

# Carers Tasmania



## Impact of the NDIS on Carers in Tasmania: the story so far

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**Acknowledgement**

Carers Tasmania wishes to acknowledge the role carers play in supporting vulnerable Tasmanians and give thanks to those who have found time to share aspects of their experience with the National Disability Insurance Scheme. Thank you also to Carers Tasmania's stakeholders who shared this survey with those they support.

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## Executive Summary

Carers Tasmania first surveyed carers on their experience with the NDIS in 2017. Carers Tasmania has again surveyed carers to see how they are faring in the roll out of the National Disability Insurance Scheme (NDIS), the most significant economic and social reform in Australia for more than a generation.

Results indicate some carers have begun to see profound outcomes for the people they care for and have developed confidence in navigating what appears to be a very complex system. Thirty percent of respondents report significant improvements for the person for whom they care.

However, there are still many carers who appear to be overwhelmed, distressed and/or disillusioned. Over twenty percent have said there has been very little or no improvement. Thirty-five percent said it is still too early to tell.

Seventy-five percent of those caring for a person assessed as ineligible stated they had no contact with a Local Area Co-ordinator. One of the roles of a Local Area Co-ordinator is to assist in accessing supports in the community for those who are ineligible.

Twenty percent of survey respondents stated they were not involved in the development of the plan for the person they care for, and a further fourteen percent said they were only 'somewhat' involved. This result may reflect the number of people being cared for who do not wish their carer to be involved in their relationship with the NDIS. However, of those involved, only fifty-six percent of survey respondents who were involved said their input was included in the plan.

This may suggest a lack of consistent carer-inclusive culture within the NDIS. This is consistent with comments you will see in this report, which illustrate carers feel dismissed, unclear about how they can be involved, and unsure where they fit in a system designed to give the person with the disability choice and control. Variable experiences may be dependent on the age of the person requiring care, the complexity of need and the type of disability.

Eighteen percent of respondents said the participant's plan would meet all of the needs of the person for whom they care. Forty percent said the plan would meet some of the needs, and twenty percent said the plan is not aligned to their needs. Over sixty percent of respondents said it was either challenging or very challenging to find services identified in the plan.

When the needs of the participant are not being met in the plan, it is reasonable to conclude the burden of care continues to fall to the informal family carer. Whilst NDIS plans are intended to take the wellbeing of the family and the carer's role into consideration, only one half of respondents said the NDIS plan had assisted them and contributed to their family's wellbeing.

Responses regarding carer wellbeing were of particular concern. Fifty-one percent of respondents said they did not feel well as carers, with many comments referring to feeling overwhelmed and exhausted as a result of navigating the NDIS.

While one quarter responded that they have more time to themselves, the remainder claimed nothing has changed or they have less time. It is not surprising therefore, that sixty percent of survey respondents said they were either no more able, or less able to meet existing work or study commitments or seek new opportunities. This challenge is set against a back drop of the Commonwealth Government articulating its push to reduce carers' 'welfare dependence'.

Carers' general comments suggest they struggle with navigating this complex system, and often appear to have been given minimal information regarding opportunities for involvement.

Carers Tasmania intends to further develop training for carers, with a particular focus on self-management. It will advocate for The National Disability Insurance Agency (NDIA) to create a carer-aware culture that routinely informs carers of their right to provide input and clearly explains processes, particularly reviews.

## Who is a carer?

It must be acknowledged there is still significant confusion with the word carer, with paid support workers often being referred to as carers. A carer is a family member or friend who provides unpaid care and support to someone with a disability, mental illness, chronic or palliative condition, alcohol or other drug addiction or who are frail aged. This includes people under the age of 18.

Examples of caring scenarios where there may be engagement with the NDIS include a parent supporting an adult child with a major mental illness and a chronic health condition, a parent of a young child with a disability, or someone caring for their partner with Multiple Sclerosis.

Caring can involve tasks such as dispensing medication or providing reminders, assisting with domestic or personal care activities such as cooking and shopping, showering or feeding, attending appointments, advocacy, supporting the implementation of strategies recommended by specialists, providing encouragement or support to attend family and social events, school or work, and/or emotional support and supervision.

## About the National Disability Insurance Scheme

The National Disability Insurance Scheme commenced five years ago in July and is currently supporting more than 5,000 Tasmanians with disabilities, more than one third of whom were not previously receiving government funded disability supports.

As of January 2019, the NDIS is available for adults aged 50 to 64 and will be available to all eligible Tasmanians from July 2019.

Some significant additions have occurred to NDIS since Carers Tasmania's last survey.

The NDIA has announced the development of a complex support needs pathway in November 2018, following extensive feedback that participant and provider experience was not meeting expected standards. This pathway will involve specialised supports for people with psychosocial disabilities, face to face planning (where preferred), a new NDIS contact centre, and a new format for NDIS plans. The NDIA is developing Complex Support Needs planning teams and a network of specialised planners with strong experience in high level co-ordination and/or allied health experience. This may improve participant experience in the future.

The Commonwealth Government has also provided \$9 million in grant funding to help support remote communities to become more inclusive and supportive.

The NDIS Quality and Safeguards Commission commenced operation in July 2018, and acts as an independent agency to improve the quality and safety of NDIS supports and services.

These measures may all improve the participant and carer experience and be reflected in next year's annual survey.

## Survey implementation

This second Carers Tasmania NDIS survey was conducted online via survey monkey. One hundred and twenty-two participants took part in the survey.

It was promoted to members of Carers Tasmania via email and the general public via Facebook and finalised in February 2019. Key stakeholders were asked to distribute the survey to the carers they reach.

## Survey report

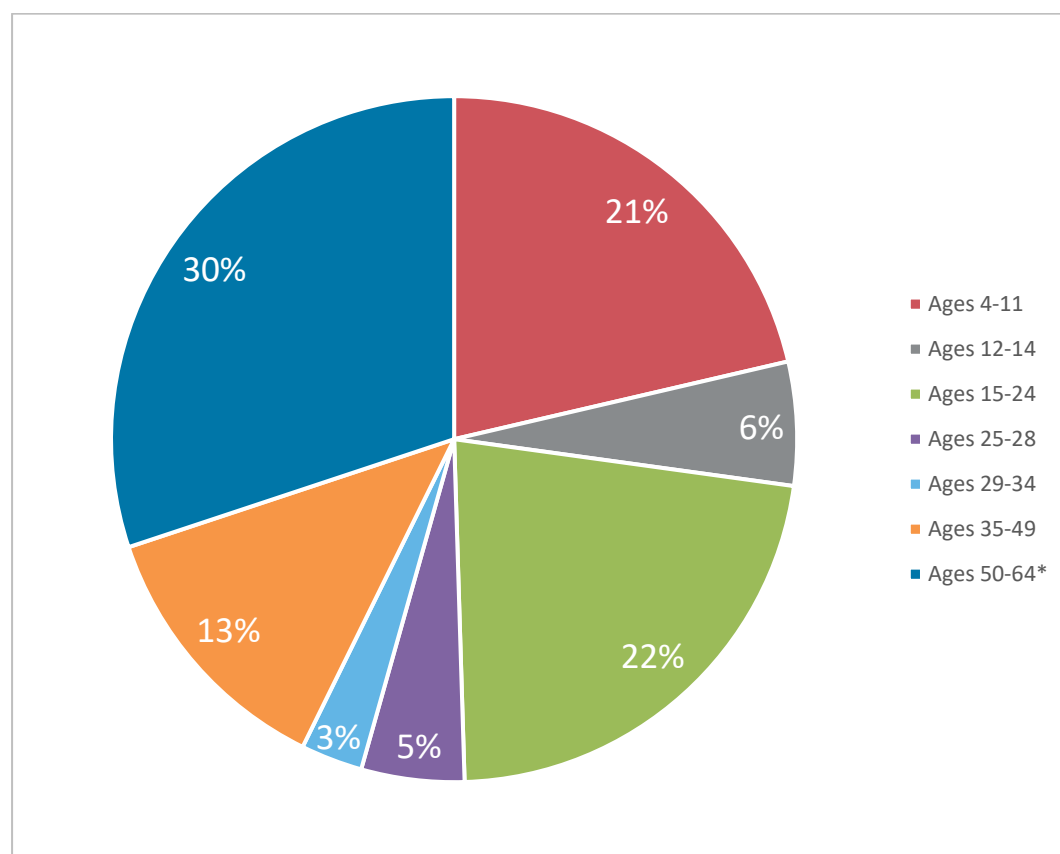
The findings of the survey are outlined in this report. Carer comments have been highlighted in text boxes throughout the paper.

## Summary of Findings

### NDIS Participant Profile

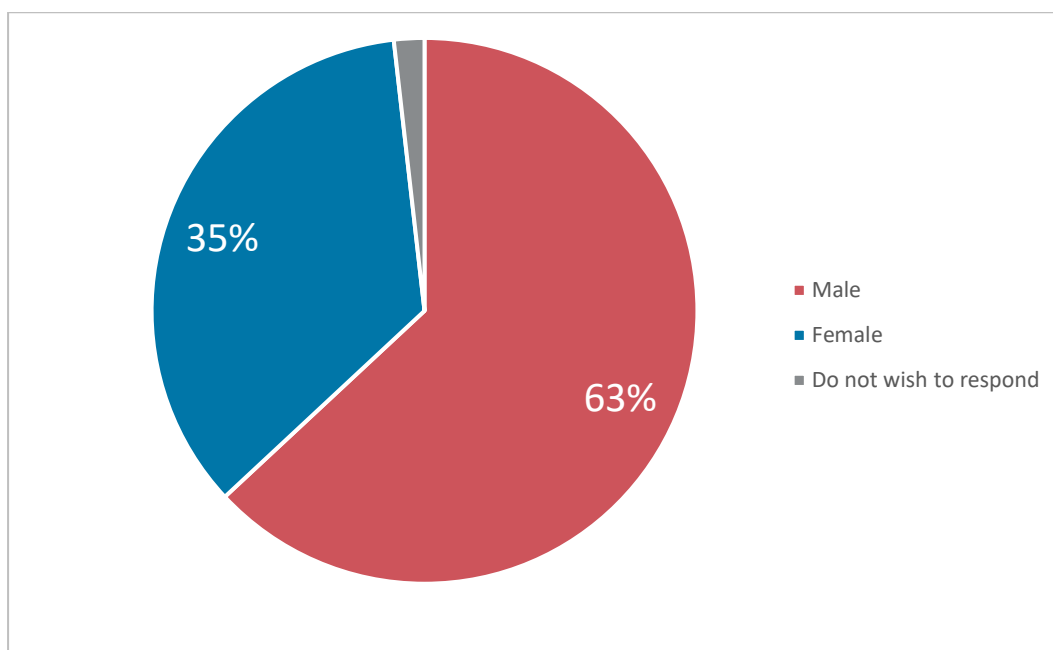
#### Question 1: How old is the person you are caring for?

At the time of survey, the NDIS was available to eligible people up to the age of 49 in Tasmania. Thirty percent of carers outside the age range at that time elected to participate in the survey. This may reflect their concern regarding the roll-out and its potential impact on them and the person or people for whom they care.

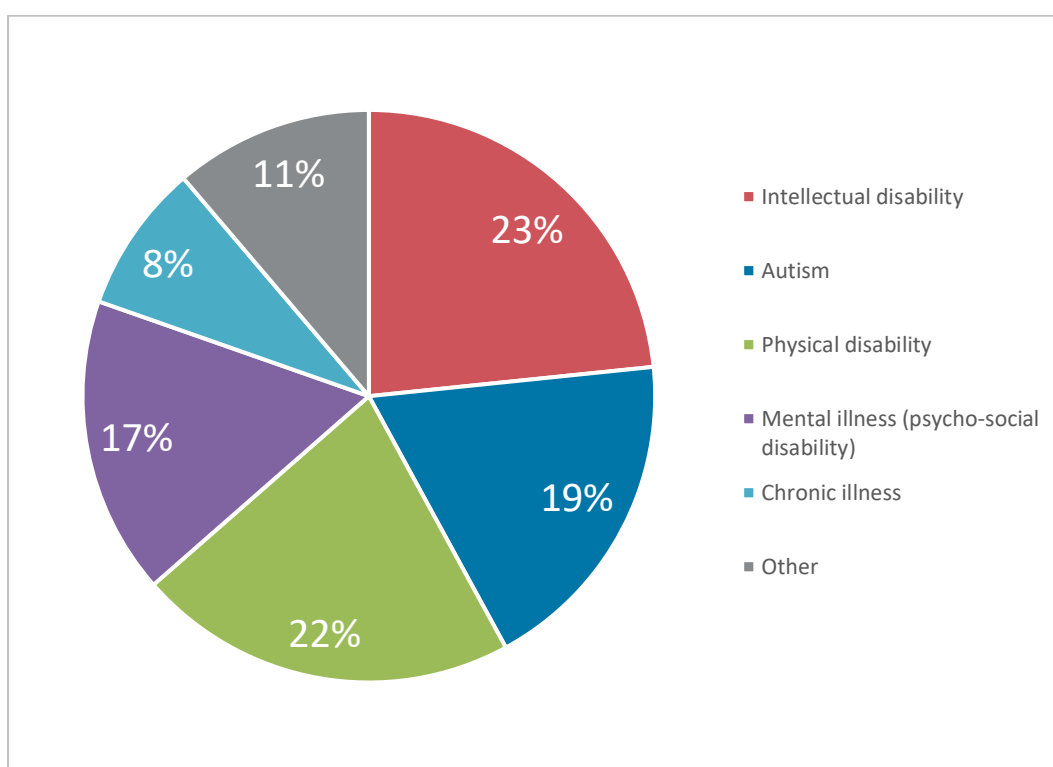




Question 3: What is the gender of the person with a disability you care for?



