



Is the National Disability Insurance Scheme supporting unpaid carers of people with a disability?

A study on the impact of the NDIS on family and friends who care for people with a disability in the ACT.

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EXECUTIVE SUMMARY

About the National Disability Insurance Scheme

The National Disability Insurance Scheme (NDIS) began as a trial site in the ACT in July 2014. It was anticipated that the NDIS would reach full roll out in the Territory in June 2016. As at 30 June 2016, there were 5,229 NDIS participants in the ACT which had surpassed the 4,278 projected participant number. The ACT was the first state or territory in Australia to transition all age and disability-type eligible participants into the NDIS.¹

The NDIS supports people who meet disability and early intervention eligibility requirements and who are aged under 65 years.

About Carers ACT and carers of people with disability in the ACT

Carers ACT is the major provider of support services to unpaid family and friend carers² in the ACT.

There are 28,000 unpaid family or friend carers in the ACT who care for people with disability under the age of 65 years. Of these, 6,700 are primary carers (the person who provides the most care to person with disability needing support) and 1,430 carers provide care to people with severe and profound disability under the age of 65 years.³

Carers underpin the disability care system and provide 74 per cent of all community care.⁴ Some care for long periods and some shorter. In the ACT, 2,600 unpaid primary carers averaged over 40 hours a week caring, 1,600 averaged 20-30 hours a week, and 4,500 averaged 20 or less hours a week caring for a person with a disability.⁵

Carers ACT has had a close involvement in the design and implementation of the ACT NDIS trial site since its inception. This involvement includes through the ACT NDIS Expert panel, carer consultations and discussions with the ACT National Disability Insurance Agency (NDIA). Carers ACT also provided NDIS readiness awareness sessions for carers and caring families, and employed a consultant to assist them with the NDIS assessment and planning process for the person they cared for. Carers ACT is a registered NDIS service provider and offers NDIS care coordination, financial management, after school care programs and a range of skill development and community participation activities.

Through this involvement and carer engagement through our carer support services, Carers ACT became aware that many carers experienced challenges associated with the NDIS transition. These included the time required to manage the NDIS participant plan and perceived reductions in

¹ NDIS trial sites in other Australian jurisdictions were restricted to specific disability types or age and life stage of people with disability.

² Unpaid carers are family or friend carers who care for an individual with a disability, a chronic condition, an alcohol or drug dependency, a mental health issue, a terminal illness or who is frail aged. A care worker, often referred to as a carer, is a person who is paid to provide age or community formal services.

³ Australian Bureau of Statistics (2017) *2015 Survey of Disability, Ageing and Carers ACT*, released 12 January 2017, Canberra.

⁴ Australian Bureau of Statistics (2014) *Caring in the Community, Australian summary of findings, 2012*, Canberra.

⁵ See 3 above. Note: this data refers to primary carers of all people with a disability, a chronic condition, or who is ageing.

provisions for replacement care, such as respite,⁶ to provide them with a break from their caring role and to improve their wellbeing.

These challenges contrast with the expected outcomes for carers and caring families under the NDIS.

About the NDIS and Carers Survey

Carers ACT contracted the Nous Group to co-design a short online survey to examine carer engagement with the NDIS and its impact on carers and their caring role. The NDIS and Carers Survey was designed to be completed by carers within 10-15 minutes. Information about the survey was distributed by email to 1,698 Carers ACT members who cared for a person with disability. A small number of hard copy surveys were distributed to carers who did not have internet or email access. There were 120 survey responses.

More information about the survey design, including survey limitations, are available in Part A of *A study on the Impact of the NDIS on family and friends who care for people with a disability in the ACT* (the *NDIS and Carers Survey Report*).

Independent statistical consultant Stacy Vueti undertook the survey analysis. Details and outcomes of the survey analysis are available in Part B of the *NDIS and Carers Survey Report*.

Key survey findings

About the care recipient

The average age of the care recipient was 27 years, with a minimum age of four years and a maximum age of 65 years. The average length of time an NDIS participant plan had been in place was 10 months, 30 months was the longest.

A similar number of care recipients had a physical or psychosocial disability, 31 per cent and 30 per cent respectively. Thirty-nine per cent identified “Other” as the disability type, although the disability identified in this group could have been included in physical and psychosocial disability types.

Twelve carers cared for a total of 28 care recipients. Two care recipients were assessed as ineligible for NDIS participation.

Satisfaction of carers with the NDIS participant plan

The “no disadvantage” principle underpins the NDIS. This principle is a government commitment that an NDIS participant will be no worse off under the NDIS and they should not be disadvantaged by less support services or the type of support they received prior to their transition to the NDIS.⁷

⁶ The level of respite included in an NDIS participant plan is lower than the respite level people with disabilities (and their carers) received prior to the NDIS. However, some funded services such as capacity building, social engagement or employment support were anticipated to provide replacement care that can provide a break from caring for carers and families.

⁷ National Disability Insurance Scheme, Fact Sheet: *What is the Principle of “no disadvantage”*. Accessible at <https://www.ndis.gov.au/document/what-principle-no-disadvantag.html>

Only 18 per cent of respondents indicated that the NDIS participant plan would meet all the care recipient's needs, 55 per cent felt that it would meet some of their needs, 7 per cent felt it was not aligned to their needs and 20 per cent were not sure.

