

ORIGINAL ARTICLE OPEN ACCESS

Expectations and Reality: The Lived Experiences of Australians With Psychosocial Disability Within the NDIS

Joel Hollier  | Jennifer Smith-Merry 

The University of Sydney, Sydney, Australia

Correspondence: Joel Hollier (joel.hollier@sydney.edu.au)

Received: 23 July 2025 | **Revised:** 13 January 2026 | **Accepted:** 22 January 2026

Keywords: choice and control | mental health | mental illness | NDIS | psychosocial disability

ABSTRACT

While Australia's National Disability Insurance Scheme (NDIS) was founded on principles of choice and control, for people with significant mental health challenges (what the NDIS calls 'psychosocial disability') these ideals often remain elusive. Support systems continue to be fractured and in the context of ongoing policy reforms, it is vital to understand expectations people have of the scheme, alongside ongoing experiences. Drawing on semi-structured interviews with NDIS participants ($n = 30$) and informal/unpaid carers ($n = 18$), this research explores these expectations and lived realities. Results showed that prior to engaging with the NDIS, participants had mixed expectations of the scheme, with a lack of information accessed and confusion about what the scheme could offer. For some, expectations were also formed in the context of acute mental illness. When expectations were expressed, these were often unmet, with interviewees reporting a lack of choice and control, frustrations with the system, a lack of appropriate services, and encounters with unscrupulous or underperforming providers. Findings should inform policy directions to better align Australia's mental health ecosystem with the realities faced by those it seeks to support. Strategies are required for planning and communication about what the NDIS offers participants to inform choice and control of needed supports.

1 | Introduction

In many high-income countries, 'choice and control' has become a cornerstone of disability policy (Abbott et al. 2025; D. Hamilton et al. 2024). Taking impetus from the Convention on the Rights of People with Disabilities (CRPD), the notion of choice and control asserts that all people with disability have the right to direct their own care (Cukalevski 2019). The introduction of the National Disability Insurance Scheme (NDIS) in 2013 represented a major disability policy reform in Australia. The Scheme aimed to address serious shortcomings of disability supports across the country. Choice and control is key to the scheme's design (Productivity Commission 2011, 5). This phrase is not well defined and it is difficult to put boundaries around. However, practically, the scheme enacts this via a process where, ideally, participants are provided the opportunity to

set their own goals, manage their own plans and choose their own providers who provide support to 'increase independence and social and economic participation, and to be part of your community' in areas of need identified through NDIS planning processes (NDIA 2024a).

To achieve the above, the scheme was set up with an individualised funding model. Individualised funding models have been adopted in a range of high-income countries (S. Hamilton et al. 2016; Hummell et al. 2025). Moving away from institution and welfare-based block (or programme) funding, individualised funding models seek to enable people with disability to self-manage their support in ways that best align with their personal needs. This new approach to support under the NDIS was embraced by the disability community but implementation has not been smooth, with concerns emerging in recent

This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial-NoDerivs](https://creativecommons.org/licenses/by-nc-nd/4.0/) License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2026 The Author(s). *Australian Journal of Social Issues* published by John Wiley & Sons Australia, Ltd on behalf of Australian Social Policy Association.

years about the cost of individualised support, fraud, uneven access to disability markets and exploitation and abuse of participants (Dickinson and Yates 2023; Hummell et al. 2025; Smith-Merry and Chang 2025). These concerns, among others, led to a major independent review of the NDIS in 2023, which suggested significant reforms of scheme design for people with psychosocial disability, including access, types of supports available to participants, and the registration of providers (Commonwealth of Australia 2023). The two latter reforms have been criticised by some within the disability community because they challenge the concept of choice and control. However, others within the disability community have welcomed the broad review findings because they offer the opportunity to address entrenched problems limiting the operation of the scheme for people with psychosocial disability (Shelby-James and Rattray, 2025).

1.1 | The NDIS and Psychosocial Disability

Acknowledging Australia's broader disability ecosystem was 'inequitable, underfunded, fragmented, and inefficient' (Productivity Commission 2011, 5), the NDIS included people with severe mental illness as a target group as one mechanism for ensuring equitable supports. While largely welcomed by mental health advocates, early data suggested 'the roll-out of personal budgets for people with mental health problems tended to be less straight forward than for people with physical or learning disabilities' (S. Hamilton et al. 2016, 720). These concerns have persisted and even heightened as implementation of the scheme has progressed. For example, data from the National Disability Insurance Agency's (NDIA) Participant Dashboards shows people with psychosocial disability have been consistently and increasingly less able to access the scheme (26% successful psychosocial applications compared to 80% across the whole scheme) (NDIA 2025).

As of March 2025 there were 64,867 NDIS participants with a psychosocial disability as their primary disability category, with an average annual budget of AU\$87,800 (NDIA 2025). This is against an estimated 686,000 people with severe mental illness in Australia (Health Policy Analysis 2024). Among all groups within the scheme, participants with psychosocial disability report the lowest level of satisfaction regarding choice and control (Mavromaras et al. 2018). NDIS participants with psychosocial disability lag other disabilities on a range of measures. For example, their employment rate (11%) does not increase as a result of being on the scheme. Similarly, their social and community engagement rate is 31%, only improving 4% while being on the scheme, compared to an average engagement for all participants of 41% (NDIA 2023). Furthermore, NDIS participants with a psychosocial disability report significant under-utilisation of individual plans, indicating systemic challenges in accessing services, even when funded appropriately (Devine et al. 2022). They also report heightened challenges in applying for the scheme (Mellifont et al. 2023), and are recognised as facing personal, programmatic and market barriers that impact their capacity for choice (Wilson et al. 2022). During the rollout of the NDIS, many jurisdictions across Australia divested funding from their mental health systems, meaning that there is a lack of alternative supports available (Health Policy Analysis 2024).