Question 4: What is the primary disability of the person you care for?



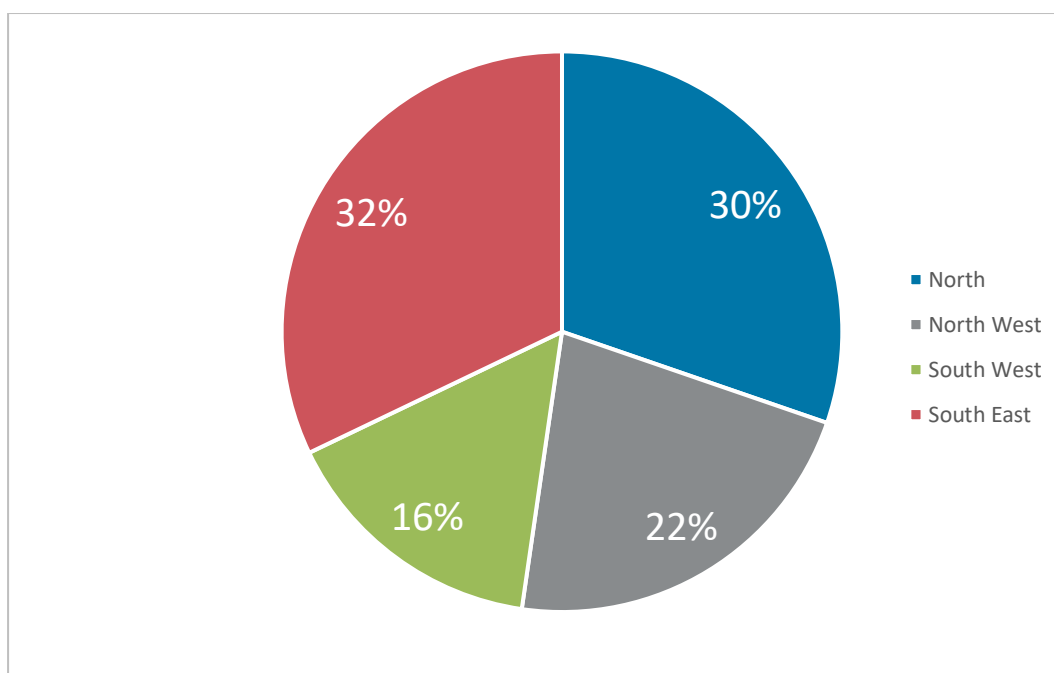
Eight percent of NDIS participants recorded primary psychosocial disability as their primary disability. Carers Tasmania notes the high response rate from mental health carers, with 20% of respondents caring for a person with a mental illness and/or psychosocial disability.

The table below demonstrates more detailed information about the caring roles of respondents, based on the condition of the person they care for and reflects carers may be caring for more than one person.

| Condition               | Number | Comments   |
|-------------------------|--------|--|
| Neurological            | 1      | Children with degenerative neurological disease - Pelizaeus Merzbacher and husband with severe injuries and chronic pain after motor vehicle accident. Parkinson's Disease, dementia, severe osteoarthritis, old spinal fracture, peripheral neuropathy. |
| Genetic condition       | 2      | 48 xxyy syndrome,<br>Gene defect HIST1H1E – over growth syndrome with intellectual disability.   |
| Multiple sclerosis      | 3      | Last stage of MS, cognitive multiple sclerosis.  |
| Mental Illness          | 3      | Complex trauma, anxiety, OCD, possible BPD. Paranoid schizophrenia.  |
| Acquired Brain Injury   | 3      | Acquired brain injury, epilepsy, and CP left side, acquired brain injury, brain injury and epilepsy, cognitive impairment from left embolic stroke, and terminal oesophageal cancer.   |
| Autism                  | 5      | Severe regressive autism, acquired at age 2, lost all language, developed severe behavioural and sensory problems. 24/7 high needs care, Asperger's (high functioning Autism), ASD, mod to severe also mod id and dyspraxia.                             |
| ADHD                    | 3      | ADHD, sensory processing disorder, ODD, anaphylaxis, allergies, learning disability, social communication disorder, chemical allergies in foods and environmental. ADHD aggression dual chromosome.  |
| Intellectual disability | 7      | Severe intellectual disability, both an intellectual disability and a chronic illness, also has intellectual disability and physical disability, intellectual disability, autism, dyspraxia, auditory processing disorder.                               |
| Cerebral Palsy          | 5      | Cerebral palsy. Right side hemiplegia, cerebral palsy and epilepsy, dyskinetic cerebral palsy.   |
| Down Syndrome           | 5      | Down syndrome with autism.   |
| Chronic Illness         | 3      | Also, chronic illness and mental illness, functional impacts (and therefore caring needs) arise mostly from physical and emotional limitations caused by the chronic illness, grand cell, giant cell arterial arteritis.                                 |
| Physical disability     | 5      | Physical and intellectual. Non-verbal and cannot work independently, had a stroke and handicapped on the right side, and can't walk very far. Uses a wheelchair to   |

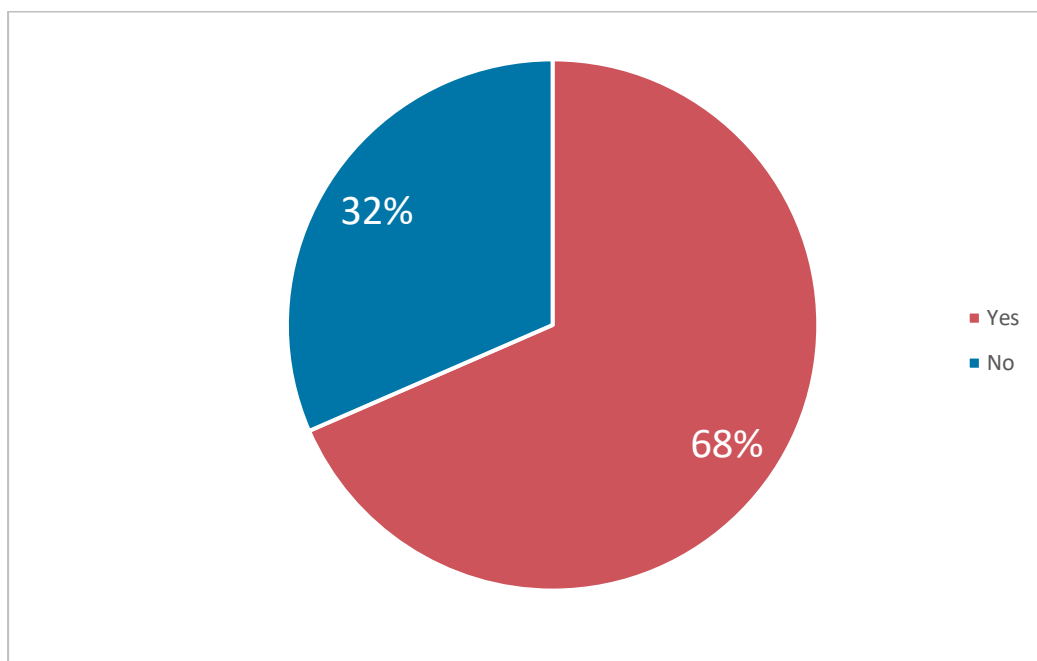
|   |    |   |
|---|----|---|
|   |    | get around outside, double leg amputee, stroke victim. Permanent bilateral hearing loss, back injury and no balance, unable to walk short distances.  |
| More than one disability  | 13 |   |
| Other comments or diagnoses which would not make someone eligible for NDIS in their own right |    | I remain a co-carer to a wife now in aged care, mixed, my husband is out of the age group above, autoimmune conditions, cognitive functions as a result of stroke, essential tremor/Parkinson's, heart failure, lowered kidney function (does not qualify as is now 68), nonverbal, no self-care skills, approximate developmental age of 18 months, old age dementia, liver cancer, diabetes, deafness, all of the box but I can't tick every box. |

Question 5: In which region does the person with the disability live?



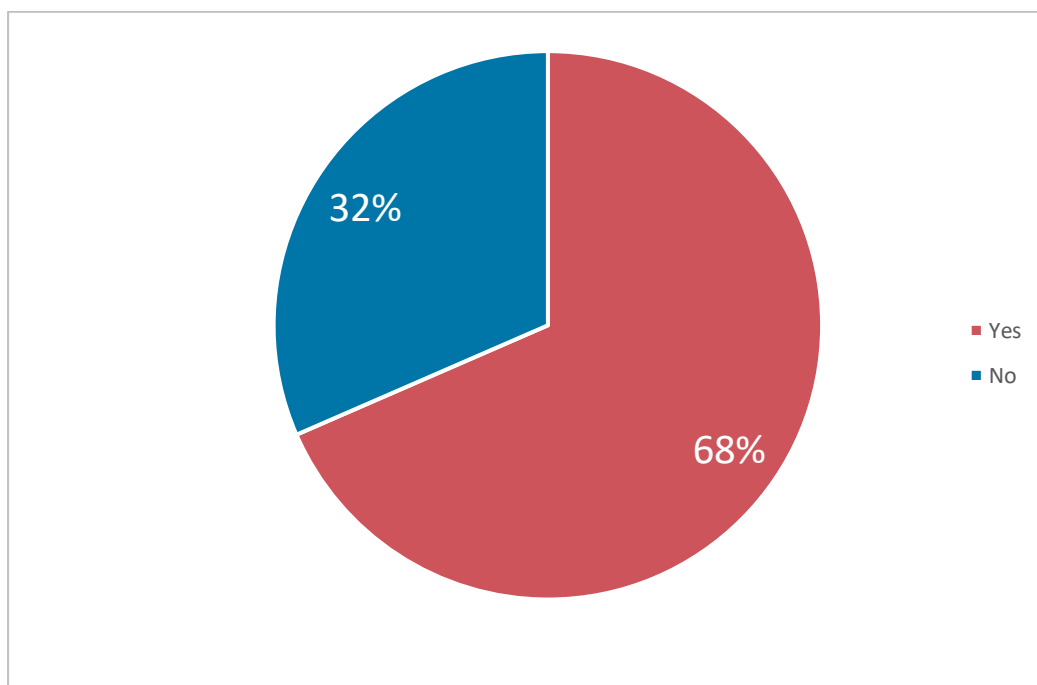
## NDIS Eligibility

Question 6: Has the person you care for been through an eligibility assessment for the NDIS?



Question 7: Was the person that you care for eligible for an NDIS participant plan after assessment?

Sixty-eight percent of respondents care for someone who was eligible for a plan.



**Question 8: Are there any comments you would like to make about why the person you care for was NOT eligible to be a participant of this Scheme and the impact of the application process on them and you as a carer?**

*“I am so disappointed my son was not accepted into the scheme. I have cared for my son on my own for 22 years and have had no help from any one. He has 3 or 4 disabilities which are very debilitating for him. I was told I didn't do enough for him. Funny that. As I do everything for him. My doctor was flabbergasted that we received no help from the government through the NDIS. I also asked them not to tell my son as he would take this as another failure in his life. And they addressed the letter to him, causing me more issues with my son. Instead of helping they just caused me more stress. They also told me his mental health report was too old. Like his autism condition just runs away? It is typical with all these government organisations. The people we deal with just wouldn't have a clue. If they don't live with it believe me, they don't know. And they are not trained in knowing anything about the conditions.”*

Dialogue in the community regarding the NDIS may have led to an expectation that it would provide support to all people with disability. Respondents demonstrate the degree of distress when the person they care for is not accepted into the scheme.

It appears carers may not have been fully informed or prepared for the application process, and as a result do not have or did not provide the required current evidence, significantly impacting on the outcomes for themselves and the person they care for.

Comments also reflect the outcome may be reliant on the carer being informed and educating their doctor, who may not be adequately informed.

