



**National Mental Health
Consumer & Carer Forum**

CAPABILITY AND CULTURE OF THE NDIA

**SUBMISSION
OCTOBER 2022**

Overview

Who are we?

The National Mental Health Consumer and Carer Forum (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 then Australian Health Ministers' Advisory Council and, until the COAG Health Council was disbanded, reported to Australian Health Ministers through the Mental Health Principal Committee.

Funding for staffing and project work is provided by the Australian Government and state and territory governments.

NMHCCF members represent mental health consumers and carers on several national bodies, including 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.

The NMHCCF has 28 members of which 14 are mental health consumers and 14 are mental health carers. These members comprise: one consumer and one carer representative nominated by each state and territory; and consumer and carer representatives from each of the following national projects/organisations:

- blueVoices, the consumer and carer reference group for Beyond Blue
- Carers Australia
- Consumers Health Forum of Australia
- Grow Australia
- Mental Health Carers Australia
- Lived Experience Australia
- Embrace Culturally and Linguistically Diverse (CALD) Mental Health Consumer and Carer Group

The NMHCCF is the Disability Registered Organisation (DRO) representing psychosocial disability.

Purpose

The Joint Standing Committee on the National Disability Insurance Scheme (NDIS) is conducting a number of inquiries into specific aspects of the Scheme. This submission is in response to the inquiry into the capability and culture of the National Disability Insurance Agency (NDIA). The Terms of Reference for the inquiry stipulate that it examine:

- a) the capability and culture of the National Disability Insurance Agency (NDIA), with reference to operational processes and procedures, and nature of staff employment
- b) the impacts of NDIA capability and culture on the experiences of people with disability and NDIS participants trying to access information, support and services from the Agency; and
- c) any other relevant matters.

The purpose of this submission is to outline issues regarding the capability and culture of the NDIA from the perspective of people living with psychosocial disability, their families, carers and supporters. Thank you for the opportunity to contribute to this important inquiry.

Definitions

The NMHCCF notes that language preferences are not consistent across the mental health or psychosocial disability sector. For the purposes of this submission, commonly used terminology is defined below and we acknowledge that some people may assign different meanings to some of these terms.

Carer: A person with a lived experience of caring for someone with a mental illness or mental health condition.

Consumer: A person with a lived experience of mental illness or mental health condition.

Distress: A feeling of extreme worry, anxiety, sadness or emotional pain.

Family: May refer to a person's family of origin or of choice.

Lived experience: A depiction of a person's experiences and decisions, as well as the knowledge gained from these experiences and choices. Commonly referred to as 'lived or living experience' to capture the ongoing experiences impacting some people.

Moral injury: Moral injury is understood to be the strong cognitive and emotional response that can occur following events that violate a person's moral or ethical code.¹

Participants: Those who have been accepted into the NDIS in receipt of a funding package.

Psychosocial disability: A person's disability experience, impairments and participation restrictions related to mental health conditions.²

¹ The Lancet Psychiatry. Moral injury: the effect on mental health and implications for treatment. [https://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366\(21\)00113-9/fulltext](https://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366(21)00113-9/fulltext)

² NMHCCF. Unravelling Psychosocial Disability <https://nmhccf.org.au/our-work/position-statements/psychosocial-disability-associated-with-mental-health-conditions>

Trauma: A high state of arousal in response to an event or events in which a person feels threatened or feels threatened. May be situational or have an ongoing impact.³

Workforce: The paid workforce employed by the NDIA and those providing psychosocial disability support services.

Issues

Psychosocial Disability Recovery-Oriented Framework

The NMHCCF welcomes the development of the [NDIS Psychosocial Disability Recovery-Oriented Framework](#) (the Framework) and looks forward to working with the agency on its implementation.

While the intent of the Framework is to improve the experience of participants living with psychosocial disability, it does not specifically address many of the issues associated with the NDIA's capability and culture. This submission will highlight outstanding issues impacting people living with psychosocial disability and those who care for them interacting with the agency.

Psychosocial disability expertise

Many people living with primary psychosocial disability report that the NDIA and broader community lack an understanding of their needs. This is particularly pronounced for populations with additional contextual needs such as the LGBTIQ+ community, those from culturally and linguistically diverse communities, rural and remote areas and people who experience co-occurring disability or chronic illness. The Agency needs to be conceptually and culturally competent to understand and therefore deliver on the needs of those living with primary psychosocial disability.

