



Getting the NDIS back on track

A survey of people with disability

November 2022

Supported by:



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Executive summary

Participants of the NDIS recognise how the Scheme benefits their lives, but also lack trust in the way it is run.

Nearly half a million people with disability are participants of the National Disability Insurance Scheme (NDIS, Scheme). They rely on its administering government body, the National Disability Insurance Agency (NDIA, Agency), to approve and allocate funding for support services, equipment and housing.

Trust between people with disability and the NDIA has suffered a series of setbacks in recent years. The new Federal Government acknowledges deep seated concerns voiced by many participants and has promised to review and reform the NDIS. Likewise, the NDIA is making efforts to increase participant feedback and co-design new policies and systems.

The government's commitment to restore the Scheme to its original intent is welcome. However, campaign promises will need to translate into concrete action before trust can be restored properly. To help ensure that the voices of NDIS participants are central to the reform of the NDIS, the Summer Foundation, supported by People with Disability Australia (PWDA), conducted a national survey of NDIS participants in July 2022. The survey asked participants to tell us 3 things about the NDIS: what works well, what they would change and how the NDIS has supported them to live an ordinary life.

The findings of the survey reveal a conundrum at the heart of the NDIS participant experience: while many individuals see the real benefits of the NDIS, there is simultaneously a lack of trust and confidence in its administration.

Key findings

- Some participants reported that the NDIS has helped them to achieve important and transformative outcomes in their lives

However,

- Accessing and navigating the NDIS is difficult and dealing with the NDIA is time-consuming and stressful
- Participants fear that the improved quality of life resulting from NDIS funding could be taken away at short notice
- Participants worry that funding cuts could stem from a change in government, updated policy, or due to miscommunication and error at planning reviews

Participants and their allies want a more transparent and collaborative relationship with the NDIA that is built on mutual trust. This would replace the pessimistic and adversarial relationship that they see now. Participants expect that a restored relationship will not only bring benefits to themselves, but also to the Agency as more efficient and less wasteful processes emerge. A range of pragmatic and clear recommendations emerged from the analysis of the survey responses.

Recommendations

NDIS participants provided clear and practical direction for improving the NDIS. These recommendations fell into 4 main themes:

- Communicating and collaborating in alliance with participants
- An easier and more responsive system
- Not living in fear of funding being cut
- Supporting people with disability to live well

1. Communicating and collaborating in alliance with participants

1.1 Improve communication

NDIS participants want the NDIA to improve its communication by:

- Ensuring that participants have the same single point of contact within the Agency, wherever possible
- Ensuring that funding decision-makers have met the participant
- Ensuring that draft plans are approved by the participant prior to submission
- Providing detailed feedback on reasoning for all funding decisions

1.2 Human approach and inquiring mindset

NDIS participants want NDIA staff to demonstrate a human and inquiring approach to their interactions with participants by:

- Adopting a strengths-based approach to the administration of the NDIS and interactions with NDIS participants
- Ensuring all verbal and written communications treat participants with dignity and respect
- Improving the accountability of NDIS staff for their decisions

2. An easier and more responsive system

2.1 Timeliness and efficiency

NDIS participants want more timely and efficient processes regarding funding decisions by:

- Making more skilled support available to help participants navigate the system
- Prioritising plan reviews for participants with 'at-risk' circumstances
- Increasing flexibility for planning reviews and approving future needs for people with degenerative conditions
- Expanding operating hours so that participants who work regular hours can make contact with the Agency

2.2 Evidence and reports

NDIS participants want the NDIA to revise its requirements for providing evidence at all planning reviews by:

- Providing more guidance to participants about the evidence required to inform NDIA funding decisions
- Ensuring NDIA staff read and understand reports submitted by participants
- Stop repeatedly asking participants with lifelong or degenerative conditions for proof of their disability

2.3 Expertise

NDIS participants want the NDIA to increase staff's disability expertise, especially for positions making decisions on funding by:

- Employing more staff with disability and more allied health professionals
- Assigning planners to participants based on disability-specific expertise of staff
- Increase training for staff, especially in relation to high-care needs
- Resources and training co-designed and delivered by people with disability

3. Not living in fear of funding being cut

NDIS participants want the NDIA to restore participants' confidence in the Scheme, particularly with regards to fears of funding cuts by:

- Providing guarantees for essential services
- Allowing participants to request funding changes without fear of a reduction in funds
- Allowing participants to renew their current plan without reassessment or review plans less frequently
- Facilitating a discretionary budget in plans for unexpected events
- Reducing the need to resort to the litigious appeals process

4. Supporting people with disability to live well

NDIS participants want to partner with the NDIA to create a scheme that is innovative, responsive and supportive of people with disability to help them live rich and rewarding lives by:

- Increasing funding for social skills and community participation
- Providing more support for participants to seek education and employment
- Improving access to independent housing and more housing options
- Ensuring equity in NDIS funding for all people with disability



Case study 1: Tobias

Tobias is 42 years old, and works doing business strategy and planning for lawyers. Until recently he was an avid hiker, doing 25 km hikes in a day. In 2021, Tobias was diagnosed with multiple sclerosis. Since his diagnosis, Tobias has experienced a significant decline in his abilities.

Tobias is new to the NDIS. Despite his communications and law degrees, he has still needed assistance from other people to apply and navigate the NDIS. At the time of having to put his plan together, Tobias was very stressed. On top of dealing with a newly diagnosed disability, work pressures and hospital visits, he was getting the reports ready for his NDIS plan without really understanding what was needed. He felt very overwhelmed, and wonders how people without his own level of education would manage navigating the complex system. He thinks people are not going into planning meetings on equal footing.

Tobias acknowledges how amazing the NDIS is. Despite all the criticisms, he doesn't know where he would be without it. The NDIS has helped him get a wheelchair, stairlift and access to a physio 3 times a week. It allows him to work, socialise, and reduces stress on his partner.

Tobias would just like the NDIS to make sure everyone is having an equal experience, and that the Agency needs to be clearer about the types of information that they require to make decisions.

Introduction

It has been nearly 10 years since the major piece of social policy that is the National Disability Insurance Scheme (NDIS) was established. The passing of the *National Disability Insurance Scheme Act 2013* gave rise to the NDIS and its implementing organisation, the National Disability Insurance Agency (NDIA). A small number of trial sites in 2013 gave way to the full national roll-out in 2016, which now sees over 500,000 ‘participants’ access funding via the Scheme.¹

The guiding principles of the NDIS include the rights of Australians with disability to exercise choice and control over their lives, participate in and contribute to society, and receive care and support. According to the *NDIS Act*, participants in the Scheme are entitled to receive funding for ‘reasonable and necessary’ support. This funding aims to:

- ‘Support people with disability to pursue their goals and maximise their independence; and
- Support people with disability to live independently and to be included in the community as fully participating citizens; and
- Develop and support the capacity of people with disability to undertake activities that enable them to participate in the community and in employment.’²

For many participants, the NDIS has had a significant positive impact on their lives. The NDIA’s *Participant Outcomes* survey reveals that across a range of outcomes, participants have experienced a positive impact since joining the Scheme. For adults over 25 who had been in the Scheme for at least 2 years, 60% felt that being on the NDIS improved their health and wellbeing, and 83% said that the NDIS had helped with daily living activities.³ Satisfaction scores have also been trending higher in the last 12 months across participant pathways,⁴ with the exception of the plan review process, where participant satisfaction dropped from 71% to 70%.

Despite the positive experiences of many NDIS participants, in the last 2 years a number of issues with the Scheme have captured public attention:

- The ongoing Disability Royal Commission has published numerous reports documenting the challenges, mistreatment and abuse faced by many people with disability and NDIS participants. Perhaps most infamous of these was the case of Ann-Marie Smith, a South Australian NDIS participant who died in hospital after suffering profound and long-term neglect by her disability support worker.⁵
- In late 2019 the NDIA announced that independent functional assessments paid by the Agency would be used to make funding and support decisions for participants. While the goal was to increase the consistency of decision-making and create a fairer system, significant push-back from many concerned participants, their families, and advocacy organisations saw the plan abandoned.⁶

¹ NDIA (2022). *NDIS quarterly report to disability ministers: Q4 2021-2022*. National Disability Insurance Agency. <https://www.ndis.gov.au/about-us/publications/quarterly-reports>

² Australian Government (2013). *National Disability Insurance Scheme Act 2013* (Cth). Section 4(11)(a-c). <https://www.legislation.gov.au/Details/C2013A00020>

³ NDIA (2022). *NDIS quarterly report to disability ministers: Q4 2021-2022*. National Disability Insurance Agency, p.52. <https://www.ndis.gov.au/about-us/publications/quarterly-reports>

⁴ Participant satisfaction scores are collected across four stages in the pathway: 1) the access process; 2) the pre-planning process; 3) the planning process; and, 4) the review process.

⁵ Australian Government (2021). *Public hearing report: Preventing and responding to violence, abuse, neglect and exploitation in disability services (South Australia)*. Royal Commission into Violence, Abuse, Neglect, and Exploitation of People with Disability. <https://disability.royalcommission.gov.au/publications/report-public-hearing-14-preventing-and-responding-violence-abuse-neglect-and-exploitation-disability-services-south-australia>

⁶ Campanella, N. (2021). ‘NDIS Minister says independent assessments model is “dead”, in win for disability advocates.’ *ABC News*. <https://www.abc.net.au/news/2021-07-09/ndis-disability-independent-assessments-model-dead-after-meeting/100277324>

- Some participants have reported significant cuts to their NDIS plans,⁷ contributing to fears that the government is reducing plans in order to address fears of the financial unsustainability of the Scheme.⁸
- There have been a series of high-profile cases of fraudulent behaviour by providers rorting the Scheme and taking advantage of participants.⁹
- A growing number of participants are appealing NDIA funding decisions by pursuing external reviews at the Administrative Appeals Tribunal (AAT). This has led to a sharp increase in external litigation costs to the Agency.¹⁰
- Amidst the COVID-19 pandemic and stretched resources at state and territory hospitals, as of mid-2022 nearly 1,500 participants were stuck in hospital despite being medically ready for discharge, in part due to the NDIA's slow processing times for funding requests for housing and support.¹¹

These issues are eroding trust between people with disability and the NDIA.¹² The new government campaigned on a promise to overhaul the NDIS and restore it to its original intent.¹³ Minister for the NDIS, Bill Shorten brought forward a review of the Scheme to 'make sure that people with disability feel like they have a real say.'¹⁴ People with Disability Australia (PWDA) and the Summer Foundation welcome the emphasis on keeping NDIS participants' perspectives central to the review. However, campaign promises will need to translate into concrete action before trust can be restored properly.

To contribute to the review, we conducted a national survey of NDIS participants in July 2022. The survey asked participants to tell us 3 things about the NDIS: what works well, what would they change and how the NDIS has supported them to live an ordinary life.

⁷ Jervis-Bardy, D. (2022). The number of NDIS plans slashed every day under the former government. *Sydney Morning Herald*, 25 July. <https://www.canberratimes.com.au/story/7832369/unimaginable-ndis-funding-slashed-every-day-under-former-government/>

⁸ Murphy, K. (2021). 'Costs are going up': Linda Reynolds warns of hard discussions on NDIS funding. *The Guardian*, 6 May. <https://www.theguardian.com/australia-news/2021/may/06/costs-are-going-up-linda-reynolds-warns-of-hard-discussions-on-ndis-funding>

⁹ Rawsthorne, S. (2022). Organised crime-linked family charged with allegedly defrauding NDIS of \$2 million. *Sydney Morning Herald*, 2 June. <https://www.smh.com.au/national/organised-crime-linked-trio-charged-with-allegedly-defrauding-ndis-of-2-million-20220601-p5aqdc.html>

¹⁰ Clun, R. (2022). National Disability Insurance Agency spends millions on external legal costs. *Sydney Morning Herald*, 17 February. <https://www.smh.com.au/politics/federal/national-disability-insurance-agency-spends-millions-on-external-legal-costs-20220216-p59wxs.html>

¹¹ Gailberger, J. (2022). Hospital patients wait to be discharged in NDIS 'bed block'. *Herald Sun*, 8 August. <https://www.heraldsun.com.au/news/victoria/hospital-patients-wait-to-be-discharged-in-ndis-bed-block/news-story/13a4b76f83c95b25be51df072c377f52>

¹² D'Cruz, K., Brown, M. (2022). What the NDIS needs to do to rebuild trust, in the words of the people who use it. *The Conversation*, 4 August. <https://theconversation.com/what-the-ndis-needs-to-do-to-rebuild-trust-in-the-words-of-the-people-who-use-it-185880>

¹³ ALP. (2022). A better future for the NDIS. Australian Labor Party. <https://www.alp.org.au/policies/a-better-future-for-the-ndis>

¹⁴ Formica, S. (2022). Interview with Bill Shorten. *4BC: Afternoons with Sofie Formica*, 16 June. <https://www.billshorten.com.au/news/bill-s-transcripts/transcript-minister-for-the-ndis-4bc-radio/>

What was the aim of the project?

Many of the problems with the Scheme have been acknowledged by the NDIA, and some progress has been made through activities like the Participant Service Improvement Plan.¹⁵ However, more needs to be done to rebuild trust based on solutions grounded in the experiences and perspectives of NDIS participants. This project is motivated by a need to acknowledge challenges, but also to move to solutions. We believe that the perspectives of participants must be at the centre of the development of a new vision for the NDIS. Therefore, this survey aimed to:

1. Obtain the perspective and priorities of people with disability regarding the changes needed to the NDIS
2. Identify stories that illustrate the benefits of the Scheme, including the difference it makes to the lives of participants, their families and the economy
3. Inform the development of a vision for the NDIS and a plan for redesign that is aligned with the original intent and built on the perspective of Scheme participants

Method

The online survey was open for 4 weeks in June-July 2022, and advertised by the Summer Foundation and PWDA through professional networks and social media accounts. Thematic analysis for each of the 3 short-answer questions was undertaken by experienced qualitative researchers. All data was independently analysed by 2 researchers, drawing upon inductive thematic analysis methods.¹⁶ Consensus discussion across the team was conducted across all stages of the data analysis. Respondents had the opportunity to consent to being contacted further about their responses in the survey. Several respondents were contacted by the Summer Foundation's co-design team to document case studies and understand participants' stories in more depth.