*“Deemed ineligible as application did not state that condition is lifelong even though part of the definition of the condition states this. Applied 6 months ago for a review and am still waiting”.*

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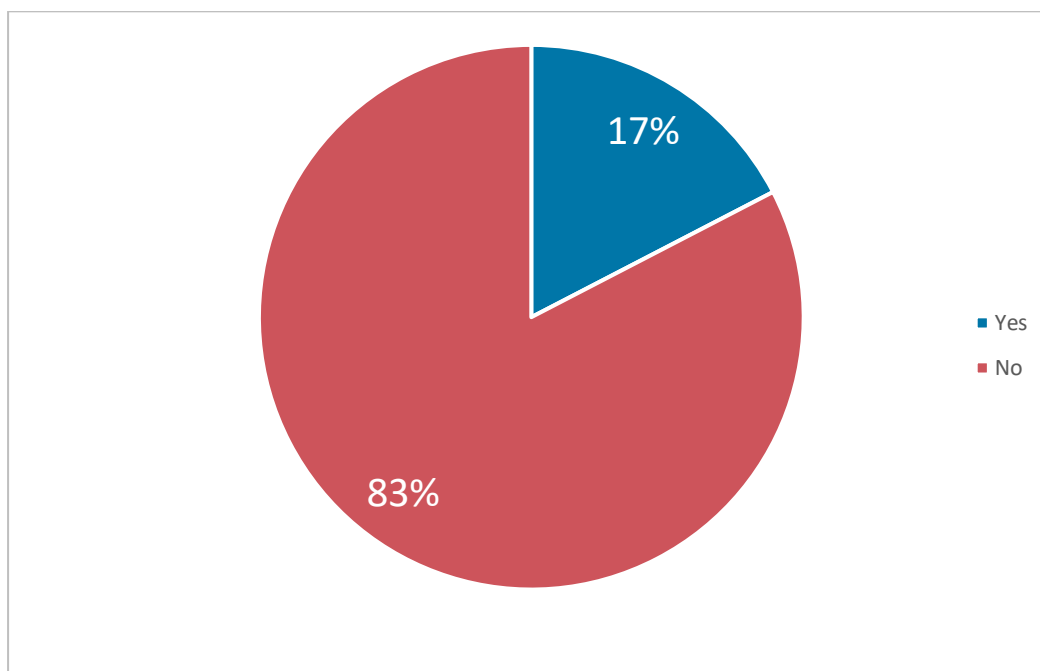
*“Extremely difficult as we have no support. He can't work, even specialists say that. I work full time and am a carer full time. I would say hopeless as he's not wheelchair bound”.*

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*“Not enough evidence initially. Hard to gather the evidence as he doesn't fit into the categories for the GP and previous assessments are out of date, even though his condition does not improve”.*

**Question 9. Were you advised in a timely way by the NDIA why the person was not eligible and provided with reasons you understood?**

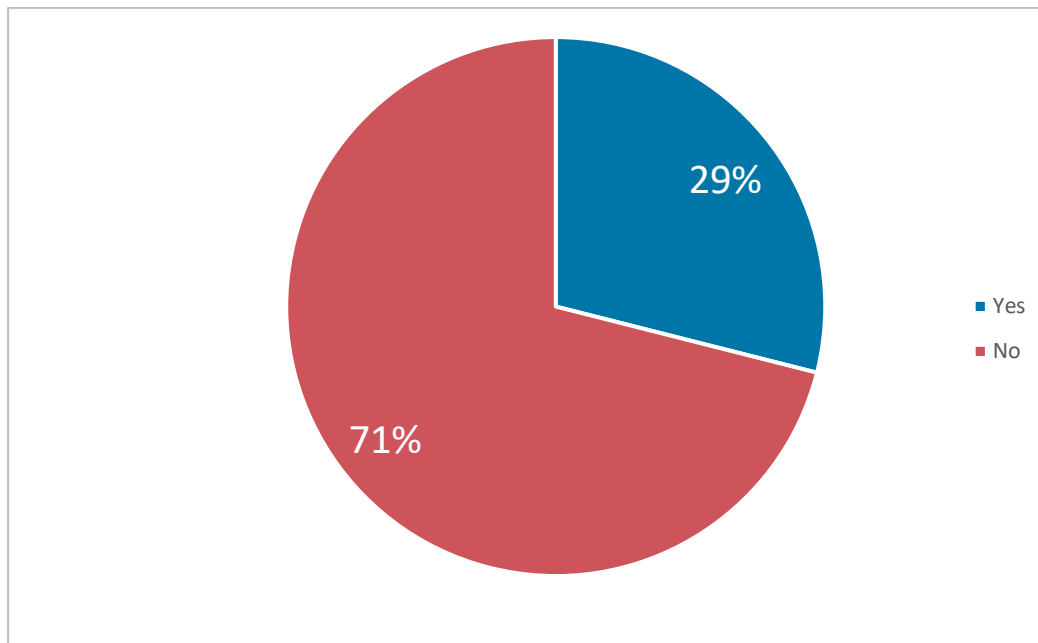
Over eighty percent said they were not advised by the NDIA in a timely way, or given reasons in a manner they understood, why the person they care for was ineligible in ways they understood.



## Local Area Coordination

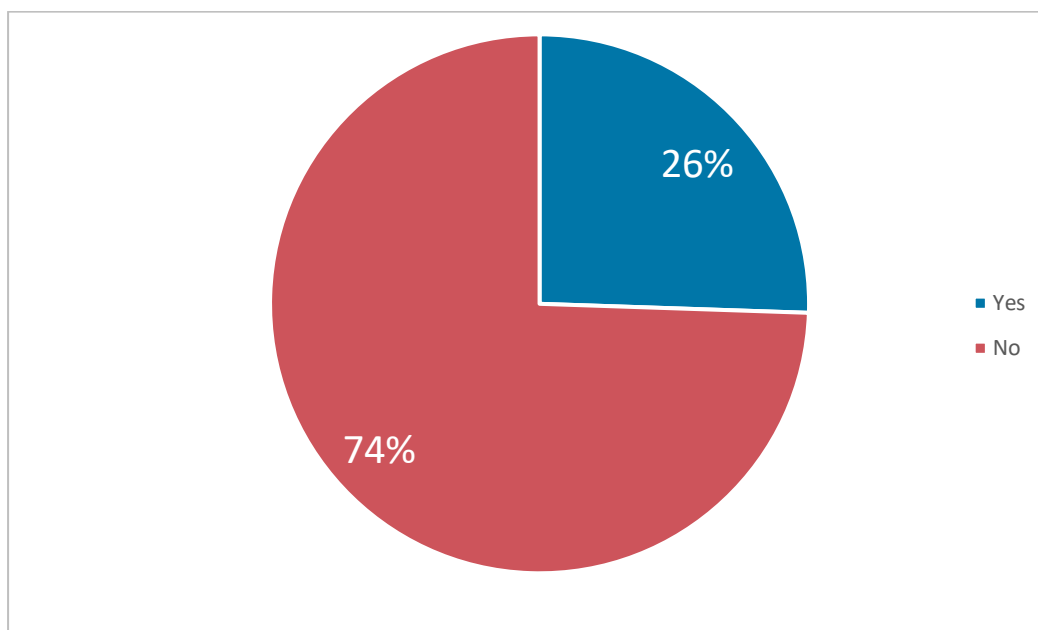
### Question 10 Were you referred to a Local Area Coordinator (LAC)?

If a person is deemed ineligible for the scheme, a Local Area Co-ordinator can provide information and assistance to access supports. However, it appears a significant number of respondents were not offered this opportunity.



### Question 11 Have you been contacted by a LAC (Local Area Coordinator) to assist you to connect to other community and mainstream supports?

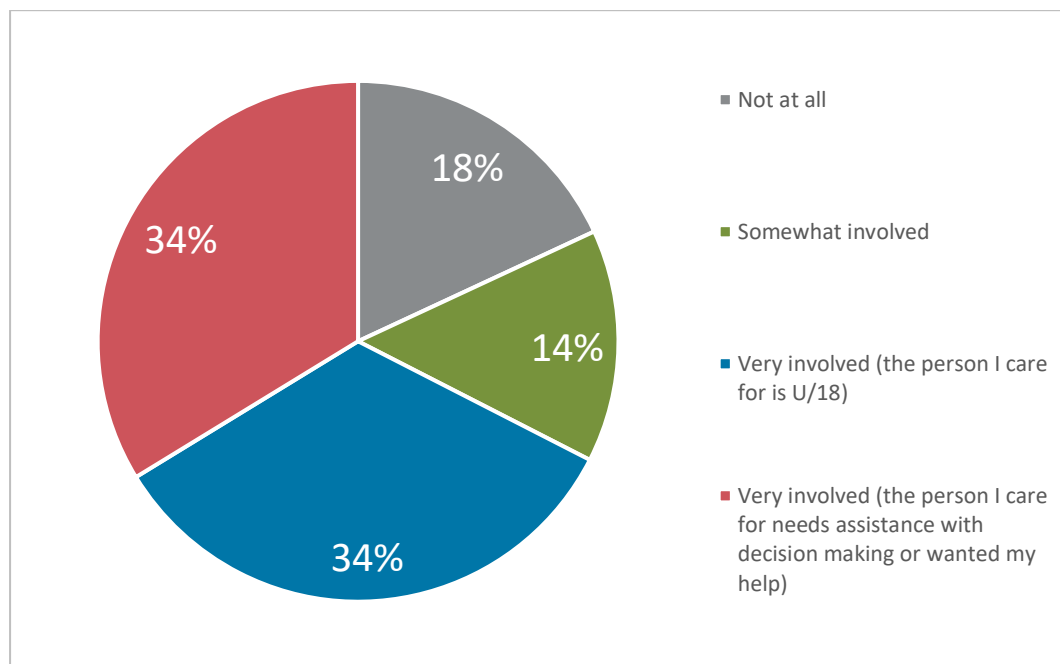
While NDIA intimates that contact with a Local Area Co-ordinator should routinely occur once ineligibility is determined, results suggest otherwise. Given the importance of accessing community and mainstream supports when the NDIS is not an option, this is of significant concern.



## Participant Planning

### Question 12: To what extent were you involved in the development of the participant plan for the person that you care for?

How carers are involved in the development of the participant plan will vary according to the individual participant's circumstances. For example, a carer may attend the planning meeting with the participant, be listed as an informal support, and/or help the participant to access funded services and supports. Over sixty percent of respondents said they were involved or very involved in the development of the participant plan, with just under twenty percent saying they were not involved at all, and a further fifteen percent somewhat involved.



Some comments suggest the NDIS may not always be inclusive or listen to carers, with particular issues when caring for an adult, and particular challenges if the person does not wish the carer to be involved. Respondents share how their lack of involvement can have significant impact on the plan. One comment states the documentation was not used in the way the carer had hoped.



*“NDIS plan was developed prior to her 18th birthday. We were involved, then as soon as she turned 18, we were excluded. It was very challenging, and it took 3 or 4 months for us to be included as nominees, at our daughter’s request. It was basically a disaster, as plan fell apart during this time”.*

- - -

*“My involvement was not encouraged by my person’s co-ordinator of support because he is an adult. We are the only unpaid people (and family connection) in his life but were repeatedly told that the process wasn’t for us to be part of”.*

- - -

*“The person I care for has the mentality of a 2 to 4-year-old and is practically non-verbal but I wouldn’t say I had a lot to do with decision making or plan”.*

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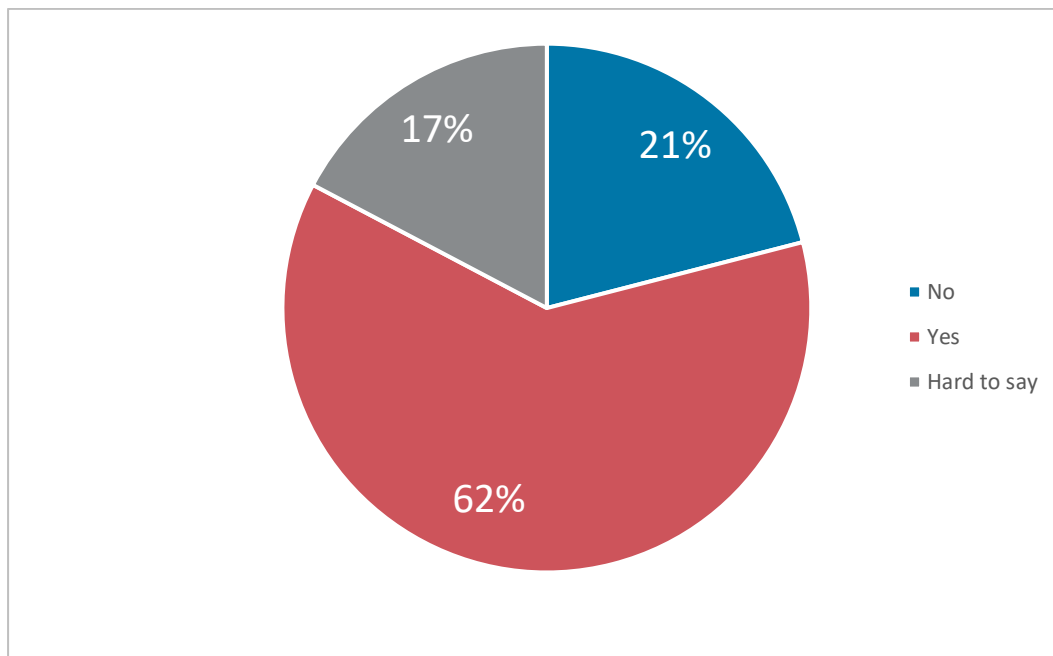
*“The participant/ person thinks he can do it alone, without my help, I disagree. I avoid more discussions about it. I have stopped and leave it to him. I only wait for him to give me info”.*

- - -

*“We provided many pages of information and a Dr’s letter etc. to NDIS prior to and during his assessment process. However, his plan was developed with very little/no consideration of the info provided - devastating as the plan was completely inadequate”.*

### Question 13: Did you feel that you were given the choice to have input into the participant plan?

Sixty-two percent of respondents feel they were given the choice of having input into the participant plan. Twenty-one percent felt they were not given the choice, and seventeen percent answered it was hard to say. Reasons for not having input into the plan could include the participant being unwilling to involve the carer, or that carers have not been invited to have their say.



Comments suggest carers can feel dismissed, unaware of opportunities for their involvement, and unsure of what their involvement should be given the focus on choice and control for the person with disability.