From the outset, psychosocial disability sat uncomfortably within the broader legislative framework of the NDIS (Williams and Smith 2021). The episodic nature of significant mental health challenges, and with the recovery framework structuring mental health policy, sits at odds with the permanence eligibility requirement for entry on to the scheme (Smith-Merry et al. 2018). The recovery movement aligns with the social model of disability, standing in contrast to evaluative criteria for the NDIS which often requires a psychiatric (or other 'professional') diagnosis to access funding.

1.2 | Centring Lived Experience

While we often hear in the media about the operational issues facing participants, in this paper we focus in on participant expectations as a frame through which to consider scheme implementation and in particular the realities of the fuzzy concept of choice and control. We do this by recounting the voices of participants with psychosocial disability and carers so that these experiences are centred as the scheme continues to develop.

In the lead up to the full roll-out of the NDIS in 2020, research found future participants 'generally had a limited understanding of the NDIS and what it would mean for the organisation of the future health and social support of people with disability' (Lakhani et al. 2018, 796). This lack of understanding resulted in varied expectations of what the NDIS could offer. Since then, limited research has asked what expectations potential participants have in entering the NDIS, in contrast to outcomes.

The NDIA, who administer the NDIS, have committed to co-designing reforms alongside people with lived experience expertise (NDIA 2024c). By exploring potential expectation-experience gaps for people on the scheme, this article highlights ways the NDIS is and isn't currently meeting the lived needs of people with psychosocial disability and carers. It also highlights the ways the NDIA may consider improving its communications/information dissemination.

In comparing expectations with experiences there are three possible outcomes: expectations may be met (expectation confirmation); expectations may be exceeded (positive disconfirmation); or the experience may fall short of expectations (negative disconfirmation) (Oliver 1980). Originally developed in the field of marketing, (dis)confirmation framing has been utilised in a range of policy evaluations and offers a helpful tool for centring lived experience of people on the NDIS and their carers (Davies et al. 2024; Merriel et al. 2024).

As governments across the globe consider ongoing policy options and opportunities for people with significant mental health challenges, understanding the expectations people with psychosocial disabilities have and the ways these expectations are developed is increasingly important. An understanding of expectations allows policy makers to better address these expectations in the way supports are offered and, where expectations do not align with scheme aims, to better communicate with the population to ensure effective understanding.

2 | Methods

2.1 | Aim

The aim of this study was to develop a deeper understanding of the expectations NDIS participants with psychosocial disability and carers have of the scheme and how these expectations have eventuated into their experiences of the scheme. This study forms part of a larger research project tasked with developing an evidence base to inform policy directions and development and these results are important both as a barometer of participant experiences and as a resource for ensuring that scheme reforms meet participant needs.

2.2 | Study Design

This study employed an approach to data collection and analysis informed by a broadly interpretivist approach (Pulla and Carter 2018) where we understood the reality of participants' interpretation of the NDIS within the context of their own lives and experiences. In accordance with this approach, we utilised a qualitative research design to enable us to explore these unique experiences via interviews and analyse them utilising thematic analysis as outlined by Braun and Clarke (2023). To capture rich narratives, lived experiences, and in-depth meaning making, semi-structured interviews were conducted with NDIS participants with psychosocial disability and carers/informal supports. Given there has been scant research into the expectation-to-conclusion continuum for this population, a qualitative approach was deemed most appropriate.

The study design, including the interview schedule, was developed in collaboration with an advisory group of people with lived experience of mental health challenges, carers, service providers and academics. This group also provided feedback on coding and analysis. Reporting follows the Consolidated criteria for reporting qualitative research (COREQ) checklist (Tong et al. 2007).

2.3 | Sampling and Data Collection

An initial round of participant recruitment was conducted via social media posts and via email contact lists, held by the NDIA, of NDIS participants who had opted in to receive information about potential studies. An initial 145 responded to these calls for participation. After the first tranche of randomly selected interviews (15 completed), purposive sampling was conducted to ensure a broad representation across contexts, ages, genders and engagement with the NDIS.

Interviews took place between November 2024 and April 2025, conducted via phone or Zoom (depending on the preferences of the interviewee). Participants were first asked to describe what they had anticipated prior to applying for the scheme, and what they had understood about what the scheme could offer them. They were then invited to reflect on their experiences of the scheme, both positive and negative.

Average length of the interviews was 57 min, ranging from 21 to 84 min. Audio from interviews was recorded with

participant consent and transcribed verbatim to ensure accuracy. Participants were given \$50 gift cards in recognition of their time.

2.4 | Data Analysis

After a process of familiarisation with the data, initial codes were developed utilising NVivo, which were then grouped into themes in collaborative discussion between researchers. These initial themes were presented to the advisory group, who provided input and direction. These themes were reviewed and refined before being contextualised within the broader research literature.

2.5 | Ethics and Positionality

Ethics approval was provided by the University of Sydney Human Research Ethics Committee. Pseudonyms are used throughout this research to protect identities. Both researchers have extensive experience working alongside people with lived experience of mental health challenges.