¹⁵ NDIA. (2022). Participant service improvement plan. National Disability Insurance Agency.

<https://www.ndis.gov.au/about-us/policies/service-charter/participant-service-improvement-plan>

¹⁶ Braun, V., and Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3:2, 77-101.

<https://doi.org/10.1191/1478088706qp063oa>



Case study 2: Anthony

Anthony is 55 years old and lives with cerebral palsy. He loves to watch sport and visit his family. Anthony is wheelchair dependent and lives in a shared support accommodation. He and his family have been trying to find an independent living alternative for Anthony since 2010.

In 2019, Anthony requested a plan review from the NDIS so that he could receive SDA (Specialist Disability Accommodation) funding. This process has taken approximately 3 years and he still isn't there. In March 2022, to receive SDA funding for a different property, he submitted the change of circumstances forms to the NDIA. Anthony and his family regularly checked in with the NDIA to check the status of this review. They had to explain Anthony's situation from the beginning each time, with new NDIS staff, who provided different information about the status of his claim.

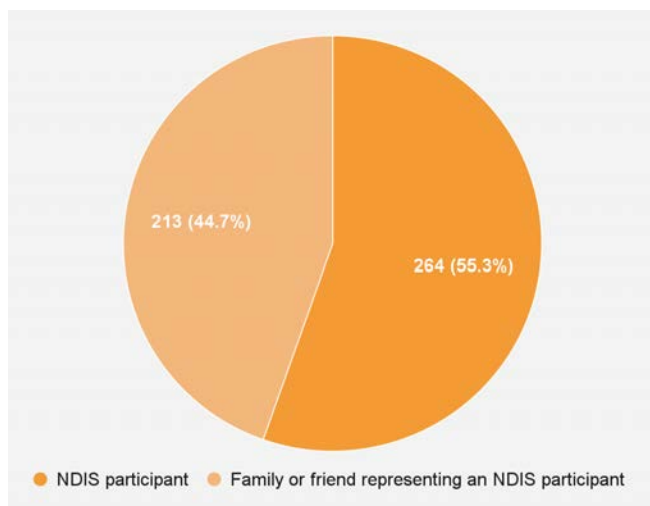
Feeling frustrated with the process, Anthony and his family wrote to Bill Shorten MP and lodged a complaint with the NDIA. In August they received a response from Bill Shorten's office and were put directly in touch with someone at the NDIA. They were then told Anthony could reallocate funds for different purposes, and therefore he had enough funding to cover 1:1 and overnight shared support (OSS) in his preferred type of SDA. Upon further exploration of why Anthony had not received the quote for SDA, the NDIA staff member found the submitted documentation and confirmed that it had been approved.

Anthony was left wondering why the NDIA had not contacted him months prior to let him know that he already had enough funding in his current plan for the services he requested. He didn't need to pursue a plan review due to changed circumstances in the first place. Anthony believes that a lack of proper training for NDIA staff is partly to blame for these delays and administrative issues.

Results

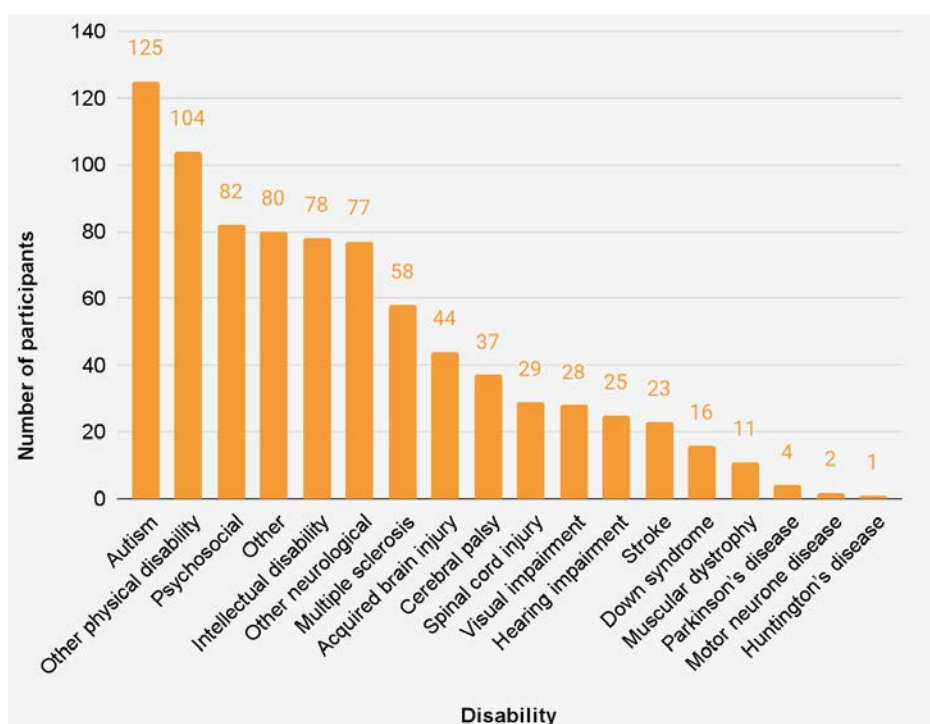
In total, 477 people responded to the survey.¹⁷ Of these, 55.3% (n=264) were NDIS participants, and 44.7% (n=213) were a family member or friend representing a participant (see Figure 1).

Figure 1 – Survey respondents (n=477)



Survey respondents were asked to indicate their disability type, or that of the person they were representing and to tick 'as many as apply', so the disability types listed may not all have been primary disabilities. The most commonly selected types were autism (15.2%, n=125); other physical disability (12.6%, n=104); psychosocial disability (10.0%, n=82); other disabilities (9.7%, n=80); and intellectual disability (9.5%, n=78) (see Figure 2).

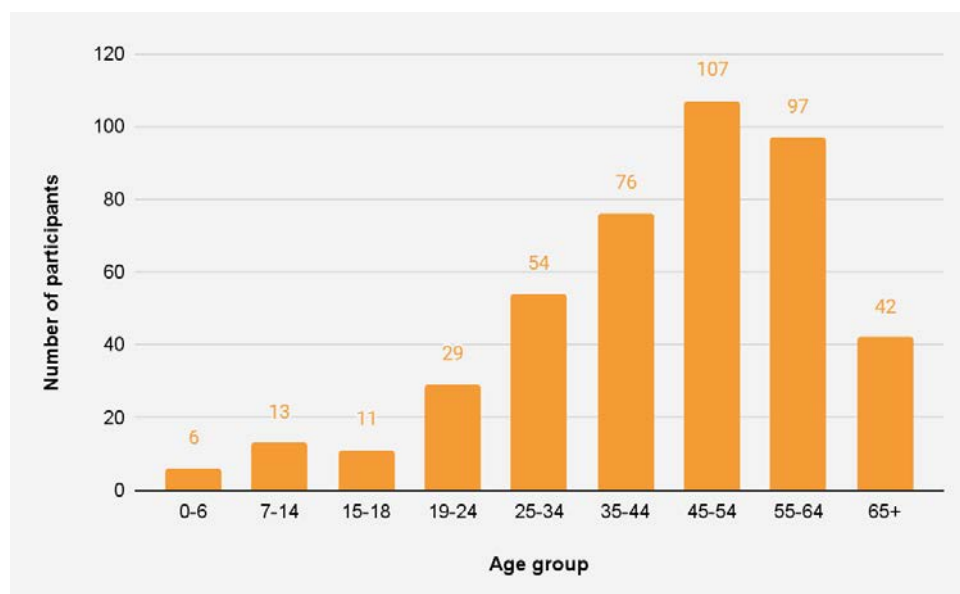
Figure 2 – Disability types of participants (n=470) (Note: respondents could select as many as applicable)



¹⁷ This includes 425 completed surveys and 52 responses in which at least 1 of the free-text response questions had been answered.

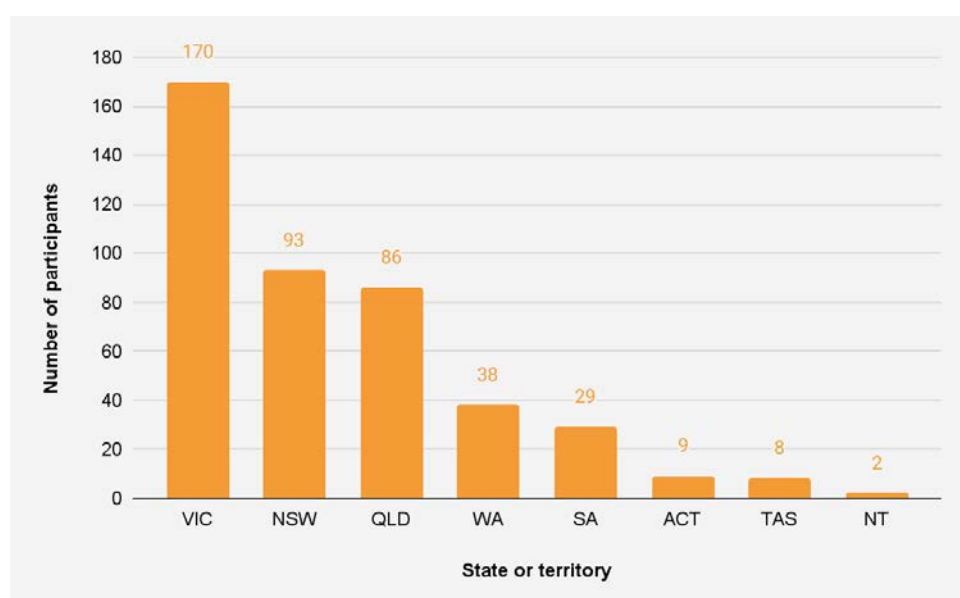
Respondents were also asked to indicate the age range to which they (or the person they were representing) belonged. Nearly a quarter (24.6%, n=107) belonged to the 45-54 age group, and a similar number (22.3%, n=97) to the 55-64 age group. Only 30 people (6.9%) were aged under 18, while 42 (9.7%) were 65 years or older (see Figure 3).

Figure 3 – Age of participants (n=435)



Finally, respondents were asked to select their state or territory of residence. A significant majority lived in either Victoria (39.1%, n=170); New South Wales (21.4%, n=93); or Queensland (19.8%, n=86) (see Figure 4)

Figure 4 – State/territory location of participants (n=435)



In addition to demographic questions, respondents were asked a series of short-answer questions relating to their experiences of the NDIS to date, as well as their suggestions for improvements. Findings from the qualitative analysis are provided below, and are organised according to the survey questions.

Question 1: In your experience of the NDIS, what works well?

The majority of respondents (over 80%) identified at least 1 example of the NDIS working well, from their own experience. Most commonly, respondents commented on the benefits of having access to NDIS-funded supports compared with before the NDIS, or compared with what they imagine life would be like without funded supports. Some participants also described how having access to this support positively impacted their life, such as enabling more independence, or opportunities to socialise and engage in the community. For example:

“My NDIS plan has allowed me to be a productive member of the community and provided me the funding to cover my ongoing care.” – NDIS participant

*“Funding is available to support me in living my life. This has made a great difference to me to be able to continue to live the life I want given the limits of my disability.”
– NDIS participant*

“For me, the ability to access capacity building supports has been working very well. NDIS has enabled opportunities to work with supports that never existed before. Prior to NDIS, I always fell into cracks in the system.” – NDIS participant

*“It has been life changing for myself and my son. He receives more support hours, he has better community inclusion and he receives therapy to a fair degree.”
– Close other of NDIS participant*

More specifically, some respondents highlighted the positive impact accessing these services has on their family, reducing their reliance upon informal support from family and friends.

“What works well is having funds to pay for all the supports that my disability requires – domestic assistance, therapies, home modifications, access to community (transport costs), support to live independently at home and support so that I don't have to depend entirely on the charity of family and friends, thus protecting my relationships.” – NDIS participant

*“Getting adequate funding for adults to live in their own home and with the right and flexible supports to have as ordinary life as possible and not rely on elderly parents to sort everything out. Life changing for the whole family as well as the participant.”
– NDIS participant*

Some respondents shared gratitude and appreciation for the NDIS and the positive impact the funding has upon their lives, while also sharing frustration and criticism about the process. For example:

“I am very grateful for the NDIS and what it does. Although it is working well for me personally, I am appalled at how complex, time-consuming and sophisticated I had to be to get what I have.” – NDIS participant

“When funding is FINALLY approved, my daughter is able to participate in a variety of activities in our community.” – Close other of NDIS participant

Several respondents emphasised the importance of being treated as an individual and how this contributes to their experience of the NDIS working well.

“When our daughter is looked at as an ‘individual’ and her needs are well understood, this works well. Especially when time is taken to come and visit her in her own home. This helps NDIS understand her unique needs better.”

– Parent of NDIS participant

“When it does work, it’s the people who listen, the people who treat PWD as humans, not as a burden. The people who recognise they are handling a person’s life, rather than managing an account.” **– NDIS participant**

A smaller number of respondents identified specific systems, policies, or processes of the NDIS as ‘working well’. The most commonly mentioned were: a) the option of self-management or plan manager, b) having choice of providers, c) flexibility of plans and d) access to quality supports.

The option of self-management or plan manager

One feature of the NDIS that was highlighted by respondents as ‘working well’ was the option of being able to self-manage plans, or have a plan manager. Respondents described that self-managing plans or having a plan manager allowed for increased choice and control over supports and services.

“As a self managed person I find the process of engaging the services and people I need to make my life more manageable works well. Submitting my paid invoices through the NDIS online payment request portal works for me.” **– NDIS participant**

“Self management of my funds [has] enabled me to employ staff directly and get better value for money. I have more choice about who supports me.” **– NDIS participant**

Choice of providers

Respondents also noted the importance of having choice in selection of service providers. Some respondents stated that being able to choose and change providers based on their own determination of quality and need worked well for them, while others valued the opportunity to choose providers that are not disability specific.

