



National Mental Health
Consumer & Carer Forum

Submission to the Joint Standing Committee on the National Disability Insurance Scheme

31 March 2021



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The National Mental Health Consumer and Carer Forum (NMHCCF) is pleased to provide this submission to the Joint Standing Committee on the National Disability Insurance Scheme.

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 Term of Reference (k) - the appropriateness of independent assessments for people with psychosocial disability and the associated links to other relevant terms of reference (including d, e, f and g).

This submission also captures the views of the broader mental health consumer and carer network through engagement of members of the National Register of Mental Health Consumer and Carer Representatives.

Information and evidence to support the consumer and carer perspective is provided for consideration by the Joint Standing Committee.

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

Handwritten signature of Keir Saltmarsh in black ink.

Keir Saltmarsh
Consumer Co-Chair

Handwritten signature of Hayley Solich in black ink.

Hayley Solich
Carer Co-Chair

NMHCCF submission to the Joint Standing Committee on the National Disability Insurance Scheme

Psychosocial disability and the NDIS

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 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 carers.

Psychosocial disability from a mental health condition can cause social isolation and economic marginalisation that can spiral into crisis, homelessness, poverty and risk of harm by exploitation. The result causes extreme hardship for mental health consumers and family, carers and friends, placing an unfair burden on some of society's most vulnerable members. This also places an economic burden on society through crisis intervention and health care supports that could be reduced if the appropriate support services were provided earlier.

The Australian community has become more aware of psychosocial disability from a mental health condition following the deinstitutionalisation of care for people with mental illness. The subsequent 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}

However, the proposed introduction of Independent Assessments as part of the NDIS could see these gains for people with psychosocial disability, and their families, carers and friends, lost in a short time. This is particularly the case for many of the individuals with psychosocial disability who have experienced trauma preceding but also following diagnosis.

The Independent Assessment model is not appropriate for people with psychosocial disability from a mental health condition and is likely to further re-traumatise individuals with psychosocial disability. In addition, the episodic nature of mental health and psychosocial disability needs to be understood to accurately assess a person's functional capacity. An allied health professional undertaking an assessment needs strong skills, knowledge and experience with psychosocial disability from a mental health condition. The standardised tools being proposed for use are not appropriate for people with psychosocial disability from

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

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

a mental health condition. There is also a need for the involvement of several support people, including family, health professionals and support workers who already have a relationship over time with the individual.

The case studies below are provided to demonstrate the inappropriateness of the proposed NDIS Independent Assessments for people with psychosocial disability from a mental health condition.

Case Study 1

Thirty years ago, my eldest brother, Peter, at age 21, previously having successfully completed a fitter and turner apprenticeship, and living a very happy life, was the victim of a “coward punch” unprovoked vicious assault, which caused not only an acquired brain injury, but also a slow deterioration in his mental state, resulting in him being on a disability support pension since that time.

Just one year later, my younger brother, Ben, at age 17, previously an A-grade high school student, suddenly became unwell and was diagnosed with schizophrenia, and he also has been on a disability support pension since that time. So, both high functioning, doing well and with lots of friends.

My family, having supported my brothers with virtually NO community support for almost 30 years, were very focussed on them becoming NDIS participants, particularly as the medical treatment model of mental illness was not helping, and in fact was leading to human rights breaches and worsening mental health. In April 2019, the lives of ALL of my family members changed – hopefully forever, and my brothers became participants in the NDIS, and received their initial NDIS plans.

Despite that our very LONG applications – Peter’s was 70 pages long - included recommendations by Occupational Therapists (OT) for 24 hour care, and there was agreement about this by our NDIA Planner, this did not happen until 12 months after their first Plans commenced, which started initially with 10 hours a day of support. The 24 hour support came about because our NDIA Planner somewhat understood psychosocial disability and allocated significant, specific funding for a Developmental Educator (DE) to further assess their support needs – basically this was similar to an independent assessment, although a major benefits was that she was recommended by someone we knew, who said she understood psychosocial disability. That assessment took a couple of months to complete, with the DE spending significant amounts of time with my 2 brothers, all of our family members and service providers and support workers involved in their care, in addition to taking into account the previous assessments and reports from the NDIS application.

Due to the difficulties navigating NDIS, many of the carers whom we know either do not even bother applying for the NDIS, and they continue supporting their adult children, which of course is not sustainable, or they apply for the NDIS but due to a lack of knowledge of their rights, they have sub-standard NDIS plans. The solution to many of these issues would be to fund case managers within plans, if not for all participants, then at least those with psychosocial disabilities and/or cognitive impairments, to understand and navigate the NDIS and the many ongoing interface issues that arise between the NDIS and state-based services such as Health, Mental Health, Education, Employment, and Justice.

There is widespread fear in the mental health sector that the introduction of IAs will exacerbate trauma and navigation issues even further, particularly as there is a significant lack of understanding of the actual needs of people with psychosocial disabilities – both in the community – and also by service providers.

Case Study 2

I am worried. I don't know how people will measure my impairment, my psychosocial disability with the independent assessments model.

