



Consumers of Mental Health WA (Inc)

Submission to Department of Social Services

Improving the NDIS Experience: Review of the National Disability Insurance Scheme (NDIS) Act and Participant Service Guarantee

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Consumers of Mental Health WA

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INTRODUCTION

CoMHWA is Western Australia's independent mental health consumer peak organisation in Western Australia. Led by and for people with lived experience of mental health issues, CoMHWA works to strengthen and advance the voice, leadership and expertise of people with lived experience.

Consumers of Mental Health WA (CoMHWA) welcomes the opportunity to make a submission on the needs and experiences of people with psychosocial disability in Western Australia in engaging with the National Disability Insurance Scheme (NDIS).

CONSULTATIVE SOURCES USED

This submission and resultant recommendations are based on ongoing feedback to CoMHWA by people with lived experience, their families and carers, providers and other sector stakeholders. Our submission was further supported through undertaking a focus group to gain further feedback on NDIS experiences and views on the participant guarantee.

PSYCHOSOCIAL DISABILITY & THE NDIS

Psychosocial Disability (PSD) is a term used by the NDIS to describe disabilities that may arise, as a result of mental health issues, but the term 'lived experience' is more often used and preferred by our members to describe their experience of mental health issues. Wherever possible, CoMHWA uses the term 'people with lived experience' in the submission, rather than psychosocial disability, to refer to people engaging, or who could engage, with the NDIS because of a need for support with mental health issues.

UNIQUE NEEDS OF PEOPLE WITH PSYCHOSOCIAL DISABILITY

There have been significant challenges in the design of the NDIS and NDIS processes to meet the unique needs and circumstances of people with lived experience. The 2011 Productivity Commission did not include mental health in early design of a disability insurance scheme, and many of the fundamental design features of the scheme were developed without reference to the unique needs of this population.¹

People with lived experience are among the most disadvantaged people in our community. They experience challenges with communication and social inclusion, finding suitable housing and employment and maintaining their physical health².

There is a need for unique engagement and support approaches for people with lived experience in the NDIS and many of these core features needed to support equal access and benefit from the NDIS were not adopted in the NDIA psychosocial pathway. This impacts on equity of access to the NDIS and positive experiences of the NDIS and the psychosocial pathway should be substantially enhanced to provide for adequate support for engagement and

¹ Mental Health Australia National Disability Insurance Scheme: Psychosocial Disability Pathway May 2018

² National Mental Health Consumer & Carer Forum (2011). Unravelling Psychosocial Disability, A Position Statement by the National Mental Health Consumer & Carer Forum on Psychosocial Disability Associated with Mental Health Conditions. Canberra: NMHCCF

assistance. People with lived experience need greater assistance to engage with the NDIS and improved NDIS processes that are lower threshold.

Unique and ongoing challenges that remain inadequately addressed by the NDIS include:

Language: The term psychosocial disability has negative connotations for many of our members who prefer to use alternative terms to describe themselves, such as 'person with a lived experience'.

Recovery: The NDIA does not include a Recovery standard for services providing support to people with lived experience, and yet this has been a core requirement for provision of safe, quality supports within the mental health sector for more than ten years. At the core of recovery is the person's capacity to reclaim their experience and identity away from the low expectations many people have had for their lives, and the requirements to agree mental illness is a permanent or enduring condition is also perceived by many as a "hopeless case" verdict on their lives that can deter application to the NDIS. It may also adversely impact the self-esteem and hope of those who do accept this requirement to gain access to the NDIS.

Thresholds for Engagement: The term 'threshold' can be used to describe how easy ('low threshold') or difficult ('high threshold') services are to access and engage with. People with multiple unmet needs and issues, and those with psychological, social, cognitive or emotional barriers to interacting with services, need low threshold service approaches. Services that have a high threshold lead to non-engagement, or disengagement, of people because they find the process too hard to access or too difficult. Low threshold service approaches include, but are not limited to:

- no user cost to apply
- choice in ways to access (e.g. face to face, phone, in-home, office visit),
- flexible time frames and processes to address individual circumstances
- easy to understand information, forms and processes
- rights and choices are explained
- the person is recognised as the expert in their life and their views about their needs are taken into consideration in decisions about whether they can access support, in addition to any other sources (referrers) may be used to assess need for service
- clarity and transparency (processes are reasonable and are followed as agreed)
- advice and practical assistance with the process
- emotional safety, cultural safety and trauma-informed care, guided by a skilled relational approach focused on the value of the person, willingness to support, continuity of support, in contrast to an agency-focused approach driven by rules, procedures and obligations the person needs to comply with

The NDIS application process is currently high threshold and is a barrier for many people to access, including people with lived experience, as discussed below.

