



National Mental Health
Consumer & Carer Forum

Submission to the Department of Social Services regarding the NDIS Act Review

7 October 2021



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The National Mental Health Consumer and Carer Forum (NMHCCF) is pleased to provide this submission to Department of Social Services regarding the NDIS Act Review.

The NMHCCF is a combined national voice for mental health consumers and carers. We listen, learn, influence and advocate in matters of mental health reform.

The NMHCCF was established in 2002 by the Australian Health Ministers' Advisory Council. It is funded through contributions from each state and territory government and the Australian Government Department of Health. It is currently auspiced by Mental Health Australia.

NMHCCF members represent mental health consumers and carers on many national bodies, such as government committees and advisory groups, professional bodies and other consultative forums and events.

Members use their lived experience, understanding of the mental health system and communication skills to advocate and promote the issues and concerns of consumers and carers.

This NMHCCF submission is focused on the needs of people with psychosocial disability and their access to and use of the NDIS. Information and evidence to support the consumer and family/carer perspective is provided for consideration.

We would be happy to provide any further information to support the issues raised in this submission. Please contact the NMHCCF via the Secretariat at nmhccf@mhaustralia.org or 02 6285 3100.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Keir Saltmarsh'.

Keir Saltmarsh
Consumer Co-Chair

A handwritten signature in black ink, appearing to read 'Hayley Solich'.

Hayley Solich
Carer Co-Chair

NMHCCF submission to the Department of Social Services regarding the NDIS Act Review

Introduction

In providing the response to the proposed legislative amendments to the NDIS Act the NMHCCF believes it is important to provide some information about psychosocial disability. A greater understanding of psychosocial disability will inform the feedback from the NMHCCF and identify ongoing challenges with the operationalising of the NDIS.

Understanding psychosocial disability

Psychosocial disability is a term used to describe the disability experience of people with impairments and participation restrictions related to mental health conditions. These functional impairments, which are frequently episodic, include reduced ability to function, think clearly, experience full physical health and manage the social and emotional aspects of their lives. As with other disabilities, the best outcome for people experiencing psychosocial disability will be achieved through access to supports that enhance their social and environmental opportunities to expand their capabilities.

Not all people with a mental health condition will experience a psychosocial disability. Many people with mental illness will lead fulfilling and productive lives with little support. However, the effects of psychosocial disability can be severe, and the impact is frequently underestimated both for people with a psychosocial disability and their family/carers.

The inclusion of psychosocial disability in the National Disability Insurance Scheme (NDIS) has been seen as a significant development to assist people have meaningful lives in the community.^{1,2}

The importance of choice and control, a recovery-orientation, life-long support and the successes that can be achieved through a well-functioning NDIS cannot be under-estimated for people with psychosocial disability. At times people with psychosocial disability will say no to supports and exhibit a lack of insight which results in them falling through gaps – a common but quite unique to psychosocial disability, compared to other disabilities.

¹ NMHCCF, Unravelling Psychosocial Disability, 2011, Available at:
[nmhccf_psychosocial_disability_booklet_web_version_27oct11.pdf](#)

² NMHCCF, Unravelling Psychosocial Disability Brochure 2021, (in publication), Available at: www.nmhccf.org.au

Feedback on the proposed legislative amendments to the NDIS Act

Proposed changes supported by the NMHCCF

The NMHCCF welcomes many of the proposed amendments to the NDIS Legislation. In particular, the NMHCCF supports:

- inclusion of psychosocial disability within the proposed Legislation and providing improved access pathways that recognise the episodic and fluctuating nature of psychosocial disability
- providing certainty on timeframes for decision-making and improving timeframes associated with NDIS decision making processes, participant plan development, internal reviews and access provisions and the inclusion of these timeframes within the proposed Legislation and Rules
- enhancing transparency on the performance of the NDIA through granting the Commonwealth Ombudsman the power to report against the Participant Service Guarantee
- the Commonwealth Ombudsman gathering feedback from participants about their experience with the NDIA
- promoting the need for co-design with people with disability of any future revisions/changes of funding and assessment modelling
- the use of inclusive language and clarification of terms such as 'reasonable and necessary'
- the inclusion of lived experience of a disability as a criterion for NDIA Board appointments. However, as outlined below, the NMHCCF believes that the inclusion of people with disability on the Board needs to be of greater significance that currently proposed.
- addressing the issues around thin markets. However, for people with psychosocial disability, particularly in rural and remote communities, the specialist skills, knowledge and expertise of support coordinators/workers continues to be a problem
- the updated references to families and carers to align with the 'recognise and respect' terminology of the Carers Act
- the changes in language that relate to moving from a transitional program into the full NDIS Scheme.

Concerns identified by the NMHCCF relating specifically to people with psychosocial disability

The feedback below focusses primarily on issues with the proposed amendments as they affect people with psychosocial disability:

- People with psychosocial disability as a primary diagnosis are still under-represented within the NDIS. Current data from the NDIA reports that shows that there are 48,460 people with primary psychosocial disability in the NDIS, as of 30 June 2021³. This is still only three-quarters of the 64,000 people with psychosocial disability anticipated to be eligible for the NDIS⁴. The NMHCCF is aware that this is due to both low application rates by people with psychosocial disability to the NDIS application and lower rates of success for those with psychosocial disability who do apply.