“The flexibility to choose or change service providers in a timely fashion as (1) the needs of our son change over time and (2) Service providers come and go, and the quality of their service waxes and wanes.” **– NDIS participant**

“The ability to be able to choose trauma-informed and properly skilled providers that suit my multiple psychosocial disabilities stemming from physical and mental health injury.” **– NDIS participant**

“The best thing for me is that I can choose my own providers and they don’t have to be disability specific (e.g. cleaners).” **– NDIS participant**

Flexibility of plans

Having flexibility of plans and funding was identified as a positive aspect of the NDIS. The flexibility of plans and funds allow more freedom, choice and control for some respondents.

“Having the flexibility to use our funding on services that matter to us.”

– NDIS participant

“[having a] flexible budget gives me choice and control.” – NDIS participant

“The flexibility of the funds (e.g., you can go anywhere in Australia and use services) gives us (on behalf of our son) more choices.” – Parent of NDIS participant

Access to quality support coordination and support workers

Some respondents identified the value of having access to high-quality support coordinators and support workers. Others highlighted the importance of high-quality services and supports that have specialist disability expertise.

“The incredible tenacity, kindness and good work of Support Workers. Invaluable help which has brought a freedom to reach my goals be included with the wider world.” – NDIS participant

“I wonder how on earth people sort out their planning without the support coordinator. People don’t necessarily know what they can ask for. It is a mine-field. Support coordinators help with this.” – NDIS participant

“Having service providers and support workers who understand and have knowledge of supporting your particular disability is essential.” – NDIS participant

Nothing works well or no response

Approximately 20% of respondents indicated that they felt nothing works well or that they couldn’t think of anything in response to this question. For example, participants shared:

“At the moment, for me nothing is working well. I have had trouble getting services, I have been denied equipment, funding and turned down for things other people have been freely given without even asking.” – NDIS participant

“None of it! I’ve been in the AAT fighting with the NDIS for more than 2 and a half years.” – NDIS participant

“None of it. As a participant I have been denied several things I requested after I have spent my funds getting the reports requested.” – NDIS participant

“The concept of NDIS is great. The implementation and delivery needs to be improved.” – NDIS participant

Question 2: How has the NDIS made a difference and supported you to live an ordinary life?

More than half of the respondents chose not to answer this question, but those who did tended to give detailed accounts of their experiences that resonated with responses to the previous question about how the NDIS works well. More than half is a lot of people not responding to this question. This may mean that over half of the respondents could not identify any way in which the NDIS had made a difference or supported them to live an ordinary life.

Respondents highlighted that access to funded supports increased their quality of life, reduced reliance on informal supports, improved physical and mental health, and created numerous opportunities. In explaining the difference made, many suggested the NDIS had allowed transformative changes, and they expressed a range of positive emotions including relief, gratitude, pride, excitement, and hope. Negative emotions, including frustration and anxiety, also featured in some respondents' accounts of NDIS processes.

Adequate access to support workers

Respondents described the value and impact that support workers have had on their daily life. Examples of adequate support included people having assistance with meals, personal care and household management, as well as having a choice of support staff and tailoring support to individual needs. Respondents often attributed access to support workers as transforming their quality of life.

"I have a wonderful support team around me now, they have literally changed my life for the better. My support workers have been so helpful and kind and help me with so much around my home I haven't previously been able to achieve. Seeing goals reached and creating more has given me confidence... I'm extremely grateful for my team of supports and for [the] NDIS allowing me to have a chance to better myself and my life and giving me some hope of a better life." – NDIS participant

"This year I've been receiving support worker assistance for the first time. It's meant that I could get my hair washed weekly instead of every 3 months, have been able to maintain the ability to work, and have had assistance to deal with years of clutter that had built up in the house because I'd been unable to physically do anything about it." – NDIS participant

Appropriate housing

People commonly identified the significant positive impact of being able to live in a house that is suited to them. For some people, this means being able to remain living at home, with the right support and equipment. For others, this is about being able to move to a house that is better suited to their needs or life stage, such as moving out of parents' homes or institution-like settings.

"I am an adult with disability and always thought I would live with my parents until they died or could no longer take care of me, then I would go into a nursing home. Now with NDIS I am able to live independently for the first time in my life." – NDIS participant

Many respondents described how this change in living environment enabled new or increased opportunities for independence in their everyday life.

"I moved from a group home to my own SDA apartment in 2019. This has given me more independence, privacy, dignity, peace and quiet, a place to call home, and the space I need to do my work." – **NDIS participant**

"It has given my son the opportunity to fulfill his long-time dream of living independently after living more than 10 years in a supported share house. This will make him a lot happier, and enable him to then focus on other parts of his life including seeking employment. Without the NDIS funding, none of this would have been possible, so it can make a huge difference to the quality of someone's life."
– **Parent of NDIS participant**

Social and economic participation

A number of respondents highlighted the positive impact of the NDIS on their community engagement, such as joining local groups, while others described being able to maintain or develop a social life.

"[My son has] made acquaintances with the baristas at our local cafes where he goes by himself, to buy his daily chai latte and buy a sandwich for his lunch. The local Community Theatre Group spotted him on his journey to a cafe one day and invited him to join them; he has since had a cameo part in two plays - he just loves acting - it has been a dream of his for a long time." – **Parent of NDIS participant**

"It has given me opportunities to engage in the community and do things I wouldn't otherwise, like horse riding. It has provided me with technology which gives me a voice and equipment which improves my physical ability. It helps me be a kid, just like any other." – **NDIS participant**

Some respondents identified that NDIS funding has enabled them to return to work or study, or to gain employment or educational qualifications.

"My NDIS supports allow me to work for the first time in full-time ongoing employment in the open employment market. Prior to the NDIS supports that I receive, this would not have been possible." – **NDIS participant**

"Having NDIS support allows me to get assistance with physically demanding tasks so I can work. My work is not physically demanding." – **NDIS participant**

"Our daughter volunteers at 3 local organisations with the help of support workers. She is supported to go shopping for herself. She attends a centre-based program for socialising and fun. She is receiving regular overnight support to help increase her independence from us, her parents." – **Parent of NDIS participant**

Frustration

Some respondents qualified their description of positive impacts by noting the frustrations and challenges that were part of the process. For these respondents, there was frustration regarding the value of the support being obvious to them yet seemingly not obvious to the NDIA. This included having to produce many reports and evidence, as part of the funding request process. Respondents communicated that they felt that the supports should have been approved more quickly and easily, given that the supports were eventually funded. Based upon these negative experiences, anticipation of future struggles with NDIA taints some respondents' views of the NDIS, but does not prevent them from acknowledging the benefits that they have experienced.

"I had to work hard to get my chair-lifting device. It took nearly two years of arguing and insisting that I knew what I want, but I got there. I now have the [device] and my family can lift me into a position where I can get up off the floor. Having the [device] has made my life heaps better." – NDIS participant

"The funding has been difficult to continue to fight for each year, having to prove lifelong disability that will never improve. However the funds received and the flexibility of using the funds has been so important." – NDIS participant

In summary, although common themes were evident across the responses to this question about how the NDIS has supported people to live an ordinary life, each response provided a detailed account of unique personal experiences. There is a depth of feeling and a diversity of experience and opinion in these stories. To allow interested readers to explore these accounts, the complete set of unabridged responses to this question is provided in Appendix A.



Question 3: If you could change 2–3 things about the NDIS, what would they be?

Respondents provided in-depth responses to this question, typically sharing frustrations with the Scheme, providing examples of problems to be addressed and identifying areas for improvement. Given the large number of responses to this question, analysis involved a process of identifying commonalities across responses and the development of a coding framework. Four key themes and associated sub-themes were developed from this analysis:

1. Communicating and collaborating in alliance
 - Communication and collaboration
 - A human approach and inquiring mindset
2. An easier and more responsive system
 - Timeliness and efficiency
 - Evidence and reports
 - Disability knowledge and expertise
3. Not living in fear of funding being cut
4. Supporting people with disability to live well

Theme 1: Communicating and collaborating in alliance

Communication and collaboration

Overwhelmingly respondents communicated a need for improved communication and collaboration between NDIS participants, their allies (trusted, family, friends, health professionals) and the NDIA. Responses suggested that the current system lacks the fundamental elements of contemporary customer service, let alone an agency designed to engage with people who may have severe cognitive and communication limitations. At a fundamental level, respondents identified the importance of NDIA staff communicating respectfully, listening to the NDIS participant and recognising them as experts of their own lives.

“Decisions about a participant is made in front of us. Not behind closed doors.”

– NDIS participant

“The NDIA engages with participants and tries to understand specific situations, rather than have either little idea or preconceived ideas.”

– NDIS participant

“More catered to people with cognitive and communication challenges (at the moment it’s not very accessible).”

– NDIS participant

Respondents sought a single contact person at the NDIA providing a personalised and continuous relationship. They identified the importance of the contact person being someone who has taken the time to get to know the participant and their unique circumstances and has met with them in person, either at home or via video conference. Respondents recognised the need to create better systems and processes that supported the development of a collaborative and productive partnership between NDIS participants and the NDIA. This included the provision of information with use of easy-to-understand language, less acronyms and in accessible formats.

They also suggested a more collaborative and transparent plan review process that included allocated time for creating a draft plan for discussion and ensuring that the NDIS participant had reviewed and approved the plan before submission. Respondents also sought a written summary of confirmation of meeting outcomes and funding decisions, including a description of the reasoning for the decision, and an opportunity to discuss the reasoning and next steps.

“To be able to actually contact the person at the NDIA who is named as contact person on my plan so that my plan and my life are not set adrift and left confused when Support Coordination is not available or working well.” – NDIS participant

“When a plan is written, the NDIS Planner should talk through the new plan with the participant, and allow for immediate feedback. The new plan should not become the current plan until it is accepted by the participant.” – NDIS participant

More specific to the process of applying to be a NDIS participant, respondents suggested a free support service to help people register with the NDIS, as well as experienced staff employed as a first point of contact.

NDIS participant recommendations

- A single contact person at NDIA per participant (someone who knows me)
- Listen to and respect the views of the participant and their allies
- In-person or video conference meetings between participants and planners
- Person at NDIA making funding decisions should meet the participant
- Draft plans approved by participants before submission for approval
- Detailed feedback provided on reasoning for decisions
- Clear and consistent information and processes

A human approach and inquiring mindset

In addition to creating better processes for communication and collaboration, respondents identified the importance of staff demonstrating a human and inquiring approach to their relationship with NDIS participants. They want to be treated with dignity and respect, with staff seeing each NDIS participant first and foremost as a unique human with individual needs, preferences, rights and choices. Many respondents described wanting NDIS staff to ‘walk in my shoes for 24 hours’, seeking recognition of, and respect for their disability experience. They also want to be seen as experts of their own life, and have NDIS staff ask questions and show curiosity to better understand their personal context. This extends to staff demonstrating an understanding of the personal impact of funding decisions upon the lives of NDIS participants.

“Treat us with dignity and respect as equal and worthwhile humans deserving of being treated well.” – NDIS participant

“Listen to us about our lived experience and what we need, we know.” – NDIS participant

NDIS participant recommendations

- More respectful call centre operators
- Communicate with NDIS participants with dignity and respect
- Demonstrate respect towards medical professionals and reports
- Improve accountability of NDIS staff for their decisions

Theme 2: An easier and more responsive system

Timeliness and efficiency

Respondents expressed frustration with very long wait times for funding decisions (support, housing, services and equipment). They recommended faster approval times across all areas of funding, especially prioritising timely decisions for people in ‘at risk’ situations and use of agreed timelines for responses to funding requests. Suggestions for improved timeliness and efficiency included procedural changes to make the system simpler and more efficient. For example, faster approval of quotes, more efficient signing of service agreements, streamlined processes with fewer steps and people involved.

“Make it simpler – Stop making participants who already struggle in life have to battle a bureaucracy and system that is complex and exhausting to understand and deal with.” – NDIS participant

“Biggest thing is time to reach a decision, ridiculous to be waiting so long for personal care approval when I’ve had my disability for 40+ years and there’s 40+ years documentation.” – NDIS participant

Better flexibility within plans was also suggested, with more opportunities to make changes within a plan in response to changing needs, as well as the possibility of not needing a plan review for changes within a certain budget, such as technology under \$15,000.

“Understand that it can take a long time for someone to have a good routine set up with supports that work for them. Allow small changes to plans without the rigmarole of a review process.” – NDIS participant

NDIS participant recommendations

- After-hours services to increase accessibility for NDIS participants who are working
- Only using AAT as a last resort
- Having advocates available to assist with navigating the system
- Better processes to enable plan nominees to support participants
- Improved accessibility for self-managing funds
- Flexibility for planning and approving future needs for people with degenerative conditions
- Prioritise plan reviews for ‘at-risk’ circumstances

Evidence and reports

Respondents expressed frustration with the amount of evidence and reports that are required in support of funding applications. In particular, respondents did not want to have to provide evidence of their disability at every planning review, especially when living with a life-long or degenerative condition in which gains in independence or capacity building is not possible or relevant.

Furthermore, concerns were raised as to whether reports are read in detail, and understood by the NDIS staff who are making the funding decisions. Respondents said that they would like more guidance on what evidence is required, as well as a more streamlined approach to the amount of evidence required, and the processes involved to gain these evidence reports. Some respondents suggested a preference for fewer allied health assessments.

“That the recommendations of long-term experts involved with a person are not second-guessed or discarded by an inexperienced & unfamiliar NDIA officer (no matter their good intentions).” – NDIS participant

“To ensure all allied health professionals are given the appropriate training and resources to know how to write reports using the NDIS language.” – NDIS participant

NDIS participant recommendations

- NDIA staff to read and understand reports submitted by participants
- More guidance given to participants on what evidence is needed
- Stop asking for proof of disability for people with life-long or degenerative conditions

Expertise

Respondents also emphasised the importance of employing staff at the NDIA who have disability expertise, especially those staff making funding decisions. Responses indicated that by having staff with more disability experience there would be improved understanding of people's needs, as well as empathy and a motivation to get the decision right for each participant. Suggestions included employing more people with disability and/or allied health experience and giving NDIA staff better disability training. Respondents also suggested assigning planners to participants based on disability-specific expertise and suggested increased accountability and consequences for funding decisions.

