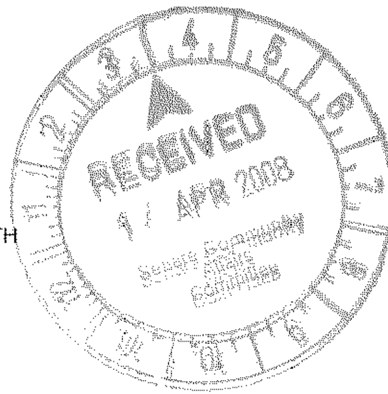

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Mental Health Senate Inquiry

Brief Submission

Term of Reference 2 d

Shortfalls and gaps in funding and services

Management of consumers with complex needs

Any state will have a small cohort of consumers with complex needs that span the boundaries of service systems, including disability, health, housing, administration, criminal justice or drug and alcohol services. These individuals need service coordination and brokerage on a continuous basis due to their own inability to manage their support needs and the absence of any advocate or carer in their life. More often these consumers languish between homelessness and/or inappropriate placements due to the lack of any coordinating service prepared or equipped to take responsibility for them. One particular population group is people with acquired brain injuries whose behaviour then brings them into contact with mental health services.

The accommodation needs of this group are often regarded as the critical unmet need. However accommodation can fail due to the lack of continuous management and advocacy for their ongoing needs. Accommodation with the conventional level of psychosocial support is generally insufficient for this group due to the higher level of complexity of their needs. The default accommodation for this group is prison or more usually mental health facilities. In Western Australia, Murchison Ward and some other wards at Graylands house a number of individuals who would be in this cohort of people with complex needs. The Office of the Chief Psychiatrist, The Public Advocate and the Disability Services Commission, along with the Department of Housing, would be aware of a number of individuals they deal with in common with complex management issues.

The Assertive Case Management System identified in the WA Plan can only meet the needs of this group where mental health services accept the consumer as their responsibility and legitimately their consumer/constituent. Where there are demarcation issues between service systems, an arbitration authority is needed to direct services to act.

Attached is a document that demonstrates an approach to addressing this issue in Victoria (Attachment One)

Clinical detoxification unit for mental health consumers on long-term psychotropic medication

The Western Australian state mental health services have a population of mental health consumers who have been patients for many years, maintained continuously on medication. There are documented side-effects and health risks from long-term use of most psychotropic medications. There is also documented evidence for the resolution of some severe mental illnesses over time. Further to this, there are some consumers maintained on medication who question the original diagnosis and are entitled to have this diagnosis reviewed in the absence of the confounding effects of medication. Consequently, there is a strong case for the establishment of a withdrawal or detoxification unit within the state mental health system to allow for the review of medication for this population. This unit would need to provide a service over a continuum from selection to participate in the process to support beyond withdrawal for the adjustments to life without the effects of medication.

Every mental health consumer who has been on long term psychotropic medication should be able to access a safe clinical service for review of their medication through measured withdrawal, review of their underlying mental health condition and re-consent where continued medication is necessary, as well as support for living without either a active mental health condition or the effects of medication.

Attached is a proposal submitted to the Chief Psychiatrist and the General Manager of Mental Health in recent years (Attachment Two)

Mental health consumer involvement in health service reform processes

Consumer participation in service planning and accountability for service delivery is acknowledged as critical to service reform. Western Australia had an active mental health consumer advocacy program until 200 when this was defunded by the Minister for Health. Consumers engaged in this program contributed actively to the generation of ideas and programs that assisted in service reform, with many moving into open employment. The loss of this program resulted in a failure of WA to meet obligations and commitments to mental health consumer participation. A properly established and funded program is needed in WA to facilitate mental health consumer involvement in service reform activities. A longer term outcome of such a program may be the introduction of consumer run services that ease the workforce crisis in mental health services across the state.

Attached is documentation to support the comments made (Attachment Three)

April 2008

State Government of Victoria, Australia, Department of Human Services

Responding to People with Multiple and Complex Needs Project

Use Google to search DHS Search

DHS home > Project home

Project home
About the project
Human Services (Complex Needs) Act 2003
Terms of reference
Project organisation
Activities
Target group
Reports
Case study
Contact us

Responding to People with Multiple and Complex Needs Project

Since January 2003, the Department of Human Services has been undertaking a project to develop and implement strategies to respond to people with extremely complex needs

The complex clients project target population is comprised of a small number of adolescents and adults who have multiple and complex needs, that require a service response that is unable to be met or sustained within existing service frameworks. While there are many clients with complex needs requiring improved service responses, this project will only consider those at the extreme end of the continuum of complexity.

