Mental Health Council of Australia Submission to:
The Productivity Commission Inquiry into Disability Long Term Care and Support
April 2011

Introduction

The Mental Health Council of Australia (MHCA) is the peak, national non-government organisation representing and promoting the interests of the Australian mental health sector, committed to achieving better mental health for all Australians. The membership of the MHCA includes national organisations of mental health consumers, carers, special needs groups, clinical service providers, community-managed mental health and disability support services and private mental health.

The MHCA strongly supports the development of a social insurance scheme for disability long term care and support in Australia and congratulates the Productivity Commission and the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) for tackling such an important and timely task. Effective long term disability support is necessary to meet Australia's obligations under the United Nation's Convention on Rights for Persons with a Disability and, most importantly, to rectify the grave and unnecessary injustices faced daily by people with a disability in Australia.

The MHCA is extremely concerned about the lack of understanding about the urgent need for disability supports for people with a mental illness revealed during the Inquiry. The MHCA is also disappointed that this lack of understanding is reflected in the Productivity Commission's Draft Report.[1] Coupled with the Productivity Commission's own targeted and highly relevant questions to the mental health sector, this has demonstrated to the MHCA how much work the sector still needs to undertake to educate the community and to demonstrate the urgent disability-based social inclusion needs of mental health consumers with psychosocial disabilities and their families and other carers.

The Productivity Commission's questions highlight the extent to which psychosocial disability and its impact on mental health consumers and carers has been ignored by researchers and policy makers to date. Providing adequate answers to the questions highlights how poorly psychosocial disability is conceptualised, described and measured, and the paucity of data available on psychosocial disability support needs in the community. Due to inadequate strategic policy development for responding to psychosocial disability, both the disability and health sectors have provided funding to fill some urgent systemic gaps, albeit at inadequate levels, but most needs have been left unmet. This is despite the recommendations of the 1993 National Health Strategy Issues Paper '*Help Where Help is Needed: Continuity of*

[1] Australian Government Productivity Commission, 2011, *Disability Care and Support, Productivity Commission Draft Report*, Australian Government Productivity Commission, Canberra.

care for people with chronic mental illness' calling for a greater proportion of Commonwealth disability funding to be directed to people with psychiatric disabilities.[2]

The MHCA considers the current Inquiry is an opportunity to highlight the gaps in psychosocial disability support and to propose innovative ways of addressing them. Therefore the MHCA is extremely concerned at the inference that many have drawn from the Draft Report that disability supports for mental health could possibly be better provided through the mental health sector than through a national disability insurance scheme. This is akin to proposing that the disability support needs of people with intellectual or physical disabilities could be met through the primary health care sector, rather than through a disability support scheme. Mental health services are not designed to provide disability support.

It would seem that a possible reason for suggesting that the mental health sector could provide disability support is that any long term disability support scheme has a limited funding base and someone has to miss out. However, it would be unjust that those with a particular disability would miss out compared to a group with another type of disability. In addition, the basis for making this exclusion is not clear.

Undoubtedly, the interface between the health and disability sectors in the area of mental health is complex, as it can be with other health conditions. However, the MHCA position is that this is not a valid reason for the Inquiry to avoid endorsing the provision of appropriate community based disability supports for people who need them and are entitled to them under the United Nations Convention for Rights of Persons with a Disability. As the Productivity Commission's report acknowledges:

> *people with intellectual disability, acquired brain injury and mental illness are over-represented among the homeless, imprisoned and among drug and alcohol service users. There is significant scope to reduce the numbers in this position through the community support funded by the NDIS.*[3]

It is the MHCA position that community based disability supports for people with mental health conditions and related psychosocial disabilities are the business of the disability sector.

Some community managed mental health disability support services already provide disability support to people with psychosocial disabilities and draw on a specialised knowledge and skills base that is different to that of the health sector. It is essential that this specialist expertise is used to meet the needs of the extremely marginalised group of mental health consumers with a psychosocial disability. This position holds despite the broader disability sector's current lack of focus on mental health consumers with a psychosocial disability and their families and other carers. The current Inquiry is an opportunity to rectify this situation.

The model for a National Disability Insurance Scheme outlined by the Productivity Commission already includes many excellent features that would effectively meet the

[2] National Mental Health Strategy, 1993, Help where help is needed: Continuity of care for people with chronic mental illness, National Mental Health Strategy, Canberra, p144.
[3] Ibid, p14.26.

needs of people with a psychosocial disability. This submission from the MHCA will broadly outline key issues around psychosocial disability and attempt to answer the questions posed by the Productivity Commission. However, the MHCA also considers that the Draft Report shows a limited understanding of both psychosocial disability and the mental health system. Hence a written submission from the MHCA may not be sufficiently detailed to address all of the issues that the Commission's report raises.

To overcome these problems, the MHCA strongly recommends that the Productivity Commission consult those familiar with the mental health sector and mental health consumers. This would enable the Commission to develop an informed and detailed position on the fair and effective inclusion of people with psychosocial disability in any long term disability care and support scheme.

This submission is divided into two sections. The first section on **Psychosocial Disability** provides an overview of psychosocial disability and mental health sector issues. The second section outlines the **MHCA's responses to specific questions asked by the Productivity Commission** about mental health.