“Planners, interviewers who know and understand the disabilities they are writing about fully – no one understands deaf. They keep trying to ring me – ughhh I am deaf. They do not understand how a deaf person lives their life. They do not understand technology required and why a certain type of technology is best – as they are not deaf and can not understand at all.” – NDIS participant

“The NDIS need to understand the complexity of living with a disability and be trained to respond with care and compassion.” – NDIS participant

“Way more education about disability within the NDIS. Even those with disability need education, because we all have different disabilities, which means we have different needs.” – NDIS participant

NDIS participant recommendations

- Employ more people with disability or allied health experience
- Assign planners to participants based on disability-specific expertise
- More training for staff, especially in relation to high-care needs
- Resources and training co-designed and delivered by people with disability

Theme 3: Not living in fear of funding being cut

Overwhelmingly, participants described the stress and uncertainty associated with the experience of living in fear that their NDIS funding will be cut. As outlined in the earlier survey responses, respondents communicated a lack of trust in the administration of the NDIS, as well as a lack of confidence in the stability of their funding. In particular, respondents communicated that this fear is exacerbated at plan review meetings.

Responses to this question pointed to a desire to remove the stress and fear from plan reviews, with a more supportive and collaborative approach. Respondents contrasted this approach to what they described as the current adversarial approach in which they have to ‘fight’ for funding and have little understanding of why in the past their funding was approved or denied. They seek planning reviews that are founded on a conversation between the NDIS participant and a planner who is familiar to the participant. Central to this process is the creation of a safe space to explore possibilities and to consider opportunities, without fear of losing current funds in the process of considering future goals and possibilities. For many, this also means not having to ‘prove’ their disability to planners, or for those with degenerative conditions, this includes planning for the future.

“Change the requirement to continually have to prove need and tell the story of disability. The mental burden, administrative burden and time burden is immense. The uncertainty is stressful. Let a satisfactory plan continue until a change of circumstances arises.” – NDIS participant

“When a participant has a plan that affords them ‘the good life’ to have this plan roll on and on. Why review and change (as it always does change) what is working for a participant. Especially when it takes sooooo much work to get a good plan.” – NDIS participant

NDIS participant recommendations

- Locking in parts of plans to be reviewed less frequently, such as every 2 years
- Guarantee essential services
- Be able to request funding changes without the threat of a reduction in funds
- Have the option for participants to renew their current plan without reassessment
- Allow a discretionary budget for out-of-scope emergencies
- Offer a less litigious appeals process

Theme 4: Supporting people with disability to live well

In response to this question about what people would like to change with the NDIS, a large number of respondents expressed a desire for the NDIS to be a system focused on people with disability living well, or what was described as ‘an ordinary life’. One participant suggested that the NDIS, ‘stop defaulting to no’.

Many of the suggested changes captured a sentiment of not just providing the bare minimum of support, but creating a Scheme that is innovative, responsive and supportive of people with disability to be supported to live rich and rewarding lives.

“Strengths rather than deficits based approach.” – NDIS participant

“Stop focusing on the things NDIS participants can't do - parents love to see what their child can do but the government plays the game of must provide what they ask for to give money. So money makes parents discuss the worst day of their child and write down for NDIS funding. Very sad for parents to do that about their own child.”

– Parent of NDIS participant

NDIS participant recommendations

- Give more funding to support social skills and community participation
- Give more support for people to be employed
- Improve access to independent housing and housing choices
- Improve access to home modifications and equipment
- Deliver more funded assessment hours for complex disabilities
- Enable access to holiday options for NDIS participants that provide much needed breaks for the families of NDIS participants living in the family home
- Ensure better equity for funding for all people with disability
- Improve training of support workers
- Give more support for people with profound disability living with ageing parents



Case study 3: Suzie

Suzie is a writer and loves the arts. She is determined to not just live an 'ordinary life', but insists on it being 'extraordinary'. Suzie has lived with an acquired brain injury for the last 25 years. Since joining the NDIS, Suzie is very grateful for the funding that allows her regular access to occupational therapists, psychologists, physiotherapists, podiatrists, and support workers.

The empowerment, choice and independence that Suzie receives via the NDIS is of great benefit. She feels such strength from the opportunity to make personal choices towards living a more independent life that NDIS has provided for her but there are things that could be improved rather than made easier.

The bureaucracy and paperwork involved with accessing the NDIS and getting supports is 'very annoying'. This is made worse by Suzie's memory that can make filling in long forms particularly challenging. She laments the rigid structures that sometimes limit the possible services and supports. For example a social capacity building group that she was involved in was abruptly brought to a halt due to changes of NDIA funding criterias. Suzie reflects on how funding cuts have led to her and others losing the opportunity for social connections with like minded people that are so integral to independence and recovery.

Suzie thinks the NDIA needs more staff who understand complex disabilities, and who are better at listening to the needs of participants. She is confident that she is the expert when it comes to her own needs and wants. Suzie knows what she needs but finds it frustrating when the NDIA staff 'on the end of the phone' aren't always listening carefully. She doesn't want to have to retell her story each time she contacts the NDIA and wants to be treated as an individual with unique needs: 'I am a person, remember?'

Discussion

This survey provided an opportunity for people with disability and their allies to share their experiences and to express their views about the NDIS. Importantly, the questions were designed to identify both what is working well and what NDIS participants would most like to see changed about the NDIS. The NDIS participant perspective captured through this survey gives valuable insights into the everyday encounters with the NDIA. Giving voice to the experiences of a broad number of people with disability is critical to improving the Scheme.

The findings reveal an important nuance at the heart of the NDIS participant experience in navigating the Scheme and interacting with the NDIA. The majority of respondents see the strengths of the NDIS, with many sharing stories of achieving important and sometimes transformative outcomes due in large part to the Scheme. At the same time, strong negative feelings about the processes involved in accessing or using the NDIS were evident. While many people with disability have experienced benefits from the NDIS, there is also a common underlying lack of trust and confidence in the way that it is administered. There's a gap between participant satisfaction with the NDIS and their confidence in the NDIA. Indeed, the survey findings suggest that there's gratitude and hope sitting side by side with fear and frustration.

There is a sense from respondents that the improved quality of life that the NDIS has brought could be taken away at any moment. This could be due to an unexpected change in policy or a simple miscommunication between participants and the Agency. In response, participants and their allies want a better, more transparent and collaborative relationship with the NDIA. This would replace the transactional and adversarial interactions that they sometimes experience. From their perspective, such a relationship would provide much needed stability for participants, as well as being more efficient and less wasteful.

When considering the responses to the question about what people would most like to see changed with the NDIS, respondents identified a number of potential improvements to the Scheme. These suggestions centred around 4 main themes: 1) Communicating and collaborating in alliance; 2) An easier and more responsive system; 3) Not living in fear of funding being cut and 4) Supporting people with disability to live well. While survey responses included a number of specific suggestions, it is recommended that the next steps include creating more opportunities for people with disability and the NDIA to collaborate in co-designing solutions. Drawing upon the findings from this survey, suggestions can be discussed, explored, tested and prioritised, adopting a collaborative approach across all stakeholders. Indeed, a key finding of this survey is that NDIS participants express gratitude towards the Scheme, and goodwill in working collaboratively with the NDIA to ensure the sustainability of the Scheme, while recognising the need for improvement to restore their trust and confidence in its administration.

A substantial number of survey respondents were willing to share personal stories about benefiting from the NDIS, despite expressing frustrations and disappointments with the administration of the Scheme. This finding calls to attention to what extent successful outcomes are captured as part of the NDIS plan review process. It may be that loss of trust means that participants (and their professionals) sometimes downplay success and development for fear of prematurely losing the safety net of funded supports. When there is an incentive to emphasise negatives, there is a risk that the participant and those around them take on this mindset in their day-to-day life. With the potential for a review of NDIS systems, it may be worthwhile considering how NDIS participants can be supported to celebrate successes and ways in which the NDIA and the administration of the Scheme could better support a strengths-based approach.

Furthermore, the NDIA measures and reports on participant outcomes and satisfaction as indicators of the health of the Scheme. The results of this survey suggest that measures of confidence and trust in the NDIS may also be relevant to track as they appear to be variables that can be independent of satisfaction or outcomes at a given point in time. Trust and confidence may predict things like: participant willingness to trial alternative and innovative supports, confidence to seek opportunities for employment or community participation, willingness to share information and feedback with NDIA, and willingness to invest time in capacity building. With an investment in rebuilding trust and confidence in the Scheme, is there an opportunity to better support people with disability to live well as valued and active members of the community?

One risk to the reform of the Scheme and co-designing solutions with NDIS participants is that it is likely informed by NDIS participants who have a voice and are able to effectively advocate for themselves. This survey makes a significant contribution by giving a voice to a broad range of NDIS participants. However, a limitation of this study is that NDIS participants who completed the study are not representative of the NDIS population in terms of geographic spread or disability type. For example, more people with autism and less people with intellectual disability completed the survey. NDIS participants living in Victoria are also over represented in the survey.

In summary, the findings of this survey reveal a conundrum at the heart of the NDIS participant experience: while many individuals see the real benefits of the NDIS, there is simultaneously a lack of trust and confidence in its administration. The findings of this survey also provide foundational learnings about the NDIS participant experience from which to build sustainable and meaningful solutions. With commitment from the Government to improve the NDIS and to restore trust and confidence in the administration of the Scheme, now is the time for the NDIS to listen to people with disability and co-design solutions. NDIS participants and their allies want and need the NDIS to work.

Conclusion

In summary, the findings of this survey make a valuable contribution from a range of NDIS participants about what is working well and what NDIS participants would most like to see changed about the NDIS. Importantly the findings highlight that NDIS participants have a wealth of knowledge of insights and goodwill that can be harnessed to transform the Scheme to be more equitable and sustainable.

NDIS participants want to see the NDIS provide great value for money and are interested in partnering with the NDIA to identify where this is not happening and to generate pragmatic and sustainable solutions. By seeking the perspective of NDIS participants, the survey findings highlight the importance of having trust in the NDIS, in addition to being satisfied with the opportunities afforded through the Scheme. This initial survey has elicited a range of valuable insights and potential solutions. Further opportunities are needed to listen and learn from end users to inform the development of a more responsive NDIS that supports people with disability to live well, as valued and active members of the community.



Case study 4: Penny

Penny's NDIS-funded wheelchair and assistance dog 'Red' allow her to connect with her community. Since accessing the Scheme, Penny has also been able to return to work.

Penny enjoys managing her own plan, and the flexibility of choosing her own supports. But she fears plan reviews and the possibility of losing funding. She recently had funding for her transportation needs cut, which means she is sometimes 'stuck at home' and cannot access her community. Penny sees her needs as an extension of her stated goals, so cuts to her plan appear to be cost-saving measures that undermine her goals.

Penny receives funding for her assistance dog, which helps her undress, open doors, retrieve items, and go shopping. She worries that funding for Red will be cut, which will not only negatively affect her physical needs, but also the significant mental health benefits provided by him. She wants the NDIA to adopt a more holistic approach to people's needs and not just focus on 'value for money and cost cutting.'

Penny finds it difficult to reach her NDIS planners via phone when she has questions or concerns. Contacting the NDIA by email is also slow and ineffective, especially given the lack of personal email addresses for planners. This makes the process unpersonable, slow, and off-putting as building a relationship with the planner is difficult.

Her disability has created unavoidable barriers in her life, but barriers she has encountered through the NDIS have added an unnecessary burden. She wants to be able to contact her NDIS planner directly rather than having to go through other Agency staff who don't know her or her needs.

Appendix A: Unabridged text

This appendix presents the unabridged text of all responses to the question “How has the NDIS made a difference and supported you to live an ordinary life?”

Please note:

- Respondents were asked to answer candidly in their own words, so the terminology used to describe disability, support needs, and NDIS processes varies considerably, and may not always align with definitions used elsewhere.
- The names of some people, service providers, cities, towns, and other potentially identifying information have been redacted or altered for anonymity.
- Responses have only been lightly edited for spelling, punctuation and to clarify abbreviations.
- Responses are presented in a randomised order.
- Some responses mention suicidality and other topics which may be distressing for some readers. Resources for assistance:
 - Lifeline **13 11 14**
 - Beyond Blue **1300 224 636**
 - Mens Line **1300 789 978**
 - Kids Helpline **1800 551 800**
 - Disability Advocacy Finder **askizzy.org.au/disability-advocacy-finder**

“My adult son ... lives with a severe intellectual disability entered into an SDA/SIL funded Supported Independent Living housing complex [a few] years ago. His formal supports, and a huge chunk of support from his parents, has seen him blossom.

He is now fiercely independent in going about his life 'by himself' when and where he is able. He has consequently made acquaintances with the baristas at our local cafes where he goes by himself, to buy his daily chai latte and buy a sandwich for his lunch. The local community theatre group spotted him on his journey to a cafe one day and invited him to join them; he has since had a cameo part in two plays – he just loves acting – it has been a dream of his for a long time. He now knows his way to the [provider] and the local [bank] where his routine of buying his meals and getting some cash for his weekly expenses has become an easy, non-anxious exercise for him.

These activities have all been achieved with the support of formal and informal supports. Without the NDIS he would not have been able to have been separated from me, his mum; he would still be very dependent on his parents. He has reached his capacity in his independence, but serendipity is still working! As he goes about his way as independently as he is able his world continues to open up unexpectedly. Sometimes NDIS funded supports need to be right there with him all the way, sometimes part of the way, and sometimes just making sure it happens for him.”

– **Parent of NDIS participant**

“In discussions with my neurologist yesterday the key factor contributing to his positive analysis of how slowly my irreversible condition is deteriorating is the work I do with a fleet of allied health professionals who use their different expertise to allow me to continue to walk, to balance (sort of), to speak, to swallow and lead a positive life with some community engagement while following my dream to continue my studies.” – **NDIS participant**

“The NDIS helped pay for my psychology for my disabilities for 3 years which is essential for me being able to engage with NDIS at all, and being able to access essential services and be able to have continuity of awareness and communicate. It's my communication aid. Prior to NDIS I had to find psychology myself and was paying over \$10,000 a year on [the Disability Support Pension] to do this. I had to eat WeetBix to afford psychology. I can afford to eat better now and my disabilities are more stable and I'm engaging with society much more now.” – **NDIS participant**

“NDIS funding has allowed [N] to have better choice and control over his life. If he doesn't like where he lives he can move. He can choose his support workers, he can choose his activities. Instead of being at a day centre, with heaps of other people, sticking to a routine he has not chosen for himself, he has a team that support him, give him choices, know his likes, engage with him and listen to him. He has grown personally and doesn't accept that he has no choices. He is happy, he does lots of different things in the community, his life is better because of NDIS and we are very grateful.”

