

CoMHWA



Consumers of Mental Health WA (Inc)

**Feedback to the
NDIS Review**

25 July 2023

Consumers of Mental Health WA

Street Address: 12/275 Belmont Ave, Cloverdale 6105

P: (08) 9258 8911 W: www.comhwa.org.au E: admin@comhwa.org.au

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 are a not-for-profit, systemic advocacy group independent from mental health services that exists to listen to, understand and act upon the voices of consumers. We work collaboratively with other user-led organisations and a diversity of stakeholders to advance our rights, equality, recovery and wellbeing.

Request for Feedback

CoMHWA works to uphold the dignity and human rights of consumers, through providing advocacy in leading change with and for consumers. We appreciate notification of the outcomes of our submission to this consultation to understand and communicate the difference made through our work.

Please provide feedback via the contact details on this submission's cover page.

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". Equally, Aboriginal and Torres Strait Islander people may have a preference for the term 'social and emotional wellbeing' as opposed to 'mental health'.

This definition is based on consumers' call for respect, dignity and choice in how we choose to individually identify. As individuals we choose different ways to name and describe our experiences that may confirm or trouble ideas about 'mental illness'.

Of particular relevance to this Submission for the NDIS Review is the ambivalence of consumers of mental health towards the term 'psychosocial disability'. While many consumers will face significant barriers to participating fully in life and to having meaningful and happy lives because of their mental health challenges, internalised stigma means that many people will not use the word 'disability' to describe themselves. We recognise that people who identify differently (for example, as people who experience mental health concerns, challenges or issues), may still require and benefit from support including that offered by the NDIS. While we understand that accessing services sometimes requires using language that does not fit with individual identities, we also respect people's right to identify how they choose and have their identity and needs taken seriously.

About the Consultation: 'NDIS Review'

Reproduced from the Terms of Reference

The NDIS aims to improve the wellbeing of Australians by investing and empowering people with disability and supporting them to achieve their goals and participate in the community and economy.

The NDIS takes a lifetime approach to achieving these outcomes, investing in people with a disability early to improve outcomes later in life and improve system sustainability.

An effective NDIS will improve outcomes for:

- people with disability and their families and carers, helping them achieve their life goals and participate in social and economic life; and
- society, by strengthening communities and reducing avoidable system costs, including social security, employment, health, housing and justice.

There will be two parts to the Review:

- **Part 1** will examine the design, operations and sustainability of the NDIS covering issues outlined in the full-Scheme bilateral agreements between the Commonwealth and jurisdictions.
- **Part 2** will examine ways to build a more responsive, supportive and sustainable market and workforce.

An overarching objective for both parts of the Review will be to put people with disability back at the centre of the NDIS, restoring, trust, confidence and pride in the NDIS amongst

them and their families and carers as well as the broader Australian community, while ensuring the sustainability of the scheme so that future generations receive the benefit of the NDIS.

Close Date: Friday 18th August 2023

Submissions to:

<https://www.ndisreview.gov.au/have-your-say>

2. Introduction

CoMHWA welcomes the opportunity to make a submission to the NDIS Review on behalf of our members, many of whom are NDIS participants receiving support for psychosocial disability, to provide insight into how the NDIS is accessed, used and understood by people with psychosocial disability. Our members regularly contact CoMHWA for advice and support in relation to either their NDIS applications or their current plan that they require further support to effectively manage, which reveals a gap in the system for sufficient support and advocacy for people with psychosocial disability to apply for and get the most out of their NDIS plans. Responses we received from our members conveyed some consistent themes:

- Discriminatory eligibility criteria.
- Burdensome, lengthy and confusing application process.
- Supports available to people did not meet their needs, but the supports they wanted were unavailable to them.
- Service providers did not consistently have sufficient training to support people with psychosocial disability.
- Feeling simultaneously over-reviewed and under-supported: consumers discussed feeling stressed about frequent reviews that could reduce their funding, but also described feeling overwhelmed with the uncertainty of navigating their plans without coordination.

