

CoMHWA



Consumers of Mental Health WA (Inc)

Feedback to:

National Disability Insurance Agency (NDIA)

PO Box 6100 Parliament House, Canberra ACT 260022

RESPONSE TO: Consultation paper: Access and Eligibility Policy with independent assessments

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Consumers of Mental Health WA

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1. Preliminaries

About the Respondents

Consumers of Mental Health WA (CoMHWA) is Western Australia's peak body for and by mental health consumers (people with a past or present lived experience of mental health issues, psychological or emotional distress). We strengthen and advance the voice, leadership and expertise of people with lived experience of mental health issues. We work collaboratively with other user-led organisations and a diversity of stakeholders to advance our rights, equality, recovery and wellbeing.

Language

CoMHWA uses the term 'mental health consumer' throughout this submission. Mental health consumers to refer to people who identify as having a past or present lived experience of psychological or emotional distress, irrespective of whether they have received a diagnosis of mental illness or accessed services. Other ways people may choose to describe themselves include "peer", "survivor", "person with a lived experience" and "expert by experience".

This definition is based on consumers' call for respect, dignity and choice in how we choose to individually identify.

2. Introduction

Impairments resulting from mental health conditions can be difficult to recognise and are less apparent than those who live with physical or intellectual disability. Systemic and cultural stigma in Australia has meant that many people with mental health conditions may try to manage or ignore any impairments. This can often exacerbate issues and cause the need for support for people with psychosocial disability to be overlooked¹.

CoMHWA and the consumer community regularly hear and acknowledge the life-changing ability of NDIS funding for individuals who live with permanent physical and psychosocial disabilities. While the psychosocial disability community is grateful, there are still many systemic barriers that impact access to the NDIS. News of the introduction of Independent Assessments coming in 2021 has caused concerns among current NDIS participants who live with permanent psychosocial disability and has also caused concern for those who are exploring their suitability for the scheme.

As the peak body for people with psychosocial disabilities in WA, we have received a vast array of feedback regarding how the Independent Assessments will work in ensuring NDIS psychosocial participants receive fair access to the scheme. The psychosocial disability community has a long and complex history of overcoming the systemic barriers that exist with engagement and access to general support, and access to the NDIS. The implementation of the recommendations listed below, and the recommendations of other mental health consumer organisations and alliances is seen as pertinent to the success of Independent Assessments, and the mental health and well-being of society's most vulnerable individuals.

As the peak body for consumers in Western Australia, it is paramount that the concerns of the community are communicated clearly. Below are concerns and recommendations from our members and the wider mental health consumer community regarding the introduction of NDIS Independent Assessments. People with psychosocial disabilities are amongst some of the most marginalised in the Australian community and many live with poverty, discrimination and social isolation as a normal part of their lives². There exists an opportunity to change this through the appropriate systemic recognition of psychosocial disability through the NDIA, and make positive future outcomes to benefit the disability community.

¹ https://nmhccf.org.au/sites/default/files/docs/nmhccf_psychosocial_disability_booklet_web_version_27oct11.pdf

² https://nmhccf.org.au/sites/default/files/docs/nmhccf_psychosocial_disability_booklet_web_version_27oct11.pdf

3. Consultation questions

Section 1: Learning about the NDIS

1. What will people who apply for the NDIS need to know about the independent assessments process? How this information is best provided?

As people with psychosocial disability applying to the NDIS often have had no prior contact with the NDIS, Mental Health Peer Support Workers can guide that engagement with individuals and their entry to the NDIS.

Mental health consumer, and participant of the NDIS Psychosocial stream stated, “Communicating big changes, like the Independent Assessments, to people who are already on the NDIS need to be done by explaining it to them in laymen’s terms, and asking, ‘are you capable of participating in an independent assessment?’ and if they are not capable, finding a different way. Some people will be capable of completing an assessment, and other people will not be capable.”

Based on the feedback received from the mental health consumer community, participants need to have their rights clearly communicated, in easy-to-understand language, through their preferred channel of communication.

Online access is problematic for many people with psychosocial disabilities, “It is very hard for me to access the NDIS online information because I am still learning to use a computer, so having the NDIS more accessible through printed paperwork would save me a lot of trouble and confusion.”

Consumer feedback indicates that participants will need to be informed *proactively* about all rights they have through this process, particularly as exercising those rights will lead to better outcomes. For example, having a support person will aid in comprehending questions, or communicating answers. They will need to know about the assessment tools being used and what to expect from the assessment tools.