*“We have had difficulty getting a clear understanding of what is an “appropriate” amount of contribution. Our person is non-verbal and has complex/very limited functional communication decision making skills. This means he is reliant, often, despite being an adult, for others to assist him to have legitimate choice and control. We offered our ideas on a regular basis but few of those were acknowledged as valid or used as part of the requested plan supports. There are now significant gaps in what our person has covered in his plan”.*

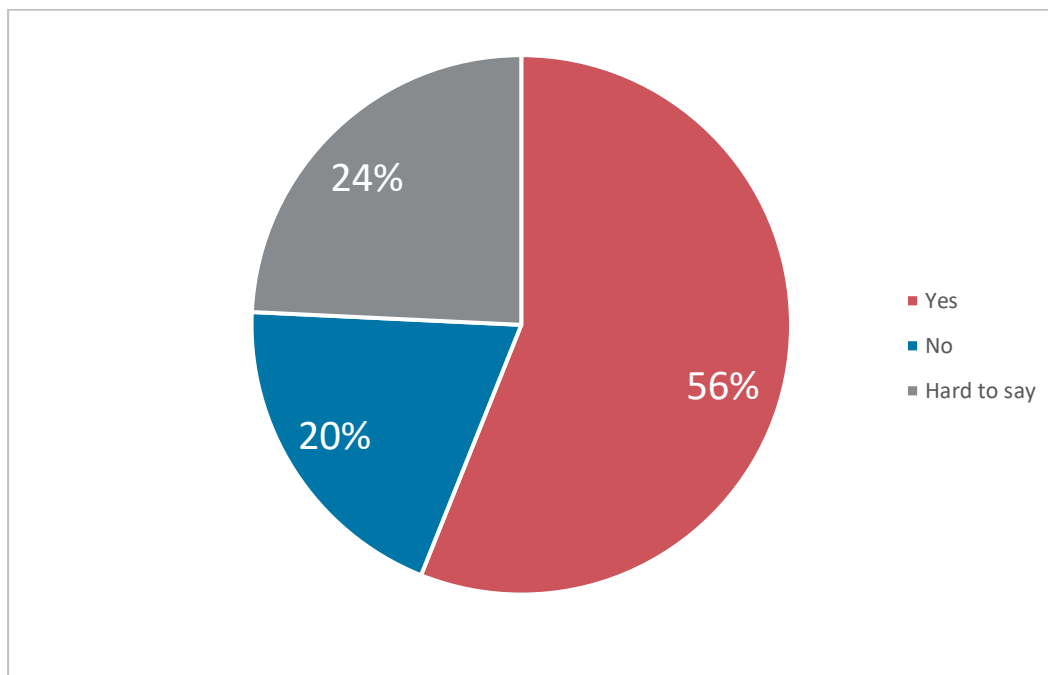
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*“They provided a plan and said it will be reviewed later on - even when we pointed out the extreme inadequacy and inappropriateness of the plan, the planners did not care or take anything on board”.*

**Question 14: If yes, you feel you had the opportunity to give input to the plan, did you feel that your input was included in the plan?**

For some participants, carer involvement in the development of the plan can be crucial to ensuring it is appropriate to their needs. A carer can be listed in the participant's plan as an informal support and can provide advice on the participant's support needs. Carers are also able to submit a Carer Statement at the planning meeting, which will provide the opportunity for the impact of the caring role, and succession planning for when the carer is no longer able to provide care, to be considered.

Fifty-six percent of respondents felt they were given the choice to have input into the plan, leaving just over forty percent who either did not feel they were given a choice or found it hard to say if they were.



Comments demonstrate some respondents feel they were adequately involved. However, other comments indicate suggestions were not always taken into account or consulted. The difficulty of lack of carer involvement is expressed by one respondent who states, while the person they care for sometimes objects to their involvement, the respondent is ultimately still in the position of providing support, without the context of the plan.

*“Any requests made by me over the counter were acted upon by my case manager”.*

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*“I had a wonderful planner and he helped and listened”.*

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*“The Health team and Tribunal have been consistent in notifying me of meetings where they are willing to involve me. Our loved one sometimes objects, but then expects us to provide support without knowing important elements of the Care Plan”.*

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*“Some things were considered, but problems with services not existing and no service provider willing to take on what we needed”.*

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*“Equipment required was regarded as medical and so not eligible”.*

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*“We did not see a final copy of the plan only the drafts then it was submitted without confirming with myself or my husband”.*

### Question 15: Rate your experience of the planning process from 1 (very poorly supported) to 10 (excellent support)

The weighted average for respondents to this question was 5.21, with over fifty percent of respondents rating their experience of the planning process as five out of ten or lower.

While some comments related to this question suggest staff were incredibly helpful in the planning process, others found while there was a willingness from staff to assist, the processes and the outcomes were unsatisfactory. There was also commentary around staff's lack of understanding of autism, and the distress associated with this for the respondent, and some dismissal of the caring role for another respondent.

*“Absolutely perfect, could not have been more supported”.*

- - -

*“We are very pleased with our current LAC - very helpful and understanding of our needs”.*

- - -

*“The man that helped with the plan was very nice to us and was as helpful as he could be, but we did not get what we wanted”.*

- - -

*“Planning was inclusive and helpful. But how the plan was to be put into place wasn't covered. A lot of assumptions were made by us and NDIS about responsibilities. Who was responsible for enacting the plan should have been discussed thoroughly”.*

- - -

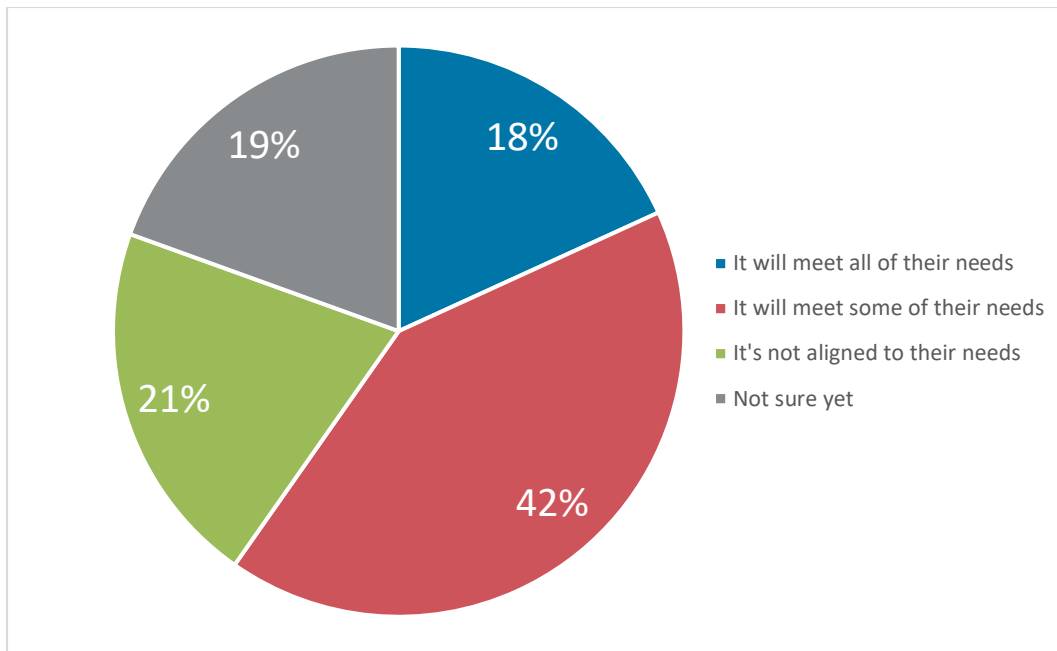
*“It's an extremely long process and it feels like the ‘mother’ / carer isn't really listened to”.*

- - -

*“Traumatic experiences with many time-consuming meetings and at times extremely rude planners many of whom had absolutely idea about autism - and still don't”.*

### Question 16: How would you describe the NDIS participant plan that was approved for the person you care for?

Eighteen percent of respondents said the participant plan would meet all of their needs. Twenty-one percent said the plan was not aligned to the participant's needs, and forty-two percent said it will meet some of the participant's needs.



Comments express frustration and distress regarding the time spent waiting for the plan to be reviewed, and for plans to be fully developed. Consequences of waiting included impact on development of the child or quality of life.

One respondent perceives their lack of access to review as impacting on their access to assessments, which may have resulted in the provision of funding for life saving equipment. While NDIS does not fund equipment that can be provided by the medical system, it does fund some equipment, through capital Supports budgets which can be funded in an NDIS plan.

Access to medical assistance, transport and equipment appear to be particularly difficult and complex areas for respondents to navigate.

While the plan may address the needs of the participant, comments reflect unavailability of services to implement the plan. One respondent suggests the use of an advocate can have a significant impact on participant outcomes.

*“It took three reviews and my son lost months of therapies!!”*

- - -

*“Did go through a plan review to sort out transport issues, but this was rejected. Couldn't review respite as it was approved, but no services available. Some OT's are fully booked had to go on waiting list, had to wait 8 weeks to access speech therapy. Not enough services available for participants”*

- - -

*“Medical is not supported by NDIS, yet they make a huge difference on his ability to move forward with his disabilities. I pay for dietitian and allergies specialist along with a biomedical therapist at very high costs so, we can get the best outcome with his OT, psychologist and speech therapy. I can't always afford his extra medical expenses as I am his full-time carer. Which limits me to work more hours than I already do. It's a difficult situation but I am very thankful that the NDIS have supported us to help him move forward. He has come so far, it's amazing. Without NDIS we would have had to choose either medical or disability therapy. At least this help allows us to do both at this current time. I appreciate the support NDIS has given us”*

- - -

*“Does not include anything we want and have been told we have to wait 3 months for it to run out while my husband sits in his room feeling as though he is dead because he has no funding to leave his house”*

- - -

*“Review request was not even acknowledged. We were told a review would occur down the track once further assessments were done, however there were not enough funds in the package to do those assessments. This delayed the process so significantly my brother died whilst waiting for urgent lifesaving equipment”*

- - -

*“I feel all considerations and necessary needs were not fully taken in consideration and therefore we are now going down the path of an External Review Process because of this”*

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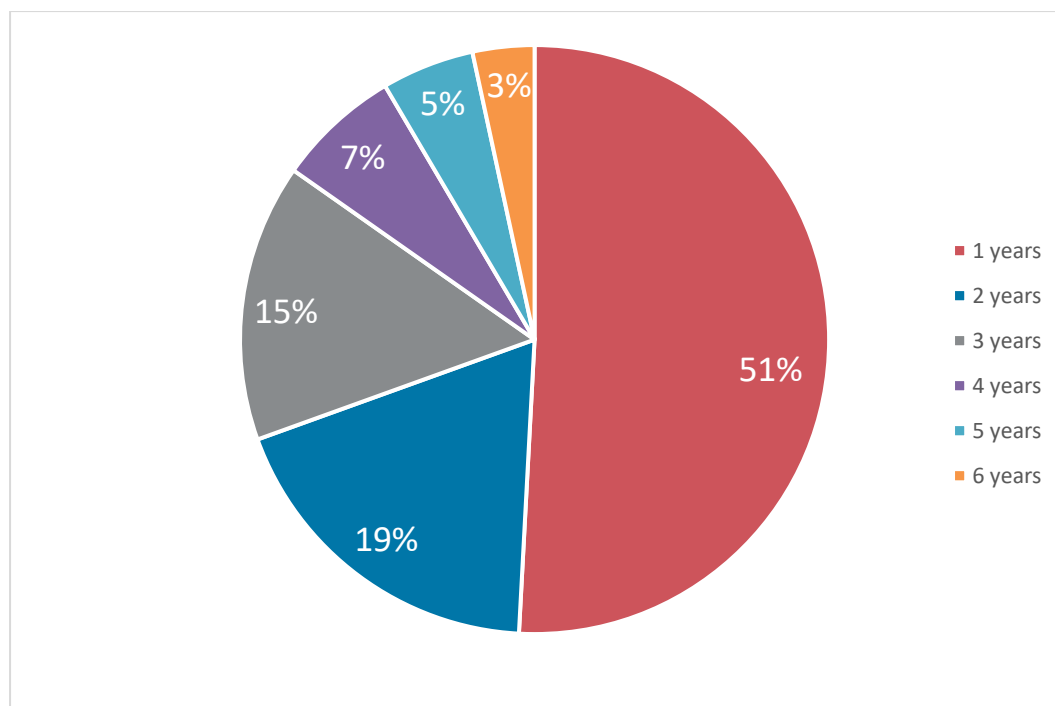
*“As the first plan was poorly implemented during a time when I had no input as my nominee form was lost by NDIS. My daughter lost all faith in NDIS as supports were incorrectly chosen and not in line with the plan”*

- - -

*“After the plan review with an advocate it will meet their needs”.*

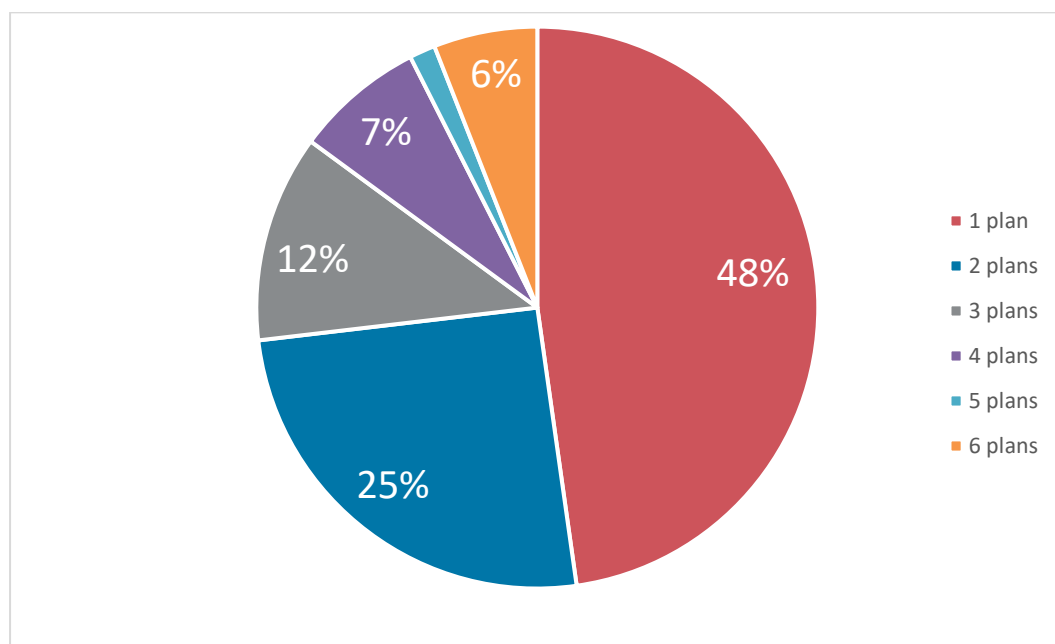
### Question 17: How long has it been since the first NDIS participant plan?