Phase 1 of the project involved the identification and profiling of the individuals with multiple and complex needs.

This phase was finalised in May 2003, culminating in the release of two reports on 26 August 2003 by the Minister for Health, the Hon Bronwyn Pike MP and the Minister for Community Services, the Hon Sherryl Garbutt MP.

The two reports are:

1. Responding to people with multiple and complex needs project - Client profile data and case studies report (672kb pdf)

2. Responding to people with multiple and complex needs Phase one report July 2003 (302kb pdf)

The Human Services (Complex Needs) Act 2003 received Royal Assent on 14 October 2003. The Act establishes the service model and defines client eligibility, establishes a Multiple and Complex Needs Panel and its functions and authorises the collection, use and disclosure of client level information necessary for a comprehensive assessment of need. The Act will be proclaimed in early 2004.

Phase 2 is currently underway and involves the implementation of the new service model developed in Phase 1.

Phase 3 will involve the ongoing management and evaluation of the strategies implemented in Phase 2.

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Victorian Legislation and Parliamentary Documents

PARLIAMENT OF VICTORIA

Human Services (Complex Needs) Act 2003

Act No.

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PARLIAMENT OF VICTORIA

Initiated in Assembly 26 August 2003

Victorian Legislation and Parliamentary Documents

A BILL

to facilitate the delivery of welfare services, health services, mental health services, disability services, drug and alcohol treatment services and housing and support services to certain persons with multiple and complex needs, to establish the Multiple and Complex Needs Panel and for other purposes.

Human Services (Complex Needs) Act 2003

The Parliament of Victoria enacts as follows:

PART 1—PRELIMINARY

1. Purposes

The purposes of this Act are—

5 (a) to facilitate the delivery of welfare services, health services, mental health services,

"**Intellectual Disability Review Panel**" means the Intellectual Disability Review Panel established by the **Intellectually Disabled Persons' Services Act 1986**;

"**member**" means member of the Panel;

"**Mental Health Review Board**" means the Mental Health Review Board established by the **Mental Health Act 1986**;

"**multi-disciplinary assessment agency**" means a person or organisation with whom the Secretary has entered into a contract under section 17;

"**nominated person**" means a person who has been nominated for assessment under section 18;

"**offender services**" means services provided by—

(a) providers of correctional services within the meaning of the **Corrections Act 1986**; or

(b) the police force in relation to persons suspected of, or charged with, criminal offences; or

(c) courts and tribunals in relation to persons charged with, or found guilty or convicted of, criminal offences;

"**Panel**" means the Multiple and Complex Needs Panel established by this Act;

"**personal information**" has the same meaning as in the **Information Privacy Act 2000**;

"**Public Advocate**" has the same meaning as in the **Guardianship and Administration Act 1986**;

Victorian Legislation and Parliamentary Documents

(d) welfare services, health services, mental health services, disability services, drug and alcohol treatment services and housing and support services provided in accordance with a care plan are to be delivered by the relevant service providers in a co-ordinated manner and for the period determined by the Panel.

Victorian Legislation and Parliamentary Documents

Attachment Two

Health Consumers' Council

Policy Recommendation *[DRAFT]*

Establishment of a De-toxification, Re-consent to medication and Rehabilitation Ward for Western Australia

Objectives of a de-toxification ward

Opportunity for mental health consumers to

- Participate in a managed reduction of medication to cessation with specialist support
- Receive a re-assessment of their mental state without medication effects
- Re-consent to medication, where medication is resumed
- Receive on-going practical and psychological support to live medication free

Background rationale

Advocates at the Health Consumers' Council encounter a cohort of mental health consumers who seek to cease taking medication after having been on medication for many years. People in this group seek advocacy assistance to argue their case for medication cessation. Issues that arise, often in combination, that compel consumers to seek advocacy assistance to strengthen their petition for medication variations are;

Persistent concern about side-effects
It is a widely held norm in the community that reliance on chemicals and use of chemicals is not ideal and may eventually be damaging to health. Where consumers experience side-effects that persist over time this contributes to the impression that the medication may be doing some harm to their health. Consumers know that psychotropic medication is powerful and constantly being modified and new types produced. Many are concerned about the long-term adverse effects of such medication. Consumers are also aware that the side-effects as listed in the Patient Information for their medication may be behaviours or signs that themselves reflect mental illness, such as hallucinations, difficulty with concentration. A detoxification unit could provide a means for a consumer to be medication free for a period of time. This time also allows for the consumer to assess the relative benefits and disadvantages of the medication for their needs and to re-affirm their support for the medication if appropriate.

