

# NDIS Review Consultations held by the NMHCCF: Summary Report

## **Aim**

This summary report is intended to inform the NDIS Independent Review Panel for its final report. It presents solutions recommended by people with a lived experience of psychosocial disability and their family, carers, and kin who, in a series of consultations, shared their experiences of accessing NDIS services and providers. The aim of this summary report is for the Review to endorse in its final report all the recommendations made herein.

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## **1. Glossary**

1. Carer: In this report, the family, carers, and kin of a person with psychosocial disability.
2. Co-design: “Identifying and creating an entirely new plan, initiative or service, that is successful, sustainable and cost-effective, and reflects the needs, expectations and requirements of all those who participated in, and will be affected by the plan. Co-designing a service involves sharing decision-making power with people. This means that people’s voices must be heard, valued, debated, and then – most importantly – acted upon” (p.1)<sup>1</sup>. It is a formalised and facilitated process whereby all parties affected by the outcome participate. It is not a form of consultation.
3. Consumer: In this report, a person with a lived experience of psychosocial disability.
4. Disability Representative and Carer Organisation: DRCO.
5. Disability Representative Organisation: DRO.
6. Intersectionality: “Intersectionality refers to the ways in which different aspects of a person’s identity can expose them to overlapping forms of discrimination and marginalisation” (p.1)<sup>2</sup>, such as one’s ethnicity, gender, sex, nationality, language, religion, age, ability, and location, *inter alia*.

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<sup>1</sup> <https://nmhccf.org.au/our-work/advocacy-briefs/co-design-and-co-production>

<sup>2</sup> <https://www.vic.gov.au/understanding-intersectionality>

7. Lived Experience: In this report, people with a lived experience of psychosocial disability or people who are the family, carers, and kin of someone living with psychosocial disability.
8. National Disability Insurance Agency: NDIA; also referred to as the Agency.
9. National Disability Insurance Scheme: NDIS; also referred to as the Scheme.
10. National Mental Health Consumer and Carer Forum: NMHCCF.
11. NDIS Independent Review: Also referred to as the Independent Review, or simply the Review.
12. Project Steering Group: PSG.
13. Person-centred approach: “Person-centred practices are used in teams and organisations to ensure that the focus is on what matters to the people receiving support and their families and pays attention to how to support staff as well. Person-centred approaches ensure that we see people as unique individuals with valuable gifts and contributions” (p.1)<sup>3</sup>.
14. Psychosocial disability: “Psychosocial disability describes disability experience, impairments, and participation restrictions related to mental health conditions which some mental health consumers and family, carers, and kin must manage. These impairments and restrictions may 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” (p.2)<sup>11</sup>.
15. Recovery-focused approach: “Recovery is a unique and personal experience. Recovery is owned and led by the individual. As people discover and pursue their goals and aspirations that go beyond health outcomes, they may find new purpose and meaning in life. It is a process where the individual is able to make choices and decisions that benefit their life. Recovery is also about the individual being able to join their community, both socially and economically” (p.5)<sup>4</sup>.
16. Social model of disability: “Says that people are disabled by barriers in society...or people’s attitudes. The medical model of disability says people are disabled by their impairments or differences and looks at what is ‘wrong’ with the person, not what the person needs. The social model helps us recognise barriers that make life harder for people with disability. Removing these barriers creates equality and offers people with disability more independence, choice, and control” (p.1)<sup>5</sup>.
17. Trauma-informed approach: “Trauma-informed services do no harm, i.e., they do not retraumatise or blame victims for their efforts to manage their traumatic reactions, and they embrace a message of hope and optimism that recovery is possible. In trauma-informed services, trauma survivors are seen as unique individuals who have experienced abnormal situations and have managed as best they could” (p.1)<sup>6</sup>. Being trauma-informed requires specialised training.

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<sup>3</sup> <https://www.ndp.org.au/images/factsheets/346/2016-10-person-centred-approach.pdf>

<sup>4</sup> <https://www.ndis.gov.au/understanding/how-ndis-works/mental-health-and-ndis#psychosocial-recovery-oriented-framework>

<sup>5</sup> <https://www.afdo.org.au/social-model-of-disability/>

<sup>6</sup> <https://www.health.nsw.gov.au/mentalhealth/psychosocial/principles/Pages/trauma-informed.aspx>

## **2. Introduction**

The NDIS has the potential to substantially benefit people living with a severe and ongoing psychosocial disability<sup>7</sup>, however those with a psychosocial disability have encountered numerous issues at all stages of the process: eligibility and application, planning, plan implementation, and review.

