

Carers Tasmania

Submission to the
2022-2023 National
Review of the NDIS



July 2023



About Carers Tasmania

Carers Tasmania is the Peak Body representing the more than 80,000 informal carers (*hereafter carers*) in the state.

Carers Tasmania's vision is for an Australia that values and supports carers.

Our mission is to work to improve the health, wellbeing, resilience, and financial security of carers and to ensure that caring is a shared responsibility of family, community, and government.

Our values drive everything we think, say, and do.

- **Carers first** – we listen to what carers need, commit to their desired action plan, and deliver results that matter most to carers
- **Care in all we do** – we care for our work, about each other, about Tasmania's family and friend carers, and the bigger world we all share
- **Integrity always** – we are transparent, act ethically, own when things don't go to plan and do what we say we will
- **Quality every time** – we don't accept 'good enough' because carers deserve our very best every time
- **Speed that matters** – we are agile and don't put off what can be done today

These values represent how we engage with and serve carers, how we work with each other, and our commitment to the broader community. Carers Tasmania encourages partnerships with governments and health and community sectors to enhance service provision and improve conditions for family or friend carers through policy development, research and advocacy.

We acknowledge and support people of all genders, sexualities, cultural beliefs, and abilities and understand that carers in Tasmania, whilst sharing the common theme of caring for a family member or friend, are diverse individuals with varying beliefs, experiences, and identities. We value and respect the diversity of carers, their lived and living experiences, and recognise that carers are the experts in their own lives.

Carers Tasmania has offices in Moonah, Launceston and Burnie.

Please direct any enquiries about this report to:

Julie Ryan
Acting Chief Executive Officer
Phone: (03) 6144 3717
Email: ceo@carerstasmania.org

Contents

1. Background.....	4
2. Introduction	5
3. Overview of the consultations	7
4. The survey	8
5. Application and eligibility.....	13
6. Feedback on Local Area Coordination (LAC) and Early Childhood Partners (ECP)	16
7. PACE trial in Tasmania.....	20
8. Plan effectiveness and satisfaction.....	22
9. Management of the plan	27
10. Access to community support	32
11. The impact of funding cuts	33
12. Unmet support needs.....	34
13. Plan review process	35
14. Overall positives of the NDIS	36
15. Overall challenges of the NDIS	36
16. Early Connections	38
17. School children and the NDIS	40
18. Families and plans	40
19. The impact of the NDIS	42
20. Recommendations	50

1. Background

Carers Tasmania is the Peak Body representing the more than 80,000 informal carers within the state.

A carer is a person who provides unpaid care and support to a family member, or friend, with disability, mental ill health, a chronic or life-limiting condition, alcohol or other drug dependence, or who are frail or aged. Informal kinship carers who care for a child under the age of 18, because the parent is unable to, are also recognised as carers.

Carers are predominantly family members, but may also be friends, neighbours, or colleagues. Informal carers are not to be confused with paid support workers who are often called 'carers', with the difference being that support workers are fully employed and remunerated with all the benefits of employment. On the contrary, informal carers perform their caring duties without remuneration, other than minimal carer payments and allowances from the Australian Government.

In addition to representing carers through the Peak Body activities, Carers Tasmania provides support to carers living in Tasmania through its service delivery arm, Care2Serve. The Commonwealth Carer Gateway program is delivered through Care2Serve in Tasmania, as are other supports and services, such as the Tasmanian Government's Home and Community Care program.

The Carer Gateway program provides a range of services and supports for carers which are designed to build resilience, increase wellbeing, improve quality of life, and sustain carers to effectively continue their caring roles. The available supports include the provision of information, advice and referrals, holistic identification of carer strengths and needs through a carer support planning process, professional counselling, peer support, and coaching which aims to support carers in achieving specific goals.

Care2Serve, through the Carer Gateway, has capacity to fund certain instances of planned, practical support services such as in-home respite, personal care, domestic assistance, and meal preparation. Care2Serve may also fund items such as laptops to assist carers who are studying or trying to enter the workforce. Care2Serve also coordinates the provision of emergency support during instances where a carer may be unable to provide the care that they usually do, resulting from unexpected illness or injury of the carer.

2. Introduction

Carers Tasmania are pleased to report on the findings of engagement with carers supporting someone on the National Disability Insurance Scheme (NDIS) in Tasmania. This report shares the consultation findings, as well as the data from Carers Tasmania's third survey on the NDIS. We seek for this report to be taken into consideration by the NDIS Review Panel, and the Disability Ministers, with the hope that changes will be implemented to better support carers throughout the NDIS process as well as the people they care for.

We draw attention to the recently enacted carer recognition legislation in Tasmania, the *Carer Recognition Act 2023*,¹ which emphasises the need to recognise and value the lived experience of carers. We particularly acknowledge and thank the carers who participated in this project by taking the time to share their stories, noting that some of the experiences faced were challenging to share. We also thank the stakeholders and individuals who assisted in sharing this opportunity and the support from venues across Tasmania such as Neighbourhood/Community Houses and libraries, who play integral roles in supporting the community.

The NDIS began as a trial site in Tasmania on 1 July 2013 for people with disability aged between 15 and 24. It was then slowly rolled out across other age cohorts under 65 throughout Australia. On 18 October 2022, The Minister for Disability, The Honourable Bill Shorten, called a National Review into the NDIS, asking that an interim report be delivered to the Disability Ministers by October 2023.

Communication about the current review process has reinforced the message that the Review Team have read all the feedback previously provided about the NDIS in recent years. We reinforce throughout this paper, that now is the time to implement changes and improve processes to better support the informal carers who support many people accessing the NDIS.² Carers Tasmania, and the other State and Territory carer organisations that fall under the banner of Carers Australia, keep reporting the same challenges, with the most prominent being that carers are not routinely recognised, identified, or included in NDIS planning, despite playing the most significant role for the person they care for. It's time for this to change.

As of 31 March 2023, in Tasmania, there were 13,049 full participants of the NDIS and 151 children accessing support through Early Connections (previously known as the Early Childhood Early Intervention Service for children 0-7).³ Concerns about small numbers of children accessing Early Connections support were highlighted in our recent response to the consultation on the *Early Years Strategy*. The numbers of participants in this program are also quite low in the Australian Capital Territory (ACT), with 165 participants,⁴ and only 111 in the Northern Territory (NT).⁵ Whilst it is positive that changes are underway in extending the age of Early Connection support up until age nine, a bigger focus on linking children to early intervention support in the states with lower numbers could be beneficial. This must be paired with routine identification and referral of carers to appropriate support.

Primary Health Tasmania, states that over one quarter (26.8%) of people living in Tasmania have some form of disability.⁶ Although not all people with disability would meet the eligibility

¹ <https://www.legislation.tas.gov.au/view/whole/html/inforce/2023-04-20/act-2023-001>

² <https://www.ndisreview.gov.au/resources/video/ndis-webinar>

³ <https://www.ndis.gov.au/media/5979/download?attachment>

⁴ Ibid.

⁵ Ibid.

⁶ <https://www.primaryhealthtas.com.au/for-health-professionals/programs/disability/#:~:text=In%20Tasmania%20over%20one%20quarter,intellectual%20disability%20and%20psychosocial%20support.>

requirements for NDIS due to their age, the type of disability, the permanence, and how it impacts their life, a large proportion of people with disability may be missing out on NDIS support. For example, currently in Tasmania, there are low numbers of First Nations participants at 1,248 (9.6% of total participants), and even lower are the number of culturally and linguistically diverse participants, with 363 (2.8%) currently accessing the scheme.⁷

The major points discussed throughout this paper include:

- A need to improve carer recognition across the scope of NDIS policies and practice
- Carers must be included as key partners in planning
- A need to streamline processes to remove the barriers experienced in trying to access appropriate support
- A need for better communication between the NDIA, service providers, therapists, participants, carers, and schools
- Reducing workforce issues such as thin markets and upskilling staff

Background on Carers Tasmania's previous NDIS surveys

Carers Tasmania first conducted a survey in 2017 to understand the impacts of the NDIS. This survey received 143 responses and the results were quite varied with some survey respondents stating that they loved the scheme to others saying that they *"quite frankly hated it"*.⁸

Common themes that emerged from the 2017 survey included:

- Carers did not feel heard or included, and needed to advocate for their involvement
- There was limited availability of appropriate support
- There were significant issues with communication and processes
- There was a continued need to provide significant care, and navigate a complex system despite NDIS supports being in place
- It was time-consuming to find and access support
- A need to broaden the eligible disability guidelines was highlighted
- Forms of respite were often counterbalanced by a high administrative burden
- There was low confidence in receiving adequate high-quality support into the future

Furthermore, almost 70% of respondents indicated that nothing had directly changed for them as a result of the NDIS being in place for the person they care for. In terms of having more time for themselves, some carers reported they had less time despite having an NDIS plan in place, which was likely due to a high burden of administrative tasks.⁹

Carers Tasmania conducted a second survey in 2019, in which 122 carers participated online.¹⁰ Some carers (30%) indicated that the person they care for had begun to experience significant improvements, however, there was still much overwhelm and distress. It was evident that some respondents were still struggling with understanding aspects of the scheme, and in the more regional and remote parts of Tasmania, there were people who had funding that was unable to be used due to service and workforce limitations.¹¹

⁷ <https://www.ndis.gov.au/media/5979/download?attachment>

⁸ <https://www.carerstas.org/wp-content/uploads/2017/06/010417CTAS-NDIS-Survey-Report.pdf>

⁹ Ibid.

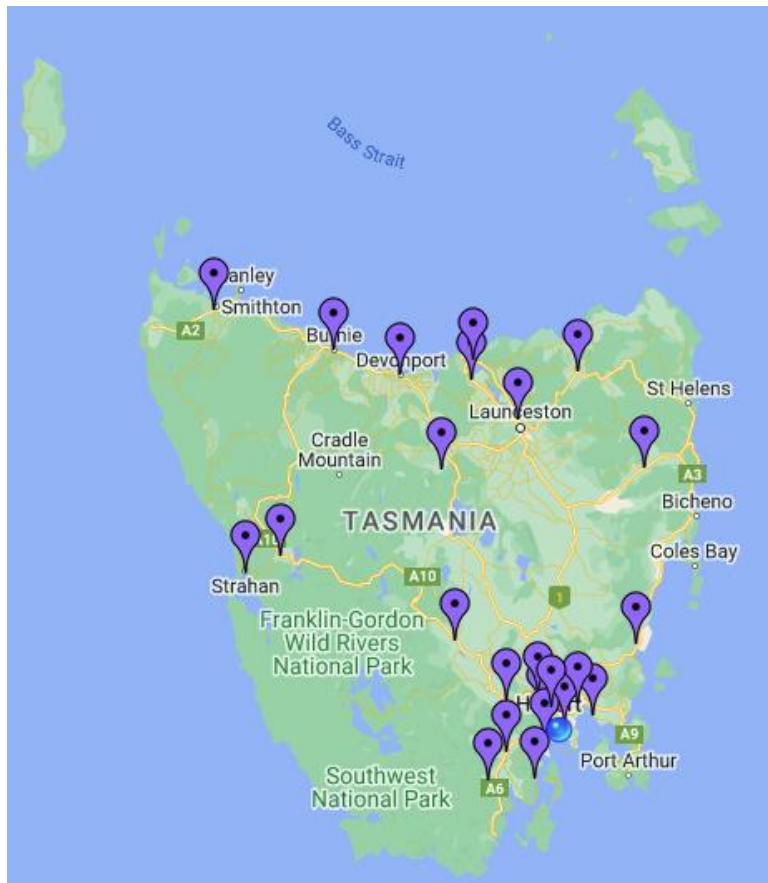
¹⁰ <https://www.carerstas.org/wp-content/uploads/2017/06/NDIS-Survey-2019-FINAL.pdf>

¹¹ Ibid.

3. Overview of the consultations

Carers Tasmania conducted 24 face-to-face group discussions across Tasmania in the early months of 2023. We aimed to cover a large geographical area so that carers had the opportunity to attend a discussion that was local to them. These sessions were primarily delivered in community or neighbourhood houses and libraries.

Group discussions were held in the following areas:



- Beaconsfield
- Burnie
- Clarendon Vale
- Devonport
- Dodges Ferry
- Fingal
- Geeveston
- George Town
- Glenorchy
- Herdsman's Cove
- Huonville
- Kingston
- Meander
- Midway Point
- Mowbray
- New Norfolk
- Ouse
- Queenstown
- Risdon Vale
- Scottsdale
- Smithton
- Strahan
- Triabunna
- Woodbridge

Figure 1: Locations of NDIS group discussions

Three online group sessions were held via Zoom, and feedback was also collected through one-on-one discussions, emails, and letters.

Throughout the process of consultation (both group and individual), Carers Tasmania engaged with and collated feedback from more than 140 carers about their experience with the NDIS. These carers were from a broad range of regions, ages, and caring circumstances and this number is in addition to the recent survey responses.

The whole process of consultation was safe, inclusive, and respectful, and carers were genuinely grateful that they had their own opportunity to share their thoughts and experiences.

Carers Tasmania invited the NDIS Review Team to participate in these consultations, however, disappointingly we received no response about this.

4. The survey

In addition to the consultations, Carers Tasmania also developed a survey (*hereafter referred to as 'the Survey'*), which allowed for both online and paper-based responses. Online responses were collected via Survey Monkey. The survey was sent to carers, shared on social media, and it was also disseminated to relevant stakeholders for distribution. Completion of the survey was voluntary.

In total, 248 online responses and 29 paper-based responses to the survey were received. After the data was cleansed for incomplete responses, 233 online, and 29 paper-based valid responses remained.

To protect privacy, the data collected from the survey was de-identified. We acknowledge that it is not representative of all carers in Tasmania, just those who participated. Due to the sample size of carers who responded to various questions, compared with the total population of carers supporting someone on the NDIS in Tasmania, the results of the survey should not be interpreted as statistically significant. It represents the experience of only those who participated. We also acknowledge that the experiences of carers will differ depending on location, age of carers, age of the people being cared for and the health and disability status of both carers and those they care for. Across Tasmania, there are low levels of literacy and digital literacy, therefore the survey results must be used in conjunction with anecdotal feedback from the consultations.

Who was providing care?

Most respondents, (217) indicated that they were currently in a caring role. 47 people indicated they were a kinship carer, and 13 people reported that they were a former carer or former kinship carer. It's important to note that some people are both carers and informal kinship carers as it is not unusual for carers to support multiple people at the same or different times.

In terms of the locations of carers, the survey asked respondents to indicate which of the four regions correlating with the Tasmanian NDIS Local Area Coordinator and Early Connections partners they live within.

The breakdown of the four regions includes:

Area	Coverage
North	Break O'Day, Dorset, Flinders, George Town, Launceston, Meander Valley, Northern Midlands, West Tamar
North West	Burnie, Central Coast, Circular Head, Devonport, Kentish, King Island, Latrobe, Waratah-Wynyard, West Coast
South East	Brighton, Clarence, Central Highlands, Derwent Valley, Glamorgan-Spring Bay, Sorell, Southern Midlands, Tasman
South West	Glenorchy, Hobart, Huon Valley, Kingborough

Table 1: Tasmanian NDIS Partner regions

The geographical breakdown of survey respondents showed good representation across the four regions. Throughout sections of the report, some responses are broken down based on location to illustrate any differences based on the region that they live in. Two respondents did not indicate where they live.

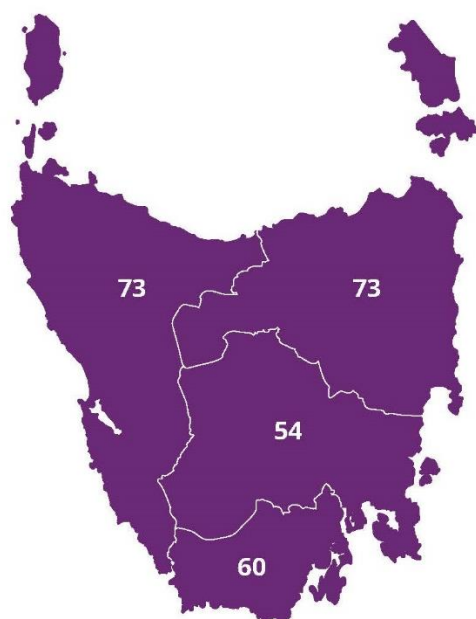


Figure 2: Survey respondent numbers across the four regions

73 valid responses were received from both the North and North West, 54 from the South East, and 60 from the South West.

A diverse range of carers responded to the survey, with the majority of people (59.4%) reporting they were aged between 35 and 64. This demonstrates that the experiences of a broad age range of carers have been captured. The survey also received a proportion of responses from young carers. Young carers are often a hidden cohort of carers, but this survey received 22 responses from young carers up to and including the age of 24.

Research shows that caring responsibilities are often impacted by gender, with a higher proportion of females generally undertaking caring roles compared to males.^{12,13} We aim to best understand and advocate on issues that present to specific groups of carers, noting that gender is quite often one of these factors. 210 respondents identified as female, 45 identified as male, two people identified as non-binary, one person reported they were transgender, and four people preferred not to answer or skipped the question.

Gender	# of respondents
Female	210
Male	45
Non-Binary	2
Transgender	1
Prefer not to answer or skipped	4

Table 2: Gender of respondents

¹² Australian Bureau of Statistics (2021) 44300DO006_2018 Disability, Ageing and Carers, Australia: Tasmania, 2018. Released at 11:30am Wednesday 5 February 2020.

¹³ <https://www.carersaustralia.com.au/wp-content/uploads/2022/04/Final-Economic-impact-income-and-retirement-Evaluate-Report-March-2022.pdf>

Within society, marginalisation of individuals and groups of people occurs due to their diverse circumstances, preferences, and needs. Being a carer often puts people at increased risk of vulnerability and disadvantage. We recognise that 'intersectionality', as coined by Kimberle Crenshaw,¹⁴ has enormous impacts on how people view and experience the world, and generally, the more categories of intersectionality a person identifies with, the more complexity and marginalisation they may experience.

More than 27 respondents indicated that they identify as LGBTIQ+, 22 respondents identified as Aboriginal or Torres Strait Islander, and 29 respondents reported that they identified as culturally or linguistically diverse.

Not surprisingly, as Tasmania has high rates of disability, ageing, mental ill health, and chronic health conditions, 62% of respondents reported they have a health concern or disability themselves despite providing care for another person. This is significant, as the health of carers is not usually considered within NDIS planning, despite the substantial impact that this can have on both carers and those being cared for. Some of the health descriptions of carers themselves included:



Figure 3: Carer self-reported health concerns

The self-reported health descriptions provided by carers raises questions about whether some of these experiences, (particularly depression, stress, anxiety, and high blood pressure) could be due to a lack of support around the caring role. We hope that consideration can be taken on how the NDIS could help improve this.