Fifty percent of survey respondents claimed it had been a year since the first participant plan, while for nineteen percent it has been two years. It has been four to six years since the first plan for the remaining 30 percent of respondents.



### Question 18: How many plans have you had?

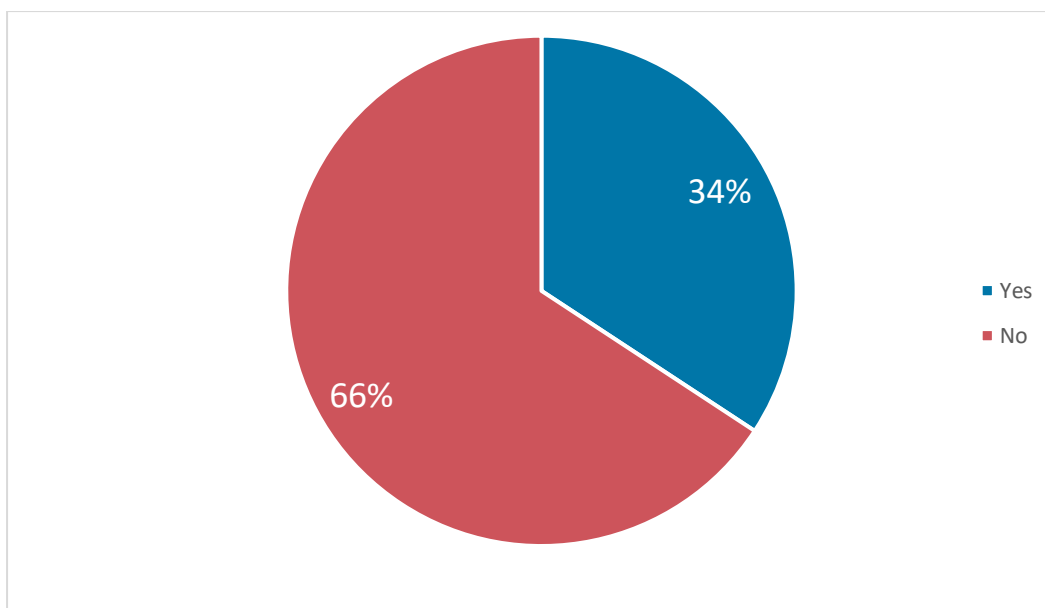
Nearly 50 percent of respondents said they have had one plan so far, with over 25 percent having had two plans. 20 percent have had three or more plans, and six percent up to six plans. This demonstrates the significant experience of those who have responded to the survey.





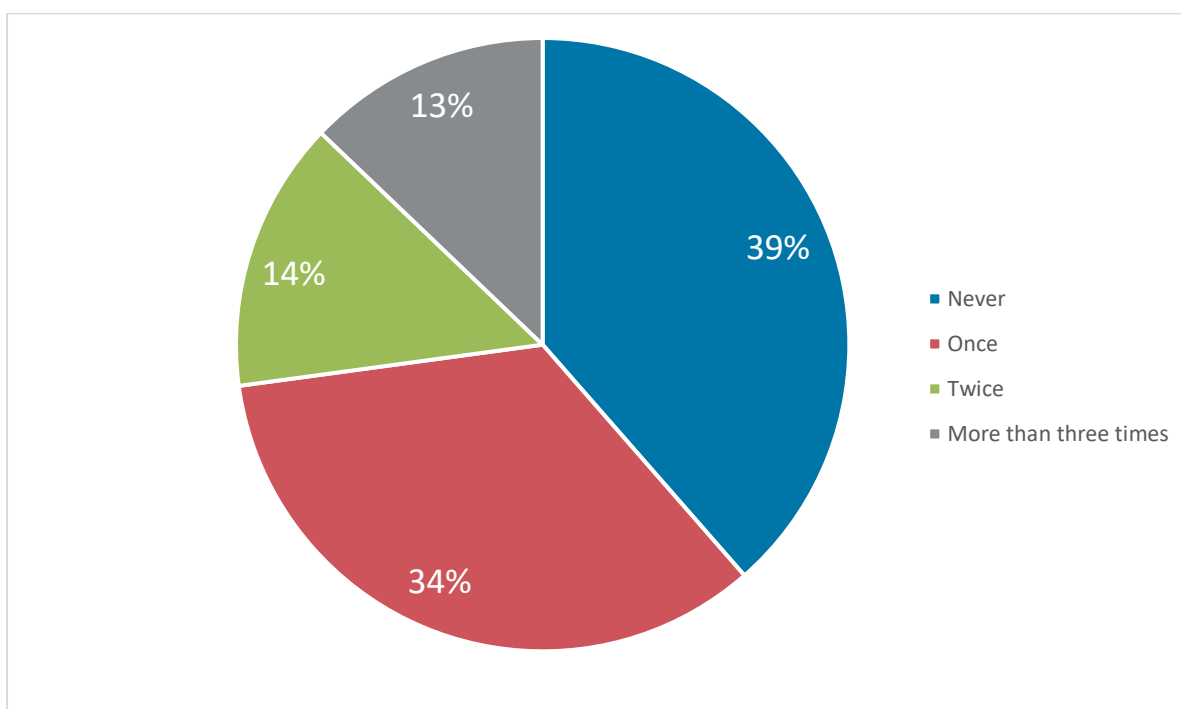
### Question 19: Has/have the plans been fully implemented?

Thirty-four percent of respondents answered the participant's plan has been fully implemented. Sixty-six percent answered the plan has not been fully implemented. This may mean there are still active goals in the plan, or that there have been challenges in full implementation.



### Question 20: How many times have you sought a plan review?

Just under 40 percent of respondents answered they have never sought a plan review. Over 50 percent have sought one review or more, with nearly 10 percent having sought more than three reviews.



One respondent stated they didn't know there was a review process. The stress involve in the review process is also evident, as is the value of an advocate.

*"The review took some time; we were desperate for assistance. Our family was falling apart and needed help straight away. We had to organise evidence to support the review. It was a very stressful period and should not be this difficult".*

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*"I have never been told I could have it reviewed".*

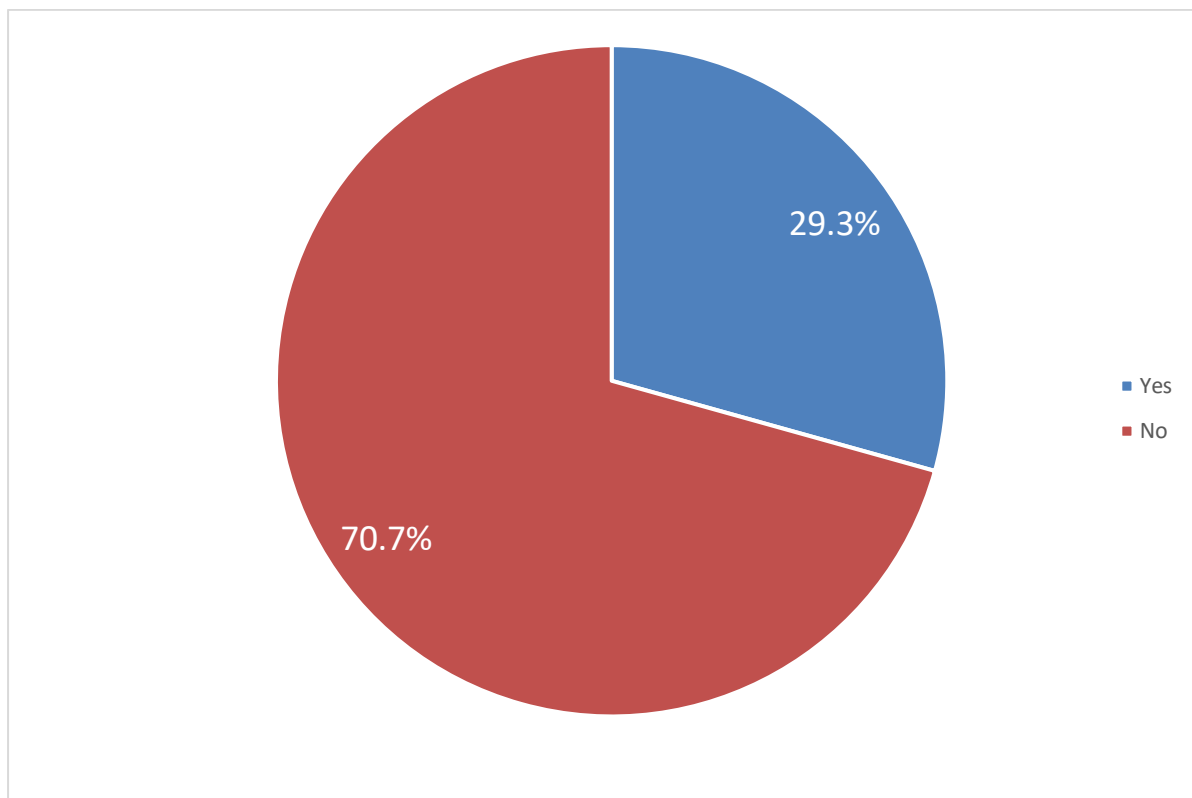
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*"It was not until we got an advocate on board that most of the recommendations were included".*

## NDIS Plan Management

### Question 23: Have you chosen to self-manage the NDIS participant's plan?

Self-management refers to the participant or their nominee managing the plan and paying for the supports with allocated funding. Individuals can choose to manage some or all of the plan. Just under thirty percent of respondents have elected to manage the plan.



#### Comments:

Comments indicate those self-managing choose to do so to maximise choice and control and ensure value for money. The need for more information and guidance around self-management is significant. One respondent shared their rationale for seeking assistance to manage the plan, was that they knew they needed help, but in doing so, they feel they were excluded from decision making. More participants and carers may choose this option if they were better informed.