The psychosocial disability expertise of families and carers is also not well recognised with poor understanding of the relational, social and family context in which someone lives. There is currently no structural integration for families within the Scheme and accordingly valuable expertise and input is missing. The impact on families and carers is also not captured within the Scheme.

Opportunities:

That people living with a primary experience of psychosocial disability can access:

- planners who have lived experience expertise of psychosocial disability.
- someone with a lived experience of psychosocial disability and/or peer worker to support them through the access and/or planning processes if desired.

³ Blue Knot Foundation. What is trauma? <https://blueknot.org.au/>

That the NDIA:

- ensures that the Psychosocial Disability Expert Advisors proposed under the Framework include people with lived experience of primary psychosocial disability and those who have experience supporting them.
- upskills its workforce on the issues affecting people living with psychosocial disability from a lived experience perspective including onboarding and current training for all staff.
- explore ways for those with a lived experience of primary psychosocial disability to provide direct feedback to support ongoing training and supervision.
- actively works with the NMHCCF as the Disability Registered Organisation for psychosocial disability work to implement the national [Lived Experience Workforce Development Guidelines](#) to expand its lived experience workforce.

Participant expertise

Issues associated with stigma, discrimination and a poor understanding of human rights frameworks permeate many social care settings and overarching entities. Across all the major scheme reviews to date, the satisfaction of people with a psychosocial disability has been the lowest of all disability groups. People living with psychosocial disability, their families and carers report feeling disrespected, as though assessors and planners do not trust them when they express support preferences.

Participants have shared a sense that staff act from a place of dismissal rather than curiosity. Many Participants report that the carefully curated documentation they collate at the request of the Agency, often at significant financial cost and administrative burden, is too often ignored and not read. Similarly, the lack of plan flexibility is a demonstration of the Agency's unwillingness to enable Participants to organise their support in the way that best meets their needs. The often arbitrary and restrictive nature of the categories used by the NDIA when allocating funds for support workers (that must already be in line with the Participant's stated goals) limits the capability of planners to cater for the individual in a holistic context and forces people to divide their lives into contrived categories and inflexible silos.

For example, access to funding to support housing, crisis avoidance or post-discharge support are core components that should be covered by the Scheme and could make a meaningful contribution to a person's recovery and social integration. This has a significant impact on NDIA's understanding of the experience of Participants and can result in inadequate packages and support services. This is a direct result of the Agency's current lack of capability to respond to Participant's needs and preferences.

People living with psychosocial disability report the emphasis on 'self-management' as a marker for capacity building as misplaced. Participants should be empowered to select self-management if it is their preference with the understanding that it is that – a preference rather than a reflection of their capacity. Self-management by a family member or carer is inaccurately labelled and while this can work well for some participants, the wording should be altered to better reflect the circumstances.

These issues are exacerbated by very few people working within the Agency experiencing psychosocial disability, as noted above.

Opportunity:

That the NDIA:

- introduce new terminology for family / carer plan management to more accurately reflect this arrangement.
- upskills its workforce on how to facilitate and promote supported decision-making.
- upskills its workforce on the intersection between human rights and psychosocial disability, for example the [World Health Organisation Quality Rights training](#).
- introduce a mechanism for Participants to review and discuss Plans before sign-off to minimise unnecessary distress of reviews and appeals and facilitate a two-way dialogue between the Agency and the Participant.
- incorporate the upholding of human rights into its accountability framework.

Psychosocial disability lived experience leadership

While the NMHCCF celebrates the recent appointment of NDIA Board members with a lived experience of disability, there is a lack of primary psychosocial disability lived experience leadership across the organisation at Board, executive and senior management level. This directly impacts the organisation's capacity to understand the support needs of people living with psychosocial disability and to create processes relevant to this population.

Opportunity:

That the NDIA:

- identify any current barriers to appointing people with lived experience of primary psychosocial disability to leadership positions.
- actively recruits people living with primary psychosocial disability to designated leadership positions.
- actively promotes expansion of the lived experience workforce in accordance with the National Lived Experience Workforce Guidelines.

Bureaucratisation of processes

Many people interacting with the NDIA report processes which are overly bureaucratic and complex to understand. There is little transparency as to how decisions are made with inconsistencies across the agency. Participants and those supporting them experience significant burden and cost collating information and the impact of being found ineligible or having funding cut results in distress, despair, exhaustion, guilt and shame. Many people find such interactions are in fact more 'disabling' and exacerbate the very conditions that have led them to apply for the NDIS.