Despite their caring responsibilities, 19 respondents stated that they have an NDIS plan themselves, and three respondents indicated they were in the process of applying at the time of completing the survey. Throughout consultations, some carers indicated that they would probably be eligible to access the NDIS themselves, but they did not have the time as they were too busy supporting the person that they care for.

¹⁴ Crenshaw, Kimberle () "Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics," University of Chicago Legal Forum: Vol. 1989: Iss. 1, Article 8. Available at: <http://chicagounbound.uchicago.edu/uclf/vol1989/iss1/8>.

Who was being cared for?

71% of respondents reported they were caring for only one person with an NDIS plan, whilst 20% indicated they were caring for two people. Furthermore, eight percent were caring for three people and two respondents reported caring for four people. Lastly, one person reported they were providing care to more than four people on the NDIS. It's important to highlight that despite the low response rate of caring for multiple people on the NDIS, during consultation, many carers identified as caring for three or more people, and this in itself is a potential barrier to them having time to complete surveys. Their feedback will be discussed later in the paper, in the section on families and plans. It must also be recognised that respondents may also be providing care to other people in addition to those with an NDIS plan.

Respondents of the survey were supporting people of various ages. The largest age group of people being cared for were for those aged between 12 and 17 years. Further breakdown of the ages of people being cared for is provided below in Figure 4. There are more responses than the total number of survey respondents due to the prevalence of respondents providing care to multiple people, or supporting people who have comorbid conditions.

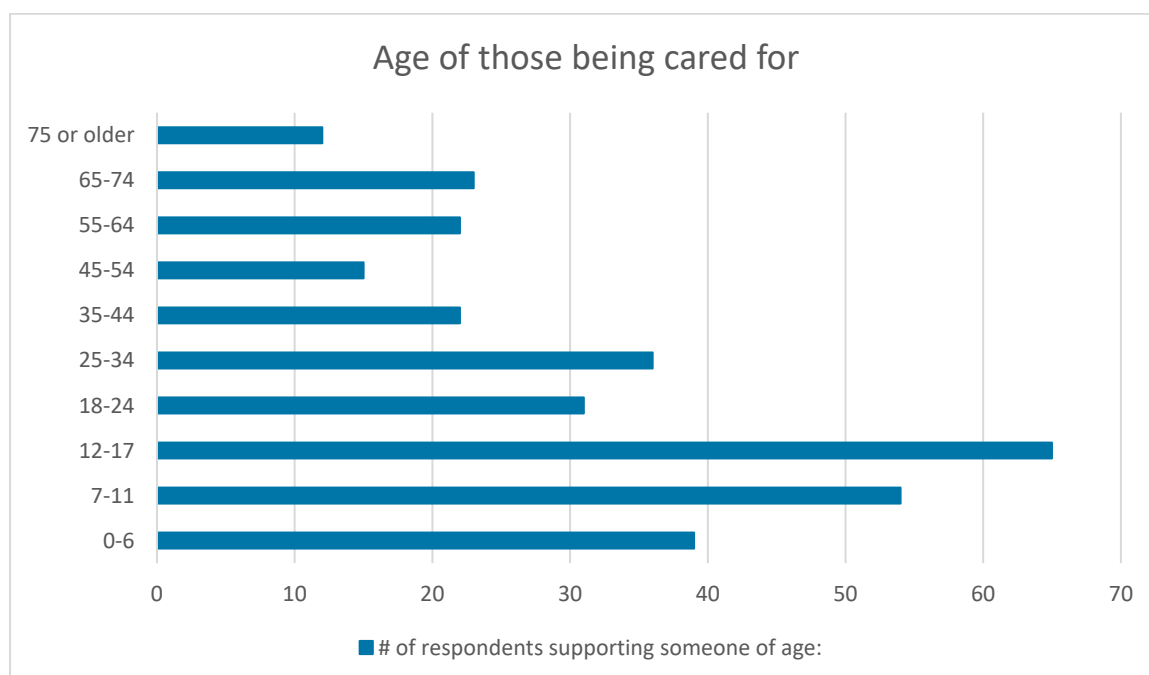


Figure 4: Age of those being cared for

We also wanted to understand the various types of disability or health concerns that carers were supporting someone with. Figure 5 shows the prevalence of disability or health conditions being cared for. The most frequently reported disability or health condition was Autism. This is not surprising as it has been estimated that there are 7,700 people living in Tasmania with Autism.¹⁵

¹⁵ <https://achievements.autismtas.org.au/wp-content/uploads/2022/10/Annual-report-29-2020-21.pdf>

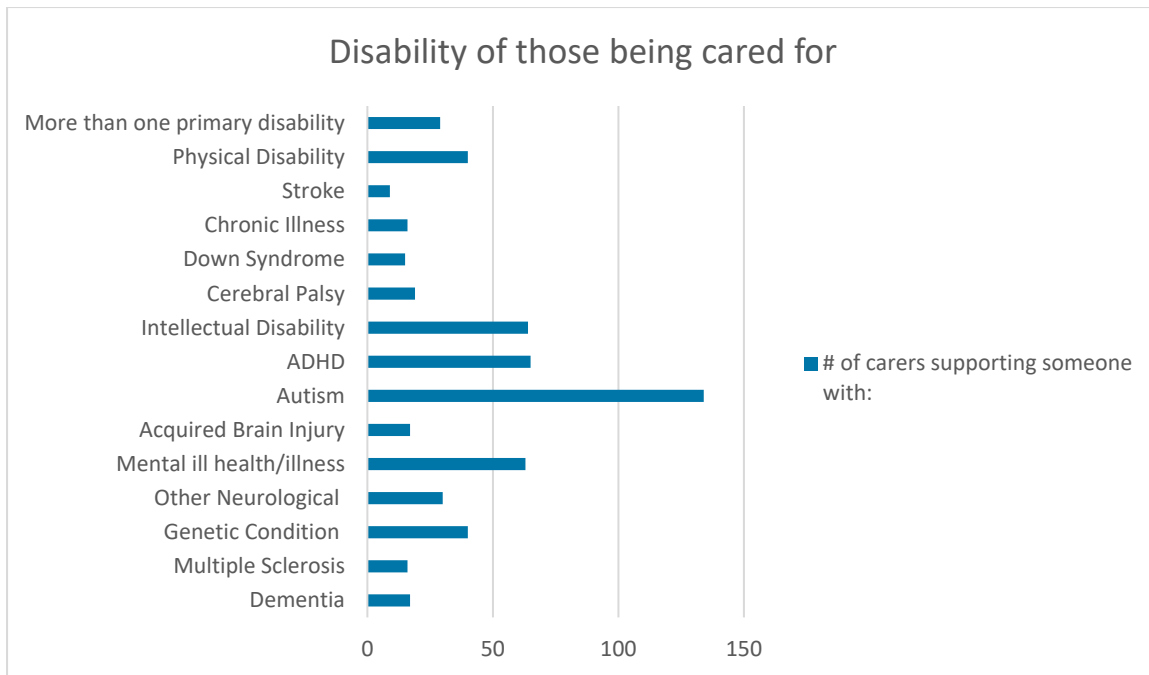


Figure 5: Disability of those being cared for

In the survey, 'other neurological' was referred to as 'other neurological such as Parkinson's, Motor Neurone Disease, Epilepsy, etc.'

Other specific health concerns or disability that respondents noted they support people with included:

- Aicardi-Goutières Syndrome
- Blindness or vision issues
- Cancer or impacts of cancer treatment
- DiGorge Syndrome
- Developmental coordination disorder
- Anxiety
- Foetal Alcohol syndrome
- Functional Neurological disorder
- Global Developmental Delay
- Oppositional Defiance Disorder
- Hearing impairment
- Huntington's Disease
- Learning Disability
- Lissencephaly
- GERD
- PCOS
- Schaff Yang Syndrome
- Speech Delay
- Tourette's
- Trauma

5. Application and eligibility

Barriers towards access

We wanted to find out how many times people were applying before being deemed eligible for the scheme. Responses from our previous NDIS surveys found that some health professionals were not aware of how to effectively word their reports to support a person to meet eligibility (e.g., not specifying that the condition was lifelong), or that they weren't correctly informed of what evidence the report would require for the client to meet eligibility requirements.¹⁶

83% of respondents reported that the person they care for only applied once before being deemed eligible for the NDIS. 11% applied twice, five percent applied three times, and one person applied more than four times.

Comments from the survey about the eligibility process included:

- *"The process is so daunting that I delayed the process for ages."*
- *"We applied once, but it took us over 20 calls and emails before it was found."*
- *"We put the application in and then were told it will not be approved as he does not have ASD, only has ADHD, anxiety, depression, ODD, PTSD."*
- *"First application was denied for all the wrong reasons. The assessor obviously had no understanding or knowledge of the applicant's condition."*

Issues were raised throughout the consultations about how difficult it can be to access the NDIS if the person requiring support has a psychosocial disability. There were concerns that people in this cohort often fall through the cracks. Carers spoke about how difficult it is to access mental health support both outside of the NDIS and also within it.

Findings from a project led by the Mental Health Council of Tasmania, in collaboration with Carers Tasmania, Flourish, and Mental Health Families and Friends Tasmania, on *Access and Affordability of Mental Health Services in Tasmania*,¹⁷ identified similar issues, with significant challenges in accessing mental health support in Tasmania, due to workforce issues, specialists who have closed books, long waiting times, and inequitable access to mental health professionals. When people who require mental health support cannot access it, regardless of whether they have NDIS funding or not, carers are often the only support available.

Recent updates on the NDIS, such as those provided by the Honourable Minister Shorten, indicate there could be changes to NDIS access for people with psychosocial disability, with comments indicating a potential reduction of approximately 27,000 people with psychosocial disability from the NDIS.¹⁸ People who have NDIS funding are already struggling to access appropriate mental health support. Additional pressure will be placed on mainstream mental health services, which is already under immense strain if people with psychosocial disability are exited from the scheme. This will also place a lot more pressure and responsibility on carers, potentially increasing the rates of mental ill health across the community.

¹⁶ <https://www.carerstas.org/wp-content/uploads/2017/06/NDIS-Survey-2019-FINAL.pdf>

¹⁷ <https://mhct.org/wp-content/uploads/2023/07/MHCT-Access-and-Affordability-Report-2.pdf>

¹⁸ https://www.abc.net.au/news/2023-06-28/psychosocial-disability-ndis-future-inclusion/102534200?mc_cid=a9f4c334cb&mc_eid=c893a4633f

Throughout consultations, concerns were raised about how currently, for people who live in Australia without permanent residency yet, if they or their child has disability, they cannot access the NDIS. They are also ineligible to receive financial support such as the Carer Payment or Carer Allowance, and they also experience barriers in obtaining or sustaining employment due to the Childcare Subsidy not being available for them. This results in not being able to pay privately for therapy or other required support. People who are not Australian citizens or permanent residents are able to access aged care support in some circumstances, and they are also not restricted from accessing support from the National Carer Gateway service. There were a lot of questions as to why eligibility rules around residency differ between Commonwealth-funded services.

Satisfaction with the application process

Most survey respondents indicated a positive level of satisfaction with the eligibility process to access the NDIS. 27% of respondents indicated they were very satisfied, and 35.4% of respondents reported they were satisfied, however, 19.1% were either dissatisfied or very dissatisfied.

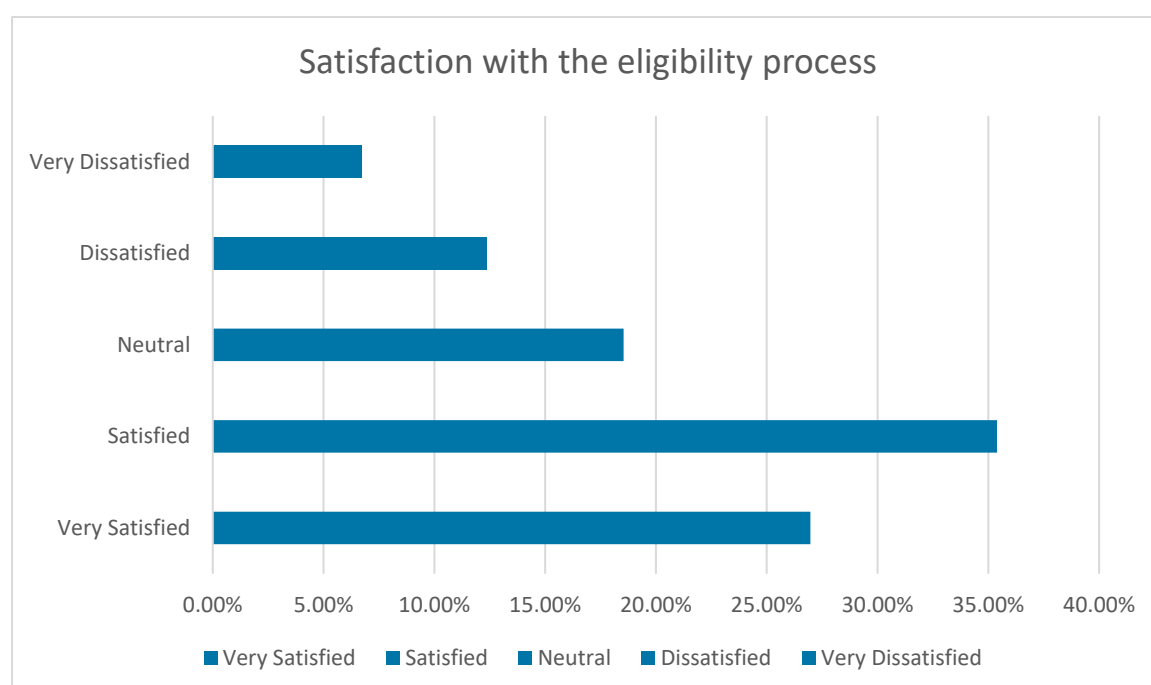


Figure 6: Satisfaction with the eligibility process

Feedback from consultations indicated that for some people, it was still quite difficult to understand how to apply for the NDIS and what they might need. Some people did not understand what support they could access to apply, or who could assist them.

Survey comments around eligibility included:

- *“The cost for acquiring the necessary documentation was difficult, as was finding the professionals to write reports using the key phrases required for the NDIS to accept the reports.”*
- *“The process is daunting. No one you speak with understands the process, this includes OT's, psychologists, support workers (unless they also live it at home like I do), support co-ordinators, local area co-ordinators. It is appalling as a carer that we have to chase up /get extremely agitated with these people to get the answers we*

need as a carer and then it takes weeks or months to get answers if we get an answer.”

- *“We were not included in the process, other than a couple of phone calls, and I was spoken to poorly by the first LAC.”*
- *“The lack of clarity for format, type, and amount of information to support applications is a problem. Some issues are not accepted and others are, there was too little clarity on what was required.”*

Accessing the evidence required for application

Within the survey and throughout the consultations, carers discussed challenges around accessing the evidence required for their applications. Comments from the survey included:

- *“We are fortunate that having a diagnosis of Down Syndrome is far less complicated than other neurodiverse, physical, or cognitive diagnosis.”*
- *“Autism diagnosis and mental health supports involve long wait lists. There are significant cost barriers. Not all (or any) services are trauma aware, and this impacts engagements. Complex circumstances can be oversimplified in the process impacting plan outcomes. Evidence may not consider the caring roles the NDIS participant engages in themselves- when an NDIS participant is also a carer”.*
- *“I am not the parent or legal guardian which creates an unnecessary barrier with agencies and trying to obtain medical history.”*
- *“Lack of knowledge and access in Tasmanian paediatric services and we needed to go private in Melbourne to access developmental paediatrician and assessment.”*
- *“The difficulty is finding the appropriate therapist in Hobart with capacity.”*

The following data is taken from the Occupational Therapy Board of Australia, for the reporting period of 01 January to 31 March 2023.¹⁹

Registration types	Registration subtypes	ACT	NSW	NT	QLD	SA	TAS	VIC	WA	No PPP	Total
General		446	7,610	238	5,860	2,264	412	7,339	3,878	315	28,362
Provisional			1		2			1	1		5
Limited	Postgrad training or supervised practice	6	62		24	9	5	49	18	16	189
	Teaching or research		1								1
Non-practising		23	210	5	156	81	7	183	137	114	916
Total		475	7,884	243	6,042	2,354	424	7,572	4,034	445	29,473*

Table 3: Registration type by location of practice

¹⁹

<https://www.ahpra.gov.au/documents/default.aspx?record=WD23%2f32755&dbid=AP&checksum=6Tx8pGBg5omifAr7c34WWg%3d%3d>

This data shows the low number of registered occupational therapists (OT's) currently practicing in Tasmania, which in total is only 412 general OT's.²⁰ Furthermore, most paediatricians in Tasmania have currently closed their books, and there are long and often costly waitlists to obtain diagnoses and support from psychologists and psychiatrists.

It is critical to highlight that some carers, particularly those supporting someone with complex mental ill health and other co-occurring diagnoses report being unsuccessful in supporting the person they care for to access the NDIS. Many reasons for this were discussed, including:

- The person being cared for does not recognise they need support.
- The person being cared for refuses to access external support and will only accept assistance from the carer.
- The condition of the person being cared for is episodic in nature.
- The person being cared for doesn't have a formal diagnosis and will not see a professional to obtain a diagnosis.
- The person is an adult and because the carer has supported them their whole life, they may have never been connected with outside support.
- The person being cared for has a diagnosis that requires significant support, however, it is not an NDIS-eligible diagnosis.
- The person being cared for is in and out of the prison system or homeless.
- There are cultural barriers that have an impact on health literacy and support-seeking behaviour.

6. Feedback on Local Area Coordination (LAC) and Early Childhood Partners (ECP)

We wanted to understand the experience of accessing support from Local Area Coordinator's (LAC's) or Early Childhood Partner (ECP's). 64% of respondents reported they had been connected to an LAC/ECP, however, 28% of respondents indicated they had not. Nine percent of respondents were unsure if they had or not.

To expand on this further, we then asked respondents if they knew how far away their closest LAC/ECP was. Under one-quarter of respondents (24.1%) indicated they lived between 5-10kms away from their nearest partner, 17.8% reported they were 11-20kms away, 12.6% reported they were 21-30kms away, and 14.4% reported they were more than 30kms away. Some respondents indicated they were unsure of how far away they were. Of the carers who were unsure about how far away their local LAC/ECP was, the highest response rate came from those in the North region (28.9%). This was followed by those from the South West (25.7%).

9.2% of respondents reported they didn't know who the NDIS partners were. These respondents were from all areas. From the South West, this percentage was 11.4%, for the Northern region this was 9.6%, for the North West this was 8.3%, and for the South East, this was 7.9%.