We base our submission on:

- An online survey open to the public and circulated to all CoMHWA members between the 17th April and 14th May 2023.
- Consultation between Mental Health Australia and other national mental health and consumer agencies, including CoMHWA, at a workshop held online on the 30th of March, 2023.

- Data recorded from our service provision streams, including our Individual Advocacy and Service Navigation programs.
- Ongoing consultation with consumers in Western Australia on joint priorities for an improved mental health system.
- Consumer representation in relevant settings, including but not limited to: Primary Health networks (WAPHA), WA regional equivalents of the Local Health Networks (regional mental health services under the WA Health Board structure), the Mental Health Commission and the health complaints agency, Health and Disability Services Complaints Office (HaDSCO).

Discussion and Recommendations

Barriers to Applying for the NDIS

A common theme that emerged from the responses of CoMHWA members discussing the design and operation of the NDIS was the difficulty consumers face when attempting to make an application to the NDIS. The consumer responses CoMHWA received that discussed difficulties in accessing the NDIS are supported by data released by the NDIS in September 2022, where people applying to the NDIS for a primary psychosocial disability were 28 percent less likely than other people with disabilities to successfully join the Scheme.¹ The responses that discussed barriers to engaging with the NDIS can be grouped into the following issues: The difficult and uncertain nature of psychosocial disabilities and the stipulations of permanence as a prerequisite for assistance, the hostility of the application and assessment process for people with a lived experience of mental health concerns, and the abandonment felt by consumers of mental health who are excluded from the NDIS due to age.

Recommendation 1: Review eligibility criteria to better reflect the experience of psychosocial disability with a focus upon *inclusion* rather than *exclusion*.

Rationale: CoMHWA members have indicated that the characterisation of psychosocial disability adhered to in the *NDIS Rules (Becoming a Participant)* does not appropriately navigate between the requirement for a participant to have a ‘permanent’ disability, and the episodic nature of most psychosocial conditions. While the aforementioned NDIS rules do attempt to provide nuance around permanence to accommodate episodic psychosocial concerns, obtaining the required proof to specifically demonstrate a medically sanctioned

¹National Disability Insurance Scheme. 2022. ‘Psychosocial disability summary: September 2022’ <https://data.ndis.gov.au/media/3567/download?attachment>

prognosis of permanence is an extremely difficult barrier for many consumers in need of help to overcome. As one member phrased it:

'The rules around criteria for support should be rewritten so that the onus of proof isn't so burdensome that it actively deters those who need support.'

Consumers of mental health who find themselves struggling to manage everyday demands—a group that the NDIS is explicitly designed to assist—will often find a lengthy, complicated application process to simply be overwhelming without pre-existing support in place to help them navigate this process. In other words, the consumers who are facing severe challenges and would most benefit from support, often paradoxically require support to access the help they need through the NDIS. Conversely, other consumers found that the lucidity and functionality they have in between chronic episodes can be disqualifying:

'As the NDIS currently is, I'm 'too functional' to receive any meaningful support from it. The criteria appear to be written to provide the most channels to deny and restrict support.'

Given the inherent fluctuating and episodic nature of psychosocial disability and the indeterminant duration of episodes consumers may experience, CoMHWA's strong recommendation is that the NDIS should be amended to make application and assessment easier. Specifically, by proactively providing options for consumers applying for the first time to access Application Support, which would help them navigate the process and help those who do not qualify for the NDIS to find alternative supports. On the one hand, the NDIS is replete with consistent reviews and checks for participants, and consumers who may end up becoming more functional over time will have no incentives to use NDIS funds on treatments if they are not required in their present condition. On the other hand, consumers who seek and obtain NDIS support when functional will have a safety net ready should they experience an episode due to psychosocial disability, which would otherwise be devastating and potentially preclude them from applying for support without assistance.

