

The Hon Jenny Macklin MP
Minister for Families, Community Services and Indigenous Affairs
Minister for Disability Reform
Parliament House
Canberra ACT 2600

8 April 2013

Dear Minister 

Re: Coverage of psychosocial disability in NDIS Rules

The Mental Health Council of Australia is writing to express grave concern over the recently released draft National Disability Insurance Scheme Rules. The Rules appear to signal a clear change in policy regarding the coverage of people with a psychosocial disability in the scheme. The Rules state:

1. *Supports for Participants Section, 7.8:*

The NDIS will not be responsible for...

(b) Early intervention designed to reduce the progression of a mental health condition (as early interventions in relation to mental health conditions are primarily the responsibility of the health system).

2. *Rules for Becoming a Participant, Section 5.5:*

An impairment is, or is likely to be, permanent if the impairment is irreversible or likely to be irreversible.

These proposals appear to (1) discriminate on the basis of type of disability and (2) contradict some extremely important principles around necessary provision of support for people with a psychosocial disability. Our concerns on both these issues are outlined below.

Early intervention for disability associated with mental illness

The Government has not yet articulated a satisfactory definition of early intervention for people with psychosocial disability, and there is not yet a common understanding in the mental health sector of what might constitute early intervention under the NDIS. It is therefore very difficult for the MHCA to understand what kinds of supports are excluded by this provision, except that they are exclusions only for people who experience mental illness. Nevertheless, excluding people from supports on the basis of a medical diagnosis suggests that assessment will be diagnosis-driven rather than needs-driven (on the basis of functional assessment). This approach contradicts the Productivity Commission's stated intention that eligibility for the NDIS be determined by functional limitations, not conditions. It will also result in many

people missing out on early intervention simply because they happen to have one type of disability (or diagnosis) rather than another.

The assertion that 'early interventions in relation to mental health conditions are primarily the responsibility of the health system'¹ is not supported in fact. There is a range of essential non-clinical services that are currently provided to people with psychosocial disability through both Commonwealth-funded programs (such as the Personal Helpers and Mentors Program) and state and territory funded programs targeting people with disabilities or complex support needs (such as the Integrated Services Program run in NSW by the Department of Families, Housing and Community Services²). Some of these services play a critical role in identifying people who are at risk of developing more serious problems and acting quickly with the right interventions. Such interventions are often delivered in the community, and include referral, assistance or advocacy with obtaining and maintaining stable accommodation, accessing employment or income support, participating in social activities, and accessing relationship support such as counselling or assistance with parenting.

These services are often not referred to as 'early intervention' *per se*; this may explain the Government's difficulties in identifying relevant programs and services and linking them to the NDIS. Moreover, it is not always easy to distinguish those aspects of a service (e.g. a PHaMS-funded service) which might be called 'early intervention' from other aspects. Despite the difficulties in classifying one service or another as 'early intervention', we know that in the absence of such services, the lives of people with a psychosocial disability can spiral into crisis, precipitating acute illness, homelessness and/or substance abuse. If support is not received early, people in such situations may experience lasting declines in daily functioning, with long term consequences both for their quality of life and for costs to the health and disability support systems.

In its inquiry into disability care and support, the Productivity Commission recommended that early intervention for people with psychosocial disability be provided by both the mental health system (for clinical supports) and the NDIS (for nonclinical supports).

Early interventions in mental health typically take a clinical approach and there are established bodies that specialise in the provision of these services (for example, the Early Psychosis Prevention and Intervention Centres).³ Responsibility for these clinical interventions would remain with the mental health sector...

However, consistent with the general criteria for tier 3 supports, the NDIS would provide non-clinical interventions (such as assistance with planning and decision making), where the evidence showed long-run returns... For

¹ Department of Families, Housing, Community Services and Indigenous Affairs 2013. *Draft National Disability Insurance Scheme Rules – Supports for Participants*.

² See the NSW Department of Family and Community Services website http://www.adhc.nsw.gov.au/about_us/our_structure/clinical_innovation_and_governance#isp

³ There is only one Early Psychosis Prevention and Intervention Centre in Australia. It is located in the north western suburbs of Melbourne and services only the young people from that region.

example, evidence may suggest that supports would help a person avoid becoming homeless or requiring hospitalisation.⁴

We are very disappointed that the range of nonclinical early interventions identified by the Productivity Commission have now been ruled out of scope for the NDIS, and confused about the Government's rationale for doing so.