3 | Findings

3.1 | Participants

Thirty NDIS participants and 18 carers/informal supports took part in interviews. Every state or territory across Australia was represented by at least one interviewee. There were 8 males and 22 females within the NDIS participant group, with one person identifying as transgender. Two NDIS participants and two carers had a language other than English as their primary language.

Taken as a whole, results showed that prior to engaging with the NDIS, participants had mixed expectations of the scheme, often formed with a lack of accessible information and confusion about what the scheme could offer. Participants reported that expectations were further clouded by the reality that people often applied for the NDIS during periods of acute illness. When expectations were expressed, these were often unmet in reality, with interviewees reporting a lack of choice and control, frustrations with the system, a lack of appropriate services and encounters with unscrupulous or underperforming providers.

4 | Expectations of the NDIS

Interviewees who expressed expectations had a wide range of hopes for the NDIS. These can largely be grouped under (1) an expectation of choice and control, (2) services accessed through an easy-to-navigate system, (3) quality supports that enabled personal recovery and (4) integrity in those services.

Before exploring how these expectations were either met, or not met, it is important though to establish the process by which expectations were developed in the first place. Study participants were asked to reflect on their expectations of the scheme prior to entry, and how the scheme had met/not met their expectations.

A complex picture emerged regarding how expectations were initially developed.

While some participants expressed clear expectations of the scheme prior to entering it, others applied for the scheme with *little-to-no* expectations, reflecting a lack of awareness about what the NDIS could potentially offer. When exploring the process by which expectations had been developed, three key themes emerged: (1) a lack of accessible information to help navigate the planning process, (2) confusion regarding what supports are NDIS funded, and what services are supposed to be covered by other systems and (3) the reality of being unwell at the time of application and thereby lacking motivation and/or awareness.

4.1 | A Lack of Accessible Information

Almost all interviewees spoke of the NDIS as a difficult system to navigate, a theme reflected in a range of previous studies (D. Hamilton et al. 2024; McKenzie and Smith-Merry 2022). For many individuals, this was perpetuated and exacerbated by a lack of clear, accessible information from the outset, significantly impacting interviewees' abilities to develop informed expectations about what the scheme could offer. One NDIS participant who has been on the scheme since 2022 reflected on the process of joining, and her experiences since:

In the beginning I didn't really have any expectations because I didn't know what I was walking into. But having since been on it for quite a few years now I'm just overwhelmed by it all. I mean it's really confusing. Half the time we don't even know what we're doing, and no one seems to be able to tell us what we're supposed to be doing.

(P23)

The confusion described was reiterated in most interviews, with significant impacts. Another participant, for example, shared her experience of plan development in her first months on the NDIS:

When you first apply for NDIS, they give you information – they give you two lists, essentially, and you have to, as a participant and your support workers, work out, well, where do I sit within each category? It's a really difficult thing to do because I don't think I would have accessed NDIS if I hadn't had my parents sit down with me and go, 'this is the category that you fit in, and this is the evidence that we need to submit to NDIS.'

(P14)

This participant was fortunate to have her parents walk her through the process of listing her impairments and appropriate supports, as per the requirements. Not everyone, however, has this kind of support available. Many participants in this study described a lack of informal networks that can provide this

assistance. One participant (P24) in South Australia exemplified the impact this lack of information can cause. When the NDIS was rolled out in Adelaide, funding for the service she had previously been accessing was folded into the scheme. She applied for the NDIS with the assistance of a public psychiatrist but was denied. 'I didn't know I could reapply' she said, 'I thought it was only a one and done sort of thing if they denied you that you couldn't access anything else'. Believing she was only able to apply once, she then lived with no support services between 2016 and 2019, largely confined to her home with deteriorating mental health.

Finally, one participant spoke of a successful application, in which they were able to source information in a way that was helpful for them:

...when I finally got on board with the NDIS, and it was my third attempt, I already had a pretty good idea of what it was that I needed, and therefore I could confidently ask for what it was that I thought could also help me with different challenges that I was having.

(P16)

This participant had gone through the process twice as a carer for two friends before she applied for the NDIS for herself, and this enabled her to navigate the process. She also made significant use of online groups not connected with the NDIS to provide her with advice.

4.2 | Confusion Regarding What Supports Are NDIS Funded

The NDIS aims to clarify what supports and services can be accessed within the Scheme, as opposed to what should be accessed through other systems. However, when considering psychosocial disability, the distinction between what is a 'health' requirement and what is considered 'social inclusion', for example, is blurred. As people formed their expectations of the scheme, one theme that emerged was a deep confusion regarding how the NDIS could provide support. One interviewee, a carer for her daughter, reflected on the process of trying to understand available options and the impact of this confusion. She shared:

I think for the average Australian with psychosocial disability, there is a huge expectation that the NDIS will help them lead better lives, but they are unable to kind of differentiate between what's disability funded, what's social services funded, and what should be health funded. Those buckets really create problems for people with psychosocial disability.

(C1)

This carer was able to draw on significant community resources to support her daughter through the process. In contrast, many participants reported being socially isolated. One interviewee, for example, was an NDIS participant with physical and psychosocial disabilities. Despite having been on the

NDIS since 2018 she reflected on the fact that she is still largely unaware of how the NDIS could support her with her psychosocial disability and thus struggled to form expectations. She stated:

I don't know what's out there that might be able to help psychosocial disability when depression clouds my whole life at the moment. So I don't know what I was hoping for and what I was looking for, I just was told 'there is help so let's try and get help.'