*"Nobody has asked, don't know anything about it".*

- - -

*"I don't trust others to do it properly or support the person I care for".*

- - -

*"Has given us more control and choice over some aspects".*

- - -

*"We live 3 hours away from city and there were not many support services in our area. So I chose to self-manage to limit travel and expenses. Also, I feel it better to pay all therapy bills on my own and make sure we are getting the best value for money".*

- - -

*"We are exhausted. We took the option not to self-manage as we (uncomfortably) tried to acknowledge we needed some help. However, as a result we have been excluded from the obvious need to support our loved one in decisions that significantly affect his life. It's devastating".*

- - -

*"I requested to self-manage after advice on the benefits with regards to choice of provider, however the plan came back not self-managed. I was going to ask for the decision to be reviewed, but I haven't and now having learned that I can vary which parts are or aren't self-managed, I don't really know what decisions to make".*

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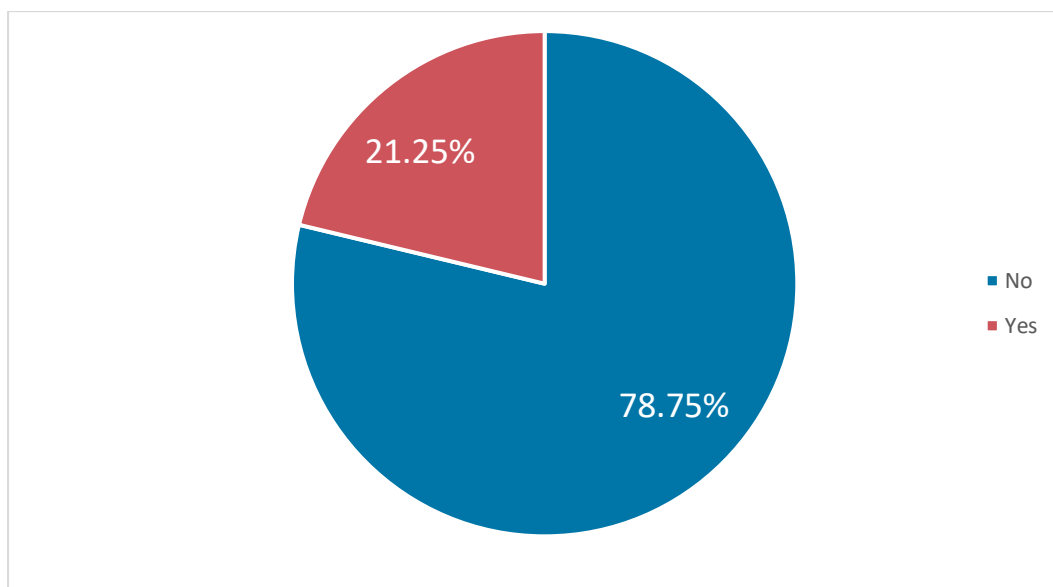
*"I thought it would be easier, but it has proved to be very difficult. I get conflicting advice from service providers, have been told they just need my son's NDIS number to pay for therapy etc, yet I still receive bills"*

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*"Lack of availability of approved therapists means we need to access therapists not on NDIS listings".*

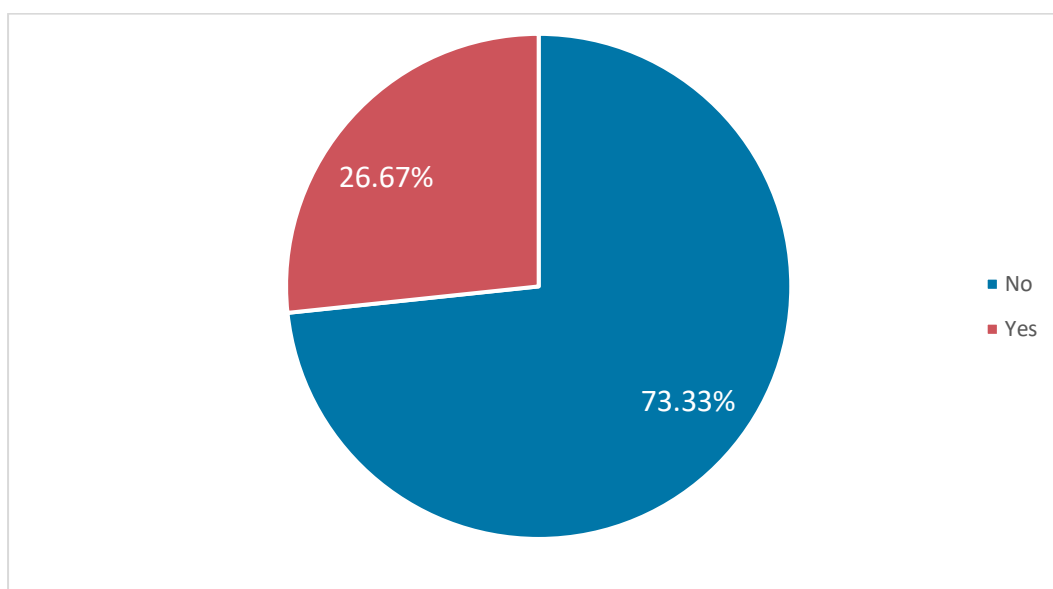
### Question 24: Do you have an involvement with the Early Childhood Early Intervention (ECEI)?

The Early Childhood Intervention approach is available to all children under 7yo with a developmental delay or disability. Early childhood partners provide families with information about the supports and services available in the local community and offer short term early intervention. These partners can help a family request access to the NDIS. Just over twenty percent of respondents said they had ECEI involvement. Nearly eighty percent were not involved with ECEI.



### Question 25: If Yes I have been involved with ECEI has this involvement enabled access to the NDIS?

Almost twenty-seven percent of respondents said their involvement with ECI has helped them access NDIS.



### Question 26: Can you suggest any ways that Carers Tasmania or NDIS or other organisation may help you self-manage?

Respondents indicate their need for more information and support to confidently self-manage the NDIS plan and ensure the best outcomes for the person they care for. Respondents suggest providers may also require more information, and some carers take cautious approach to their decisions so not to make a mistake or “waste” the government’s money. One respondent also expresses their concern regarding the vulnerability of the person they care for when they can no longer self-manage.

*“I suggest that Carers Tas be prepared to act as a mouthpiece for their clients from time to time. It is not easy for one person to be persuasive for a client cohort that feels disadvantaged, and for whom there is little political will to make improvements”*

- - -

*“I think there needs to be more information about self-management- perhaps a guide what supports can be used in what categories of funding. This is something I worry about - using the wrong therapy or support worker for community funding or capacity building funding. Sometimes I feel that he needs a certain therapy person but am not sure if it’s allowed in current plan. So, we don’t use it. I budget his money very tightly and feel that helping to save the government money is the way to go. So, more information on different supports and best prices to get the best from his plan and the best outcome for him”*

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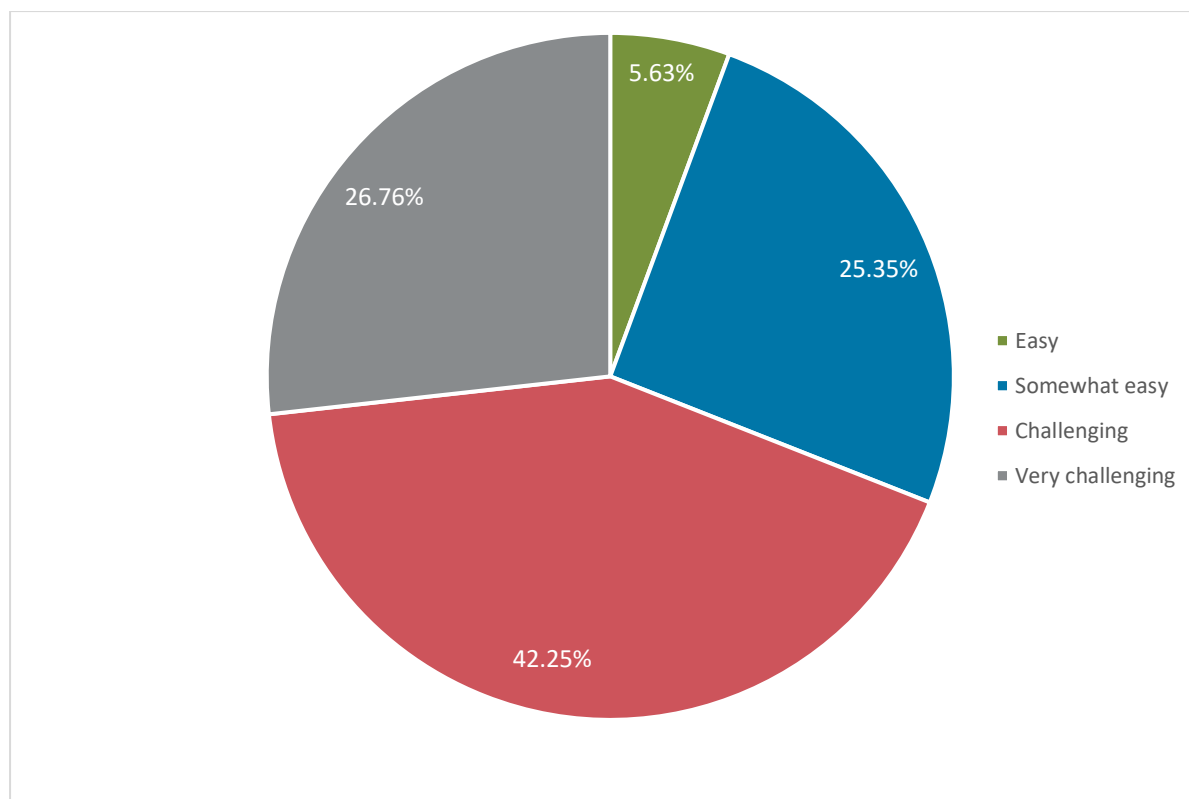
*“A more in-depth explanation of exactly how and what you need to do to access funds. Education of health care providers as I have been told so many different things. I am a registered nurse and am still finding it very difficult to navigate”*

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*“Describe a viable transition process for the management for when I die. i.e. Remove the single person dependency that self-management creates”*

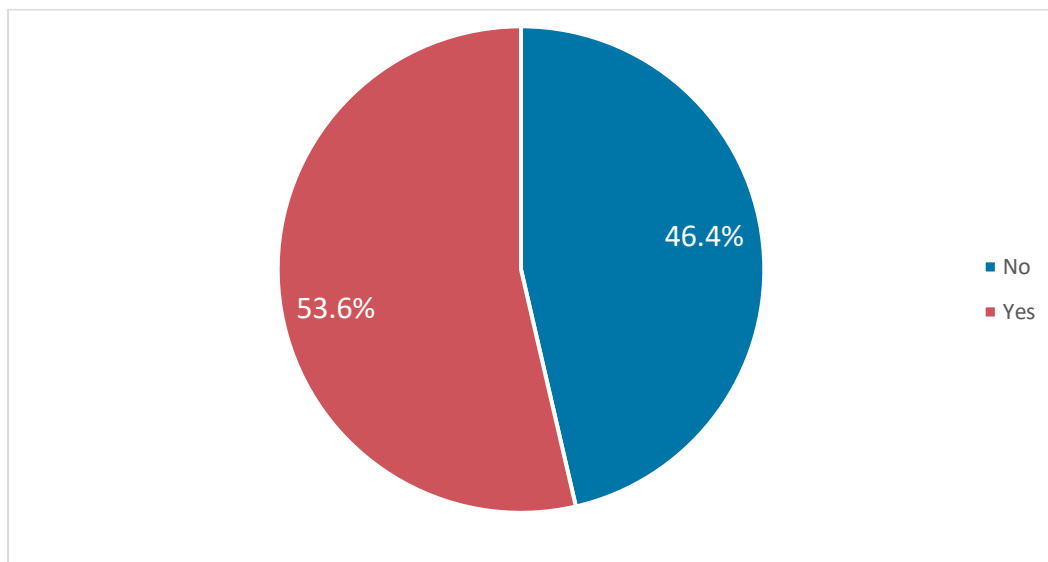
### 27: How easy has it been to source services funded under the plan?

Nearly six percent of respondents have found it easy to source services funded under the plan. A further twenty-five percent have found it somewhat easy. Forty-two percent have found it challenging, and a further twenty-six percent very challenging.



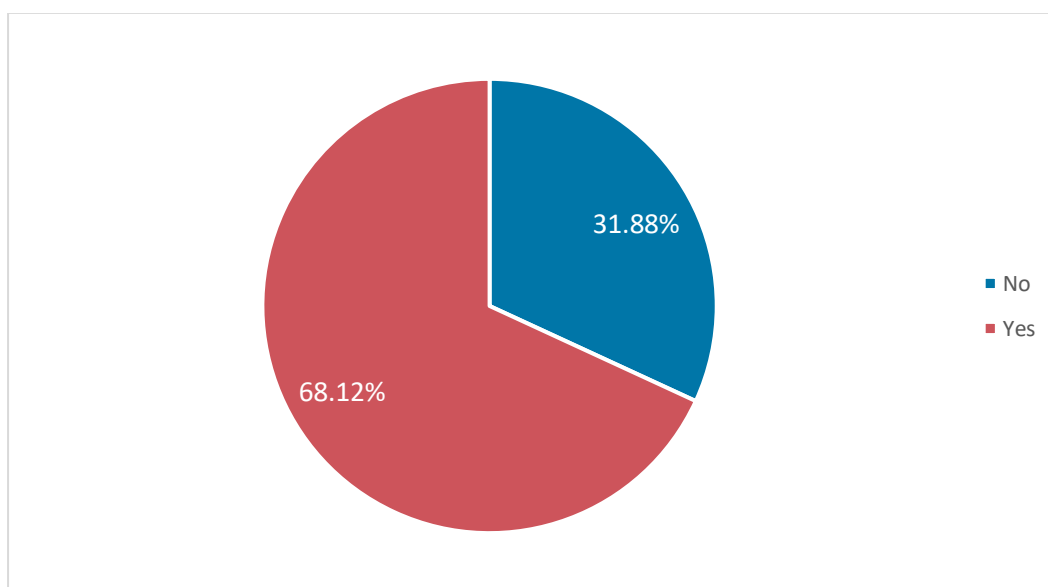
## 28: Is there a Support Coordinator in the plan?

Three levels of support co-ordination are available in an NDIS plan. This includes support connection (to build capacity to connect with informal, community and funded supports), support co-ordination (to build the skills needed to understand, implement and use the plan), and specialist support (for those with complex situations). Over fifty percent of respondents have a Support Co-ordinator in the plan.



## 29: Did you use a Local Area Coordinator (LAC)?

A Local Area Co-ordinator can help participants and their nominees (usually their informal family carers) to create a plan, find services, and assist with any issues. The Local Area Co-ordinator can help make changes to the plan through review processes. Nearly seventy percent of respondents used a Local Area Co-ordinator in Support Co-ordination.



Comments suggest access to a LAC may be difficult in remote areas and the quality is variable, but that LAC involvement can influence what is achieved in a plan.



