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Understanding the NDIS experience: a qualitative study on participant perspectives

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ABSTRACT

Background. The National Disability Insurance Scheme (NDIS) looms large in the lives of Australians with disability. This qualitative study aimed to better understand the experiences of NDIS participants interacting with the scheme in the management of their supports. **Methods.** Thirteen adult NDIS participants, including 10 people with neurological disability, were interviewed. Interviews were audio recorded and transcribed, and interview data were analysed using constructivist grounded theory methods. **Results.** Analysis provided insights into NDIS participants experiences. Participants described improvements in their lives since joining the scheme, alongside experiences of frustration with the challenges of navigating the scheme. Three key themes, and associated sub-themes, were identified: (1) living a better life, (2) losing trust in the NDIS, and (3) hopes for the future. **Conclusions.** The findings highlight a complex interplay of gratitude alongside fear and frustration among NDIS participants with complex disability. While participants welcomed increased choice and control, they also expressed concerns about inequities and difficulties in navigating the scheme. The importance of supportive interpersonal relationships, or 'allies', in successfully navigating the NDIS was emphasised. For reforms to be effective and responsive, it is critical they are designed and implemented in partnership with people with lived experiences as NDIS participants.

Keywords: acquired brain injury, cerebral palsy, disability, lived experience, multiple sclerosis, National Disability Insurance Scheme, neurological disability, qualitative research.

Introduction

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) outlines the right of people with disability to exercise self-determination and make decisions about their own lives. In recognition of these rights, there is currently an international shift towards personalised funding models that strive to increase choice and control for people with disability (Gadsby *et al.* 2013; Robinson *et al.* 2022). In Australia, the National Disability Insurance Scheme (NDIS) is a key mechanism for meeting these obligations. The *National Disability Insurance Scheme Act 2013* (Cth) created an entitlement to 'reasonable and necessary' individualised funding for eligible Australians (i.e. those under 65 years of age who were either born with, or acquired, a permanent and significant disability, referred to as 'scheme participants'). The National Disability Insurance Agency (NDIA) assesses needs and allocates individual budgets for NDIS participants to purchase services and supports aligned with their goals. Research in countries with comparable entitlements has found that participants experience increased participation in social and economic activities (Lord and Hutchison 2003) and increased satisfaction with services (Crozier *et al.* 2013).

Despite the NDIS being a significant step towards meeting obligations in the UNCRPD, challenges and criticisms of the scheme have occurred throughout the first 10 years since it was legislated (Australian National Audit Office (ANAO) 2016; Hansard, Commonwealth Government of Australia 2018; Commonwealth of Australia, Department of the Prime Minister and Cabinet 2023). Previous research on NDIS experiences suggests that successfully navigating the scheme's administrative systems requires specific skills and resources (Carey *et al.* 2021; Devine *et al.* 2022). The complexity of the system presents significant challenges for participants, who must make multiple decisions across a wide range of service options and providers (Heneker *et al.* 2017). As a result, an individual's access to these skills and resources influences both the burden of the process and their ability to obtain the 'personalised' supports the scheme was designed to provide (National Disability Insurance Agency (NDIA) 2018; Malbon and Carey 2021). One key resource that facilitates successful NDIS navigation is access to supportive interpersonal relationships, such as family members, friends, support staff, or advocates (Mitchell 2015; Fleming *et al.* 2019). Research indicates that individuals with strong support networks are more likely to experience positive outcomes, including greater choice and control (Williams and Porter 2017; Meltzer and Davy 2019). In contrast, individuals without informal support networks may face additional barriers in accessing and utilising the scheme (Collings *et al.* 2016). Given the importance of skills and resources in achieving positive outcomes, it is unsurprising that the administrative burdens placed on participants contribute to inequities within the system (Carey *et al.* 2021; National Disability Insurance Scheme (NDIS) 2021; Duffy and Brown 2023).

Furthermore, it has been argued that people with complex disability, such as neurological disability with associated cognitive and communication difficulties, face additional challenges navigating the scheme (Skinner *et al.* 2023). While there is limited research conducted with this population, available studies suggest that people with brain injury may have difficulty understanding or gaining the knowledge required to take responsibility for managing their funding and support (Lakhani *et al.* 2018; Skinner *et al.* 2023). More specifically, a study conducted by Foster *et al.* (2021) found that people with brain injury faced multiple obstacles across the continuum of funding management, including acquiring and implementing funding and managing day-to-day service provision. Indeed, Blaxland *et al.* (2020) found that only 4 and 7% of people with brain injury and stroke self-managed their NDIS funding plans and only 8 and 13% partially managed their plans. Unsurprisingly, as with the broader NDIS participant population, people with neurological disability are dependent upon the support of family and others to navigate the NDIS system and manage their NDIS plans to secure the necessary funding and support (Stephens *et al.* 2014; Foster *et al.* 2021; Skinner *et al.* 2023).