Psychosocial disability

Using the definitions of disability referenced by the Productivity Commission's report, psychosocial disability can be defined as:

> *the interaction of long-term physical, mental, intellectual or sensory impairments, and attitudinal or environmental barriers that 'hinder ... full and effective participation in society on an equal basis with others'. The World Health Organisation (2009) similarly characterises disability according to the interaction between a person's body and features of the society in which they live. The interaction of long-term physical, mental, intellectual or sensory impairments, and attitudinal or environmental barriers that 'hinder ... full and effective participation in society on an equal basis with others'. The World Health Organisation (2009) similarly characterises disability according to the interaction between a person's body and features of the society in which they live.*[4]

Psychosocial disabilities related to mental health conditions are those disabilities that result from the complex interrelationship between the impairments associated with mental health conditions and the society in which people live.[5] For those unfamiliar with mental health conditions, psychosocial disability may appear daunting to define because of the range of impairments that can be involved. These include the symptoms of mental illness, which for some people can continue to occur or recur episodically depending on how well the illness is controlled. For some people, these symptoms may continue for the rest of their life, or take some years to be controlled.

[4] Ibid, p1.2.

[5] The term 'mental health condition' refers to the range of features that characterise living with the results of a mental illness or having mental health issues that have not been diagnosed as an illness.

Not all people with a mental health condition will develop major impairments or psychosocial disabilities, but a significant proportion of people who experience a severe mental illness will do so. The clinical treatment of mental health conditions has progressed dramatically in the last twenty years, and it is likely this will continue. But for many people, these treatments are not sufficient to combat symptoms of illness. These people are in a similar position to someone who has an accident or illness causing serious injury. The health system will be able to meet their needs to a certain extent, but may not be able to return them to their previous state of functioning. They may have ongoing symptoms and impairments that will cause them disability.

These impairments may range from mild to severe, and commonly include difficulties with communication, cognition, planning, goal setting and task management, and an inability to recognise one's own impaired functioning.[6] Impairments may also include physical symptoms such as extreme tiredness, lack of motivation, obesity and specific conditions such as metabolic syndrome and diabetes.[7] Some impairments may be misinterpreted by others as indicating uncooperativeness or lack of interest , which can reinforce stigma and result in a loss of social support and difficulty in dealing with.

It is likely in the case of severe and persistent mental illness that these impairments will be significant, and may worsen if illness recurs. The person's disability support needs may therefore change over time.

Some impairments may be associated with use of psychotropic medication and can include weight increase, muscle spasms, and cognitive and behavioural difficulties.[8] Other impairments may relate to childhood trauma or abuse encountered whilst experiencing an episode of mental illness.[9]

Research on disability and social inclusion has shown the complex interrelationship between impairments, disability and life circumstances, including poverty and isolation.[10] Yet appropriate supports to assist the participation of people with a psychosocial disability in the community are severely lacking in Australia.[11]

---

[6] David A and Amador X, 2004, *Insight and Psychosis: awareness of illness in schizophrenia and related disorders,* Oxford University Press, Oxfordshire; Boston University Centre for Psychiatric Rehabilitation, *What is psychiatric Disability and Mental Illness*, accessed from website on 27 Jan 2011, http://www.bu.edu/cpr/reasaccom/whatis-psych.html

[7] Lawrence D, Holman CDJ, Jablensky AV, 2001, *Duty to Care – Preventable Physical Illness in People with Mental Illness*, The University of Western Australia.

[8] National Mental Health Working Group (2005) *National safety priorities in mental health: a national plan for reducing harm*, Health Priorities and Suicide Prevention Branch, Department of Health and Ageing, Commonwealth of Australia, Canberra.

[9] National Mental Health Consumer and Carer Forum (NMHCCF), 2009, *Ending Seclusion and Restraint in Australian Mental Health Services*, NMHCCF, Canberra.

[10] Social Exclusion Unit, 2004, *Mental Health and Social Exclusion: Social Exclusion Unit Report*, Office of the Deputy Prime Minister, London.

[11] Senate Standing Committee for Community Affairs, 2008, *Towards Recovery, Mental Health Services in Australia*, Senate Standing Committee for Community Affairs, Canberra.

Jim's story[12]

Jim is a young man in his mid-thirties. He lives in a Department of Housing unit and is on a disability support pension. He has a diagnosis of Obsessive Compulsive Disorder and is a hoarder to the point that the Department of Housing have threatened to evict him as they regard his home as a fire hazard.

While Jim has a mental illness he receives no clinical assistance from the local specialist mental health service because he does not meet the criteria under the Mental Health Act. That is, when he is ready to accept treatment the specialist mental health services does not believe he is ill enough but when they believe he is ill enough to need assistance, he refuses treatment.

Jim has no family supports except for a cousin who lives interstate and has no friends who could provide assistance long term. He has one NGO funded support worker in his life but they do not have the time needed to support Jim to do his food shopping, pay his bills, etc. As a result he is in a constant state of threat by utilities companies to turn off his gas, electricity and phone.

He can be difficult to work with but a local community welfare agency has established enough trust with Jim to be able to step in when he is in crisis. However, they do not have the resources to provide Jim with the long term support that he needs, which would include engaging him in some normal life activities that most people take for granted. They feel this crisis management approach is not good for Jim's mental health and that he would benefit by having someone visit him daily, take him out of the flat, help him purchase nutritious food, assist him in managing his budget, take him to appointments with his general practitioner, take him to community group meetings where he might be able to develop some friendships. However, this sort of support is not available to Jim.

Jim needs service support that can provide the time and skills to engage with him effectively and provide some long term assistance. This would help to develop Jim's own capacity for self care and minimise his risk of ill health, further social marginalisation and homelessness. These services are desperately needed to prevent the downward spiral into homelessness and need for acute care that can result from psychosocial disabilities such as Jim's.