The interim report delivered by the NDIS Independent Review Panel found that the NDIS was never designed to support all people with disability<sup>8</sup>. This is certainly true for people with a psychosocial disability. The NDIS rolled out Australia-wide in 2016 to fund supports for people with a general disability that was likely to be lifelong and substantially impact on a person's ability to complete everyday activities<sup>9</sup>. Psychosocial supports started to be funded through the NDIS in 2017<sup>10</sup>, however people with a psychosocial disability struggled to gain access to the Scheme due to the fluctuating and episodic nature of the disability itself<sup>11</sup>. Moreover, the introduction of psychosocial supports on the NDIS led to the erosion of funding from government-funded support services in the community and previous support services being incorporated into the NDIS<sup>12</sup>. This resulted in the eventual decommissioning of functional programs such as Partners in Recovery<sup>13</sup>. As of 2020, there is an estimated 154,000 people requiring psychosocial supports that are deemed ineligible to apply for the NDIS and are unable to access community services that have been abraded under current policy levers<sup>12</sup>. These circumstances have left many people with a psychosocial disability and their family, carers, and kin in a state of crisis and despair.

It is not only a need for a deeper understanding and support of psychosocial disability nor a lack of funding for supports that people with psychosocial disability are concerned with. Navigating the complexity and rigidity of the NDIS application and planning processes is also a major issue, along with how people with a psychosocial disability are treated when interacting with NDIA staff on the Scheme. The Productivity Commission's mental health report echoes these known issues, and further adds: "1) the application process to gain access to the NDIS can be overwhelming; 2) there are comparatively poorer experiences upon entering the Scheme for some participants; 3) many are choosing not to apply for the NDIS even though they would likely be eligible; and 4) the interface between the NDIS and mainstream services is unclear" (p.851)<sup>7</sup>.

The NDIS was structured to cater to people with clear signs of a physical or intellectual disability<sup>14</sup>. However, psychosocial disability differs from most other forms of disability, and therefore requires a different approach<sup>11</sup>. The fluctuating and episodic nature of psychosocial disability is one difference. Another is the lack of choice and control often experienced by those with a psychosocial disability. Moreover, psychosocial services differ to general disability services in that they should be recovery-oriented and use a personalised approach

<sup>7</sup> <https://www.pc.gov.au/inquiries/completed/mental-health/report/mental-health-volume3.pdf>

<sup>8</sup> <https://www.ndisreview.gov.au/resources/reports/what-we-have-heard-report>

<sup>9</sup> <https://www.ndis.gov.au/about-us/glossary> - 'Permanent and significant disability'

<sup>10</sup> [https://www.aph.gov.au/About\\_Parliament/Parliamentary\\_Departments/Parliamentary\\_Library/pubs/rp/rp1819/Chronologies/NDIS](https://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/pubs/rp/rp1819/Chronologies/NDIS)

<sup>11</sup> <https://nmhccf.org.au/our-work/position-statements/psychosocial-disability-associated-with-mental-health-conditions>

<sup>12</sup> <https://www.abc.net.au/news/2023-06-28/psychosocial-disability-ndis-future-inclusion/102534200>

<sup>13</sup> <https://mhcc.org.au/publication/partners-in-recovery/>

<sup>14</sup> <https://www.sydney.edu.au/news-opinion/news/2020/01/22/the-ndis-and-mental-illness-what-needs-to-change.html>

tailored to address people's specific disability support requirements<sup>11</sup>. Other issues include, general disability support services not having the skills or knowledge to meet the support needs of people with psychosocial disability<sup>11</sup>, the heightened stigma and discrimination experienced by people with psychosocial disability<sup>15</sup>, and the common involvement of trauma in the experiences of people with psychosocial disability<sup>11</sup>. In evidence from multiple 'Listening Workshops' conducted in August 2022 by the NMHCCF to inform the NDIA on improving their NDIS access and planning processes, consumers repeatedly stated that the continuous requirement to establish the permanency of their psychosocial disability is difficult due to the inherent fluctuating nature of psychosocial disability<sup>16</sup>. In addition, constantly having to recount the worst period in their lives is leading to the retraumatisation of participants and their supporters. Furthermore, a diagnosis-centred model of categorisation rather than a person-centred approach – more in line with the social model of disability<sup>5</sup> – entirely misunderstands the nature of wellbeing and recovery for people with a psychosocial disability. This is also an issue as many have co-occurring disabilities that are not taken into account. Additionally, the NDIA's poor understanding of psychosocial disability leads to inadequate assessments of what is 'fair and reasonable', as well as increased stress for participants and their family, carers, and kin<sup>16</sup>.