I have a florid 'brittle' bipolar illness. Prior to the advent of the NDIS, I found myself homeless, fired from a job, in a violent relationship, and some financial difficulty. I spent all my days sitting in a day program run by a service provider in my area. I was admitted to a mental health unit every 12 to 18 months and would spend three months at a time in the hospital.

The NDIS changed my life. It wasn't medication, and it wasn't a change of circumstance. It was the supports that have made the difference. Now I have a home, I have started working, my social life has settled, and I pay the bills. I have only been in hospital once since going on to the NDIS. This is the longest time I have been out of hospital for decades.

I receive supports funded by the NDIS to help me do these things. I get help with the housework, with financial matters, to get out, cooking, and doing my work. They have enabled me to go back and have an 'ordinary' life, really, nothing more, nothing less.

My question, then, is 'how will independent assessors decide what my impairment is and how much support I will need?'. I imagine to the outside world I am living a relatively 'standard' kind of life these days, and screening by someone who doesn't know me might think I don't have an obvious impairment.

I live that life, though, because I have the support that allows me to do this. My capacity has increased over the years, but I also know that tasks others find simple I need assistance with.

That support has changed my life dramatically. I don't want to lose it because someone cannot measure it or does an assessment that does not understand the dramatic change in circumstances I have been in through.

Case Study 3

My daughter Shana is bright, friendly, creative and articulate. She developed paranoia and self-harm towards end of primary school with no evident cause. Her resultant behaviours drastically affected school, friendships, life at home and her health and safety. In early high school Shana was diagnosed with major depression and the medications tried resulted in suicidality.

Eventually she developed psychosis and medications resulted in lactation, massive life-threatening weight gain and severe tremors. By grade 9 Shana completely refused school and completely withdrew, trusting no one except family when not psychotic. Over the

following years as she experienced constant cycles of psychosis between periods of depression, self-harm and lived in a state of constant disorganisation, chaos and reactivity. Eventually in young adulthood Shana was diagnosed with Bipolar and BPD.

When Partners in Recovery started, one of the workers over several years eventually gained her trust, resulting in supporting Shana as a young adult to finish her year 10 certificate at the local TAFE, learn to drive, attend TAFE courses, some volunteering and take more personal control for her recovery.

The NDIS supports the past couple years are assisting Shana to finally live independently in public housing, stay out of hospital and required less support from our family so we can just be family with her.

The psychosocial disabilities she has from mental illness still affect her functional abilities for practical daily living, she is still very much a socially isolated and her coping fluctuates from day to day, however Shana will never admit to anyone that she needs much help, as she thinks she is only unwell when in hospital and blames her lack of coping and daily disorganisation on her poor sleep or stress and so much wants to be considered a normal adult.

It is not choice and control for her as a NDIS participant, to have it legislated that a total stranger as an independent assessor with a standard assessment product will provide appropriate and necessary supports with no appeal processes, instead of using the clinicians reports that know her episodic fluctuations.

To limit her to only have one person with her limits her choice and control. It is not 'fair' to enforce a participant to only have one person such as either a paid worker or family/ friend. When she initially applied, she chose to have both attend, when her plan was reviewed, she also chose to have both attend. Shana will only ever say she is managing great and doing well whenever asked any questions.

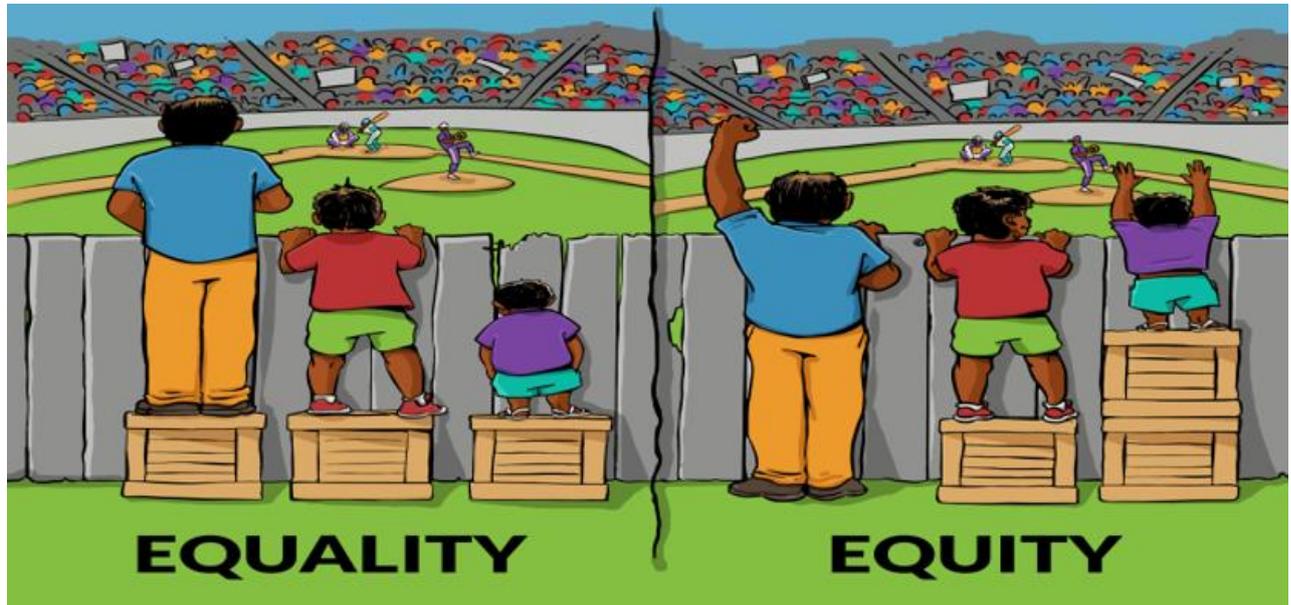
For our family and as her aging parent and as a tax payer, it is utterly disheartening to think the NDIS would so substantially change its values and ethics, removing participant empowerment, choice and control from the very processes that will ensure appropriate lifelong supports for a contributing life.

