



Submission to the Joint Standing Committee Inquiry: NDIS participant experience in rural, regional and remote Australia



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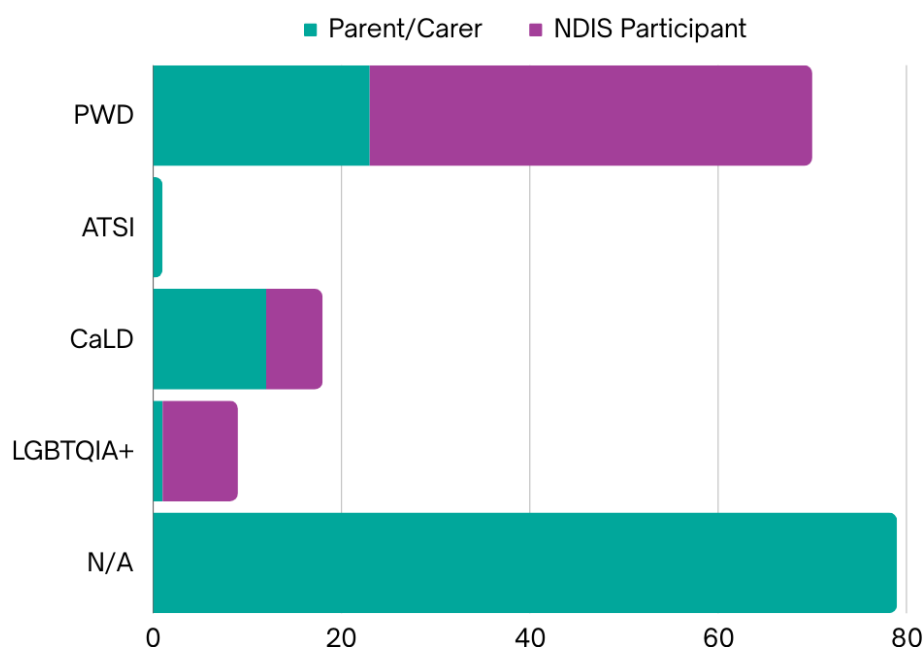
Acknowledgements

SWAN acknowledges the traditional owners of the land on which this submission was produced, the Wardandi Noongar people. We acknowledge the deep spiritual connection to this land and extend our respects to community members and Elders past and present.

Submission preparation

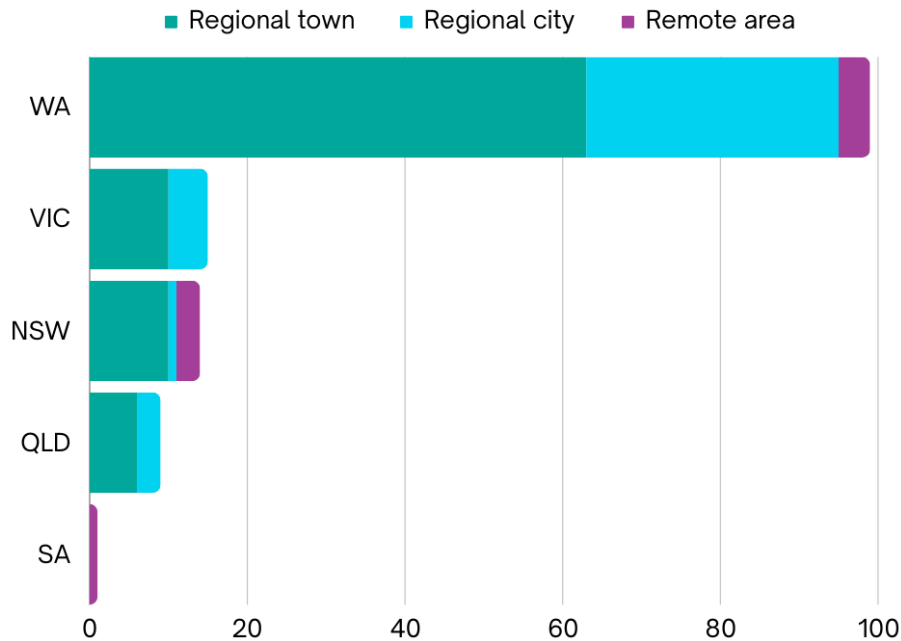
This submission was prepared by South West Autism Network Inc (SWAN). In order to write this submission, we listened to the views and concerns of people with disability, their families and advocates living in regional Australia. To aid in gathering quantitative and qualitative data, SWAN created a survey and invited people nationally to participate. We listened to people throughout regional Australia about their NDIS participant experience. SWAN received 156 responses and 114 completed surveys (73%) were received.

Survey Respondent Demographics



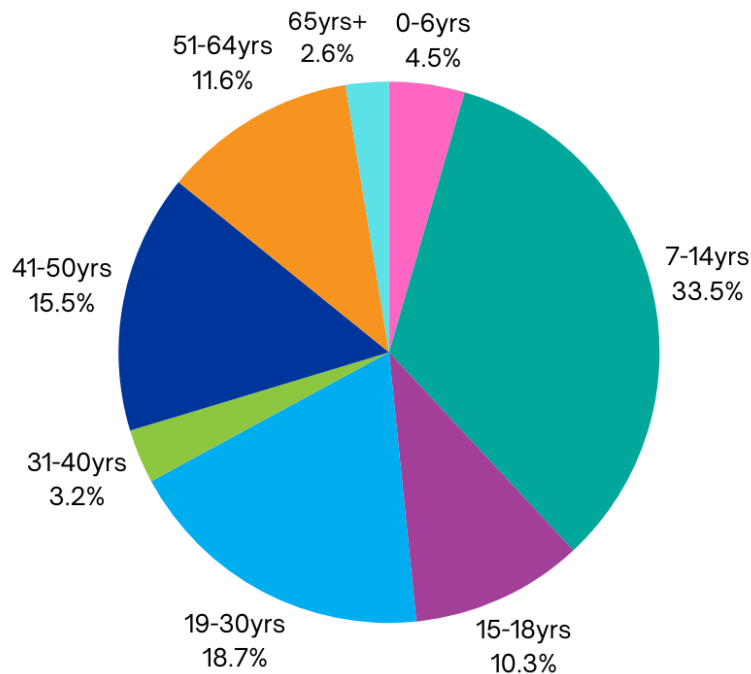
SWAN opened the survey to respondents throughout Australia and received responses from regional cities and towns, and remote areas as can be seen in the chart below.

Location of Survey Respondents

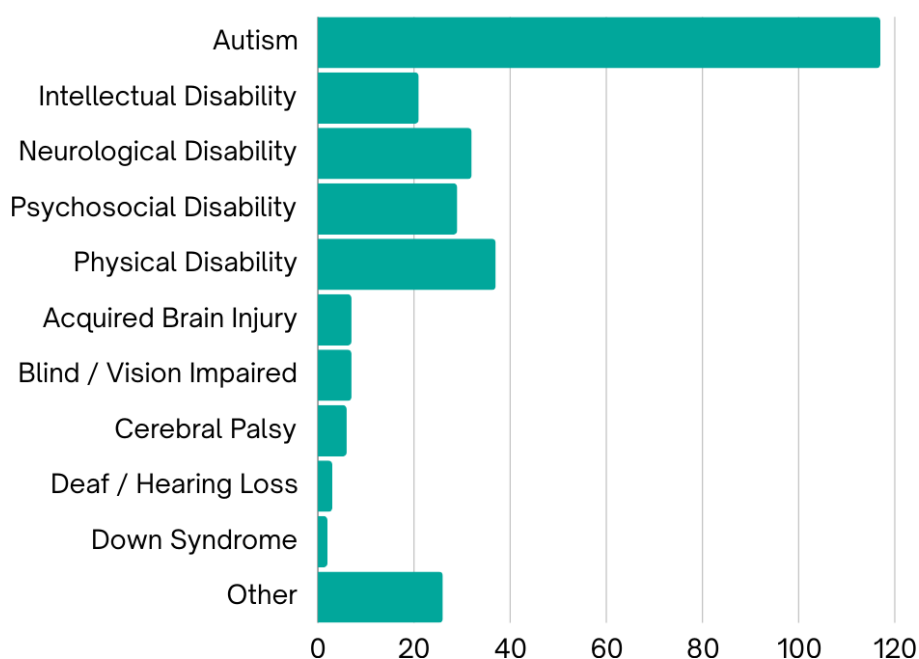


We also asked survey respondents about what type of disability the NDIS participant has, and whether they have more than one type of disability. Of note, 64.1% of NDIS participants in our survey have more than one disability.

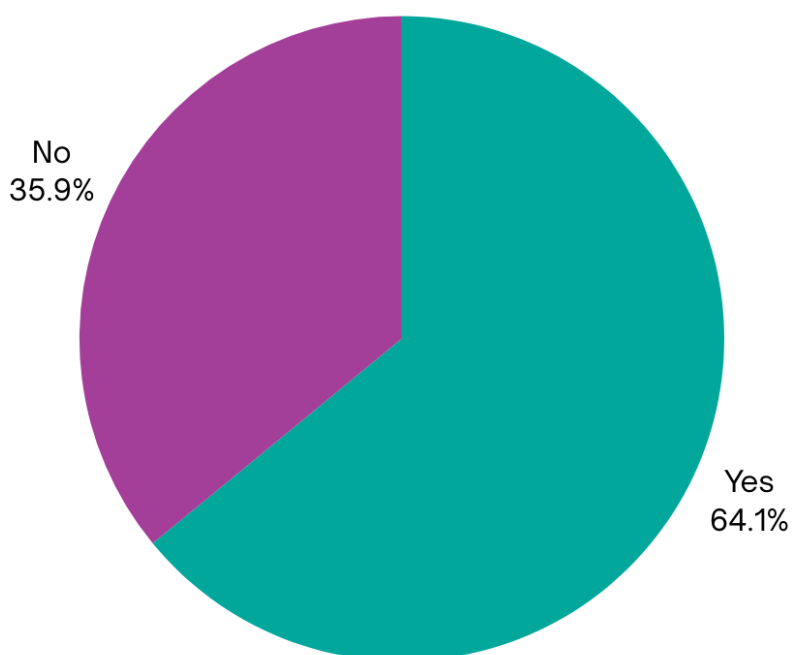
Age of NDIS Participant:



Disability Type



More than One Disability?



As a regional not-for-profit Disabled Persons and Families Organisation (DPFO) providing information, peer support and advocacy, we are able to draw on fifteen years' experience supporting autistic individuals and their families, carers, therapists and the wider community. Our submission aims to include the voices of people who are NDIS participants, and families throughout rural, regional and remote Australia.

Introduction - About Us

The South West Autism Network (SWAN) is grateful to The Committee for making available this opportunity to provide feedback on the NDIS participant experience in rural, regional and remote areas of Australia.

SWAN is a not for profit, charitable organisation supporting autistic individuals and their families living in the south west region of Western Australia for the past 15 years. We are a Disabled Persons and Families Organisation (DPFO) who are currently delivering two Commonwealth funded Information Linkages and Capacity Building (ILC) projects. We have almost 2000 registered members, with hundreds more people with disability and their families accessing free support from SWAN. All staff, volunteers and Board members either have a disability, or are the family member of someone with disability.

Our primary role in the community is to provide information, peer support, advocacy, and connection to mainstream and disability services, building the capacity of people with disability and their families to navigate Government and non-government systems in order to meet their needs and participate in their local communities. We support people seeking diagnosis, post-diagnosis, and across the lifespan, and provide autistic safe space group programs for autistic children, teens and young adults through our AutStars and YES Program, in addition to Youth Mental Health First Aid training.

The Application Stage

Participants and families consistently reported confusion, difficulties and a lack of support in applying for access to the NDIS. Survey respondents were able to make an optional comment about their experience of applying for NDIS access. None of the comments reported a positive experience in applying for access, except where there was significant support from an advocate or peer support organisation.

“I tried asking LAC & other providers to help me with understanding how to apply but was told they couldn't speak to me until I had an NDIS plan. I didn't know anyone who had NDIS and didn't understand the terminology. I was so distressed.”

“I tried to apply on my own over the phone. But when they asked for additional evidence I had no idea what to do so I did nothing and my application expired.”

“Our claim was lost, misdirected, refused, accepted and went to multiple people and divisions that even my advocate couldn't believe the mess and lodged a formal complaint.”

“Very confusing and over complicated if I hadn't been referred to SWAN for help I wouldn't have managed it.”

“It was extremely stressful and confusing.”

“It was good, but only because I had good advocacy. Other than that I was pretty much told I wouldn't qualify so I wouldn't have bothered, nor did I have the skills to apply myself.”

“It was really overwhelming. Without help from SWAN I wouldn't have known what to do.”

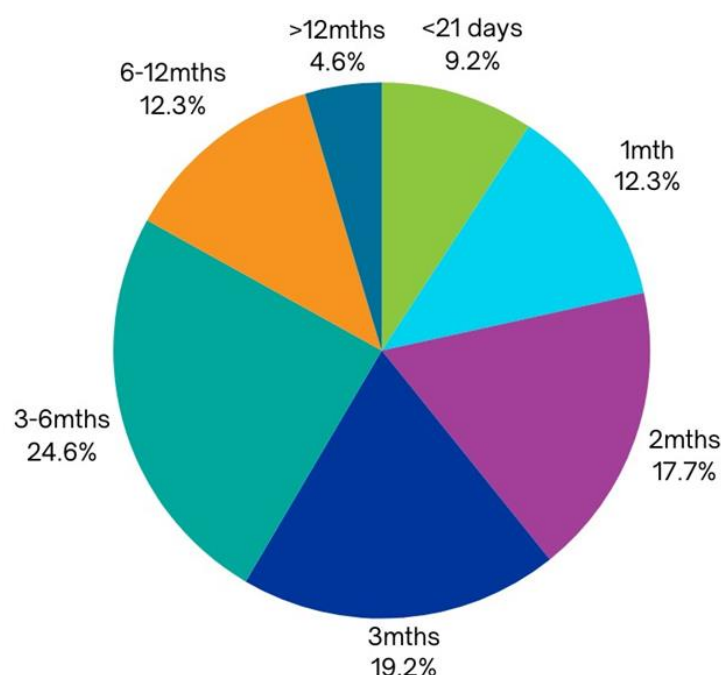
“Overly complicated and costly to source diagnostic assessments and get reports etc from clinicians.”

“The form is far too complicated. I understand NDIS well, so knew that with autism level 2 being on list A for eligibility, I didn't need to have a health professional fill out the confusing section 2.”

“We were seen to and organised through early intervention in Queensland. Moving into regional WA and adding additional since diagnosis and a new child to NDIS has been extremely difficult and lengthy process.”

Many respondents were transferred to NDIS from the state-based disability systems and reported significant errors in the transfer which had serious impacts. A commonly reported issue in the transfer from WA state-based disability services to NDIS was that the primary parental contact on transfer to NDIS was listed as the other parent (often Dad), instead of the primary contact in the state system (most frequently the Mum). Families reported NDIS representatives refusing to discuss anything with the parent who was primary contact in the state-based system until the other parent contacted NDIS to authorise their access.

Access Application - Time Taken

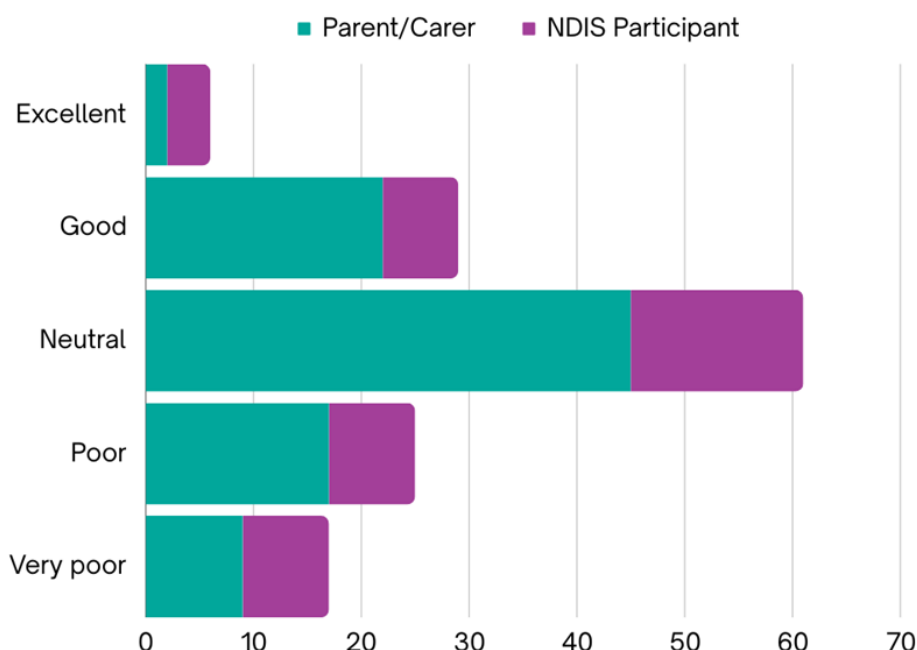


Another common issue reported was loss of documentation, with participants and families having to resubmit documentation 2-4 times. People also reported errors in how information was recorded. SWAN recently polled participants and families throughout Australia to ask whether a NDIS representative had ever checked with them that the information on the participant's file was correct. 82% advised that no one had checked for accuracy of the participant's information. Participants and families who have submitted Participant Information Access Requests have advised significant errors in the participant's information on record, requiring significant complaints and escalation through various levels of NDIA to have the information rectified.