The importance and value of one-to-one respectful relationships is paramount but not currently acknowledged or addressed by the agency. Similarly, there are no current mechanisms to support individual communication preferences. For example a Participant expressed that they did not wish to receive decisions about their plan around key holiday periods. This request which was ignored twice and resulted in significant distress.

Opportunity:

That the NDIA:

- adopt a more person-centred approach that prioritises people's individual communication preferences and continuity of contact.

Distress and trauma

As indicated above, the agency's current mode of operation can cause people living with psychosocial disability and those who support them significant distress and trauma. Central to this is the reality that the scheme is not yet recovery focused with participants forced to speak the language of impairment rather than highlight their own strengths. This results in moral injury whereby the participant can experience distress so severely that their 'impairments' are made worse.

Planning meetings in particular have been triggering for many participants as the current format of interrogating functionality results in a fear of losing crucial support. Many people living with primary psychosocial disability report that such interactions are reminiscent of difficulties with obtaining the Disability Support Pension, and they report that they are left feeling as though they are undeserving of such support.

Chronic under recognition of loved ones providing unpaid support, coupled with a chronic underinvestment in carer support services, is exploitative of families with the default expectation that they will be able to meet support needs not met by professional support services. While Carer Statements can be useful articulations of the participant's support needs and existing support gaps currently plugged by families, it can also negatively impact family relationships and cause undue distress through quantifying the level of support provided.

Opportunity:

That the NDIA:

- explore opportunities to authentically develop trauma competencies, such as the establishment of an Memorandum of Understanding with the Blue Knot Foundation.

Limited feedback mechanisms

Currently, there are few mechanisms for people living with psychosocial disability to provide feedback to enhance the scheme. This results in a lack of individual and systemic accountability across the operation of the agency. Many people have reported that the existing feedback channel of ['Participant First'](#) inadequate to address the needs of people with a psychosocial disability. This impacts the ability for the NDIA to directly address issues affecting those living with primary psychosocial disability.

Similarly, the Mental Health Sector Reference Group has very low representation of those living with primary psychosocial disability as participants of the scheme and those who love and support them. There is currently one person out of approximately 20 members of the Mental Health Sector Reference Group with primary psychosocial disability who is a participant in the scheme, and one family member of a participant with primary psychosocial disability.

The NMHCCF welcomes the numerous processes underway to enhance the operation of the scheme, but has witnessed some processes labelled as co-design which are in fact consultation. This speaks to the current culture of the agency to override the expertise of those it exists to serve, as noted above. Facilitating more opportunities for genuine co-design with people living with psychosocial disability would enhance the operation of the agency for this population. Where genuine codesign is not considered possible by the Agency, this should be plainly stated.

Opportunities:

That the NDIA:

- establish alternative feedback mechanisms to capture the issues experienced by people living with primary psychosocial disability, their families and carers.
- upskill its workforce on the principles of co-design to incorporate the expertise of people living with psychosocial disability in the operation of the scheme.

Psychosocial disability support engagement

People living with primary psychosocial disability reporting the best outcomes accessing the NDIS have significant support from a psychosocial disability provider. While we acknowledge that family members and carers also provide crucial support to access the scheme, it is our position that this role should be performed by psychosocial support services to alleviate undue stress on already-stressed families⁴ and achieve the best outcomes for participants. Unfortunately, facilitated support does yet not occur in the majority of cases.

Currently people found to be ineligible for the NDIS are not actively referred to psychosocial disability support services. While it could be argued that doing so would be acting outside of the scope of the NDIA, creating a person-centered agency that is part of the fabric of our society means referring to other agencies and services that can offer support.

Opportunities:

That the NDIA:

- provide people living with a psychosocial disability who are deemed ineligible for the NDIS with a warm referral to a suitable psychosocial disability support provider.
- support calls for expansion of the psychosocial disability support sector to ensure there are adequate services for those deemed ineligible for the Scheme.
- support calls for expansion of the psychosocial disability support sector to ensure there are appropriate services for participants in the Scheme to address current under utilisation of packages.

⁴ [Ellenor Mittendorfer-Rutz](https://academic.oup.com/schizophreniabulletin/article/45/4/794/5090132) et al, *Schizophrenia Bulletin*, Volume 45, Issue 4, July 2019, Pages 794–803
<https://academic.oup.com/schizophreniabulletin/article/45/4/794/5090132>