in prison had a drug related disorder;
- 51.5% had an anxiety disorder;
- 44.7% had a depressive disorder;
- 42.7% had a personality disorder; and
- 23.7% suffered psychosis.

The *Victorian Prisoner Health Survey* reveals that:

- Over 30% of women prisoners have attempted suicide;
- 60% have hepatitis and 40% have asthma; and
- 65.9% of non-Indigenous Australian women and 53.8% Indigenous Australian women in prison reported having injected illegal drugs and began to inject drugs on average at age 17.

Women prisoners have alarmingly high rates of experiences of physical, sexual and emotional abuse, including abuse and neglect as children. Overall, the population of women prisoners are among the most vulnerable, unwell and disadvantaged group in the community.

Term of Reference K

The practice of detention and seclusion within mental health facilities and the extent to which it is compatible with human rights instruments, humane treatment and care status and proven practice in promoting and engagement and minimising treatment refusal and coercion.

We have already addressed the limitations of the legal processes which are supposed to regulated and scrutinise involuntary treatment. Unless people have confidence in those systems their treatment will continue to be deeply aversive. And there is increasing evidence that adequate procedural fairness is crucially therapeutic.³²

It is clear that expressions of distress, depression or other mental health issues are often responded to punitively. Although we do not usually represent people who are incarcerated (this is the role of Legal Aid in Victoria) we do represent people trying to get off their Community Treatment Orders (CTOs) and information is shared with us about past treatment in areas of seclusion. Seclusion areas and High Dependency Units are of particular interest to the MHLIC. Again it is relevant to refer to the Four Corners program about Cornelia Rau. It amazed us that there seemed to be a collective sigh of relief when Ms Rau was transferred to a High Dependency Unit at Glenside hospital in Adelaide. Low stimulus High Dependency Units can be very difficult places for people. They are no more places of sovereignty then detention centres.

Experiences of seclusion are often diabolical, one person reports:

³⁰ Department of Justice – Deloitte Consulting, *Victorian Prisoner Health Survey* (February 2003).

³¹ Tye, *Framework for Working with Women in Prison Draft* (2002).

³² BJ Winnick "Therapeutic Jurisprudence and the Civil Commitment Hearing" (1999) 10 *Journal of Contemporary Legal Issues* 37.

“I was admitted to an acute psychiatric unit. I was really terribly distressed. I kept trying to grab something to cut myself with and yet, at the same time, I was saying sorry to everyone. Sorry. Sorry. Sorry. I felt so guilty that I had survived the suicide attempt. A really nice nurse was allocated to be with me. It was called specialling. I wasn’t really with it yet because I was still groggy from the overdose. I had black tar all over me. This is what they gave me in the Emergency Department to vomit up the pills. I felt horrible with the black tar. It felt like it was yelling out, “she even failed to kill herself! No hope! The nurse ran me a bath and she stayed with me. I was surprised that she stayed all the time but later I learned that that is what they have to do when you are being specialled. The water was warm and she wasn’t angry with me. She helped me wash the black tar off my body and then find some clothes to wear. Later she followed me unobtrusively around the unit talking to me not like a therapist but just like a friend who cared a great deal about me.”³³

Another experience

“I became involved with consumer stuff and learnt a lot more about the mental health system. I learnt that specialling was being phased out. They told us there were new and better ways to keep an eye on particularly disturbed patients. They said that seclusion units were being built and that you put someone in there with no stimulation they will calm down. They didn’t tell us that this was all about the cost of specialling and they made it look like it was about finding a better alternative for us. I couldn’t imagine anything being more therapeutic than that bath with a nurse who cared about me.”

Two years later when I was a little bit famous the same hospital sent me an invitation to the opening of their brand new Seclusion Unit. By then I had so many friends who had had dreadful experiences in seclusion. Experiences that totally denied human rights. One friend was denied her tampons and she bled everywhere. Another person I knew was not allowed to have any clothes. They said this was progress but I didn’t go to the opening. I thought it was a sham.”³⁴

There is almost no ‘specialling’ in Victorian psychiatric hospitals any more. With the mainstreaming of acute units consumers lost the trees and lovely grounds and often gained seclusion cells. It is too expensive to employ the number of clinicians needed to provide specialling. Clients suggest sometimes that perhaps they could be employed to be with people and keep them safer.

Forced treatment is different from forced detention and raises many breaches of human rights. The World Network of Users and Survivors of Psychiatry (WNUSP) is very critical of the human rights issues raised when people are forcibly treated. They have recently made a policy that describes forced treatment as torture. The MHLC is following this international debate.