"It took 4 years for NDIS to approve my physical disability. Supplied tons of consistent information, but had to lodge a formal complaint after a massive funding cut before anyone bothered to look at everything I had submitted and approve it. Found out that the original Access Request form had been entered wrong. The person had not ticked the box for secondary diagnosis."

"Although we were first told our application was complete and successful etc we were later informed this was not the case, even when the application was eventually successful supporting documentation was then lost and NDIS support was later revoked without any contact from the NDIS, when we contacted NDIS because our therapy provided was unable to access my sons NDIS they said the appropriate department would call back, 3 months later they had not and I was required to call them yet again. I was told my son was too old for intervention without a diagnosis, of which he had and had been provided, they were able to reinstate his access that day, despite months of delays."

Experience of NDIS Access Process



In considering the graph above, it's important to note that respondents to this survey gained access to the NDIS prior to the rollout of PACE in late October 2023. The vast majority of people who applied for access since October 2023 had not gained access to the scheme whilst this survey was open. This issue has been noted in the latest [NDIS Quarterly Report](#).

SWAN regularly support people with disability and families to apply for access to the NDIS. With the rollout of PACE in late October 2023, there have been systemic problems seriously impacting people applying for access. There are currently delays of more than 3-4 months in processing of NDIS Access Requests. People are receiving an autoreply from the National Access Team, then no further contact from any NDIS representative for more than 3 months. When they contact NDIS to follow up, the National Contact Centre are incorrectly advising participants and families that Access Requests can only be made through Partners in the Community (PITC), and that the NAT@ndis.gov.au email address is no longer being monitored. Others have been instructed to email the NDIS Access Request Form to enquiries@ndis.gov.au. If they receive a response from Enquiries, it's to instruct them to contact the PITC or to resend to NAT@ndis.gov.au.

On contacting the National Contact Centre to follow up on the Access Request Form (ARF), some people are informed that the Access Request has been received, but not processed, and to contact the Partner In The Community. PITC are also incorrectly advising people that they will only gain access to the NDIS through the PITC, and only after a Community Connections Plan has been written. PITC are claiming that the NDIS Access Request Form is no longer in use, and that they do not have access to the form (despite the ARF remaining publicly available on the NDIS website, with instructions on page 1 and the webpage to email the completed form to NAT@ndis.gov.au).

Where people have attempted to refuse a Community Connections Plan meeting, they are threatened by the PITC that they will not gain access to the NDIS without one. PITC are also claiming that they are unable to escalate Access Requests which are far outside of the NDIS Participant Service Guarantee, and that their IT system will only permit them to do it this way.

This issue is not only affecting people throughout WA (Carers WA have also identified the issue), but we have also heard from people in NSW, Victoria and QLD affected. People are being booked in for meetings at the PITC, and are not being advised that access has not yet been granted. They think they are going in for a planning meeting. SWAN has since learned that NDIA have moved forward the step of confirming the participant and child representative/nominee's identification to before access has been granted (previously identification was confirmed during the planning meeting). However, this is not being conveyed by PITC to the participants and families. An advocate from SWAN recently attended another forced Community Connections Plan with a parent who had travelled 2 hours one way to attend the PITC appointment, only to be told that they would need to return with identification before access for their child could be approved.

To-date, SWAN have supported more than 40 people impacted by this change of process to access applications. Of note is the incorrect information PITC are giving to people where the applicant is List A eligible for NDIS. PITC are informing people that they need to source additional, unnecessary and costly reports to evidence impact on function to support their NDIS application. These issues have been raised with the senior executive at NDIA, and SWAN now have a direct contact within the National Access Team to escalate cases where this issue has occurred. The senior executive have identified that this is a behavioural change within the NDIA, NCC and PITC, rather than a directive from the senior executive.

As we are already seeing significant impact and delays to NDIS applications as a result of transferring responsibility for assisting with access requests to the PITC, this raises major concerns as to how the recommended changes to NDIS eligibility and access in the NDIS Review Report will impact people with disability applying for the scheme. Of particular concern is PITC forcing participants and families to undergo a meeting to develop a 'Community Connections Plan'. The Community Connections Plan is supposed to be an **optional** plan for people with disability who are **not** eligible for NDIS – not a required step for people who are List A eligible for the scheme. Community Connections can also be an inclusion in a funded NDIS Plan for NDIS participants.

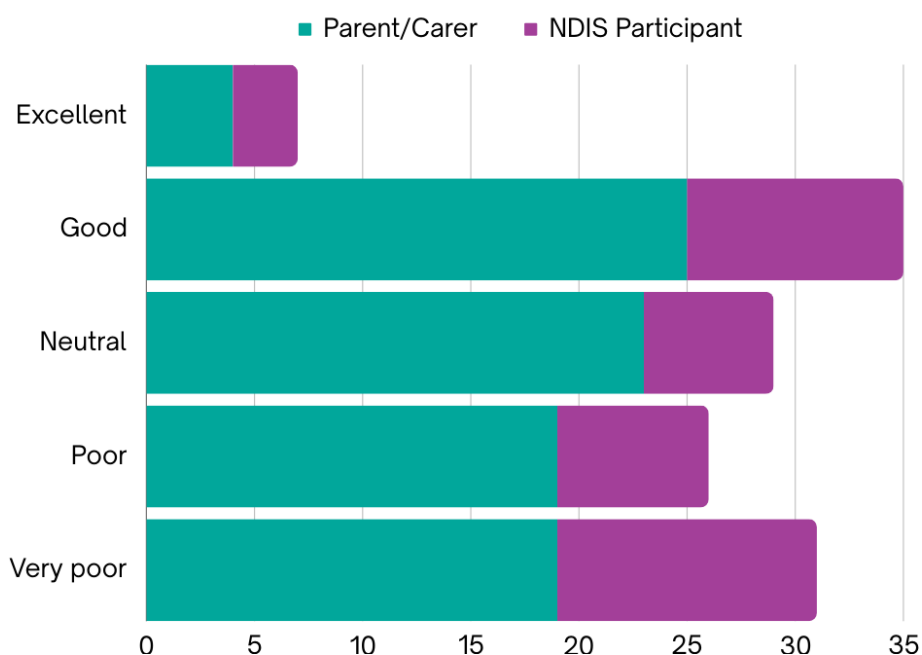
The Community Connections Plan essentially redirects the person with disability back to mainstream services which in many cases either do not exist, have extensive or closed waitlists and the person is unable to access support. In rural, regional and remote Australia, the issue of lack of mainstream supports for people with disability is far more significant than in metropolitan areas. Even as an inclusion in a funded plan, the community connections section is a source of frustration and confusion for NDIS participants and families – especially for people in rural, regional and remote Australia, where these mainstream services are non-existent, or have closed or extensive waitlists. The resulting impact of being forced to write a Community Connections Plan prior to access being approved is confusion, frustration, distress and for some people, despair.

“Still working on access. Spent couple of months putting together evidence of disability. I submitted application in Nov 23, received automated response saying my application had been received. Heard nothing more. Rang in Jan 24 and told there was new system to apply for access and I would have to start again. Finally had community connections meeting with LAC. Had to start from scratch LAC refused to use information from the application I had submitted. After the CC meeting was provided with ridiculously basic cut and pasted information that was not at all specific to my situation.”

Planning

Survey respondents raised significant concerns with the current NDIS planning process, which is also reflected in the advocacy work and peer support SWAN provides. Some people also reported that the planning meeting seemed supportive and understanding, but the resulting plan did not adequately reflect the needs of the participant, and/or included significant errors (eg. cut and paste of a different participant’s name, goals etc).

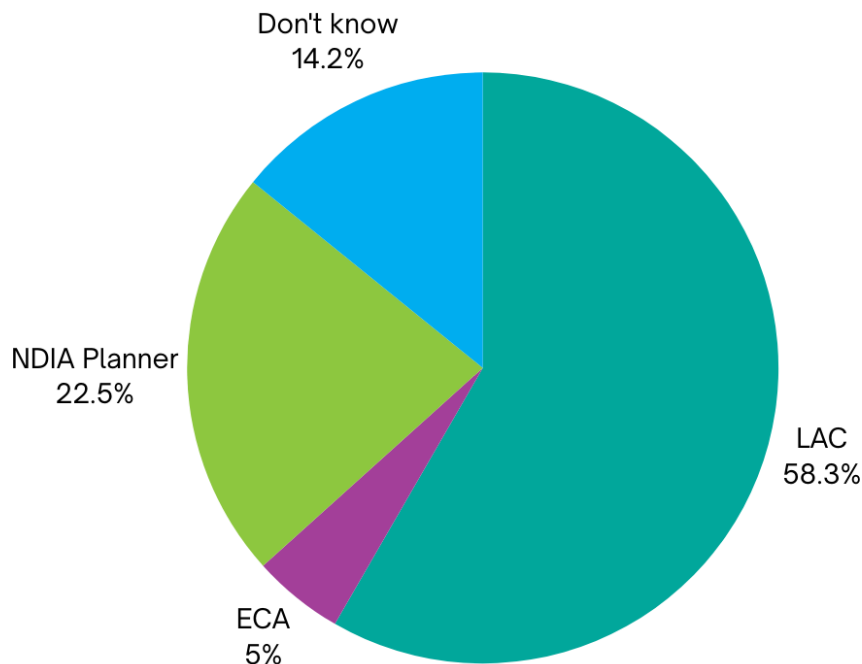
Rating of NDIS Planning Experience



The above graph clearly reflects the inconsistency of the planning experience for participants and families. It’s very much a geographic and staffing lottery as to whether the experience of the planning meeting is positive or negative for participants and families. Of note, only 7 people out of the 128 people who responded to this question rated their planning experience as excellent.

58.3% of survey respondents had their planning meeting with a Local Area Coordinator, while only 22.5% had their last planning meeting with a NDIA delegate planner (as per the pie graph below). This is reflective of the high number of planning meetings held with LAC Partners In The Community prior to the rollout of PACE in late October 2023.

Planning meeting was with:



Survey respondents raised numerous concerns about having planning meetings with PITC, such as:

“The LAC didn't understand my disability or NDIS and didn't submit all my information.”

“This was a disaster with many errors in the system brought to light. One disability was wiped "ended" in the system, a whole required support (disability enterprise employment support) completely missed and all recommendations from allied health professionals completely ignored. This required the painfully slow process of S100 appeal and then an AAT appeal which took nearly 2 years to address.”

“It was a phone call. Lasted less than 10 minutes. Got support coordination withdrawn, funding decreased, and told how to spend the money on services we don't use and won't use. Frustrated and angry.”

Having such a large proportion of the participants and families interaction with NDIS being funnelled through Partners In The Community has led to significant confusion and frustration. People have been unable to speak directly with NDIS representatives empowered to make decisions, are unable to access a consistent point of contact, and very often are given different answers each time they contact the National Contact Centre or PITC. Very often the answers to questions are incorrect.

“I really do not understand the role of the LAC as It seems there is a discrepancy between what you get from the meeting and the actual plan approved.”

“A man from a company I don't recall the name of ask over the phone if we could role the plan over. I just agreed to make it easier as they said they were way behind.”

“Frustrating to the max!! [LAC Partner] seem to be the gatekeepers of NO. They are quick to tell me particular supports are not funded / available by NDIS, when I am

*fully aware that friends with autistic children are receiving those same supports. I feel like I have to show ***** what NDIS will and won't cover."*

Another common concern raised by survey respondents was evidence and recommendations from treating professionals being ignored.

"Our last meeting was via phone as I asked for a review on the decision to disregard all recommendations. I am always confused by all of the different positions/ terms."

The first NDIS planning experience is an extremely confronting experience for participants and families alike. There is a heavy focus on the things the participant is unable or struggles to do, and requires an empathetic and trauma responsive NDIS representative. Unfortunately, this is often not the case, with many people reporting feeling judged, shamed, and have their legitimate concerns, reasonable and necessary support requests dismissed by the NDIS representative in the meeting.

"I wasn't prepared for the very invasive questions about my personal hygiene support needs. I became non-verbal and rocked on the floor. Despite this, I was unable to get personal care funded due to lacking 'evidence' I needed it- so the invasive questions were useless. This was later rectified- but it took getting 4 plans in 18 months to get my plan right."

NDIA and PITC continue to require extensive evidence from third parties in order to fund supports, which are too often ignored. Participants and families frequently complain of not being believed and having to waste large portions of their therapy budget in sourcing evidence for requested supports, rather than being able to use the funding for reasonable and necessary supports.

"The planner didn't listen to me and made me confused all the time."

"I explained during the meeting that my 13 year old son was becoming increasingly physically violent, and that I would like to get a Positive Behavioural Support Specialist included in our plan for 12 months. Our LAC then asked "Did your son's therapist include this information in their NDIS Report"? I advised that no it was not, though I had asked our therapist to do so. The LAC went onto say "You will need your therapist to include this information in support of a PBS provider". I then asked the question "Why? So you'll believe it if I tell our therapist and then she tells you? But not believe me if I tell you directly?". Ridiculous."

"The LAC was very dismissive of specific requests and kept pushing back "parental responsibility" and that "they most likely won't fund it" whilst reluctantly proceeding. All supports requested were approved."

"I felt unheard. The planner was rushing through the meeting without giving me time to speak. I had to stop her a number of times by interrupting as she attempted to move to the next item. I made a complaint to NDIS about her behaviour. We had same planner for an implementation meeting requested by me to get explanation of decisions to not fund some requested therapies. During that meeting, she was abrupt, combative and even arguing against a therapy that was funded in the plan."

"I was led to believe that everything I needed would be supplied. HOW WRONG I WAS."

“I was not listened to, and unfounded, derogatory comments were made to me about my parenting/ my child.”

“LAC kept giving misinformation. Delegate refused my secondary diagnosis despite masses of consistent evidence, and LAC refused to give me an explanation of the decision. Incorrectly stated that I would have to put in an Freedom Of Information request.”

Prior to the rollout of PACE in late October 2023, participants and families primarily had their first NDIS planning meeting with a Partner In The Community (PITC) who drafted the plan, which was then finalised by a NDIA delegate planner. There were numerous problems with this process. SWAN frequently witnessed or received reports of PITC:

- failing to accurately record information
- gatekeeping reasonable and necessary support requests (refusing to submit support requests to the NDIA delegate planner for consideration)
- copy and pasting plans from one participant to another, often with incorrect names (due to unreasonable Key Performance Indicators imposed by the PITC organisations)
- failing to confirm accuracy of information in the participant’s file
- denying participants and families the right to determine the goals in the NDIS plan and changing participant goals without consent.

There were also issues once the drafted plan reached the NDIA delegate planner, such as:

- failing to review and consider documentation in the participant’s file
- removal of reasonable and necessary funded supports from the drafted plan
- failing to consider the previous NDIS plan in the development of the new NDIS plan
- Prioritisation of ‘value for money’ over all other reasonable and necessary criteria

These issues are reflected in the comments received in our survey, and have been witnessed repeatedly by SWAN staff, as well as frequently reported by our clients.

“The LAC did not understand my disability or my situation and changed things to match her expectation not mine. I have a long history as a I’m area general manager for a large national corporate but she told me she needed to use her words for my goals as NDIS liked these words. She also misunderstood and hence misrepresented my needs hence I lodge an S100.”

“The LAC thought he was the dictator of NDIS and wouldn't submit all my information to the planner. The LAC didn't understand all the NDIS rules and regulations and my Support Coordinator had to point out things on the NDIS website.”

“The LAC kept deciding that what I was asking for was not going to be funded so didn't bother including it in the plan. Gaslighting at it's finest!”

Refusal by PITC to include reasonable and necessary support requests in the drafted NDIS plan has been an ongoing issue for participants and families. When SWAN support people to submit a S100 Internal Review of Decision request, the outcome letter often rejects the requested supports due to the supports ‘not being requested at the planning meeting’. Participants and families are then told to submit an S48 Change of Circumstances request instead, which again results in an underfunded NDIS plan, requiring yet another S100 Internal Review of Decision, sometimes followed by appeal to the Administrative Appeals

Tribunal. This process is extremely frustrating, confusing and distressing for participants and families, as well as substantially delaying access to desperately needed supports.

Since the rollout of PACE in October 2023, the NDIS Partners in Community are no longer drafting NDIS plans with participants and families. Planning meetings are now supposed to be held with NDIA delegate planners, however SWAN have heard from numerous people that they received an extremely brief phone call (less than 5 minutes) from a NDIA delegate to inform them how much funding would be in the first NDIS plan and ask how they want the funding to be managed. They are then told to get an OT report if they are unhappy with the amount of funding, then put in an S48 Change of Circumstances Reassessment request. Since October, SWAN have only spoken with one person who had an actual planning meeting with a NDIA delegate planner. Everyone else who has contacted SWAN regarding their first NDIS plan since October 2023 received an extremely brief phone call to advise how much funding there would be in the plan, with **no actual planning meeting**.

It is deeply concerning that this important stage is being missed for so many participants and is reflected in the quality of the NDIS plans they are receiving. The one participant who actually had a planning meeting received a NDIS plan with sufficient funding to enable them to access support. All the others were either grossly underfunded, or the plan was constructed in such a way as to render it unusable due to funding being allocated in unsuitable support categories with a lack of flexibility.

SWAN also asked survey respondents if they had a NDIS pre-planning meeting with a Disability Peer Support Organisation or an Advocate prior to the official NDIS planning meeting:

“I wrote my own pre-planning meeting notes based on my child's interests, needs and goals using the NDIS pro forms. The NDIS planner said that as my son only had Autism he wouldn't be entitled to any funding. He didn't want to look at my pre-planning notes at all as he said there was no time. Instead he gave me several questionnaires to complete and then told me the meeting was over. SWAN helped me to lodge an appeal and my son received a proper plan and funding.”