There have been attempts since the introduction of psychosocial supports on the NDIS to implement policy into the Scheme that would accommodate this different approach, such as a Psychosocial Disability Pathway in 2018<sup>17</sup> and the introduction of the Psychosocial Disability Recovery-Oriented Framework in 2021<sup>18</sup>. Unfortunately, these efforts have been inadequate, are not having their intended effects, or have gone unimplemented. Those with psychosocial disability and their family, carers, and kin are still touting the same problems and solutions that they have been since 2017. However, in their apprehensive optimism, they view the Independent Review as a significant opportunity to improve the Scheme and remain hopeful that their solutions to the Scheme's problems will finally be turned into meaningful reform.

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<sup>15</sup> <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/justice-and-safety/disability-discrimination>

<sup>16</sup> <https://nmhccf.org.au/news/living-with-psychosocial-disability-on-the-ndis-listening-workshops?highlight=WyJsaXN0ZW5pbmciLCJ3b3Jrc2hvcHMilCJsaXN0ZW5pbmcd29ya3Nob3BzIl0=>

<sup>17</sup> <https://mhaustralia.org/our-projects/ndis-psychosocial-pathway-project>

<sup>18</sup> <https://www.ndis.gov.au/understanding/how-ndis-works/mental-health-and-ndis>

### **3. Process**

In October 2022, the Hon Minister Bill Shorten announced an Independent Review into the NDIS, run by the Department of the Prime Minister and Cabinet. In March 2023, the NDIS Review Panel offered funding to the DROs to consult with their members and networks to gather on-the-ground information as to how the NDIS could work better for people with a disability. In conjunction with the Review, the NMHCCF, as the DRO for psychosocial disability, developed an engagement plan in order to inform the Review's final report, due in late October 2023.

As part of the engagement plan, the NMHCCF planned a total of six consultations, each lasting two hours: three with people with a psychosocial disability, and three with the carers, family, and kin of people with a psychosocial disability. Furthermore, the NMHCCF attempted to target cohorts that are underrepresented in the data for psychosocial supports, such as NDIS participants and their family, carers, and kin with co-occurring disabilities, and Lived Experience with intersectionalities. Consultation sessions were held from 28 August to 6 September 2023, and totalled 32 participants: 18 consumers and 14 carers.

To develop this project, the NMHCCF founded a PSG with knowledgeable members in the psychosocial disability sector and each with Lived Experience. The PSG held three organisational meetings to develop recruitment strategies for consultation facilitators, peer support workers, and the differing participant cohorts, develop the content of the consultations, and select cohort participants. A final meeting was conducted on 18 September 2023, together with the PSG and facilitators, to draft outcomes using the material gathered from the consultations and surveys.

This summary report was handed to the Review Secretariat on 2 October 2023, with the goal of having all of its recommendations included in the Independent Review's final report. This is with the ultimate aim of subsequently having the recommendations implemented by the Australian Government to benefit people living with a psychosocial disability and their family, carers, and kin.

*"My son spent 28 years constantly in and out of psychiatric hospitals. Mental Health Act; Guardianship and Administration Act; treatment orders – constantly for 28 years! Now, 5 years under the NDIS – this is no exaggeration – he's never been to hospital. Now that is an incredibly successful story that the NDIA should be talking about!" – Carer Participant.*

#### **4. Themes of the consultations**

The following themes were gathered from applicant expression of interest forms, the survey report, email feedback, consultation notes and transcriptions, as well as the NDIS Review Panel's DRCO Forum presentations. They covered the whole array of NDIS processes, from applying, planning and enabling the plan, to the agency, review processes, and services outside the NDIS.

##### General NDIS Issues

###### *Issue 1 – The NDIA having a poor understanding of psychosocial disability*

The content of this issue centers around the known problem of the NDIA having an inadequate understanding of psychosocial disability and the needs of those with a psychosocial disability<sup>19</sup>. Participants felt dejected at the prospect of having to interact with yet another NDIA agent that was deficient in their knowledge of psychosocial disability and unconscious to the requirements of psychosocial participants and their supporters. They also felt worried that this lack of understanding could lead to their application being rejected, their funding and supports denied, or their review dismissed.