The number of people with psychosocial disabilities

There is no precise data that accurately describe the number of people with a psychosocial disability in Australia. Most estimates, including those for psychiatric disability, are based on having a mental health condition although some data sources have attempted to define the degree of capacity limitation experienced by people with mental health conditions.[13]

According to the Productivity Commission, of people captured by the 2003 Survey of Disability Ageing and Carers (SDAC), an estimated 446,000 reported mental illness

[12] This is not Jim's real name. Permission has been obtained to use Jim's story and the names have been changed.

[13] Australian Bureau of Statistics, 2003, *Disability Prevalence and Trends*, Australian Bureau of Statistics, Australian Institute of Health and Welfare, Canberra.

as their primary condition. Of these 214,000 were identified as having a disability related to their mental health condition. Of these around 70% (149,800) had 'core activity limitations' and 30% (64,200) were restricted in 'non-core' areas such as schooling and employment.[14]

The Productivity Commission also found that the 2009 SDAC figures show that of the 263,000 people with profound core activity limitations, 40% or 105,200 people had mental health conditions.[15]

A 2010 report on the proposed National Disability Insurance Scheme estimated the 2009 prevalence of people with disabilities under 65 with a severe or profound core activity limitation at about 600,000 people, with condition groupings as follows:

- Congenital anomalies and intellectual disability (82,000)
- Nervous system disorders (41,000)
- Injury (15,000)
- Mental illness (206,000)
- Sensory conditions (12,000)
- Physical conditions (223,000).[16]

For people with mental health conditions, this comprises about 41,000 people in the age range 0-14 and 165,000 people in the age range 15-64. Because we know little about the disability status of these people, it is unclear what sort of supports are specifically required by this group.

In the absence of adequate and accurate estimates on the numbers of people with psychosocial disabilities, the MHCA proposes that any long term disability care and support initiative must at the very minimum budget for the 149,800 to 206,000 people in this group. A small proportion of these people would be too ill to access supports at a given time. Additions to this number would be people whose support needs are significant but whose impairments are not covered by the current focus on core activity limitation.

At the same time, work must be to be undertaken to ensure that any ongoing disability support initiatives develop assessment and data collection mechanisms that are able to encompass all the severe and profound functional limitations associated with psychosocial disability, and not just those that relate to core activity limitation. The Productivity Commission has already acknowledged the inadequacy of using core activity limitation as a proxy for disability in the *Draft Report of the Inquiry into Disability Care and Support*. This is demonstrated in relation to people with intellectual disability, where the Productivity Commission has explicitly broadened the definition beyond 'severe and profound core activity limitation' to include people with a significant disability:

---

[14] Australian Government Productivity Commission, 2011, *Disability Care and Support Draft Report*, Australian Government Productivity Commission, Canberra, Vol 1, p3.25.
[15] Ibid p 1.4-1.5.
[16] PricewaterhouseCoopers, 2009, *National Disability Insurance Scheme - Final Report* (October 2009), accessed from the FAHCSIAwebsite http://www.fahcsia.gov.au/sa/disability/pubs/policy/National_Disability_Insurance_Scheme/Pages/default.aspx on the 27 April 2011.

> *This is because people with intellectual disability may not necessarily be restricted in core activities but may still require assistance with non-core activities, such as catching public transport.*[17]

It would appear that a similar case has not been made for psychosocial disability associated with mental illness because comprehensive data to identify this group are currently lacking. However, this must not be used to exclude this group from ongoing disability care and support.

Further, consideration must be given to the changing nature of psychosocial disability and its relationship to the episodic nature of mental illness. There are many types of physical illness such as arthritis and multiple sclerosis whose impairments and disability support needs can also be episodic. Psychosocial disability support needs are comparable in this respect.

The development of assessment instruments to measure psychosocial disability and its functional support requirements has been explored by the small number of current providers of psychosocial disability supports (see next section). However, further development is required to ensure that these are consistent with the International Classification of Functioning, Disability and Health (ICF), as proposed by the Productivity Commission. The MHCA supports this proposal because the ICF is probably the only current assessment framework that can adequately describe psychosocial disability.

Disability support provided through the mental health sector

The mental health sector is dominated by, but not solely funded through, the health system. The health system traditionally provides clinical services provided by the public and private health systems and which aim to treat and cure illness. The very real issue of providing specific disability supports for people with mental illness has not been well addressed under this model. Understanding of the nature of psychosocial disability and the service implications have largely been developed by the community-managed mental health sector, which provides some specialist psychosocial disability support services. This is why the MHCA proposes that disability supports are most appropriately provided by those with expertise in this area, rather than by the clinical services run by the health system. Clinical mental health services are not set up to provide psychosocial disability.

Mental health consumers and carers have long argued for the need for a focus on whole of life needs, and not just illness and treatment. In line with this approach, the MHCA has consistently advocated for an expansion of services for people with mental illness to include accommodation and employment services to support effective community participation.[18]

---

[17] Australian Government Productivity Commission, op cit, p14.5.

[18] Mental Health Council of Australia (MHCA), 2007, *Let's Get to Work: A national mental health employment strategy for Australi*a, MHCA, Canberra; MHCA, 2009, *Home Truths: mental health, housing and homelessness in Australia*, MHCA, Canberra; MHCA, 2009, *Adversity to Advocacy: the lives and hopes of mental health carers*, MHCA, Canberra.