(P22)

Finally, some NDIS participants signed up expecting certain services, but were surprised when these services did not eventuate in the ways they had hoped. One participant reported having a very smooth application process with the assistance of an advocacy group. This advocacy group helped shape his expectations, however even so there were expectations that were not in line with reality. Reflecting on the journey since his 2019 application, he shared:

There's a lot of things out in the community that I can no longer access because I have an NDIS plan. So, I used to attend mental health community groups and stuff. I'm no longer allowed to access them, because I have an NDIS plan... So, I think, I wasn't expecting that. I was expecting maybe some of my other needs, like my psychology or something like that, would be covered.

(P25)

4.3 | The Realities of Mental Ill Health

Finally, when considering how expectations were developed, it is important to note that some participants recounted applying for the NDIS during acute periods of mental ill-health. Reflecting on his application process, one participant shared:

Cognitively I wouldn't have been fantastic. I would have been feeling terrible.... I felt a bit intimidated by it all and I didn't really have any expectation from it... When you are unwell, depressed, you don't care.

(P5)

For this participant, the lack of expectations revolved around what services could be offered. Beyond what the NDIS could provide, another participant reflected that in the complexity of her mental health challenges she was not able to identify what could help at all:

I had no idea when I went on NDIS, because I don't know what can help because I just feel so bad. It feels like nothing's going to ever help. So I don't know what to ask for because I don't know what I can ask for because I don't know what will help.

(P22)

The realities of significant mental health challenges meant that this participant struggled to form clear expectations. At its most extreme, one carer reported on the impact coercion can have on how participants approach potential services. Reflecting on his brother's application to the NDIS, this carer shared:

My brother signed up to it because basically he's had 20 years of being on the CTO (Community Treatment Order) and being taken to mental health institutions against his will and so on. So, when presented with something like this, he sees it as being part of what you have to do...

(C19)

When combined, the lack of accessible information, the deep confusion about what services and supports are supplied by the NDIS, and the realities of significant mental health challenges all provide a complex picture of expectation development.

5 | Expectation-Experience (Dis)confirmations

5.1 | Expectation Confirmations and Positive Disconfirmation

For six interviewees, the NDIS had largely met their expectations (confirmation) or their expectations had been exceeded (positive disconfirmation). In some instances, this was coupled with moderately high expectations of the scheme. For example, one carer was hoping for accommodation support for his brother, and this had been achieved. Similarly, an NDIS participant who also experiences a physical disability found the NDIS had met his expectations regarding his mental health:

I was expecting that the NDIS would help me with that [physical disability] and also help me with mental health. It's definitely helped me with the mental health. It's helped me.

(P17)

Almost all participants were able to offer examples of where they thought the Scheme was working well for them. These ranged from having reliable support people to assist them to engage in the community and employment (P2, P18, P28, C18, C19), through to supported accommodation arrangements (C2, C3) and allied health interventions (C17, P21).

While these interviewees offered general comments regarding some of their expectations being met, others were quick to caveat their expectations confirmation. For example, an NDIS participant felt as though her expectations had largely been achieved, sharing '[My expectations] have been met, and I'm in very grateful... so far that it's been above and beyond what I have expected at the beginning'. This was caveated as she went on to say:

However, I'm like, pretty much, I guess, everyone else on the NDIS, I'm very fearful in case someone sends me a letter with 28 days warning to compile

evidence for re-entry... So that's the only thing I'm very worried about, but it has generally met my expectations, yes.

(P21)

It is positive that a number of people interviewed shared that their experiences of the NDIS had been what they were hoping for.

For some there remain sharp discrepancies between participants' expectations prior to joining the scheme and their experiences once on the NDIS. This was reflected in participants' (1) ongoing lack of choice and control, (2) frustrations with the system, (3) lack of appropriate and available supports and (4) experiences with unscrupulous and/or inept providers.

5.2 | Ongoing Lack of Choice and Control

For several participants in this study, their expectations of choice and control had largely been unmet. For example:

The NDIS is about choice and control, and it's enabling participants to be able to have as normal a life as possible.... That was the major hope that I had...

(P16)

Expecting there to be a strong element of choice and control, P16 assumed that she would be able to utilise funding in ways she understood would be best for her mental health. One of her goals was to obtain a driver's licence to foster community access. She was surprised when driving lessons were knocked back in her plan, stating:

... But having support like having driving lessons on NDIS is really, really going to benefit me. Not only will I be able to take myself out, I'll be able to take other people out as well, and that will improve my time with my boyfriend. We'll be able to participate in society together without having the support worker there. Those were my hopes, dreams and goals.

(P16)

Similarly, other participants spoke of surprise at being knocked back for funding they saw as key to their personal recovery journey. For one participant, the reforms of October 2024 significantly changed her NDIS experience, with equine and music therapies removed. For her, this directly contrasted with the expectations she had prior to applying:

My understanding was that NDIS was about trying to assist with having a better quality of life. And for me, if it comes down to funding and if they funded therapy and nothing else, I would accept therapy and nothing else. Because the therapy is what helps me with my day-to-day existence.

(P24)

Having this funding removed was a source of significant stress, and left her largely house bound. This was reflected further by P26, who shared her expectations of choice and control and how they had not been met:

I was eventually told you have no choice because everything that exists that you're currently getting services for will not deal with you anymore unless you've got NDIS. So, I had no choice... my expectations would be it would simple, it would be choice and control, that my support coordinator would handle all this difficult stuff, deal with people, and that. None of that has been the case. None of it whatsoever. It's been the most traumatising experience.