Specific training in psychosocial disability was a consistent solution across all the consultations. Furthermore, embedding person-centred practices and Lived Experience within the NDIA came across as a common theme amongst participants, which would allow participants greater choice and control over their plans. In addition, it was paramount for participants that the Agency gain a better understanding of how intersectional factors and comorbidities affect those living with a psychosocial disability. Moreover, the definition and classification of psychosocial disability seemed to be an issue in and of itself, therefore updating these to reflect how people with a psychosocial disability define their experiences is crucial. A focus on a person's recovery and wellbeing was echoed across groups too. Participants saw a holistic approach to a person's care as the best solution to this, rather than focusing on someone's diagnosis and then categorising them as such in terms of supports. It was commonly suggested that the NDIA could improve their knowledge by engaging Lived Experience in its trainings and introducing a supervision/mentorship program with people with a lived experience.

*"I completely agree that there needs to be a competency-based system in place, but we need to also look at who's giving that. I've got a mental health nurse attached to the hospital here who's giving psychosocial training to a provider, and she comes from a medical model, and her ideas of mental health and people with mental health comes from a safety factor. So, she's pumping that people with mental illness are unsafe, so the provider's then putting it in security systems and things like that. I think we have to have a really good system, competency-based system that is – I don't want to add more regulation to things, but we need to watch who's training who, and what they're being trained on" – Carer Participant.*

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<sup>19</sup> <https://onlinelibrary.wiley.com/doi/full/10.1002/ajs4.245>

### *Issue 2 – Lived Experience workforce*

The lack of both consumer and carer peer workers in and outside of the NDIA was a major issue for both cohorts. They both feel unsupported and misunderstood when interacting with people without a lived experience, which often leads to greater stress and more setbacks in their journey through the NDIS.

Carers, across the three consultations, echoed that they would be better assisted by having access to carer peer workers that would help with support coordination, navigation, carer advocacy, the application process, assessment, and assistance in the writing of documentation, such as completing the Carer Impact Statement.

Consumers, across the three consultations, saw role clarity and specialisation for peer workers as important. It was a consistent view that peer workers should hold roles right across the NDIA and be embedded within the Agency at all levels. In addition, peer work roles should be permanently employed by the NDIA to represent their value and have the same employment protections as permanent employees.

Both groups agreed that their lives would be improved if there was a permanent Lived Experience (i.e., both consumer and carer) Support Coordinator workforce.

### *Issue 3 – Traumatic encounters and interactions with the NDIA*

Participants across both carer and consumer groups spoke of their traumatic encounters with the NDIA, and how these would best be alleviated. Furthermore, the onus on participants to continually prove their disability, which is typically fluctuating and episodic by nature, often retraumatizes them when needing to recount the worst period in their lives. Both consumers and carers stated that they are frustrated at what appears as a 'gatekeeper' mentality from NDIA staff, who seem to hold the view that the majority of applicants/participants are trying to 'free ride' off the system and that it is their job to stop them receiving 'too much' support. In essence, there is a lack of mutual trust and an ongoing, respectful, collaborative relationship.

The primary solution to this is providing NDIA staff with extensive trauma-informed training in order to engage in trauma-informed practice based on the six core principles of safety, trustworthiness, choice, collaboration, empowerment, and respect for diversity<sup>20</sup>. This looks like having considerate, empathetic face-to-face conversations with people with a psychosocial disability and their family, carers, and kin. Having a strong understanding of trauma, both of one-time events and the accumulative nature of it, is important. In addition, having knowledge of the disproportionately high correlation between trauma and psychosocial disability would assist in participants not being systemically retraumatized. Allowing the participant to lead their narrative and tell NDIA staff what they need in terms of support, thus increasing self-determination, choice, and control, is important and was the original intent of the NDIS Act. Consistency and transparency in communication is also vital.

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<sup>20</sup> <https://mhaustralia.org/general/trauma-informed-practice>



Both carers and consumers want the opportunity to review information and discuss this before a decision is made at the assessment, planning, and review stages.