These case studies demonstrate the importance of choice and control, a recovery-orientation, life-long support and the successes that can be achieved through a well-functioning NDIS. The case studies also demonstrate that saying no to supports, a lack of insight and thus falling through gaps is common but quite unique to psychosocial disability, compared to other disabilities.

We do not agree that Independent Assessments are the way for the NDIS, and the community, to achieve overall fairness and equity. The issue of equity within the NDIS has been raised as a problem to be solved through the introduction of the Independent Assessments.

If equity in both access and plans is an issue, then the NDIA needs to improve its internal systems and not develop a 'solution' which is being forced on people with disabilities. The Independent Assessments model appears to be an uninformed attempt to conflate standardisation of tools and processes with equity of outcome to address the inequitable result of their current approaches.

Equity doesn't mean everyone gets the same thing in the same way, as demonstrated in the image below.



Source: Craig Froehle, 2012, [The Birth, Weird Life, and Afterlife of an Internet Meme | WIRED](#)

This image is particularly apt for psychosocial disability as it highlights the needs for the different, non-standard approaches that are needed from the NDIS when the NDIS keeps trying to have a uniform approach to all disabilities. A uniform approach is 'equality' not 'equity'!

There are several other concerns that people with a psychosocial disability from a mental health condition, and their families and carers, have identified with the Independent Assessments model:

- The Independent Assessors are not actually independent, other than for the person being assessed, as they are not independent of the agency, having been contracted by the NDIA.
- Independent Assessors do not even address the first step in determining eligibility – that is, an assessment to evidence a diagnosis of a disability. Individuals will still need to fund these assessments themselves, which does not support the notion of equity.
- Other concerns are the removal of the access lists, the lack of clarity on who may be exempt from Independent Assessments and what the alternative pathway will be, the lack of culturally valid assessments in the toolkit, the lack of time available for assessors to build trust with participants and their families, and the focus on avoiding sympathetic bias rather than a focus of therapeutic alliance, which is the most efficacious aspect of

any evidence-based engagement.

- The proposal only allows for one support person to be present for the assessment. This does not allow choice or control for individuals, or their families and carers.. Further, it is unclear who will fund support workers or existing therapists to attend independent assessments with prospective participants and there is no appeals process for the Independent Assessments.
- The application of standardised assessment tools does not acknowledge the complexity of psychosocial disability nor its episodic nature. Further, standardised tools do not allow for a recovery-oriented approach to assessment or planning.
- The application of the WHODAS as an assessment tool is not appropriate for use with people with psychosocial disability. The WHODAS will not address the social, relational and citizenship unmet needs of people, nor the structural disadvantages they face.
- While we are pleased that the proposed Independent Assessments will be free and will provide more consistency in decision making than that provided by the National Access Team, the process does not address other barriers that exist, such as language, culture, homelessness and rural locations, for people with psychosocial disability.

What is required to support people with psychosocial disability and Independent Assessments?

For people with psychosocial disability to have choice, control and life-long support through the NDIS mental health consumers and carers propose that:

- The NDIA provide funding for appropriate access and assessments to be undertaken by an allied health professional known to the individual
- Assessment tools for use with people with psychosocial disability be co-designed with consumers and carers
- More than one support person be involved with any initial or re-assessment process
- Instead of requiring a re-assessment for each new plan, the NDIA should accept the reports of the current providers
- NDIA should ensure the upskilling of their planners and reviewers including from consumers and carers with lived experience of psychosocial disability from mental health conditions
- Assessors need to understand psychosocial disability from a mental health condition when this is a primary or secondary diagnosis
- Strategies to overcome lack of insight are essential. Such strategies include spending time with the participant and their family to build trust
- The need for 'nothing about us without us' and thus the need for co-design with consumers and carers from the beginning to the end of NDIS processes, including the drafting of legislation
- The need for additional free assessments evidencing the presence of a permanent or likely to be permanent disability, particularly for participants who have not accessed disability supports in the past

- The need for the appointment of a case manager (similar to what occurred in Partners in Recovery) to oversee all assessments, including the independent assessments, ensure all relevant stakeholders are involved, and to assist with navigation of the scheme. This is particularly the case when a participant is vulnerable, has not accessed disability support in the past, has no informal supports, or they are being supported by ageing carers.

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