The COAG National Mental Health Plan 2006-2011 provided significant funding for community based supports for people with psychosocial disabilities. This includes the *Personal Helpers and Mentors Program*, funded by the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) and the *Support with day to day living* program funded by the Department of Health and Ageing.[19] These initiatives provided a much needed boost to community based disability support for people with severe mental health conditions. However, the Senate Standing Committee on Community Affairs in 2008 acknowledged that such community based support services have been so underfunded that substantial further investment is urgently needed to meet community need.[20]

Community managed, community based services, delivering specialist psychosocial disability support, provide an innovative mix of service models for people with psychosocial disability.[21] As demonstrated by the COAG funding described above, they are funded through a range of state and territory and Australian Government health and community services funding streams. However, because there has been little strategic consideration of the extent of psychosocial disability support required in the community, the sector has great difficulty in meeting demand.

The Fourth National Mental Health Plan published in 2009 acknowledges that a whole of life approach is needed for people with mental illness, but to date, few governments have successfully boosted the proportion of funding to community-based services, both clinical and disability support, and away from acute inpatient services.[22] Insufficient Commonwealth, state and territory funding has been directed to the urgent areas of unmet need in the mental health disability support sector.[23] Unless there is fundamental change in the way government funding is allocated, this is unlikely to change.

The resulting circumstances of people with psychosocial disability has been characterised by the 'revolving door syndrome' whereby, on substantial completion of clinical treatment, people are discharged with few supports to assist them.[24] Without supports, they can again become unwell, require crisis mental health support and risk exacerbation of their impairments and disabilities.

Any inquiry into long term disability supports must consider these issues. For too long the needs of people with a psychosocial disability have been neglected. It

[19] Council of Australian Governments, 2006, *National Action Plan on Mental Health 2006-2011*, Department of Health and Ageing website http://www.health.gov.au/coagmentalhealth, accessed 24 April 2011.
[20] Senate Standing Committee for Community Affairs, 2008, *Towards Recovery, Mental Health Services in Australia*, Senate Standing Committee for Community Affairs, Canberra
[21] Psychiatric Disability Services of Victoria (VICSERV), 2010, *Community managed mental health in Victoria, the case for investment*, VICSERV Melbourne; Mental Health Coordinating Council (MHCC), 2010, *The NSW Community Managed Mental Health Sector Mapping Report 2010*, MHCC, Sydney.
[22] Australian Health Ministers, 2009, *Fourth National Mental Health Plan An agenda for collaborative government action in mental health 2009–2014*, Australian Health Ministers, Canberra.
[23] Psychiatric Disability Services of Victoria (VICSERV), 2010, *Community managed mental health in Victoria, the case for investment*, VICSERV Melbourne.
[24] Mental Health Council of Australia (MHCA), 2005, Not for Service: Experiences of injustice and despair in mental health care in Australia, MHCA, Canberra.

would seem that the lack of dialogue between sectors, and concerns about cost shifting, have been used to avoid providing adequate services to people in need.

As one mental health consumer has stated with regard to this inquiry:

> *We need to get angry, very angry. These people [people with psychosocial disabilities] have no voice. They are our peers and loved ones they need us to be very vocal. Their disability support needs have been ignored too many times. This is exactly where disability services need to step in and someone has to start taking up the critical needs of our forgotten Australians, the statistical no-bodies, who don't belong to health, don't belong to disability, don't belong anywhere. The bureaucracies play virtual ping pong with their responsibilities and the needs of these people needs go unserved. They are the underbelly of our Australian Social Exclusion policies.*

Other disability supports for people with psychosocial disability.

Much support for people with psychosocial disability is, as with other disabilities, provided informally through families and other carers. Mental health carers regularly report that they do not have the information and skills to provide the support that they feel is appropriate.[25] This compromises the physical and mental health of carers, their labour force participation and social inclusion. In effect carers are being disabled by the same lack of supports that limit the lives of people with a psychosocial disability Long term disability support initiatives must include consideration of carer needs, such as the need for respite.

Apart from informal carer support, and support provided through the community managed mental health sector, which is funded under the Commonwealth State Territory Disability Agreement (CSTDA) with some additional funding from the health sector, some disability support is also provided for people with a psychosocial disability through generic disability support services funded under the CSTDA, such as Home and Community Care (HACC).

Of the 245,746 people across Australia who made use of services funded under the CSTDA in 2007/8, psychiatric disability rated as the second most commonly reported primary disability (16.3% or approximately 40,000 people) after intellectual disability (31.5% or approximately 77,400 people) and ahead of physical disability (14.8% or approximately 36,400 people).[26] This estimate should be compared to the figures quoted above: 2003 Survey of Disability Ageing and Carers estimate of 149,800 and the Disability Investment Group's estimate of 206,000 people with mental illness and severe or profound core activity limitations who would require some form of disability support. Taking into account the fact that some of these people may be too unwell to access disability services, it is clear that there is likely to be a significant discrepancy between the number of people with psychosocial disability who could be eligible for disability support services, whether specialist or generic, and those who are currently accessing them.

---

[25] Mental Health Council of Australia (MHCA), 2009, *Adversity to Advocacy: the Lives and Hopes of Mental Health Carers*, MHCA, Canberra.

[26] Australian Institute of Health and Welfare, 2011, *Mental Health Services in Australia 2007-08*, AIHW Canberra, p115.

Generic disability services routinely fail to recognise the disabling psychosocial impacts of mental health conditions and do not always have the skills to provide appropriate support, with services often being lost because clients are too difficult to deal with. These include HACC-funded neighbour aid, community transport and home care services. Some generic disability services explicitly exclude people with a psychosocial disability from their target group for no apparent reason. This results in the needs of people with psychosocial disability remaining unmet and those people 'falling through the cracks'.