“I wish, I contacted advocate services but none had anyone free to help me.”

“Shouldn't need one and assumed being transferred from the state-based system that all evidence was given over. The fact that nothing was mentioned and that nothing new was requested was a huge red flag. It has become quite clear that Advocacy and Peer Support is a HUGE unmet need and needs to be reviewed as a matter of urgency.”

“I couldn't find anyone to help me as they all wanted to be paid with NDIS funding which I hadn't received at that stage.”

“In hindsight I would have done this.”

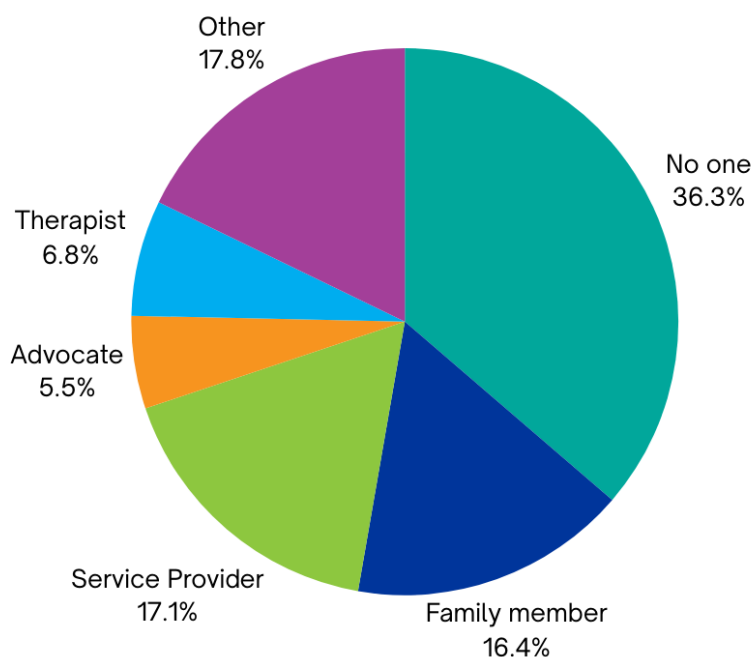
“No. This probably would have been useful as I was confused when the focus was on goals and not what my needs are.”

Several people who responded to the survey had pre-planning meetings with SWAN, which they found to be extremely helpful in preparing for the NDIS planning meeting. Our experience has been that having a pre-planning meeting with a Disability Peer Support organisation or advocate is extremely helpful in supporting participants and families to

understand NDIS processes, what to expect, and build self advocacy skills to understand their rights, what supports are relevant to their support needs, and how to appeal poor decisions by the NDIA.

We also asked survey respondents if they had a support person present during the planning meeting. As shown in the pie graph below, 36.3% of people had no support person present during their planning meeting. 17.1% were supported by a service provider, and 17.8% were supported by someone else (mostly a Support Coordinator or Psychosocial Recovery Coach). 16.4 % of people were supported at the planning meeting by a family member, and only 5.5% were supported by an independent advocate / representative from a Disability Peer Support organisation.

At the Planning meeting, I had support from:



SWAN are concerned by the high proportion of people supported at planning meetings by service providers, who have a conflict of interest when supporting participants at these meetings. We are extremely concerned that 36.3% of people had no one supporting them at the planning meeting. Of note, a proportion of that number would feel sufficiently confident and knowledgeable to attend a planning meeting without support, however, we raise concern about the high number of participants and families who need and are unable to access a support person at the planning meeting.

“The LAC was horrible, I'm so glad [advocate] was there for support. I was crying most of the time.”

*“Very glad that SWAN helped me with the meeting. I don't think it would have gone very well without ***** there to stand up for me.”*

“Did not know what was supposed to happen or what was goal or aim - little information - support coordinator very dominating and did not support properly.”

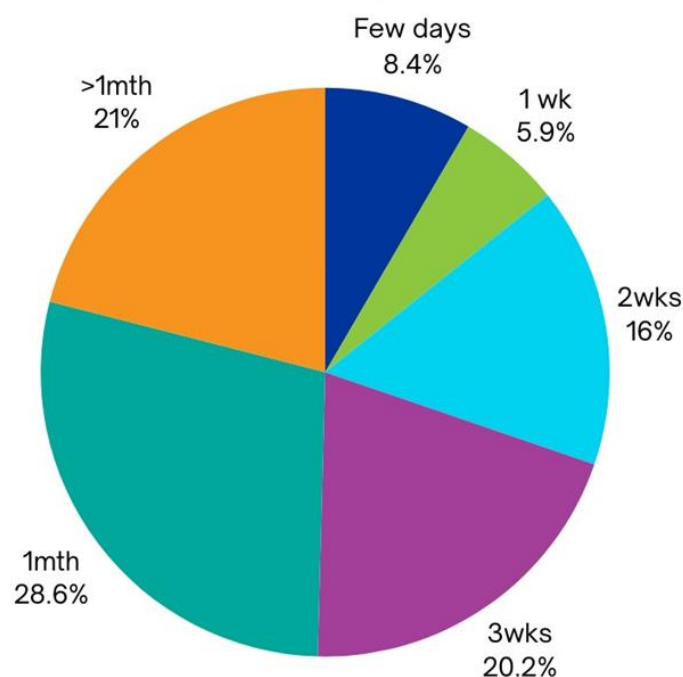
“The LAC was really rude. So grateful to the advocate from SWAN for being there. It was horrible.”

We also received feedback that where people had their planning meeting with a NDIS representative who did not live in the local community, the representative did not understand or consider the unique difficulties and barriers that come with living in rural, regional and remote Australia.

“I found they lacked understanding of the systemic and socioeconomic barriers people face in country areas, which prevent us from utilising the funding in our plans. I've been told to move closer to supports in a regional city several times, completely ignoring the fact this is not a simple option for people on low incomes like a DSP.”

We anticipate increased issues with this, as planning meetings and plan reassessments are conducted by NDIA delegate planners with the rollout of PACE. These planning meetings are being conducted remotely, typically via phone, and often for extremely brief duration.

How long after meeting was plan received?



As reflected in the pie chart above, there is significant variability in the wait time from planning meeting to receipt of the NDIS plan, however a wait of three weeks or more is the most common.

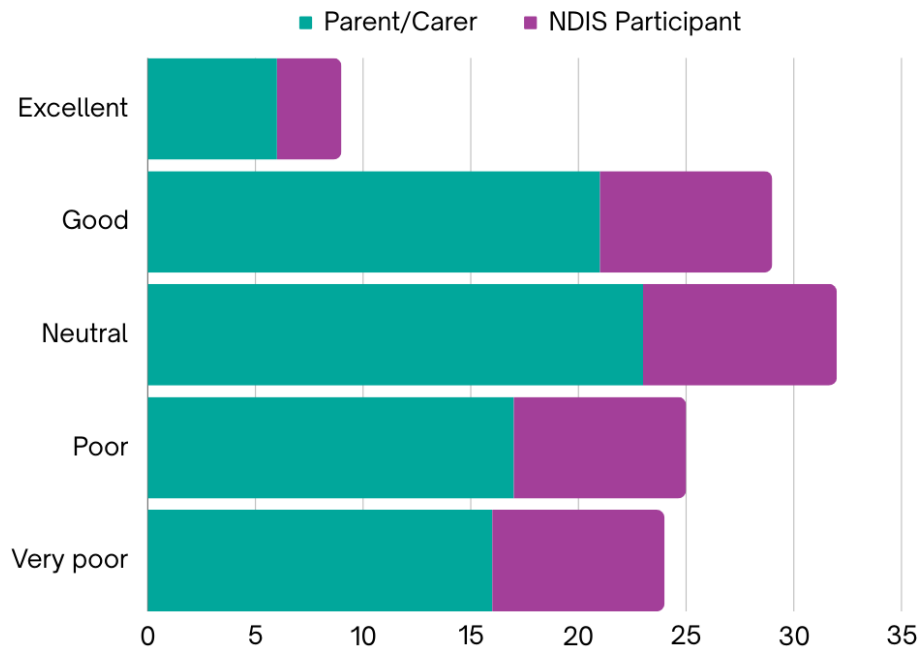
Survey respondents raised numerous concerns about the NDIS plan they received.

“Full of mistakes and very wrong decisions. No one at the NDIA bothered to read any of the supporting information I supplied,”

“Devastating 83% funding cut. Plan was essentially unusable. LAC did an extremely poor job of the planning meeting, NDIA delegate didn't bother to look at any of the submitted documentation. Stated there was none, despite participant booklet 3 being completed, 3 physiotherapist reports and 2 Functional Capacity Assessment reports being in my file. Also ignored the fact that I'd spent 97% of the previous NDIS plan because it was insufficient. Wasn't able to spend the full amount because some was in a category I couldn't use.”

“The plan was originally copy and pasted from another person who was male. I had to make several corrections but I feel the OT did not test my daughter she just asked me questions and made up a plan based on my answers.”

NDIS Plan Quality Rating



As reflected in the bar graph above, there continues to be significant inconsistency in the quality of NDIS plans being received. 41.2% of survey respondents rated the quality of the NDIS plan as being poor or very poor, with only 7.6% rating the NDIS plan quality as excellent, and 24.4% rating the plan quality as good.

Plan Design

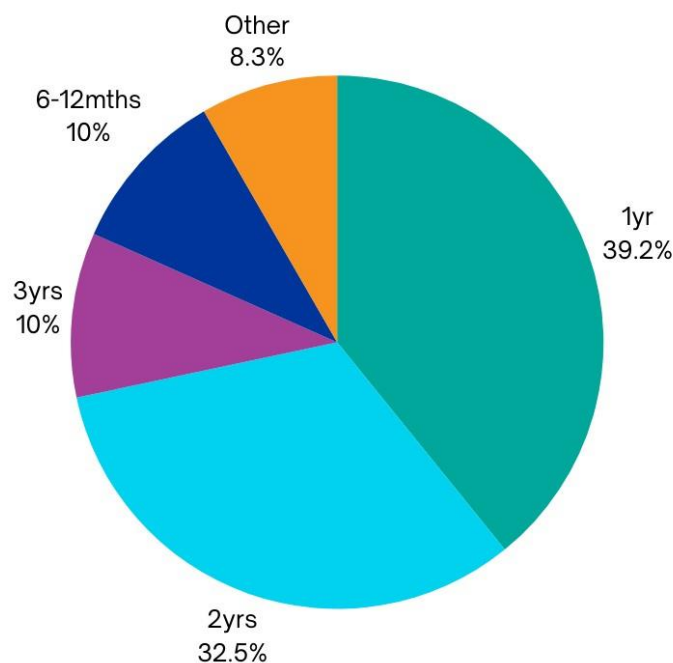
Another issue with NDIS plans we are seeing since the introduction of PACE is the change to layout of the NDIS Plan. In the previous operating system, NDIS plans averaged 12 pages in length. In the PACE system, we are currently seeing NDIS plans averaging 21-25 pages in length. Not only does the PACE plan feature a lot of unnecessary information preceding the relevant information about plan funding, but the funding section of the plan is now excessively long, confusing, and automatically lists every Capacity Building support category as a 'Stated Support'. Funds listed as 'Stated Support' in an NDIS plan can only be used for the purpose stipulated in the plan. This automated change is extremely concerning given that since late 2021 NDIS representatives have increasingly been stipulating in plans what funding can be used for. We commonly see NDIS plans with overly prescriptive funding budgets, such as:

*“\$3879.80 of funding for Assessment Recommendation Therapy or Training - Occupational Therapist to address your independent living skills.
\$1933.90 for a Speech Pathologist to complete a Speech/communication assessment.”*

If PACE Plans are written in likewise prescriptive terms, then participants are unable to use their plans to meet their actual needs. As stipulated above, no more than \$3879.80 can be spent on Occupational Therapy, and no more than \$1933.90 can be spent on Speech Pathology – regardless of what the participant’s actual therapy needs might be. To date, we have not seen an overly prescriptive PACE plan as stipulated above, however participants and families have reported that their Capacity Building – Improved Daily Living budget is displaying in these overly prescriptive terms in the new PACE participant portal.

Further complicating PACE plans is the fact that every single support category is listed in the plan, whether it includes funding or not. This means that participants are receiving NDIS plans which show \$0 ‘Stated Support’ budgets for various Capacity Building support categories or show \$0 budgets for every single Core support category, as well as the Capital support categories. SWAN are currently supporting an adult participant who recently received their first PACE plan after a four-month delay on processing their NDIS access request (access was only granted after escalation of their case by SWAN), and have received a Capacity Building only budget with everything listed as ‘Stated Supports’, rendering much of the plan unusable.

Current NDIS Plan Duration

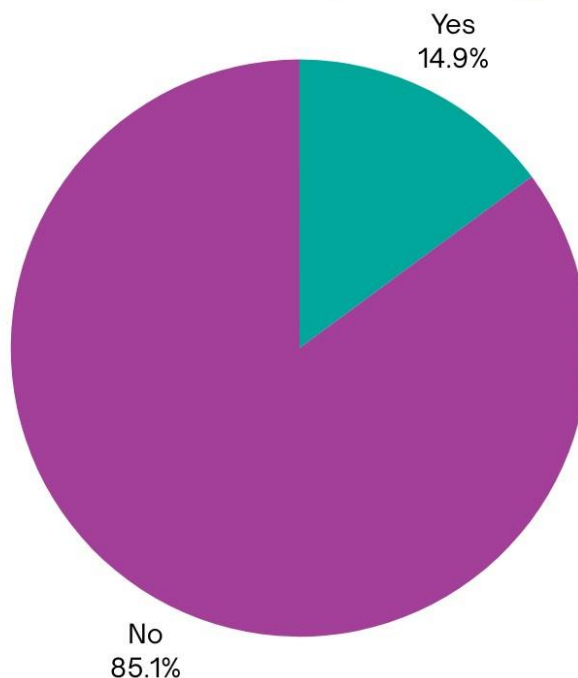


The pie chart above shows that survey respondents have plans of varying lengths. The most common plan length for survey respondents remains 12 months, however there are also a high number of participants with an old plan which has been auto-extended or rolled over repeatedly. One survey respondent advised that they are still on their original NDIS plan from when they joined the scheme 6 years ago, and that the plan has been auto-extended or rolled over ever since. Other respondents have had the same plan auto-extended or rolled over each year for three or four years. As NDIS plans also include ‘about me’ information and goals which may be quite specific, it’s extremely concerning that these details are often very outdated or no longer relevant – especially as participants are required to ‘spend funding in line with their plan’. It’s quite unreasonable for NDIA to require participants and families to spend funding in line with a NDIS plan which the NDIA has failed to update for several years.

We also asked survey respondents if they were able to decide the length of the NDIS plan. 85.1% of respondents advised that they were not able to decide the length of the NDIS plan, as shown in the pie graph below. This response was in line with SWAN’s expectation and matches what we hear from clients or have witnessed when advocating in planning meetings. Very often participants and families are told by Partners In The Community or NDIA delegate planners that they do not have the right to decide the duration of their plan. Incidences where participants and families are enabled to decide the length of their plan are unfortunately extremely rare. This is an area that the NDIA can and should take steps to improve choice and control for participants and families.

“Two year plans are not appropriate for a child going into their teens. Too many changes take place in that time and I have spent the last six months requesting, organising and waiting for a review which STILL has not been booked. Some of our funding has run out and we are currently in crisis, yet no appointment for review has been booked yet. [PITC] advice has been inconsistent with the decisions made by NDIS.”

Able to decide plan length?