Recommendation 2: The NDIS assessment and application processes should be co-designed with people with lived experience of psychosocial disability.

Rationale: A number of CoMHWA members discussed the difficulties that they faced in the application and assessments prior to becoming participants in the NDIS. In order to help mitigate against the possibility of making the application and assessment process overly

difficult and burdensome for some of the most vulnerable members of the community, CoMHWA strongly recommends that the structure of NDIS applications and assessments should be reconfigured through a process of *co-design* with people with a lived experience of psychosocial disability. The inclusion of lived experience expertise and leadership would help designers to pre-empt the difficult situations and circumstances that could prove challenging for consumers applying for NDIS support. Such consideration could help to address the needs of consumers who have struggled with the current instantiation of the NDIS, such as the following respondent:

'My experience of applying to the NDIS was a long wait, no consideration of many disabilities, inaccessible.'

To reiterate, it is CoMHWA's view that *participants*, or their peer representatives, should be *participating* to help shape the fundamental design of the service that was created to help them. Without this valuable input, the calculated models and abstracted predictions of policy planners will risk letting the most vulnerable consumers, bound in the inherent uncertainty of life and messy circumstance, fall through the cracks.

Recommendation 3: The NDIS access assessment approach should be person-led.

Rationale: In their responses, CoMHWA members repeatedly emphasised the anxiety and fear they felt about their assessment prior to NDIS approval, as well as the stressful nature of the review assessments. The critical importance of providing a person-centred and welcoming application process for people with psychosocial disabilities is underscored by the comparative isolation and lack of assistance consumers can often have to overcome: According to data released by the Australian Institute of Health and Welfare, People with a psychosocial disability are 18.4% less likely to have friends or family to act as informal supports,² and potentially provide consumers with assistance in navigating the application process and initial assessment. In order to facilitate a more understanding assessment framework for consumers, this recommendation argues that assessments should be redesigned to have a 'person-led' focus, where the consumer is treated first and foremost as a person in need of help and not a 'case' of disability, and which empowers the consumer's autonomy over their healthcare journey and supports.

² Australian Institute of Health and Welfare. 2022. 'Psychosocial disability support services' <https://www.aihw.gov.au/mental-health/topic-areas/psychosocial-disability-support>

Problems implementing and maintaining plan.

Beyond the barriers to obtaining NDIS support outlined in the above recommendations, CoMHWA members were passionate in their discussion of difficulties that exist in managing their plans once they became participants in the NDIS. These responses outlined a need for person-centred support that focuses upon the unique challenges individuals face rather than standardised recommendations for a 'cases' of a particular disability. Respondents also found the process of having plans reviewed regularly extremely anxiety-inducing, a problem that was compounded due to not knowing whether they could rely on continuous support, or whether some supports would be removed from their plan.

Recommendation 4: Improve and expand current avenues of encouraging feedback from participants about service providers and about the NDIS itself.

Rationale: The responses CoMHWA received from consumers cast a light upon the gaps between what supports NDIS offered and what the individual themselves wanted from their plan. Some responses described a lack of funding for particular services or equipment that they felt were crucial, even while receiving *more* funding for supports that they did not find helpful. Other surveyed consumers found that, if they felt that the services offered were not appropriate, they were afraid of raising the issue with the NDIS. As one consumer phrased the issue:

'I'm not getting the benefit of the funding. I'm not living my best possible life. I'm quite isolated. I live in fear of dealing with service providers, and the NDIS office.'

Comments such as the one above represent an extremely concerning experience with the NDIS, which is designed to assist vulnerable individuals rather than add to their distress. To help prevent such experiences, CoMHWA strongly encourages the development of more accessible and understanding pathways for consumers to offer feedback on their experiences with service providers and the NDIS more broadly. In particular, there should be supports available, such as independent advocates, who operate outside of the NDIS and have the ability help consumers navigate potential issues they may experience with the NDIA.

Recommendation 5: Improve transparency about services so participants can find information about a provider to make their own decisions more easily.