Leanne's story[27]

Leanne is a 26 year old Indigenous woman. She lives with her mother, sister and her partner and their two sons in a three bedroom house in a remote community.
She is supported by a disability pension from Centrelink and her mother receives a carer's allowance.

Leanne spends most of her day locked in her room, often not coming out to eat but will occasionally walk to the local store for fast food. She will not engage with mental health services but has allowed a health worker from the local clinic to administer her medication.

Leanne is easily aggravated by other people or events, sometimes becoming abusive toward her family and her mother in particular. She has a very large and supportive family but most of the day to day care is provided by her mother who also works part-time.

Leanne's mother admits that she is very unhappy most of the time and would love to see her daughter's circumstances improve and allow her to have a future. However there are no service options that would support this outcome.

Leanne's mother has accessed carer respite services in the past and is waiting for another turn. She identifies this as her only break from the responsibility of looking after her daughter.

Leanne needs services that are able to work with her to determine some life goals and potential requirements for support. Such services would also assist in taking pressure off Leanne's mother and family who urgently require this type of respite but are not able to obtain it. This type of family situation causes its own physical and mental health problems requiring an ongoing need for health interventions and crisis support.

MHCA responses to the Productivity Commission Report

Clarification of MHCA Submission August 2010

In its last submission, the MHCA outlined that:

[27] This is not Leanne's real name. Permission has been obtained to use Leanne's story and the names have been changed.

> A number of historic and sociological drivers have isolated people with psychosocial disability to positions of disenfranchisement from mainstream discussion in the disability sector. It is from this vulnerable position that mental health consumers and carers seek a voice and disability support through this scheme…
>
> There is tension in both the mental health and disability sectors around the most appropriate language to describe persistent mental illness or psychosocial disability. For the purpose of this paper psychosocial disability is primarily used, although where people with mental illness or mental health consumer is used, it should be taken to read as some with psychosocial disability related to persistent mental illness.[28]

Having spoken to the Productivity Commissioners, the MHCA now realises that there is little shared understanding outside the mental health sector about psychosocial disability. For instance, most in the mental health sector would assume that people with persistent mental illness would have a psychosocial disability, so the terms are often used interchangeably as a shorthand. Further, the episodic nature of mental illness is probably better recognised within the mental health sector than by those unfamiliar with mental health conditions. So in using the term 'persistent mental illness' in its previous submission, the MHCA assumed that this would imply the often episodic nature of persistent mental illness. In retrospect, both these issues should have been spelt out in more detail.

Further, the MHCA also wishes to rectify any notion that the views put forward in its initial submission, which are held generally in the mental health sector, are not just an opportunistic grab for funding by a sector that has been otherwise neglected. It is true that action to address the disability support needs of people with psychosocial disabilities has been neglected, but this has been in no small part due to a lack of coordinated and strategic needs assessment and planning. Indeed a simplistic analysis of the present poor servicing of people with a psychosocial disability could lead to the current disability system being seen as discriminatory. Instead the MHCA would hope that this Inquiry is an opportunity for people with psychosocial disability, who are amongst the most disenfranchised Australians, to be acknowledged and their disability support needs addressed in an equitable way.

Eligibility for the National Disability Insurance Scheme

The MHCA agrees that any long term disability care and support scheme must focus on those people with a disability most in need of services and that under the terms of the Inquiry, the target group for the NDIS will be a subset of the broader community of people with a disability. The MHCA also understands the Commission's decision to limit this group to those people who require considerable support. The solution of a tiered system for the NDIS, providing supports to three different populations of

[28] National Mental Health Consumer and Carer Forum and the Mental Health Council of Australia, 2010, *National Mental Health Consumer and Carer Forum and the Mental Health Council of Australia submission to the Productivity Commission Inquiry into Long Term Disability Care and Support*, submission number 357 on the Productivity Commission website http://www.pc.gov.au/projects/inquiry/disability-support/submissions.

people through the strategic approach is also endorsed as a good way of providing services by

- *Minimising the impact of disability by promoting opportunities for people with disability and creating awareness of the issues that affect people with a disability (Tier 1)*
- *Information and referral services (Tier 2)*
- *Provision of funded individualised supports (Tier 3)*.[29]

However, the MHCA is most concerned that the proposed categories of people who will receive individualised support may exclude people with psychosocial disability. The categories describe eligibility as:

> *A person getting individualised support would have a permanent disability, (or if not permanent, expected to require very costly disability supports) and would meet at least one of the following conditions:*
> - *have significant limitations with communication, mobility or self-care (3a in figure 1) and accounting for about 225 000 people*
> - *have an intellectual disability (3b) (about 50 000 people not included in 3a)*
> - *be in one of two early intervention groups (3c) (about 80 000 people). One group would be those for whom there was a reasonable potential for cost-effective early interventions that would improve their level of functioning (as in autism, acquired brain injury, cerebral palsy and sensory impairments). The other would be those with newly diagnosed degenerative diseases, such as Multiple Sclerosis and Parkinson's disease, for whom early preparation would enhance their lives.*
> - *have large identifiable benefits from support that would otherwise not be realised. This takes account of the difficulties in slotting everyone into the specific groups above. Guidelines would inform the use of this last criteria.*[30]

People with psychosocial disabilities and high support needs would fit into the last two of these categories. However, because they are not specifically named as one of groups included, the MHCA is concerned that they could be excluded from the proposed national disability care and support scheme. This concern is increased by the fact that people with an intellectual disability have been given a separate eligibility status, even though they would also appear to fit into the last two categories.