– **Close other of NDIS participant**

“I now have suitable accommodation with 24-hour care.” – **NDIS participant**

“I have been able to live independently and obtain more help for specialist assistance which I would never have been able to get without NDIS.” – **NDIS participant**

“[G] has a severe acquired brain injury, with hemiplegia and several other conditions. He had a goal of competing in the Paralympics, on a recumbent tricycle. But the NDIS refused necessary capacity building funding and so while he has a recumbent trike to ride, he has not started on capacity to compete even at a local level.

Oh, you wanted something positive... sorry! At least we were able to get him out of a dreadful group home and into a unit of his own, though it does not meet his needs in many ways – as he was only funded for shared SDA, not individual.” – **Close other of NDIS participant**

“My daughter is [a teenager] and has [a neurological condition]. The NDIS did not make a huge difference in her life except for her hearing about it on the news a lot more. Prior to the Scheme being introduced she already had community access, and capacity building supports.

Community access was paid for through the ‘block funded model’. She accessed weekend activities like a monthly visit to the zoo or the like, through a local provider that had been around for >35 years. She also accessed specialist school holiday programs through the same provider. The provider had other programs that encouraged community involvement that we were involved in (e.g. camps, movie nights, etc).

When she was young, we accessed what was then considered ‘respite’ through the local council, and a support worker visited ~2.5 hrs a week while we went for an outing. Most of the [allied health] interventions were paid for with support from private health, or Better Start schemes, or with packages. She had a case worker from [an organisation] who helped provide packages. As other working parents do, we paid for childcare afterschool through standard childcare, or if my daughter was too fatigued to attend, we paid for a person privately to look after her a couple of days a week, when this was necessary.

[She] entered the Scheme [several years ago] when she was [younger] at a time when an ordinary life was being supported – attending school, making friends, going to gymnastics, swimming, bike riding, holidays. Normal family life.

Mother’s perspective:

The Scheme is supporting people like my daughter fine. However, it relies on motivated ‘informal supports’ to have a part time unpaid job to maintain reasonable/necessary supports.

2017-2020: Several plans Supports provided one S100 [Internal NDIA review] lodged (successfully)

2021: S100 lodged (unsuccessfully). AAT when funding cut by 35%

2022: Agreement reached – funds fully reinstated (all information had been provided – Agency had not read info).

Create change, as the Scheme has unreasonably created burn out.”

– **Parent of NDIS participant**

“I am an adult with a disability and always thought I would live with my parents until they died or could no longer take care of me, then I would go into a nursing home.

Now with the NDIS I am able to live independently for the first time in my life. This is due to supports for living at home and assistive technology such as a power wheelchair.” – **NDIS participant**

“The supports I access enable me to do things I otherwise could not – a cleaner here for 2 hours can do what would take me 8 hours if I could even do it at all. This enabled me to pick up an extra day at work.” – **NDIS participant**

“To have the support to really get involved with community groups [and] participate with others. To develop, create myself, to learn about mental health and participate.” – **NDIS participant**

“The NDIS has changed my life dramatically. Whereas I was unable to have help to do all the things I need to do to live independently at home, I now have the ability to have support workers to assist in the way I need. This has meant that I can manage my life, which is very constrained due to severe physical limitations.

As a self managed participant, I can employ people I know and trust to share my days and activities. I have been able to have modifications done for my bathroom which I would not have been able to afford. I am able to seek physio and occupational care and advice when needed which I could not afford without support. I am also able to afford support to work from home. If I need transport by wheelchair taxi on the rare occasions that I go out I have the funds to pay for this too. All of this makes my daily life so much better. Sometimes I wonder how I would cope without these supports.”

– **NDIS participant**

“My son ... is quite high functioning, but if left alone, he can collapse into fits of anxiety and loss of impulse control. He needs constant guidance and support and has no capacity to understand things like finances, planning, people who could take advantage of him or self-regulation. Having support workers, respite care with qualified people has been instrumental in his day-to-day life and planning for the future. I feel sick to my stomach at the thought of him without the support he needs.”

– **Parent of NDIS participant**

“My son lives in his own home. With a purposeful team around him. The amount of communication we all have is an integral part of how this works to allow him a normal life. This indirect support and communication within the team is not understood by planners. If we were to go into drop-in supports only it would be catastrophic in 2 weeks. There’s a lack of understanding that people can develop their own models of living arrangements.” – **Parent of NDIS participant**

“The NDIS has enabled me to get smart technology around my home which has made a huge difference for the better of me living independently around my home.” – **NDIS participant**

“My 2 sons who have extensive psychosocial disabilities were living with me right up until they became participants of the NDIS. They started to receive 24-hour care (shared between them as they live in a family home, which is divided into 2 flats) 2 years ago and we were also lucky enough to find an agency who understood psychosocial disability and work really well with my sons. They are now [older], and although they will require support for the rest of their lives due to the extent of their disabilities, they are gradually becoming more integrated into the community, which was difficult to achieve, but with the right support, this can occur. It will take a long time before we can say they live an ordinary life, but at least, now we are working towards this – and there is a management team which looks at all aspects of their lives. My husband and I can now live our own lives and look after ourselves, as we are now in our mid- and late-70s with health issues of our own to contend with. Our support was no longer sustainable.” – **Parent of NDIS participants**

“I am now 71 years, and have been diagnosed with [condition] for 50+ years. I have needed to use a wheelchair for the last 12 years and it has not been possible for me to use public transport unassisted. With the support of NDIS funding I have been able to live alone and maintain my independent living (with Capacity Building, Daily Activities and Transport funding) and continue earning an income (and pay tax) using my university qualifications. It also assists me to maintain contact with my children and grandchildren who live and work more than 100kms from me...” – **NDIS participant**

"It has provided the means for my parents to seek professional guidance to expected developmental outcomes and given helpful strategies to implement. It has provided the means to seek help with daily living with human beings ... yes, people ... who are a good fit for my personality and culture. It has given me opportunities to engage in the community and do things I wouldn't otherwise, like horse riding with [Riding for the Disabled Association]. It has provided me with technology which gives me a voice and equipment which improves my physical ability. It helps me be a kid, just like any other."

– **NDIS participant**

"After the initial shit show of applying a few times and being sent the application forms, same questions, myself and my Chronic Nurse etc, were getting frustrated with ...

Then finally offered to have a phone conference approximately 1.5 hours, or face-to-face.

I chose face-to-face, then asked 'why'?

a) To see whom I'm dealing with.

b) For them to see whom they are dealing with. To see and understand my disability, situation.

c) 1.5 hours on the phone I would've fallen asleep.

d) Final results, I advocate for myself, seems the way to get things moving and done."

– **NDIS participant**

"My ... son had a motorbike accident 3.5 yrs ago which left him with an acquired brain injury. For 3 years I provided primary care for him in a 1-bedroom unit where he slept on the couch. Hence, for the past 6 months he has been living in a [Supported independent living] house. This has started to give him a better quality of life but still a work in progress." – **Parent of NDIS participant**

"The NDIS has allowed me to keep living in my own home for longer." – **NDIS participant**

"The NDIS changed my son's life and lifestyle, it allowed him to move from a day service to 1:1 support. At his day service he was unhappy and developing behaviors to gain staff attention. As his mother, I tried to speak with staff and stressed to them to follow his goals. The best thing I did for my son was to use his NDIS funding to employ 1:1 workers and AHT. We all worked as a team plus his medical doctors were all kept in the loop. My son attends a local gym, his physio directs his programs, all workers have a copy of the exercises, he does hydro-pool programs with an allied health assistant, bowling, shopping at various shops and has meals at local venues. He is recognised and spoken to by name at local shops and venues. All his support workers take directions to assist [him] and celebrate with mum his achievements.

He has been accepted in a proposed SDA project to be hopefully completed [soon], he knows 2 other residents in the house. He was lucky to have [support coordinator] do his SDA application, knowing the process to gain a SDA helped us achieve a SDA allocation. As a mother, I am doing my best to put all the programs in place at our home and in the community to make the transition smooth from family home to a home of his own. [My son] is a living example of skilled people working together to improve a participant's ability to live and be a valued member of their community. The challenges are huge that we have both faced dealing with the disability system, but I am very grateful to people I knew who helped us achieve the best outcome for my son." – **Parent of NDIS participant**

"In theory it sounds great but I have found that the NDIS funding decides what a person can do or not do. The NDIS has all the choice and control and will not fund at a level to be able to attend a day service or community as they expect everyone to cope with a group and no one will take this amazing incredible participant who is a joy when supported at the right ratio." – **NDIS participant**

“There was no adequate support for people with brain injury and through the NDIS my son does not have to be with old fashioned institutions that did not provide him with what he needed. He is now at TAFE with support, training hard to hopefully get to the Paralympics one day and is living in his own home with support.” – **Parent of NDIS participant**

“I’ve been able to access allied health to undertake preventative programs [degenerative condition] where previously Medicare rebates/public health would not.” – **NDIS participant**

“Support by peers closer in age for my son to be in the community without his parents, he is [a teenager] and does not want to be chaperoned by parents. Ability to choose what he does on these outings.” – **Parent of NDIS participant**

“Prior to receiving NDIS funding I had nowhere comfortable to sit. I was using pillows and cushions to prop me up in bed to sleep. I was only showering every 10 days or so because of the effort it took to shower. I now have a comfortable chair. A bed that adjusts so I can sleep tilted and assistance to shower 3 times a week. I feel human again.” – **NDIS participant**

“The NDIS has been life-changing for me in so many ways:
I now have regular support for meal prep and cooking, so that I can actually eat 3 meals a day (something which I couldn’t manage alone when I was cooking for myself and my child and we have different dietary needs).

Having capacity building funding has enabled me to make huge progress in understanding and managing my disabilities better (I’m autistic and have a psychosocial disability).

I’ve been able to start making art again, which is really important to me. I’ve been able to make art again because I am fairly well supported, and not constantly totally overwhelmed by trying to survive day to day.” – **NDIS participant**

“The NDIS has allowed me to develop social skills in the community.” – **NDIS participant**

“Enabled the NDIS participant to get out of residential aged care.” – **Close other of NDIS participant**

"I have [a condition] that is funded under the NDIS ... The NDIS in home assistance is enabling me to stay employed as well as study part-time at University.

I have lost my marriage as a result of the impact of my [disability] on my husband and the lack of support we had. He ended up being a full time carer for me, when there was no NDIS and this burnt him out. Ironically I am now funded for in-home domestic assistance that is equivalent to a little under the carer's fortnightly pension, yet for considerably fewer hours than the full time care expected of my husband when he was caring for me for a similar amount of money. I was also on the disability pension for a number of years.

If I were to partner with someone and cohabit, this funding would be reduced as the 'burden' of my disability would be expected to be born in part by someone who is a romantic partner. So as a single person getting support workers in is great, but it also means this autonomy is threatened if I entered into a cohabitation relationship

Without the NDIS funding I would not be able to maintain full time work, which would mean I would not be able to afford to live in my own home. I was on [a state-funded] housing waiting list for over 10 years as a high priority, with not one offer of housing being made. Luckily I was able to maintain full time work & this eventually enabled me to obtain a mortgage on my current home.

Since my diagnosis ... my standard of living has been much lower than my peers and my housing circumstances have been very precarious over a number of periods of time. Being 'in need' and vulnerable seems to bring out the narcissistic do-gooders and the exploiters who 'get' that you have no options and are keen to act like the hero with their own self-satisfying agenda in mind.

Without the NDIS when I am unwell with a relapse I would not be able to get out of the house, work, cook for myself or do other household things like cleaning, washing etc. I use funding for some of these things even when I am not having a relapse as [disability type] really limits your energy even outside of a relapse, so prioritising my energy, even when relatively well, is important.

I use NDIS funding to attend medical appointments which become frequent when I am having a relapse. Living in a regional area ... there are no bus or viable train transport options. I also often need physical support – literally someone to lean on and help me. My cognitive function is affected as well. I have a lot of pain and mobility problems as a result of the [disability type], so car transport is the only workable solution when I am sick and at that point in time I am often unable to drive myself. While I have a driver's license I am not eligible for transport funding under NDIS so I have to use my social assistance funding – supposedly so I can interact and engage in the community, but in reality it enables attendance of long distance medical appointments.

The NDIS has made it possible for me to live a more ordinary life than before the funding, to continue to work and study towards working in a field I would like to work in. It also means that when I need help with basic things, the person being paid is not 'doing me a favour' or holding it against me, they are doing paid work they have chosen to do. This greatly reduces the risk of abuse and exploitation. It has reduced the 'beggar' element of my life and enabled me to be more autonomous. The only thing worse than someone helping you out of pity, is someone who makes out that it's no problem to help you, but then holds that against you.

The NDIS has most definitely raised my standard of living as well as access to specialised disability services such as exercise physiologist and occupational therapist which I would not and could not afford without it." – **NDIS participant**

“The NDIS has supported my son in Supported Independent Living (SIL) in a small group with home with 4 other young men, with 24-hour support. It has given him independence from the family and as his parents, it has given us peace of mind when we are no longer here. NDIS has provided therapy support to assist him manage his frustrations and fears and enhance his independence with simple tasks, such as shoe lace tying. The Community Support has provided him with activities that he enjoys in the community, such as cooking classes. My son works at a [organisation] and loves it; however, the NDIS funding is not enough to support his participation and these services are in danger of closing. He is not able to work in open employment and he would be devastated if he did not have [activity] to attend 3 days per week. He loves his job, his friends and his support workers.”