*"I consider myself fairly high-functioning, and I found that (planning) meeting very traumatic in the fact that it was almost like a business arrangement – this is what you've got, see you later, bye, no further discussion. So, for it to not be dramatic, it would be a safe environment. I did not find it safe. For it to feel like they're in my corner, they weren't. To be given time to process the information, to ask questions, and to realise it might be distressing for me and I might need to take a break" – Consumer Participant.*

#### *Issue 4 – Carers, family, and kin going unheard*

This arose as an issue in the pre-consultation survey report and was specifically discussed in the carer groups. Carers felt neglected by not being included in assessments and worried for the person they care for not being able to advocate for themselves in this process since often the family of people with psychosocial disability are their spokespeople.

The following solutions came from these consultations: 1) that a thorough assessment of the family and caring environment is completed as part of individual assessments; 2) that there is a carer advocate within the NDIA to help complete forms, raise concerns and issues, and herald the needs of carers; and 3) there is Lived Experience engagement at all levels of governance and service delivery in the NDIA.

*"So, that respect of family relationships (is important)...and I feel really sad because a lot of this hesitancy by NDIS to work with families is because there are the bad seeds, there are the ones abusing the system, but they're treating us all like we're abusing the system. We're treated like criminals. Anything we're requesting, it's dodgy. And that's really a hard basis to work from. There's no trust from them, and they don't even know our lives" – Carer Participant.*

#### *Issue 5 – Support dogs not being funded by the NDIS yet guide dogs are*

It is confusing to applicants that completed the pre-consultation survey as to why support dogs, or any support animal for that matter, are not funded by the NDIS if they are truly implementing the Psychosocial Recovery-Oriented Framework. The majority of participants with animals spoke of how important they are to their wellbeing and recovery.

The key solution provided to improve this is allowing more flexibility in plans and support packages, as well as tailoring individual solutions to those with a psychosocial disability. It was also suggested that a Lived Experience worker should sit on the panel of independent assessors.

## Issue 6 – Intersectionality

Certain organisational attitudes, systems, and structures can negatively affect a person based on their intersectionality and result in inequality and exclusion leading to disproportionately negative outcomes<sup>2</sup>. LGBTQIA+ and First Nations participants spoke of systemic discrimination in their treatment by NDIA staff, as well as being connected to support services that were deficient in understanding how aspects of their identities intersected and thus adversely affected their psychosocial recovery process.

It is important to participants that it is understood how intersectionality can affect one's NDIS experience and finding the appropriate supports. It was specifically suggested that intersectional representation in the Lived Experience workforce, from service delivery, leadership, and policy to process improvement, is paramount. Intersectional trauma education in this respect is important to understand the impact of intersectional, diverse, and complex trauma, including intergenerational, vicarious, and intersectional trauma<sup>21</sup>. Further solutions to consider are: 1) establishing Intersectional Advisory Groups on the NDIS that include people with psychosocial disability and their family, carers, and kin; and 2) developing comprehensive training programs for NDIA staff specifically on the intersectional nature of disabilities.

## Applying for the NDIS

### Issue 7 – Independent assessments

It became known through the NDIS Review Panel's presentation in Newcastle<sup>22</sup> that the Panel will recommend that the NDIA maintain authority to decide what is 'fair and reasonable' in terms of supports, and that they will propose independent assessments. The primary reaction to this throughout all the consultations was disappointment, followed by confusion to understand how a 20-30-minute assessment by an unknown person can gain a real understanding into the support needs of someone with psychosocial disability, compared to a support worker that has been involved in their treatment over a long period of time.

Assuming that independent assessments will be introduced, participants then suggested that a team approach should be taken, whereby case conferencing is conducted between the NDIS and engaged supports. There is also the option of holding 2-3 assessment meetings before deciding on outcomes. These meetings would need to be held in different contexts and involve interviews and observations with people who know the participant.

*"I think it's devastating that they're going this way. I think it takes away your choice and control. It took me a long time to build rapport with any psychologist or mental health OT that actually allows them to see my dissociative disorder as real and the different personalities that come out...(that) don't come out unless they feel safe. So, they're not going to get a whole picture of my disability in a few sessions with someone that doesn't*

<sup>21</sup> <https://link.springer.com/article/10.1007/s11125-020-09461-6>

<sup>22</sup> <https://www.ndisreview.gov.au/news/future-ndis-and-where-we-are-heading>

*understand Associative Identity Disorder and doesn't understand the triggers and traumas that come out. During that session, I could be just a mute little girl that just doesn't talk. You need longevity rapport-building for it to be successful" – Consumer Participant.*

#### *Issue 8 – The complexity of the language used by the NDIA*

All participants in the consultations talked about the complexity and inaccessibility of the language, jargon, and acronyms used by the NDIA in its documentation, forms, and information.