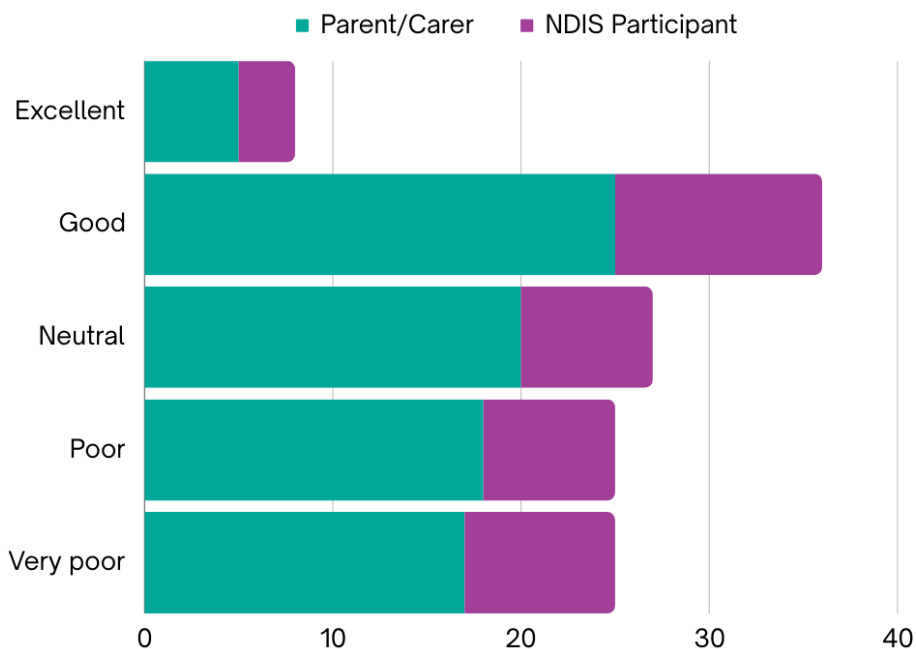
For participants and families, however, the most important part of the NDIS plan is the funding. NDIS funding enables people with disability to access reasonable and necessary support to live life, be a part of their community, work and access therapy supports. We asked survey respondents to rate the funding in the NDIS plan, with guidance on how to rate the funding as explained in the table below:

Excellent	Enough funding to meet all my needs, and I will be able to explore new support options
Good	Enough funding to meet all my needs, but I will not be able to explore new support options
Neutral	Not enough funding to meet all my needs, but I will be able to manage

Poor	Not enough funding to meet my needs, and I will need to seek a plan reassessment
Very Poor	The funding is so low that it caused a crisis

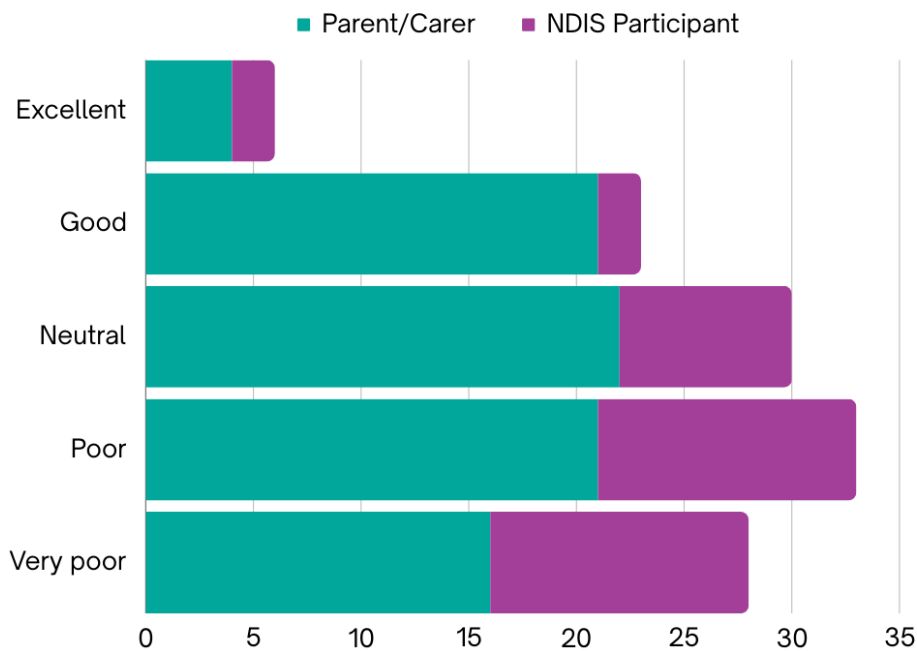
As shown in the bar graph below, there remains inconsistency in decisions on how much funding should be in a participant’s plan, which may or may not be reflective of the participant’s support needs. Of note, more participants and families rated the plan funding as good (29.3%) or excellent (6.5%) than was typical between 2021 and the middle of 2023 – during the period when many participants were experiencing very significant funding cuts. 22% of survey respondents rated the funding in the NDIS plan as neutral, while the remainder rated the funding as poor (20.3%) or very poor (22%). As per the rating system described above, 64.3% of survey respondents currently have NDIS plans which are insufficient to meet their disability needs.

Rating of NDIS Plan Funding



We also asked survey respondents to rate the flexibility of the NDIS plan, as indicated in the bar graph below.

NDIS Plan Flexibility rating:



24.2% of survey respondents rated the flexibility of the plan as good or very good, whereas 50.8% rated the plan flexibility as poor or very poor. While these ratings are unsurprising and reflective of the issues we consistently hear from people with disability and families contacting SWAN for support, it is also indicative of the need for greater plan flexibility in rural, regional and remote Australia where support services are typically limited or non-existent.

“We needed a support worker and the funding put in capacity building and told we weren’t allowed to use it by the LAC.”

“Having funding restricted to Capacity Building or Core has meant that its not as flexible as we would prefer. In the past our daughter needed a lot more therapy, and couldn’t use the Core budget to bump up the therapy she needed.”

“I couldn’t use my funding the way that was best value for money. I would have preferred to use some of my CB funding for core supports.”

“I have too much Capacity Building funding and adequate but limited Core funding. I would like to use the funding for different things by CB funding is too rigid.”

“I’m an adult WHY was I given a therapy only plan?”

“There wasn’t enough funding for it to be flexible. The plan was unusable.”

“Too rigid in its definitions and guidelines as to what they will or won’t fund. There seems strange line between this.”

“Totally doesn’t suit my needs.”

For NDIS participants living in rural, regional and remote Australia, flexibility of the NDIS plan is vital. It’s extremely common for participants under the age of 18 years to be refused

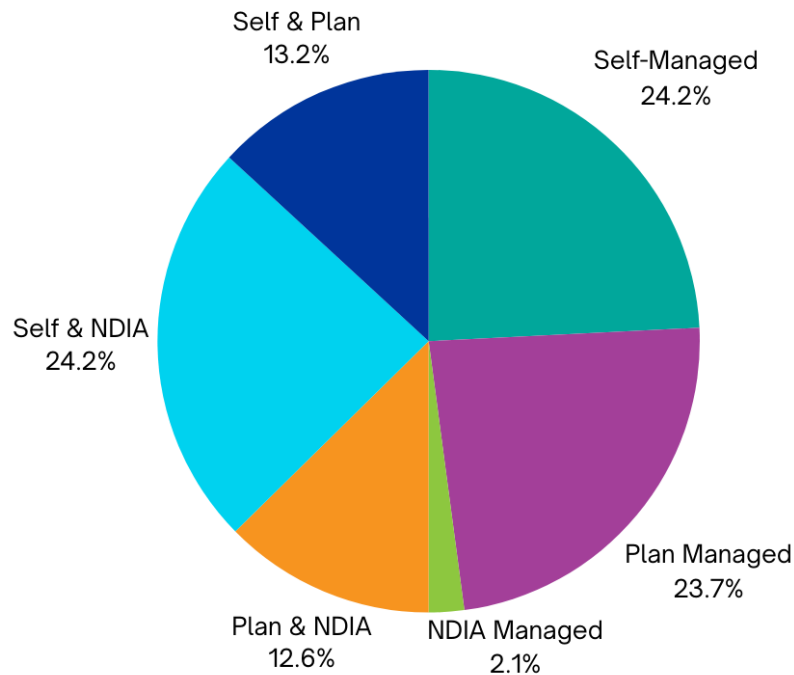
any Core funding in their NDIS plan, which essentially means there is no flexibility at all. SWAN are also seeing NDIS plans for adults lacking any Core funding. School aged participants in rural, regional and remote Australia are often required to travel long distances to and from school each day, which increases the fatigue experienced just by trying to cope with a typical school day. It's not uncommon for students to be forced to travel 90 minutes to and from school. On the rare occasion there is support worker funding included in a NDIS plan for children and youth under 18 years, this funding is most commonly included in the Capacity Building budget, rather than the Core budget. This seriously limits flexibility, as the funding can only be used on weekdays. For youth with disability attending school, there is rarely energy or capacity to undertake after school activities, and there are minimal social and community opportunities on weekdays in rural, regional and remote Australia. Participants outside of metropolitan areas must have flexible funding to enable supports to be used in the way that works for the participant, at the times that work for the participant – including weekends and evenings.

We asked survey respondents how the funding in the current NDIS plan is managed. Only 2.1% of plans were fully Agency (NDIA) Managed, while 36.8% were partly Agency Managed. As there are some funded supports that NDIA typically require to be Agency Managed (eg. Positive Behaviour Support), it's likely that these NDIS plans included these types of supports. 61.6% of survey respondents were entirely or partly Self Managed, while 49.5% were entirely or partly Plan Managed, as per the pie graph on the next page.

Of note, there appears to be very high incidence of Self Management and Plan Management in participants living in rural, regional and remote areas of Australia, where access to NDIS registered providers is either extremely limited or non-existent. As NDIA does not report disaggregated data to show how funding is managed for participants living in metropolitan vs regional or remote locations, the need for access to non registered providers in rural, regional and remote Australia was not factored into considerations by the NDIS Review panel in recommending mandatory provider registration in their final [report](#).

Of significant concern is the fact that the independent NDIS Review Panel held a consultation event with service providers and advocacy organisations in Western Australia but did **not consult participants and families in WA**. SWAN's CEO attended the provider consultation event (after five requests for the Microsoft Teams link in order to attend), and asked Professor Bruce Bonyhady to explain why WA based providers were being consulted for the NDIS Review, and WA based people with disability and families were not. Our CEO was assured in the meeting by Professor Bonyhady that the Panel would return to consult WA people with disability and families, however no one from the Review Panel fulfilled this promise. **WA based people with disability and families living outside the metropolitan areas experience the greatest geographic isolation in the country, and the unique barriers and difficulties experienced by people with disability in WA were not considered by the independent NDIS Review panel and were ignored in the final report.**

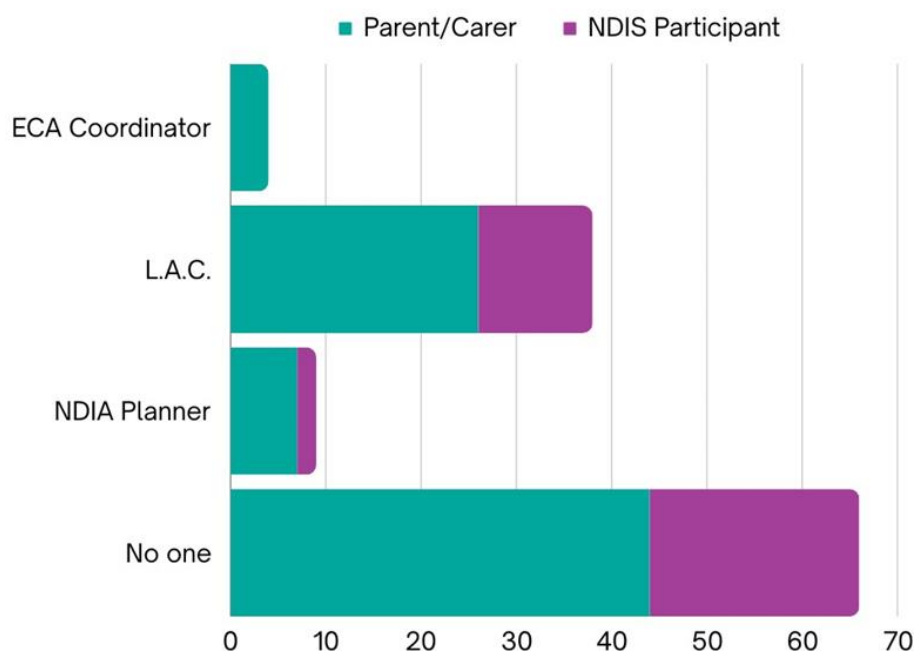
NDIS Plan Funding is:



Implementation

Support to participants and families to implement their NDIS plans continues to be sorely lacking. Where people are given an implementation meeting, the information and support is too often confusing, insufficient, or incorrect. SWAN asked survey respondents who they were contacted by after the planning meeting occurred. 56.4% were not contacted by any NDIS representative for implementation support, as shown in the bar chart below.

After receiving my plan, I was contacted by:



"We have never been contacted for Plan Implementation Support."

"No one ever contacted me about this plan. No one contacted me to tell me the plan was created and funding was available. I ended up just setting up/accessing this myself online after over a month of waiting on a return to my emails/calls. The first contact I ever received from an NDIS representative was after I submitted an S100 form."

"No one has ever contacted me to help me understand or implement my NDIS plan in four years."

"I had to contact them!"

"No one has ever contacted us to help us understand the plan or how to use it. We had to figure it out by ourselves."

"I remain deeply shocked that I was not contacted by an NDIA Planner. Nor did I receive any notification about my new plan. I had to look it up on the portal by myself and try to make sense of it."

"I had to make contact with the LAC."

SWAN are frequently contacted by NDIS participants and families seeking information and support to understand and implement their NDIS plan. Less than 5% of the people contacting SWAN for this type of support have received any official implementation support from a NDIS representative.

Where people were contacted for support to understand and implement their NDIS plan, the feedback indicated the support was insufficient, confusing and/or unhelpful, and typically too late after plan was completed to help in a meaningful way.

"Didn't explain plan just said what was written in plan, no cost break downs. No understanding."

"It was long after and I was left confused and told so many incorrect things."

"The first time I was contacted for implementation support was 17 months after our daughter's first plan was received. The LAC phoned our 18 year old autistic daughter without warning, despite several notes on her file that I was to be contacted as nominee. We have never been contacted for implementation support for our son in 8 years as a participant."

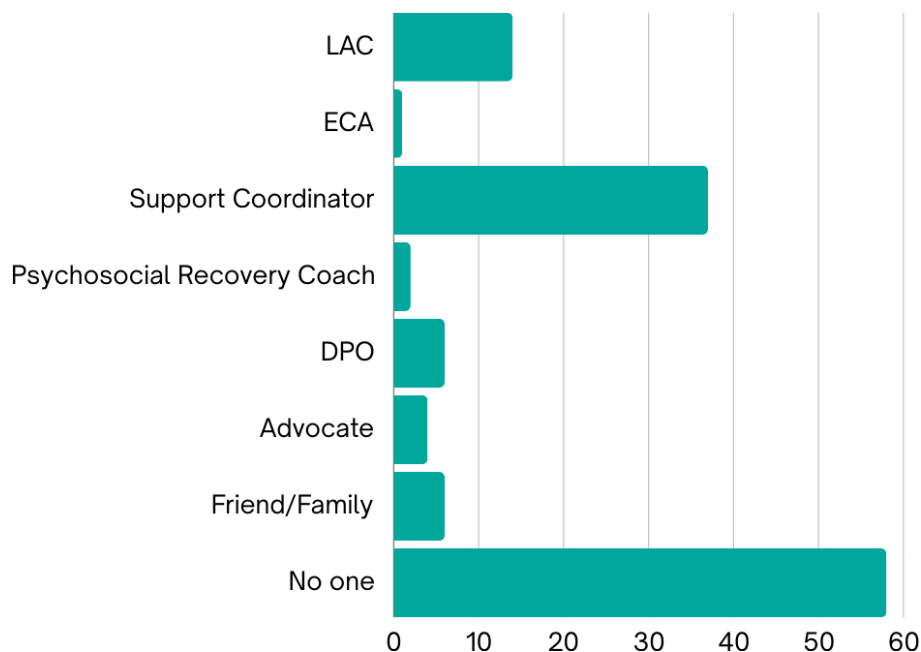
"The LAC sent an email with how the plan was funded."

The lack of plan implementation support, particularly in the south west region of WA, has been ongoing since the rollout of NDIS in this area. The issue is so significant that SWAN was given special permission to provide implementation support as part of our Information, Linkages and Capacity building (ILC) projects, despite this being the responsibility of the NDIS Partners In The Community.

We asked survey respondents who supported them with plan implementation, with only 12% advising that they were supported by a NDIS Partner In The Community to implement their

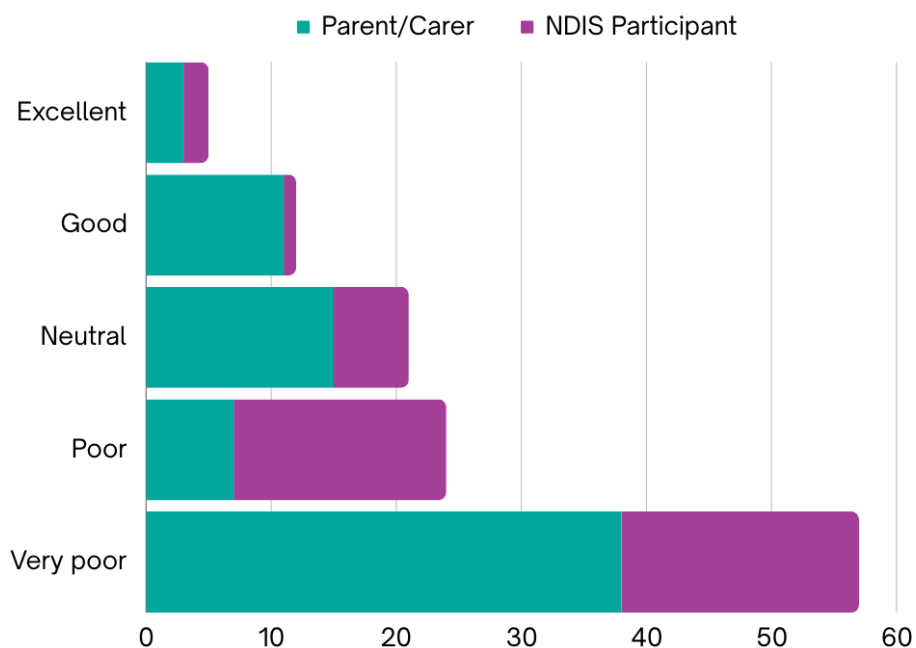
plan. 45% of survey respondents did not receive any implementation support, 30% were supported by a Support Coordinator or Psychosocial Recovery Coach, and 8% were supported by a Disability Peer Support Organisation or advocate.