*“Well she is 3 hours away, but she is classed as our local one”*

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*“My daughter’s case way too complex for a LAC. First Coordinator was very good, present one we have just given notice too as not proactive at all”*

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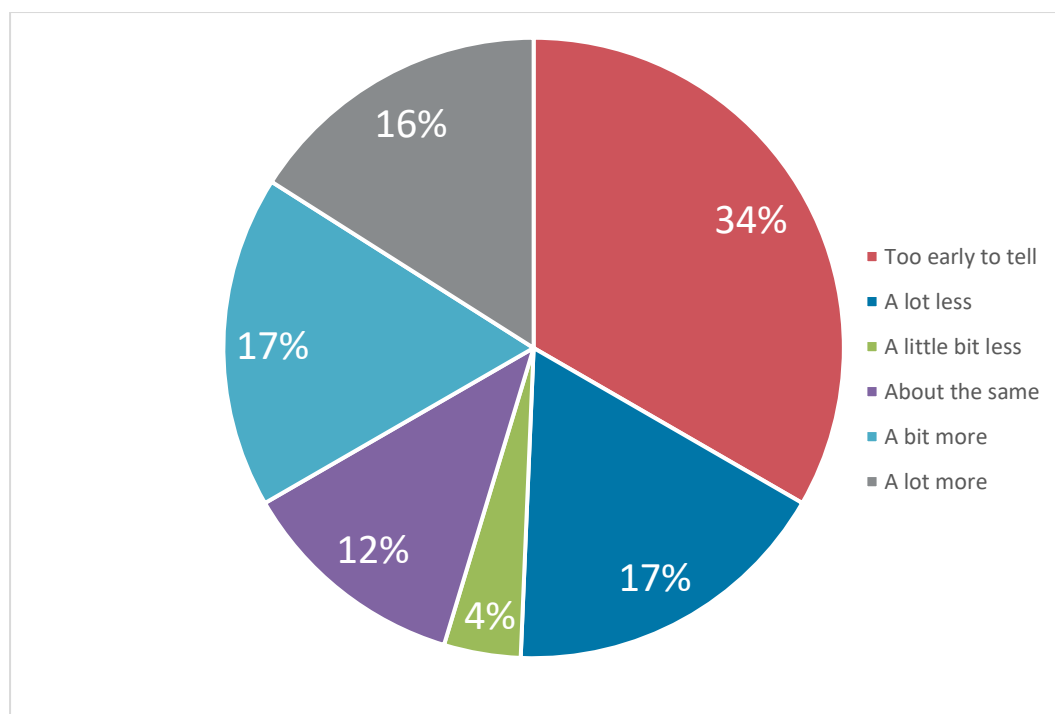
*“The LAC has not always answered emails and does not always know the answers to question”*

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*“Originally there was, but we didn’t know, then there wasn’t so little got done in the early years. Now we have a LAC for some parts, and I self-manage other section”*

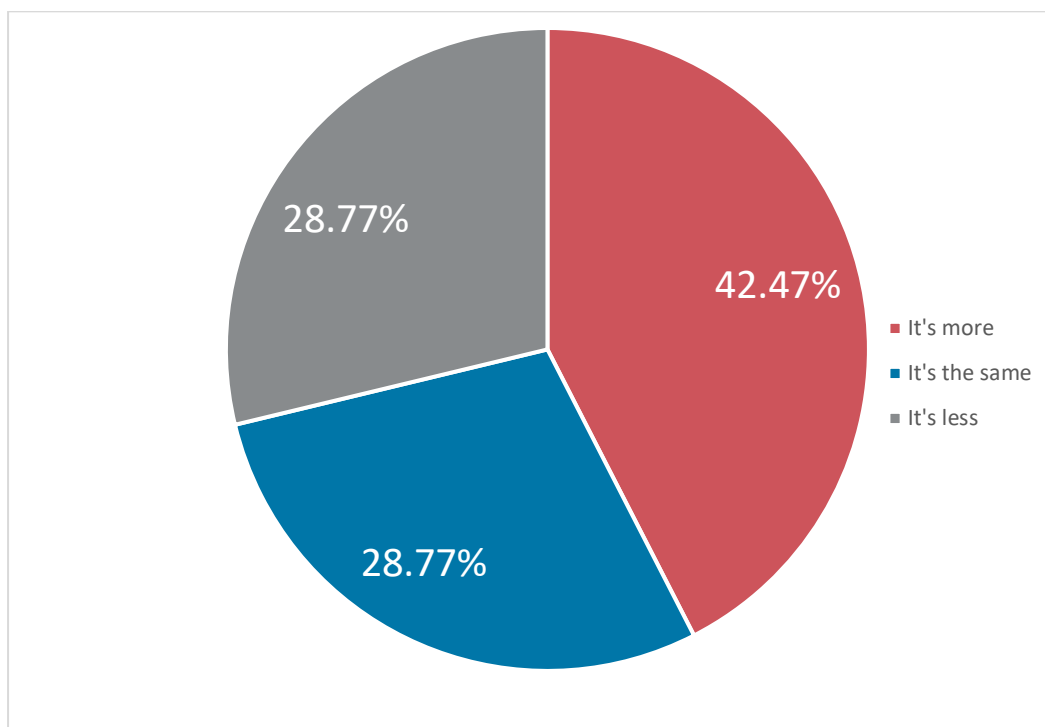
### 30: Do you feel the NDIS supports provided have improved outcomes for the participant?

Sixteen percent of respondents answer NDIS supports have significantly improved outcomes for the person for whom they care, and a further seventeen percent that NDIS supports have improved outcomes a bit. Seventeen percent state that supports provided have improved outcomes a lot less, with sixteen percent stating it is about the same or a little bit less. Thirty-four percent answer it is too early to tell.



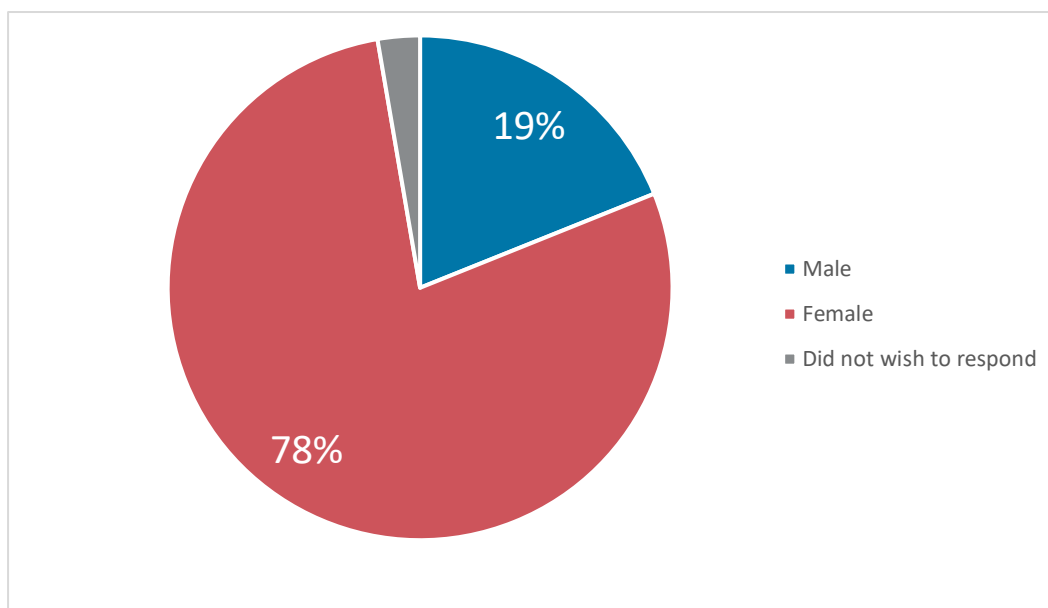
### 31: Has the level of support provided by the NDIS participant plan changed from supports before NDIS?

Nearly sixty percent of respondents say the level of supports provided by the NDIS plan are the same or the less than prior to NDIS, with just over forty percent stating supports have increased.



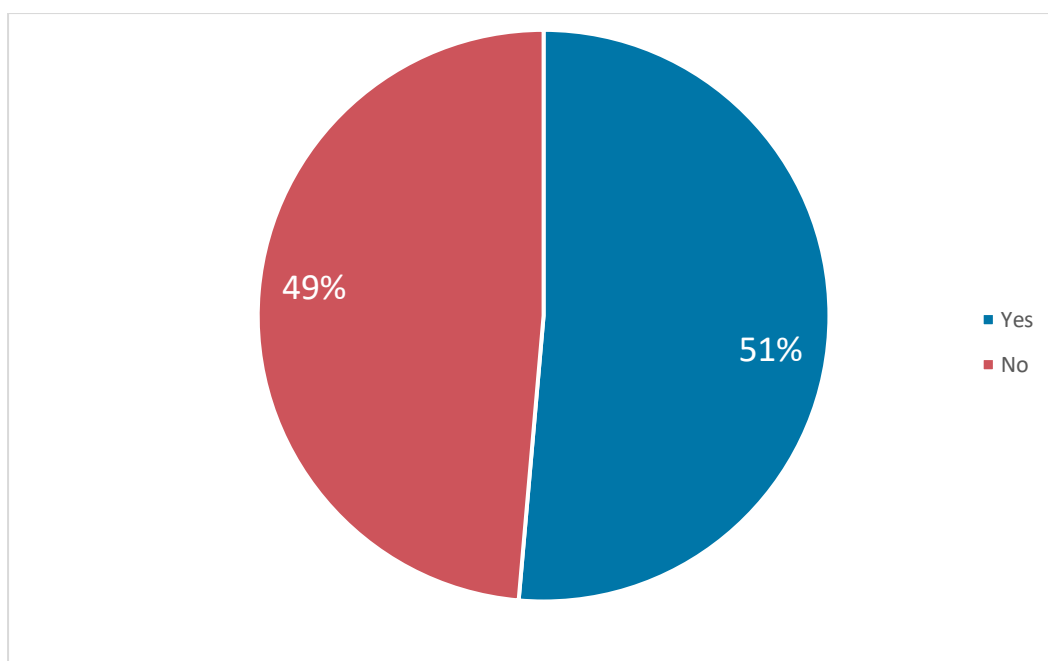
## Carers of family members or friends with a disability

### Question 2: What is your gender?



### Question 21: Have the funded supports in the plan assisted you as the carer and helped to maintain family wellbeing?

The NDIA states supports for the person requiring care may have direct or indirect benefits for the carer, and it may consider supports to maintain carer health and wellbeing. Just over fifty percent of respondents say the funded supports in the plan assist them as a carer and help maintain family wellbeing.



The cost of providing current assessments as part the application process can have an impact on families and this is reflected in the comments. The impact of uncertainty and waiting for funding to be approved can also be difficult.

For some respondents the NDIS has provided access to respite through the provision of short terms accommodation for the person requiring care outside the family home. For others, incidental respite occurs as a result of the participant's engagement in the community.

Comments reflect the carer can still be heavily involved in engaging the person they care for in their supports.

*“My son is more involved in the community as a result of NDIS”*

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*“We have monthly "short term accommodation" i.e. respite in our plan which allows us to spend time together”*

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*“A little, but nowhere near what we thought. We are still doing quite a lot of 'caring and supporting' (e.g. appointments etc) as things wouldn't happen otherwise. We thought the NDIS would relieve some pressure on our health, but not yet”*

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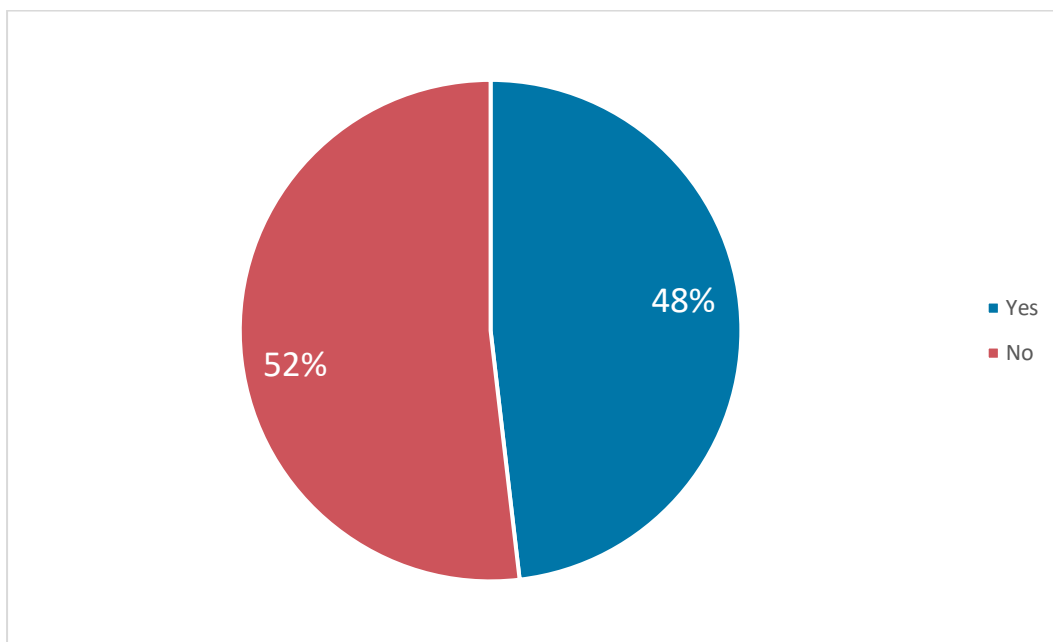
*“Have a huge amount of supports, but it has cost our family hundreds of thousands of dollars to get on scheme and has been hugely stressful”*

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*“Yes, when we get the limited equipment to try and meet some of our child's needs it would help. Have been waiting for months to find out if equipment we need is going to be funded. Still waiting”*

### Question 22: Do you feel well as a carer?

Of significant concern is over fifty percent of respondents answered they do not feel well as a carer.



