Mental Health
Coordinating Council

Productivity Commission Inquiry into Disability Care & Support

Aug 2010

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The Mental Health Coordinating Council (MHCC) is the peak body for community managed organisations (CMOs, otherwise known as non-government organisations) working for mental health throughout NSW, representing the views and interests of over 200 members and the sector. Member organisations specialise in the provision of services and support for people with a disability as a consequence of mental illness. MHCC provides leadership and representation to its membership and seeks to improve, promote and develop quality mental health services to the community.

Facilitating effective linkages between government, non-government and private sectors, MHCC participate extensively in public policy development. The organisation consults broadly across all sectors in order to respond to legislative reform and sits on National, State (NSW) and state government department committees and boards in order to affect systemic change. MHCC manages and conducts research projects and develops collaborative programs on behalf of the sector, and is a registered training organisation, delivering mental health training to the workforce.

The sector in which MHCC operates provides us with a unique opportunity to gain insight into the lived experience of consumers who interface with mental health services. Consultation with the sector has consistently shown that many people with mental health disability are unable to access the services they need, their difficulties exacerbated by the absence of a care and support scheme enabling them to make choices about what they need to provide them the care and support they need, and the opportunity to maximise their quality of life.

It has been widely acknowledged that the system providing for people with disability needs review. The Productivity Commission Inquiry into Disability and Care and Support has been commissioned on the basis that current arrangements are inadequate in meeting the needs of all eligible people with disabilities and their families. Only a cultural shift and redesign of the system and the bureaucracy that manages it will bring about the systemic changes necessary.

The Mental Health Coordinating Council welcome the opportunity to comment on the Inquiry undertaken by the Productivity Commission to identify the best national disability scheme for the support of people with disabilities, and to investigate how such a scheme could be designed, administered, financed and implemented. We congratulate the Government on this initiative.

MHCC is one of seventeen organisations [i] that recently participated in workshops facilitated by People with Disability (PWD) and the Australian Federation of Disability Organisations (AFDO) in NSW; to develop a framework for a National Disability Insurance Scheme (NDIS) consistent with the rights-based approach.

MHCC support the principles identified by the group as critical to a design for systemic reform and endorse the key elements defined as the necessary components of sustainable and equitable scheme.

MHCC do not intend to repeat the detail contained in the Framework document in this submission but refer the reader to the paper now available at http://www.pwd.org.au

This submission serves to elaborate on certain issues and focus particularly on the matters of concern to the mental health sector, particularly in relation to defining disability for the sector and describing the similarities and differences that may apply to assessment/eligibility.

Central to the joint objectives of the working group established for the development of a framework for a NDIS, is that an insurance scheme must encompass the full range of human rights recognised by the *UN Convention on the Rights of Persons with Disabilities*, meeting Australia's obligations under the Convention.

MHCC particularly emphasise the point made in the Australian Human Rights Commission submission to the Productivity Commission (June 2010) that the definition of disability in article 1 of the convention: *is inclusive, not exhaustive. In particular the list of types of disability (physical, mental, intellectual or sensory) is not exhaustive; and reference to "long term" impairments is not exclusive – and does not exclude impairments which are long term but episodic, or long term but not necessarily lifelong*. [ii]

In developing a NDIS it is necessary to refer to the preamble to the Convention that clearly articulates a 'Social Model of Disability' approach: *disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.* [iii] This statement proposes that entitlement must take into consideration the psychosocial impact of disability as experienced by the individual in equal measure to the medically assessed impairment; the aim of the NDIS must be to both compensate for the impairment and reduce the barriers to social inclusion.

International standards for upholding the rights of people with disabilities are set out in the *UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities*. [iv] The 22 rules set out important principles for responsibility, action and co-operation. They point to areas of decisive importance for the quality of life and for the achievement of full participation and equality. [v]

A Social Model of Disability

The ***social model of disability*** *proposes that barriers, prejudice and exclusion by society (purposely or inadvertently) are the ultimate factors defining who is disabled and who is not in a particular society. It recognizes that while some people have physical, intellectual, or psychological differences from a statistical mean, which may sometimes be impairments, these do not have to lead to disability unless society fails to accommodate and include them in the way it would those who are 'normal.'* [vi]

People with disability, whatever their impairment, are demanding that their disability be viewed through their lived experience: that they are the experts in what they need, and that society must not impose its definitions of normality as the criteria for a meaningful existence. Any scheme that aims to provide care and support must be open to respect and respond to individual perspectives, and reject the medicalization of disability which hereto disempowered the very people they have sought to support.