NDIS Plan Implementation Support from:



Due to a lack of feedback from participants and families, it remains unclear whether plan implementation support from NDIS representatives will improve with the planning changes implemented with the rollout of PACE. We asked survey respondents to rate the implementation support they received from NDIS representatives (Partners In The Community or NDIA delegate planners):

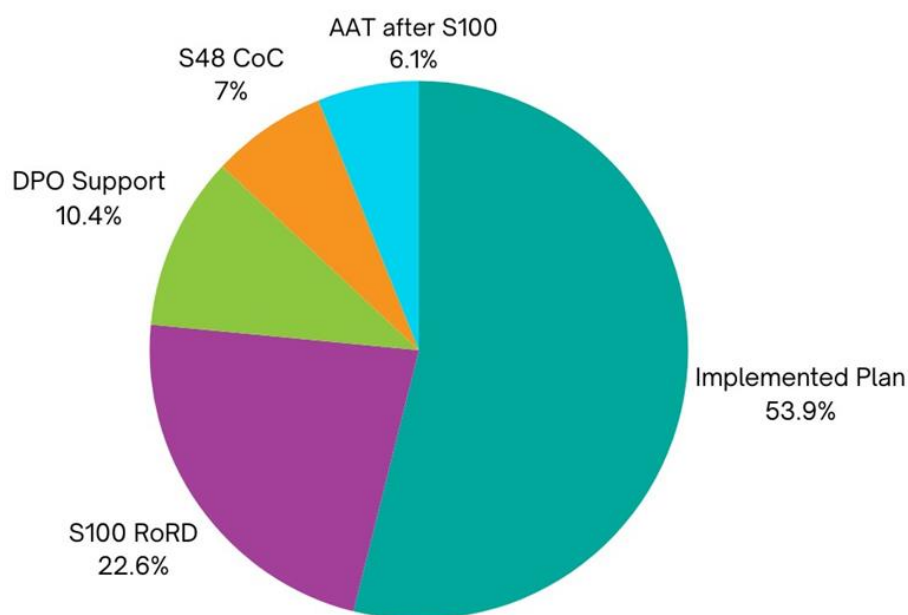
Implementation Support from NDIS rating:



Concerningly, 47.9% of respondents rated the implementation support from NDIS representatives as very poor, and a further 20.2% rated the implementation support as poor (68.1% poor/very poor). Positive responses were also very low, with 10.1% rating the implementation support from NDIS representatives as good, and a further 4.2% rating this support as excellent.

We next asked survey respondents for feedback on their next step on receiving the NDIS plan, as detailed in the pie chart below. 53.9% of participants and families commenced using their NDIS plan once received, however 35.7% needed to seek a review of the plan. Respondents also commented in the survey about their concerns regarding the NDIS plan.

Next step on receipt of NDIS Plan:



Some comments made by survey respondents include:

“\$5000 for support workers over two years = \$50 per week, which is less than one hour for most support workers. No one can hire a support worker for one hour, minimum shift lengths apply [2hrs], so effectively we can only have a support worker once every few weeks. We have been advised my son needs support workers three days per week, a total of 18 hours. The funding is grossly inadequate, yet applying for a review has taken more than 6 months and we are STILL waiting.”

“I was devastated when my plan came, there wasn't enough funding for anything I need.”

“Funding was adequate but not allocated as per real need - so current NDIS Behaviour Support Practitioner is recommending Change of Circumstance Review.”

“I am still suffering a mental crisis daily because of the cutting to my funding and services by 30%.”

“Less than half the funding that he needed.”

“It's not the total funding that I have an issue with...it's the amount in core that isn't as much as I need. I need more flexible funding.”

Other respondents raised issues which are unique to participants in rural, regional and remote areas, and frequently not given consideration by PITC or NDIA delegate planners.

“They still did not take into account that at least half our funding goes into provider travel, so the therapy they say we have funded doesn't stretch as far as they gave allocated for.”

“Excellent Core and Capacity Building funding, but Transport component is completely inadequate for even one taxi trip per week if I want to travel outside of my suburb.”

“The funding was not enough to cover a travelling speech therapist on their base rates, the therapy provider themselves wrote a letter detailing their costs for the year and this was not provided and the person on the phone told me if the NDIS plan does not cover the costs as a parent I must cover them myself as that is what a loving parent does - which I believed to be invalidating and manipulative and almost insinuate of myself not being a loving parent if I cannot afford to pay thousands in therapy.”

“We were unable to afford basic therapies based on our location and the cost of travelling therapists in the area therefore there was not a lot for them to do.”

“The cost of the most suitable or even nearest therapies should be taken into consideration when determining the persons plan. And if a travelling therapist is the most sensible/ appropriate way to support the person with a disability the travel fees should be considered in the funding amount also otherwise the therapy is not accessible.”

“The funding is okay, but I'm struggling to access supports due to thin markets and having to travel to access supports, which is difficult due to cost of living pressures.”

We asked survey respondents if they use non-registered providers, with 63.7% responding that they do use non-registered providers. As 28.2% of survey respondents reside outside of Western Australia, we suspect that there is greater access to NDIS registered providers in these states, especially NSW and VIC, which is reflected in the response to this question. In regional WA, there is extremely limited options for NDIS registered providers, with a great many towns having no NDIS registered providers at all. In the south west region of WA, for example, there are 14 towns with no NDIS registered providers located in the community. Note also that the south west region is the most highly populated region in WA, outside of the Perth metropolitan area.

“Don't have a choice in my rural location.”

“I only use non-registered providers because registered providers are consistently very dodgy.”

“Because they suit our needs and had a less wait time. We couldn't get in with a registered NDIS as their wait list is so long and most of them said they had shut their books altogether for new participants.”

“I have to choose who will be the best fit for my daughter’s complex needs. Just because a provider is registered doesn’t mean they are any good.”

“My psych is not NDIS registered I am his only NDIS client. He is AHPRA registered and has supported me since I went into a wheelchair 10 years ago. My SW is not NDIS registered but is excellent and I was unhappy with the registered provider.”

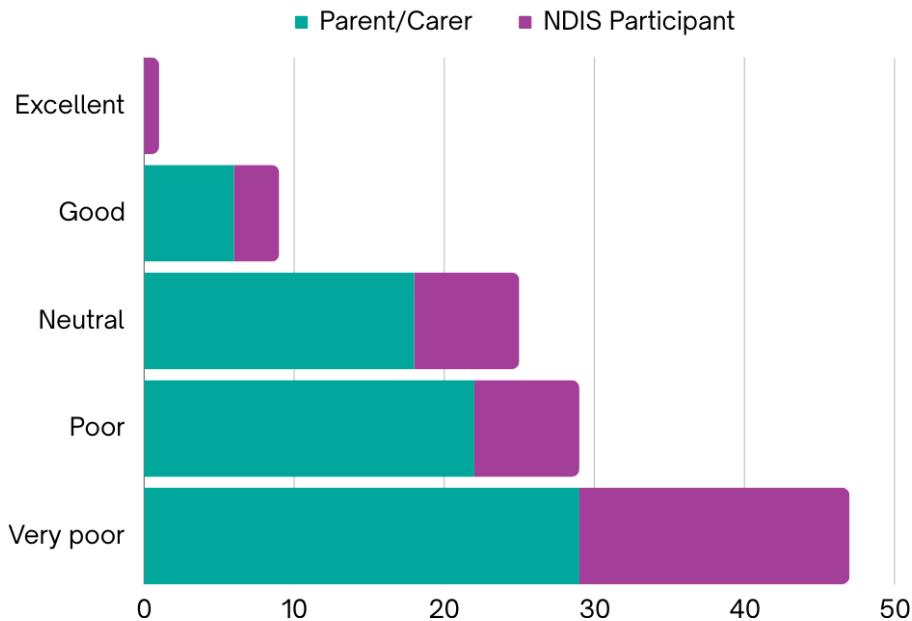
“Only suitable providers in my area are not NDIS registered as they see non-NDIS clients too.”

“Our daughter would have no support at all if we didn't use unregistered providers. And the registered providers here are awful.”

“There are hardly any NDIS registered providers in my area. They are far more expensive, and offer lower quality supports. For the vast majority of supports I need, there are literally no registered providers in my town. Further, as an advocate I need my privacy protected, and need to be able to advocate with no conflict of interest. I can't help people make a complaint about a registered provider that I'm also forced to use.”

SWAN reiterate our concern that the recommendation in the NDIS Review report for mandatory provider registration has failed to consider the experience of people with disability in geographically isolated communities. Forcing providers to register in order to provide supports to NDIS participants risks disincentivising provision of support to the NDIS participants in that community – especially where they make up less than 5% of a provider’s client base. In the south west region of WA, it’s very common for a non-registered allied health practitioner to have only 1-3 clients who are NDIS participants, out of a total client base exceeding 100. SWAN have been canvassing non-registered providers in the south west community of WA, and when asked, each has stated that they would not register as a NDIS provider, regardless of how simplified the process was made. They also stated that NDIS participants are simply too small a portion of their overall clientele to be worth the effort or cost.

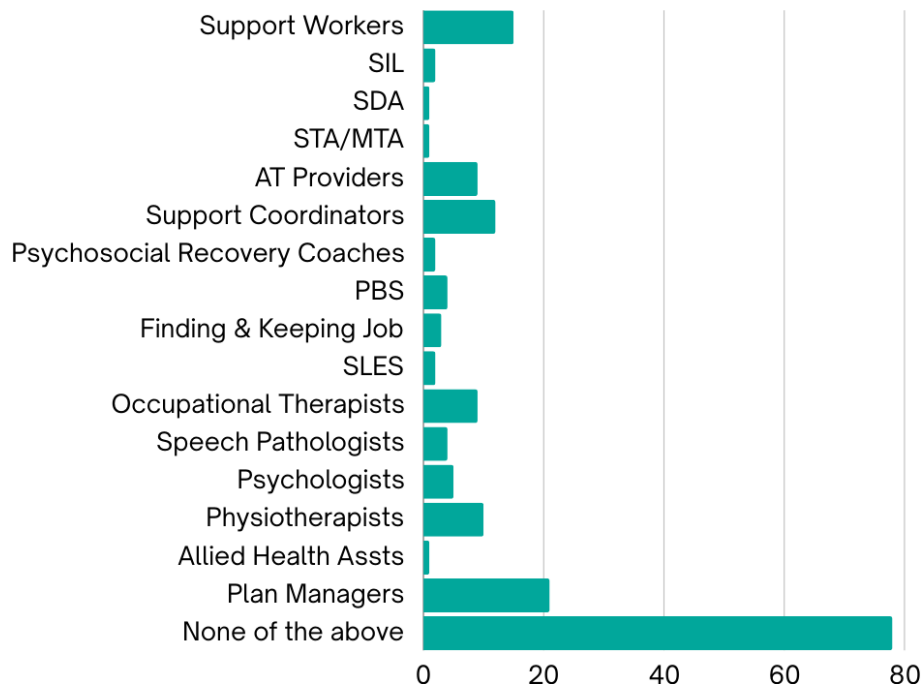
How would you rate the availability of NDIS funded services you use?



As shown in the bar graph above, 68.4% of survey respondents rated the availability of services as poor (26.1%) or very poor (42.3%). Only one person rated the availability of services in their community as excellent (0.9%), and a further 8% rated the availability of services as good.

Both people with disability and families contacting SWAN for information and peer support, and survey respondents, noted difficulties finding support services to use their NDIS funding on. 67.8% of survey respondents stated that there are not enough of any NDIS funded support services in their community, and a further 32.2% advised that there are between 1 and 8 of the 16 types of NDIS funded support services that are in sufficient supply in their community. The bar graph below indicates which support services respondents noted were in sufficient supply in their community. Please note that the highest number of respondents indicating sufficiency of providers was 21 – for plan managers. This is likely indicative of the fact that plan management is a service which is most often provided remotely, rather than in the local community. Only 15 survey respondents indicated that support workers were sufficiently available in their community, 12 indicated that Support Coordinators were sufficiently available to meet demand, and a further 10 indicated that Physiotherapists were sufficiently available. Notably however, 76% survey respondents indicated that there were no support services sufficiently available in their community.

In my region there are enough providers:



We also asked survey respondents to indicate which types of support services were in short supply in their community, with responses displayed in the bar graph below. Note also that most survey respondents only answered this question based on services they themselves were seeking.

Provider shortages in my region:

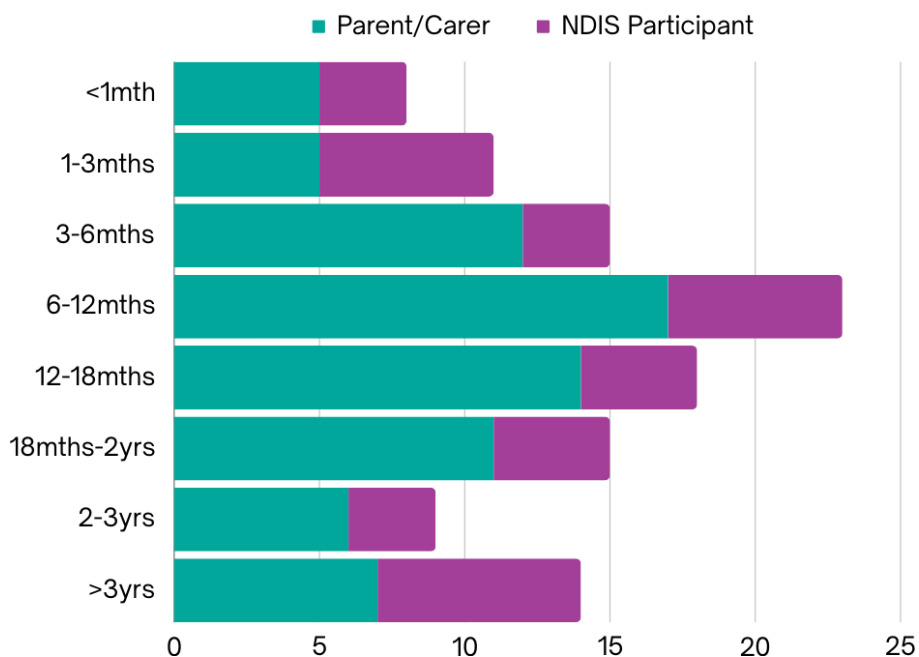


As anticipated, the greatest shortage was for Occupational Therapists (93 responses). NDIS consistently include Occupational Therapy in every NDIS plan, as well as requiring Functional Capacity Assessments, Assistive Technology Assessments, Home and Living Assessments and Driving and Vehicle Modification Assessments all be conducted by

Occupational Therapists. This is extremely problematic given the highly prescriptive nature of the Capacity Building – Improved Daily Living Skills (therapy) budget in most NDIS plans. We frequently see NDIS plans stipulating Occupational Therapy for building emotional regulation skills in autistic participants – which should more appropriately be allocated to Psychology.

This also means that too many rural, regional and remote participants are unable to use all, or part of their NDIS plans for exceedingly long periods of time – due to thin markets and lack of plan flexibility. We asked survey respondents to identify the longest period of time they waited to access support services. Again, we believe that the responses from states other than Western Australia where support services are more readily available significantly affected the result, as shown in the bar graph below. In the south west region of Western Australia, for example, the wait time to access an Occupational Therapist typically varies between 8 months and more than 3 years, depending on the age of the NDIS participant, location, and the type of disability they have.

Longest wait time for services was:



“I had my plan for 2 years, unable to access anything. Everywhere had waiting lists. I was on every waiting list, even Mandurah and Perth. I ended up going Self-managed, so I could actually access something.”

“Unable to find service providers with capacity.”

“There are extremely limited services available to meet the demand, and very long waitlists. No decent PBS or SLES providers in the region at all. Without access to unregistered providers we would have no support at all.”

“As my child's carer I know how to research and am very aware of what is needed to help. But trying to access services is difficult. I can't buy sensory aids until I have a report from OT - and it's taken 18 months to get an appointment.”

“Because we Self-Manage and can use unregistered providers, we have quite good flexibility. But requiring that Positive Behaviour Support be Agency Managed meant we were unable to use that part of the plan at all.”

“I waited 3 years and 7 months to access an Occupational Therapist. I was on waitlists everywhere, but the providers would contact me and say that the OT had left, and to try somewhere else. Meanwhile NDIS kept slashing my funding – I still needed the support, but couldn’t access anyone to provide it. So when I finally gained access, there wasn’t enough funding for the OT to do what I needed.”

“Due to being in a regional area, we have a lack of resources and many services have waitlists.”

“Just about impossible to find local registered carers. I want the choice of sole providersam worried that will be an enormous barrier to help.”

“Very thin markets. I'm entirely reliant on unregistered providers to be able to access any supports at all. The recommendations in the NDIS Review report for mandatory provider registration is terrifying - I'll lose all supports.”

“There has been some increase in services available in our regional centre, but we still need to go to Perth at least twice a year to access services not available locally. That is a round trip of about 900km, with additional expenses of accommodation, travel costs and disruption to our son’s structured routine.”

“I called therapists sometimes as far as 2 hours away looking for available services and comparing distance and wait times.”

“Definitely not enough, we also see therapist from the metro area as we can’t get what we need in our area.”

“I need to get supports from outside my town, go online, change my requirements or go without.”

“Need aboriginal workers, respite and disability housing our mob don’t want to live with white people.”

“Use services outside area either in the city or town over 400km away”

“Terrible here. And if you do get something elsewhere huge travel costs from workers taking me there and back which you don’t get in a plan so the travel cost comes out of support hours so a rural person gets less overall hours of support.”

“Just not enough providers in our area to meet the needs of everyone.”

We also asked survey respondents if they used Telehealth in order to improve access to support services. 42% of respondents advised that they do use Telehealth, whereas 58% do not. The most commonly accessed Telehealth services were Psychology, Speech Pathology, and Dietitian. Some people also use Telehealth for Occupational Therapy, Physiotherapy, and employability skill building supports.