When a person is taken down and forcibly injected it scares and horrifies – staff as well as other patients. Some clinicians become hardened but many don’t. Everyone needs de-briefing but this is rarely provided. Clients with histories of abuse and trauma particularly need looking after absolutely regardless of whether they were the person who was pushed to the floor or not. Some exceptional clinicians have the capacity to defuse potentially volatile situations. These are really important skills that need to be shared and learned by everyone working in an acute environment. Staff violence against patients is unacceptable. It should be an offence. Clients report that some staff provoke ‘incidents’. Wadsworth³⁵ describes the forces within acute settings that lead to this response from clinicians. She postulates that clinicians need to justify their claims that the job is a dangerous and demanding one. Intriguingly this becomes more important because of professional hierarchies within

³³ Victorian Mental Illness Awareness Council, Understanding & Involvement (U&I) A Project’s Beginnings” Melbourne 1994

³⁴ Ibid

³⁵ Wadsworth Y. The Essential U&I, Victorian Health Promotion Foundation 2001 p. 176
Perhaps some of the most important...[things everyone does to protect their own emotional stability]...

health settings and mental health professionals being disregarded by the general community and general medicine practitioners. The cut and thrust of these most restrictive environments does give some the security that they are indispensable.

We need to be more sophisticated in our understanding of how to engage people in treatment without resorting to force. It is also frightening that consumers still report sexual offences by staff. It is too easy to pretend that all this stopped with the end of the big 'bins'. This is not the experience of some. It is worrying that it is still happening and it is equally worrying why the culture is still closing around and protecting perpetrators.

It must be acknowledged, too, that it is not only involuntary treatment involving actual physical force which is counter therapeutic. Though it appears sometimes to be underestimated by authorities such as the Victorian Mental Health Review Board, clients are deeply distressed and disempowered by the infringement of their civil liberty constituted by non-consensual treatment. Even the newer atypical medications have debilitating side effects for many people, quite apart from the psychological impact of involuntary treatment. It is disturbing to see how the weight gain caused by, say the newer anti-psychotic Olanzapine, can psychologically impair a client.

One treatment which causes particular alarm is electroconvulsive therapy or ECT. Whilst many people report it has saved their life, just as many are traumatised by the experience and report troubling side effects in terms of issues such as memory loss. In Victoria there is still no access to the Mental Health Review board or any other independent tribunal to challenge a service's intention to give ECT without consent. All state and territory legislatures must be brought in line with international instruments such as the UN Principles in terms of legal safeguards around involuntary treatment.³⁶

Alan Rosen³⁷, speaks and writes about the recovery potential of treatment refusal. He argues that coercion defeats people and knocks the anger out of them leading to compliance but not necessarily recovery. He argues that treatment refusal is actually sometimes the best sign that someone has the capacity to recover because it shows a capacity to fight and not take for granted ways of being seen in the community that will lead eventually into chronicity.

Strip searching

The act of strip searching, is used with people in prison, we are not aware of the practice in psychiatric settings though we are aware of people being stripped, gowned in hospital gowns and removed to seclusion. Within prisons save for the fact that it is legislated and that particular authorised persons only are to conduct strip searches, is a sexual assault by any lay interpretation. Within hospitals there are no requirements that only authorised persons strip unruly patients, there is no accountability as to how they do it in our view it also is a sexual assault.

Terms of Reference I

The adequacy of education in destigmatising mental illness and disorders and in providing support service information to people affected by mental illness and their families and carers;

³⁶ I. Freckelton and B. Wilson "Electroconvulsive Therapy: Law, History and Practice" (2001) 8 *Journal of Law and Medicine* 389.

Mental Health Legal Centre Inc. *A Position Paper on the Law and Electroconvulsive Therapy in Victoria*. March 2000.

³⁷ A public psychiatrist in Sydney

Since the launch of the First National Mental Health Strategy in the early 1990's the Australian mental health community has been eager to try and educate the public about mental illness in a way that would mean that the levels of discrimination would fall. However despite some success two things do not seem to have been significantly appreciated. Clients³⁸ report that some of the worst discrimination happens in mental health services themselves. Attempts to address this issue through the First and subsequent National Strategies have met with a great deal of defence and sometimes hostility. The national project on the Attitudes of the Mental Health Workforce had to change its name and focus before it could make any headway. Furthermore, the focus of the discrimination within services seems to have evolved to the point where:

"A new kind of stigma has emerged within mental health services. It relates to legitimacy: the mark of infamy is not now that of being 'mad' but rather that of not being 'mad'.³⁹"

This may be seen as innocent in the sense of the judgement of the health institutions. But this is not the case.