With the number of scheme participants and costs increasing far beyond the original expectations (Johnson and Gifford 2022, compared with Australian Productivity Commission 2011), an independent review of the NDIS was commissioned in October 2022 (Shorten and Rishworth 2022). The review was conducted over a period of 13 months and made 26 recommendations involving 139 actions (Commonwealth of Australia, Department of the Prime Minister and Cabinet 2023). A key feature of these recommendations was recognition of the necessity to develop solutions in partnership with NDIS participants and to gain deeper insights into the lived experiences of those who interact with the scheme. With the initial legislative reforms having recently passed the Australian parliament (National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Act 2024), large-scale changes now look certain, but the impact on participants will depend on implementation.

The present study was conducted prior to the review and legislative change. The aim of this study was to contribute a better understanding of the lived experiences of NDIS participants. We were interested in understanding the experience of people with complex disability interacting with the scheme in the ongoing management of their supports. As attention turns to implementing reforms, an understanding of what participants have experienced thus far is of great importance. Although we initially sought to capture experiences across disability types, the final sample predominately comprised NDIS participants with neurological disability. The study is therefore particularly relevant to understanding this cohort.

Methods

Design

This study was guided by a qualitative research design given the focus on understanding the lived experience of the scheme from the perspective of NDIS participants. Qualitative research is embedded in the epistemological paradigm of interpretivism, which acknowledges subjectivity and recognises the influence of multiple perspectives and the social world upon the construction of individual experience (Charmaz 2014; Nayar and Stanley 2024). Consistent with this paradigm, this study was informed by constructivist grounded theory methodology (Charmaz 2014). Constructivist grounded theory seeks to explore and uncover underlying social processes to support the generation of a theory or framework and is often chosen in areas of research that are emerging or where there is little known (Charmaz 2014; Nayar and Stanley 2024). In this study, constructivist grounded theory was chosen given the relational context in which NDIS participants interact with the NDIS system, the congruence between this relational context and the axiological positioning of the researchers (Nayar and Stanley 2024), as well as the lack of research evidence informed by the lived experience of NDIS participants.

Recruitment

Our initial aim was to recruit adults significantly dependent on their individual NDIS funding and open to participating in interviews. To achieve this, we employed a multi-channel strategy that involved posting advertisements on the website of the Summer Foundation (a non-profit disability organisation), dissemination through social media, and leveraging established networks. The advertisements targeted three characteristics:

1. Individuals living in 'Specialist Disability Accommodation' (SDA);
2. Individuals currently living in, or having previous experience of living in, a shared supported accommodation (group-home) model funded by NDIS Supported Independent Living funding; and
3. Individuals who 'self-manage' their NDIS funding.

Procedure

This study was approved by the La Trobe University Human Ethics Committee (HEC21269) and conducted between November 2021 and January 2023. Following informed consent, one-to-one interviews were conducted at a time convenient for participants via video conference (Topping *et al.* 2021). The interviews followed a semi-structured guide whereby broad, open-ended questions were used to elicit personal accounts. Participants were encouraged to elaborate on their thoughts and feelings whenever they described a positive or negative NDIS experience. Where a particular experience or opinion seemed important to that person, exploring that issue in-depth was given priority over exploring a breadth of topics. Interviews were designed to accommodate cognitive and communication needs of participants with use of plain language information, verbal and visual prompts, rest breaks, and use of text-to-speech communication devices (Paterson and Scott-Findlay 2002). Interviews were conducted by skilled researchers with experience working with people with complex disabilities and communication difficulties and/or disability lived experience. The interviews were audio recorded and professionally transcribed. Consistent with grounded theory methods, data collection and analysis occurred concurrently, and changes to the interview guide were made to accommodate new areas of inquiry in response to data analysis (Charmaz 2014). Participants were given a A$40 gift voucher as payment for their participation.

Data analysis

Transcript analysis was informed by constructivist grounded theory methods (Charmaz 2014). All transcripts were de-identified to maintain anonymity and pseudonyms were applied. Three of the authors (MB, KD, and SO) coded all transcripts, with 50% of transcripts double coded to ensure consistency of coding across the authors. Double coding supported each of the three authors to actively engage with and code the transcripts, with each transcript being coded by at least two of the authors, facilitating consensus discussion. Analysis followed two main phases of open and focused coding. Open coding commenced at a line-by-line level to capture the participants' experience and constant comparison analysis supported the development of focused codes. Focused coding supported exploration of relationships across the data, resulting in the development of categories and themes. Analytical discussions occurred regularly between the three authors (MB, SO, and KD) with any discrepancies resolved through consensus. Consistent with constructivist grounded theory, memo writing and diagramming supported further abstraction of codes and exploration of the interconnections between the emergent themes. Data collection and analysis were repeated until no new themes were evident, theoretical sufficiency was apparent, and no further sampling was necessary (Hennink *et al.* 2017; Vasileiou *et al.* 2018).