To prevent the exclusion of people with psychosocial disability who require disability support, the MHCA recommends the development of guidelines on how psychosocial disability would fit into these categories. These should be developed collaboratively with mental health consumers who have a lived experience of psychosocial disability and their families and other carers. Knowledge should also be drawn from that of the community managed mental health sector who have significant expertise in meeting the support needs of people with a psychosocial disability.

[29] Productivity Commission, 2011, p3.1
[30] Australian Government Productivity Commission, op cit, p3.1.

Response to Productivity Commission's questions on mental health

The Productivity Commission has also stated that:

> *Clearly, the boundaries between the roles of the disability and mental health sectors are blurred for the most severe and enduring mental illnesses.*[31]

This blurring of boundaries does not seem problematic to the MHCA. We assume this refers to the challenges around meeting the disability support needs of people living in the community who continue to require clinical treatment to manage the symptoms of their mental illness. This can mean a person may be concurrently receiving both disability support as well as clinical treatment. The MHCA proposes that the disability support needs of these people should be identified by their level of functioning and their aspirations for quality of life as would those of anyone with a disability. The system should be flexible enough to work with these needs and adapt as they may change.

These challenges are similar to those who may experience severe disability and health problems at the same time, such as someone with multiple sclerosis. Where someone becomes too ill to utilise their usual disability supports, these would be postponed until they were able to make use of them again. In the event that they remained symptomatic, but still required disability supports, an effective long term disability support plan would involve assisting them to determine interim support needs.

Under such circumstances, mental health treatment teams and disability support services would need to work closely together to ensure that eligibility for support remains up to date and well targeted. The Productivity Commission has proposed an elegant streamlining mechanism to address this relationship:

> *Draft Rec 34*
> *The NDIS should put in place memoranda of understanding with the health, mental health, aged and palliative care sectors to ensure that individuals do not fall between the cracks of the respective schemes and have effective protocols for timely and smooth referrals.*[32]

The community managed mental health disability support sector already has some experience with this sort of MOU arrangement, has used it to define roles and responsibilities and operational protocols, and has pioneered achieving shared understanding between health and community services in many areas across Australia, such as the Hunter region of NSW.[33] This is a new and exciting part of the whole of government approach to providing services that was supported through the COAG National Action Plan.

However, it is likely that such an MOU would need to include provision for ongoing review. Such collaborative arrangements rely on formal mechanisms to ensure that both parties are able to work together to address challenges that arise as part of the

[31] Ibid, p3.29.
[32] Ibid p 3.34.
[33] Mental Health Coordinating Council, 2010, *The NSW Community Mental Health Sector Mapping Report*, MHCC, Sydney, p 156.

arrangements. These formal arrangements would need to be implemented and include the measurement of the satisfaction of services and of people with disabilities who are being supported.

The Productivity Commission has also sought answers to the following questions:

> *The Commission seeks feedback on where the boundaries between the mental health sector and the NDIS might lie. In particular, the Commission would appreciate feedback on which system would be best placed to meet the daily support needs (not clinical needs) of individuals with a disability arising from long lasting mental health conditions (such as schizophrenia), including:*
> *• which services would be provided by the NDIS and not the mental health sector and how these could be clearly identified;*
> *• the magnitude of the budget that would be required;*
> *• how to guard against cost shifting.*
> *• how the NDIS would practically integrate any role in ongoing non-acute services with the wider mental health sector, including any shared responsibilities of case managers in the two systems.* [34]

Services under the NDIS

Currently, neither funding of the community managed mental health sector through the CSTDA, with supplementation from the Australian government and state and territory mental health budgets, nor funding under the CSTDA by the disability sector of generic disability services and specific programs such as Personal Helpers and Mentors Program is sufficient to meet the disability support needs of people with a psychosocial disability. There is clearly room for both sectors to expand these roles, but there is also a need for a long term disability support scheme to ensure an adequate response to the disability support needs of people with psychosocial disability.

Many people with severe and persistent mental illness (and associated psychosocial disability) are keen to obtain disability support from outside the health system, which has a natural tendency to view people as their illness, whatever the discipline or illness type. As part of recovery and rebuilding their lives, mental health consumers and carers are keen to forge or reforge an identity outside the health system. Best practice disability support is based on the philosophy that people are more than their disability and should have the access to the supports that they need to realise their full potential.[35] Therefore, the eligibility of people with a psychosocial disability for services under a long term disability support scheme should be assured.

In particular, both Tier 2 and Tier 3 services should be accessible to people with psychosocial disability. While some people may not be eligible for high level support under a long term disability support scheme, many would benefit from the innovative delivery of information and referral to appropriate services.

John and Mark's story[36]

[34] Australian Government Productivity Commission, op cit, p 67.
[35] Council of Australian Governments (COAG), 2011, *National Disability Strategy 2010-2020*, FaHCSIA, Canberra.
[36] John's permission has been obtained to use this story. All names have been changed.

John's son Mark was an adult with a physical disability, brain damage and a mental illness. John was Mark's primary carer on and off for many years until Mark died in 2009.

Mark's brain damage and physical disability were sustained from a drug overdose which was likely to have been related to self medication for his mental illness.

Mark lived in a Department of Housing unit which had been adapted for wheelchair use but he was not provided with any other assistance. He received some assistance from meals on wheels but this was sporadic and had stopped at some point. Mark did not clean his flat or receive assistance with this but he did manage to use the local laundromat.