In Emergency Departments of large public hospitals physical needs are dismissed and trivialised if there is a diagnosis of mental illness in the file. People report having broken arms not x-rayed and gall stones not explored because of the simple assumption that mental illness equals 'con artist'. This is highlighted by this clinician's statement:⁴⁰

"One imagines that people who repeatedly set fire to their own houses and then call the fire brigade would get short shrift, no matter what their mental state. Self-harmers who attend hospital habitually are unable to take responsibility for their own lives and actions, and it might be that by being so patient and non-judgemental we are fostering that destructive cycle... Any doctor could tell you that in psychiatry, crisis management means rolling up at 10.00am the next morning, latte in hand, when the blood and vomit have been cleared away and the patient is no longer drunk and abusive."

It also seems that in all the public conversations that have taken place around issues to do with stigma and discrimination over the fifteen years since the launch of the First National Mental Health Strategy issues of gender and class have drawn little attention. A British study revealed that psychiatrists are more likely to diagnose people with middle class or ruling class names (backgrounds) with acceptable 'real illness' diagnosis such as Schizophrenia or Bipolar Affective Disorder whereas they are more likely to diagnose people with working class names (backgrounds) with diagnoses such as, "malingersers, addicts or suffering from a personality disorder."⁴¹ It is bewildering that there has been very little public debate about the role of male violence in women's 'mental illness' and issues about sexual assault, around childhood abuse are rendered invisible such is the power of the medical model which has been so dominant in the discourse over the past fifteen years.

Finally it is pertinent to just mention the difference between the campaigns that have taken place in New Zealand and the campaigns that have been preferred in Australia. In New Zealand clients rarely talk about stigma, rather they are focused on the many forms of discrimination that affect their day to day existence. Anti-discrimination campaigns are funded eg Like Minds, Like Mine Project- meaning 'equal to and greater than'. There is considerable emphasis on the Maori community and matters to do with cross-cultural discrimination, linked with the publication and promotion of resources and mutual support. Finally, it is supported by the activity of the Mental Health Commission which is a very

³⁸ National Community Advisory Group in Mental Health, Let's Talk About Action, Australian Psychiatric Disability Coalition

³⁹ Mental Health in Australia – Collaborative Community Practice Meadows G. and Singh B.eds. Oxford University Press, Melbourne 2001 p. 17

⁴⁰ Letter to the Age 9/9 an A&E doctor who calls herself Rachel James (not her real name):

⁴¹ The Age 9/9 2000

authoritative national mental health watchdog that leads by example and employs a consumer as one of the three Commissioners. By way of contrast in Australia, the office of Disability Discrimination Commissioner with HREOC (responsible for issues of disability generally) has only been downgraded in terms of resources and status.

In Australia things have been done the other way round: and from the top down. A lot of money was spent developing large media campaigns during the First National Mental Health Strategy. SANE Australia has continued to provide a key leadership role although consumers comment that this has been discriminatory in itself as it has focussed so openly on psychotic illness. This has been evident to everyone. Although SANE is not an acronym it seems to stand for Schizophrenia And Nothing Else. Beyond Blue in Victoria, has also been very active and the impression is that some of the ground is starting to move in relation to discrimination of people experiencing depression however, some view the unbalanced division of resources only to depression as divisive. These problems are not apparent in New Zealand where the emphasis is on community culture and life rather than diagnosis.

Terms of Reference M

The proficiency and accountability of agencies such as housing and employment, law enforcement and general health services in dealing appropriately with people affected by mental illness.

From our experience generalist agencies cater poorly for people with a psychiatric disability. Mainstream services often inappropriately refer on people with particular needs to specialist agencies believing that a service will be provided. Specialist agencies tend to prioritise those with the most serious, chronic or most discrete disabilities, have long waiting lists and no guarantee of service. Nevertheless generic agencies insist on referring on and once having done so deny service to many clients with disabilities.

Law enforcement agencies show poor understanding of disability, in trying to improve this they grapple with assessment tools to identify when a person has a disability. We are aware of some situations where police have been fantastic in their support and understanding of people's mental health issues.

However, we know that too often police disregard a person's illness and lay charges, rather than exercising their discretion to appropriately divert to the mental health system. A recent example of this is a case where a person living with the most serious type of illness was charged and put through an incredibly complex and resource intensive court process when the police charged him for pocketing the change at a McDonalds restaurant and claiming a second amount of change.