Results

Participants

The recruitment strategy resulted in 13 participants. Although the recruitment strategy was not targeted at any specific diagnosis, most participants (10) had neurological disability. In addition, two participants did not disclose their disability, and one had a rare condition that is not reported here to preserve anonymity. Two of the participants chose to be interviewed alongside someone who knew them well and were involved in their NDIS experience. Although recruitment was open to participants in any state or territory, the majority of participants lived in Victoria and ranged from 30 to 62 years of age ($M = 46.8$, s.d. = 10.3). Table 1 summarises participant characteristics.

Themes

Analysis of the interview data revealed insights into the participant experience of being an NDIS participant. The participant experience included the process of joining the scheme, choosing supports, and the ongoing processes of plan reassessments and managing funding use. Participants shared reflections on ways in which their life has improved since becoming an NDIS participant and articulated problems, issues, or phenomena that they have experienced directly and saw as important to understand. Despite different circumstances in terms of disability, support needs, and NDIS plan management, common experiences were evident across participants. Data analysis informed the development of three key themes and associated sub-themes that, when considered in relationship with each other, represent the experience of NDIS participants in interaction with the NDIS. The themes are: (1) living a better life, (2) losing trust in the NDIS, and (3) hopes for the future. Fig. 1 provides an overview of the themes and sub-themes.

Theme 1: living a better life

Most participants were keen to highlight their positive experiences to balance out and contextualise their criticisms.

Table 1. Participant characteristics.

Characteristic	*N* (%)
Gender	
Male	6 (46)
Female	7 (54)
State/territory	
Victoria	9 (69)
New South Wales	3 (23)
Western Australia	1 (8)
Disability	
Multiple sclerosis	4 (31)
Traumatic brain injury	3 (23)
Cerebral palsy	2 (15)
Stroke	1 (8)
Other/undisclosed	3 (23)
Living arrangement	
Specialist Disability Accommodation	5 (38)
Shared supported accommodation (funded as Supported Independent Living)	2 (15)
Public housing	1 (8)
Other/undisclosed	5 (38)
Self-managing	
Yes	4 (31)
No	9 (69)

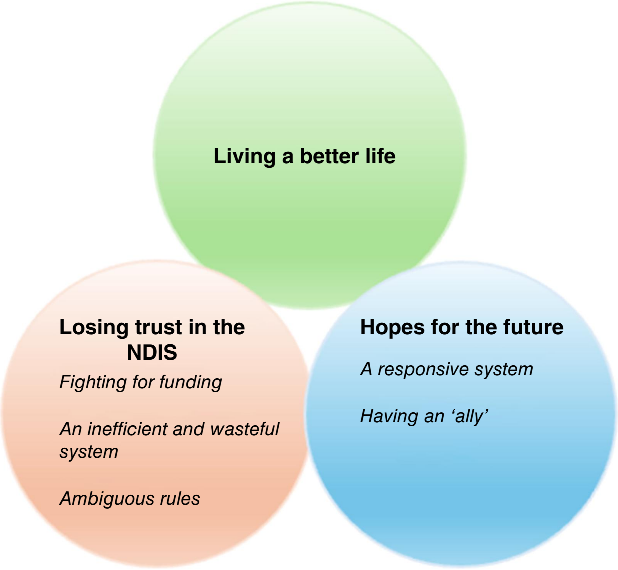

Fig. 1. Experiences of being an NDIS participant: themes.

In this way, most participants conveyed that, despite ongoing difficulties and challenges, the NDIS has enabled them to live a better life. Most participants expressed gratitude for the scheme and the opportunities afforded through individualised funding. One participant summed up this sentiment with the following statement:

> 'The NDIS has improved my life amazingly. Like just the fact that I get to go out and I get what I need and things like that. And part of me just wanted to take a full-page ad out in one of the papers just saying, "Thank you, Australia."' *(Harmony, NDIS Participant)*

For some of the participants, their gratitude for the scheme was linked to comparisons with pre-NDIS experiences of State Disability funding, or for some, a lack of disability funding and a reliance on the Health and Aged Care system. They reflected upon their initial excitement about the introduction of the NDIS and the anticipation of a scheme that espoused 'choice and control' for people with disability. Some recalled campaigning for the introduction of the NDIS and their hopes for a better quality of life with access to comprehensive and secure funding. One participant described moving geographical location to be part of the early rollout of the scheme:

> 'We were handling everything completely alone, with no support, either formal or informal. And we moved … For a number of reasons. Close to family being a big one. And also because of the early rollout of the NDIS in this region.' *(Roy, NDIS Participant)*

The participants living in NDIS-funded SDA were particularly grateful for the opportunity to move into independent housing of their choice. Participants described this as a life-changing opportunity that was not available prior to the introduction of the NDIS. For example, one of the participants, a young adult with cerebral palsy who recently moved into her own NDIS-funded SDA apartment, reflected upon the ways in which this move improved her life. She shared, 'Just being able to have my own space and being close to town' *(Gina, NDIS Participant)*. Another participant with a progressive neurological disability reflected upon the opportunity to live alone in a home that meets his current and future physical needs, with access to support workers to assist with tasks like meal preparation.

> 'I feel like I'm very lucky – I do receive support from the NDIS and it makes, it's made, an incredible difference to life, and I never anticipated such a thing would exist.' *(Andy, NDIS Participant)*

For those participants who self-manage their funds, a 'better life' was often defined by the comparative choice, control, and flexibility over their funding. They valued the opportunity to have responsibility for managing their funds relative to their needs and preferences. For some, this value was about having oversight of the financial management, whereas for others it was about being in control of decisions about the use of their funds, with inherent flexibility and tailoring to their needs.

> 'I'm just very lucky that I can do that [self-managed funds]. I know a lot of people can't, I understand that, but I just want to be independent and have control over it.' *(Peta, NDIS Participant)*

More generally, participants talked about the positive impact of having access to a range of quality support and services, such as support workers, funding for equipment, as well as allied health intervention. Participants described how access to these services helped them to feel supported, as well as more able to participate in everyday life. For example, one of the participants shared, 'I wouldn't say I'm perfect, but, like, I'd say that I'm, like, I'm more complete now that I can do things that I couldn't ever do with no money' *(Bruce, NDIS Participant)*.

Theme 2: losing trust in the NDIS

Although participants expressed gratitude for opportunities afforded by the NDIS, this theme describes the challenges and cumulative effect of these challenges upon trust in the scheme. Most participants referenced challenges that they had experienced directly, as well as those that they had heard about from friends and through the media. In a variety of ways, participants indicated they felt insecure in their relationship with the NDIS and expressed profound disappointment and a lack of confidence in the administration of the scheme.

Sub-theme: fighting for funding. People varied in their experiences and their current relationship with the NDIS, and yet, each of the participants shared experiences of having to fight for their NDIS funding. Some shared experiences of fighting to get their initial NDIS funding approved, while others talked about an ongoing fight for recognition of their needs and appropriate funding. Participants used phrases such as 'having to fight', 'adopting a don't take no for an answer approach', 'advocating', 'applying pressure', and 'rocking the boat'. Participants expressed a view that ultimately funding is not based solely on need but how strongly and effectively participants advocate for each component of their funding using the 'correct' terminology.

This experience of 'fighting' for funding undermines participants' confidence and trust in the stability of their funding. Roy articulated how this sense of insecurity persists even after appropriate funding is approved:

> '[S]o for the next year, we are sitting pretty. We're fine… But of course you know, after that who the hell knows. And it's been very forward in mind… it doesn't matter what your capabilities are, we're both, particularly we have to fight for ourselves, or advocate. But we shouldn't have to do that. You know, first of all, it's wrong that that is what – that that is the demand. And second, what about the people who do not have access to those facilities?' *(Roy, NDIS Participant)*

Roy's concern for others was shared by most interviewees. They felt fortunate to have capacity or confidence to research, navigate, self-advocate, and persist (or fortunate to have an ally helping them with this) but were concerned for NDIS participants who may not know the 'tricks' or may not have advocates they trust to support them. When asked about her experiences, Veronica connected her frustrations to how similar experiences must affect other NDIS participants:

> 'There are – don't get me started. It makes me so angry. [There are] people who already have in their families quite enough on their plate, enough challenges. Without an organisation – [which should be] there to assist and help them – making it more difficult.' *(Veronica, NDIS Participant)*

Each of the participants expressed profound disappointment with the experience of not feeling valued, heard, or supported, as well as the sense of being overwhelmed with the burden of the 'fight' for funding. Participants communicated the personal toll of being caught in a relationship that they are dependent upon but in which they feel disempowered. They described the burden of being forced to be assertive while at times experiencing the futility of self-advocacy and their dependence upon others to successfully advocate or fight for their needs. They emphasised the necessity of having an advocate or what they described as an 'ally': someone who is on your side and is prepared to fight on your behalf or support and encourage you to persist when experiencing knockbacks. Allies were identified as close others and friends with whom they have a personal relationship, as well as support coordinators or health professionals.