(P26)

For P26, the NDIS itself has been a source of trauma. This was amplified by her rural context. At the time of conversation, she and her son were largely isolated and house bound.

5.3 | Frustrations With the System

Further negative expectation disconfirmations were centred around the complexities of the system. While quotes above related to how the complexities of the system impact participants' expectation development, the following examples show how expectations were unmet because of this system.

A number of participants expressed frustration at how their plans were developed. Lilly shared, for example, her frustration at having strict boundaries regarding what could and could not be accessed:

We were told at the time that it was going to be the catchall - like the one-stop shop so that we wouldn't have to go around chasing, well, this comes from this place, and this comes from that place. You get a little bit of funding here, a little bit of funding there... I didn't expect it to be quite so definite in, 'oh, we will fund this, but we won't fund this...'

(P12)

P12's expectation was that she would be able to access flexible funding over which she retained control. When this was not the case, she was disappointed in the scheme. Similarly, P19 found that bureaucratic delays and excessive administrative demands made the system fraught for participation:

I thought it would be the golden life changer of everything in my life. I didn't expect it to be as traumatic and troublesome as it has been for me... it definitely has been life-changing, but it has come at a cost. For instance, delayed support. My situation deteriorating quite badly. I was also in a family situation that was becoming increasingly abusive...

Sometimes these systems don't realise the impact that they can have on people's lives.

(P19)

This comment further reiterates the 'caveated' nature of expectation confirmation seen above. For P19, the scheme has been 'life-changing', but he went on to offer multiple caveats to that condition.

One final way in which the system itself did not meet expectations was the process of change. For some people, there was constant change that felt hard to keep up with. For others, reflecting on recent legislation changes showed how their expectations were being jeopardised. One participant shared:

I guess my expectation was that it was always once you applied, once you got approval, you're on it for life because you'd already gone, jumped through the hoops. I know the legislation has changed so they can now kick us off.

(P24)

P24's fear regarding getting 'kicked off' was demonstrative of an overall lack of trust that the NDIS was setup to support her for life.

5.4 | Lack of Support and Services

When discussing negative expectation disconfirmations, participants reflected on both the lack of supports available and confusion regarding how supports functioned and how they could be accessed.

As reported above, lack of understanding regarding available supports hindered expectation setting. This confusion continued however beyond the initial phase of setting expectations and significantly impacted some participants' experiences. One interviewee shared, for example:

I was overwhelmed. I was approved and then they're like, okay and you can go into these different avenues, to find ... what the fuck do I do with them?

...

(P6)

This participant found herself handed a large bucket of money, with very little guidance regarding how to use it, and what she could access. She was told to call services, but as someone with severe anxiety she spent 2 months unable to pick up the phone. Eventually she managed to get on to a service who supported her in her referrals, and her experience with the NDIS changed. 'I've stayed with them the whole time' she said, 'and they've been brilliant.' Another NDIS participant shared a similar experience:

So it was my LAC (Local Area Coordinator) who basically suggested we would (sign up)... and my

wife. But yeah, I didn't really have any idea of what was available or what I could make use of.

(P1)

P1 was unsure how to utilise funding, and found his LAC was unable to provide guidance as they too were unsure. For others still, funding was available for appropriate supports but accessing them proved difficult. This was particularly the case for multiple participants in rural and regional areas. One participant shared for example her experience in the outer suburbs of Adelaide, stating:

when I was in the Western Suburbs, I had all my stuff I needed covered, like disability support and all that stuff. It was offered through different organisations in government programmes. But moving into these areas in the south where I am now, there aren't the same support services. So, I went from high intense support to absolutely nothing.

(P6)

P6 was one of five participants who reflected on the impact on services accessibility of living in regional and rural areas.

5.5 | Experiences With Unscrupulous and/or Inept Providers

Finally, negative expectation disconfirmation was evident in participants' experiences with unscrupulous and/or inept providers. One carer reported that the system continuously overlooked her brothers' accommodation needs and was let down by multiple providers. She shared how:

these so-called registered companies of providers are not monitored. It doesn't seem to be any consequence when you raise issues that you're observing and when I say that, I mean direct observation, I'm meaning reports. they're not evidence based, they're very poor quality and nothing seems to be done about it when you raise it with the Quality and Safeguarding Commission.

(C7)

Ultimately, she concluded that for her, the system was set up in a way in which the guardians and the participants are 'attacked' rather than unscrupulous providers. Another participant shared the impact of multiple providers whom she reported had committed fraud. When asked to reflect on her expectations of the scheme, she shared:

I just thought they would actually help so much to improve the quality of my life, but I've had so many issues over the last four years of various natures that have actually caused - impacted my mental health quite severely. Over the last four years, there have been various issues on different levels. I've had fraud

committed on my funding, primarily by support coordinators, on three separate occasions by three different service providers.

(P7)

P7 joined the NDIS to support her with her mental health, but found that the providers she accessed with NDIS funding had now impacted her mental health 'quite severely'.

6 | Discussion

The aim of this study was to develop a deeper understanding of the expectations NDIS participants with psychosocial disability and carers have of the scheme, and how these expectations have eventuated into experiences. We found that participants shared an expectation of choice and control, a need for services accessed through an easy-to-navigate system, quality supports that enabled personal recovery and integrity in those services. Findings also showed there is a complex process of expectation development, with participants describing a lack of accessible information to navigate the application process and significant confusion regarding what supports the NDIS could provide. These results build on other studies both within psychosocial disability and more broadly and confirm that issues raised in earlier studies are ongoing despite attempts to improve the scheme (Hancock, Bresnan, et al. 2018; Stewart et al. 2020).