– **Parent of NDIS participant**

“This year I've been receiving support worker assistance for the first time. It's meant that I could get my hair washed weekly instead of every 3 months, have been able to maintain the ability to work, and have had assistance to deal with years of clutter that had built up in the house because I'd been unable to physically do anything about it.” – **NDIS participant**

“The NDIS has supported my daughter in so many ways. It has paid for my daughter's wheelchairs, special bed, and a recliner that helps her to stand. It saves my back by not having to lift her out of her chair. A commode for the shower, car modifications so she can go out, a pool hoist so she can swim and do hydrotherapy as public hydro pools are impossible to use because they use the hoist and pool areas for swimming lessons in the only hours she can do hydrotherapy. NDIS also has provided the much needed physiotherapists, occupational therapists and homecare. The main issue that is so wrong is the fact that we can't get a ceiling hoist or a bathroom modification to get the bathroom to the Australian standards for a disabled bathroom. We have been trying for 4 years because the NDIS people have no common sense and do not understand what needs to be done to make it possible to give my daughter independence in the bathroom or to make it easier on carers when showering her as the toilet is right on top of the shower.” – **Parent of NDIS participant**

"In multiple areas of life; housing, poverty, unemployment, education, lack of access to affordable health and other services and lack of access to daily living supports (despite \$300K/year funding) I fit the 'ordinary for someone with a severe psychosocial disability.'

In 1 exception an NDIS support delivered beyond expectations and has given me aspects of an 'ordinary life'. Four years ago I completed a 4-year goal to get an assistance dog.

Since getting [assistance dog], I have stayed out of hospital (common pre-[assistance dog]). This saves the taxpayer, and has meant I can remove myself from the toxic, abusive mental health system after decades. I have been able to go off all medication; sorting out side-effects from functional limitations. I now live alone. My adult sons have peace of mind because [assistance dog] is with me. They are free to contribute to society.

Life is more manageable but when systemic hurdles and aspects of my disability impact on me I now have the means to manage my distress. [Assistance dog] has given me something that no human (and I've tried many disability 'supports') can; timely, appropriate, affectionate, efficient, consistent and good-natured service.

He does his job. He makes me laugh every day. He does no harm.

Instead of my various (often offensive) labels, I now have an identity of 'dog owner' which is the first time I've been 'ordinary' in a social sense. With [assistance dog] I have made friends outside the disability bubble. We meet for play dates and 'do lunch'. People talk about my dog, not my disability. I belong to a community on Facebook that celebrates their dogs which is a huge contrast to the NDIS and mental health page where most of us are dealing with huge bureaucratic and service struggles. A 200 word limit is not enough words to express how the idea of an 'ordinary life' is flawed. I want the safe, contributing life I was promised. We can never be 'ordinary' as long as we are afraid, restricted, under resourced and accompanied by logo-wearing providers." – **NDIS participant**

"I moved to Melbourne from Sydney. The NDIS helps me because I can survive independently now for the first time." – **NDIS participant**

"I now live as an independent person in my apartment with a supporting provider within the same building, providing support when required. However, this took me nearly 2 years to achieve. I had to take them, the NDIS/NDIA, through their Tribunal process, the AAT. Being what they are, they waited until I was within 3 weeks of the hearing to concede, which they did. I was one of the 400% increase in AAT hearings. I am confident that they wanted me to give up and just disappear."

– **NDIS participant**

"I'm sharing on behalf of my husband who lives with young onset Alzheimer's and I am his primary carer. As his disease is terminal and progressive, the NDIS has enabled us to ensure he has a team of both therapy and social supports that together assist him to participate in meaningful activities. A roundtable meeting 3 yrs ago with [husband] and all supports resulted in him agreeing to try art therapy – something he'd never done before. He has just participated in his first ever art exhibition and won the people's choice award. The boost to his self esteem is immeasurable; he is now open to trying all forms of art. All our family and friends now have some of his beautiful art as a legacy of the positive aspects of his disease." – **Close other of NDIS participant**

"It let me have the right equipment to remain on my farm." – **NDIS participant**

"Having care and support daily has changed my life. My scooter has also, as without it I would be unable to go out anywhere. When I finally move into my SDA, that will benefit me so much as I'll have everything I need around me." – **NDIS participant**

"In some ways the current support workers help me to live an ordinary life. Despite currently residing in aged care they take me to some of the Canterbury Bulldogs matches and to take me shopping and go on outings." – **NDIS participant**

"Funding support workers to drive me places, like medical appointments, day trips, movies etc."
– **NDIS participant**

"It has taken since 2013 and 2 x AAT full 3 day hearings. Much stress and harm to family. Now it is a good plan and parents supported, but review coming up and more stress." – **NDIS participant**

"My life used to be hell. Every day I would have to go to the shop alone and work out what to buy for the day. Due to the difficulties my disability causes with this, I would be in severe distress the entire time, and couldn't plan past the next 24 hours if that. I'd sit in my car after exiting the shop and hit myself in the head to stop the meltdown to be able to drive home. Often, I'd forget important things and have to go back, maybe twice. Every day. Once at home I'd be frozen and exhausted, and do nothing but make dinner and go to bed. Now my support worker helps me plan my shop and execute it, make phone calls I'd never make or delay for years so I can have regular checkups and get my prescriptions filled, and I even visit the library often. I can do art therapy and it helps me manage my anxiety a lot. I've mostly stopped hitting myself. I might even be able to go to TAFE, with some help."
– **NDIS participant**

"Work. Contribute to society. Access community." – **NDIS participant**

"I now use a wheelchair as a result of [condition]. I work as a disability advocate and through the NDIS I have been funded for a hoist in my car to enable the mobility scooter to be transported and taken out of the car to enable access to my workplace and many other places in the community."
– **NDIS participant**

"Funding to assist me to stay in my home safely and with dignity. Funding to access therapies that assist me to maintain my condition." – **NDIS participant**

"I have been well supported by the NDIS which in turn has allowed my husband to continue to work. Not only is this a benefit to the government in the \$40,000 tax he pays, it also saves the government money because we are both ineligible for any Centrelink income support payments."
– **NDIS participant**

"Before having support from the NDIS, I was completely drowning in my disability. I had no support frameworks in place, was at risk of being unemployed, and felt isolated, helpless and like I had a dark future ahead with a lifelong disability. With the support of the NDIS, I now have a network of support workers and allied health professionals that have allowed me to gain independence, manage my disability sustainably, and create space in accessing the community and connecting with people. It has allowed me to gain confidence in becoming more independent and having support to carry out daily activities that I was unable to do means I feel I can be comfortable in my home, safely exercise and seek access to tailored support workers to holistically benefit my life." – **NDIS participant**

"Regular visits by an introverted autistic teenager (girl) to both a provisional psychologist and support worker have helped to provide expectation of a positive view of her future and so possibly develop to be independent." – **Close other of NDIS participant**

“My daughter has a micro enterprise which is very low key because she can’t work too many hours on it. She paints and decorates terracotta pots and makes gift hampers. She has a Facebook page through which she sells, she also has various stores which sell her products and she sells at markets a few times a year.” – **Parent of NDIS participant**

“Prior to the NDIS we nearly begged the state government to provide our loved one with therapy and day options – we were ignored for years and it was truly awful. The NDIS provided us with the funds to seek therapy etc and to seek a new SIL provider.” – **Close other of NDIS participant**

“Having NDIS support allows me to get assistance with physically demanding tasks so I can work. My work is not physically demanding.” – **NDIS participant**

“Before the NDIS we couldn’t even access respite or STA for our daughter, which meant we did nothing as a family unit. My husband would take our other 2 daughters to functions or on holidays while I stayed at home with our daughter. This was the case for 25 years – how our marriage stayed together has me beat. We had our first family holiday without our daughter which was wonderful. My husband and I over the last 4 years have grown together again because she can access STA on a regular basis. She loves going on her own holiday to spend the weekends with her friends. She has thrived and just loves it. Although now we have been told it could be taken away! If this happens I don’t know how I will cope!!” – **Parent of NDIS participant**

“Having finally got the funding needed for our daughter to live independent of us, her parents, we were able to go around Australia on a caravanning trip. Pretty neat to be able to do this at 70 years of age.” – **Parent of NDIS participant**

“The NDIS has enabled me to stay living in my own home. Without it, I would have needed to go into residential care. With it, I have been able to have the yoga which has been critical to maintaining some degree of mobility and relatively normal bladder function. I am far happier living at home but I would be in care.” – **NDIS participant**

“Not yet ... We have tried in the last 3 plans (which is 3 years of ticking boxes & jumping through all the hoops) – to progress our daughter to independent living. She is now 28 years old! The REALLY annoying part is that they won’t even acknowledge although this is stated as a goal on her plan ... it’s completely ignored when the plan drops. Last year, we lodged a complaint – as the planner admitted lack of experience and had not even reviewed her file before doing the plan meeting over phone. All this achieved – was auto rollover of the existing plan for the next 2 months, and a new plan which STILL contained NOTHING to progress this goal.

This year we have the support worker agency (which has expanded its function to advocate specifically on independent living options plan and design) working with us and lodged a Home and Living application in early May. The NDIA acknowledged receipt of the same, as we were going for a ‘light touch’ review, and requested funding to do exploration and design to identify the housing needs of our daughter. Yesterday I finally got a phone call, to set a date for the annual planning meeting?!? Not because of our application ... but because it’s now within 100 days of the existing plan expiring! WTF!!!! The application we made – they knew nothing about it.” – **Parent of NDIS participant**

“Though my son lives in aged care it is in a small town where the community over the years have come to embrace my son and his NDIS carers, they go out of their way to include him and cater for his needs.” – **Parent of NDIS participant**

“It’s made zero difference. In fact it’s just made life much much harder. Three years in and zero benefit, just huge frustration.” – **NDIS participant**

“I look forward to answering this question once I have moved into my SDA apartment. My wheelchair, funded by the NDIS, is important because it allows me to access the community like catching transport, going into wheelchair taxis, accessing concerts, cinemas, shopping etc.”

– **NDIS participant**

“I’m accessing mobility aids and support workers to allow me to care for my 2 year old son independently. This is allowing me to take him out to cultural events, allowing my partner and I to eat healthily and live in a clean house without choosing between active parenting and chores, is giving me my freedom and weekends back because I don’t need to take recovery time, is allowing me to participate in an active social life, etc.” – **NDIS participant**

“My partner has received a package of supports that provides her with all the personalised support and assistive technology she needs.” – **Close other of NDIS participant**

“Access to fatigue management programs plus individualised support (e.g. cleaning, cooking, AT) allowed me to get my life back. I can now spend energy on family, work and connecting with friends and the community whereas before I was in a cycle of just managing everyday tasks.”

– **NDIS participant**

“NDIS funding for personal care assistance allows me time and energy for enjoyable engagement rather than puffing through ordinary survival activities which are either impossible or time-consuming. Funding also assists me to have help to complete research and other preparation, for book writing and publicity, public speaking, and other tasks related to life administration (e.g. gathering tax information for my accountant). Carers can also accompany me to the more difficult medical appointments allowing my busy working family who live half an hour away more freedom. Carers also accompany me to swimming and hydrotherapy, for exercise and feeling of well being. My valued carers above all, provide the opportunity to live at home independently preventing my premature entry into a more regimented aged care facility. I LOVE MY FREEDOM.” – **NDIS participant**

“I have had a below knee amputation which has confined me to a wheelchair most days. I have been funded to have a motorised wheelchair and prosthetic leg which allows me to mobilise in my home and still work. I have workers that come each day to help me with personal care and moving about in the community which has also allowed me to continue to live independently in my own accommodation.” – **NDIS participant**

“Has enabled my son to live in his own home, have a job and have friends. But at each review this all is in jeopardy :(.” – **NDIS participant**

“I have an orthopedic bed that helps me sleep and turn around.” – **NDIS participant**

“My sister in law resided in an aged care facility for 9 years, the last 5 years in a locked dementia ward. She does not have dementia. Whilst there, all human rights were taken away so much so that she stopped speaking to us, and allowed the schizophrenic voices to take over completely. It was very difficult to watch. But finally she moved into her own home in August 2019. The transformation is incredible, she goes out visiting her hometown, she goes shopping, she goes out to dinner enjoying life to the best of her ability. With the assistance of NDIS funding for her rent and supports this was all made possible.” – **Close other of NDIS participant**

“[S] is non verbal autistic and she is supported in her own unit 24/7 to live a life of capacity.”
– **Close other of NDIS participant**

“I'm autistic and I have a psychosocial disability (which includes PTSD). Before having NDIS supports I was extremely isolated, having to regularly miss meals because I couldn't manage feeding my disabled child and my own disability related diet, and suffering very significant cognitive decline. Having regular support from skilled peer support workers, and excellent trauma informed capacity building, has meant that: we not only survived 2 years of further significant trauma during COVID, but that I'm now in a period of huge post-traumatic growth. I'm involved in systemic advocacy as well as personal advocacy for myself and my child. I'm better able to use my own journey to understand and support others who are having similar struggles, and my relationship with my child is finally growing in strength rather than worsening due to complete overwhelm trying to manage both our disabilities and sometimes conflicting needs.” – **NDIS participant**

“NDIS has helped me to live an ordinary life with help of a home services worker and sufficient travel money to continue to meet [group]. Big help with physio to help with mobility and psychology to help keep me sane.” – **NDIS participant**

“I have a progressive form of multiple sclerosis and I require much care. I have a support worker who has given me the opportunity to be involved in art and community access. This has given me incentive to be the best I can and be an active part of the community.” – **NDIS participant**

“Access to physio that helps me live my best life and keeps me strong and engaged in everyday activities.” – **NDIS participant**

“The NDIS assists me with my current living arrangements in Disability Accommodation Services. It helps me within my plan allowing staff to support me daily and helping me to achieve my goals. Support staff allow me to advocate for myself, giving me the support and a sense of value when accessing the community by myself. NDIS assists me with monthly outings, supports employment through day program activities and allows me to visit my mother ... and other places I like to visit.”
– **NDIS participant**

“NDIS carers have enabled me to maintain work, and also to escape a domestic violence situation. I can now live in peace and safety.” – **NDIS participant**