Rationale: Some consumers responding to CoMHWA reported that they had difficulty in understanding what services could be made available to them on their plan, and struggled to

find relevant information about some providers to help them to request or decline particular supports. The confusion about potential supports that may be available under plans is summarised nicely by the following comment from a consumer:

'No one knows what they're allowed to spend their funds on. Inconsistent answers from NDIS and plan managers.'

By making the scope of plans clear to consumers, the NDIS could offer far more autonomy to participants to choose the supports that would best assist them, and additionally help to address the confusion many consumers feel in relation to their options under the NDIS.

Recommendation 6: Proactively encourage support coordination via Recovery Coaches to all NDIS participants with psychosocial disability.

Rationale: A number of the consumers contacted by CoMHWA emphatically outlined the need for support coordination and/or supported decision making to assist them finding the right services for their needs. The conditions of psychosocial disability can sometimes prevent or profoundly challenge the ability to engage with services or otherwise seek out support. Utilising psychosocial recovery coaches to help consumers with co-ordinating their care, and developing the skills to manage this co-ordination over the long term. A more proactive approach to empowering consumers to manage their plan could help to address situations such as the one outlined by the following CoMHWA respondent:

'We are not using services. We have complexities which prevent us from accessing services and do not have the capacity to advocate for ourselves to get Support Coordination.'

This perspective of inadequate support coordination was bolstered by other comments that expressed strong feelings of being left to fend for themselves without being checked on by representatives of the NDIS. A particularly concerning example of this circumstance was expressed by the following consumer:

'I have had a plan for 3 years and never used it. Apparently, the NDIS takes a long time to realize that someone has fallen through the cracks and not used 3 years' worth of funding. No one's called to even see if I'm alive.'

Conversely, other respondents who received Support Coordination noted they felt that their choices were being 'gatekept' by the coordinators without sufficient investigation of all options. As one consumer responding to CoMHWA noted:

'Most Support Coordinators feel it is their job to 'police' the request and will not submit any requests they feel do not meet the conditions for funding. Where is choice and control in that?'

The key insight revealed from the above consumer is that people employed as support coordinators should receive training to ensure that they understand that their role is to provide assistance to consumers, and focus on explaining decisions in dialogue with consumers to ensure they are not perceived to be gatekeeping a plan's funding. There should be a focus on educating support coordinators about their key goal: to help their participants achieve, where possible, the autonomy of choosing the supports that help these consumers best in their unique circumstances of disability. While this obviously does not entail a *carte blanche* process of simply approving any and every request, the communication of decisions to participants should *always* clearly evince why a particular decision is in the best interests of the consumer.

Recommendation 7: The NDIS should improve support for recovery-oriented services.

Rationale: A key insight revealed by the consumers surveyed by CoMHWA was the deficiency experienced by NDIS participants regarding the quality of recovery-orientated services made available to them. While CoMHWA acknowledges the valuable steps the NDIA has taken to create and implement the Psychosocial Disability Recovery-Oriented Framework³, the following feedback from consumers indicates that this program is in need of further expansion and development. In an example provided below, one consumer was provided with support in the form of coaching, a service which they felt had inadequate understanding about the physiological and psychological difficulties involved in their disability:

'I have often felt misunderstood and my needs ignored and some services offered such as coaching do not have an understanding of lived experience of either or both mental and or physical challenges. Trying to communicate and feel heard has left me extremely distressed in many situations.'

Beyond the question of the quality and appropriateness of recovery-orientated services made available to consumers in their plans, there was also a sentiment reported to CoMHWA that the quantity and variety of recovery-orientated services was lacking:

'Allocation of funding – very support worker heavy, not enough capacity building.'