Boosting proactive engagement with people looking to access the NDIS for psychosocial supports through organisations such as CoMHW, there are more opportunities to mould the NDIS into a fit-for-purpose scheme for those who need it.

Section 2: Accessing the NDIS

2. What should we consider in removing the access lists?

In removing the access lists, it would be safe to assume there is going to be heavier reliance on the Applied Principles and Tables of Supports document, as well as the future finalised version of the 'NDIA Plan for psychosocial disability'. The NDIS needs to carefully consider, uphold and be led by the feedback and consultation from a diverse range of consumers.

The framework should be robustly designed given the wide array and complexities of conditions experienced by people with psychosocial conditions. This will require the NDIS to consult with mental health consumers and psychosocial stream participants in a productive manner, ensuring the consultation is as comprehensive as possible, and all feedback is considered.

In removing the access lists, the NDIS also needs to ensure access decision-makers understand psychosocial disability and mental health.

People applying to the NDIS for psychosocial recovery support will need the support of the NDIS for a variety of reasons. When removing the access lists, the NDIS should continue to consider that not all people with psychosocial disability fit into specific lists or diagnosis and that each person should be treated as equal, individual and unique.

3. How can we clarify evidence requirements from health professionals about a person's disability and whether or not it is, or is likely to be, permanent and life long?

Evidence of people with psychosocial disability can be difficult for health professionals to ascertain. We have heard reports of participant's LACs experiencing many health professionals stating a disability is lifelong or permanent and there are no existing treatments, but this has been ignored by the NDIS delegates. If certain assessments are preferred (e.g. LSP-16) communicate this to health professionals.

4. How should we make the distinction between disability and chronic, acute or palliative health conditions clearer?

n/a

Section 3: Undertaking an independent assessment

5. What are the traits and skills that you most want in an assessor?

With assessing people with psychosocial disability, the assessor should be someone who is known to the participant's NDIS journey. An NDIS participant and consumer representative mentions, "Doing an assessment with someone you have never met before will impact some people more than others. It will be hard for people who are new to the NDIS, or who are looking to apply for it because it is daunting and unfamiliar. It may even cause them to not access it, even though they need support."

Feedback from the wider mental health consumer community indicates that taking part in an assessment with a stranger to the participant, will cause people to re-live trauma, un-doing and unravelling the positive achievements of complex recovery journeys, leaving the participant worse-off than before.

A key trait of an assessor should be that they have a lived experience of mental health issues or of permanent disability. Preference would also be for a person whose role is designated by their lived experience such as a Mental Health Peer Support Worker.

The assessor needs to be able to travel to meet the participant at their nominated location. For example, an NDIS participant made the following comment, "I would prefer to meet at the public library because that's where I feel comfortable to meet people. My home is a private place and driving to new place is a hard for me, especially when parking is in a busy place."

When talking about accessing the NDIS office, she mentions, "the parking at the NDIS office near me is impossible, so most of the time, I can't park my car to go the their office. It would be very useful if the NDIS could meet me at my preferred meeting location."

They should have some level of experience and knowledge of the NDIS processes and complexities. They should be clear communicators, being able to work with participants, families and carers, as well as have the ability for strong cross-cultural communication and understanding.

6. What makes this process the most accessible that it can be? For example, is it by holding the assessment in your home?

Consumer feedback indicates four key aspects to making the assessment process as accessible as possible:

1. Conduct the assessment with an assessor who is familiar to the participant.

"Doing an assessment with someone you have never met before will impact some people more than others. It will be hard for people who are new to the NDIS, or who are looking to apply for it because it is daunting and unfamiliar. It may even cause them to not want to access it, even though they are eligible."

2. Conduct the assessment in the preferred method by the participant (webcam, phone, face-to-face, etc.).

"If it's on the computer, I'm in a whole world of trouble... I'm still learning how to use a computer, and I meet with someone once a week who helps me to learn, but I'm still struggling... There are people a lot worse than me who don't know how to use computers at all, and don't know how to access one."

3. If it is decided by the participant that the assessment should be conducted face-to-face, conduct the assessment at a venue that is nominated by the participant.
"I would prefer to meet at the public library because that's where I feel comfortable to meet people. My home is a private place and driving to new place is a hard for me, especially when parking is in a busy place."