The MHCA acknowledges the inevitable difficulties in negotiating whole of government approaches to service provision to people with complex needs. However the inability of governments to resolve these challenges in the extremely short timeframe available should not be the reason that people with a psychosocial disability miss out on early intervention under the NDIS.

Defining permanent or irreversible impairment

The principle of irreversibility is unacceptable within the context of a human rights based approach to supporting people with psychosocial disability. It is in direct opposition to well-established principles of recovery, which aim to promote a strengths based approach to living well with a psychosocial disability. Recovery principles dictate that a sentence of lifetime irreversibility should not be a prerequisite for participation in the NDIS. Though it is beyond our expertise this also appears at odds to modern thinking about all forms of disability.

A diagnosis of mental illness often results in a lifelong need for support, but just as often it results in a journey of recovery with lower levels of ongoing need. It is difficult and sometimes impossible to determine whether a given diagnosis will in fact lead to lifetime disability – reinforcing the need, outlined above, to look beyond diagnosis. Uncertainty about what supports might be required in the longer term should not be a reason to exclude people whose needs might be ongoing.

The National Mental Health Standards describe recovery as:

'... Gaining and retaining hope, understanding of one's abilities and disabilities, engagement in an active life, personal autonomy, social identity, meaning and purpose in life, and a positive sense of self.

It is important to remember that recovery is not synonymous with cure. Recovery refers to both internal conditions experienced by persons who describe themselves as being in recovery—hope, healing, empowerment and connection—and external conditions that facilitate recovery—implementation of human rights, a positive culture of healing, and recovery-oriented services.⁵

The MHCA acknowledges that many in the disability sector might be concerned that recovery principles could undermine the need for lifelong support to someone with an irreversibly disabling condition. However, it is critical to recognise the language

⁴ Australian Government Productivity Commission 2011. *Disability Care and Support Inquiry report*. Commonwealth of Australia, Canberra, p.189.

⁵ Commonwealth of Australia 2010. *National Standards for Mental Health Services*.

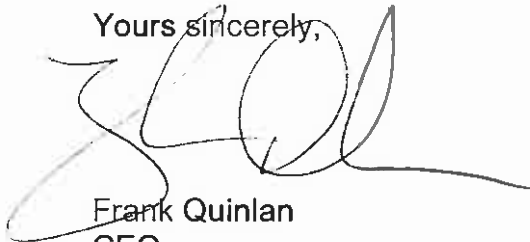
and principles of recovery from the mental health field and to use appropriate and respectful language when referring to NDIS participants with a psychosocial disability.

The MHCA therefore proposes that an explanatory note is added to the NDIS Rules under Part 5: *When does a person meet the disability requirements?*

For a person with a psychosocial disability related to a mental illness, the issue of irreversibility is not relevant to the definition of permanency.

The MHCA is extremely disappointed that despite the person centred aims of the NDIS, challenges that appear to relate more to the allocation of services between governments than to the needs of individuals are blocking access to effective disability support to people with a psychosocial disability. Without changes to the Rules in their current form, the MHCA anticipates that many of the most marginalised people in our society, including those with lifelong a psychosocial disability, will continue to fall through the gaps in disability service provision.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Frank Quinlan', written over a white background.

Frank Quinlan
CEO

To: The Hon Jenny Macklin MP
Minister for Disability Reform
Minister for Families,
Community Services and Indigenous Affairs
Australian Parliament House
Canberra
ACT 2600



19 August 2013

Dear Minister Macklin

Re: Emerging issues for participants with psychosocial disability in DCA launch sites

As you know we have been active participants in advisory groups that have helped to develop the work of DisabilityCare to this point. We welcome the NDIS and the role of DCA, especially given the bi-partisan commitment to double the funding available to support people with significant ongoing disabilities over the next few years. We believe it is absolutely appropriate that the scheme includes people whose disabilities result from mental illness. The objectives of portability across Australia, life-long support if required, and greater personal choice and control over the services people receive all promise considerable benefits for both the people directly affected, and the people who care for them. However, we are writing to express our mutual and grave concern about several issues arising for people with psychosocial disability in the early stages of the scheme's implementation. These include:

Assessment

Initial feedback from across the launch sites indicates that the mental health sector is having serious difficulties understanding how people with mental illness are to be assessed. We are confident that these problems are unintentional, and we will continue work with DCA and stakeholders to resolve them as soon as possible.