Uncertainty about the basis for the medication in respect to the diagnosis for which it was originally intended.
Consumers who have been on medication for mental health reasons for many years can be very unclear about the original basis for the medication and about the diagnosis that led to mental health treatment. Many consumers have had a range of diagnoses and treatment regimes and may not always see the reason and logic offered for these by the clinicians that they are treated by. Consumers also often wonder whether the original symptoms that they were medicated for have resolved or

varied. A de-toxification unit can allow for a re-assessment of the underlying condition of a patient without the effects of the medication confounding such an assessment.

Frustration with negotiating with varied practitioners
A consumer may have a long history with a mental health service but only short, perfunctory relationships with any particular practitioner. The staffing profile of teaching units dictate that consumers may not have the opportunity to engage with any one clinician over time. Where consumers see the consultant infrequently and the registrar more frequently, it is not easy to press a case for medication variation. Registrars may be amenable to minor reductions but are reluctant to take responsibility for major variations. A de-toxification unit can allow for progressive reduction to cessation under a specialist's supervision, within a partnership arrangement.

Given the above considerations, and the fact that many consumers in this group are actively seeking to withdraw their consent to the administration of medication or their compliance with taking medication, there may be a case for providing a system for managed withdrawal from psychotropic medication.

The need for psychological support for a trial of cessation of long-term mental health medication.

Consumers who have succeeded in having medication dramatically reduced or ceased find it extremely difficult to do this on their own. Many return to mental health services based on the reports of others who are either aware of the ceased treatment, or who are concerned about the change in the person's presentation. Consumers argue that the change in their presentation need not be seen as a bad thing and is in fact a likely outcome of withdrawal. Where these changes are not understood by those around then, consumers can be the victim of possibly unfair reports to mental health services by third parties, re-instating them in the cycle assessment, diagnosis and treatment.

Dignity of Risk

Many consumers speak of the desire for mental health practitioners to accept their capacity to both recognise the risks of stopping medication and the consequences of this decision. 'Dignity of risk' refers to the acknowledgement of the entitlement of consumers to take risks in their own life with respect to their mental illness, in order that they may engage with the experience of autonomy in their health care decisions. This entitlement to 'experiment' or take risks is not afforded to mental health consumers to any where near the extent it is to health consumers with other long term chronic illnesses. Clinicians in the area of asthma or epilepsy care do not have recourse to involuntary treatment for patients resisting medication or who are having trouble coming to terms with their diagnosis or medication regimes. Such clinicians need to assist the patient to reconcile themselves to their condition through negotiation and trial. It is through these processes of negotiation in partnership that

patients learn to understand and accept their illness and the necessity for medication. Mental health clinicians vigorously resist permitting such experimentation and trial by mental health consumers.

Diagnostic variability in mental health care

Individual characteristics play a significant part in the manifestation of illness in mental health consumers. Despite the existence of diagnostic criteria for mental illnesses, there is considerable variability in the diagnoses given to patients from practitioner to practitioner and from service to service. Patients may receive varied diagnoses over time and a variation in views about the best treatment for their condition. Re-assessment of both the condition and the best treatment is essential for people on serious medications for extended periods. As there are no objective tests for psychiatric disorders, a clean slate assessment is seen by consumers to be a reasonable approach to testing the continued need for mental health treatment.

Maxine Drake
Advocate

January 2005

Attachment Three

Health Consumers' Council
Submission

Petition No 12 – Mental Health Consumer Advocacy Program

The Mental Health Consumer Advocacy Program (MCHAP) evolved from a recommendation of the Task Force on Mental Health (1995) presided over by the then Minister for Health Graham Kierath. The Task Force recommendation was for the establishment of a mental health consumer representative training program, to support mental health consumer participation in WA, in line with the commitments of government to the objectives of the National Mental Health Plan.

The program was auspiced by the Health Consumers' Council (in 1996) and three workers were employed on a part-time basis, with all governance resting with the Health Consumers' Council. Over time, this workforce expanded to 4 and a range of consumer participation activities were underway throughout mental health services, with the staff and many members enthusiastically engaged.