The key solution for this issue is that the NDIA simplify its language into Plain-Language. In addition, participants suggested having a template that interprets the language used in the NDIS and guides participants with a psychosocial disability and their family, carers, and kin on how to provide the information that is sought. Another helpful resource would be to provide a glossary of terms, definitions, and criteria on the website, in the form of digital pop-ups or cross-referencing links.

#### *Issue 9 – Decisions made with little transparency*

A lack of transparency in communication from the NDIA was another common theme across all consultation groups. Participants and their family, carers, and kin were often perplexed as to why and how the NDIA makes certain decisions, such as rejecting applicants in need, refusing particular supports, or determining either the success or failure of review decisions.

First, a draft version of both the application and plan was suggested as a necessary solution, which could be reviewed and discussed prior to a concrete decision being taken. Second, participants would appreciate knowing the outlined reasons for a given decision, so they know what piece/s of information they need to provide in order to satisfy evidentiary requirements. This is also important for accountability concerns, as people with a psychosocial disability and their family, carers, and kin may think the reasons for refusal are arbitrary. Third, more responsiveness and closer engagement with participants and their loved ones is an important trauma-informed practice that can be put in place with better training for, and understanding from, NDIA staff. Finally, rulings and decisions from the Administrative Appeals Tribunal should be freely published on the Internet.

*"Three years ago now, I had a planning meeting with a lady. She was really nice, we got on really well with her. But then, when it came to look at my funding, I'd lost \$30,000 out of my funding for the next two years. No explanation as to why or whatever or anything like that. I'd explained exactly what I needed and what had happened...so I couldn't do this, I couldn't do that, I couldn't do heaps of other things that were helping me to keep well. I couldn't do those things anymore because I didn't have the funding for (them). \$30,000 of my funding had been taken like that for no reason, no explanation at all" – Consumer Participant.*

### *Issue 10 – NDIS navigators*

Due to the complexity of the NDIS, its many processes often become an overwhelming experience for participants with psychosocial disability and their family, carers, and kin to navigate. There is currently minimal effort from the NDIA to assist in the application process, aid participants and their family, carers, and kin to understand the planning process, and help to connect a participant to suitable and appropriate services.

Across the consultation groups, there was broad agreement that there needs to be an employed NDIS Navigator workforce with coverage and access Australia-wide. Whether this role sits within or outside the NDIA, it requires the transparency and objectivity of an external agency alongside the stability and accountability of a government agency. Participants agreed that, ideally, NDIS Navigators would be people with a lived experience who not only help navigate the system but act as advocates for applicants/participants and their family, carers, and kin, and facilitate the sharing of information. They would be highly connected and engaged with NDIS processes, trauma-informed, and have the soft skills of empathy, understanding, and listening.

### *Issue 11 – NDIS rejections*

Taking the time to apply to the NDIS is taxing and difficult for those with a psychosocial disability, and rejections are particularly traumatic. This is made worse by the NDIA neither offering an explanation as to why this decision was made nor outlining where participants can improve their application for the future.

Referring to feedback from consultation participants, this process could be improved by having NDIA staff maintain a trauma-informed approach and empathise with applicants. This would involve clearly explaining why the decision was made, as well as providing additional support and information on both how to make a stronger application in the future and about alternative appropriate community supports they can access. The employment of an NDIS Navigator peer workforce and referring applicants to them would go a long way in assisting them through the application process.

## Planning processes

### *Issue 12 – Planners having little knowledge of psychosocial disability*

Participants observed that planners typically have inadequate knowledge of psychosocial disability or understanding the needs of someone with a psychosocial disability. Due to this, many participants are adversely affected by receiving inadequate supports and services, receiving inadequate funding and/or funding aligned with an inadequate support or service, having unsuitable coordination of their supports and services.

The NDIA could repair this by maintaining specific recruitment standards for planners, requiring both high levels of technical and behavioural competencies, as well as the appropriate soft skills. Ideally, these would be specialist planners in a particular area of

disability. Employing a peer workforce with the appropriate qualifications would be a reasonable solution to this issue.