³National Disability Insurance Scheme. 2021. 'Psychosocial Disability Recovery-Oriented Framework' <https://www.ndis.gov.au/media/3957/download?attachment>

CoMHWA's consultations with consumers revealed a common perspective that the NDIS plans for people with psychosocial disability were heavily weighted towards core supports (which "enable participants to complete activities of daily living"), rather than capacity building support (which "support and enable a participant to build their independence and skills"). Moving forward, CoMHWA recommends that the NDIS takes steps to ensure that the supports available to consumers follow the Psychosocial Disability Recovery-Oriented Framework, and offer the critically important services that help to develop capacity building for participants.

Recommendation 8: Allow for the episodic nature of psychosocial disability in plan reviews.

Rationale: The consumers who responded to CoMHWA often shared a common fear that some supports on their plan might be removed during reviews if the support was not made use of in the reviewed period. In reality, psychosocial disabilities are predominantly episodic and do not require to be managed consistently through the same supports. The degree of, and help required for, associated functional impairment is contingent on an individual and their plan. Occasionally, consumers may use less support over a review period than their particular plan accommodates—the support provided in this time may have been particularly effective, or their psychosocial disability may simply involve less severe symptoms during this timeframe. If these supports are deemed superfluous when reviewed and are removed, the consumers' psychosocial disability may come to manifest more severe challenges, requiring more intensive and expensive supports that have to be arranged by a consumer in acute distress. Accordingly, it is critically important that those responsible for reviewing plans for consumers living with psychosocial disability have specific knowledge, experience and skills relevant to psychosocial conditions so that plans can accommodate a given consumers' range of potential need. Ideally, peer-workers (people with lived experience expertise in living with psychosocial disability) should be employed to help review the plans of consumers.

Experiences of NDIS service providers

The following recommendations are developed to address the responses CoMHWA received from consumers about their experiences with service providers, and can be grouped around three key issues: Firstly, the difficulty of obtaining supports that were responsive to a consumers' broader life circumstances and adopted a trauma-informed model of care. Secondly there were a number of comments that felt NDIS service providers would be far more helpful for consumers if they were trained in specific techniques relevant to psychosocial disability. Finally, a strong theme of some responses was that service providers could appear

to have a mercenary outlook on consumer care, focusing on securing further funding instead of adopting a person-centred approach with those under their care.

Recommendation 9: NDIS and mainstream supports should work collaboratively to ensure people with psychosocial disability receive the holistic support they need.

Rationale: A number of consumers discussed the problem of their supports being unintegrated and adopting a clinical, symptom-focused approach. CoMHWA's recommendation is that the NDIS should ensure that 'best practice' approaches are embedded in their core principles of service delivery. For example, one approach that is recognised in Australia and internationally as a 'best practice', drawn from evidence-based literature, is trauma-informed recovery-oriented practice. This approach is designed to foster a person-centred, strengths-based model of working with consumers that promotes their agency over the direction of treatment towards the whole of their health and wellbeing. It once again must be noted that the mechanism for offering a more holistic person-led approach has been developed by the NDIS in the form of the Psychosocial Disability Recovery-Oriented Framework. Accordingly, CoMHWA strongly advocates for the expansion and strengthening of this framework, and the thorough integration of a Recovery-focus into the plans of consumers with psychosocial disabilities. By strengthening the existing Recovery-Orientated Framework, the NDIS could offer professional, person-led support with clear policies, implementation strategies, and benchmarks to measure impact.

Another theme that emerged in our consultations with consumers was the difficulties experienced with regard to the range and co-ordination of supports offered for their disabilities, be they psychosocial or otherwise. This sentiment is captured by the following response from a surveyed consumer:

'Funding does not always cover essential support services...whether it be therapy, access to courses or programs to assist individuals improve their daily living mentally and or physically. Clients with a physical disability are often unable to access basic living essentials or commodities to assist with mobility or health concerns.'

In order to ensure that a holistic program of care—that is to say, a program that is directed towards helping a person flourish rather than simply addressing their symptoms *in abstracto*—is being provided to consumers in need, the NDIS should take steps to develop the range of supports offered and more thoroughly coordinate their role in a consumer's plans.