Mental health consumer participation was progressing well until September 2003 when the central program supporting this work was de-funded by the state government. This program was a victim of a brutal cost-cutting regime at the time and its loss was catastrophic for the emerging mental health consumer movement in WA. The level of activity before the funding cut was considerable, with over 120 mental health consumers actively participating in a range of decision-making settings, a membership of 350 and approximately 60 people on the Consumer Advisory Groups in each of the Mental Health Services throughout the metropolitan area. With the loss of the support structures and the participation payment scheme, this movement has never recovered and there are very few consumers involved in this work currently. The Minister has committed to the re-instatement of the program, but this has not been followed-through at a bureaucratic level by the Mental Health Division of the Department of Health.

The nature and manner of the decision to de-fund the MHCAP reflects a disrespectful and indifferent attitude of Government towards a group of people in the community only newly finding their place and dignity in community life. The mental health consumers involved in the program consistently reported finding benefit and purpose from involvement. This program met critical consumer participation objectives for health services. It is hard to imagine a more mutually useful and dynamic partnership addressing the interests of the community and the health system.

If there is one area of health service in need of consumer reform, it is the area of mental health services. The Health Consumers' Council currently provides an individual advocacy service to Western Australians experiencing difficulty in the entire public and private health system. At any point in time 30 – 40% of our advocacy cases are related to mental health services, despite the existence of other NGO's dedicated to servicing only mental health consumers (the Mental Health Law Centre and the Council of Official Visitors.) System reform through consumer participation provides a valuable avenue for promoting the lessons learned from individual advocacy and individual experiences of the mental health system.

A power for service reform

Mental health consumer participation in health service policy, planning, research and service delivery has the potential to assist mental health service reform in a positive and constructive way. Consumer representatives on committees, boards, advisory groups and

as consultants provide a means of influencing the way services operate and policy decisions are made. Consumer representation also provides a tremendous avenue to assist mental health consumers to return to participation in community life, by validating their expertise and knowledge about mental health services and providing an area of activity that is not rehabilitation focussed but contributes significantly to recovery and well-being. The long term benefit of such involvement helps to reduce the stigma and social isolation associated with having a mental illness and makes a positive contribution to the community.

The Mental Health Consumer Advocacy Program was transformative and empowering in the true sense of the word. The constituency of the project was enormous and diverse; the volunteer workforce was enthusiastic and highly motivated and the coverage of the project was extensive. Simply stated, the value in effect for every dollar expended was considerable, especially given the small budget that sustained the program ($139,000.00 at the time of closure).

Consumer disappointment and anger at the closure of the MHCAP was directed at the Health Consumers' Council for not fighting hard enough to challenge the decision by Minister McGinty to withdraw funding. The efforts of the Council to challenge the decision by every means available were not obvious to the consumers involved and residual resentment prevails in some quarters. This may go some way to explain the low number of petitioners, which is also potentially explained thought the loss of the network and the isolation of many people living with a mental illness. Lobbying efforts of the Health Consumers' Council have persisted in meetings with the Minister for Health, letters to many parties including the Premier. Assurances that steps are in train to establish some from of replacement system for mental health consumer participation are hollow, as we are now two years from the closure and nothing has eventuated.

At the time of the closure of MHCAP, election promise funding had been released to add a further component to the Program, of Staff Consumer Consultants in mental health services (known as the Consumer Consultant Trial – CCT). This new component **relied** upon the existing infrastructure. The removal of funding from the foundation program, while keeping the new one, was a further insult and compounded the fracturing of the mental health consumer movement in WA.

The Health Consumers' Council supported the CCT until funding was removed from that initiative recently. The Director of the Office of Mental Health, Dr Aaron Groves, was significantly involved in both decisions to end funding for consumer participation. He has also been the one entrusted by the Minister for Health to sort the situation out. Dr Groves leaves WA soon for Queensland, possibly providing an opportunity for a new approach, or a return to the structure that was gathering momentum, recognition and that worked so well for nearly 7 years.

Back to the Future

The re-instatement of the mental health consumer participation program could be implemented fairly easily on similar or revised terms as the original program. A consumer workforce could be readily identified and harnessed and the tasks for that workforce are clearly defined. The Health Consumers' Council would support such a program again or assist in the process of identifying any other suitable agency to auspice this program.

Any further detail on this program, including its history, the period of the funding cessation or subsequent actions of the Health Consumers' Council in respect to this, please contact Maxine Drake, Advocate, on 9221 3422