*“Look, I’ve just got Bill Shorten’s, one of his speeches in front of me. And he says the first priority is to increase the capacity and capability of the NDIA through a focus on building a specialised workforce. And to me that’s the most important thing, and I hope he really means that. Because if a planner is a planner who has knowledge and experience of psychosocial disability, they will be fine” – Carer Participant.*

### *Issue 13 – Designing own plans*

A major concern for all the participants was the lack of discussion and ability to review NDIS plans. Planners are supposed to work in a collaborative process with NDIS participants to identify their goals, really understand their support needs, and the types of services and supports that will help them achieve their goals. The majority of participants in the consultations found that this is not the case, and that decisions on plans are then finalised without consultation, resulting in lengthy and uncertain review processes.

Across all consultation groups, two clear solutions stood out: 1) having the ability to review plans and suggest amendments prior to plan finalisation, and 2) the NDIA taking a person-centred, participant-led approach to constructing their plan. The former solution highlights the need for transparency, and the latter supports a co-design approach. For participants who experienced a ‘good’ planning process, their plans were developed in a collaborative manner with an understanding planner. Planners having the ability to listen deeply, empathise, and be more responsive was very important for participants. Importantly, carers, family, and kin should be involved in the planning process. For consumers, it was important that they be viewed as a whole person with sometimes multiple, interrelating disabilities. Moreover, unilateral cuts to plans made by NDIA staff without consultation or explanation deeply affects NDIS participants and their family, carers, and kin. Engagement with applicants/participants at all stages of the process is recommended.

Part of a person’s recovery process is for them to be able to celebrate their wins without the fear of losing funding, especially funding towards capacity-building. Most of all, participants with a psychosocial disability want to feel heard by their planners. A more trauma-informed approach, with planners having significant training on the subject, or ideally being a person with a lived experience, is what is required.

### *Issue 14 – The NDIA only recognises the impact of one disability*

As previously stated in this report, viewing the person as a whole, and not as a primary disability, is vital to understanding the experience of someone with a psychosocial disability. Where this becomes a pitfall is seen in the following statement from one participant:

*“...I sort of got on (the NDIS) quite easily at the start. But I’ve struggled because I had the psychosocial disability and I had support workers and a cleaner and a gardener and a*



*psychologist and I had everything I needed. But then when I got diagnosed with FND (Functional Neurological Disorder) – my psychosocial disability got disregarded. They said I didn't have that anymore, that I only had FND. So, all my psychosocial supports got taken away and I've been fighting for two years to try and get them back.” – Consumer Participant.*

It is important for the NDIS to recognise that multiple disabilities interconnect and interrelate. In addition, often medication used to treat psychosocial conditions can have adverse effects on comorbidities<sup>23</sup>. There needs to be more understanding of the physical health issues that can arise from having a psychosocial disability. Again, plans should be co-designed and have the ability to be reviewed prior to a decision being made, in order to rectify any incorrectly included or excluded disabilities.

#### *Issue 15 – Psychology sessions are difficult to obtain*

It was clear from the consultation sessions that ongoing psychology sessions are a vital support for people with a psychosocial disability. Australia's current mental health system is unequipped to deal with the ongoing, heightened, and necessary psychological support that people with a psychosocial disability require in order to maintain functional ability and focus on long-term recovery<sup>24</sup>.

This is an issue that either needs to be considered through a whole-of-government approach or by making psychology sessions more easily attainable as an NDIS support. As the Better Access Scheme was designed as a time-limited service for people with mild to moderate short-term mental health issues, it is not a suitable program to refer people with a psychosocial disability. Therefore, a whole-of-government approach would require a specific program for this cohort under the Department of Health and Aged Care, and fluid coordination between the NDIS and the program. On the other hand, the NDIS could simply fund ongoing psychology support for people with a psychosocial disability. Security around ongoing availability of funding for psychology is also important so as not to create unnecessary distress for participants. Carers stated that there should also be access to psychology services for family, carers, and kin, including the option for family counselling.

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<sup>23</sup> <https://www.aihw.gov.au/reports/mental-health/physical-health-of-people-with-mental-illness>

<sup>24</sup> <https://ourguidelines.ndis.gov.au/how-ndis-supports-work-menu/mainstream-and-community-supports/who-responsible-supports-you-need/mental-health-and-psychosocial-disability> - 'What is the mental health system responsible for?' and 'What are we responsible for?'