We asked survey respondents to tell us about difficulties they experienced finding and keeping support services in their community.

“Extreme thin markets, lack of knowledge of my disability. Housing crisis has also meant that cleaners, gardeners and support workers are not able to afford rentals in my town due to being on lower incomes, so have had large gaps in supports.”

“Monthly trips to metro area to access Clin Psych was taking a toll on work, school, family and uncovered costs.”

“I have struggled to find services that service my area. Often I have to travel a fair distance to receive supports which adds extra pressure - fuel costs, car wear and tear, time from school, time from work, time from other family members etc. We have previously (prior to workers leaving) travelled to Mandurah (45+ mins), Bunbury (30mins+) and Busselton (1.5hours) to receive adequate supports for my child. This is a huge outlay for our family. It also involved having to take my younger son on these travels as we cannot always get day care spots, have the funds to pay for day care or have someone available to baby sit.”

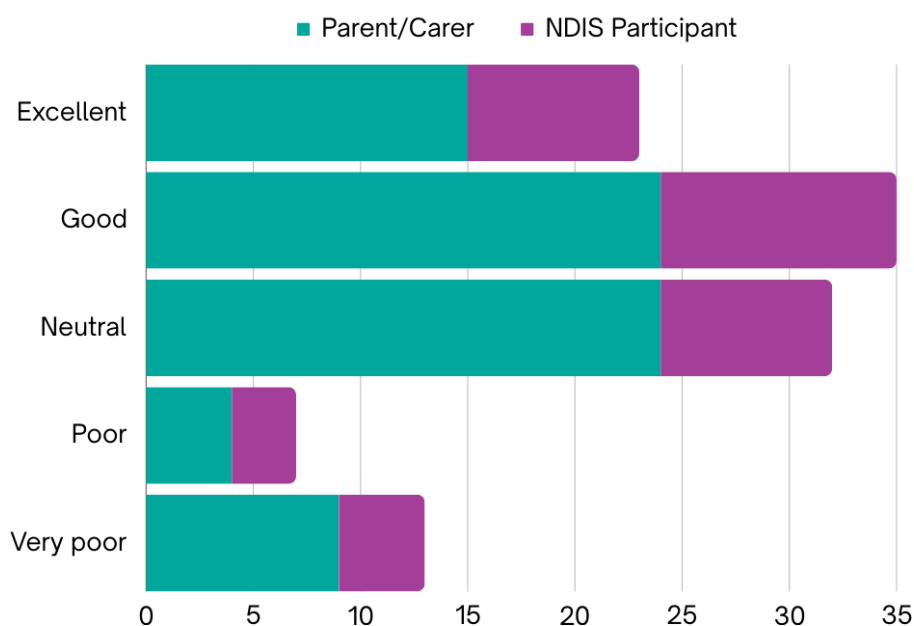
“Service providers find it difficult to retain staff in regional areas.”

“Not enough services available in regional areas, lot of staff changes, so when you get near the top of a waitlist, the staff leave and then you're waiting for a replacement staffer.”

“There is nothing where we live. I have to drive at least 1 hr to access anything. The plan doesn't take in the fuel money I have to fork out to help my child.”

It's important to note that despite the difficulty accessing support services and the high usage of non registered providers, survey respondents rated the quality of the NDIS funded services they use quite highly. As shown in the bar graph below, 52.7% rated the quality of services used as good (31.8%) or excellent (20.9%), whilst 18.2% rated the quality of services used as poor (6.4%) or very poor (11.8%).

How would you rate the quality of NDIS funded services you use?



Delving further into the comments on quality of support services used, we find some common themes.

“I have a pretty good small team, but that has taken 5 years to build, without help. However, there's no permanence with any of these people: need far outweighs supply in my district.”

“Because we can s\Self-Manage, use unregistered providers and have full control over the supports we use for our family member, we are able to maintain an extremely high quality of support. For example, we direct employ the support workers, saving \$30,000 each year. They are permanent part time employees paid \$42 per hour plus superannuation, tax and insurances are managed for them, and we also organise plenty of appropriate training for them to make sure that they are meeting our family member's needs. All this and we are still saving the taxpayer \$30,000 per year on support workers alone!”

“Because we are using unregistered providers. The registered providers were dreadful.”

“Not good so far feel like cash cow people only after access to your funding while doing bare basic services to you.”

“The support workers and psychologists that we have accessed for our son through his Self-Managed plan have been excellent but they are in short supply.”

“We have had excellent supports from the unregistered providers we use. The NDIS registered providers were absolutely dreadful, and now we actively avoid them.”

“Some are truly sucking plans dry and not building skills or capacity.”

“My psychologist is excellent in helping me to navigate relationships etc and understand how to live a full life with my disability. Support workers are mostly good,

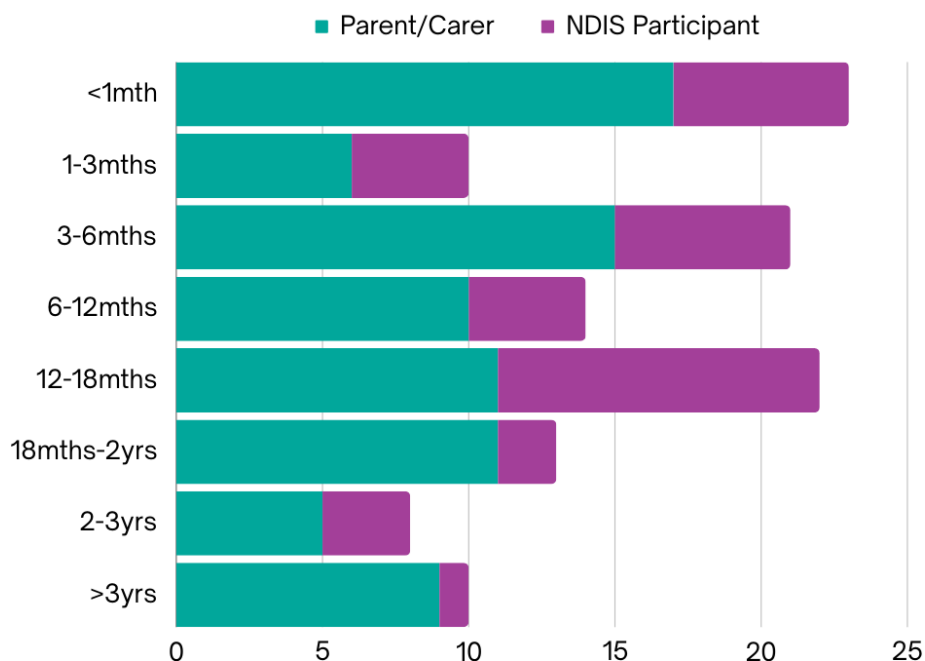
but the upper management and coordinators of the support worker organisation I use are a bit poor, with constant changes to the staff and a lack of continuity. They appear to be understaffed and regularly drop the ball, leaving me waiting for a support worker who doesn't show, or having a support worker turning up when I have told them I don't need support that day, etc. They are frustrating to deal with a lot of the time."

"Those within our team are amazing, but it's taken us a long time and a lot of advocacy to get what we have."

Many comments refer to the flexibility and control of Self-Managing NDIS funding and access to non-registered providers in successfully accessing and maintaining quality supports. Most concerns about quality were related to poor experiences with NDIS registered providers, inconsistency of supports due to staffing shortages, and charging practices. As participants and families in rural, regional and remote Australia are often charged extensive provider travel costs, which NDIS representatives commonly fail to factor into the development of NDIS plans, concerns over charging in these areas are common.

We asked survey respondents how long ago they were last contacted by a NDIS representative. As shown in the bar graph below, the results were quite inconsistent,

Last Contact from NDIS Representative was:



Of concern is the fact that SWAN are seeing NDIS participants with plans which have been auto-extended annually for three of four years, with **no contact from any NDIS representative** during that time. There were also survey responses to this effect, indicating that the issue is likely to be systemic nationally, rather than a quirk affecting the south west region of WA. Others have been offered multiple plan rollovers via letter or phone call, with no other contact from NDIS representative. One survey respondent advised that they were still on their first NDIS plan which was drafted six years ago, and had been rolled over unchanged ever since.

“2020 when the S100 was held. Since then the 12mth plan has been auto-extended repeatedly, with no one contacting us. We are too scared to contact NDIS about it in case they slash the funding, as happened to his family member.”

“I always have to initiate contact if there is an issue or need clarification. Even when I request LAC to call they don't. Now we have to request appointments and still don't get return follow up calls after the appointment.”

“I cannot remember the last time anyone contacted me about my son. I used the NDIS portal to find out information about his review which was scheduled for December 2023. Now it has been rolled forward to December 2024 but no one from NDIS has written or telephoned me about this. I don't know who our current NDIS LAC is as it changes each time I have telephoned or emailed which is not good for continuity of care for participants.”

“My plan was rolled over 2 years ago and an NDIA planner rang me. I've not had a planning meeting in 4 years.”

“Phoned to offer a rollover. Daughter is trans, and despite being informed of the change of name and gender since previous plan was written, she was deadnamed and misgendered throughout the new plan. They didn't bother to correct the information and we had to lodge a complaint. It took more than a month for this to be sorted out, and was actually only sorted out when parent's atrocious NDIS plan was being fixed.”

“Other than a letter, have never spoken to anyone other than the initial appts to set up the plan.”

“Only contacted after emailing repeated complaints to Bill Shorten, NDIS CEO, feedback and complaints emails, Q&SC. The system has been broken from the outset because the goal of governments is to spend the least possible in supporting PWD's, even if that means spending \$72M a year on lawyers to fight vulnerable people at AAT.”

“The email received basically stated that no further funding or supports were necessary as the funding was adequate - not even enough to do a FCA. It also accused myself and the wonderful therapy providers of not implementing the supports effectively. Poor.”

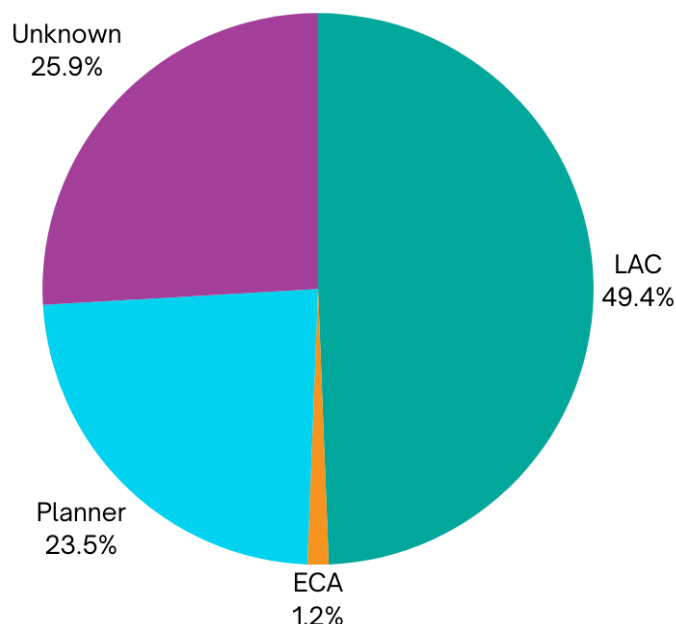
“Via email. The person did not answer my question. Yet to hear back again.”

“I have had contact more recently as I reached out, my question was unanswered and no follow up was made despite being told it would. The last time someone contacted me was at the beginning of my plan (12 months ago).”

Plan Reviews

75.2% of survey respondents have been through a NDIS Plan Reassessment. We also asked who the NDIS Plan Reassessment meeting was with, and were disturbed to learn that 25.9% of survey respondents did not know who the meeting was with, as shown in the pie chart below.

The NDIS Plan Reassessment meeting was with:



As NDIS representatives typically contact NDIS participants and families from unlisted numbers and planning is increasingly being conducted via phone call only; **failing to clearly identify who the NDIS representative is, their role and where they are calling from is deeply concerning**. There is high risk of NDIS participants and families falling victim to NDIS scams and fraud through this approach, especially as NDIS representatives phone from a silent number and then require identifying information before proceeding.

“They didn’t tell me, I never heard from them before or after, so have no idea who or what they were.”

“I was so confused as they gave us a different child’s name and different LACs name and in the end I don’t even know who did it.”

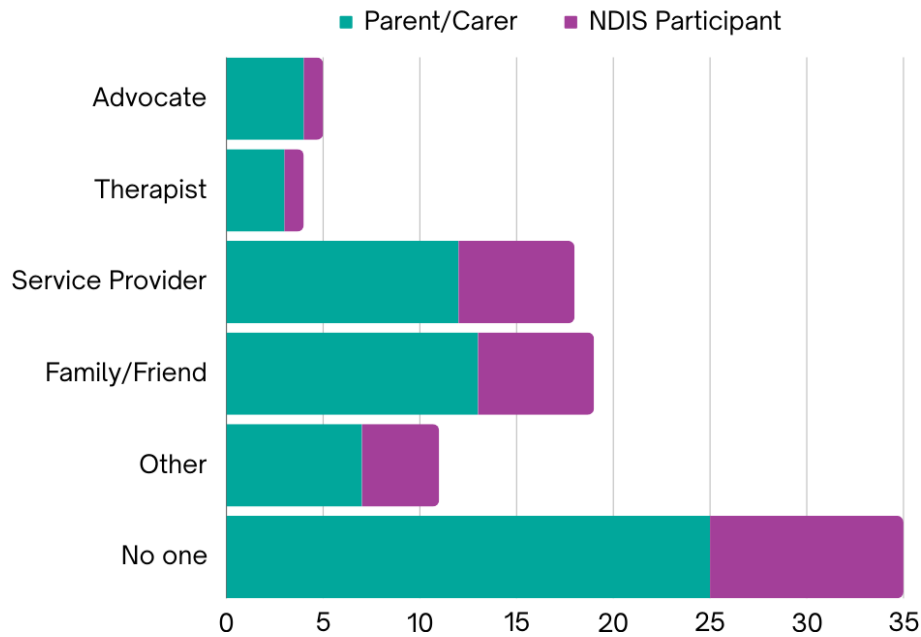
“They didn’t bother to tell me what their role was.”

“Someone phoned saying they were from NDIS. Next thing I knew there was a new plan. There was no warning at all.”

“They didn’t tell me. Just said that they were from NDIS.”

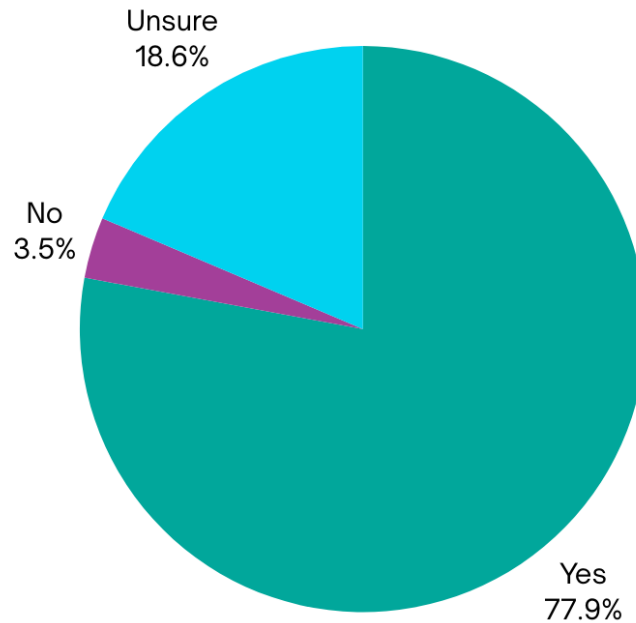
We asked survey respondents who (if any) supported them during the NDIS Plan Reassessment meeting. As shown in the bar graph below, 38% had no support person present, 20.7% were supported by a family member or friend, and 19.6% were supported by a service provider. Only 5.4% were supported by an advocate.

At the NDIS Plan Reassessment meeting I had support from:



We asked survey respondents whether progress reports from providers were submitted, and again were shocked that 18.6% of respondents were unsure, as shown in the pie chart below.

Were progress reports from providers submitted?



Many survey respondents made comments regarding this question, with a lot of common themes. Many felt that the progress reports were a waste of funding, particularly as they were often ignored by NDIS representatives. Others were not given enough prior notice of the Plan Reassessment meeting occurring, in order to organise reports from providers. SWAN have received numerous complaints from clients as well as survey respondents

being phoned by a NDIS representative without warning, and a new NDIS plan being received the following day. Others also raised concerns that requests for progress reports were ignored by providers, and lastly, many people have advised that reports were submitted to enquiries@ndis.gov.au as directed and were not uploaded to the participant's file.

"For the previous plan we submitted reports, but unsure this time as we didn't expect a whole new plan to be implemented."

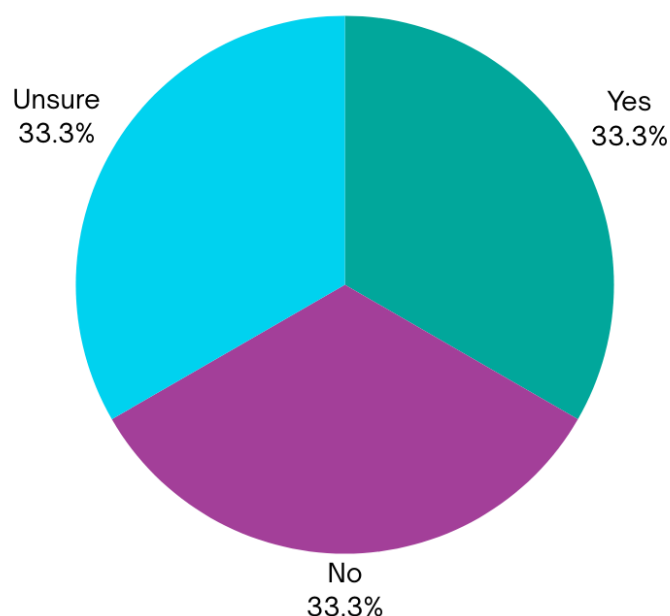
"I do it because it is a requirement but I find this to be a waste of funds personally. Of course they are going to say I should continue with them. I know myself which services I need so why does NDIA waste money demanding reports from providers to support me continuing to use them?"