'Permanent' disability

Further discussion is required about the notion of permanency in relation to conditions that are often episodic and not necessarily predictable across the life-course. While permanency may be a meaningful concept for some kinds of disability, in the context of mental illness it contradicts the well-understood principle that individuals should seek to maximise recovery. The mental health sector, including potential participants and carers, seeks to work closely with DCA about the implications of the permanency requirement for eligibility and assessment of people with serious and persistent mental illness.

Early intervention

We suggest that DCA needs to give serious consideration to the meaning of 'early intervention' in the context of mental illness. At the very least early intervention needs to incorporate programs and services beyond the mental health sector, and should not be confined to children and young people. Again, we would welcome the opportunity to work with DCA and others to develop a satisfactory definition of early intervention for people with mental illness.

Our major concern however, arises from the interaction between DCA and existing programs designed to serve people who experience mental illness. It appears to us that there are major implications for people who will remain outside the scheme. We seek a clear commitment that none of the 'cash and in-kind contributions' being planned to meet part of the costs of DCA will result in less access to services for those who are not eligible for DCA-funded supports. It is not enough to say that 'no current consumer will be disadvantaged'. Over the past decade and more, many thousands of people with psychosocial disabilities have been able to access relevant supports, funded by all jurisdictions, for the first time.

This process of new populations emerging is still underway, as stigma and shame gradually reduce and 'hard-to-reach' groups begin to find help tailored to their special needs. Many of these people make good recoveries, moving on to greater independence and a better quality of life. Many more will fill the place of current consumers, with most programs reporting waiting lists. It is those people to come that are our key concern. The funding of the NDIS must not result in the unintended consequence of denying many thousands of Australians access to supports that took decades of slow progress to achieve.

The necessary changes in the services environment are considerable, involving both government and non-government providers, and funding from all jurisdictions, and we recognise these will take several years to complete. In those processes, we will advocate to ensure that people who are currently entitled to clinical and community supports due to psychosocial disability will have at least the same, and preferably improved access to those forms of support when they need them.

As we have said, there is a growing sense of concern as implementation commences. MHCA members and stakeholders are gathering in Canberra to discuss these issues on August 27th, any reassurance that could be provided to them ahead of that date would be very welcome indeed.

You can contact us anytime directly on 02 6285 3100.

Sincerely



Frank Quinlan
MHCA CEO



David Meldrum
MIFA ED

The Hon Jenny Macklin MP
Minister for Families, Community Services and Indigenous Affairs
Minister for Disability Reform
Parliament House
CANBERRA ACT 2600

Dear Minister Macklin 

Inclusion of people with a psychosocial disability associated with a mental health condition in the National Disability Insurance Scheme.

The Mental Health Council of Australia (MHCA) is committed to the success of the National Disability Insurance Scheme (NDIS) and is keen to ensure that people with a psychosocial disability associated with a mental health condition are included in the trials that are being commenced around Australia. For this reason I am writing to seek information on any measures that are in place to ensure that the trials specifically identify and address the needs of this important group of people with disabilities.

The MHCA is the peak, national non-government organisation representing and promoting the interests of the Australian mental health sector. The membership of the MHCA includes national organisations of mental health services, consumers, carers, special needs groups, clinical service providers, community and private mental health service providers, national research institutions and state/territory peak bodies.

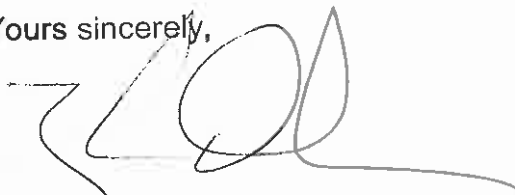
The reason for the MHCA's concern is the traditional lack of awareness of and understanding about psychosocial disability that is encountered in the delivery of mental health, disability and community services.

The MHCA believes that the trial sites will provide an opportunity to ensure that the needs of all people with disabilities are adequately met by monitoring, reporting and managing the barriers to success, including those barriers that are common to different client groups.

However, information available from each of the trial sites to date makes it difficult to ascertain how the needs of people with psychosocial disability will be adequately identified and met. We are particularly interested in any estimates of how many people with a psychosocial disability are anticipated to be covered in each of the trial sites and are also keen to hear about any plans for evaluation and monitoring which would involve collecting population data to monitor service use and unmet need amongst people with a psychosocial disability.

I would be pleased to discuss this issue with you or FaHCSIA representatives further and look forward to assisting in this most important initiative.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'F. Quinlan', with a long horizontal flourish extending to the right.

Frank Quinlan
CEO,
Mental Health Council of Australia

3/10