Stewart et al. (2020) found that people with psychosocial disability accessing the NDIS had limited understanding of the scheme, potentially reflecting a lack of accessible information. Specifically, language complexity was noted as a barrier to understanding, as was locating accurate information. We too found a lack of accessible information, and add specific confusion regarding what supports are available. The NDIA introduced Recovery Coaches as a new support in 2020 in part to deal with the ongoing issues around poor understanding of the scheme, and to better connect people with supports while foregrounding recovery (NDIA 2024b). Evaluations of the Recovery Coach initiative show their involvement is generally positive for clients, but our results show they are only one part of the picture (Elmes et al. 2023).

As the NDIS continues to promote a model of choice and control, there is a need to ensure potential participants and carers are well-informed about what the scheme offers, access options, and plan development and that this information is provided in a way that corresponds with the recovery journey of individual participants.

Findings focus our attention on the importance of having clear strategies for early planning and communication about what the NDIS can offer participants. Adding to the literature, this study shows how expectation development was complicated by the presence of acute mental illness, often present at the point of application. To account for this, there is a need for services to provide wraparound services that include carers and informal supports every step of the way. In one national survey, 70% of carers of people with NDIS plans reported being involved in planning and decision making. Concurrently, 40% of carers felt they were not provided with necessary information for their

role. Carers NSW concluded 'although service providers engage with carers and involve them in the delivery of care, their needs as carers are often not taken into account, and their expertise is often disregarded by NDIS services' (Carers NSW 2025, 23). This, however, is further complicated for those who reported no connection with carers, relying solely on paid support. There is a distinct lack of research exploring the experiences of people attempting to apply for the scheme in the absence of informal support.

There is also a need to take seriously the journey participants go on as they first encounter the scheme, and determine which supports are right for them. This is an evolving process and not just a set-and-review process. A phased approach to initial engagement with the NDIS would enable planning to address both the acute illness of many participants and the poor understanding of the scheme discussed above. This could involve an initial assessment resulting in an initial plan, followed by a longer-term planning process which reflects their ongoing needs for support. Accounts of recovery journeys have shown that needs change over time, which means that plans and supports should also change, particularly as people move from the challenging phases of early recovery (Hancock, Smith-Merry, et al. 2018).

The 2023 NDIS Review recommended the development of a Psychosocial Recovery Navigator role. The Navigator is to provide a central point of connection between participants and potential services. As outlined in the review, Navigators 'should work with participants to understand their journey and what treatments and supports they have tried. They should help participants identify evidence-based supports to live the life they want to lead' (Commonwealth of Australia 2023, 133). Our findings show this is essential for participants' navigation and personalisation of supports. We recommend the Psychosocial Recovery Navigator, while important at all phases of an individual's engagement with the NDIS, is the central support provided when participants enter the scheme, and they are funded as standard for participants with psychosocial disability. It is essential that these roles have strong recovery competencies, as identified by Brophy et al. (2021).

Once on the NDIS, a small number of participants stated their expectations had been largely met (expectation confirmation). Despite this, most participants highlighted their experience of the NDIS had not met expectations (negative expectation disconfirmation). For many participants, these negative disconfirmations once again centred around a lack of choice and control. Such concerns are widespread and have been reported in previous research beyond psychosocial disability (Smethurst et al. 2021; Wakely et al. 2023). In the context of psychosocial disability, Hamilton et al. (2024) recommends that to remedy this, a focus on recovery, a trauma-informed approach, a psychosocial disability attuned workforce and the centring of lived experience voices are needed.

Findings related to frustrations with the overall system also resonate with and develop extant research (McKenzie and Smith-Merry 2022). This study adds to the literature a focus on how participants expected systems to function, noting some had anticipated a 'one-stop-shop' for support requirements which would be easy to navigate and permanently available. The NDIS

is a Federal Government-funded and implemented programme, which interacts with numerous other programmes at state and local levels. These complex interfaces form the backdrop for many frustrations NDIS participants recount, with collaborative and coordinated care across systems often lacking (B. Williams et al. 2024).

Furthermore, in many ways it is difficult to ascertain with precision the extent expectation disconfirmations are caused by failures of the NDIS, and which are caused by other systems. As reforms to the NDIS continue, further research is required to more fully understand these system interactions, and the way other systems may support the operation of the NDIS for this group.

Finally, it is evident that both communication and practices need to be clearer. There is an urgent need for the NDIS to consider both the content and mode of communication channels it is providing for potential participants and carers. Expectation management should be considered at every point of a participant's journey, with clear and accessible information provided regarding the role and scope of the Scheme. It is important that there is improved psychosocial orientation for the National Disability Insurance Agency, and the services that provide supports to this group so that there is understanding of people with psychosocial disability as a participant group. This will necessitate training for all agency staff so that they have a base understanding of psychosocial disability. This competency needs to be extended to those who provide supports, with careful regulation that supports providers to offer recovery-oriented best practice, quality and safeguarding.

7 | Limitations

This study's qualitative process does not seek to capture generalisable trends across Australia. Themes drawn out here should not be taken as indicative of broader outcomes, and future research should explore expectation management more broadly. While use of interpreters was available, only one participant utilised this, meaning culturally and linguistically diverse populations are underrepresented. We did not ask participants to share whether they identified as Aboriginal or Torres Strait Islander. Only one participant self-disclosed being part of the LGBTQIA+ community. Most interviews were conducted via phone, which enhances accessibility in some ways, but hinders it in others. Those without access to technology may not have heard about the study, or may not have had the means to participate.