Recognising the expertise and authority of people with impairments is very important. The disability movement is all about speaking for ourselves. This is what it is like to be disabled. This is what it is like to have such and such an impairment. It is about demanding that we are respected as the real experts on disability. It is encapsulated in the slogan, "Nothing about us without us" (Shakespeare, 2001).[vii]

The focus for change

The societal changes people with disability characteristically focus on relate to a number of issues including:

- financial security; a choice of accommodation
- social support removing barriers to access i.e. to services; resources; aids; housing and financial security; educational and employment opportunities; social connectedness;
- physical accessibility
- eradicating stigma and promoting positive community attitudes particularly with regard to how an impairment or disability may present to others
- educating the community not to underestimate the potential quality of life possible for those with impairments
- accessible information; cultural appropriateness (Oliver, 1996) [viii]

Any efforts to ‘fix or cure’, particularly without the consent of the individual are seen as discriminatory and inequitable. The value system supporting the medical model is often responsible for the social exclusion experienced by people with disability and the resulting loss of a sense of self as a valued member of society (Oliver, 1996). [ix]

Some communities have strongly resisted innovative treatment or interventions, *defending a unique culture and set of abilities.*[x] Controversy around deaf parents not consenting to cochlear ear implants for their deaf infants was a typical example of the resistance to the argument of clinicians that this was against the children’s best interests.

Similarly, people diagnosed with, for example, a mental illness or who within the autism spectrum have disagreed with efforts to change them to be more ‘normal.’ The argument is that society needs to be able to accommodate neuro-diversity, and that people with disability should not be social excluded or discriminated against merely because they are ‘different’ and do not conform.

The social model suggests that practices such as eugenics,[xi] [xii] are founded on discriminatory social beliefs and values surrounding the potential and value of those labelled as disabled.

A Socially Just Society

20% of people living in Australia have a disability. That is nearly four million Australians. *The range of impairment is so diverse that we are often surprised by the sheer number of people who are affected by disability every day* (Australian Bureau of Statistics, 1998).

Only recently have people with disabilities begun to be seen as significant contributors to ideas, inspiration and innovation important to all society. The disability movement is invoking change in society and communities that affect all people, not just those with disabilities. This movement is one of citizenship rather than disability.

In a socially just society people with disabilities have a right to equitable access to all the benefits that participation in that society offers. To accept conditions within a society that excludes any of its members from full participation, for reasons beyond their control, is legally and morally indefensible.

This large proportion of the Australian population experience levels of unemployment and underemployment far beyond that of their non-disabled fellow citizens. In Australia, as in most western societies today, lack of access to paid employment impacts financially on people with disabilities to the extent that many of them are effectively excluded from full participation in society. [xiii]

In a globally competitive market place, nations are striving to maximise the potential contribution of all its members. The exclusion of a significant number of its people from the mainstream of society impedes this goal and weakens the overall economic potential of Australian society. This was recognised by the Commonwealth Government in its 'Bridging Pathways' document: *Over 16% of the Australian working age population has a disability…. (and) are currently not participating in or contributing to our society to anywhere near their full potential* (Australian National Training Authority, 2000). [xiv]

Defining Disability

Defining disability is complex and controversial. Though arising from a broad spectrum of physical, psychiatric or intellectual impairment, disability has social as well as health implications.