John felt that Mark was really left to fend for himself including making his own way to medical appointments. He received no assistance with shopping or other activities to help him live in the community with any real quality of life. He was in receipt of the Disability Support Pension but on many occasions, John had to rescue him financially. John advises that his son became reliant upon others who he felt took advantage of Mark.

Mark was an intelligent and passionate man who did undertake some TAFE studies but, without appropriate supports, never had any real prospect of working. On most days he spent the morning in bed.

There are many people in the community in Mark's position, simply not able to seek out appropriate help for themselves. John believes his son would have greatly benefited from active follow up with a worker who had the time and skills to engage with him and meet Mark on his own terms. John believes that this is what appropriate psychosocial disability support could have given his son.

Budget required

The Productivity Commission has also sought information on the budget required for including people with psychosocial disability in any ongoing disability support scheme. The required budget parameters should be informed by the estimated number of people with psychosocial disability already accepted by the Productivity Commission and outlined above: between 149,800 and 206,000. Provisional budgeting should be undertaken as a first step while costs of meeting psychosocial disability support needs are better established.

Cost estimates could be drawn from the provisional cost estimates made from current disability funding and extrapolated to apply to the agreed estimates of people with a psychosocial disability. There would be little need for spending in the areas of aids and appliances or home modifications. Support for people with psychosocial disabilities is more likely to be in the areas of personal and advocacy support and mental health promotion and early intervention. Additional costs may need to be incorporated to cover the skill levels required by staff to effectively engage with people with psychosocial disability. At least two states (NSW and Victoria) fund

packages of psychosocial disability support for people with different levels of need, and these could be used as indicative costs.

It should also be noted that it would be unlikely that the full cost of service provision would be expended in the first few years of the scheme's operation. For instance, it would take time for people with psychosocial disability and the people in their potential referral pathways such as mental health clinicians and GPs to become aware of supports that may be available to them. It is also likely that the complete range of services required by people with a psychosocial disability would need time to be established.

The MHCA is concerned that current cost estimates outlined in Chapter 14 of the Productivity Commission's Draft Report only use estimates for people with a diagnosis of schizophrenia. While this may be useful in the absence of other data, we propose that there are likely to be more effective ways of estimating psychosocial disability support needs than using this one diagnostic group as a proxy. Some in this group, with appropriate intervention and support. will not experience a recurrence of their illness, and associated disability, and be able to obtain employment. Further, as the case studies in this submission, *Jim's Story* and *Mary's Story,* show, diagnosis is not necessarily an indication of level of functioning.

As an alternative to using estimates of people with schizophrenia, the MHCA would again suggest use of data already accepted by the Commission and outlined above: between 149,800 and 206,000 people.

Cost shifting

From the point of view of service management and funding arrangements, risks around cost shifting could be easily mitigated by appropriately controlled funding provision, contracts and administration. It should be relatively straightforward for services to be able to distinguish between disability supports and clinical treatment that they may provide, and report on outcomes that pertain to each. This is notwithstanding the benefits that may be gained by offering the two sorts of services from the same location or through the same service provider. Current funding arrangements with specialist disability support services and the Department of Health and Ageing and FaHCSIA should be explored to assess the risks, if they exist.

If it is a concern that clinical mental health services already under pressure may neglect their responsibilities and shift the burden of care to disability support services, then the implementation of appropriate governance and accountability measures should be negotiated between the two areas. This could be done as part of the MOU previously highlighted, which must include appropriate focus on outcome measures that determine the satisfaction of mental health consumers and carers with psychosocial disability as well as the two service areas involved.

Given that COAG promotes whole of government partnership approaches, particularly in relation to mental health, it is not acceptable for the disability and mental health sectors to avoid one another for fear of cost shifting. While it is not the role of either to monitor the performance of the other, it is the role of both systems to

negotiate appropriate outcome measures, monitor how well these are achieved and work together to ensure that challenges are met as they arise.

Integration of the NDIS with the mental health sector

This last question from the Productivity Commission has already begun to be answered by the Productivity Commission's suggestions of an MOU to be negotiated between the disability and mental health sectors. This would need to identify appropriate roles, responsibilities and expectations. Indeed, perhaps this detail could also be included in local level MOUs of the type pioneered in the NSW Hunter region, as mentioned previously in this submission.

The community managed mental health sector, which provides much of the existing specialist psychosocial disability support, is indeed already funded under a mixture of disability and health funding streams. This model should be explored for other examples of best practice integration approaches.

Mary's Story[37]

Mary is a mother of young children who developed very severe post natal depression after the birth of her fourth child. Because they had a mortgage her husband (Jim) needed to continue working. Mary was sufficiently disabled by her depression that she was struggling just to get out of bed and needed assistance to run her household.

An innovatively funded service for people with mental health conditions was able to step in. The service receives some funding from the state government department of health and some funding from FAHCSIA through the Disability Advocacy Support Scheme.

An advocate from this service was able to assist in obtaining the necessary clinical supports for Mary by getting her to appointments. They were also able to obtain additional supports to get the children to and from school, and help with shopping, cooking, housework, etc. They continued to follow up with daily phone support and occasional visits to ensure that these issues were being managed as smoothly as possible and other issues were addressed.

Help was gradually withdrawn as Mary's health improved and finally ceased after 12 months when Mary was well enough to look after her family independently.

Mary's story is a good example of effective support for episodic psychosocial disability (in this case, one-off) currently being funded through disability support funding streams. It also shows the importance of this small but targeted intervention in the lives of Mary and her family whose needs were not insurmountable but could have become overwhelming without support.