One of our focus group participants described having to apply three times before being accepted.

"I submitted evidence on two occasions and I was rejected – I finally had support to ask why" – I found out that it was the way the letter from my GP was worded"

We also received an anonymous case study of an individual, who had no assistance to apply, waiting 10 months for access. This individual:

- Waited over 3 months for outcome and then advised by the NDIA on calling them that the evidence provided had gone to an official email address that had since changed, and they had therefore not received evidence and could not assess the application.
- Application and parts of the application got lost in the system 5-6 times, multiple phone calls were made to follow up. Had to return to General Practitioner due to missed signatures.
- Then found out the application was approved accidentally, when asked for their experience of the NDIS.

A less determined individual would have given up much earlier in the process.

The Critical Need for Low Threshold Approaches for People with Lived Experience:

Some of the reasons low thresholds are important to access and experiences of the NDIS for people with lived experience include:

- Higher rates of homelessness, unemployment, exposure to family and domestic violence
- Barriers to engagement related to mental health, which differ between individuals with lived experience but can include difficulties with memory, planning, problem-solving, communication, self-advocacy, and need for supports such as transport, support persons and practical assistance such as with forms and appointments
- Many individuals lack family members or carers to act as support persons and assist in engagement, with only an estimated 1 in 5 individuals having carers under the former Commonwealth mental health programs;
- Low exposure and awareness of the NDIS, disability sector and individualised funding approaches
- Ongoing issues with lack of mandatory NDIA staff training in mental health to support emotionally safe interactions
- Service related barriers to proving eligibility, such as lack of an ongoing care history due to fragmented care, lack of access to allied health care to demonstrate functional impacts, and lack of knowledge and resourcing for health professionals to support applications;
- Mistrust of agencies is more common due to past negative experiences, such as due to trauma associated with involuntary care, guardianship and administration orders, or loss of access to disability support pensions under Centrelink review processes
- Greater risk of disengagement from processes that are stressful (e.g. difficult or hard to understand), due to already high levels of psychological and emotional distress
- Stress associated with NDIS applications is exacerbated by the high impact of what is decided, as people who are not accepted into the NDIS are not being adequately supported.

RECOMMENDATIONS FOR IMPROVING NDIS PARTICIPANT EXPERIENCE

1. Establishment of a Strengthened NDIS Psychosocial Pathway that includes:

1.1 Investment in dedicated independent NDIS Transition Support Programs, particularly in Western Australia, to provide a clear and low threshold access pathway into the NDIS

Dedicated NDIS transition support programs are critical to supporting NDIS application and entry by individuals who do not have existing services to support the process, particularly in Western Australia where WA has the lowest proportion of people with primary psychosocial disability accessing the NDIS (6.5% compared to 9.6% average, and 1,411 participants compared to 6,800 WA full scheme target). The aim of dedicated NDIS transition support programs is to provide independent supports to understand, apply, gather evidence, prepare for planning, plan and select plan supports.

1.2 Mandatory Mental Health Training for NDIA Staff

Training should be based on a recovery-oriented approach with lived experience leadership in design and delivery of training.