> 'I think one of the things that was really important to remember is that we had so many allies in getting our particular submission over the line. And without those allies we could not have succeeded.' *(Roy, NDIS Participant)*

Sub-theme: an inefficient and wasteful system. A central concern contributing to the overall lack of trust in the NDIS was the experience of the NDIS as an inefficient and wasteful system. Participants described a combination of challenges underpinning this experience, including a lack of transparency, ambiguities on rights and responsibilities, poor communication, and administrative delays. Delays were associated with plan reviews, emergency plan changes, home modifications, and equipment provision. Delays were perceived as a waste of time for participants, close others, and service providers. They were also seen as a waste of support funding and government resources.

Sue, one of the study participants, gave the example of waiting for approval for an increase in support worker hours following surgery. Despite being an urgent request, there was a 5-week delay for approval, which left Sue without sufficient support hours. She described, 'So, they didn't even give me an interim plan until I've got my plan – they just left me with basically nothing' *(Sue, NDIS Participant)*. The support provider stepped in to provide the support hours without funding, as they recognised the safety concerns for Sue.

Some participants communicated concern with annual funding reviews, describing them as a stressful and wasteful process. Annual reviews were associated with uncertainty and fear due to a lack of trust in the system to consistently allocate a fair and reasonable level of funding for essential supports. Participants also expressed frustration in the need to 'prove their disability' at funding reviews, regardless of whether they had experienced a change in circumstances or needs. For others, the lack of trust in the NDIS translated into a preference for yearly or twice-yearly reviews, ensuring that their ongoing and potentially changing needs would be met. A shared concern across all participants was the need for timely decision-making and action following reviews. Suggestions were made to prioritise efficiency with processing urgent reviews, such as a change in circumstances, and to have expected timeframes for completion of reviews:

> 'If you're going to do a plan review every year, that's fine. But if you're going to do a plan review, you need to put that plan in place within that week. You can't leave it six weeks without getting approved, that's not fair.' *(Sue, NDIS Participant)*

Participants also emphasised the significance of timely support decisions for people with limited or no family/informal support. Hannah, the parent of an adult NDIS participant who is a current SDA tenant, reflected on the uncertainty of funding brought about by yearly plan reviews and the negative effects for her daughter, the participant, and their informal support networks:

> 'And I think it's crap that we've got this year-to-year worry, and for these older parents, it worries me enough. Imagine how, if you're in your 80s, and you had a 50-year-old or a 60-year-old [child] – that you were looking after and caring for, they've got no – they've still got no peace of mind.' *(Hannah, parent of an NDIS Participant)*

Inefficiencies with equipment funding were also raised. For example, Andy shared, 'I had to wait more. I think a bit over 2 years to actually have my own wheelchair. We were hiring a wheelchair at $160 a week for a period of 2 years' *(Andy, NDIS Participant)*. Along with long waits for approval of equipment, participants also described inefficiencies in the planning and allocation of funds to support the use of equipment. For example, one participant, Chris, recounted how he had received NDIS funding for a muscle stimulation device for rehabilitation but no further funding for training or support in using the device, which meant it was largely unfit for purpose:

> '… I'd got a device, a stimulation device, funded but they wouldn't fund me to go back and see them or get an iPad to use it to change the settings, because they said, "Oh, you don't need that." So, they bought me this $5000 device that I don't really know how to use, and that was a year ago.' *(Chris, NDIS Participant)*

The hidden costs associated with support and finding the right support agency (e.g. initial consult fees) were also highlighted, such as overpaying for some services when only 1.5 h of support is required but there is a 3-h minimum shift. Travel costs for therapists were also highlighted as expensive and inefficient, and concerns were raised about service providers exploiting the system. Pam shared, 'As soon as you mention 'NDIS', the fees go up. I don't know why…I've never seen a scheme that caters for such [rorting] to be honest' *(Pam, NDIS Participant)*

Sub-theme: ambiguous rules. The participants in this study described the NDIS as a new and challenging system. Furthermore, they shared frustrations with the administration of the scheme. Despite claiming to support the choice and control of NDIS participants, many felt the system was disempowering due to its ambiguous rules.