²⁰ Ibid.

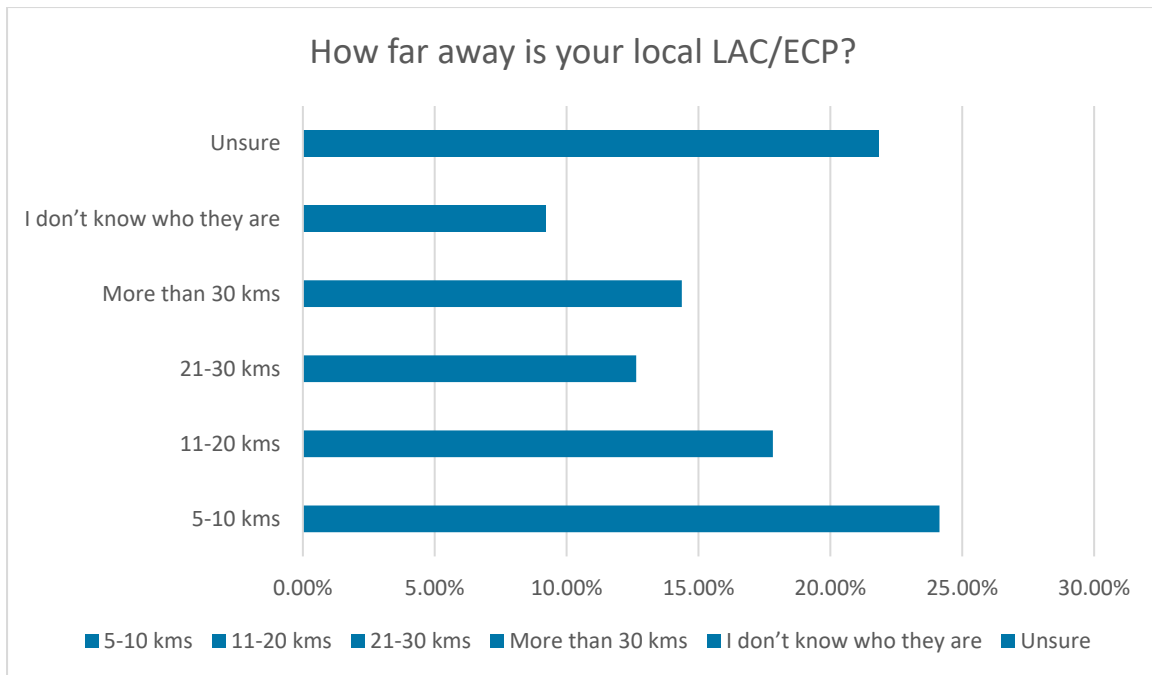


Figure 7: How far away is the local LAC or ECP?

To build on this, we aspired to better understand carers' satisfaction with their LAC/ECP. Responses showed varying levels of satisfaction, with some respondents reporting they hadn't received any support from an LAC/ECP, and some level of uncertainty about whether they were or weren't satisfied, with a neutral response rate of 14.%. Overall, 26.6% of respondents reported that they were satisfied, and 16.6% were very satisfied. A proportion of respondents indicated they were dissatisfied (15.9%) and 11.8% stated they were very dissatisfied. Figure 8 below provides further data.

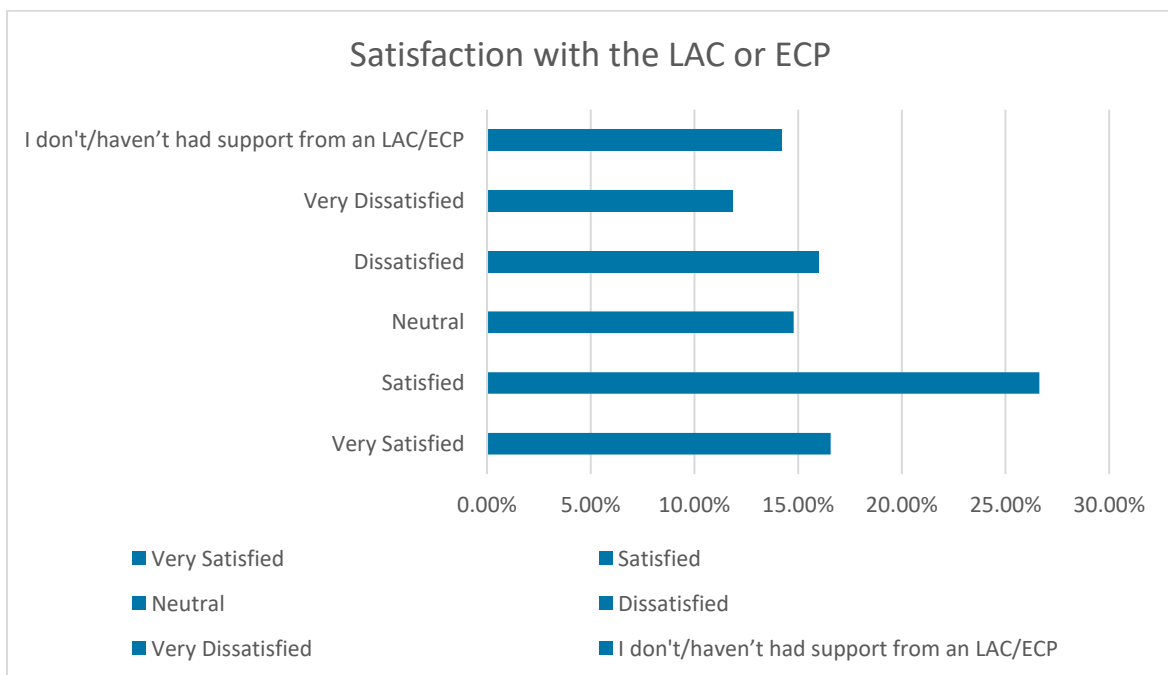


Figure 8: Satisfaction with the LAC or ECP

The following comments taken from the survey provide further insight into why some of these responses were received:

- *“Very unhappy. She hasn't contacted me since making a complaint as she would laugh at me when I explained our situation and she yelled at me the last time we spoke on the phone.”*
- *“Initial application for my eldest child, no. I didn't know who my ECEI was or plan manager was. The plan required review and I had no idea what to do or how to utilise the plan for 6 months until I moved and got support from a provider. There was an awful plan, then an unscheduled plan review. That went awfully so I asked to have the LAC changed. I now have great contact and rapport with the LAC. It took 3 years to get to somewhere close to what the professional evidence says my child needs. I'm still having to privately fund the difference.”*
- *“Never available, met my son once in 4 years.”*
- *“No idea who they are or what they're doing. Don't hear for them and I have had too many to count.”*
- *“We are onto our 4th LAC, our first was excellent. The 2 after that not so much.”*
- *“Didn't respond to my emails, phone calls, messages. I just know her name from the front cover of my daughter's NDIS plan - otherwise have no other information or contact.”*
- *“If I didn't have a good understanding of the rights of my daughter and what the NDIS is/was supposed to be I would be quite dissatisfied. Our LAC is a nice person with lived experience with disability but totally overworked....consequently has made errors in the plan.”*
- *“Our LAC was proactive, very helpful in providing information about the NDIS and the providers.”*
- *“ECEI was great, 1st LAC was useless.”*
- *“We have a brilliant LAC who is very knowledgeable and responds quickly to any concerns I have.”*
- *“Our LAC/s, plural because we haven't had the same one over the years, have always been absolutely dreadful. They act like they care, and understand but don't fight for us and when we don't receive the funding we need, they wash their hands of it and say it's out of their hands, and to ask for a plan review. Disgusting, disrespectful behaviour.”*

Carers often report that it's difficult to keep up with who does what, who they should connect with for support, and that it's frustrating and sometimes re-traumatising to repeat their story. We wanted to understand the opinions and experiences of carers on the geographical division of Tasmania's NDIS system into the four service areas.

37% of survey respondents reported that they feel the system is fine as it is, split into the four regions. 51% were unsure if they would prefer the four areas, or one provider across the whole state. 14% of respondents stated they think there should only be one provider to cover the whole state.

The following survey comments provide further context:

- *"I think the LAC should be further diversified into one per council region to better represent each region and have sufficient resources to know each applicant and fairly support their application and circumstances."*
- *"Too many, there is not any consistency with decisions from any of them."*
- *"Two support providers is confusing."*
- *"Would make it simpler if everyone was the same."*
- *"Local people know what is actually available locally."*

Throughout face-to-face consultations, many carers spoke of how confusing, and sometimes disruptive it was being divided by location. This was especially a problem for those who were renting and moved house to an area that fell under a different partner location. This meant they needed to change NDIS partners. For some carers, they may have only moved a few kilometres away, such as across to the other side of the river, but because this fell into another area, they had to change their LAC/ECP. Some carers stated that it would be easier if the NDIS partners were not assigned by location and instead fall under one banner, such as the Primary Health Network across Tasmania, Carer Gateway, and My Aged Care.

Carers also expressed concerns about constant staff turnover, particularly with reference to LAC's. Carers spoke about how they had experienced difficulty when trying to contact their LAC or ECP, and that they barely received communication from them. The overwhelming feedback from carers was that they want a trusted and consistent point of contact who knows what was going on, so that they don't have to re-tell their story or repeat processes time and time again. Carers felt that this would make a significant and positive difference.

The following case study describes the experience that a carer consented to share, in the hope that it will encourage better communication regarding LAC's, the participant, their carer and all relevant people involved in the plan.

Case Study:

Ms. H became a carer for her husband suddenly after he experienced an unexpected stroke. There were no warning signs, and he was previously fit and healthy. Prior to the stroke, her husband was working full-time and was very active. Ms. H described their initial experience with the NDIS as being thrown into the deep end. She said it was not user-friendly and difficult to manage. She recalled it being *"a stressful and tumultuous journey."*

Their first encounters with the NDIS were not positive. They had an LAC, but Ms. H was never told about support for herself as a carer. Ms. H described their first LAC as appearing to have very little training and knowledge. They kept telling her to contact the NDIA directly as they didn't have the answers she needed.

Ms. H said this significantly added to her stress. She kept calling the NDIA, left multiple messages, and spoke to about 10 people before she finally asked to speak with someone more senior. The senior staff member informed her that the current LAC should have been able to support them, and within days, they were assigned a new LAC.

It took about six weeks to get everything up and running. It was problematic at first because the initial plan was not fit for purpose.

Ms. H mentioned that trying to organise supports felt somewhat like a spider's web. She had phoned several therapists and had gotten her husband on the waitlist for them. She said it felt like being in a pinball machine trying to liaise with all of the therapists and other supports. She spoke with the LAC about this. Ms. H asked why they couldn't just have a team meeting. The LAC informed her that this wasn't standard practice, but they would try and support this to occur.

Eventually, through persistence, team meetings were implemented and there are now open communication channels between the LAC, Ms. H, her husband, support staff, and therapists. This has made an enormous difference. Ms. H said it is far less stressful to communicate and this format would also save money. Ms. H. said it feels like they have a team and a supportive, collaborative approach that works.

Ms. H said she feels like this should happen for everyone, it just makes sense and gets everyone on the same page working together. Ms. H hopes that this is something that can be considered as standard practice moving forward within NDIS plans.

7. PACE trial in Tasmania

In Tasmania, from November 2022, the PACE trial began for current and upcoming NDIS participants. PACE involved the introduction of a new computer system to replace the current Customer Relationship Management (CRM). The trial began rolling out to those accessing the NDIS for the first time, and then it was rolled out further to some existing participants. Along with the new system, changes were implemented to the application and planning processes.

The trial was evaluated, and a report '*The NDIS test in Tasmania: Insights from our evaluation*', was published on the experiences of PACE from 14 November 2022 until 31 March 2023.²¹ The report states that more than 1,600 participants from Tasmania were involved in the trial during the evaluation period., The report also notes that as part of the evaluation, the NDIA spoke with providers, NDIA staff, and NDIS partners to understand their experience with the process.²²

The report states that 400 responses to a survey were received which were completed by people with disability, participants, their family members, and carers. It also states that Tasmanian Disability Representative and Carer Organisations were partnered with to run focus groups. We highlight that disappointingly, neither Carers Tasmania as the Peak Body for carers in Tasmania, nor Care2Serve as the Tasmanian provider of the National Carer Gateway program, were contacted to specifically collaborate on these focus groups.²³ We seek for better collaboration to occur on this front in the future.

The report found that 72% of participants rated their experience with the Tasmania PACE trial as either 'good' or 'very good'. Despite this, only 31% of NDIS partners said they had enough information about the new system before the start of the trial, and only 27% said they had received helpful training on the new computer system.²⁴ Carers stressed throughout the consultations that it was really important for all involved with the NDIS to have the appropriate skills and knowledge to support people. This data is an example

²¹ <https://www.ndis.gov.au/media/5993/download?attachment>

²² Ibid.

²³ Ibid.

²⁴ Ibid.

indicating that many NDIS partner employees were not well supported prior to the rollout of this trial so that they could effectively support the participants and carers involved.

To extend on the feedback provided in the *Evaluation Report*, we wanted to understand what carers thought of the PACE trial, or if they were even aware of it. The results from our survey found that a lot of respondents were not aware of or involved in the PACE trial. 68.9% of respondents indicated they were not involved, and 19.8% reported that they were unsure. The uncertainty could be because they were not involved, or it could be that this wasn't clearly explained to them.

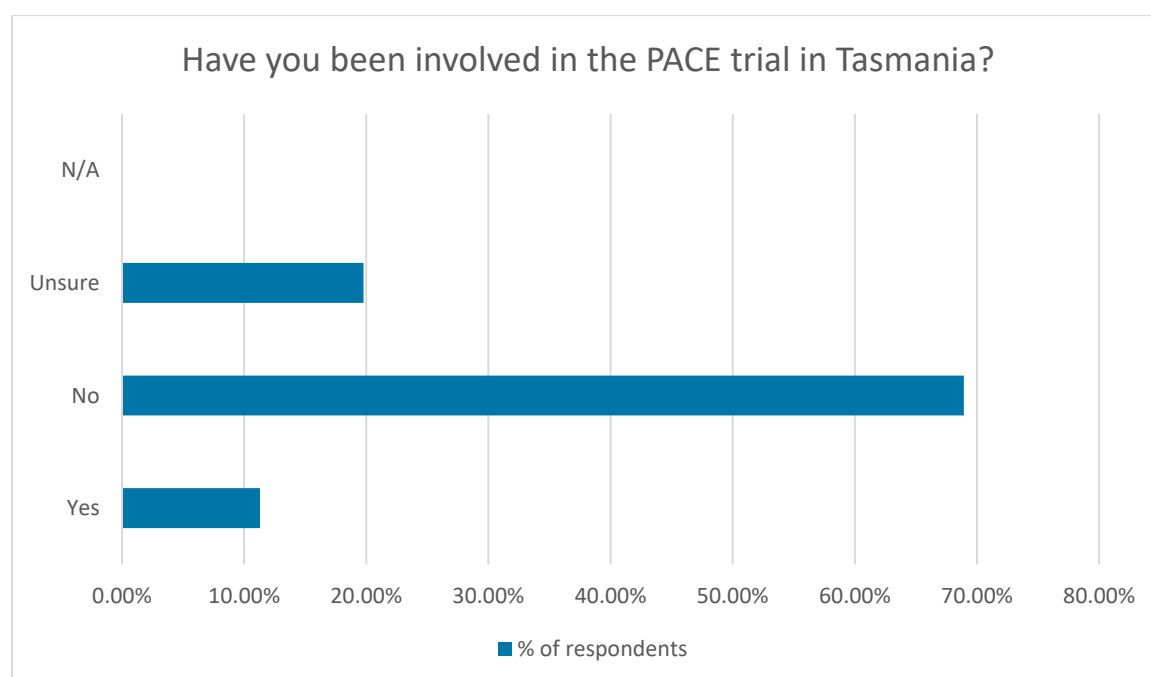


Figure 9: Involvement of the PACE trial in Tasmania

Some of the comments received via the survey regarding the PACE trial in Tasmania included:

- *"It is a lot better than the previous system, in every way. Easier to navigate, easier to see where my children's budget is at, and faster to make claims. I don't want to go back to the old system."*
- *"No idea it was even happening. The NDIS can't even change the bank details in our plan, let alone use a new system!"*
- *"This caused my youngest child to fall into a period where no prompt occurred 100 days before plan review and he ran out of funding completely as nobody was able to see the current balance. He had no access to services for 3 weeks with multiple poor outcomes occurring during that time. As such as had to go for a like-for-like plan as a temporary solution to then gain reports."*
- *"I don't want to be on this trial. It meant that the NDIA person from Canberra who contacted me in November for a move and early plan review (with plan end date in January) wasn't able to complete my review and I was put into waiting for someone trained in PACE to contact me."*
- *"Our service coordinator spoke to us about PACE and it sounds like it will work well."*
- *"The app has been a recent addition to the lodging of documents, would rather use one area. At the moment, having to use the portal and then the app to upload docs. Hopefully after the trial it will just be the app."*

8. Plan effectiveness and satisfaction

We sought to understand how satisfied carers were with the NDIS plans of those they provide care for. Our previous surveys found that carers were not routinely or consistently included in planning processes, and that only 40% of carers felt the plan would meet some of the needs of the person they were caring for. The previous surveys also found that 20% of respondents reported the plan did not meet their needs.²⁵ We aimed to compare satisfaction levels from the previous surveys to the satisfaction levels now.

The present survey found that 10% of respondents strongly agree, and 39% agree that the plan meets the needs of the person they care for. This means that overall findings from the current survey are quite similar to previous findings, showing that less than 50% of carers feel that the plan is meeting the needs of those they care for.

17% of respondents indicated that they disagree, and 9% strongly disagree that the plan meets the needs of the person they care for. This could be leading to frustration, stress, and increased responsibilities placed onto carers.

We combined the responses of strongly agree and agree, to rank satisfaction of the plan meeting needs, and then looked at this by location. Respondents from the South East of the state reported the greatest levels of satisfaction (strongly agree and agree combined at 53.5%) regarding the plan meeting the needs of the person they care for.

There are many contributing factors to this feedback. Some of the factors relate to the parameters of what plan is funded to cover, and some are a consequence of the lack of available and appropriate. A significant frustration and fear that was mentioned was that for those who had funding for certain things, if they were not actually able to access the services, then they had lost it or feared they would lose the funding for it in the next plan. Other comments we heard informed us that sometimes carers would access the reports that were required, for example from OT's as evidence that the person they care for needed a specific support or item, and then when this went for approval, it was declined, despite having specific and clear evidence from qualified professionals. Others told us that there simply was not enough funding in the plan, or that it couldn't be used for what they felt it was really needed for, therefore making the plan unsatisfactory or ineffective.