"I thought the support coordinator would organise those but didn't. I tried to organise, some reports had other people names in it like copy and paste."

"Some did but some didn't. It was very burdensome to my service providers and in particular a waste of valuable therapy time for my allied health professionals."

Importantly, we asked survey respondents whether they thought the progress reports were helpful for the plan reassessment meeting, with respondents equally split between yes, no and unsure (as shown in the pie chart below). This is reflective of the inconsistency with which NDIS representatives consider progress reports from providers.

Were progress reports from providers helpful?



"NDIA completely ignored the reports and slashed my funding. When I lodged a complaint they could see notes from the delegate saying there was no documentation in my file. They clearly didn't bother to look. There were 2 Functional Capacity Assessments, 4 physiotherapist reports, a psychologist report, and I'd completed participant booklets 2 and 3. Also reports from diagnosticians."

“Having those reports makes it more likely I will be believed when I say I need the funding for that service.”

“NDIA did not look at any reports. It was a waste of time and money providing them. The NDIA recommendations clearly indicated they did not read the reports, and were in direct contradiction to several treating therapists professional recommendations.”

“Advocate was more helpful as reports seldom read or understood.”

“I don't think they took any notice of the progress reports. They increased my funding because they could see it wasn't enough to be able to do anything, but only put in half what my therapists recommended.”

“Ignored completely. Waste of time and funding.”

“Change of Circumstance application rejected but planner has recommended early plan review, so now we are required to get service providers to submit more reports, at more expense to NDIS taken out of funding meant to be used to support our son. Overall in this plan, more of the funding has been used for administrative work than supply of services.”

“I thought the reports were comprehensive but didn't reflect in the outcome of plan-disappointing.”

“NDIS did not take recommendations after thousands where spent on reports by specialists. It's disturbing that the answers from NDIS are not value for money. How can they say a human beings life is not value for money. Disgusting.”

Of note, prior to 2021, while NDIS required progress reports from Capacity Building support providers, there was substantially less requirement of evidence for the funding of reasonable and necessary supports. NDIS representatives more readily listened to and believed the evidence presented by participants and families. From mid-2021 onwards, the culture within NDIS noticeably shifted. There was clear distrust of participants and families, and the requirement of extensive and expensive therapist reports to justify inclusion of all supports. **Very often the report to justify a particular support, costs more than the requested support itself.** When the NDIA commenced auditing of plan managers, the problem was exacerbated. Plan Managers started to require reports from therapists to justify approving payment over various support claims.

Unsurprisingly, these changes coincided with public and political concerns over a NDIS cost blow out. Whilst NDIA are increasingly requiring more and more extensive reports to justify the continuation of supports and the addition of funded supports, NDIS representatives are simultaneously reducing the amount of funding participants are given in the Capacity Building – Improved Daily Living budget. SWAN have seen children aged 7-14yrs in particular given NDIS plans with funding as low as \$4000 for a 12 month period. For context, it costs more than \$5000 per year to cover only one hour of Occupational Therapy or Speech Pathology per fortnight. Psychology and Physiotherapy are allocated higher rates in the NDIS price guide. This means that not only are participants and families spending thousands of their NDIS plan funding on reports to justify supports, but they are able to access substantially less actual therapy. SWAN are increasingly hearing from participants and families who are being told by NDIS representatives that they no longer need therapy funding (or in some cases, NDIS funding at all), because all the therapy they

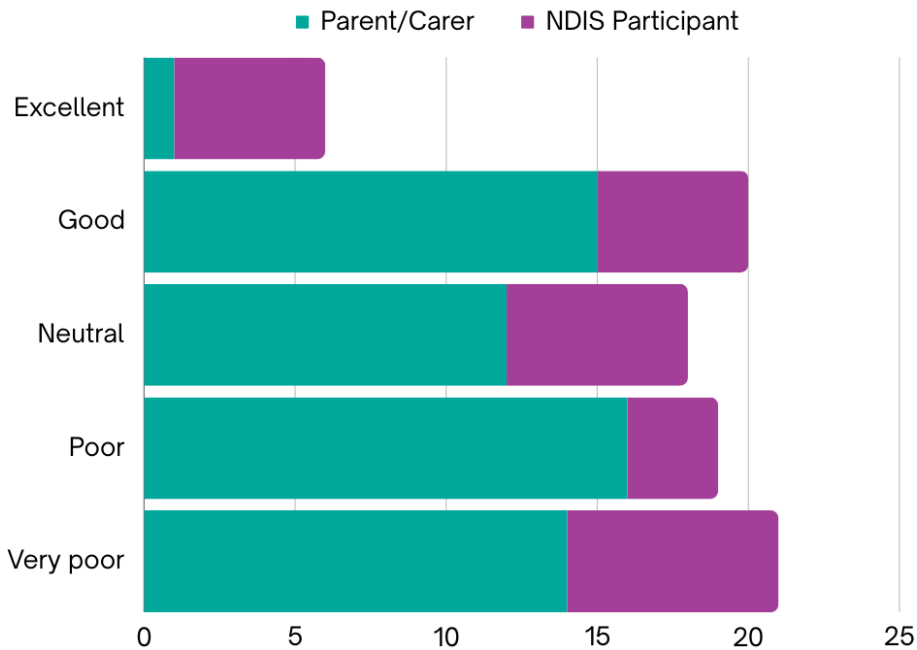
have been having should have built their skills and capacity. This commentary from NDIS representatives is not only distressing for participants and families, but fails to recognise the fact that large portions of the therapy funding is being wasted on reports for NDIS, rather than being able to be utilised for capacity building. It also fails to consider that the vast majority of NDIS participants were required to prove they have a permanent disability in order to gain access to the NDIS.

Furthermore, NDIS representatives frequently fail to take into consideration the additional cost of travel for rural, regional and remote participants – both for therapists to travel to NDIS participants to provide assessments and therapy, or for participants and families to travel to therapists to access therapy. It's common for NDIS representatives to deny the inclusion of travel costs in the Capacity Building – Improved Daily Living budget, telling participants that they must source therapists in their local community. This is hugely problematic for participants in rural, regional and remote Australia. Where there are local therapy providers, they very often have closed or extensive waitlists which may exceed the duration of the NDIS plan. The only option in these circumstances is to use Telehealth or use therapists willing to travel into the area (or the family travel to the therapists). Telehealth is unsuitable for many NDIS participants, and travelling out of town to access therapy is extremely costly, time consuming, and an additional stressor for participants and families who are already time-poor, stressed and often exhausted. Where participants take the only available option of an out-of-town therapy provider and have travel charged to the NDIS plan, the therapy budget is quickly expended – resulting in gaps in access to therapy supports.

Another issue impacting NDIS participants in rural, regional and remote Australia is the narrow scope of clientele that therapy providers typically will see. Many services are paediatric only, leaving adults without access to therapy supports, or waiting in excess of 18 months to 3 years to access supports. There are significant staffing shortages, and many participants and families report being on a provider's waitlist for many months, only to be advised that the clinician has left the provider to return to the metropolitan area, and to try a different provider.

We also asked survey respondents to rate their experience of the Plan Reassessment meeting, as shown in the bar graph below.

NDIS Plan Reassessment Experience:



47.6% of survey respondents rated the NDIS Plan Reassessment meeting as poor (22.6%) or very poor (25%), with only 30.9% rating the experience as good (23.8%) or excellent (7.1%).

“The plan had already been written before the meeting, the additional supports that we requested were declined.”

“We had sent in information which she did not have access to. When I re emailed it to her in the meeting, she did not read any of it. When I asked what extra information on my condition I should supply she said it wasn't needed. But on the rejection, they included treatments that weren't relevant to my particular condition.”

“They were rude and dismissive.”

“All supporting information had been uploaded to their portal, but the LAC hadn't read any of it. Had no idea what my child's diagnoses were or any background info on his conditions and when asked if they want more info so they knew what they were talking about, they said it wasn't needed. Funny that the review got rejected.”

“It was a 10 min phone call and suddenly I had a new plan. She didn't even tell me that would happen.”

“LAC was more interested in shutting down requests for funding that helping us establish a plan that is helpful.”

“I got a random call which was not scheduled from the planner who admitted he had not read the appeal and asked me to tell him briefly instead. Very disappointing as a lot of time spent preparing the appeal and then it was not read. I was worried I would miss out important things and did and then emailed after the phone call and this changed his view of what would happen,”

The availability, responsiveness, consistency, & effectiveness of the NDIS in serving rural, regional, and remote participants

A common complaint in rural, regional and remote Australia is lack of access to NDIS representatives. There are frequently no NDIA or Partner In The Community offices in local communities, and thus no opportunity to speak in-person with NDIS representatives. Where there are local offices for NDIS representatives, they may not be disability accessible. In the south west region, the Partner In The Community offices are a sensory nightmare for autistic participants, and the Busselton office includes meeting rooms too small for wheelchair users. The two meeting rooms are also not sound-proofed, so when there are concurrent planning meetings occurring, participants are able to hear each other's private information.

NDIS participants and families in rural, regional and remote Australia are less likely to be contacted for implementation support than their metropolitan counterparts, and less able to access accurate and timely information and support. NDIS LAC Partners In The Community no longer allocate a specific LAC to each participant, and expect participants and families to contact a generic email address and phone number which is only listed in the NDIS plan, but not listed on the NDIS website or any other NDIS documentation. This is extremely problematic as participants and families contact the National Contact Centre for information and advice which is often incorrect, and frequently are told to contact their LAC. As most participants and families do not know who their LAC is, there is no way to achieve this. SWAN also hear from participants and families who have contacted the generic NDIS Partner In The Community email or phone number and were told that the LAC would return their call, but no one followed up. In too many cases, participants and families simply give up and try to figure it out on their own, unless they are lucky enough to be able to connect with a knowledgeable Disability Peer Support Organisation or online NDIS community.

"I asked an LAC to help but never got their help."

"I had a conversation with the LAC once, then that LAC left and I had maybe an email or two with the person after them and then I just gave up and found my own services with the help of my OT as it was difficult to get good answers from the LAC and they did not seem to have knowledge beyond what could be found with a quick Google search and certainly did not have many recommendations for anything more specific or tailored to me individually (which to be fair can be really difficult to find in the regions)."

"Initially I had trouble with my LAC as she was moving onto another job. She left me floundering and unable to sort through the paperwork which is so overwhelming."

"Our local NDIS office sent me a list of support services when I requested information about psychologists with a specialist interest or experience with autism. The list was out of date, many of the agencies listed did not deal with the field of psychology at all. It wasn't helpful. Many wasted phone calls and much of my time wasted. In the end I used Google to search for local psychology services and started phoning around again."

"No LAC support at all. In fact for the last 5 years, I have never had my LAC contact me to ask how I was going."

*“No one from NDIS has ever contacted me to help me understand or use my plan.”
“Once I lodged S100 the LAC took it personally and stopped communicating.”*

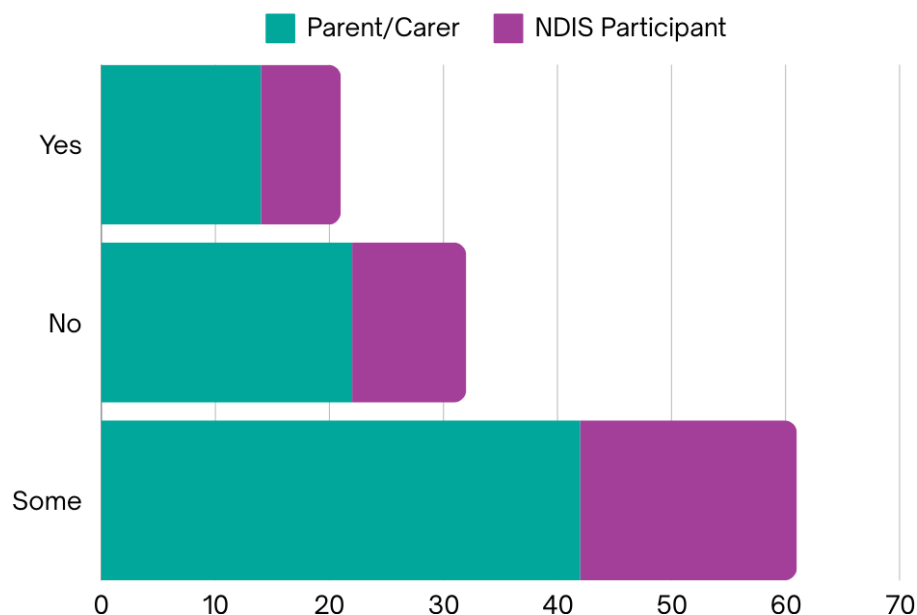
As there are fewer NDIA staff and PITC representatives in rural, regional and remote Australia, participants and families are often forced to continue dealing with NDIS representatives there may previously have been problems with. Where participants and families lodge complaints about NDIS representatives, there is rarely action taken and the participant and family may have no option but to continue interacting with a NDIS representative who knows they lodged a complaint about them. Rural, regional and remote communities are small disability communities, and it's common for everyone to know everyone else. This can lead to a lack of privacy for NDIS participants and NDIS representatives alike.

NDIS participants and families in rural, regional and remote Australia are more likely to be phoned for planning and reassessment meetings, which commonly result in poorer outcomes for the participant. Phone calls may also be with metropolitan based or interstate NDIS representatives, with little or no understanding of the barriers and difficulties the participant faces in their local community, or the lack of access to support services. Rural, regional and remote locations typically have very few or no NDIS registered providers, so participants in these areas need funding which is Self-Managed or Plan Managed in order to access any support. Since the amendments to the NDIS Act in 2022 to introduce a risk assessment for Plan Management to be approved, this has impacted participants in rural, regional and remote Australia. SWAN have received reports of NDIS representatives changing participant plans to fully Agency Managed without warning or discussion, resulting in the participant losing access to all existing support services, and being unable to access NDIS registered providers.

Participants' choice and control over NDIS services and supports including the availability, cost, and durability of those services

SWAN asked survey respondents if they feel they have choice and control over NDIS funded supports. As shown in the bar graph below, 53.5% felt they had some choice and control, whereas 28.1% felt they had no choice and control.

Do you feel you have choice and control over NDIS funded supports?



There are many factors impacting the experience of choice and control for participants in rural, regional and remote Australia, the most common being:

- Lack of flexibility of NDIS Plans
- Insufficient funding in NDIS Plan to meet needs
- Lack of access to appropriate support services
- Overly complicated NDIS processes, and lack of support to navigate these processes
- Lack of implementation support to understand and use the NDIS Plan

Below are some comments about choice and control made by survey respondents:

“Because we use unregistered providers and direct employ his support workers, we have choice and control. This is limited by lack of flexibility in his NDIS plan though.”

“Lack of flexibility seriously limited choice and control. Terrified of being forced to use NDIS registered providers - it would mean no support at all. The providers I use all have only a couple of NDIS participants as clients, so have all said that they wouldn't bother to register, would simply stop supporting NDIS participants.”

“Can't always travel over 500km to access some services not available in the area.”

“Some things need to be added as approved therapy. Not every child or person resonates with clinical practices. Animal therapy, water therapy - if we are paying for qualifications and much higher cost to those without being on the NDIS that can still access these services. Something really needs to be done to access services in a not so clinical setting.”

“I feel that I have choice and control as a self-managed participant. There is significant effort and work required for me to be able to maintain this though.”

“My plan dictates how I can use it. There's no flexibility, and I don't have choice and control. I wanted to use NDIS registered providers because I thought that would be better, but none of them would take me on because there wasn't enough profit for them.”

“Using unregistered providers gives us choice and control, but this is limited by inflexibility in the NDIS plan.”

“My first plan was terrible. The only thing I could do with it was a Functional Capacity Assessment, none of the supports I need were funded.”

“You have to take what you can get which means there is NO choice and control.”

Other Issues

The current funded National Disability Representative and Carer Organisations (DRCOs) are all located on the eastern coast in capital cities. These representative organisations are consulted on all disability issues by the NDIA, Department of Social Services, the independent NDIS Review, and the Minister for NDIS. The needs of people with disability living in rural, regional and remote Australia are frequently forgotten in these consultation and codesign engagements due to the simple fact that the advocates do not have direct experience of true geographic isolation. Whilst these DRCOs are funded as national representative bodies and do engage with the disability community, their engagement with people with disability and families in regional and remote Australia, particularly Western Australia and the Northern Territory, are either non-existent or extremely limited. This is extremely problematic, as decisions are being made which have serious repercussions for people with disability in rural, regional and remote Australia, without consideration of the potential consequences. The recommendation in the NDIS Review report for mandatory provider registration is a key example.