The NMHCCF recommends that any proposed changes to the legislation support increased access to the NDIS by people with psychosocial disability.

- The NMHCCF is concerned that the health and NDIS boundary issues are not adequately addressed by the proposed changes. NDIS participants with psychosocial disability report that they often experience significant barriers to accessing medical supports and that they get caught in a cycle where they need to access medical support for their disability and need NDIS support for their disability and the two mechanisms don't work well together. Recognition of the need for both access to health services and the NDIS is important for people with psychosocial disability.
- A distinct lack of any information in the proposed amendments about the 'Recovery Framework' as the guiding principle for the application of the NDIS with people with psychosocial disability
- the need under the Participant Service Guarantee that participants must 'request' reasons for decisions and receive and discuss a draft plan before it is approved. Many people with psychosocial disability would not have the supports required to enable them to make such a request.

The NMHCCF recommends that all participants automatically receive information on reasons for decisions and can discuss a draft plan before it is approved.

- The issue of 'permanency' continues to be an issue for people with psychosocial disability, regardless of the proposed changes to the NDIS legislation.

The NMHCCF recommends the complete removal of the permanency requirement for people with psychosocial disability.

³ Data obtained from: <https://data.ndis.gov.au/explore-data>

⁴ According to Productivity Commission Review, pp 851-2

Other concerns identified by the NMHCCF

There continue to be several issues of concern to the NMHCCF in regard the proposed changes to the Act and Rules of the NDIS. Specifically, the concerns identified by the NMHCCF are:

- The lack of prior experience of the NDIA in ‘co-design’ and the need to promote the concepts of co-production and co-design as opposed to the reliance on consultation process. The short timeframe for consultation on the proposed amendments is an example of poor co-design!

The NMHCCF has much experience in co-design and co-production and has provided guidance on the levels of lived experience engagement in Appendix 1.

- The opportunity for a Plan to be varied without consultation with the participant. This does not demonstrate any of the principles of co-design.

The NMHCCF recommends that all participants must be consulted with prior to any changes to their Plan.

- The move of some elements of the Act into the Rules creates a situation of reduced transparency and accountability around application of the general principles of the NDIS. The right for choice and control appears to have been diminished by this proposed change.
- Need for clarity of some terms and information about their application to different disability groups.

- ‘Permanent disability’
- ‘Appropriate treatment’
- ‘Substantially reduced capacity’
- ‘Fluctuating conditions’
- ‘Managing a condition’
- Substantial improvement
- ‘Treatment’
- ‘All avenues explored’

The NMHCCF recommends clarity of these terms and use of language that is ‘Rights-based’.

- Changes have also been proposed regarding the way in which supports are paid, with the intention of making it easier for self-managing participants to make claims. The NMHCCF is concerned that the currently proposed amendment which states that payment is to be made ‘to the person determined by the CEO’, reduces choice and control, accountability and transparency in ensuring correct payments are made and provides uncertainty for self-managed participants around being able to continue their existing payment methods.

- The NMHCCF is concerned that there will continue to be a lack of ‘lived experience of disability;’ of NDIA Board members. While a criterion will now be included in Board selection regarding lived experience of disability, this ignores the fact the people with a disability are not a homogenous group and their needs are not represented by one or two people. Further, the lived experience of families/carers is also required to ensure that the Board has a truly representative view of the experience of participants and their families/carers.
- There is a need to ensure that all proposed changes are to the betterment of the NDIS for all people in the community. The needs of people from a Culturally and linguistically Diverse Background (CALD) and people from Aboriginal and Torres Strait Islander (ATSI) backgrounds are not clearly identified.

The NMHCCF would ask that the final version of the amended legislation be made publicly available prior to going to Parliament.

Appendix 1

Figure 1: Levels of lived experience engagement

Level of participation		Elements of this participation	What does it mean
1	Consumer- and carer-led	Consumers, carers and families set priorities, lead major activities and drive the organisation to meet its objectives	People doing it for themselves
2	Co-Production	Consumers, carers and families are equal partners in the design, implementation and evaluation. Equal influence over decisions	Doing it with people
3	Co-Design	Consumers, carers and families are partners in the policies and programs with significant influence over decisions	
4	Meaningful engagement	Consumers, carers and families engaged to influence policy and program direction but are not decision makers	Doing it for consumers and carers
5	Peripheral engagement	Consumers, carers and families are involved in policy development and projects but have limited ability to influence outcomes	
6	Consulting	Consumers, carers and families' views are sought but may have no influence over decisions	
7	Informing	Consumers, carers and families' views are not sought. There is one way communication about policies and programs	Doing to consumers and carers
8	Excluding	Consumers, carers and families are excluded services, systems or decisions	Excluding

Source: Adapted by the NMHCCF from the University Hospitals of Leicester NHS Trust, Patient and Public Involvement Strategy, June 2019,