Carers spoke about how they often did not know what might be relevant to ask for, what certain things meant, and also how to ask for them. Some examples that came up in conversation during consultation included:

- *"They asked us if we wanted an OT in my daughter's plan. They didn't explain to me what an OT could assist with. I'm an older carer and I'm not up to date with some health terms. I said I didn't think we needed it. Now, a little bit down the track, I've learned that we do need an OT to assist with a few things, but I have to wait until the review to ask if we can have that funded. It would have been so helpful if they had explained this in the first instance."*
- *"Nobody ever told me, until this meeting, that we could possibly access behaviour support to assist with strategies for when my son has violent outbursts. He's getting bigger and stronger, whilst I'm getting older. We've had to call the police several times."*

²⁵ <https://www.carerstats.org/wp-content/uploads/2017/06/NDIS-Survey-2019-FINAL.pdf>

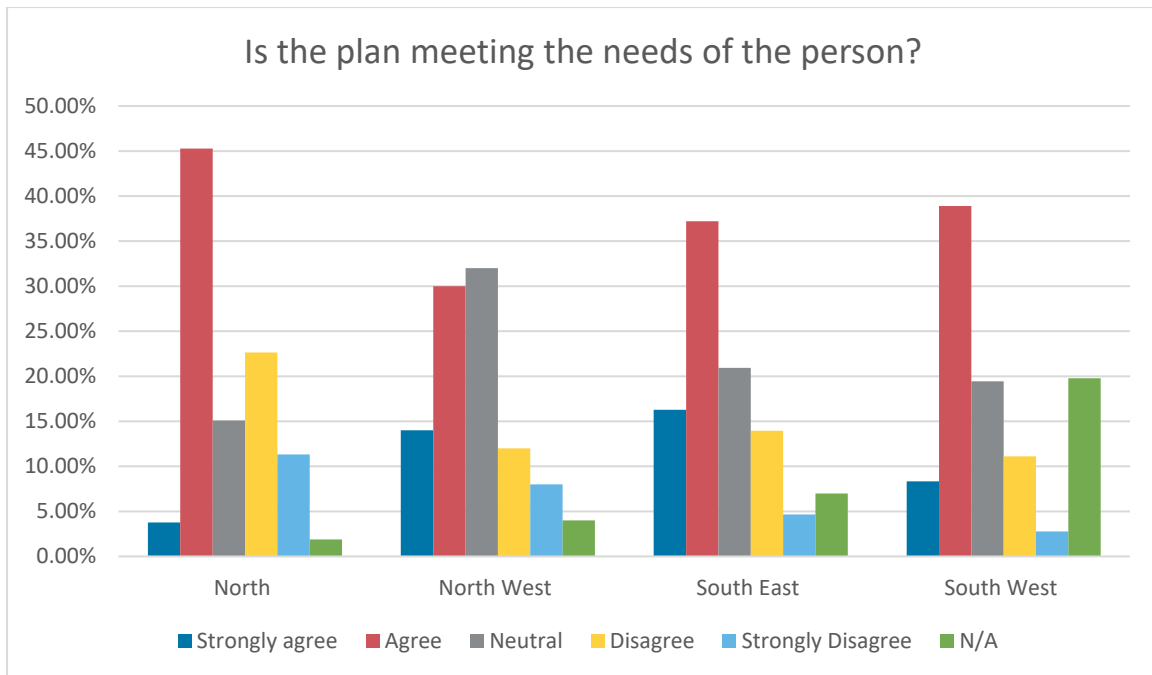


Figure 10: Is the plan meeting needs?

We wanted to understand more about the difficulty in being able to access funded services. Carers indicated during discussions that they often found it difficult to access the support funded in NDIS plans due to workforce issues.

We combined the results of strongly agree and agree and found that the region reported as most difficult to access the services funded was the Northern region, with a response rate of 64.2%. The South West was reported as the second most difficult at 63.9%. This was followed by the North West at 62%, and lastly the South East at 47.5%.

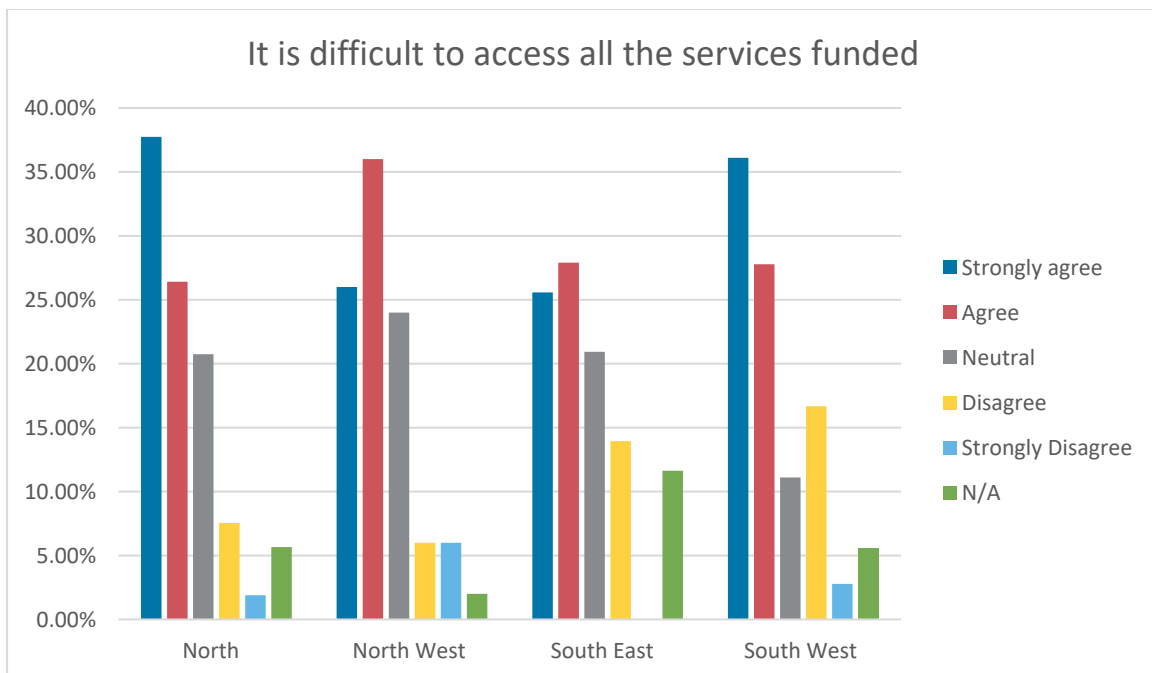


Figure 11: Difficulty of accessing what is funded

In terms of having access to a good range of local services, respondents from the South East reported the highest rate of agreement, with 35.7% of South East respondents indicating they either strongly agree or agree that there is a good range of services where they live.

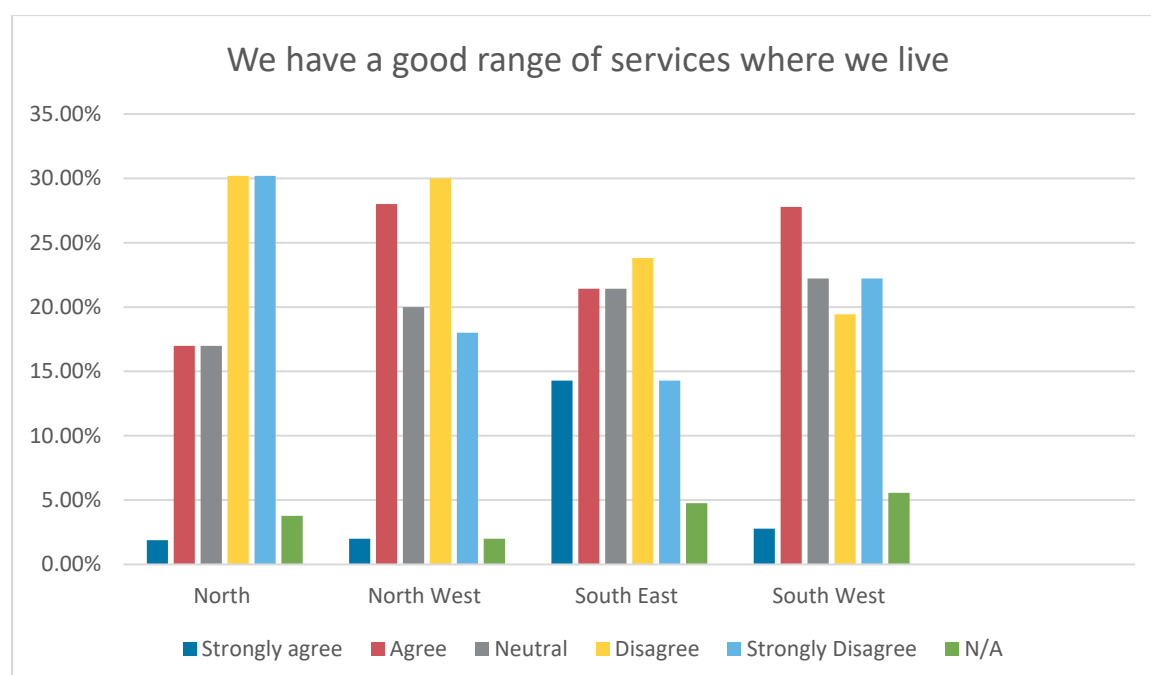


Figure 12: Are there a good range of services available locally?

Some of the overall comments around the effectiveness and satisfaction of plans included:

- *"It is so hard and too much red tape to get approval for the things the participant needs. You don't really get a say when approval is based on OT reports, my experience is always what the OT thinks, not what the participant actually needs."*
- *"Finding therapists for children has been challenging - long wait list and limited choice and whilst some have good clinical skills, their ability to engage well with children also plays a part to success of therapy sessions."*
- *"It's difficult to get a break. I do get free days but have constant phone calls from my daughter, she relies on my approval which is very hard for me to have free time."*
- *"Plan funding is appropriate however we had to fight extremely hard to get the required funding. Also equipment trials are difficult, and providers charge more than they should. A local provider quoted us \$800 for a piece of equipment, this included fitting and trials. Our child didn't require this particular piece of equipment as it was way too supportive for his needs. The provider didn't care and still wrote the report and submitted it. We travelled to Sydney, had a trial of the actual equipment that was more suitable. The cost was \$1500 for the equipment in Sydney and there was NO trial cost. NDIS want to use Key Worker Model. This does not work for children who are complex, no we have to pay to have an OT and a Physio at every appointment so our hourly appointment cost has gone from \$230 for our physio to \$430 to have both physio and our OT key worker at each appointment. It's a waste of money and means we get less therapy."*
- *"We have an excellent coordinator of services that helps us to be well coordinated. We were and have been waiting for some services for considerable time. The lack of a number of allied health professionals has made considerable difficulties in accessing services."*

- *“So many things are no longer funded and it is difficult to find the supports needed. The plan I have is unsuitable for my son.”*

Throughout consultations, many carers spoke about how difficult it sometimes is to access the necessary equipment required by the person they care for, and that there are often lengthy processes and long wait times before they receive what is needed. This seemed to be consistent across all areas of the state, with between 20% and 32.4% of survey respondents reporting that they strongly agree that there are long waitlists to access necessary equipment across the state.

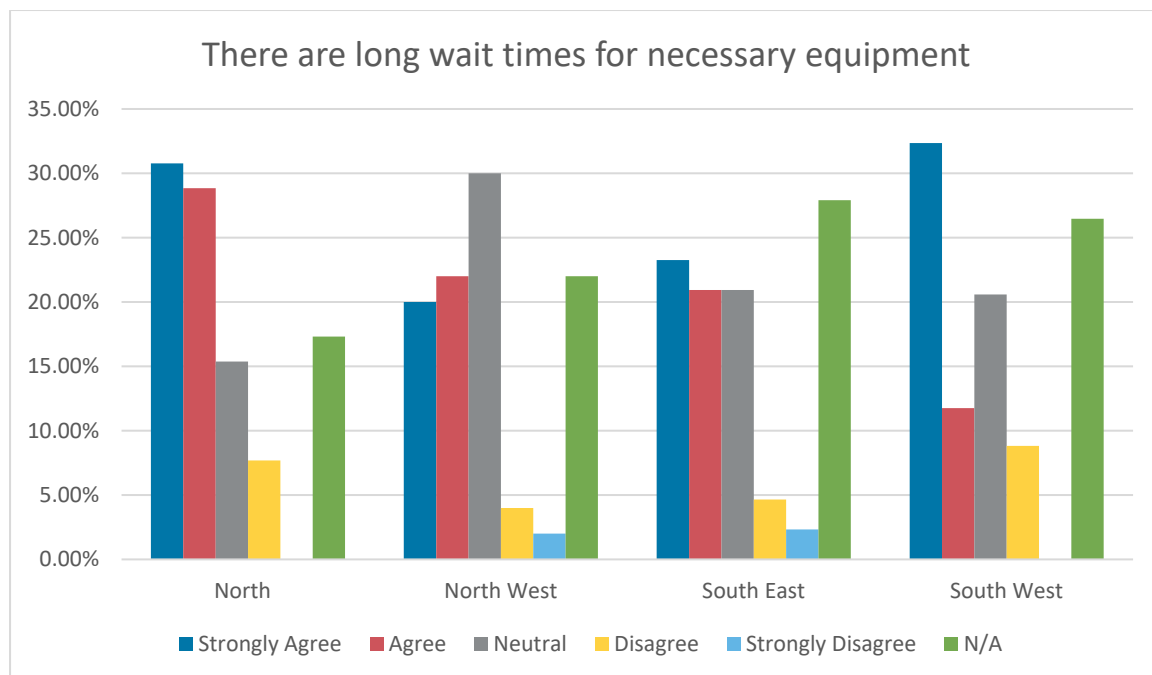


Figure 13: Long wait times for equipment

Feedback regarding service providers, their staff, and availability

The feedback provided from the consultations and the survey indicated that there were various challenges experienced when interacting with service providers and their staff. Many carers reported that they sometimes found it difficult to organise the services funded within the plan, that services are not always culturally or diversity appropriate, and that some providers charge high prices. There was also some level of ambivalence on whether the plan meets their expectations around safety and quality.

Some carers said that support workers were not encouraging and that they would sometimes just be sitting on their phones instead of trying to engage the person they were meant to be supporting in conversation or another activity. There were also some concerns shared about lack of cultural awareness, lack of a range of skills, and that there never seemed to be any interest in future planning.

- *“Unfortunately, some support workers do not seem to understand their role, e.g., overstepping the mark with things such as making decisions for my daughter when she is quite capable of doing so herself and very much wishes to do so herself. Some have been verbally abusive. Some show very little interest in their work and would be better suited to a different type of employment. Some are also unreliable.”*

- *“Living south of Kingston, support workers are hard to find who are willing to travel this far south.”*
- *“Very hard to get in to see an OT. Have had to resort to telehealth.”*
- *“The Support company only just found out that my son has an emergency management plan for his seizures. I’m not sure how that kind of information a) falls through the gaps, or b) is up to me to disseminate. He basically can’t attend any OOSHC or Vacation Care programs either due to issues with Inclusion, funding, and staffing, so we are pigeonholed to use our NDIS for Support Workers for school holidays.”*
- *“Hobart is just terrible, I can’t even imagine how bad it is in rural Tassie - waitlists are impossible, and when you finally get a spot, the staff change and you lose your time.”*

A topic that arose frequently through the consultations was that support workers often cancelled due to illness or other reasons at short notice, which is unavoidable, but sometimes there was no replacement staff member, therefore this responsibility would fall onto the carer. However, if a participant and their carer needed to change a shift, they would generally need to do so with a greater notice period, otherwise they would be charged. Some carers found this quite difficult, especially for those caring for someone who, because of their health or disability status regularly becomes unwell suddenly. In these instances, it usually meant that carers had to call in sick to work, or cancel whatever else they had planned to undertake during this time, and they lost the funds that would have covered the shift. Some carers suggested that it would be helpful to have some sort of ‘buffer’ whereby they would be able to have a discounted rate for a certain amount of cancelled shifts, before having to be charged the full fee.

Furthermore, some carers reported their concerns about reporting and administration costs using up large chunks of plan budgets, resulting in an inadequate amount being left to cover the support they really needed. Data from the survey found that 39% of respondents strongly agree and 33% agree that providers charge a high cost for their services.

Throughout consultations, there was a lot of discussion about the need for a higher level of training for support workers, including minimum standards. Carers strongly felt that there should be a minimum requirement for disability support worker training, whereby it must be mandated that all support workers have at minimum a Certificate III in Individual Support, and also undertake First Aid and Mental Health First Aid training. Other comments included the need for support workers to be skilled in understanding and practising trauma-informed care, Aboriginal and Torres Strait Islander cultural awareness training, cultural safety training, child safe training, LGBTIQ+ awareness, and training that is specific to particular health conditions. Some carers, in particular older carers, were concerned about the lack of mentoring and guidance especially to support the participant with future planning.

Only 8.8% strongly agree, and 39.6% agree that the plan meets their overall expectations around safety and quality. Furthermore, only 8.4% strongly agree and 22.4% agree that the services provided by the plan, are culturally or diversity appropriate.

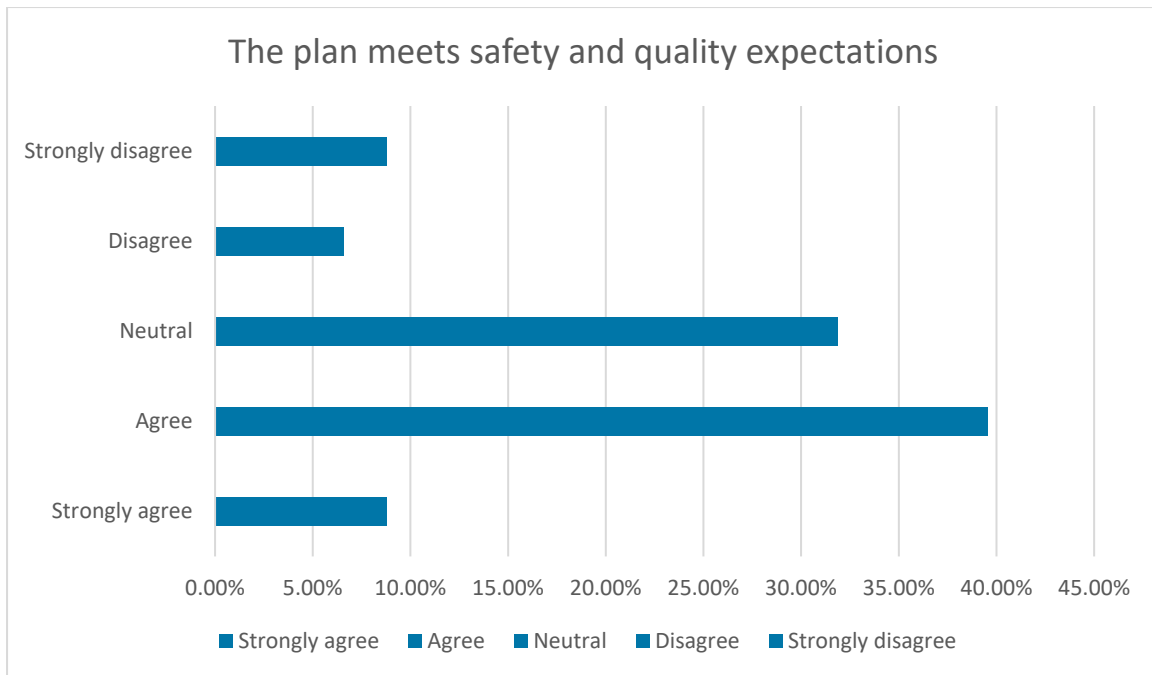


Figure 14: Does the plan meet expectations of quality and safety?