Recommendations

- 1) NDIA to establish an Advisory Committee comprising NDIS participants, families and advocates from regional and remote Australia, with priority given to advisors in geographically isolated areas such as the Pilbara in Western Australia and the Northern Territory. SWAN's CEO has already proposed this recommendation to the NDIA senior executive, and the recommendation has been accepted; however it's important to note that the NDIS is now in it's eleventh year of operation, and the introduction of a rural and remote advisory group is only now being introduced.
- 2) The newly established NDIS Provider and Worker Registration Taskforce include a rural, regional and remote advisory group to ensure that the impact of their solutions and recommendations are considerate of the impact on people with disability in regional Australia, their specific barriers and needs. Ideally the Taskforce should include at least one rural, regional and remote representative from geographically isolated areas like WA and NT on each advisory group.
- 3) Department of Social Services to open Disability and Carer Representative Organisation funding to organisations specifically representing rural, regional and remote Australia, even where they may not meet other national representation requirements. Prioritising the disability communities commonly left out of consultation and co-design – Western Australia and the Northern Territory.
- 4) Commonwealth Government to reject the NDIS Review Panel's recommendation for mandatory provider registration and the removal of plan management. The risk of harm and neglect to NDIS participants in rural, regional and remote Australia is too significant.
- 5) Commonwealth Government to simplify and arrange free NDIS registration processes and provider audit, as well as provide practical support to encourage providers to register. Whilst the NDIS Review Panel recommended mandatory provider registration, there was no recommendation to make the process free. In making this recommendation, the Panel neglected to consider providers supporting extremely small numbers of NDIS participants as part of a much larger, non-disabled client base. Any compulsory costs and bureaucratic burden disincentivise providers from supporting NDIS participants. Further to this, Auditors should interview current and past users of the service as part of Quality and Safeguards monitoring. It's important to find out why participants left a service, as well as why they chose to stay.
- 6) Any and all changes to the NDIS proposed by the Independent NDIS Review must be fully co-designed with participants, supporters, Disability Representative and Carer Organisations (DRCOs) and Advocacy Organisations. We emphasise that co-design processes must include diverse voices, and take particular consideration of the unique barriers and difficulties faced by people with disability in regional and remote Australia, and ensure their voices are prioritised. Impacts of decisions on people in the metropolitan area are amplified in regional Australia.
- 7) All NDIS Plans to include a minimum Core budget to enable a modicum of flexibility for NDIS participants in rural, regional and remote Australia.
- 8) NDIA to ensure that NDIA delegate planners conduct full planning meetings with NDIS participants, rather than brief phone calls to stipulate funding amounts (without asking the participant and their family about their support needs). Rural, regional and remote

participants should have planning meetings with NDIA delegate planners who are also located in rural, regional and remote communities – to ensure understanding of the unique barriers the participants face.

- 9) NDIA to simplify the format of the NDIS plan in PACE, ensuring that Capacity Building support categories are not automatically shown as 'Stated Support'.
- 10) NDIA to improve participant choice and control by giving participants greater autonomy over supports in plan, flexible funding, and plan duration.
- 11) In order to address the cultural issues within the NDIA and Partners In Community, we recommend targeted recruitment of people with disability as part of the Government's budget priority to build the NDIA's Workforce Capability. Ensuring that NDIA develop staff's expertise in specific disability types rather than having minimal general knowledge of all disabilities would significantly improve outcomes for participants. Further, we strongly recommend that all staff and partner organisations ensure all staff undertake training in:
 - Trauma Responsive Practice
 - De-escalation skills
 - Conflict resolution
 - Incidental Counselling
- 12) All communication from the NDIS must be provided in formats accessible to the participant. Culturally and Linguistically Diverse (CaLD) participants must be provided a NDIS plan in their language, or funding included in the plan for a translator to do this. Vision-impaired and blind participants must be provided a copy of their plan in large text or braille if required, and the NDIA must ensure that the rollout of PACE will enable screen readers to accurately read the plan. Participants requiring Easy Read versions of their NDIS plan must be provided the plan in this format, or funding included to produce an Easy Read version. Plain English must be the minimum standard for all communication from the NDIS. We note also that Easy Read documentations must be released at the same time as standard versions, not weeks or months later (or not at all).
- 13) NDIS must shift from a focus of keeping funding in participant plans as low as possible to a focus on ensuring that the participant's NDIS plan accurately reflects their needs and reasonable and necessary supports. **NDIS needs to get the participant's plan right – the first time, wherever possible.** Planning meetings need to be conducted by NDIA Delegates and need to be a negotiation between the participant / nominee and the Delegate. **This can be achieved by providing a draft of the plan to the participant / nominee and have them sign their approval of the plan in order to finalise it.** This system was successfully used in the WA trial sites for the State version of NDIS. We note also, that getting the plan right in the first place will immediately address the issue of inter-plan and intra-plan inflation.

Ideal NDIS Process



- 14) NDIS representatives must check the accuracy of participant information on file – directly with the participant and their supporters regularly. SWAN’s advocacy work is increasingly identifying very significant errors in NDIS participant records which seriously impact participants. We are uncovering errors such as NDIS Access Requests being entered into the NDIA’s operating system incorrectly, diagnoses listed incorrectly (e.g. diagnoses missing from the participant’s file), and more. In April 2023 SWAN’s CEO sought feedback in several NDIS related peer support groups on whether NDIS representatives are checking that participant information on file is correct. These polls identified that **more than 80% of participants have never had their information checked for accuracy by NDIS representatives.**
- 15) NDIS Planning meetings must be held with the actual decision-maker. With the rollout of PACE, LACs and ECA Coordinators are now ‘assisting’ with collection of information. Currently, too many LACs and ECA Coordinators are acting as gatekeepers, refusing to submit information which accurately reflect the supports requested by participants and families. When the participant or their nominee submit an S100 Internal Review Request, we are increasingly seeing the requested changes rejected because there is no record of the original support being requested. Outcome letters from the Internal Review team state that the support was not requested at the planning meeting, and to request an S48 Change of Circumstances Reassessment. Further to this, LACs and ECA Coordinators are submitting S100 Internal Review Request forms without the input of the participant and failing to provide the participant with a copy of the submitted form. If the participant is forced to appeal to the Administrative Appeals Tribunal, they then need to request release of their information from NDIS, which takes as long as 5 months to receive. Notably, this information generally includes only the case file notes, but doesn’t include the S100 form.
- 16) We **strongly** discourage the Government and the NDIA from proceeding with the NDIS Review Panel’s recommendation that participant budgets be decided prior to the planning meeting. This methodology fails to acknowledge the expertise of participants and supporters, is not individualised, and will not meet the unique support needs of most participants – especially those living in rural, regional and remote Australia. Whilst this method would reduce costs, the risk to participants is extreme. Further, this places participants at the mercy of the whims of future Governments. All Australians with disability need certainty about the future of their supports, and this is **not** the way to achieve that.
- 17) Participants must be given the full name and contact information of the NDIS representative responsible for negotiating and finalising their NDIS Plan, **prior** to the NDIS planning meeting. Failing to do this results in participants being unable to submit further evidence, including written details of the supports they are requesting. This enables gatekeeping and limits participants’ opportunity for successful S100 Internal

Review requests. This is because the Internal Review team are now only reviewing the notes submitted by the NDIS Partner in Community or NDIA Delegate at the planning meeting, and comparing this with whatever was submitted in the S100 Internal Review request form. Currently, the only email address most participants have for submitting documentation is enquiries@ndis.gov.au, which generally takes 6 weeks or longer to be processed. This isn't an option when many participants are given as little as 2 days' notice of their meeting. With more than half a million participants as well as providers using the one email address, there is also the issue of emails to enquiries@ndis.gov.au not being actioned at all.

- 18) NDIS participants must be provided an explanation of all decisions made by the NDIA about them and their supports, without the requirement of the participant or their supporters to submit a Freedom of Information request.
- 19) NDIA must cease all use of algorithms in determining funding for NDIS Participants. Planning, Review and Reassessment processes must be returned to individualised, person-centred and collaborative processes, acknowledging and respecting the lived experience of the participant and their supporters. The Typical Support Package (TSP) lacks evidence and external scrutiny to ensure efficacy and is entirely unsuitable in determining funded supports. Notably, NDIA delegate planners are routinely developing NDIS Plans for autistic children aged 7-14yrs with funding amounts less than half the TSP for this age group.
- 20) NDIA's use of 'Primary Disability' for NDIS participants must cease. Participants and supporters are never informed which of their diagnoses have been approved for NDIS eligibility but are expected to only claim supports for the diagnoses NDIA has decided are eligible. The NDIS Act 2013 (amended 2022) does not include the terms 'diagnosis', 'diagnoses' or 'diagnosed' anywhere in 307 pages. We ask the Joint Standing Committee on NDIS whether the NDIA's cherry-picking of participant diagnoses, and not advising them of this, is compliant with the Legislation. Furthermore, NDIS representatives appear to randomly select a diagnosis to list as the 'Primary Diagnosis', again without advising participants. This selection of 'Primary Diagnosis' then impacts the algorithms used to determine Typical Support Packages, which again are inaccurate as they do not factor in the participant's multiple disabilities.
- 21) As per the [NDIS Participant Charter](#) standard 'Connected', ensure that participants and nominees are contacted according to their expressed preferred method of communication. If a participant has requested to be contacted by email, then contact should be via email. If a participant is blind or vision impaired, then contact should be made using accessible documents.
- 22) The website <https://ourguidelines.ndis.gov.au/> must be deleted. All Operational Guidelines must be reviewed to ensure compliance with the legislation, and be co-designed with people with disability, advocates and disability representative organisations.
- 23) In order to ensure holistic support for children and young people with disability, we recommend that mainstream services such as Education, Health, Mental Health and Allied Health be invited to participate in NDIS Planning meetings where appropriate. Since the rollout of NDIS in the south west region, we are increasingly observing a siloed approach to support for children and youth with disability. This has the effect of families being referred back and forth between mainstream services and the NDIS, unable to

access the supports which are desperately needed. There needs to be a more collaborative approach to supporting youth with disability, ensuring greater understanding of what supports NDIS can and should provide, and what supports mainstream services can and should provide. There is a higher rate of young people with disability (particularly autistic kids) disengaging from mainstream schools due to insufficient support. Whilst this is not the responsibility of NDIS, a more collaborative approach and shared responsibility is beneficial in improving outcomes for youth with disability.

- 24) The [3 NDIS Participant booklets](#) need to be redesigned to ensure that participants and supporters are able to easily submit information about their needs and requested supports in writing. A more user-friendly system would be to have 1 booklet explaining NDIS processes, 1 booklet for preparing for the first planning meeting, and 1 booklet for preparing for a Plan Reassessment. Further, a separate version should be developed for families of children aged 0-6 years accessing the Early Childhood Approach. Participants and families have better outcomes when dealing with NDIS processes where they are able to submit information and support requests in writing, rather than relying on the NDIS representative to remember the discussion and submit all information discussed into the system.
- 25) Participants and families need access to a single NDIS contact person for support, rather than having to tell their life story to numerous random people. LAC Partners in Community are no longer assigning an LAC to specific participants. Since late 2021 it has been luck of the draw as to which LAC will conduct your planning meeting, and if you are lucky enough to be provided plan implementation support, another random LAC **might** contact you about this. Participants are given a generic email address and phone number for the LAC Partner in Community organisation on the front page of the NDIS Plan, but this number and email address are not listed anywhere else. The participants and families contacting SWAN consistently complain that they have no idea who their LAC is, or how to contact them.
- 26) Sub-contracting, outsourcing and casualisation of the NDIS workforce greatly reduces the accuracy of information being supplied to participants and families, while increasing operational costs. We need to build the necessary expertise within the NDIA and retain this expertise by ensuring that staff have full employee benefits. In late 2023 the NDIA contracted new organisations not tasked with LAC and ECA services to phone participants for check-ins. This is a huge breach of the participant's privacy, as well as being extremely confusing for participants and supports. We draw your attention to how this practice puts participants at higher risk of being scammed or defrauded. All communication to participants about the NDIS needs to come from the NDIA direct – using their preferred communication method.
- 27) All participants, regardless of age, must have a minimum Core budget in their NDIS plan which can be used flexibly to meet their needs. The majority of children and teens, particularly in the south west region of WA, have no Core budget, or as little as \$100-\$300 for Core supports. Typically, we see Capacity Building – Daily Living only NDIS Plans for 7-14yr old children of \$4,000-\$9,000 per year. To illustrate the inadequacy of this, \$5000 per year equates to **less than** 1 hour of Speech Pathology or Occupational Therapy per fortnight, with no funding allocation for assessments, writing of reports required by NDIS, or therapist travel costs.

28) Participants must retain the choice to use registered OR non-registered providers, and minimum qualifications must **not** be required. The Certificate III in Individualised Support - Disability is an extremely general course with graduates still requiring extensive training to understand the individual support needs of each person they work with. SWAN were recently contacted by a representative from the TAFE for the south west region, who advised there were plans to change delivery of the course to a blended Certificate III in Individualised Support (Disability & Aged Care), which would further dilute the quality of the training and expertise of graduates. Of note, the qualification is not available at many regional and remote TAFE campuses.

Values and ethos are far more important factors, and those are innate. Allied Health professionals are already registered with appropriate professional bodies, such as AHPRA, which is a much stronger regulatory body than the current NDIS Quality and Safeguards Commission. Mandatory provider registration creates significant risk for regional and remote participants - many towns have no registered providers, which means that many people in regional and remote Australia would be left with no support at all. We note also that there are self-managed participants successfully direct employing support workers (not via ABN) at significant cost saving to the NDIS. One of our members is direct employing two support workers as permanent part time employees with superannuation, leave entitlements and insurances – and still saving the NDIS in excess of \$30,000 per year.

29) To address issues of Quality and Safeguarding, rather than limiting supports to registered providers, NDIA need to conduct regular check-ins with participants. Check-ins should ensure they are able to access the supports they need, monitor the participant's satisfaction with providers, how they are billing and the quality of the support being provided. Check-ins need to ensure participants understand their rights when negotiating with providers, how to complain, identifying signs that participants and families need more support – triggering a Plan Variation to include funding for Support Coordination in the participant's plan. Of vital importance, check-ins must engage directly with the participant in order to check for signs of violence, abuse and neglect. Currently, there are unacceptably high numbers of participants who have not heard from any NDIS representative for up to four years, with 12 month plans auto-extending each year.

30) Funding for advocacy, the National Disability Strategy, and for Information, Linkages and Capacity Building (ILC) must be expanded. People with disability and their families rely on Disabled Persons and Families Organisations (DPFO) for independent information, support, advocacy and referral. Ensuring the sustainability of DPFOs to meet the ongoing needs of people with disability and their families is vital to improving outcomes for people with disability and ensuring the effectiveness of the NDIS. The National Disability Advocacy Program must be opened to new applicants, and management of ILC needs to be returned to NDIA. Since the ILC program was transferred to DSS in 2020, there has been a loss of connection and information sharing between ILC providers and NDIA. Prior to the change, ILC providers were able to quickly contact their NDIA grant manager and discuss issues and concerns identified in the community. There was opportunity for feedback direct to NDIA, and to work with NDIA to address systemic issues at a local level. This connection has been lost to the detriment of both NDIS participants and how NDIS operates.

31) NDIA, Commonwealth and State Governments to work together to address the issue of thin markets, particularly in the allied health space. A significant increase in university

places for Allied Health courses is urgently needed, with improved access for prospective students living in regional and remote Australia – without the requirement and additional cost to relocate to capital cities. These courses must also be amended to include co-designed disability content.

Recommended amendments to the NDIS legislation:

- 1) Removal of risk assessment in deciding whether participants can have their funding Plan Managed. This is urgently needed for participants in regional and remote Australia, where there is extremely limited or no access to NDIS registered providers. Participants living in thin market areas with Agency (NDIA) Managed funding are trying to manage with limited or no supports, which is entirely unsustainable.
- 2) Amendment to ensure that the NDIA's Compliance Team's decision that a participant has incurred a debt is a reviewable decision. Currently, if the NDIA decides that a participant has incurred a debt, the only recourse a participant has is to request that the debt be waived by the NDIA. If the NDIA refuse to waive the debt, that decision can be reviewed. However, the record of the debt remains on the participant's file, with potential to impact the participant and how their funding is managed long-term. Participants, nominees and child representatives must have legislative right to challenge the NDIA decision that a debt has been incurred. Whilst the current NDIA's Compliance Team have advised that they are researching Administrative Appeals Tribunal decisions to aid them in decision-making, there is no legislated requirement for them to do so. This part of the legislation must be amended to protect the rights of participants in future. As has been evidenced in the very recent past, there is high risk of this process being changed in the future.

Conclusion

David Tune reported in 2019 that *“the NDIS Act is broadly fit for purpose, but there are a number of areas that can be amended to remove red tape and improve the participant experience”*. In light of the amendments to the legislation made in 2022, we believe this statement continues to accurately reflect the experience of participants navigating NDIS processes. As an organisation with more than 14 years' experience advocating, negotiating and working in the disability sector, supporting thousands of people with disability living in regional WA, SWAN has an excellent understanding of the difficult reality faced by people with disability and their families in gaining and maintaining access to the NDIS and to Reasonable and Necessary funded supports – particularly those living in rural, regional and remote Australia. SWAN can provide case studies to the Joint Standing Committee if requested.

On behalf of SWAN members and the wider disability community, we are grateful to the Joint Standing Committee for investigating the systemic barriers and difficulties experienced by rural, regional and remote NDIS participants and their supporters. SWAN is deeply concerned about the increasingly negative effects of inconsistent and inefficient NDIS processes on people who are already amongst the most disadvantaged in Australia. As the peak body supporting autistic people in the south west region of WA, we would be happy to discuss the issues further with the Joint Standing Committee members.

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