Although it was initiated a decade ago, participants saw the NDIS as a new system. They described their relationships with the NDIS as an ongoing process of adjustment and new learning of rules and processes. Although participants were hopeful for an improved funding system and a 'better life' at the scheme's inception, they emphasised their lack of choice in moving to the new system. When introduced, the NDIS replaced existing disability systems. As a result, the move to the NDIS system was not optional for people with disability in Australia who participated in those systems. Underpinning their experience of the system is the obligation and, in some instances, the burden of learning the ways of a new disability scheme. Sue shared her reflections on this experience of moving to the NDIS:

> 'I used to self-manage my [pre-NDIS state funding package]. So, when I heard about NDIS, I was basically freaking out, because I didn't know – yeah, it's a whole new system. Yeah, so I didn't know how to navigate myself.' *(Sue, NDIS Participant)*

When talking about their current NDIS plan, participants were unsure about funded hours and the language used by the NDIA to describe funding applications and processes. Although some participants, especially those who self-managed their funds, had some sense of confidence and autonomy in processes, the majority were frustrated with a lack of transparency in how and when decisions are made. They described insufficient communication with participants, without a clear process for seeking feedback, advice, or assistance from the agency. One participant, Jake, described the system as a labyrinth:

> 'Not really [understanding what is in the NDIS plan]. I suppose it's like going into a labyrinth really. It's just so all over the place and there's only rules, policies and procedures…I get to a point where you don't really want to know too much.' *(Jake, NDIS Participant)*

Insufficient or inconsistent information to assist people to make informed decisions was also highlighted. Andy described his difficulty in understanding how to select a suitable support provider and the lack of assistance from the NDIS with making this decision:

> '…part of the problem there was that the initial [provider] agency wasn't all that great, and I got a list of agencies which I can investigate on the internet, but there was no rating system, you know. It was up to me to decide who I wanted to work with, and I've been lucky, I think, to find some good people to work with, but there was some inefficient providers.' *(Andy, NDIS Participant)*

Each of the participants recognised that it is not unusual to receive a knockback from the NDIA for funding and that you then need to try again with different wording to be successful. Participants talked about the need to use the 'correct' language to get suitable funding, noting that the language evolved over time and it was very hard to get it right. Similarly, they also spoke to the large volume of documentation required for funding requests and a lack of clarity about the requirements. Many of the participants, like Bruce, talked to the importance of having support to assist with navigating the funding system:

> ' …now I know in the NDIS plan, with all that wording, is that obviously if they've said no the first time, it's because you've somehow said it the wrong way. And so you need to get your support coordinator to – well, that's what she is. A support coordinator. She supports you … to get better things, yeah? That's her job. And now I know that if I get a knock-back, it's because I've stuffed up and put it in wrong.' *(Bruce, NDIS Participant)*

Theme 3: hopes for the future

This theme describes the hopes of participants for an improved NDIS. Despite many disappointments, participants went to lengths to communicate the importance of the NDIS for people with disability in Australia and their commitment to building an improved scheme.

> 'The NDIS has plenty of holes, and they need to be held to account. That doesn't mean we should scrap it, which is a lot of the rhetoric which is starting to come out, you know, is the NDIS even working? Yes, it's working. Stop saying that. It needs to work a lot better.' *(Roy, NDIS Participant)*

Sub-theme: a responsive system. Informed by their experiences of the NDIS, participants expressed hope for an improved scheme that is more responsive to the needs of individuals, including their changing needs over time. Participants want a scheme that is accessible, with systems and processes that are inclusive and respectful of the rights of people with disabilities. A more responsive system is one in which updates and feedback are shared with NDIS participants in line with established expectations and compassion is demonstrated through opportunities for consultation and communication. As one participant asked, 'Isn't the NDIS meant to be all about us? So why are [NDIS] making decisions for me?' *(Harmony, NDIS Participant)*.

Although the principles of 'choice and control' are foundational to the current scheme, participants in this study do not feel that the scheme lives up to the principles. They want a shift to a more human-focused approach in which the NDIS staff interact responsibly with NDIS participants. Participants described feeling misunderstood in their interactions with NDIS staff, with everyday experiences that attest to a lack of understanding of disability. Therefore, participants in this study want NDIS staff to have disability experience or expertise and to demonstrate this understanding in their interactions with NDIS participants, as well in their feedback and responses to funding requests. Sue captures this hope for NDIS staff with disability experience:

> 'Yeah, more people that know how to deal with people with disabilities, and have that understanding better, and not asking you 20 times 'Oh, can you repeat what you're saying again?' That is very, very frustrating.' *(Sue, NDIS Participant)*

Sub-theme: having an 'ally'. When thinking about their hopes for an improved scheme, participants reflected upon the importance of having an 'ally' to help with navigating the system and advocating for rights. Allies were described as someone who is ready and skilled at helping people deal with the NDIA. Having an 'ally' was therefore seen as an essential feature of an improved NDIS system. Chris described it as having someone 'to go into bat for you.' Although a few of the participants had allies who were friends of family or an allied health worker, the majority did not have access to such support and relied upon their support coordinator. A good support coordinator was seen as good fortune, feeling lucky to have an 'ally' who gives advice, assistance, or support. Support coordinators also acted as a *constant* helper who participants could rely on for continuity of information and communication. Participants contrasted this experience to the lack of continuity in other aspects of the scheme. For example, they described the value of having their support coordinator present at their annual support reviews, but the NDIS appointed planner was a different person from review to review.