9. Management of the plan

There was some level of confusion throughout the survey and the consultations about how the NDIS plans of the people they care for were managed. Some people seemed to have a good understanding of how the plan was managed, and whether or not they had support coordination, whilst other carers were confused and unclear on what support they had in place. Some carers had a combination of different management types, some people also had support coordination, and some carers seemed as though they were struggling with very little assistance.

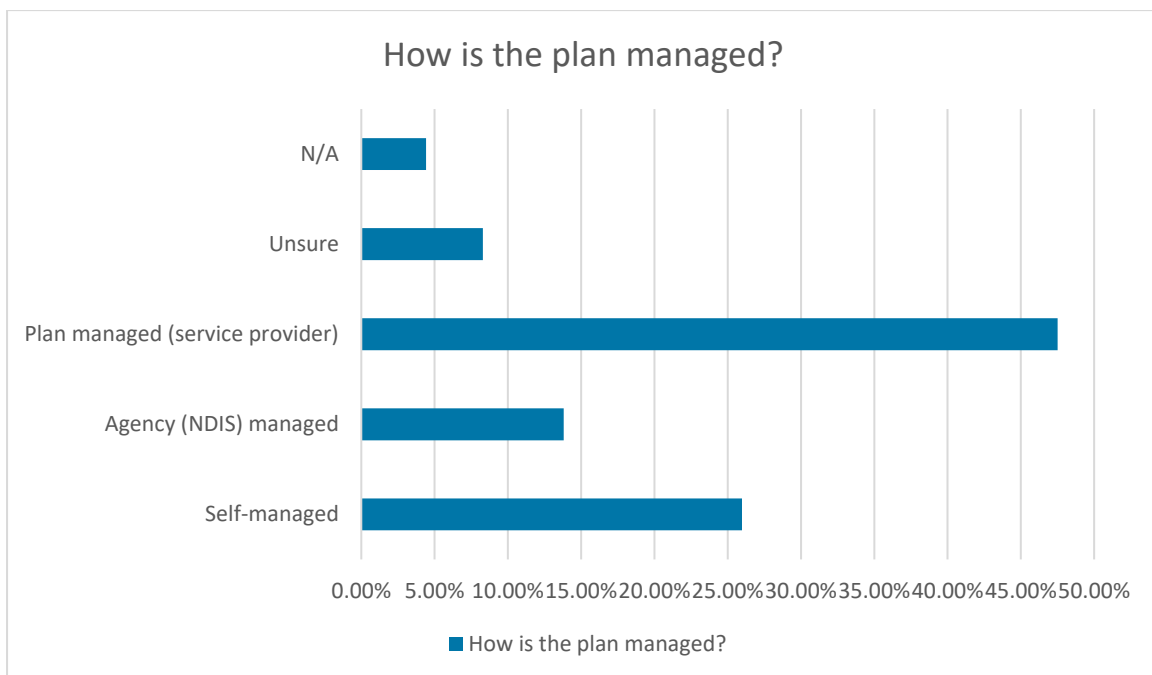


Figure 15: How is the NDIS plan managed?

Some of the specific comments around this included:

- *“Unsure if we still have someone in place.”*
- *“Confusing who is responsible for what. Also waiting for right person to help.”*

Effectiveness of self-management

Most respondents (55%) were very satisfied with being able to self-manage the NDIS plan and 25% were satisfied with this process.

The survey aimed to explore what the best things were about self-management. The following are some of the comments that were provided:

- *“I can upload accounts and pay the next day & don't lose money by using third party for something I can do myself.”*
- *“Knowing that invoices are paid promptly. Being able to confirm invoices match support provided. Not having to use registered providers provides flexibility.”*
- *“Being able to choose items at lower costs and stretch the funding further.”*
- *“Flexibility and choice.”*

The survey also asked what the most challenging things were about self-management. Some of the challenges reported were:

- *“Actually sitting down at a computer, logging on to my Gov, navigating to NDIS, entering data, uploading invoices.”*
- *“It can be time-consuming. Some providers have cumbersome invoicing procedures and make mistakes in invoicing. One provider I have to regularly check and monitor their invoicing system. They send out monthly statements and the information is not always correct. I have to provide proof of bank statement that the invoice has been paid. They seem to be slow in reconciling their payments.”*
- *“Keeping up with two self-managed plans required organisation.”*

We wanted to understand if there was anything with regards to self-management that carers would change if they could. The survey asked if something could be changed about the self-management process what would it be? Some of the comments included:

- *“Easier access to other funding sections when used all allocated funds for daily activities.”*
- *“Have the ability to update my own details, e.g. bank details, address etc.”*
- *“I need to be able to use a phone number to access the new portal instead of an email. I would also prefer to login with an email address or username instead of my NDIS number.”*
- *“Funding to help with paperwork.”*

Agency (NDIA) management of plans

The survey asked respondents to rate how satisfied they were with the NDIA managing the plan of the person they care for. Most respondents said they were satisfied (28.6%) with this arrangement. Figure 16 below shows further responses.

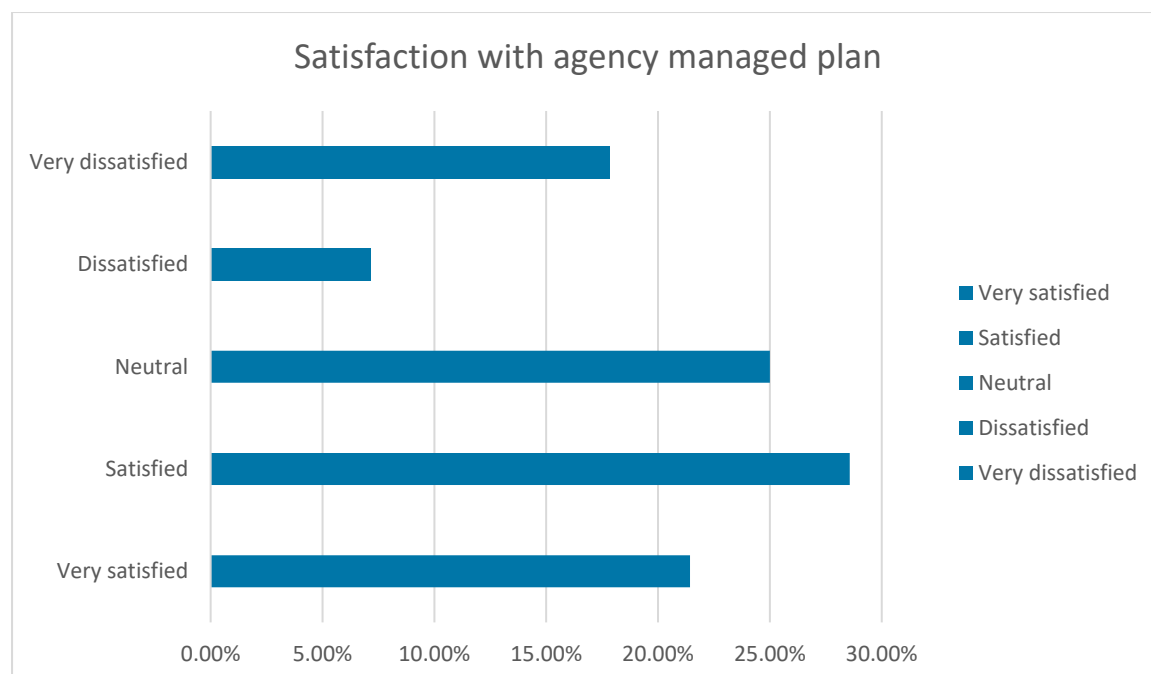


Figure 16: Satisfaction with the NDIA managing plan

To understand satisfaction levels, we asked what the best things about the NDIA managing the plan were. The following comments were received:

- *“Virtually stress-free for me. Receipts etc all go to NDIA.”*
- *“Providers can invoice the agency directly, less for me to do.”*

We also asked what the most challenging things about NDIA management of the plan were. The following comments provide more detail:

- *“They're strangers, they don't look at the bigger picture of what our everyday lives are like & they certainly have their own minds made up about your funding before you walk in the door.”*
- *“Bureaucracy”*
- *“Accessing a customer services officer and getting the plan reviewed in a timely manner.”*
- *“Having to chase them up for replies etc.”*
- *I wish we could speak to someone face to face in my home state (Tasmania) instead of a know it all from Queensland who doesn't listen to the medical experts and thinks making a plan with a dementia patient directly is a good idea.*

Plan management (managed by a service provider)

We wanted to understand whether respondents were satisfied with having a service provider manage their plan. Most respondents indicated they were very satisfied (22.2%) with a service provider managing the plan, and 36.1% of respondents reported they were satisfied with this type of plan management.



Figure 17: Satisfaction with a service provider managing the plan

We asked carers what they felt were the best things about having a service provider manage the NDIS plan. The following comments were received:

- *"Working together with industry specialists."*
- *"Flexibility with providers. Plan managers pay the invoices."*
- *"That other people do the paying and organising so I can focus on my daughter."*
- *"Having help navigating the ridiculous rules and guideline interpretations."*
- *"Having someone who knows about what services are available and how to access them."*
- *"One less thing I need to do as I have enough on my plate."*
- *"Simply not having to put invoices through due to how busy life is with 2 children that require daily care and therapy (so there would be a lot of invoices)."*

We wanted to understand some of the challenges people experience with having a service provider manage the plan:

- *"Being only told no, no, no, no."*
- *"The provider books ahead for the whole year. This doesn't give flexibility or choice if my son needs those funds to access another service for particular needs. The provider makes it difficult to cancel the bookings and release the funds."*
- *"Still waiting on one bill to be paid 60 days overdue."*
- *"Staff changes, lack of communication, denial of fair goal-related purchases."*

We asked what people would change about plan management, and the following comments were received:

- *“Ensure there are local plan managers.”*
- *“I’m currently happy and there are no changes needed.”*
- *“That I was not spoken to like someone that doesn’t know what I’m talking about when I’m the one telling them how it should work.”*
- *“To be heard & respected, to have a plan manager who actually helps or at least attempts to try.”*
- *“More forthcoming with local options for participants and their individual needs.”*

Support coordination

More than half (55%) of carers indicated that support coordination was supported in the plan, but 18% of respondents indicated that they were unsure if they had this service or not. During consultation discussions, some carers did not know what this was. According to the NDIA, support coordination helps people to make the best use of their plans and it is funded as a capacity-building support to assist with:

- Understanding and using the NDIS plan to pursue goals.
- Connect participants with NDIS providers, community, mainstream, and other government services.
- Build confidence and skills to use and coordinate supports.²⁶

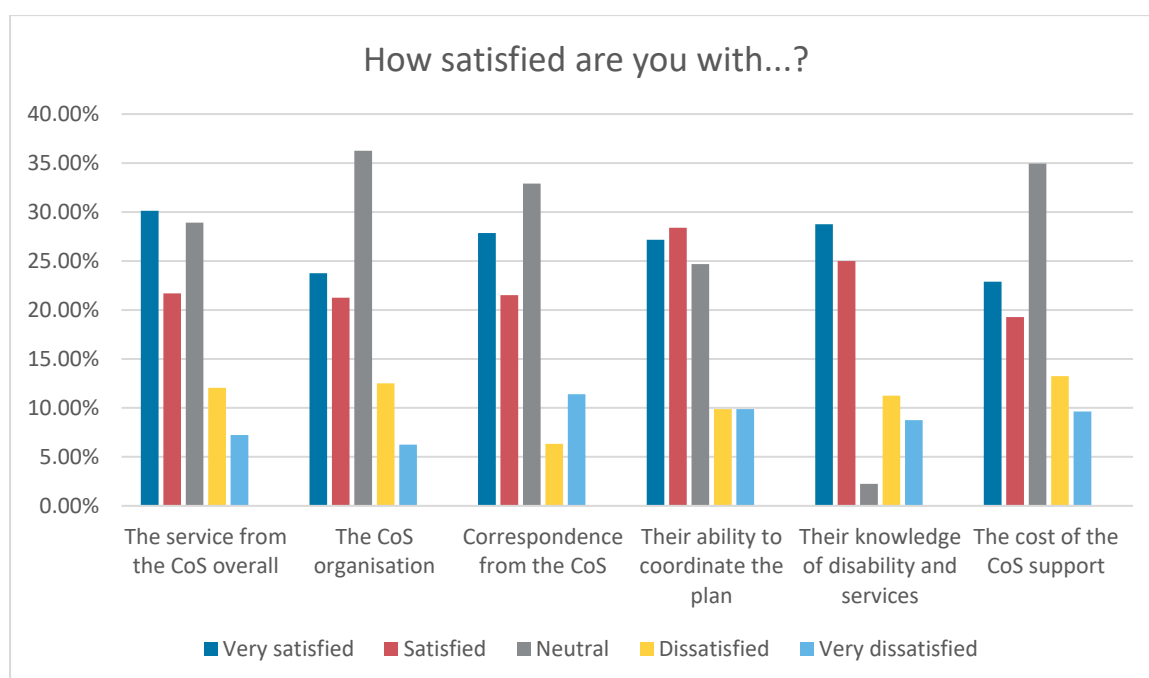


Figure 18: Satisfaction with aspects of support coordination

Comments show that support coordination can be helpful, and for some, it is very much needed.

- *“We had the co-ordination of supports defunded which left me in my 60s to care for my son in his late 20s and my 90-year-old mother.”*
- *“I don’t know what I don’t know, I rely on the CoS to know stuff.”*

²⁶ <https://www.ndis.gov.au/participants/using-your-plan/who-can-help-start-your-plan/support-coordination>

- *“They have been fabulous. Just limited by time (funding available in our plan).”*
- *“Every carer should have access to a CoS.”*
- *“Our support coordinator is based in Sydney with MS. She has great knowledge of everything NDIA as she was one of the staff that started it from the beginning 2013. We were lucky to get her..”*
- *“Have our Support Coordinators have smaller case loads and give them extra funding for the plan reviews as they're more aware of what supported is required for the clients and able to advocate for it.”*

Throughout discussions, some carers spoke about how initially they did not know support coordination was an option and that they had only learned about it later on from friends, other carers, or from support organisations. Some carers mentioned they were worried about losing support coordination and that they may not be able to effectively coordinate the plan without it. Some carers also spoke about how because of their own age, disability, or health status, they really need this support, and they don't know how they would manage without it.

10. Access to community support

We wanted to find out if people were connected to community support outside of their NDIS plan. Most people (56%) reported that the person they cared for was not.

- Some of the comments around this were:
- *“School”*
- *“My husband takes my independent special needs adult child out to the community as is her community access.”*
- *“We are involved in some ‘Free’ clubs - Badminton Group and dance school.”*
- *“Other supports in the community have now been dismantled so NDIS model is the only way to access supports publicly.”*
- *“Yes, he is connected through ECEIS supporting him to transition to kinder next year he is also supported through Inclusion Support at childcare.”*
- *“I do this myself.”*
- *“The NDIS doesn't seem to consider under 18's support needs. They don't seem to prioritise funding or early reviews for adolescents and they put a lot back onto the parents/carers. Carers deserve a life as well.”*

Many people are not eligible to access the NDIS, and for these people, the support available or accessible outside of the NDIS may be very limited. Throughout consultation discussions, we heard from some carers supporting people with diagnoses that were NDIS ineligible, but they did not have the resources to fund the supports they required.

11. The impact of funding cuts

Some carers reported significant funding cuts to the plans of those they care for. Some cuts were experienced to services such as psychology, with reasons provided stating that it can be covered by the Better Access Program. The Better Access Program has seen the number of sessions available for rebate cut from 20 to 10. Some carers reported fear about reviews, thinking that plan funding will be slashed. Others expressed concerns about not being able to use allocated funds by review time (because of lack of available services) and that they were fearful they would lose it if they couldn't use it within the timeframe. Some of the specific comments that we received about this in the survey included:

- *"Funds were halved in the last review."*
- *"Transport allowance was cut. stopping participant from accessing supports and community. Advised by NDIS to pay support worker to transport participant which costs more than transport allowance- but, oh well, planners know best."*
- *"The reasons given for funding cuts have been that our son is getting older so they just cut hours for therapy. Not entirely sure that reason is valid."*
- *"Funding cuts are never discussed prior to the plan being approved. We just got the new plan, and funding has been cut by 70% with NO warning or explanation. Even though new evidence for the following 12 months has been provided to support a renewal of funding at the same level. This isn't for a request for additional funding. Then it takes 8 months for the RORD to be assigned, then 3 months for a decision to be made - all the while my son sits with no support. Then due to not being able to attend therapies because funding has been cut for no reason, the therapists kick you off their list. Then when the funding is finally reinstated 11 months later, it's a 1-2 year wait list to re-engage with the therapists due to the shortage of therapists. So my son sits with no therapies regressing for 2 years, costing NDIS more in the end. Just when you thought the system couldn't get any better, you remember that right back at the very start NDIS paid thousands of dollars for the qualified therapist/specialists to write the reports for the plan review, just for an unqualified person to disagree with the qualified people and pull 70% of funding."*
- *"Things being taken off the list of items that were once previously funded such as swimming lessons, regulation, and sensory items."*

Case Study:

Ms. P provides sole care for four children. Three of these children have NDIS plans.

One of her children, Miss L is 20 years old. Miss L has an intellectual disability, as well as Epilepsy and Sotos Syndrome which causes physical issues including poor muscle tone. Miss L had some funding for personal training approved in her NDIS plan after it was recommended by one of her specialists. She was able to access some specialised personal training at a local gym. She found it really beneficial.

Participating in sessions with a qualified trainer was increasing her self-confidence and self-awareness, building her social skills, and was alleviating some of the issues she experienced with muscle weakness. It was working well as a preventative measure.