[37] This is not Mary's real name. Permission has been obtained to use Mary's story and the names have been changed.

Service development for specialist psychosocial disability services.
The MHCA supports the Productivity Commission's caution that:

> *The broad aspiration of creating a disability system centred around people with disability themselves…is very much an unfinished project.*[38]

Such a system will also need to evolve over time and will need to be able to conduct effective evaluation and review on how well it is achieving outcomes for its clients.

The MHCA therefore also supports the proposed provisions for a responsive and flexible system that is accountable to its clients and takes into account the needs of its service providers. Adequate review and evaluation processes will need to be included as part of ongoing quality assurance. Review processes must include mental health sector involvement and must consider eligibility under the scheme, costs and outcomes for people with a psychosocial disability to determine if these are currently meeting the needs of the sector effectively and efficiently.

Some MHCA members are particularly concerned that service provision opportunities for small providers will diminish over time, and that this will diminish the diversity and responsiveness of services. Innovation around service provision and opportunities for mental health consumers and carers to be involved in local level service provision need to be maintained to ensure effective and best practice service provision into the future.

The MHCA therefore also endorses the Productivity Commission proposal that service development and innovation will need to be protected under a support scheme through the role of limited block funding:

> *where markets would not otherwise support key services, to enable a timely response to crisis and to support innovation.*[39]

In addition, in the United States, mental health consumer and carer controlled community organisations and the employment of peer workers have been particularly successful in meeting the psychosocial disability needs of mental health consumers and carers.[40] In Australia, this peer workforce is not yet well utilised but is growing in size and importance. . MHCA sees a National Disability Insurance Scheme as a natural way of encouraging growth in such services as consumers and carers vote with their feet, and seek services that give them the outcomes that they need. It would be therefore be unfortunate if opportunities for these sorts of services diminish through a lack of core or start up funding.

The appropriate development of assessment tools based on an assessment of functioning, as informed by the International Classification of Functioning is also supported. As highlighted by the Productivity Commission's report, this will need to include development of an appropriate skills base for assessors. The MHCA would

[38] Australian Productivity Commission, 2011, op cit, p 8.2.
[39] Australian Productivity Commission, 2011, op cit, p 8.2.
[40] National Mental Health Consumer and Carer Forum (NMHCCF), 2010, *Supporting and developing the mental health consumer and carer identified workforce – a strategic approach to recovery*, NMHCCF, Canberra.

also like to emphasise for the importance of skills in the assessment of psychosocial disability. For example, an ICF informed assessment tool is currently being used in Job Capacity Assessments in the employment sector, but consumers and carers continue to identify that this process is not yet working well for people with psychosocial disability.[41] There have been no formal reviews of this process, so it is unclear if the problems are with the assessment instrument or the skills of assessors or both. However, any long term disability support scheme would need to ensure its assessment process does not unfairly disadvantage some of its most vulnerable clients.

The MHCA is pleased to see that the Productivity Commission has also included a consideration of the needs of carers and of including carers in all consultation processes including assessments in its NDIS. Mental health carers are currently very disadvantaged by a lack of knowledge around psychosocial disability and this makes it difficult for them to access appropriate information, carer allowances, support payments and to set up special disability trusts even when they are eligible under current arrangements. It will be important for mental health carers to be specifically to be consulted on the arrangements for carers under the NDIS processes will ensure that these disadvantages can be addressed and other potential disadvantages under the Scheme minimised.

Conclusion

The MHCA strongly endorses a long term disability support scheme for people with psychosocial disability, putting them at the centre of their support and decision making about their care. But the MHCA is equally keen to ensure that the development of the scheme includes the input of all key stakeholders in the mental health sector, including the knowledge of current disability support service providers, so that the scheme is workable and sustainable. This should also encompass mental health carers, who play a key role in the lives of many people with psychosocial disability.

While it is still difficult to determine exact numbers of people with a psychosocial disability, the Productivity Commission has already accepted a set of estimates. These can be refined through consultation with the sector, and used to inform budgeting and costing for the provision of long term supports.

Many people with a disability already use the health and allied health system as a regular part of managing disabilities associated with impairments arising from their condition. These include multiple sclerosis, arthritis and some of the syndromes that result in intellectual disability. Like most cases of severe mental illness, multiple sclerosis and arthritis, are conditions which are also episodic. They therefore provide a useful reference point for the Productivity Commission when considering the inclusion of psychosocial disability supports in the proposed NDIS. This would ensure that neither ignorance nor stigma is influences decision making around inclusion or exclusion of psychosocial disability in any ongoing disability support scheme.

[41] Madden R, Glozier N, Mpofu E, Llewellyn G, 2011, *Eligibility, the ICF and the UN Convention: Australian perspectives,* in press.

The development of MOUs across the disability and mental health sectors will be important in operationalising the scheme at a local and national level. These will assist to define roles and responsibilities and provide guidance for services unfamiliar with psychosocial disability and unused to collaborating with other sectors.

The mental health sector has changed dramatically in the last thirty years. Yet it is clear that further action is necessary to ensure that the needs of mental health consumers and carers are effectively met. The mental health sector now recognises that not only clinical, but also disability supports are essential for people with a mental illness to reach their potential as citizens, and that to date, a significant proportion of psychosocial disability support requirements remain unmet. Whatever decision is made around long term disability care and support, the mental health sector and the disability sector have a responsibility to work together to meet the needs of these most vulnerable citizens, and the Productivity Commission *Inquiry into Long Term Disability Care and Support* must clearly address this in its findings.