“The NDIS has provided a plan revision for me to get handrails in my bedroom, as it was not in my original plan.” – **NDIS participant**

“My NDIS supports allow me to work for the first time in full time ongoing employment in the open employment market. Prior to the NDIS supports that I receive, this would not have been possible. My support from therapists, support workers etc, allows me to get out more in the community and participate in more community festivals, markets, activities, whereas prior to my supports I was very isolated and would remain indoors most days. I still remain socially isolated, however I feel confident that I am making small and gradual progress to build up my skills in this area.” – **NDIS participant**

“For my son, at 40 years of age, he isn't totally reliant on me to support him manage his life. He has been able to choose people to support him without me (his mum) having to know every single detail about his life. This enables him to live a much more typical life, as an adult, making his own choices and decisions with good guidance from people other than his mum.
For my sister ... she is able to live in a home of her own, without relying totally on her siblings ... She has paid support to enable her to live her life independently of us. We manage her supports but don't have to provide them ... it's a win/win for all of us.” – **Parent of NDIS participant**

“The NDIS has enabled our PWD to remain at home. Without the wonderful support workers that we have I highly doubt we could have sustained having PWD at home still.”
– **Close other of NDIS participant**

“People with disability are being isolated from loved ones and forced to be with strangers, who are not family, not friends. Turned into money making commodities by many who exploit participants' funding in group houses, medical reports and services, gardening and cleaning services. Yet, many are denied basics for day to day requirements such as wheelchairs, mobility assistance, proactive therapies, safe place to live (if with family, be supported for that). True independence, not what those who are going to profit financially. Support informal supports, which is more of an 'ordinary life' than the divide of disabled communities and non-disabled communities.”
– **Close other of NDIS participant**

“My adult son is able to be supported individually to live a good life. He doesn't have to join a noisy group program if he doesn't want to. He is able to be supported to live as independently as possible.”
– **Parent of NDIS participant**

“The NDIS is critical in allowing people (like me) to manage their situations. We want to contribute to our families, workplaces, and society. But we need assistance to do this. By helping us manage our respective illnesses we can minimise the impact this has on us and by assisting with day-to-day activities it helps us focus on the areas/issues that we view as important. The NDIS helps us to manage ourselves and improve our self-worth and value to society.” – **NDIS participant**

“Our daughter volunteers at 3 local organisations with the help of support workers. She is supported to go shopping for herself. She attends a centre-based program for socialising and fun. She is receiving regular overnight support to help increase her independence from us, her parents.”
– **Parent of NDIS participant**

"The NDIS has saved the life of my dear young friend and he is now safe and he's so grateful for the massive change in his lifestyle. He was at very high risk of being destroyed; however, having the links with me and those I contacted, he's come through so many difficult times that bring tears to my eyes. He's a gentle, clever and very sensitive person and I believe he's got the capacity to tell his story and help people understand what should change.

My daughter was very disabled and she passed away 10 years ago. She never went into care as I was in a pilot project with [state government program] since 2003. When the crisis finally came and she was to be placed in care, I took on all the training I'd had and fought the government for full time funding. I had [federal Labor MP] as our local member. I used immediate contact with her staff and I also used all of the legal avenues I'd been given to put our needs together. [Federal Labor MP] told me late that we were the first family, with the new State Labor Government legislation introduced, that succeeded in getting the funding we did. It was a massive achievement as I'd had a significant cardiac arrest not long before that. So yes, life with disability-living with it and working endlessly with families over many years, is beyond words really.

My daughter has blessed me and my young friend who is still in ongoing contact with me and I am like his dear old friend forever." – **Close other of NDIS participant**

"Supporting me in my micro enterprise and allowing me to employ my own support staff and set up a good life." – **NDIS participant**

"It's meant that our son can access his community and interact with both disabled and non-disabled people in ways that would never have been possible otherwise." – **Parent of NDIS participant**

"They have only brought negatives, heartache to my life and cost me money on supports they have not paid for. I call this entrapment and preying off my good nature." – **NDIS participant**

"NDIS has given me better mobility by providing the required orthotics and orthotic shoes. Plus, the civic participation budget enables me to participate in social activities." – **NDIS participant**

"I am currently requesting a plan review from the NDIS so that I can live a semi-independent life in a place of my own and away from group housing. This process has taken approximately 3 years since I first applied and with the COVID restrictions and the increased barriers the NDIS has put in place, I am still waiting to get that approval." – **NDIS participant**

"Our son lives in a semi-supported apartment. The carers are able to help him access supported employment as well as skill sessions. As a parent it is reassuring that he is cared for as one gets older. The activities to enjoy the community a parent would find difficult and work as well." – **Parent of NDIS participant**

"Before I received funding for exercise physiology I was using a walking stick on and off. I was not walking in the city where I knew the pavement was cracked in fear of tripping. I had ungraceful falls where my legs would give out when stepping off a gutter because of strength issues. After working with an exercise physiologist, joining a gym and walking regularly I don't use a walking stick anymore and I have the confidence to walk about the city. I don't remember my last fall from weakness either. I would not have been able to afford my 1:1 sessions without this financial help and I know my physical well being would be in a lot worse state now without it. I still work part time and I don't believe I would be still working still without the help of the NDIS in general." – **NDIS participant**

“My daughter was in a day program before she got the NDIS, doing things with people with different disabilities. She hated being in a group of people with disabilities because they stuck out in the community. Now she and her support worker can go and do activities she is interested in without it being immediately obvious she has a disability.” – **Parent of NDIS participant**

“I WAS lonely but now I have a few friends.” – **NDIS participant**

“My son has been able to move into his own home.” – **Parent of NDIS participant**

“I am having a bathroom built which will ensure my independence and have a [orthotic device] which ensures that I can walk.” – **NDIS participant**

“I come from a culturally and linguistically diverse background and I am vision impaired and do not read print. I need assistance with filling out some government forms and other related documents and attending appointments in unfamiliar locations. Prior to the NDIS, my primary support in this regard would be my parents, in particular my mother. However this is difficult as English is not my parents first language. My father works and my mother has her own health problems at the moment and is unable to drive. Utilising supports such as support workers, occupational therapists, and transport funding has meant that I am able to fill in any forms without the process being stressful due to the language barrier and the fact that I don't read print, I am able to socialise more with friends, and I am able to be as independent as possible all while managing my disability and health concerns.”
– **NDIS participant**

“Better strong support for me.” – **NDIS participant**

“Having funding to assist with household cleaning has been great to assist with fatigue management. Access to neuro physio is assisting in maintaining and improving mobility and balance which I turn is keeping me ‘safe’. Being able to purchase low cost items to assist me with my day to day activities in order to stay independent has been mentally beneficial.” – **NDIS participant**

“Funding has allowed me to be in control of my home and garden. Much better for my mental health. A lovely non-judgmental support worker adds value to my very diminished life. She takes me as I am, which allows me to feel less damaged.” – **NDIS participant**

“I moved from a group home to my own SDA apartment in 2019. This has given me more independence, privacy, dignity, peace and quiet, a place to call home, and the space I need to do my work.” – **NDIS participant**

“Still early days, due to COVID putting a lot on hold for 2 years, but NDIS funding is helping me to discover myself and identify key areas to improve. So far, it's been a lot of self discovery, but now that things are returning to something normal, I can start to address issues more directly. This will help me participate more in the community and especially economically.” – **NDIS participant**

“It provided me with a coordinator who went above and beyond even in my darkest times, and without funding due to NDIS and their lack of ability to actually read. It also provided me with a support worker after being consistently ripped off, physically hurt and manipulated. Said support worker is teaching me how to build relationships which I have never learnt or been able to do. It has provided me with a psychologist that assists with capacity building with my disability so I can try and build skills to manage my incredibly rare disability better.” – **NDIS participant**

“I am unable to do gardening because of chronic pain and sensory issues from autism, I now have a regular gardener. I have also been able to see a psychologist regularly that has done wonders for my mental health and daily wellbeing.” – **NDIS participant**

“I’ve recently accumulated a disability from a medical condition. This makes work and everyday life difficult. The program encompasses a lot of things taken for granted, small things like cleaning, to the chair I use for work, or big things, like the stairlift to make living in my house easier. The NDIS provided the support required so I can continue work, access the community and contribute generally.” – **NDIS participant**

“I had struggled. I have congenital disability but fell through the cracks on assistance. My mother bought my first wheelchair. I had total informal care from my husband and daughter. Then one died and one went to uni just as I aged in the NDIS. This saved my life. I now have equipment and care I need to lead a full, active and productive life. I can go to conferences again with support. Attend concerts, protests and workshops and work! I am a fully rounded person again.” — **NDIS participant**

“It has given my son the opportunity to fulfill his long-time dream of living independently after living more than 10 years in a supported share house. This will make him a lot happier, and enable him to then focus on other parts of his life including seeking employment. Without the NDIS funding, none of this would have been possible, so it can make a huge difference to the quality of someone’s life.” – **Parent of NDIS participant**

“This will take me hours to type as it has been an ENORMOUS battle to achieve. And then it only lasts 1 year!!!” – **NDIS participant**

“Supports give my son the ability to study at university.” – **Parent of NDIS participant**

“My son lives on a property with sheep, cattle and crops. His support workers take him to the sheep saleyards and onto the Woolstore and he gets to see the actual sheep sale and talks to many farmers and agents. When he goes to the Woolstore he gets to see what happens to all the wool and he even gets to see our wool in the store, means so much to him. He is learning what happens once the wool leaves our shearing shed.” – **Parent of NDIS participant**

“The NDIS has meant that our daughter can live in her own home with the support required to work on her goals of independence. It has enabled her to participate in work and other community activities.” – **Parent of NDIS participant**

“A support worker helps me lift my daughter into her car seat, supervises me driving so I don’t faint, helps me change her and take her into the swimming pool and then helps me access the inaccessible pool safely so I can take my daughter swimming without her dad. My car hoist helps her put my scooter in the car without hurting her back when we go to places where the scooter can fit, like shopping centres. It’s so nice to be a parent without a family member supervising me.” – **Parent of NDIS participant**

"I can tell you how they haven't: I live in an apartment that is partially owned by my mother and by myself. When all my equipment is in my bathroom as well as my support worker, there is no room left to move around. I cannot access my laundry or my balconies. I chose this apartment 9 years ago, and at that time, my disability was not what it is now and I was able to access the rooms in my apartment much more easily, including the bathroom.

I applied for SDA, but they have basically said that I am not disabled enough to live in accommodation where I can access everything. Why should only 6% of the population be allowed to have easy access to their place of residence? What about the rest of us? Aren't we entitled to live in a house where we feel comfortable and can access all rooms as easily as the able-bodied population? Isn't that what an ordinary life is?" – **NDIS participant**

"Saved my marriage; Scheme supports have enabled me to maintain full-time employment; supports directly contribute to my family's well-being." – **NDIS participant**

"My brother is a story of a young person who would have ended in aged care if it wasn't for the NDIS – instead it took a team of people to fight for him to ensure that didn't happen. He now lives in an SDA with the support he requires in place to achieve this." – **Close other of NDIS participant**

"My brother who has [condition] has an ILO and good care but not because of NDIS, he was in this arrangement pre-NDIS thanks to the WA government before the transition."
– **Close other of NDIS participant**

"Cheaper rent. \$600 for a week is too much for a person with a disability. Housing would be a plus for me and not having to pay \$600 a week rent. It's crazy." – **NDIS participant**

"At the age of 49, I was able to take my first plane trip interstate because I had the right support. This gave me the confidence to attempt an overseas trip 2 years later. I had spent a lifetime watching friends and family going overseas and I never thought it would happen for me. I used my NDIS Core supports to pay for support hours I needed and I paid for all the other costs." – **NDIS participant**

"Able to live in supported accommodation with peers rather than aging parents." – **NDIS participant**

"This might seem like a very basic level of difference, but before the NDIS I had no supports except for a privately funded fortnightly clean, when I could afford it. Meanwhile, as just one example, I often do not have control of my bowels, yet I spend most of my life in bed and can't change my bed sheets, and I can't shower more than around once a week. I also had dangerous falls, with some serious injuries.

My life lacked dignity, safety and hygiene.

Now, my house is clean, my sheets get changed, and I have a far greater level of dignity in my life. Plus, I have better control of my bowels in the first place because I have someone to help provide me with the diet my health professionals recommend, which I couldn't do before. I am fairly new to the NDIS and I still have bad falls, but the risks are being addressed and I have high hopes of greater safety in my home.

I am able to do a better job of describing this: I did a Statement of Lived Experience for my access request, which outlined the worst of my daily or frequent experiences of a life that would not be considered acceptable in any other circumstance, such as residential care or parenting or in the workplace." – **NDIS participant**

“My daughter has become more independent and confident about living out of home. However she does require a higher level of support which cannot be provided in her current accommodation (2-bedroom unit). She would need to move to a 3 bed unit – easier said than done!”

– **Close other of NDIS participant**

“I lived on the edge and very fragile. Every day was exhausting and the focus was on surviving. It was terrifying, fragile and tough. NDIS has given me a life not a survival.” – **NDIS participant**

“The increased level of support I now receive has meant I have been able to develop support routines with little-to-no corner cutting. Consequently, I've never been healthier or happier or healthier. I'm able to live, work, and contribute like pretty much anyone else.” – **NDIS participant**

“The NDIS has greatly improved my confidence in cooking abilities and some social skill supports. It has also helped me on the mental health side of things.” – **NDIS participant**

“I had to work hard to get my chair lifting device. It took nearly 2 years of arguing and insisting that I knew what I wanted, but I got there. I now have the [device] and my family can lift me into a position where I can get up off the floor. Having the [device] has made my life heaps better.”