Suddenly they were informed that the funding for this had been cut and that they would no longer be able to access this service. This was very upsetting and distressing and they took it to the AAT to be appealed, however, it was resolved prior to meeting with the tribunal.

12. Unmet support needs

Most people indicated that there were still things they wished the NDIS plan could fund, with 44% of respondents indicating that they strongly agree and 28% reporting that they agree.

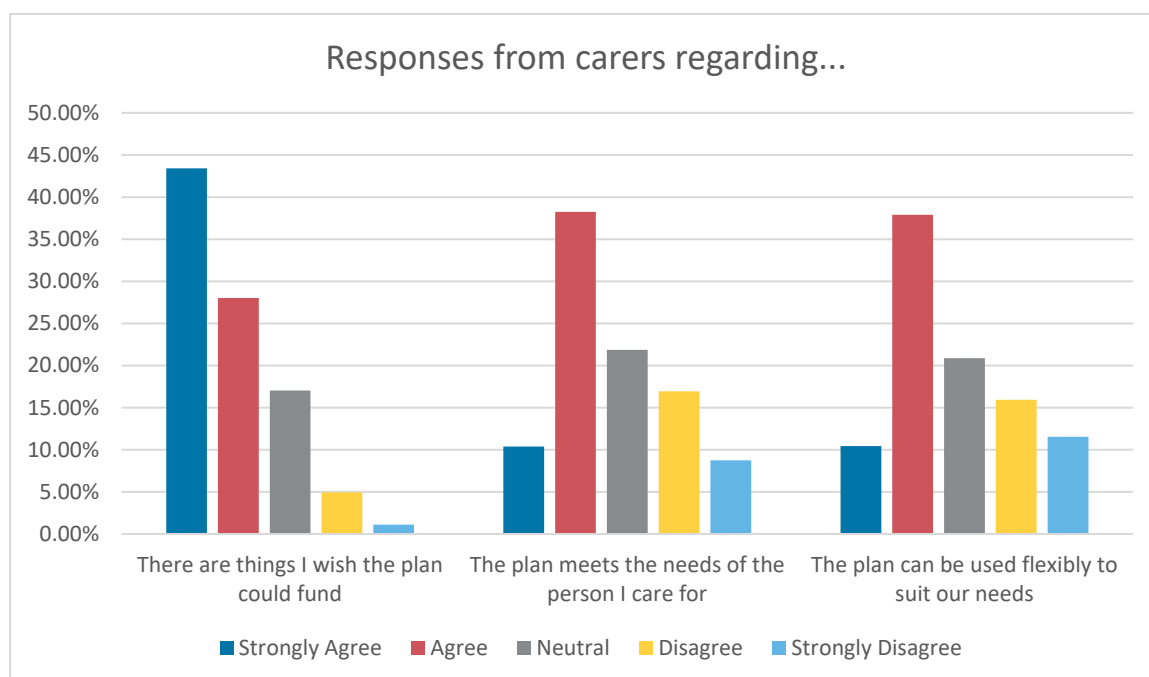


Figure 19: Gaps in needed support

- “Access to a cleaner for my daughter's unit as she is unable to do the job thoroughly herself. I must constantly 'fill in the gaps' (of which there are many). A mentor.”
- “Respite hours for parents who are in the caring role. Some funding for education purposes - for parents to attend sessions related to the disability of their child so we can better understand and help them. Some practical help to the whole family - such as light cleaning, and gardening.”
- “Someone who actually read the final medical summary by the OT.”
- “A cleaner, more support hours, a mentor.”
- “Equipment such as all-terrain chairs etc”
- “The plan is a joke. Nothing has been done apart from incontinence aids in the past 2 years.”
- “Domestic assistance to sustain the viability of informal supports, respite care, a support worker for my son to build independence and engage in the same activities as same-aged children.”
- “The out-of-pocket expenses for: diagnosis gap payments sufficient support coordination supports for us as young carers to achieve normal life like learning skills or attending activities where in other families the parents could teach those skills or participate in those activities.”
- “We have just gone through the tribunal to fix funding and were still denied funding for Music Therapy as it is seen as doubling up.”
- “Cleaning help around the house. My 10yo daughter is incontinent, dribbles, is clumsy with eating due to control and concentration and leaves plenty of mess. She would also constantly draw on walls, tip water, and empty out contents of pantry and bathroom cupboards. I am cleaning and scrubbing daily (and have 3 other children to care for), but my request for a few hours of help weekly has been denied.”

- *“Psychology is difficult. We have been told we need to go through our GP for a health care plan first, but that is more time-consuming and not all mental health care professionals are covered by that.”*
- *“Recognition/funding of my son’s certified qualified assistance dog.”*
- *“My daughter (who has the plan) has had a baby nothing supports this. Support workers are unable to take the baby in the car.”*
- *“Yes, swimming lessons, trampoline, support worker, regulation and sensory items such as compression sheets, vests, and other items.”*
- *“We will need home and car modifications but are really hesitant based on how long a simple wheelchair has taken.”*
- *“The out-of-pocket expenses for diagnosis, gap payments, sufficient support coordination supports for us as young carers to achieve normal life like learning skills or attending activities where in other families the parents could teach those skills or participate in those activities.”*

13. Plan review process

Throughout the discussions, many carers spoke of experiencing difficulty and anxiety around NDIS plan review processes. Carers were really concerned about review processes taking a long time, or running out of funding before their review was due, and the significant impacts this has. If there isn’t adequate funding, then services can’t go ahead. Without access to these services, often all of the previous hard work, particularly that of a therapeutic nature can come undone, and then people actually decline rather than progress. This places significant stress not only on the carer, but also to those being cared for.

- *“Have just had a plan review after my son’s first 12 months of living in supported accommodation, and funding has been cut in half, putting my son and his carers at risk. Some information quoted about my son was totally inaccurate.”*
- *“After our first plan, my son’s funding was considerably cut so time and brain space I didn’t have had to be used for a plan review.”*
- *“We had at least \$14,000 taken off our plan when we went for review and I am disgusted with the service we have received.”*
- *“The stress of every plan review, losing funding, fighting to get it back, sitting without supports for months and months waiting for decisions etc. is by far the most stressful part of my life. In fact, I am now on antidepressants because of it.”*

Emergency situations

Carers expressed their concerns during consultations about the fact that they are not able to access unexpected support quickly through the NDIS. Many carers felt like there was no support for unexpected or emergency situations which are bound to happen. Carers strongly felt that there should be a simple process in place to enable them to access emergency support promptly when needed.

- *“I have had to fund significant items that were required but were just too urgent to go through the bother of reports and explanations of need that should have been obvious. Security concerns such as fencing and glass replacement with safety glass were a struggle, I funded the fence and only after 3 broken windows and a trip to hospital were we able to get some funding for window replacement.”*

14. Overall positives of the NDIS

There were many comments provided about the positive aspects of the NDIS. Some of these included:

- *"The people you connect with who genuinely care for the participant."*
- *"Funding for a range of help including activities, which previously did not exist."*
- *"Having an allied health team, OT, speech and psychologist."*
- *"The support that it provides for people with disability."*
- *"NDIS funding for our children has allowed them to access therapies and support that my husband and I would not have been able to afford to pay for privately."*
- *"My young person can live in a supported living arrangement without me working two jobs."*
- *My daughter is living her dream living independently with her dog ,just wonderful for her*
- *"The access it gives my son to early intervention, helping him build long term skills. The access to vital equipment my son needs to be able to be included. Not having the additional financial stress of having to fund all of this ourselves."*
- *"Not having to pay for all the OT and speech and behavioural - I mean there are no words for how grateful I am. Truly."*
- *"My person can have a better life and access to supports that we would not be able to afford."*
- *"Access to services we couldn't afford, having support we hadn't received for over a decade. Knowing I'm doing everything in my power to support my child."*

15. Overall challenges of the NDIS

Comments from carers on the challenging or negative aspects of the NDIS:

- *"The ongoing assessments. Centralised NDIS assessors/ those who approve the funding. We struggle to have the assurance that this young adult won't receive the necessary adequate support that we believe this young adult requires, once we are unable to keep providing the core and support, either through ill health or death."*
- *"The bureaucracy. The endless, repetitious paperwork, trying to find a suitable worker with some of the knowledge required plus a positive attitude."*
- *"When you have a change of circumstances and need extra funding."*
- *"Inconsistency. Sometimes help is according to talent and experience."*
- *"The wait times for equipment to be approved."*
- *"Watching various businesses leach extraordinary money out of the government."*
- *"The inconsistency of information regarding what is able to be paid for with NDIS funding. Also, dealing with LAC's who are unsupportive, overstep their job responsibilities and who don't take the time to get an insight into the life of the PWD before making their recommendations on what supports are 'reasonable and necessary'. The readiness of NDIA to assert that supports necessary for a child participant are parental responsibility when parents of children without a disability do not require the same amount of support from their parents - for example, no parents of my 8 year old son's same aged friends are still bathing, toileting and dressing their children but we are expected to provide this support multiple times daily without assistance because NDIA claim it is 'parental responsibility'."*
- *"The cost of service providers as they eat up the NDIS money."*

- *"Keeping on top of all the administration - paperwork, invoicing, organising the logistics around multiple appointments every week and transport to get to them."*
- *"Communication, red tape, plan reviews, again communication...and mistakes made by planners who approve the plans, which Carers have to "pay for" in the way of time, stress, mental load and emotional energy...all of which we have a very limited supply of."*
- *"My son not meeting requirements with ADHD even though it clearly impacts development of him and he will be worse off without continued NDIS support."*
- *"Not having access to enough services where we live and having to travel interstate to get the support he requires."*
- *"As per the last plan, dealing with an office in Perth, for a person on the NW Coast of Tasmania. They had no idea of what was available here !!!!"*
- *"Non-communication, no empathy, bad service, overloaded workers"*
- *"The waiting times for it to be finalised."*
- *"Paperwork, fighting for more help and trying to keep what currently have, getting appointments with specialists."*
- *"The diagnostic element of the NDIS is clearly buckling under the demand, and is burning out clinicians who, in many cases, are spending all their work hours JUST doing report-writing. Appeals seem to go unanswered for long periods of time, after which the appeals are no longer relevant, and time is then spent gathering evidence, appeal submitted, etc. It's enough to make you lose your mind. I'm sorry, but it's true."*
- *"Knowing what is funded and what isn't, understanding the plan and what it actually provides, accessing what he needs, having the most important therapies listed and funded appropriately. Having the plan reviewed is not easy."*
- *"Fighting and dealing with the NDIS over funding disputes for things that are needed."*
- *"The uncertainty about what to ask for, what's available and the time takes to navigate services. Being unable to contact the NDIS contact listed or NDIS via anything but phone."*
- *"Not having enough services in Tas."*
- *"It's extremely stressful to fight for what your child needs to then have it not delivered when you provide evidence from professionals. Still a constant fight and stress. LAC is useless and doesn't help a lot."*
- *"Never, not even once, has the NDIS (LAC) asked how I am, if there's anything I need, or how can I be supported to continue caring for my children. There's no care or consideration for the carer. Respite for the carer is a forbidden concept when dealing with NDIS. God help you if those words are mentioned in the request for any support for a participant. That's an automatic NO. Finally, we are given funding for our children to build capacity, attend therapies, access the community e.t.c but there's no consideration of how the carer (me) will wave my magic wand and make it all happen, when I have multiple children with NDIS funding."*

16. Early Connections

We note there are changes underway to the support provided through Early Connections and that the ages of eligibility for this service is being extended up until the age of nine, rather than previously seven years old.

Only a small number of survey respondents answered the questions about Early Connections supports. As mentioned earlier in this report, this is most likely because there is only a small proportion of children (151) as of 31 March 2023, in Tasmania currently accessing this service.²⁷ We also included a response about this in our recent submission on the Early Years Discussion Paper.²⁸

Of these respondents there was a mixture of results regarding the satisfaction with the process to accessing early intervention supports. Overall, 55.6% of respondents indicated that they were either 'very satisfied' or 'satisfied' with the process to access Early Connections support.

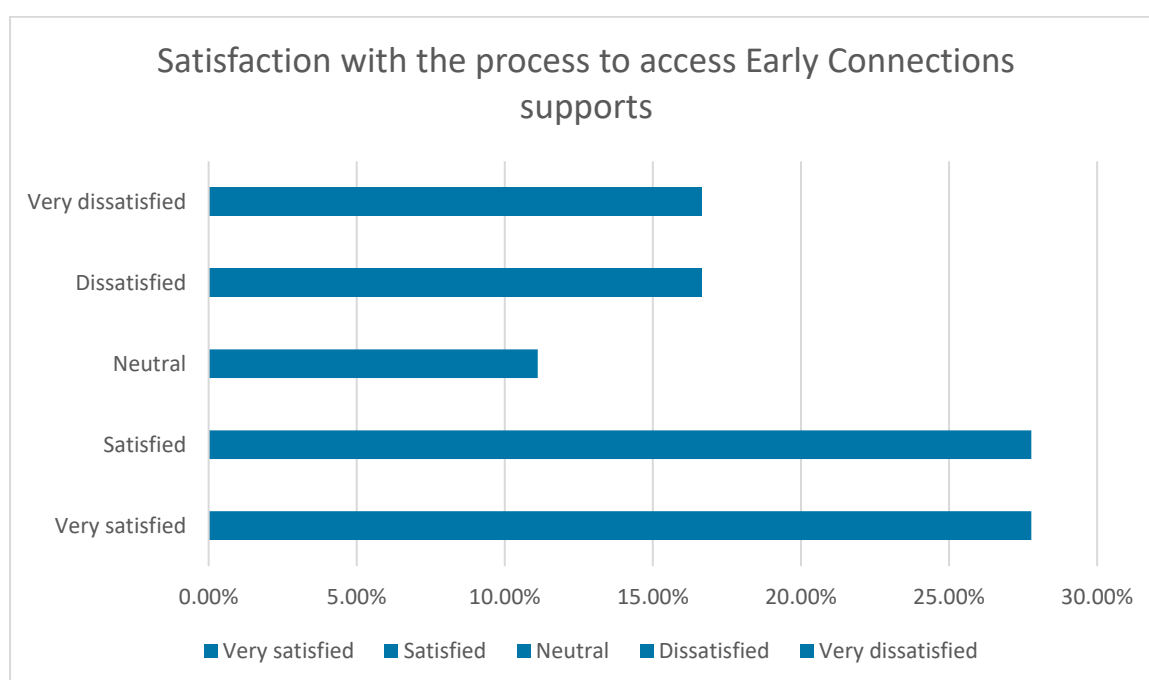


Figure 20: Satisfaction with access to Early Connections

Most respondents indicated that they were satisfied with the support their child is receiving through Early Connections supports, with 61.1% of respondents reporting that they were either very satisfied or satisfied with the Early Connections support.

²⁷ <https://www.ndis.gov.au/about-us/publications/quarterly-reports>

²⁸ <https://www.carerstas.org/wp-content/uploads/2017/06/Carers-Tasmania-Submission-on-the-Early-Years-Strategy.pdf>

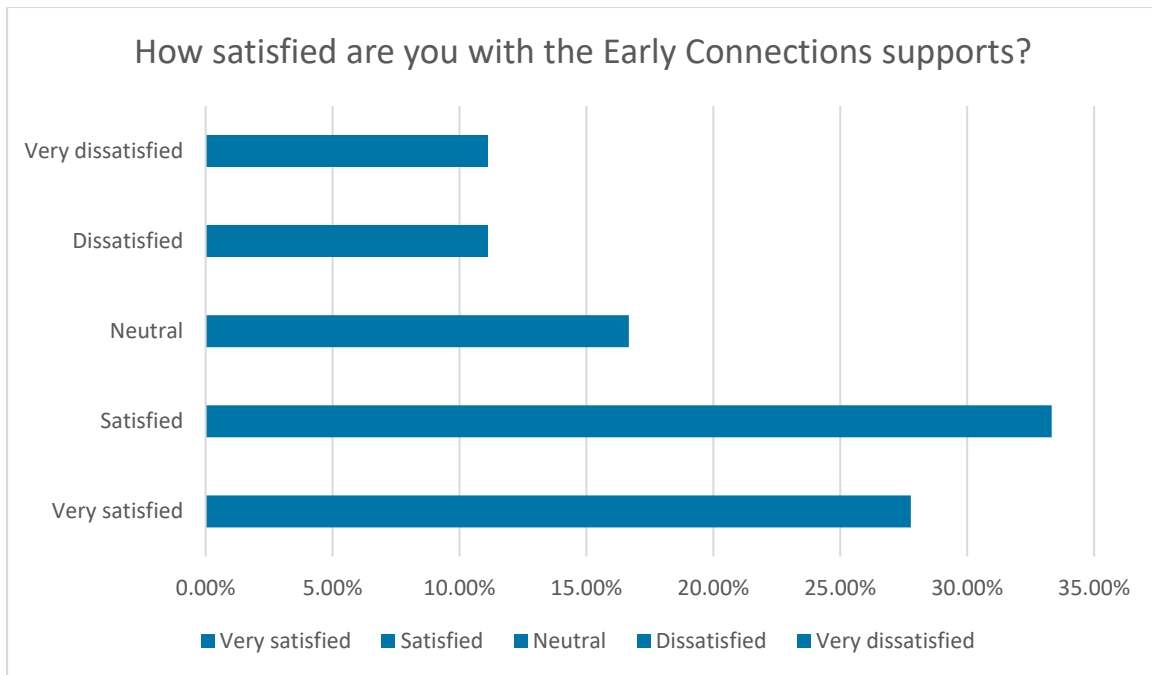


Figure 21: Satisfaction with Early Connections support

Some of the specific comments received about Early Connections support included:

- *“Great to be able to access early intervention. OT has been our biggest support and we have gained a lot of knowledge through this which improves our understanding and skills to care for her.”*

Various feedback was discussed throughout consultations. There was some confusion about the eligibility processes and what support was actually available. Some carers indicated that they wished the Early Connections support could be extended to above the age of seven and it is pleasing to see that this is currently being rolled out. There was still difficulty experienced by parents in terms of what is deemed as ‘normal parental responsibility’ and what they personally felt were additional needs compared to the general population of parents due to the extent of the additional support they find themselves providing which would be considered by others as more than normal parental responsibility.

There were discussions about how parents who are carers generally have more responsibility and lower wellbeing in comparison to parents from the general population. Carers said they feel NDIS should support them to have time to themselves to sustain their caring role and support their own wellbeing, and because of the demands of their caring role, this is usually not possible without support. They are less likely to be able to organise appropriate childcare when needed or find support from family or friends due to the level of specialised care required. Enabling parents who are carers to have time to look after themselves is in fact early intervention as it supports them to sustain their caring capacity.