4. If a participant has indicated that they are not capable of participating in an assessment, find another way to conduct it by asking the participant how that might work.
"To people who are already on the NDIS simply ask, 'are you capable of participating in an independent assessment?' and if they are not capable, finding a different way. Some people will be capable of completing an assessment, and other people will not be capable."

"The best way to help some people through this process is to ensure they are allowed to bring a Peer Support Worker with them in case they forget anything during the assessment."

5. Allow continuity for the participants

If they have previously had an assessment it would be beneficial to have the choice of seeing the same individual if possible. Providing choice of where/when/who completes the assessment.

7. How can we ensure independent assessments are delivered in a way that considers and promotes cultural safety and inclusion?

Listening and learning from the consumers and participants that this pertains to. Learn from the Aboriginal people from the dozens of language groups across Western Australia to learn each of their unique cultural safety and inclusivity methods.

Employ Aboriginal and/or Torres Strait Islander Peer Support Workers to support Aboriginal and/or Torres Strait Islander participants accessing the scheme. Also employ Aboriginal and/or Torres Strait Islander peoples to conduct the independent assessments with Aboriginal and/or Torres Strait Islander people respectively.

The NDIA should also review the assessment tools being used in the process. Many formal assessment tools are biased towards the norms of western cultures. Similarly, some tools such as the LSP-16 are reliant upon the opinions of the assessor on what constitutes appropriate levels of hygiene and self-care.

Section 4: Exemptions

8. What are the limited circumstances which may lead to a person not needing to complete an independent assessment?

Mental health consumer feedback indicates that if a participant is unable to be assessed by someone who is a stranger to the participant's NDIS journey, they should not be forced to go through with the assessment.

A participant should also be exempt if they have indicated past trauma based on similar experiences. If individuals have trauma from past experiences working with health professionals, it may be confronting for individuals to undertake the assessment process at all, and more harm than good may come of their participation.

Section 5: Quality assurance

9. How can we best monitor the quality of independent assessments being delivered and ensure the process is meeting participant expectations?

Quality assurance can only really come from one place; by communicating with the participants through their preferred mode of communication. Using their preferred mode of communication, you will be able to find out if the process is meeting expectations, from the people who will know best; the people experiencing it.

Provide clarity throughout the process and ensure there is appropriate recording of complaints and feedback. Consumers must be able to express their thoughts on the process in a meaningful way. Consumers must be viewed as experts of their own lived experience and must be enabled / allowed to challenge the results of their assessment if they feel they have been viewed unfairly.

Section 6: Communications and accessibility of information

10. How should we provide the assessment results to the person applying for the NDIS?

Results should be provided based on the preferred communication method of the participant.

For some, digital information is possible, but for others, printed paper and phone calls are preferred. For example, one consumer and NDIS participant mentions, “It is very hard for me to access the NDIS online information, so having the NDIS more accessible through printed paperwork would save me a lot of trouble and confusion.”

“If it’s on the computer, I’m in a whole world of trouble... I’m still learning how to use a computer, and I meet with someone once a week who helps me to learn, but I’m still struggling... There are people a lot worse than me who don’t know how to use computers at all, and don’t know how to access one.”

Care should be taken to support their mental health and wellbeing when delivering the outcomes of assessments to individuals. People have reported feelings of distress when they receive notification of being unsuccessful which can adversely impact their mental health and wellbeing. Ensure the participant/applicant has the opportunity to discuss the results on a one-to-one basis and are supported if they are rejected.

General Feedback & Queries

- Further clarity is required on how the NDIS will ensure consistency of Independent Assessments across the country.
- Clarity on who decides “all reasonable supports and treatments have been identified and/or administered”
- If it is not appropriate for assessors to visit someone’s living space (hospital, shared spaces, judicial settings) and the participant cannot attend an external setting are they exempt?
- Will participants be able to access a complete copy of their assessment?
- There are consistent references to mainstream services and community groups; these are not always accessible, available, or appropriate. Furthermore, many programs are subject to funding changes and cannot be considered long-term supports.
- There is potential for extra information to be required beyond the independent assessment or potentially prior. There is a lack of clarity on if NDIS funds can be used for this or if this is the responsibility of the participant. Furthermore, while all the evidence will be reviewed by the delegates, there will undoubtedly be a bias towards the independent assessments.

Key concerns

- The decision to grant exceptions is not a reviewable decision. This could potentially ostracize individuals from gaining NDIS access.