A thorough understanding of disability recognises that it has a powerful human rights dimension frequently associated with social exclusion, and increased exposure and vulnerability to poverty. A definition within a social model of disability characterises that: *Disability is the outcome of complex interactions between the functional limitations arising from a person's physical, intellectual, or mental condition and the social and physical environment* (DFID, 2000).[xv]

Disability is multi-dimensional, and whilst the lived experience of a person with disability is unique to each individual, it is far broader than an individual health or medical problem. On this basis, the working definition of disability must be adopted in a National Disability Strategy to clearly state for example; that disability can change over time, and be a: *long-term impairment leading to social and economic disadvantages, denial of rights, and limited opportunities to play an equal part in the life of the community.*[xvi]

The needs of people with disabilities differ widely. People with mental illness; children; older people; women; indigenous and culturally diverse people; refugees and displaced persons; and minorities may all experience disability differently. Some may suffer multiple disadvantages as a result of their wider social or economic status. The consequences are particularly severe for women with disabilities who may also be subject to social, cultural and economic disadvantages due to gender discrimination. Similarly people with co-morbid disability as a consequence of their HIV or Hepatitis status may experience particularly acute discrimination and isolation in the community. Characteristically, many of these groups fall through the gaps in benefit/ service delivery, either as a result of ineligibility or barriers to access.

The language surrounding mental illness and psychiatric disability

Frequently the terms mental illness and psychiatric disability are erroneously used interchangeably. Mental illness is a term that describes a broad range of psychological and emotional conditions. More precisely, mental illness refers to the actual disorder, while psychiatric disability refers to the impairment the individual experiences as a result of mental illness. Mental illness does *not* refer to mental impairment such as a developmental disability, organic brain damage, and learning disabilities.

The term ‘psychiatric disability’ is used when mental illness significantly interferes with the performance of major life activities, such as learning, working and communicating, among others.

Someone can experience a mental illness over many years. The type, intensity and duration of symptoms vary from person to person. Symptoms may come and go and do not always follow a regular pattern, making it difficult to predict when symptoms will decrease or altered functioning will appear, even if treatment plans are adhered to.

Whilst not every person who has had a mental illness will experience a disability, it is critical to acknowledge the disability that a person with mental illness may experience over their lifetime as a consequence of: the side effects of medication; poor physical health; educational disadvantage; unemployment; poverty and social isolation to name a few.

It is therefore necessary to define the language in order to inform the debate for and against the separation of clinical and disability support services (VicServe, 2010).[xvii] Examination of the relevant legislation including the Mental Health Acts concerning disability and minimum standards clearly identifies two differing approaches to client rights and entitlements to service delivery. Perceptions by people with disabilities about their rights to services in the community, their rights to dignity and integrity and the right to control all aspects of their lives are integral to the ways in which disability is viewed and policy is developed in Australia. People with psychiatric disability, on the other hand, are faced with a number of conflicting messages about their 'rights'. [xviii]

Even the so-called 'right' to treatment for a person with a mental illness may be transformed into a 'right' to be imposed by the treating agency under statutory powers. This makes no sense unless there is some attempt to differentiate 'mental illness' from resultant 'psychiatric disability'. A person with a psychiatric disability, then, has exactly the same rights to community services, dignity and integrity as any other.[xix]

The recently ratified *UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities* (UN Rules) has moved away from a previously more medical and diagnostic approach which often confused impairment, disability and handicap. The *Disability Discrimination Act* includes in its definitions of disability, as does the UN Rules, the consequences of a:*disorder, illness or disease that affects thought processes, perception of reality, emotions or judgement or that results in disturbed behaviour.*

This is one of the first attempts at a Commonwealth level to articulate within disability policy and legislation, some form of definition involving psychiatric disability.

Whilst it may be obvious that psychiatric disabilities are significantly different from many other disabilities in that they fluctuate and are a result of an intermittent and episodic process, it also must be recognised that the distinctions between the disease process and the resultant disabilities are also less clear than for other disabilities. This has resulted in the confusing use of the terms 'mental illness' and 'psychiatric disability' as interchangeable. (VicServe, 2010). [xx]

This use of language in the mental health arena often means that mental health policy makers and practitioners define an area of practice as 'mental illness' to include almost every aspect of a person's life. As a consequence this locks people (with a diagnosis of some form of mental illness) into a clinical service system which dictates that all aspects of their life require intervention by this system. These people frequently find their world defined and controlled in terms of psychiatric diagnosis and treatment.[xxi]

It is exactly for this reason that debate about the separation between 'mental illness' and 'psychiatric disability' arose. The proposal being that if integration and active participation in community life is the desired outcome for people with a diagnosis of a serious mental illness, then providing community support in an environment which facilitates their identify as other than 'mentally ill' is also desirable.