Support provided to children from people other than their parent or carer can also build resilience, independence, and social skills, but often parents are not told of what may be available or they don’t know how to ask for or access it.

17. School children and the NDIS

During discussions, many carers who were parents of school-age children accessing Early Connections or NDIS supports voiced their concerns about how effectively they felt schools provide for children with disability. Some carers/parents spoke about how their children would regularly be suspended and/or sent home. This issue has also been in the media in Tasmania, with a recent report finding that almost 9000 suspensions were handed down in Tasmanian schools last year, which included more than 60 children in kindergarten and prep.²⁹ Other reports have found that in 2022, Tasmanian students with disability represented 30% of all Tasmanian school suspensions.³⁰

Another issue raised was that the discretion of allowing a child's NDIS support at school is decided by each school principal. The feedback was that some schools were just downright refusing this support, saying that it would be too disruptive. Carers indicated that they would love to see a more collaborative approach between the NDIA/NDIS, service providers and therapists, with agreement between both Federal and state-based education departments. Some carers noted that if their children's supports were more accessible in school, perhaps their children would be better supported to manage at school. As schools are limited with psychologists, social workers, and additional support staff, more collaboration with available supports funded under the NDIS could be a way to better support children with disability to stay in school and access the education that they deserve.

Many parent carers spoke about how they had turned to homeschooling after experiencing a lack of support and understanding. They reported feeling that the schools did not provide a safe and inclusive learning environment for their child. Further discussion indicated that the decision to homeschool is not an easy choice, as it has significant consequences on the parent carers and the whole family unit. It can contribute to a reduced or completely diminished capacity for employment.

- *"I wish psychology was more easily accessible at school."*

18. Families and plans

In families where there are multiple people with NDIS plans, comments indicate inefficiencies and lack of collaboration which for some families, has made it really difficult to navigate the different supports and funding available.

Some of the feedback from the survey included:

- *"I'm mum, and I have 2 children with complex disabilities both with NDIS plans. There is no consideration of this when applying for NDIS, requesting supports, when doing plan review, when implementing services/supports etc. Having one person in the family with a plan, verse 4, makes no difference to the NDIS. I've never had an LAC care about the fact that I'm a carer for 2 children on the NDIS. This is because the NDIS has no focus on supporting the carer. Its focus is on the participant, capacity building, and what is 'reasonable and necessary'."*
- *"We negotiated to have the same LAC this I believe should be standard not the exception. Of course, each individual has separate needs, but we are a family, and having someone understand the dynamics of our home is incredibly important."*

²⁹ edition.pagesuite.com/popovers/dynamic_article_popover.aspx?artguid=6fb70fe3-6227-4878-a1cd-b6c47526392a

³⁰ <https://www.examiner.com.au/story/8232018/education-head-concerned-about-vaping-and-school-suspensions/>

- *“NDIS claims to consider the family as a whole but it does not. My whole family is disabled and would greatly benefit from as much support as possible. I find I have to make phone calls and be very assertive to have further consideration given.”*
- *“Different LAC for children One child has lots of funds for respite the other does not.”*

Case Study:

Ms. P is the sole parent and carer of four children with additional needs. Three of her children currently have NDIS plans due to various forms of disability, including intellectual disability, epilepsy, a genetic condition, and autism. Ms. P finds it challenging to keep up with the administrative burden of three NDIS plans on top of providing significant care to all of her children. One of her children have not received a formal diagnosis yet, so they do not have an NDIS plan, despite Ms. P describing clearly significant additional needs.

The support across the three plans is not collaborative. The needs of Ms. P are not considered. She has little time for herself to enable her to sustain her caring role, and the support does not take into account that there is a child within the family not yet on the NDIS.

Ms. P said that she feels this is just absurd. She said she feels like the supports are so siloed. She would love for supports to collaborate and see the whole family as integral to each other. As an example, she would love for the children to go out together on social activities that build their resilience, independence, and social skills. It would also provide her with some minimal time for rest and recuperation.

The survey asked whether it would be helpful for the NDIS to take a family approach for those who have multiple people within a family accessing NDIS support. Overwhelmingly, 35% of respondents agreed that it would be extremely helpful if this occurred in the future.

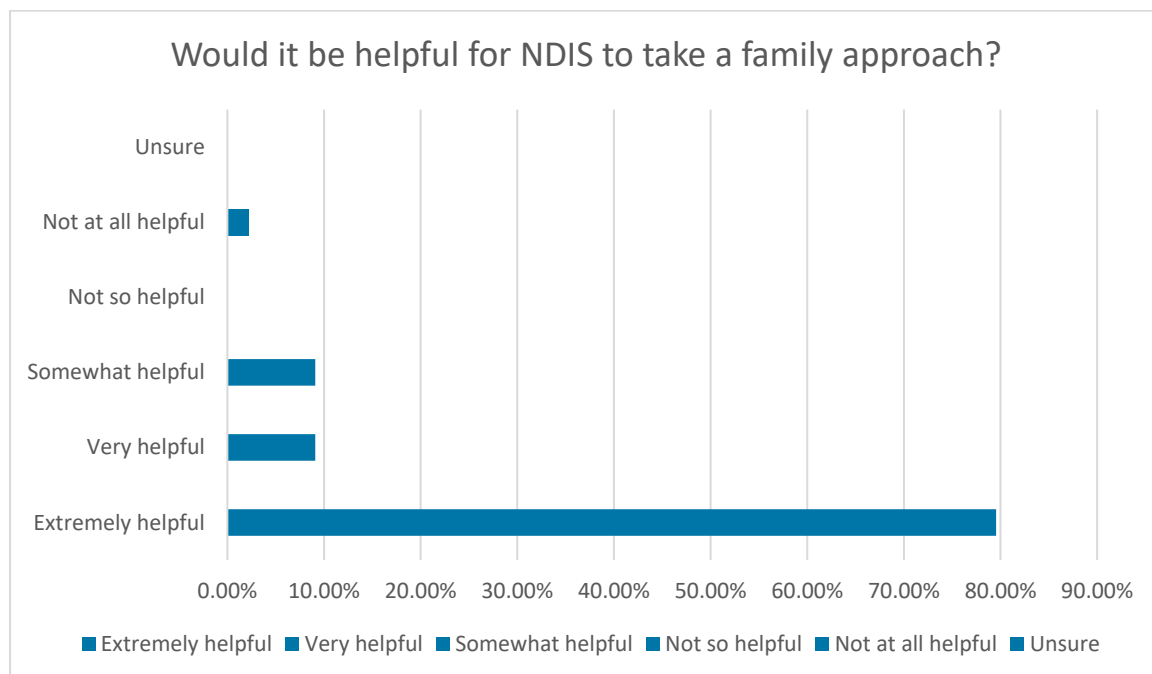


Figure 22: Would it be helpful for NDIS to take a family approach?

Comments about a family approach included:

- *“Consideration must be given to the family approach, i.e, our carers ages/health considerations, also approach us as a system that believes us without these constant assessments, if the disability is lifelong and permanent.”*
- *“Each individual in a family impacts the whole, more so for one with a disability. Arranging for services to support and coordinate with the family as opposed to disrupting it should be a central aim.”*
- *“Please do this!”*
- *“If we had NDIS approach our family arrangement as a whole, instead of 3 individual people, I think it would make a huge difference to what supports we were offered.”*

We wanted to understand what this might look like, so the survey asked ‘*how could the NDIS approach be changed to better support your family as a whole?*’. The following responses were some of the comments that were received:

- *“Having respite care for the three children at the same time.”*
- *“Looking at how a disability (or even just the caring role itself) impacts on other family members, and incorporates supports into the plan for those members.”*
- *“More funding for support workers and respite for families supporting more than one child with a disability.”*

19. The impact of the NDIS

***This section is prefaced with a trigger warning as it does discuss the topic of suicide. If you or someone you know is experiencing or affected by suicide, please contact**

000 for emergencies

or Lifeline on 13 11 14 to talk with a trained professional*

Impact of the NDIS on participants

Throughout some of the consultations, the topics of distress and suicide emerged, particularly as a result of trying to access NDIS support. One carer shared her story about supporting someone who had attempted suicide on several occasions. She explained that extreme distress was caused by the large number of processes involved in trying to access NDIS support. This carer recalled the constant re-traumatisation of having to retell their story and repeatedly provide evidence. She spoke of experiencing a false hope about how they could benefit from the NDIS, only to be let down. For this carer and the person that she cared for, the concept of the NDIS became a significantly detrimental experience, rather than a positive one.

Further discussions arose about lengthy processes to access equipment and support, being told to undergo OT assessment, and then having the OT assessment, only to be declined for the support.

Three percent of the survey respondents indicated that the NDIS had made life worse for the person they care for. Despite these difficulties, the survey did provide some positive results. 31.1% of respondents reported that the NDIS had made the life of the person they care for much better, and 47.9% reported that it had made life better.

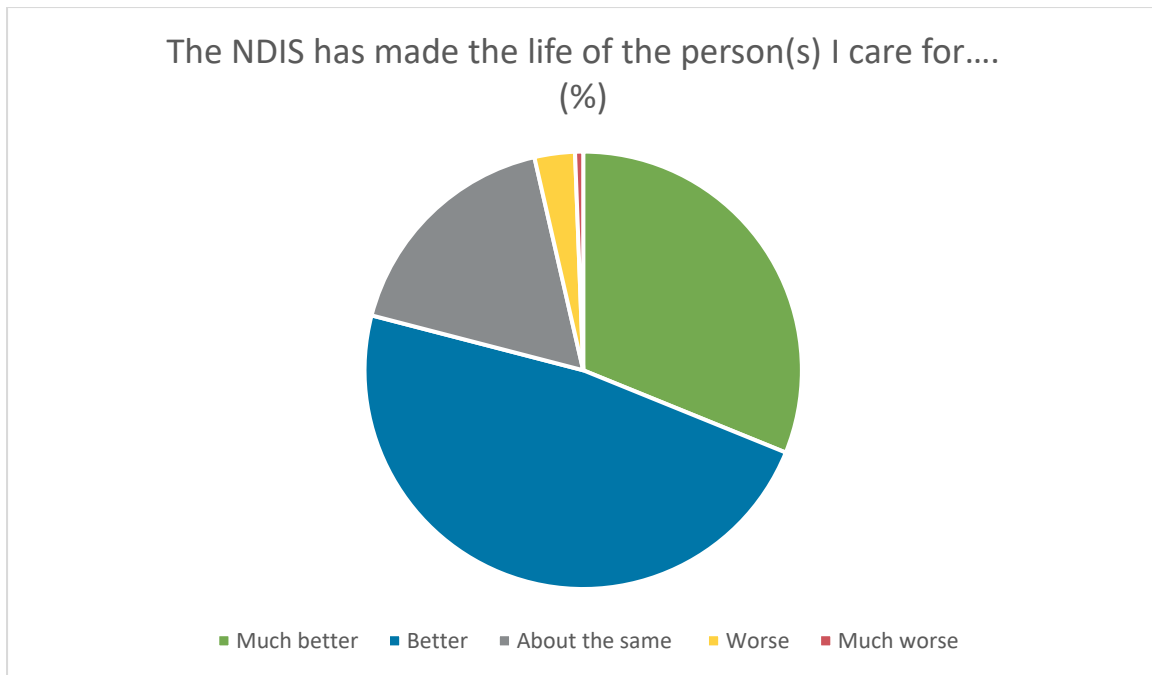


Figure 23: The impact of the NDIS on those I care for

Most carers indicated that the plan assists the person they care for to have a better quality of life (65% strongly agree and agree combined). Most carers also reported that the plan assists the person they care for to have greater independence (52.6% strongly agree and agree combined).

In terms of the plan supporting the participant to gain access to new skills, employment or volunteering, most carers reported a neutral response (35.2%), and 25.7% disagreed. In terms of the plan enabling the person being cared for to spend more time with family or friends, most carers reported a neutral response (36.9%), 27.4% agreed, and 21.3% disagreed.

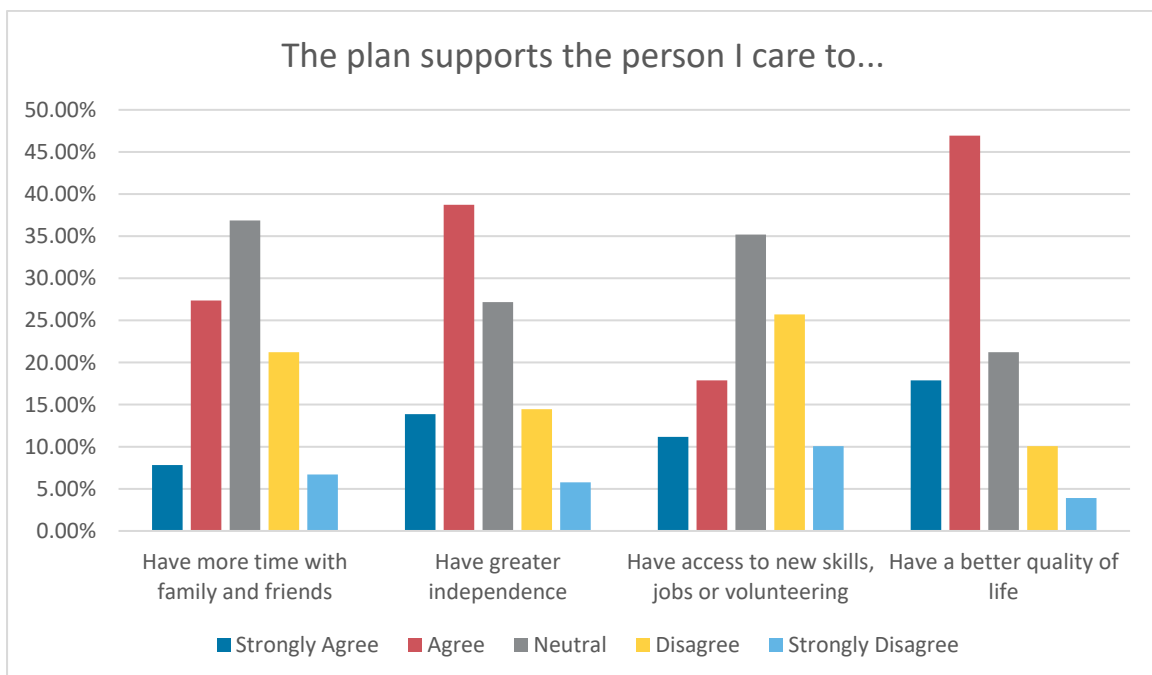


Figure 24: Positives supported by the NDIS plan

Positive comments from the survey included:

- *“He has a lot more independence and freedom due to the way we are able to use the NDIS funding.”*
- *“Our child has a much greater sense of independence and support that has made a significant positive impact on their life.”*
- *“We have been able to access some amazing providers who has helped our son develop skills and knowledge to improve his quality of life and that of our family. His development trajectory accelerated with the access of the providers through the NDIS.”*
- *“We went from being supported before the NDIS to going round and round in the system of paperwork with no support.”*
- *“Better, but worse.”*
- *“By ‘friends’, it’s more support workers we’ve chosen who are age appropriate and whose company he enjoys.”*

Impact of the NDIS on carers

While there has been some presumption that the NDIS makes life easier for carers and may result in increased capacity for their economic and social participation, the survey findings show that this is not always the case.

Some carers shared their experiences about how distressing the process to access the NDIS had been for them. In particular, a carer at one of the discussions shared her story of how the process of trying to access NDIS support for the people she cared for had significantly contributed to her suicidal experiences. This experience was traumatic for her and her family. After reaching rock bottom, she managed to access support for herself, and when she became well enough, she shared her story with the Disability Royal Commission as she did not want anyone else to have the same experiences that she did.

The previous *Carers Tasmania 2019 NDIS survey*, found that 51% of respondents reported that the NDIS supports for the person they care for had helped maintain carer and family wellbeing.³¹

The current survey found that the NDIS had positively impacted life for the majority of carers. 38.1% reported that it had made life better, and 19.6% of carers indicated that it had made life much better. A small proportion of carers reported that the NDIS had made their life worse (11.3) or much worse (1.2%).

³¹ <https://www.carerstas.org/wp-content/uploads/2017/06/NDIS-Survey-2019-FINAL.pdf>

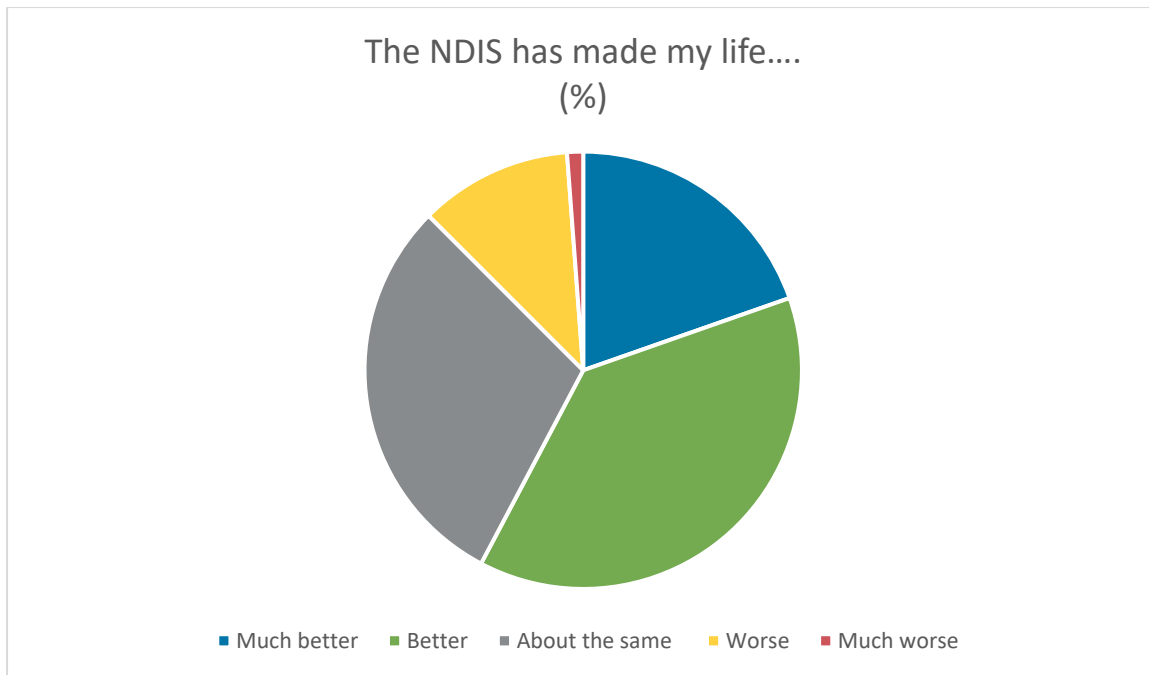


Figure 25: The impact of NDIS on carers

Specific comments on this included:

- *"I'm doing the bulk of the caring and have been unwell myself."*
- *"Just harder to live after years of caring for my son and not being able to work, now finding myself without superannuation of adequate savings to use the free time I have now."*
- *"Life is more stressful for the carer."*
- *"In some cases, it's worse as I am stressed and anxious all the time as to whether we will get the support we need."*
- *"I have been able to access services that have helped him which has helped his regulation, reducing the stress I feel at home but only marginally."*
- *"In some ways better, can afford minimum required therapy now, however worse because of all the stress caused by trying to advocate for increased funding etc."*
- *"My hubby and I have not spent a night away together literally for years,...never since our daughter was born. As she cannot leave home, we would like funds for in-home overnight supports so we can go away for a weekend. It would be good for our daughter too as she would become a little more independent. We would also like more support hours during the day so we could work more hours. We have been sharing a job for a few years so we can both have a job of sorts. Our daughter is an adult and needs support at home at least 5 days a week so she doesn't have to rely on mum and dad and so we can get on with a 'normal' life too."*

We heard from carers throughout the discussions, that their needs are rarely considered throughout NDIS planning and processes. Responses from the survey indicated that only 33% of carers had been asked if they needed support as a carer. We strongly encourage that consideration is taken on how to better identify and refer carer for their own support throughout the application, planning and review processes of the NDIS.