Recommendation 10: Encourage training for service providers specific to psychosocial disability including de-escalation techniques, education on different communication needs and styles, and training from Lived Experience perspectives.

Rationale: A repeated motif in the responses from consumers about service providers was that many of these services did not have a well-developed set of skills to engage people with a psychosocial disability. Specifically, there was an unfortunate lack of training in de-escalation techniques and managing different communication needs and styles. These concerns were well summarised in the following consumer response:

‘Many services do not have the knowledge to assist clients with either a lived experience with mental health or a physical disability and require training to improve the system.’

In order to address this lack of training about methods to help consumers with psychosocial disabilities, CoMHWA strongly recommends that service providers tasked with supporting these consumers ensure that their staff are trained about and from Lived Experience perspectives. Ideally, this training would be conducted by a peer worker with relevant lived experience expertise and would address the aforementioned lack of de-escalation techniques and education about different communication needs consumers may have. In order to encourage the key training and ensure NDIA providers maintain funding for ongoing upskilling, the government could consider introducing a requirement that providers allocate a set amount of their funding for training (An example of a similar arrangement is the 1990 Federal Government Training Guarantee Levy).

Recommendation 11: The NDIS should ensure that service providers are subjected to scrutiny and are orientated primarily towards the wellbeing of their clients rather than simply securing funding.

Rationale: This recommendation was developed from the large volume of responses CoMHWA received from consumers who felt extremely jaded about the motivations of service providers that they had dealt with as NDIS participants. There was a commonly expressed belief that some service providers were focused upon their profits and operations over and above the needs of the consumers who they were tasked with supporting. The following consumer response is representative of this frequently expressed concern:

‘All services should have training to ensure clients and carers are cared for in an ethical way. Services should NOT be a business where there is a focus on funding yet not the wellbeing of the client.’

Another consumer offered a similar response notable for both brevity and directness:

'Providers try to rip-off the system.'

To address these experiences of participants and help restore trust between consumers and service providers, CoMHWA recommends that the NDIS should develop processes to hold service providers accountable if consumers or other parties register complaints. Taking proactive steps to address exploitative profit-orientated providers would prevent the erosion of consumers trust, as well as potentially save the NDIS from supporting disreputable providers with much needed funds.

Concluding remarks

The key themes—drawn from consultation and survey with consumers—that informed CoMHWA's recommendations to the NDIS Review can be summarised as follows:

- The eligibility criteria for consumers with psychosocial disabilities should be amended to account for the particularities of these conditions, and the process of application should not exclude people experiencing acute psychosocial distress.
- The application for, and assessment of, prospective NDIS participants with psychosocial disability should be reconsidered through a process of co-design between the NDIS and people with a lived experience of mental health challenges.
- Consumers have a strong desire to have access to more information about service providers involved with the NDIS, as well as more responsive and direct channels to register feedback about their experiences with service providers.
- The NDIS should utilise Recovery Coaches to facilitate greater coordination between service providers, plan managers and consumers to prevent incoherent support integration and avoid participants feeling like they have been abandoned.
- Service providers tasked with supporting people with psychosocial disability should be encouraged to undertake appropriate training and follow person led best practices in their engagement with consumers.
- Those people conducting NDIS plan reviews should ensure that they understand that psychosocial disability may involve periods where particular supports are not used, but may be needed in the longer term.

Since its creation, the NDIS has already helped a huge number of Australians with a wide variety of disabilities. While some of the recommendations CoMHWA has made emerge from a critical lens informed by issues consumers have faced, it is our sincere hope that the experiences drawn from our members will help to develop a stronger and

more effective NDIS. Collectively, Australians have a remarkable opportunity to draw out the potential of the NDIS to ensure that people with disabilities are offered comprehensive, consistent, and high-quality support. It is CoMHWA's belief that adjusting the NDIS to accommodate this submission's recommendations would help to build a stronger and more just system that both consumers and their communities can be proud of.