8 | Conclusion

Despite a complicated process of establishing expectations, and then often failing to meet expectations when set, almost all participants voiced gratitude for the NDIS. For some it had been life-changing, and at least one individual, 'life-saving'. It is hoped insights from the voices in this study will be used in the ongoing process of reform. This begins with clear, accessible communication pathways that provide accurate, timely information to people with psychosocial disability and carers. There should be ongoing work to simplify the system, expand

the availability of high-quality supports and ultimately invest in elevating choice and control for participants.

Author Contributions

Joel Hollier: conceptualization, investigation, writing – review and editing, writing – original draft, methodology, validation, formal analysis. **Jennifer Smith-Merry:** conceptualization, investigation, writing – review and editing, methodology, validation, formal analysis.

Funding

This work was supported by the Australian Research Council, IL230100154.

Acknowledgement

Open access publishing facilitated by The University of Sydney, as part of the Wiley - The University of Sydney agreement via the Council of Australian University Librarians.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

References

- Abbott, D., E. Coleman-Fountain, and H. Humphrey. 2025. "Disabled People Negotiate Gender, Sexual Identity and Self-Directed Social Care Support in England: How Does Choice and Control Operate?" *Critical and Radical Social Work* 13, no. 1: 112–128. <https://doi.org/10.1332/20498608Y2024D000000043>.
- Braun, V., and V. Clarke. 2023. "Toward Good Practice in Thematic Analysis: Avoiding Common Problems and Be(Com)ing a Knowing Researcher." *International Journal of Transgender Health* 24, no. 1: 1–6. <https://doi.org/10.1080/26895269.2022.2129597>.
- Brophy, L., C. Brasier, E. Fossey, N. Whittles, and M. Jacques. 2021. *The Future Horizon: Good Practice in Recovery-Oriented Psychosocial Disability Support. Stage Two Report*. Mental Health Victoria and La Trobe University.
- Carers NSW. 2025. *2024 National Carer Survey Summary Report*. Carers NSW. <https://www.carersnsw.org.au/about-us/our-research/carer-survey>.
- Commonwealth of Australia. 2023. *Working Together to Deliver the NDIS: Independent Review Into the National Disability Scheme Final Report*. Commonwealth of Australia, Department of the Prime Minister and Cabinet.
- Cukalevski, E. 2019. "Supporting Choice and Control—An Analysis of the Approach Taken to Legal Capacity in Australia's National Disability Insurance Scheme." *Laws* 8, no. 2: 8. <https://doi.org/10.3390/laws8020008>.
- Davies, A., M. Larkin, L. Willis, et al. 2024. "A Qualitative Exploration of Women's Expectations of Birth and Knowledge of Birth Interventions Following Antenatal Education." *BMC Pregnancy and Childbirth* 24, no. 1: 875. <https://doi.org/10.1186/s12884-024-07066-x>.
- Devine, A., H. Dickinson, M. Rangi, et al. 2022. "Nearly Gave Up on It to Be Honest": Utilisation of Individualised Budgets by People With Psychosocial Disability Within Australia's National Disability