CMO mental health rehabilitation and support services incorporate many of the principles by which other disability support services operate and conform to the minimum standards prescribed by the Commonwealth which protect and encourage consumer participation and direction. Many of these services have, in fact, been at the forefront of the movement towards consumer-directed and responsive service delivery.

So whilst acknowledging that the terminology is less than perfect; for the purposes of defining people with an impairment as a consequence of their mental illness, whose entitlement we want to be fully recognised in the development of a NDIS, MHCC propose that the language utilised be *psychosocial disability.*

Age-related issues

Australian Institute of Health and Welfare data indicates that one in four mental health-related illnesses are experienced by people aged 65 years and over; a higher rate than any other aged group, although it does not extrapolate the degree to which these figures represent lifelong disability (AIHW, 2008a, p. 11).[xxii]

It is important to note that people with lifelong disabilities characteristically age sooner, particularly as a result of the physical/and or psychiatric disabilities and the side effects of medication. People who live with a mental illness encounter many problems on a daily basis which are magnified as they age. As consumers age, other mental health problems associated with the ageing process are more likely to emerge, including dementia, depression and bipolar disorder (Lee, 2007, p. 16).[xxiii]

A central issue identified in the literature is the capacity of people with a lifelong psychiatric/ psychosocial disability to access services. There is a need to provide a flexible services system that can be tailored to meet the changing needs of consumers as they age, taking into account factors such as fluctuating wellness, respite and carer support. Draper et al., (2003) [xxiv] identify access to a diversity of co-ordinated services such as supported accommodation, primary care and other public health services; psychosocial support; respite and employment as critical to maintaining health.[xxv]

MHCC are concerned that age-related disability has been excluded in the terms of reference for this inquiry. A NDIS needs to consider this group in exactly the same way as the needs and support strategies are needed across the lifespan. People with disabilities under the age of 65 when a new scheme is introduced should continue to be eligible beyond this age and for the remainder of their lives.

Workforce development issues

There are some different interests across the disability sectors that were expressed during workshops to develop a framework for the NDIS. However, MHCC stress that the mental health sector has progressed well down the road of professionalising its workforce, setting a goal of minimum standards, as well as promoting post-graduate training and higher salaries. We do not endorse the position that without unskilled labour the disability sector would be unable to maintain and sustain capacity and growth. In our view, a National Disability Strategy and NDIS must embrace the need for workforce development and improved working conditions.

Non-negotiables

MHCC elaborate on matters relating to the ***NON-negotiables*** identified in the PWD Framework submission as follows:

1. ***People with disabilities and Disabled People's Organisations (DPOs) must be involved at all levels of governance in a new funding model.***

Consumer participation and advocacy

A rights-based approach to disability and development implies a right to self-representation. Such rights are best promoted by people with disabilities themselves. The growth of a democratic, representative disability movement is critical to ensuring that government provision is appropriate to the needs and rights of people with disabilities. In this way target groups can be actively involved in the policy development, planning, implementation and monitoring of all disability systems and service delivery; take measures to remove barriers to participation; and to combat discriminatory behaviour, practices, policies and environments.[xxvi] It is about an ability to share power and collaborate on the part of service providers, as well as empowerment, persistence and cooperation of people with disability.

2. ***The UN Convention on the Rights of Persons with Disabilities is the framework for the design of a new system requiring a significant cultural shift based on a rights-based approach and a social model of disability.***

Oliver (1996) described the cultural shift as the development of the social model and the expression of the lived experience of people with disability, whilst not denying the problem of disability: *locates it squarely within society*.[xxvii]

3. ***The NDIS will form a major initiative under the National Disability Strategy.***

The policy framework - A Vision

MHCC propose that in delivering National Disability Strategy policy framework in which the NDIS is the major initiative, that such a strategy must embrace a Vision, which might read something like the following:

> *'In Australia by the year 2020 all people with disability will be included and respected as equal members of society, enjoying equal opportunities and choices to improve their quality of life'.*

The National Disability Strategy must provide a framework to deliver this vision, together with the goals, policy objectives and strategies to implement a NDIS.