– **NDIS participant**

“The NDIS has meant I can have support to live a more individualised and meaningful ordinary life.” – **NDIS participant**

“They have not supported me except to enable me to access some therapy. BUT to get to the sessions the gate is closed. So how does this compute?? Let a person have a chance to speak with the person slashing the budget.” – **NDIS participant**

“I applied for SDA funding a few years ago, unbeknownst to me the SDA funding was not added on to my NDIS plan. After a couple of plan reviews, I found myself on the verge of homelessness as my apartment was going to be sold and I was to be evicted. I wanted to continue living by myself, independently, with supports coming in as they had done for the last 7 years. It took me 3 years to get that SDA funding, 3 years to get to live an ordinary life. One that I wanted to live, not one decided for me, not one that was chosen for me. One where I didn't need to share, and be watched by support workers, where my every move would be questioned! I move into my new place in about 10 days time and I am happy!” – **NDIS participant**

“I have been able to get the rehab I need. It's allowed me to cook what I want to eat for dinner. It's allowed me to have a clean house.” – **NDIS participant**

“It will once we get through AAT, get a truly Robust residence built and able to implement the vision for ordinary life.” – **NDIS participant**

“When I receive adequate funding in my plan (before funding cuts) it was amazing to be able to receive supports that genuinely made a difference. Capacity building through physio helped me become more independent in what I was able to do. A support worker/cleaner in the home ensured I was able to spend the little energy I had achieving something satisfying, as opposed to using up my energy on bare basics and then not being able to do anything but the basics.

Funding for activities (e.g. learning sewing, studying a graphic design course) helped open up new avenues of activity and work that I was able to participate in, when previous work/activities have had to stop due to change in health/mobility etc.” – **NDIS participant**

“I have a neurological condition that results in physical and cognitive impairments. I am housebound and unable to manage many everyday tasks like cleaning, cooking, laundry etc. Having the NDIS means I can get the rest I need, while being able to live in a clean, tidy and safe space, which is incredibly important since I rarely leave the house. Recently, my best friend has been going through a tough time, caring for her sick mother. Because I have NDIS support and the basic tasks are taken care of, I have been able to use my very limited energy to help my friend through a difficult time.”
– **NDIS participant**

“At first my experience was stressful and confusing. It took some time to find the right support fits for me and learning to trust they have me in mind when they walk through my door and not just my funding. I have a wonderful support team around me now, they have literally changed my life for the better. I have physical and psychosocial disabilities and my health and life was a mess. I had no hope for anything at all and couldn't see a future for me let alone making plans and goals.

I now have a brilliant psychologist who genuinely listens and together we create goals and ways for me to be able to accomplish things I need to in my life. I have a wonderful psychosocial recovery coach / support coordinator who is amazing with finding resources I need to participate in my community with support and goals. My support workers have been so helpful and kind and help me with so much around my home I haven't previously been able to achieve. Seeing goals reached and creating more has given me confidence and learning how to navigate NDIS and funding and budgeting has been teaching me new skills and a better understanding of the terms and acronyms used. I'm extremely grateful for my team of support and for the NDIS allowing me to have a chance to better myself and my life and giving me some hope of a better life.” – **NDIS participant**

“I have cerebral palsy and use a power chair. I used to walk on crutches and eventually developed significant injuries in my shoulders and neck. I was forced to stop working. A doctor said I needed to go on the disability support pension. Of course, the government disagreed.

Initially, I was paying for my own treatment – trying to relieve the pain and spasms I was experiencing and regain some of my mobility to a point where working again might actually be possible. When the NDIS started, I was able to access specialist physiotherapists without spending a fortune. Unlike the physio service at the hospital, I could choose when the appointments happened and I could go for as long as I was finding them helpful. Over a long period, things did improve. I had less pain and was able to retain and restore some mobility. I could keep on crutches some of the time.

After a medical treatment that didn't go to plan and made me more disabled than ever, access to specialist physios has again enabled me to see some recovery over a long period. Walking on my crutches had become extremely difficult. Now it is becoming possible again. Before the NDIS, I didn't have that kind of access to specialist physios who understand my condition. I think I would be experiencing more pain and be less mobile without my NDIS funding. NDIS also makes me the client rather than the patient. It gives me more say in the supports I receive.” – **NDIS participant**

"It has absolutely made our life liveable. We couldn't get through a single week without the NDIS. Our child's disability is so complex and time consuming to manage that we rely on NDIS for not only therapy supports, but also support workers and house help to get through the week."

– **Parent of NDIS participant**

"Bad depression is part of my mental illness, seeing and using all my support is definitely a big help. I am grateful and consider myself lucky and makes me want to improve." – **NDIS participant**

"I have always been an active person who participated in water sports especially. Finding myself in a wheelchair plus hands that I have problems using was devastating. When I came out of hospital in a wheelchair I was suicidal. The support of a psychologist helps me through the darkest times, now intensive physiotherapy is getting me moving again and a hand therapist is helping with pain and movement in the hands. These are paid for by NDIS and that has been the greatest benefit for me. Since seeing these allied health therapists I have improved movement and reduced pain. This is helping me regain some of my former independence and to continue to work a little plus I have been able to reduce the medications that I take.

I also now have hand and wrist adaptations that allow me to hold my kayak paddle and can get out on the water regularly which for me provides massive physical and mental improvement. Then simple things like having someone clean the house once a week takes a little pressure off me and allows me to concentrate on some of the things that only I can do, like the little bit of remote work that I am still able to do or spend time with my family, especially helping my daughter get through her uni course in spite of her own problems." – **NDIS participant**

"My husband has been able to obtain part time work as I have carers to look after me. I am able to spend time with my grandchildren with the aid of my carer." – **Close other of NDIS participant**

"It has given my 23 year old autistic grandson hope for the future. He knows I'm a strong advocate for him and knows that I regularly engage with his support coordinator. I believe ALL providers should be registered and all case workers have skills that can support people with specific disabilities. So, maybe there could be a minimum standard of training and experience for case/support workers."

– **Close other of NDIS participant**

"For 4 years I had to hitchhike to get to my local town from my rural home. Over those 4 years, I struggled to go to therapy sessions, I lost friends that I could not visit, and struggled to get my shopping and my assistance dog home. Some trips of under 20 mins took me over 3 hours to make. I was vulnerable and exhausted by these trips. Now my support workers takes me shopping. Support workers have helped me with my sleep, my meals, my loss of hope has lifted, my faith in myself also. When I have a problem, I am not so alone. I see hope for my future again." – **NDIS participant**

"As a family member I can see my brother is more happier and confident. He was diagnosed with late onset diabetes and struggled to understand how to manage this. His sugar levels fluctuate between 1 to 29! (should be 5). He has permanent nerve damage and family were constantly worried he could face blindness and/or an amputation. Meal delivery ensures he has regular meals and the support workers ensure he eats the meals delivered and attends his medical appointments. This has enabled me to continue to work full time, focus on my family, care for our 93 year old father and to worry less. I still find myself taking on a coordinator role as there are limited hours available for this."

– **Close other of NDIS participant**

"I was already having home care, hydrotherapy and physiotherapy which were largely paid by me (some subsidy for home care), but having their cost covered has made a huge difference. I have been able to have more sessions and afford more chiropractic, plus for the first time having regular therapeutic massage paid for, which is really helping with my condition, I'm the best I've been in 20 years. Having the services of OTs to help set me up better at home, do more gardening, I'm more independent. I've been able to finish my book because of the extra supports and therapies."

– **NDIS participant**

"Purchased my first wheelchair." – **NDIS participant**

"Enabled my daughter to: improve her reading and writing skills; live with her best friend in her supported share house; go out with an independence worker; have tailored personal training to improve personal well-being; progress her music talents; have holidays without mum and dad."

– **Parent of NDIS participant**

"As a migrant with no English I have managed to overcome all the challenges and build the life I wouldn't dare to dream. I was only schooled for 6 years, completed a [master's] degree, traveled for an exchange [overseas] and landed a job all with my saviour physical disability in a power wheelchair. I have tried and tried not to give up and be an active community member and was only able to do so with the support to have someone to act as part of limbs that doesn't work as expected. To continue fulfilling the ordinaries of life was due to having the required support." – **NDIS participant**

"The funding has been difficult to continue to fight for each year, having to prove lifelong disability that will never improve. However, the funds received and the flexibility of using the funds has been so important, my son is able to have the assistance to go out in the community and feel safe and have others safe around him. he is able to get medical care as the behaviour supports allow him to be able to practice getting medical care, which every person is entitled to but some are denied due to being seen to be unsafe. The ability to self-manage gives the ability to search for options and change those options when they are no longer working. It gives the ability to have a life that would otherwise not occur due to requiring such intensive supports." – **Parent of NDIS participant**

"My support worker makes meals for me, my gardener is amazing, my support worker and my whole team are amazing. I have deaf support workers mostly which is wonderful because Auslan and my culture is intrinsic to me and when we get to see my parents we have total communication. I don't have to be the interpreter, I can just be their daughter." – **NDIS participant**

"The only difference the NDIS has made for me has been to fund 2 prosthetic legs to allow me to get around. My other needs, assistance around the house and garden and various items which would make my life easier have been so difficult to source, that I have given up. So the NDIS is not helping me to live an 'ordinary' life, not even the life I should be able to lead through the NDIS. As a life-long tax-payer, this is so disappointing." – **NDIS participant**

"The NDIS has allowed my son to have access to equipment, carers, support, transport, SIL and SDA to allow him to live as well as he can with what he needs." – **Parent of NDIS participant**

"The NDIS made a difference once I appealed and was approved to live 1:1 in a 1-bedroom apartment with carers on-site 24/7 ... My NDIS plan was renewed quickly and after 17 months of living in hospitals I was able to experience independence and experience an ordinary life." – **NDIS participant**

“Freedom is a guide dog and the ability to fund him. The NDIS has its flaws, but once things are running and all the red tape is overcome, the outcomes are life changing and empowering. I am retired now and living off my super. I wish this had been around when I was working full time.”

– **NDIS participant**

“As we have 3 service providers supplying a minimum of 7 people a day over 4 different time periods each day there is no way we could afford to keep my husband at home.”

– **Close other of NDIS participant**

“I wish I had a positive story as that was my hope in joining the Scheme; however during the past 2.5 years the NDIA have humiliated me, breached various laws in dragging me through the AAT, and consequently exacerbated my pre-existing medical and mental health conditions and almost killed me.” – **NDIS participant**

“Remain living in the community. Remain working – if they could just keep funding Work Based Support (they keep taking it off me, then I have to keep fighting for it) I have my own business. Remain to choose who comes into my life – I would like a social life but they keep taking that funding off me and then I have to fight.” – **NDIS participant**

“My daughter is now able to have a holiday with enough support for her needs.”

– **Parent of NDIS participant**

“I am an advocate, guardian and person responsible for 4 ladies who share their home. The NDIS has allowed all ladies a better quality of life. However there is always room to improve. One lady needs more time at her day care. One lady needs more social time to enjoy music. Two ladies need cooking, reading classes. These are what I am working towards for these ladies.”

– **Close other of NDIS participant**

“Support services that were previously prohibited to me because of cost are now available. In the short time I have been awarded the NDIS, I have felt physically stronger and, in turn, mentally improved. I feel more hopeful about what I achieve on a daily basis.” – **NDIS participant**

“I was a recluse. Now I have an interest in getting out and I am becoming more independent.”

– **NDIS participant**

“After a terrible Plan 1, my second NDIS plan was very good. It enabled me to achieve my key goal of living in a house on my own (independent of my parents) with 24/7 support. The support includes enough hours each day with 2:1 support to give me a satisfying level of choice and control over when I get in/out of bed, when I shower/toilet and when/where I eat. The support is portable, meaning I can choose to have the same level of support wherever I am. My support workers are able to help me with household tasks which I enjoy, such as cooking meals as well as tasks I don't enjoy such as hanging my washing on the line.” – **NDIS participant**

“I had someone to advocate for me and this made the package much easier to access. When completing the documentation I was asked to go personally to the office and they guided me to what I had to provide in regards to my disability.” – **NDIS participant**

“The NDIS has enabled my son, now in his 30s, to learn to live independently in his own home with 24/7 supports. It has given me, his mother and carer, the promise of my own independence at a later stage of life (in my 60s). My son is now actively thinking about how he might find work, achieve a healthy lifestyle, and develop friendships. This is occurring at age 36 (better late than never).”

– **Parent of NDIS participant**

“Funded an accessible van. Funded personal supports, gardening maintenance, support coordination. Looking to fund an assistance dog. Funded split system at work. Funded a recumbent trike disability bike to be able to get back to goals post strokes. Funding the disability increase in accommodation for holidays to be financially reachable to disabled people!” – **NDIS participant**

“I hire a cleaner, laundry service and gardener, all local and some traders. My sheets get changed regularly instead of a couple times a year. My week is not deciding between living in a mess or being exhausted doing things that the cleaner and gardener can quickly get done. No one needs to know if it's NDIS or it's because of disability, I don't have to have time consuming humiliating OT reports to get it approved. It's straightforward for everyone involved.” – **NDIS participant**

“My son moved from home where he functioned as a grown child to supported independent living where he is kicking goals and has become an independent young man.”

– **Parent of NDIS participant**

“I have a progressive disease that is unpredictable and debilitating. Without the funding from NDIS it would be unlikely I would be able to afford the powered wheelchair I now need. Having this piece of equipment has allowed me to accept my disability and I am now working part time. Something I did not think I would ever do again. The funding has allowed me to build confidence and find my new purpose.” – **NDIS participant**

“I'm a wheelchair user, as well as autistic: because of this I need extra support to get out and about, and also specialised housing. Like anyone else I can now do my shopping 1-2 times a week, and move around my apartment unassisted.” – **NDIS participant**

“Better access to the funding programs, and shorter waiting times for equipment and personnel care providers.” – **NDIS participant**

“Supports to help me maintain my independence rather than do the job for me. I had a lot of pressure to get cleaners rather than a robovac to let me do it when I wanted for example. Same with food prep ... a Thermomix changed my life and made me safe while cooking as the auto function shuts down at the end of each step rather than me forgetting the stovetop is on.” – **NDIS participant**

“The NDIS has helped me move into my own unit, but still next to the house so staff can help me. I have lots of space for my things. My family can visit in my own place.” – **NDIS participant**

“The NDIS' lack of contact, support or responsibility has caused me undue angst and stress whilst trying to manage my son's care.” – **NDIS participant**

“Because we (my daughter with my assistance) self manage we assert ourselves as the driver of how supports and services are delivered. However this means that often many support workers don't stay if they won't take direction.” – **Parent of NDIS participant**