- Insurance Scheme." *Social Policy & Administration* 56, no. 7: 1056–1073. <https://doi.org/10.1111/spol.12838>.
- Dickinson, H., and S. Yates. 2023. "A Decade on: The Achievements and Challenges of the National Disability Insurance Scheme's Implementation." *Australian Journal of Social Issues* 58, no. 3: 460–475. <https://doi.org/10.1002/ajis.4.277>.
- Elmes, A., R. Campaign, E. Wilson, C. Brown, J. Kelly, and P. Campbell. 2023. *Psychosocial Recovery Coaching: Client Outcomes and Experiences*. Swinburne University of Technology. <https://doi.org/10.26185/apjw-6x94>.
- Hamilton, D., N. Hancock, and J. N. Scanlan. 2024. "Impeded Choice and Control Within the NDIS: Experiences of People Living With Psychosocial Disability." *Disability & Society* 39, no. 12: 3312–3333. <https://doi.org/10.1080/09687599.2023.2263629>.
- Hamilton, S., J. Tew, P. Szymczynska, et al. 2016. "Power, Choice and Control: How Do Personal Budgets Affect the Experiences of People With Mental Health Problems and Their Relationships With Social Workers and Other Practitioners?" *British Journal of Social Work* 46, no. 3: 719–736.
- Hancock, N., A. Bresnan, J. Smith-Merry, J. Gilroy, I. Yen, and G. Llewellyn. 2018. *Mind the Gap: NDIS and Psychosocial Disability—The Victorian Story*. Psychiatric Disability Services of Victoria and SalvoConnect.
- Hancock, N., J. Smith-Merry, G. Jessup, S. Wayland, and A. Kokany. 2018. "Understanding the Ups and Downs of Living Well: The Voices of People Experiencing Early Mental Health Recovery." *BMC Psychiatry* 18, no. 1: 121. <https://doi.org/10.1186/s12888-018-1703-1>.
- Health Policy Analysis. 2024. *Analysis of Unmet Need for Psychosocial Supports Outside of the National Disability Insurance Scheme: Final Report*. Health Policy Analysis.
- Hummell, E., M. Foster, K. Burns, and S. H. Rimmer. 2025. "Policy Shifts and Drifts: From Intention to Implementation of Australia's National Disability Insurance Scheme." *Australian Journal of Public Administration*. <https://doi.org/10.1111/1467-8500.12689>.
- Lakhani, A., D. McDonald, and H. Zeeman. 2018. "Perspectives of the National Disability Insurance Scheme: Participants' Knowledge and Expectations of the Scheme." *Disability & Society* 33, no. 5: 783–803. <https://doi.org/10.1080/09687599.2018.1442321>.
- Mavromaras, K., M. Moskos, S. Mahuteau, et al. 2018. *Evaluation of the NDIS: Final Report (Australia)*. Department of Social Services. <https://apo.org.au/node/143516>.
- McKenzie, K., and J. Smith-Merry. 2022. "Responding to Complexity in the Context of the National Disability Insurance Scheme." *Social Policy and Society* 22, no. 1: 139–154. <https://doi.org/10.1017/s147474642000562>.
- Mellifont, D., N. Hancock, J. N. Scanlan, and D. Hamilton. 2023. "Barriers to Applying to the NDIS for Australians With Psychosocial Disability: A Scoping Review." *Australian Journal of Social Issues* 58, no. 2: 262–278. <https://doi.org/10.1002/ajis.4.245>.
- Merriel, A., M. Toolan, M. Lynch, et al. 2024. "Codesign and Refinement of an Optimised Antenatal Education Session to Better Inform Women and Prepare Them for Labour and Birth." *BMJ Open Quality* 13, no. 2: e002731. <https://doi.org/10.1136/bmjopen-2023-002731>.
- NDIA. 2023. *Psychosocial Disability Summary: June 2023*. National Disability Insurance Agency. <https://dataresearch.ndis.gov.au/reports-and-analyses/participant-dashboards/psychosocial>.
- NDIA. 2024a. *Accessing Mental Health Supports*. NDIA. <https://www.ndis.gov.au/understanding/how-ndis-works/psychosocial-disability/accessing-mental-health-supports>.
- NDIA. 2024b. *Psychosocial Recovery Coach Information*. NDIA. <https://www.ndis.gov.au/media/2412/download>.
- NDIA. 2024c. *Working Together to Improve the NDIS*. NDIA. <https://www.ndis.gov.au/community/making-ndis-stronger-together/co-designing-reform#approach>.
- NDIA. 2025. *Psychosocial Data to March 2025 [Dataset]*. National Disability Insurance Agency. <https://dataresearch.ndis.gov.au/reports-and-analyses/participant-dashboards/psychosocial>.
- Oliver, R. L. 1980. "A Cognitive Model of the Antecedents and Consequences of Satisfaction Decisions." *Journal of Marketing Research* 17, no. 4: 460–469. <https://doi.org/10.1177/002224378001700405>.
- Productivity Commission. 2011. *Disability Care and Support: Productivity Commission Inquiry and Report (No. 54)*. Productivity Commission.
- Pulla, V., and E. Carter. 2018. "Employing Interpretivism in Social Work Research." *International Journal of Social Work and Human Services Practice* 6, no. 1: 9–14.
- Smethurst, G., H. M. Bourke-Taylor, C. Cotter, and F. Beauchamp. 2021. "Controlled Choice, Not Choice and Control: Families' Reflections After One Year Using the National Disability Insurance Scheme." *Australian Occupational Therapy Journal* 68, no. 3: 205–216. <https://doi.org/10.1111/1440-1630.12715>.
- Smith-Merry, J., and K. J. Chang. 2025. "Equity First: Mapping Who Gets What Is Essential to Re-Designing the NDIS." *Medical Journal of Australia* 222, no. 3: 131–132.
- Smith-Merry, J., N. Hancock, J. Gilroy, G. Llewellyn, and I. Yen. 2018. "Mind the Gap: The National Disability Insurance Scheme and Psychosocial Disability (Australia)." <https://apo.org.au/node/130666>.
- Stewart, V., K. Visser, and M. Slattery. 2020. "Supporting Choice, Recovery, and Participation: Clear and Easy to Understand Information Is the Key to NDIS Access for Those With Psychosocial Disability." *Journal of Social Inclusion* 11, no. 2: 33–46.
- Tong, A., P. Sainsbury, and J. Craig. 2007. "Consolidated Criteria for Reporting Qualitative Research (COREQ): A 32-Item Checklist for Interviews and Focus Groups." *International Journal for Quality in Health Care* 19, no. 6: 349–357.
- Wakely, L., E. Green, A. Little, et al. 2023. "The Lived Experience of Receiving Services as a National Disability Insurance Scheme Participant in a Rural Area: Challenges of Choice and Control." *Australian Journal of Rural Health* 31, no. 4: 648–658.
- Williams, B., R. Charleston, S. Innes, and S. McIver. 2024. "Understanding Collaborative and Coordinated Care in a Mental Health and Well-Being Context: Essential Elements for Effective Service Integration." *International Journal of Mental Health Nursing* 33, no. 2: 397–408. <https://doi.org/10.1111/inm.13244>.
- Williams, T., and G. Smith. 2021. "Mental Health and the NDIS: Making It Work for People With Psychosocial Disability." In *The National Disability Insurance Scheme*. Springer. https://doi.org/10.1007/978-981-16-2244-1_9.
- Wilson, E., R. Campaign, S. Pollock, L. Brophy, and A. Stratford. 2022. "Exploring the Personal, Programmatic and Market Barriers to Choice in the NDIS for People With Psychosocial Disability." *Australian Journal of Social Issues* 57, no. 1: 164–184. <https://doi.org/10.1002/ajis.4.154>.