4. ***The NDIS is a national scheme which is:***
    a. ***Based on entitlement for all who are eligible.***
    b. ***Properly funded to address additional costs related to disability so that a person is able to have full enjoyment of their human rights.***
    c. ***Based on equity for all who are eligible.***
    d. ***Takes into account the impact of gender, indigenous background, cultural diversity and specific needs of children.***
    e. ***Based on self-determination.***

f. ***Committed to the empowerment of people with disabilities.***
g. ***Portable (a national scheme).***
h. ***Responsive to changing circumstances of an individual over their lifespan.***

To ensure effective delivery of reform agenda programme, MHCC propose that the system needs to be entirely overhauled. Without such a cultural shift, the objectives may not be possible.

We propose the following recommendations:

- That government commit to a vision for a strategy for improving the life chances of disabled people, developed fully and timetabled with milestones, communicated widely, and aimed at steady progressive reform to 2020.

- That coherent and explicit standards be developed, bringing legislation and other rights into a coherent framework.

- To provide a broad range of government and community services that are sustainably funded.

- That review of service provision should address ways of encouraging effective delivery of services that meet the needs of disabled people and build workforce capacity.

- That a strong focus is maintained within government to make sure that priority is given to disability issues over time by providing oversight of a process to reform delivery in line with the public service reform agenda.

- That arrangements are established to secure participation of disabled people in policy design and delivery at all levels.

MHCC likewise agree with the following proposals:

5. **That all existing obligations and commitments to non-discrimination and inclusion of people with disabilities are maintained outside this scheme – i.e. – costs not to be shifted to individuals and preventative mechanisms put in place to prevent this happening.**

6. **A strong independent advocacy support program is separately funded under the scheme to support and protect the rights and interest of people with disabilities eligible for funding.**

7. **That there is transparency in funding arrangements and appropriate consumer rights protection mechanisms.**

MHCC hope that this submission has provided some addition clarification around the particular differences and interests of people with psychiatric/psychosocial disability and their carers in the development of a framework for a NDIS.

We thank the Productivity Commission for their interest and express our willingness to participate in any future consultations. We look forward to the Commission's recommendations in the near future. For further information please contact Corinne Henderson, Senior Policy Officer at corinne@mhcc.org.au or telephone: (02) 9555 8388, extension 101.

Yours sincerely,

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[i] Deaf Australia Inc.

Australian Communications Consumer Action Network /

Women with Disabilities Australia

Queensland Advocacy Incorporated

People with Disability Australia

Australian Federation of Disability Organisations

National Council on Intellectual Disability

Disability Discrimination Legal Centre of NSW

Disability Advocacy Network Australia

NSW Mental Health Coordinating Council

National Ethnic Disability Alliance

Deafness Forum

Physical Disability Australia

NSW Consumer Advisory Group - Mental Health Inc.

Blind Citizens Australia

Vision Australia

Australian Human Rights Commission

[ii] AHRC (2010). *Inquiry into Long term disability care and support.* Submission to the Productivity Commission Inquiry.

[iii] UN Convention on the Rights of People with Disabilities. Available: http://www.un.org/disabilities/convention/conventionfull.shtml

[iv] UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities A/RES/48/96. Available: http://www.un.org/documents/ga/res/48/a48r096.htm

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[vii] Shakespeare,T. (2001). *Understanding Disability.* Disability with Attitude International Conference. University of Western Sydney, February 2001.

viii Oliver, M. (1996). *Understanding disability: From theory to practice.* New York: St. Martin’s Press.

ix Ibid.

[x] Ibid.

[xi] *the study of or belief in the possibility of improving the qualities of the human species or a human population, esp. by such means as discouraging reproduction by persons having genetic defects or presumed to have inheritable undesirable traits (negative eugenics) or encouraging reproduction by persons presumed to have inheritable desirable traits (positive eugenics).*

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[xvii] Psychiatric Disability Services of Victoria Inc. (VICSERV). Available: http://webcache.googleusercontent.com/search?q=cache:2F3xKf7Y5LsJ:www.vicserv.org.au/library/papers/mentalillness.htm+mental+health+acts+concerning+disability+and+minimum+standards&cd=1&hl=en&ct=clnk&gl=au [Accessed: 13.08.10].

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[xix] Ibid.
[xx] Ibid.
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