> 'It would be nice if everyone could have the same planner, I think that would make life a lot easier. Because then the planner will get to know you, you'll get to know the planner. You're able to build up that rapport with the planner.' *(Sue, NDIS Participant)*

Participants also noted that in the absence of communication from the NDIS, particularly in response to the progress of funding reviews and review decisions, an 'ally' such as a support coordinator was critical to being informed. Self-managing participants thought it was important to have an 'ally' to help advocate for them and share the administrative burden of navigating the complex NDIS system. Chris shared his experience of dealing with multiple government departments and agencies simultaneously to receive funding for rehabilitation, drawing attention to the need for an 'ally' who can assist NDIS participants to navigate the system:

> 'There seems to be a big grey area where the Health Department, or the hospitals, or the rehabs say, "That's covered by NDIS." NDIS say, "Oh no, that's covered by the health system." There's this grey area and the only people that are affected are us, 'cause the health people don't care and the NDIS people don't care. You're in limbo in the middle.' *(Chris, NDIS Participant)*

Discussion

This qualitative study aimed to capture the perspectives of NDIS participants on what it is like to interact with the scheme. Our findings suggest that the NDIS is often viewed as essential but unreliable for people with complex disability, including those with neurological disability. This highlights a paradox: the coexistence of gratitude and empowerment alongside fear and frustration. Consistent with previous research, which found NDIS participants experience increased choice and control over support and services (Crozier *et al.* 2013; Douglas *et al.* 2024), participants in the current study expressed gratitude for the opportunities the NDIS provides. However, participants were also frustrated by the challenges and inequity of navigating the scheme. These experiences echo previous research highlighting the administrative complexity associated with the implementation of personalised funding schemes and the negative implications on equity and sustainability for scheme participants (Heneker *et al.* 2017; Carey *et al.* 2021). Participants talked about the overall positive impact the NDIS has had on their quality of life and future opportunities, but these experiences coexisted with feeling as though they must fight for that entitlement and a fear that these gains can be swiftly undermined or revoked. Crucially, these mixed feelings were typically evident at the level of the individual participant. Within the same interview, heartfelt stories of positive outcomes from the NDIS were contrasted with participants' uncertainty of their future funding and major criticisms of the scheme's administration. These feelings were shared across all the study participants and underlie a lack of trust with the NDIA and the necessity of strategies to navigate the NDIS, including the reliance on allies.

One finding of the current study was the importance of having an 'ally' or someone who provides ongoing positive support to navigate the scheme. An ally was identified as being important to achieving positive outcomes through the NDIS. This finding echoes previous research that has highlighted the importance of supportive interpersonal relationships for NDIS participants to achieve positive outcomes (Collings *et al.* 2016; Williams and Porter 2017; Meltzer and Davy 2019; Skinner *et al.* 2023). This insight points to the irony of a scheme that was designed for people with disability but is difficult for anyone to navigate, especially NDIS participants with neurological disability and associated cognitive and communication challenges. Indeed, it could be argued that allies are a layer of cost and resourcing needed in the current system to make up for the fact that the NDIA interface is not designed to be accessible or readily navigated by end users. Moreover, allies play an important role in helping people make decisions on how best to use their NDIS funding. Previous research has raised concerns for NDIS participants who do not have access to supportive interpersonal relationships, particularly those with complex needs (Collings *et al.* 2016; Skinner *et al.* 2023), such as those with neurological disability or those with few informal supports. Additionally, the importance that participants placed on allies, points to what they consider is missing from their relationship with the NDIS. Relationships with allies were characterised by empathy, understanding, availability, adaptivity, and ongoing collaboration. Participants highlighted this as a contrast to their experiences of interacting with the NDIS.

Our findings suggest that NDIS participants experience a lack of trust and collaboration with the scheme. While most participants described being greatly dependent on the NDIS long term, with their quality of life relying on adequate ongoing funding, this coincided with experiences of uncertainty regarding funding security and ambiguous rules.