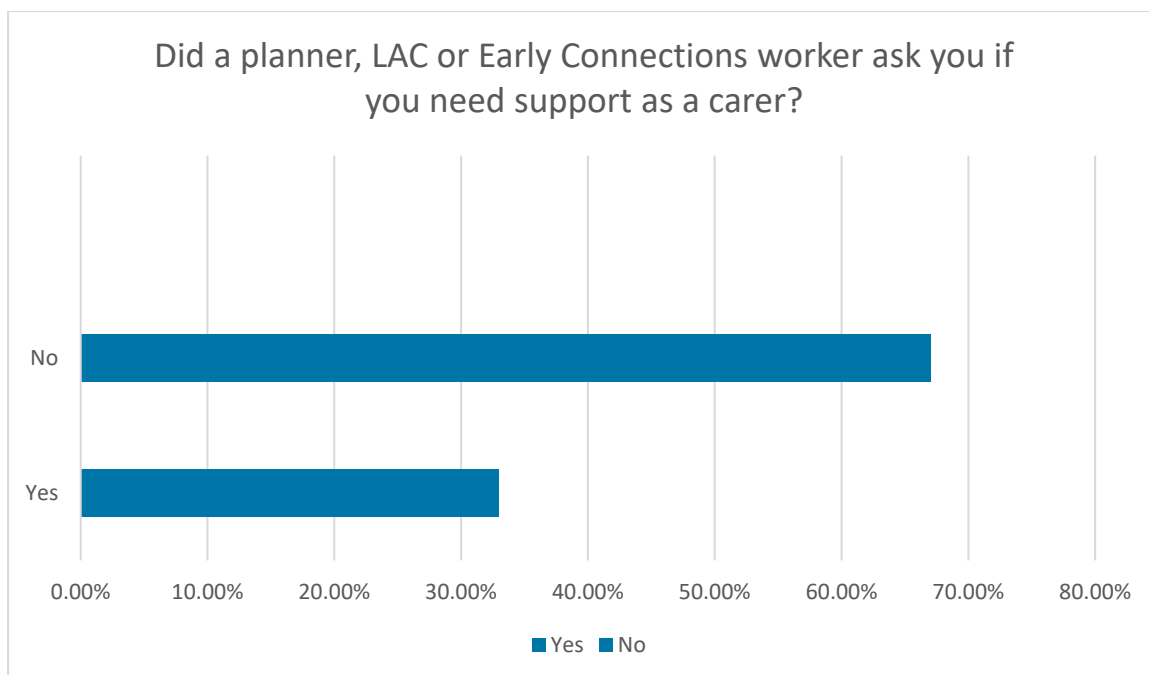


Figure 26: Identification and consideration of carers

In a 2021 Carers Tasmania survey about the Tasmanian Carer Recognition Legislation, 80% of respondents who were supporting someone on the NDIS indicated they had never been informed they could provide a carer impact statement.³²

Feedback from consultations indicated that carers rarely felt like they were considered as part of the picture when speaking with Local Area Coordinators, Early Connections workers, planners, and other staff associated with the NDIS.

Comments from the survey included:

- *“They need to be more inclusive with carers who are a spouse or de facto to the person receiving NDIS services. I received no help or say in anything as I was left out.”*
- *“LACs and Planners do not express an interest in the carer - ever.”*
- *“It's been a really emotional and hard road for both my partner and myself and not once did she ask how we are feeling or if we need anything instead she laughed.”*
- *“I connected with Care2Serve myself from a letter drop, it has never been mentioned to me from either a LAC or ECEI.”*
- *“I'm currently utilizing these services to splint what I do not have access to with the NDIS.”*
- *“What a great question if they did add that into the process.”*
- *“I found out about it myself.”*
- *“My personal experience of the NDIS overall as a carer has not been positive and I have felt mostly isolated from it without any real say in anything despite how much it has affected my life.”*
- *“Carer burnout isn't something to be taken as a joke. You shouldn't have to fight for respite.”*

³² <https://www.carerstas.org/wp-content/uploads/2017/06/Carers-Tasmania-Response-to-the-NDIS-Review-Our-Approach-Paper-2022.pdf>

Research indicates that carers have lower wellbeing in comparison to the general population.³³ We wanted to understand the wellbeing of carers supporting someone on the NDIS. We note that this does not provide a statistically significant correlation, however, this does support the findings of other research about the wellbeing of carers. It may also indicate that the NDIS is not currently providing any significant improvement to the wellbeing of carers. Most respondents (49%) indicated that their own wellbeing was average, and 41% indicated that it was below average.

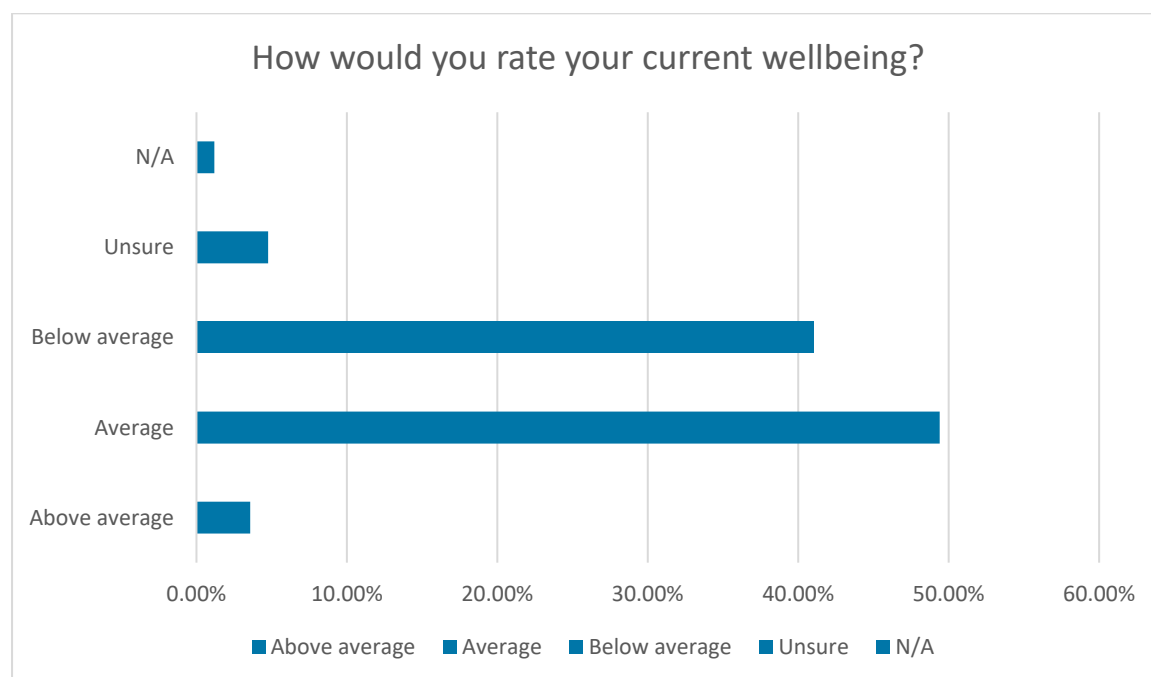


Figure 27: Self-reported carer wellbeing

Alarming, 75% of the respondents who indicated they identify as LGBTIQ+ reported having below-average wellbeing. 66.7% of respondents who indicated they identify as Aboriginal or Torres Strait Islander reported their wellbeing as average, and 33.33% reported their wellbeing as below average. Of the respondents who reported that they identify as culturally or linguistically diverse, 46.2% rated their wellbeing as below average.

Comments from the survey about carer wellbeing included:

- *“Very good. Happy and content.”*
- *“I am not trained as a carer, so bathing and toileting my wife is very difficult for me. Our bathroom and toilet inadequate, the solution suggested by NDIS rep will not work.”*
- *“I battle at times with being able to keep up the support because of my health and ageing, I burn out easily not having enough breaks.”*
- *“I am still recovering from years of exhaustion and probably some depression. I am feeling better with each year our child has been receiving more support.”*
- *“I know I am dealing with burnout. I feel I handle it well, but it’s not an easy place.”*
- *“Recently resigned from employment to care again for my child.”*

³³ https://www.carersaustralia.com.au/wp-content/uploads/2021/10/211011_Carer-Wellbeing-Survey-Executive-Summary_FINAL.pdf

To explore the potential ways that NDIS plans could support the wellbeing of carers, we asked some additional questions. The first question looked at whether the plan enables some form of break or time for self. We split the results geographically, to identify if perhaps some regions were more proactive in this sense than others.

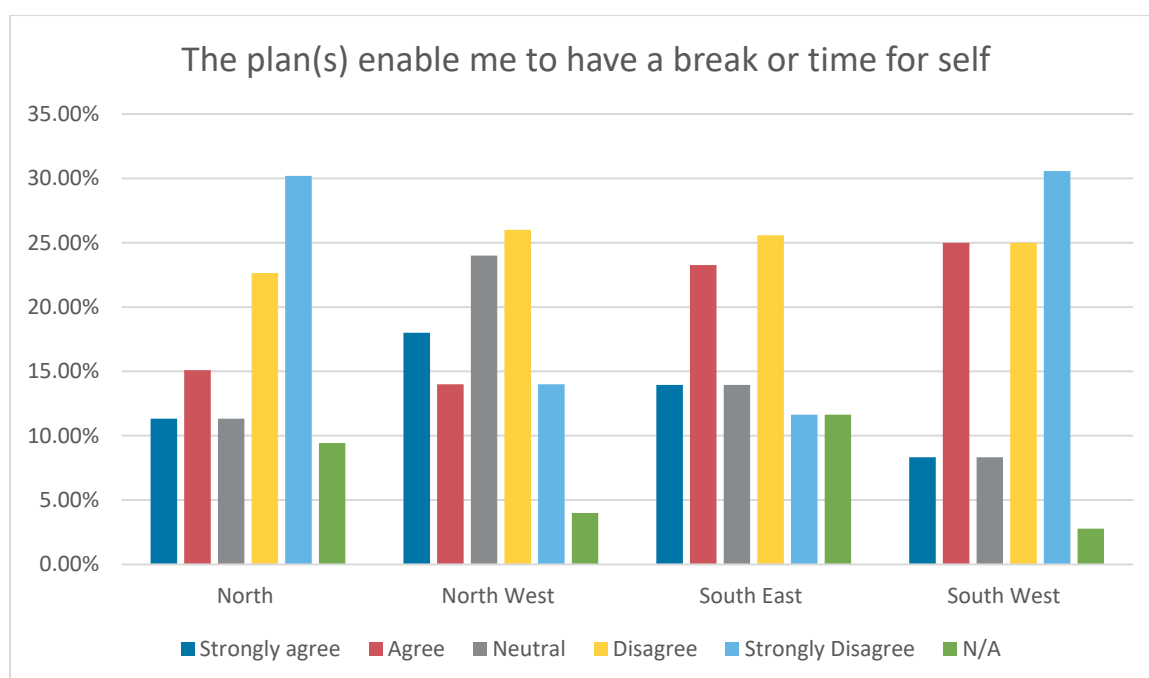


Figure 28: Do NDIS plans support carers to have some time for self?

This showed that more carers (18%) from the North West strongly agreed that the plan enables them to have a break or time for themselves, whilst 25% from the South West and 23.3% from the South East said they agreed. This shows that there is still a large proportion of carers supporting someone on the NDIS who do not feel that support in the plan enables them to have a break or time for themselves. Carers need adequate opportunities for rest and recovery in order to sustain their caring capacity. It should not be accepted as normal for carers to experience poor wellbeing because they are a carer, rather they should be supported to sustain and improve their wellbeing.

NDIS plans are not specifically aimed at supporting the carers to participate in paid work or to study, however, some reports published by the NDIA provide statistics on the employment status of carers and family members, for example, the *Employment Outcomes for Families and Carers of NDIS Participants*.³⁴ There is a risk that the data in this report could be interpreted as NDIS plans supporting carer participation in employment, however, we urge caution on this, as many people might be working because they have to. Carers who do work find a way to make support work around their employment, not because the NDIS plan enables them to work. We encourage a strong and genuine approach to ensure that there are supports included in the NDIS plans to assist carers to participate in employment or study if they wish to.

The survey found that only 6% of respondents strongly agree, and 18% agree that the NDIS plan of those they care for enables them to participate in paid employment or study.

³⁴ <https://data.ndis.gov.au/media/3014/download?attachment>

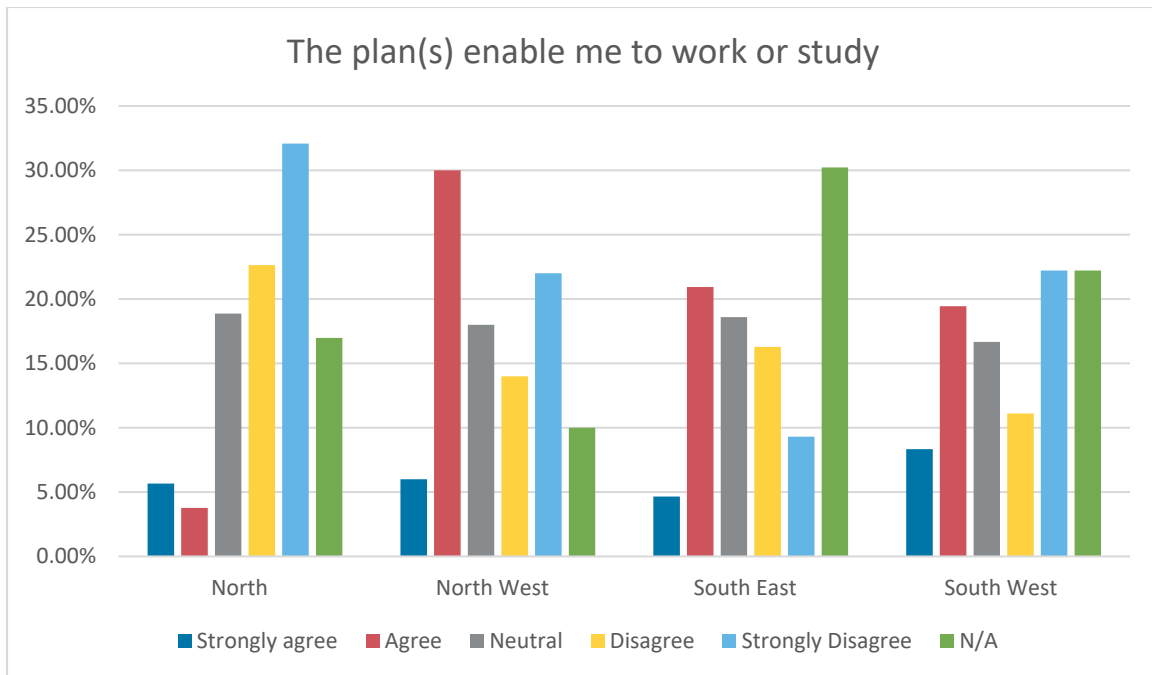


Figure 29: Do NDIS plans assist carers to work or undertake study?

The findings from our survey and the consultation activities demonstrate that whilst there are positive aspects of the NDIS for both participants and carers, further improvements are required to ensure that appropriate support is accessible for those who need it, when they need it. Carers must be recognised, included, and supported as they are integral to the success of the NDIS.

We strongly encourage the NDIS Review team to conduct further accessible consultation opportunities for carers who are supporting someone on the NDIS so that meaningful change can be made.

20. Recommendations

- **Embed the routine identification, recognition, and inclusion of carers across all levels of NDIS policy and practice.**
- **Ensure that all carers are asked if they need support, information, and referral.**
- **Consider one overarching LAC/ Early Connections partner across Tasmania.**
- **Review policies and processes with input from participants and carers to make it easier to access what is needed.**
- **Allocate a small emergency pool of funds within each plan that is simple and fast to access in unexpected circumstances.**
- **Implement a targeted plan to increase education, access, and the support provided by Early Connections.**
- **Implement a targeted and consistent approach to improve relationships with schools, so that children can access what is necessary for them, especially in circumstances where the school cannot provide what is required in a reasonable timeframe.**
- **Reduce the requirements to continuously provide proof of disability.**
- **Ensure that support coordination remains available and implement a process at the planning stage to ensure that participants and carers are routinely informed that this is an available option.**
- **State and Federal Governments must work in collaboration to ensure there is adequate and accessible support for people who don't quite meet NDIS eligibility or who are awaiting approval.**
- **Include a small amount of funding that carers can use to learn specific skills that will support them in their caring role.**
- **Develop a process in which collaborative team meetings occur as a standard and funded function between providers, participants, carers, support coordinators, and specialists.**
- **Include carer awareness training as standard within the NDIS worker induction modules.**
- **Implement a process to enable more flexible and appropriate use of plans for families with multiple participants. Include carers and participants as part of co-designing this.**
- **Implement targeted strategies for young carers of parents who are NDIS participants.**

- **Increase accessible community awareness to build literacy and understanding around what the NDIS is, how to apply, what supports may be available, and how to access the supports required.**
- **Introduce minimum requirements of training for disability support workers.**
- **Governments must collaborative on an equitable approach to incentivise pathways to increase employment of OT, psychology, speech therapy, paediatrics, and other allied health professions.**
- **Support planners must routinely consider the needs of carers and how this can be supported within the participant's NDIS plan.**