## **5. Recommendations to be adopted**

1. Specific psychosocial training for the NDIA to improve its understanding of psychosocial disability as separate to that of a mental health condition and other disabilities. This will better inform Agency staff of the impairments and needs of those with psychosocial disability and the challenges they face from these impairments. A good example is the Course in Supporting People with Psychosocial Disability provided through the Victorian Skills Gateway<sup>25</sup>.
2. Specific training on a trauma-informed approach that teaches NDIA staff how to engage in trauma-informed practice.
3. A person-centred approach for the NDIS to recognise and support co-occurring disabilities. This requires a change in the collective thinking of the Agency – one that takes a whole-of-person, holistic approach rather than a narrow, diagnosis-led perspective.
4. A true recovery-focused approach and real implementation of the Psychosocial Recovery-Oriented Framework that is developed by co-design. This is to put into practice the understanding that there are differences between psychosocial disability and psychosocial support services to that of general disability and general disability support services. Psychosocial participants require flexible, individualised support plans. They would have greater choice and control over their support package if their plans and budgets were not together, allowing the inclusion to fund support animals. This should abolish the need for line items (which is already being recommended by the NDIS Review<sup>22</sup>).
5. Embedding Lived Experience at every level of the NDIA (i.e., system design, co-design processes, delivery, evaluation, recruitment, and review) for psychosocial disability to be better understood and to ensure more empathetic, trauma-informed, and recovery-oriented approaches and interactions were taking place between Agency staff and applicants/participants.
6. The establishment of a permanent Lived Experience (i.e., both consumer and carer) Support Coordinator workforce to ensure equitable compensation and employment protections. Advocacy was seen as very important, therefore, as part of the job description of this position, it would be important to intentionally include a consumer and carer advocacy function to herald the needs of participants and their family, carers, and kin.
7. Consistency and transparency in communications, processes, and decisions, including, but not limited to, publishing Administrative Appeals Tribunal decisions, providing reasons for NDIA decisions at all stages of the NDIS process, providing available data and metrics, and openness in email communications in a timely manner.

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<sup>25</sup> <https://www.skills.vic.gov.au/s/account/0014a000007UmzPAAS/course-in-supporting-people-with-psychosocial-disability>

8. The ability to review assessment and planning drafts before they are finalised, as often NDIA workers have misrepresented, misheard, or misunderstood what a participant needs in terms of support.
9. The inclusion of intersectional Lived Experience workers and providing intersectional training for NDIA staff. This will enable Agency staff to have a greater understanding of how intersectionality affects one's disabilities and access to appropriate services.
10. Individual assessments around support needs to be a multi-stage process that involves a team that has had extensive contact and provided support for the participant over a long period of time. These need to be conducted by assessing the individuals' family environment too.
11. NDIS documents, forms, and information to be written in Plain-Language without acronyms or jargon. NDIS documents translated for people from CALD communities to be translated from these Plain-Language documents, not from the originals.
12. The implementation of a dedicated NDIS Navigator workforce of people who have a lived experience of psychosocial disability, understand NDIS processes from end-to-end, and who are permanently employed by the NDIA to provide continuity.
13. Outline specific recruitment standards for specialist planners, which incorporate both high levels of technical skill in a particular area of disability, appropriate behavioural competencies, and trauma-informed soft skills.
14. Engage in true co-design with people with a psychosocial disability and their family, carers, and kin. This does not mean solely consultation, but ongoing discussion and decision-making shared amongst those in the design process (please see the glossary section for a definition and the additional resources section for a more in-depth understanding).
15. Psychology sessions to be funded as an essential psychosocial support on the NDIS, as psychological therapy supports for people with psychosocial disability are ongoing and necessary. Do not refer NDIS participants to the Better Access Scheme, as it is not equipped to provide continuous services for people with a psychosocial disability.



## **6. Additional resources**

1. Co-design and co-production: <https://nmhccf.org.au/our-work/advocacy-briefs/co-design-and-co-production>
2. Person-centred approach: <https://www.ndp.org.au/images/factsheets/346/2016-10-person-centred-approach.pdf>
3. Psychosocial disability: <https://nmhccf.org.au/our-work/position-statements/psychosocial-disability-associated-with-mental-health-conditions>
4. Recovery-focused approach: <https://www.ndis.gov.au/understanding/how-ndis-works/mental-health-and-ndis#psychosocial-recovery-oriented-framework>
5. Social model of disability: <https://www.afdo.org.au/social-model-of-disability/>
6. Trauma-informed approach: <https://www.health.nsw.gov.au/mentalhealth/psychosocial/principles/Pages/trauma-informed.aspx>