Comments suggest the process of navigating and advocating to access support, and having inadequate support, impacts on wellbeing, with carers often feeling stressed and exhausted.

A range of other emotions associated with caring, including grief, fear and powerlessness, are reflected in the comments.

Respondents describe coping with significant stress before the plan is fully developed and adequate supports are in place. One respondent described the need to remain vigilant about the care and supports that are provided. This may refer to the quality of the supports, or ensuring supports are maintained.

*"Yes, now that we are accessing services. However last year when we had a plan that did not meet our son's needs, we had over 12 months where we were constantly stressed, not enjoying our life and not knowing where we were heading. Now we have supports in place we are feeling happier and our son is progressing. We are now able to deal with issues when they arise".*

- - -

*"I feel as well as can be expected; "carer" is not a role I expected to take on, nor would I have volunteered for it".*

- - -

*"Feel exhausted with all the battling, stressed, and constantly having to be vigilant about supports and the care my daughter receives".*

- - -

*"I am exhausted, scared for my physical safety and worried about our future. We want our person to be safe, engaged, and independent, build capacity for himself. I cannot see this happening in the medium to long term".*

- - -

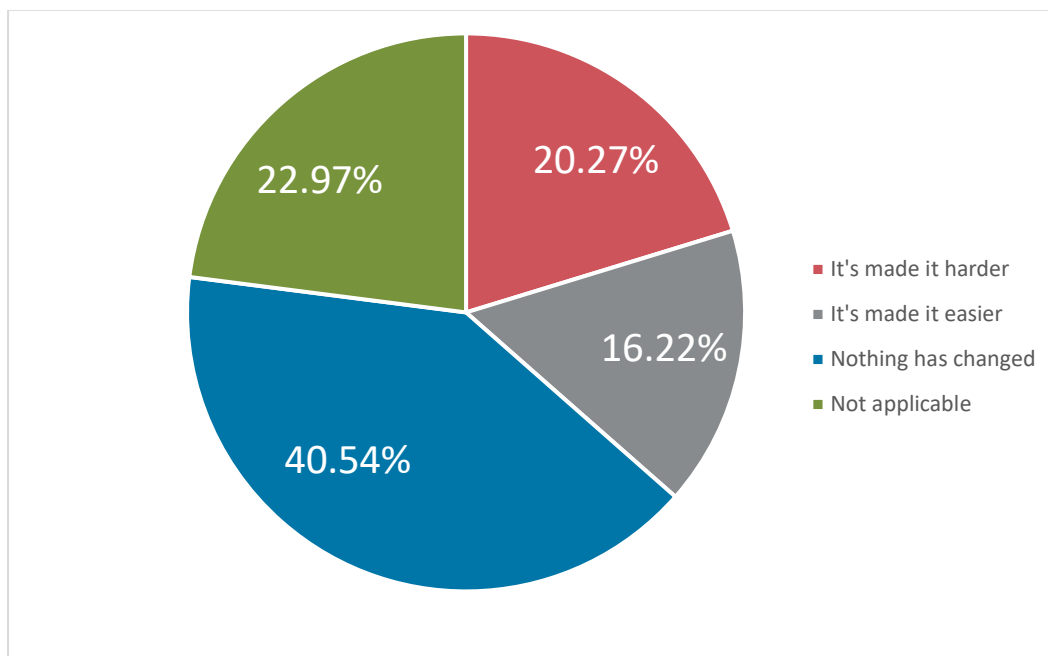
*"This is hard to answer as it varies so much. My son has not been able to access short term accommodation for three months and I am very tired. Hoping to feel stronger when have been able to access more supports across the week and also regain a respite placement".*

- - -

*"It's draining, depressing, generally unrewarding with no end in sight and very little support emotionally or financially. It is the worst thing that has ever happened to me. There should be other alternatives".*

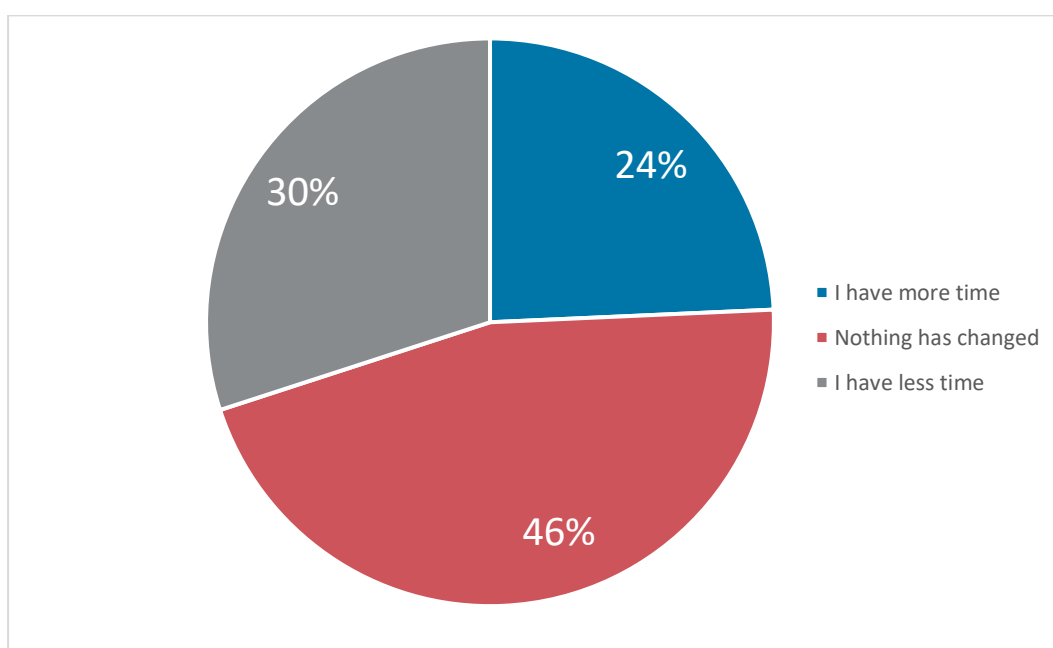
**32: Has the fact that the participant is now an NDIS participant had any influence on your ability to meet existing work or study commitments or seek new employment or study?**

Forty percent of respondents state they are no more able to work or study, with close to twenty percent stating it is harder, and sixteen percent finding it easier.



**33: Has the NDIS meant that your time out from caring has increased and that you have more time for yourself?**

Twenty-four percent of respondents say they have more time out from caring. However, nearly thirty percent say they have less time and a further forty-six say nothing has changed.



The relief felt by carers to have quality care in place and be seeing significant outcomes is evident in their comments. Other comments illustrate additional work is spent navigating NDIS, that in rural

areas services are not always available, and there are significant financial consequences for some carers. Also, while direct support may alleviate some of the caring load, carers may be using this time to address other aspects of care. Some respondents state NDIS supports don't provide an adequate break from their intensive caring responsibilities.

*"I have 3 hours' time out from caring a week now. It might not seem much, but I am very happy to get this time. The best thing about this time is my boy is happy to go, and I know he is being cared for and is safe and well supported by someone who is qualified. She helps him with his therapy which also takes the pressure off me - I don't have to do his OT and speech therapy cards because he has done them with his support worker. This also gives us a break. So, it's not just 3 hours, we are getting so much more, and Mr 5 is learning to move forward with someone else, not just me".*

- - -

*"Having respite carers has been amazing. I can work a little more and support my family more financially, and my daughter is extremely happy with her carers".*

- - -

*"We live in a rural area, so the only service we access in our area is in home help and an occasional social "date" for our older son, where he is taken out in his chair for a walk, milkshake or to visit to a neighbour".*

- - -

*"Means more commitment to appointments. More time in the car on the road as we live in a rural area".*

- - -

*"Because my daughter is now away from us some of the time, we have lost the Carers Payments from Centrelink, and yet much of the ongoing cost of her daily care is subsidised by us".*

- - -

*"I work part time and my free time is taken up with appointments, however I would not change this as I can see the benefit, he is getting from accessing supports".*

- - -

*"Can only hope that eventually things will improve but currently only able to access 13 hours a week of support. This leaves me unable to work and very much the carer for my son who cannot be left home alone, still needs lots of help with daily routines, and has no road safety awareness".*



### 34. Are there any general comments that you would like to make about the impact of the NDIS on your role as a carer?

#### General comments:

General comments demonstrate how variable the NDIS experience can be for carers. The individual carer experience may be dependent on the disability and circumstances of the participant and their family. After some time in the scheme, some respondents are beginning to understand how significant the outcomes can be, are seeing remarkable results and are incredibly happy with the outcomes for the people they care for. Others are still experiencing confusion and exhaustion and feel uninformed, undervalued and excluded. Their comments reflect a loss of hope, significant distress, and trauma.

"The NDIS has made it possible to live more of a "normal" life with all 3 people in our home. The supports have helped not just the person with disabilities but each of us. The therapy supports have built all of us together, made love and friendship in our home. It's made us socially acceptable within our community. Mr 5 has improved dramatically and it's wonderful to see so many things moving forward. Without the NDIS supports this would not have been possible. I feel that Mr 5 will one day be able to be like a "normal" boy. He will one day manage his everyday life skills on his own and will not need the support from the NDIS. I believe the government have got it right by giving support to children when they are young. For us the NDIS has been remarkable".

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"I don't think there is any emphasis on looking after the carer. I am put at serious risk for injury as I have to carry/ lift my heavy child (who is unable to walk) from car to house, toileting, bathing, bed et, and yet trying to get help with equipment is so difficult".

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"Overall happy and life is easier with the NDIS. Happy with all the supports that have been in place".

*"The role of the carer isn't acknowledged as a legitimate need. NDIS does not (in my experience) care for the carer. I feel lost amongst all the bureaucracy and less important than ever!"*

- - -

*"I was thinking the other day how NDIS has changed our lives. I worry at any moment the money may be cancelled by the government. We just hope and pray it doesn't, NDIS is enabling us to have time out for ourselves, have our daughter cared for by amazing carers - helping her become more independent and less reliant on me I can work more and provide for my family better...she is learning so many things to assimilate into society".*

- - -

*"It's been a long 18-month journey of learning, challenges, numerous hours of research, tears, stress, it's time consuming and affecting our own health".*

- - -

*"The NDIS delays contributed to my brother's death - they need to urgently change their processes so no one else has to suffer like my brother while he patiently and hopefully waited and then gave up hope and died, also so that no other family has to grieve the loss of a loved one like we have had to".*

- - -

*"I am confused. I have less information on my role as a carer under NDIS. The participant believes I have less of a role, and he controls it. He believes my participation will make it complicated. He is confused himself. I am desperately stressed, and I don't care anymore".*

- - -

*"My health has declined, I have had to leave my full-time job just to try and manage the system as there is no captain of the ship leading you to the next port. In fact, it's like being on a sinking ship and having to push and shove for a place on a life raft".*

- - -

*"It is an administrative nightmare at present, and very top-heavy in our experience...I hope it will become more usable as time passes, because tired mothers like me do not have the energy or emotional strength to tackle a stack of bureaucratic negotiations".*

- - -

*"It has taken a couple of years, but I feel as though I'm finally getting my head around the NDIS. Our family feels fortunate to have found a LAC who knows what he's doing. As for the impact of the NDIS on my role as a carer - realistically, I'm still accessing all the same services that I used to access, but now I have more paperwork to do, more bureaucracy to deal with, and a plan that has to be re-visited every year".*

## Conclusion

It is pleasing that some survey respondents are beginning to see significant results for the person they care for and are grateful for what the NDIS means for their future.

Carers Tasmania fully endorses the principles of the scheme for its potential for early intervention, independence and social and economic participation of people with disability and what this can mean for their informal carers.

It is understandable that a scheme of such enormity will experience challenges as its policies and procedures are communicated and implemented in the context of communities that are not yet market ready, and the complexity of individual circumstances.

This is evident in survey results. Respondents are still grappling with understanding some components of the scheme, and their comments suggest service providers and those within the NDIS are still on a steep learning curve, with significant consequences to wellbeing. Eligibility, application processes, reviews, carer inclusion, and self-management are all areas where families require more fulsome knowledge and support in order to navigate the system and its imperfections and get the best from the opportunities that an NDIS plan can bring.

Results suggest the NDIS is still at times grappling with the balance between the right of the individual and involvement of the informal carer, particularly when the participant is an adult. Carers Tasmania will continue to advocate for the involvement of the carer to be the default position of NDIS, and that carers are made fully aware of their right to be involved and processes for this to occur.

Respondents' comments suggest that carers in rural and remote areas are unable to find the services they need, despite funding being available in the NDIS plan. Carers in this situation have no choice but to continue to provide the support.

Informal family carers faced with the challenges demonstrated in this survey are, understandably, still finding it difficult to return to any real focus on their own social and economic participation. Carers should no longer be perceived as welfare dependant, but fully acknowledged and supported for the contribution they are making to sustaining those who would otherwise face significant vulnerability.