The experience of fear and apprehension of police involvement is common to our clients who report many incidents which highlight the inappropriateness of police intervention, these include: a woman in country Victoria with a mental illness deeply distressed by the experience of police spraying her with capsicum spray in her kitchen at home; police officers approaching a man with a mental illness on a train and scaring him to the point where he jumped off the train whereby they chased him down the railway track; a man who called the Crisis Assessment Team to assist his son with a mental illness and was visited by 16 armed police officers at his home; a woman who has twice had armed police siege teams including a dog squad at her home in the context of concerns about her suicidality.

It is not appropriate for people who require health care to be treated as criminals. We are concerned that police intervention places extraordinary demands on officers who lack the skills and knowledge to appropriately deal with people in mental health crisis. It is our view that they must be supported in

crisis situations at all times by the presence of skilled and experienced mental health professionals who can assess, defuse and resolve.

Terms of Reference N

The current state of mental health research, the adequacy of its funding and the extent to which best practice is disseminated.

We find drug company funded research problematic, they are selective and self interested but pour huge resources into mental health research which is inevitably compromised.

Many researchers have an agreed hierarchy of research methods ultimately valuing double blind trials and devaluing interpretive first person accounts. These place the “real” knowledge in the hands of the external expert and almost no knowledge in the hands of the person with the lived experience of mental distress and illness. Research method critique is as much about corporate power as it is about science. In many developing countries Participatory Action Research (PAR) is the dominant method and has considerable status however, in Australia, it is dismissed as ‘not good science’.

We are critical of the role played by professional organisations in corralling research money and expertise amongst elitist professional organisations and configurations, such as the National Health and Medical Research Council (NH&MRC) and the continual and exclusive funding of large scale positivist research at the expense of small, grounded pieces of consumer generated interpretative work. The opposition to qualitative research, in general, and interpretive research, in particular, happens regularly and even on occasions which are nominally concerned with consumer perspective research methods and practice.⁴² Research which neglects the wholeness of people’s stories and dismembers people is by definition problematic.

If non-government sector attracts funding it is more often philanthropic funds, the outcomes are tenuous relying on the good will and interest of Government for implementation.

Terms of Reference O

The adequacy of data collection, outcome measures and quality control for monitoring and evaluating mental health services at all levels of government and the opportunities to link funding with compliance and national standards.

The National Mental Health Practice Standards and the National Mental Health Service Standards were developed with significant input from people with psychiatric disabilities. The documents produced appear useful, however they are not being met.

Furthermore we are wary of outcome measures which attribute outcomes to mental health clinical service and other institutional interventions, unless there is genuine and effective consultation with consumers as to what they know has been good for their mental health. Clients may be happier and healthier, but it might be because they’ve fallen in love or had great sex or moved out of their parents’ house and have nothing to do with the interventions of mental health services.

Terms of Reference P

⁴² Australian National University centre for Consumer Research in Health forum; Canberra 2004

The potential for new modes of delivery of mental health care including e-technology.

We have made many suggestions above as to the sorts of services which need to be made available if Australians' rights to best practice mental health services are to be realised. Ultimately what is required are services that consumers want and themselves believe are therapeutic.

We are aware that consumers have consistently argued that one of the ways to solve some of the problems that presently occur in the mental health system, is to create services that are run by and for consumers. At the present time we don't have any of these services in all States. However there are many examples of successful services overseas and a few in Australia⁴³. Such services need to be realistically funded.

Consumer run services hold potential for future delivery of mental health care and we recommend money be made available for consumers to travel abroad to study and document how successful consumer run services have happened in other parts of the world. We recommend it as a high priority in terms of finding new ways of providing services that make and sustain mental health.

At the very least services need to be based genuinely on extensive consumer advice - way beyond the tokenistic level of consumer participation which generally prevails.

Conclusion

No one wants another Burdekin Inquiry, in the sense of extensive resources being used to identify the problems with little progress towards their resolution. We know the awfulness of the lives of people with psychiatric disabilities. What is required is action based on the views of people who experience mental illness.

We are aware that we have raised a large number of complex issues and look forward to the opportunity to provide further information or clarification at the Inquiry's public hearings in Melbourne.

⁴³ For example there is a consumer run consumer peer support and recovery centre attached to the Northern Beaches Mental Health Service in Sydney. Consumers are responsible for the governance of this services.