1.3 Lower the Threshold for Access and Engagement with the NDIS

- Increase flexibility of time frames to return NDIS evidence, from the current 28 days to at least 4 months
- Ensure individuals notified they are ineligible have access to support to find alternative supports in their community
- Adopt an Application Progress Notification System to allow applicants to track progress and internal check points (time limits by which the individual is updated by the NDIA on their applications, in addition to time frame guarantees on outcomes)
- Ensure individuals are provided with clear information on why they were ineligible and how to re-apply, as well as how to appeal, for the NDIS
- Reduce discontinuity in NDIS interactions through provision of:
 - Access to pathways for participants to escalate matters locally and in person, when they are having difficulties with the national call centre
 - Provision of a dedicated team or staff member for the person to contact in relation to applications. Currently there is feedback that applications move across departments in the NDIA and get lost in the system creating extensive delays.
- Develop specialist strategies to assist and support young people with mental health and homelessness, through dedicated youth NDIS transition support programs, ease of access of young NDIS participants to youth friendly NDIS providers, and mature minor recognition and assessment for young people who do not have parental guardians.

2. Greater investment in Psychosocial supports for People Ineligible for the NDIS

It is estimated only 25% of people being supported through Commonwealth psychosocial programs have transitioned to the NDIS in Western Australia. However, Transition Support funding is only committed for the 19/20 Financial Year. Individuals who were not Commonwealth program participants on or before 1 July 2019 do not have continuity of

support arrangements and need assistance to access alternative supports. There are an estimated 79,991 individuals affected by severe mental illness in any year in Western Australia. CoMHWAs estimates a current Commonwealth investment of under \$65 per annum per person for psychosocial supports for those not eligible for the NDIS, which constitutes a major problem for the safety, welfare and life prospects for individuals not assisted by the NDIS.

3. Establish a Public National Mental Health Strategy for the NDIS

The NDIS should clarify its vision, principles and objectives for assisting people with lived experience through publishing a mental health strategy, to guide and drive reforms and improvements to the NDIS including the psychosocial pathway.

4. Ensure Safety and Financial Equity are Included in the Participant Service Guarantee

Participants of our focus group were overall supportive of the principles outlined by the service guarantee. Two key principles were missing and it is recommended these are included:

4.1 Financial Equity: *The NDIA is free for all people regardless of their income level. It is free to access and be assessed for the NDIS.*

Currently individuals can be reliant on private purchase of assessor activities (to complete functional assessments to prove disability to the NDIS). This excludes NDIS access for people on low incomes and the NDIS should bear the costs of disability assessments for those seeking to apply, as has been the usual case in public provision of disability services. An individual in our focus group shared: *“I would happily take a loan to pay a professional to gather the evidence I need, if I knew I would be reimbursed after I access the Scheme” - “I can’t afford it now” ...*

4.2 Safety: *The safety, dignity and wellbeing of people with disabilities are at the forefront of NDIA interactions, procedures, processes and decisions.*

The NDIA has no clearly available policy information or guidance on the matter of how the NDIA identifies, manages and works to prevent the human risks of NDIA processes and decisions, despite the major impact that lack of supports can have on people’s lives. Risk management should be occurring on an individual level with respect to safeguarding level and in the design of policies and processes in partnership with people with disabilities and the sector.

NDIA decisions have clear impacts on people’s lives. As one participant in our focus group shared:

“I received a rejection letter – I was so distressed. I lost hope and went into a spiral – I don’t think I want to try again” ... “what happens now”?

There is a particular need for clear policy from the NDIA on:

- processes in place at an individual and agency level to prevent and manage emergency welfare situations (e.g. sudden homelessness), critical and notifiable incidents arising from NDIA processes
- procedures and clear contact information for individuals, informal supports and providers to communicate, seek help and work together to resolve serious and imminent risk to participants, such as suicide risk and emergency welfare situations

CoMHWAs have had multiple anecdotal reports of suicides and suicide attempts associated with NDIA decisions and procedures, including (i) rejection decisions with no access to alternative supports (ii) urgent changes in circumstances such as crisis not reflected in plan hours and that are not addressed by the NDIA within emergency time frames (iii) suicide risks being unaddressed by providers, due to inconsistent information being provided to providers about what to do in emergency situations and lack of awareness by support staff of how to manage emergency situations associated with shortages, or lack, of funded supports for individuals. This is a clear major issue that the NDIA will need to resolve, given that providers are expected to meet safety and quality safeguards with no similar clear obligations on the part of the NDIA, which similarly interfaces with individuals and makes significant decisions in their lives.