Participants sought more confidence in the scheme and a more accessible relationship with the NDIS to build their trust and security. Indeed, developing trusting relationships with participants has previously been found to be a challenge of personalised funding models (Heneker *et al.* 2017; Fleming *et al.* 2019; Carey *et al.* 2021). This is in part due to the complexity of the system and inaccessible or unclear information (Fleming *et al.* 2019). For example, previous research has found that NDIS participants with psychosocial disability face challenges in navigating the scheme, with unclear funding decisions eroding trust in the system (Devine *et al.* 2022). Additionally, the limited existing research indicates that NDIS participants with brain injury find the scheme confusing and require support to access and implement their funding. Concerns have also been raised about missed opportunities for people with brain injury who either can't access the funding and services they require or 'give up' due to a lack of support (Foster *et al.* 2021; Skinner *et al.* 2023). Our findings extend on this and suggest the need for a more relationship-centred approach to the delivery of the NDIS, that is designed with, and for, people with disability, and is inclusive of people with cognitive and communication difficulties. Additionally, our findings highlight the importance of a funding system that has continuity in both service provision and communication so that it is accessible for people with complex neurological disability, including people with brain injury.

The NDIS review recommendations and first tranches of legislative changes arising since our study was conducted can be seen as a recognition of, and an attempt to, address some of the issues identified in the current study (Commonwealth of Australia, Department of the Prime Minister and Cabinet 2023; National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Act 2024). However, meaningful change will rely on effective implementation. Recommendations such as longer plan durations, clearer definitions of NDIS supports, and more objective assessment of funding needs may well reduce uncertainty and simplify navigation of the scheme. Indeed, participants in the current study described stressful and negative experiences due to inconsistencies and inefficiencies in relation to plan reviews and allocation of funding. The recent recommendation of introducing local navigators as first points of contact and support also has potential for improving the clarity and accessibility of information and may help redefine the relationship between participants and the scheme. While these reforms signal progress, it is essential that they are designed, implemented, and evaluated in partnership with people with disability to ensure they result in meaningful improvements.

This study fills an important gap in the literature by providing valuable insights into the nuanced experiences of NDIS participants with complex disability, including those with neurological disability (Skinner *et al.* 2023). However, it is important to note that a limitation of the current study is that the insights are derived from a small, self-selecting sample. While the findings of the study highlight the complexity of the system as identified by people with neurological disability, further research is needed to determine whether these insights apply beyond this sample, as well as to other cohorts who access the NDIS. The coexistence of positive and negative sentiments towards the NDIS has been documented in a survey whose sample was more diverse, including people with neurological disability (Winkler *et al.* 2022). This may help explain why the NDIA reports majority satisfaction among participants and nominees (National Disability Insurance Agency (NDIA) 2022), whereas problems and complaints dominate media coverage and policy discourse (Gilchrist and Perks 2023). Further research is needed to explore how these mixed experiences emerge across different cohorts and how they influence participant engagement, trust, and outcomes within the scheme.

As reforms are implemented, it may be useful for future research and evaluation to specifically measure the quality of relationship between NDIS participants, the NDIA, and other stakeholders in the scheme. Concepts highlighted in this study including trust, confidence, allyship, and collaboration, may be useful constructs that are distinct from satisfaction with NDIS funding or outcomes. Longitudinal mixed-method research of this kind could investigate whether relationship quality predicts more creative use of funding, greater pursuit of personal goals, greater community participation, and other important outcomes. If these constructs are established as generally important, future research should monitor how relationship quality varies over time and between participant groups.

Future research with NDIS participants is also needed to develop and evaluate practical proposals for NDIS improvement. While participants in this study shared valuable reflections pertaining to their experience of the NDIS, it was challenging to generate discussion about potential solutions in a one-to-one interview format. Participants need to feel heard regarding the problems before they feel able to address solutions; a sense that changes to the scheme's operation are genuinely up for discussion may also be necessary to facilitate effective discussion. Integral to this process will be investment in an authentic co-design process in which the lived experience contribution of NDIS participants is reflected across all stages of the co-design process, including problem identification and prioritisation, brainstorming, solution design, development, and evaluation (Slattery *et al.* 2020).

In conclusion, despite the inception of the NDIS marking a vital stride towards realisation of rights for people with disability in Australia, NDIS participants with complex disability experience a range of challenges, including navigating ambiguous rules, having to 'fight' for funding, and witnessing an inefficient and wasteful system. The experience of these challenges has contributed to a lack of trust with the NDIA. As a result, participants have developed different strategies, including the reliance on allies, to achieve the enhanced choice and control the NDIS was designed to enable. However, our findings also highlight the value and importance of the

NDIS for people with complex disability, such as neurological disability, and their commitment to building an improved scheme. If the NDIS is to achieve its aims going forward, it is important to cultivate a more empathetic, transparent, and reliable relationship with participants.

Ethics

This study was approved by the La Trobe University Human Ethics Committee (HEC21269).

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