A significant survey finding about a carer's satisfaction with the NDIS participant plan appears to be correlated with how carers felt their input was valued and respected by the NDIA during the NDIS planning process. Twenty-three per cent of carers who felt their input wasn't respected or valued indicated the NDIS participant plan was not aligned to the needs of the person they care for compared to 4 per cent who felt their input was valued and respected. This is an area for further investigation.

The level of support offered to carers for their caring role under the NDIS

Carers are not the focus of the NDIS and are not considered NDIS clients. However, it is anticipated services funded in the NDIS participant plan will provide direct or indirect benefits to carers. The NDIA can link or refer carers and families to mainstream and community services to assist their caring role.⁸

The majority (80%) of respondents indicated they were not offered services to support their caring role, with 20 per cent offered services that supported their caring role.

As 97 per cent of carer respondents were engaged in developing the NDIS participant plan this low level of reported support offered to carers through the NDIS is concerning. Particularly, as evidence indicates carer-focussed support has a positive impact on carers wellbeing.⁹

Several carers commented on the lack of support for carers, including direct support, under the NDIS. These included:

"There is no direct support for me any longer as a carer ... I was better off before the NDIS as a carer."

"... perhaps some acknowledgment that the carer needs caring for [is required]."

The lack of support for carers in the NDIS participant plan may be related to carers seeking the best outcomes for care recipients during its development with limited consideration of how support services included in the plan would support them and their caring role. It may also be related to limited awareness that direct funding for carer support services is outside the role of the NDIS. The survey did not ask the type of support carers were offered. This is an area for further investigation.

Increased engagement in employment by carers

In the ACT, 62 per cent of carers were employed full-time, compared to 71 per cent of people without caring responsibilities. Carers were more likely to be employed part-time than non carers.¹⁰ This lower carer employment participation rate means that many caring families experience financial disadvantage.

An expected outcome of the NDIS commencement was that it would reduce the level of care provided by carers and families and increase their capacity for employment or education.

⁸ National Disability Insurance Scheme, Information for families and carers webpage. Accessible at: <https://www.ndis.gov.au/families-carers/information-families-and-carers.html>

⁹ Cummins, Robert A et al, *Carers counselling intervention study*, Deakin University, Geelong.

¹⁰ See 3 above.

Survey findings indicated that the largest proportion (35%) of carers felt that there was no change in their ability to meet existing work commitments or seek new employment since the start of the NDIS. Twenty-seven per cent found it was now harder and only 11 per cent found it was now easier.

This outcome strongly correlates with the reported increased time carers spent communicating with the NDIA and others about the NDIS and time taken to manage the NDIS participant plan. Carers who spent more time managing the support needs of the care recipient found it harder to meet existing work commitments.

The impact on carers to self-manage the NDIS participant plan

NDIS participants or their carers and families have the choice to self-manage or partly manage the support planning and coordination of the NDIS participant plan. Alternatively, carers or participants can choose to engage an organisation or another individual¹¹ to undertake these roles.

Of carers who answered the question on self-management of the NDIS participant plan, 41 per cent chose to self-manage. The majority (59%) of carers chose not to.¹²

Even with the benefits associated with self-managing an NDIS participant plan – choice and control over who delivers support services, and a wider option to purchase supports from non NDIS registered service providers¹³ – self-management had a significant impact on carers time, their wellbeing and their ability to engage in other activities.

One carer commented:

“[Self-management] has also increased my workload and stress ... I am now doing the work of managing the plan, services, keeping up the with the NDIA and their IT issues, paying invoices on top of my caring role and parenting role etc. I am doing full-time unpaid work with the stress load increasing health issues.”

The impact of time out or a break from caring because of the NDIS

Carers have the lowest wellbeing of any large population group in Australia,¹⁴ and are more likely to have a chronic condition than people without similar caring responsibilities. Respite, or replacement care services, are supports to help improve carers health and wellbeing and to assist carers sustain their caring role.¹⁵

Although the NDIS does not provide direct carer services, the NDIA has the capacity to build reasonable and necessary supports into the NDIS participant plan to provide time out or a break for carers from their caring role.

¹¹ An organisation or an individual who is engaged to manage an NDIS participant plan for the participant is required to be a registered NDIS provider. If the NDIS participant plan is managed by an organisation or another individual the case coordination costs are included as an additional cost in the NDIS participant plan. If the NDIS participant plan is self-managed by the participant or their carer no plan coordination costs are included in the NDIS participant plan.

¹² In certain circumstances e.g under guardianship, the age of the NDIS participant or where the participant has reduced cognitive capacity carers are able to support the self-management of an NDIS participant plan.

¹³ National Disability Insurance Scheme (2016) *Module 2: Self-directing my NDIS plan, September 2016*. Accessible at <https://www.ndis.gov.au/medias/root/h7b/h15/8798097932318/Self-managing-your-plan-PDF-254KB-.pdf>

¹⁴ Australian Unity (2015) *What makes us happy*, Melbourne.

¹⁵ See 8 above.

Most carers (82%) who answered the question to identify if a carer's time out had increased since the NDIS began reported that time out had not increased. Fifty-seven per cent of carers also indicated that their care recipient's NDIS participant plan didn't include services to provide a break from their caring role.

These outcomes, and the finding about the additional time 63 per cent of carers spent to manage the NDIS participant's support needs, identify the need for further investigation into how the NDIS can improve support for carers through replacement care and support services built into NDIS participant plans.

Conclusions

The outcomes of the NDIS and Carers Survey indicate that the transition to the NDIS in the ACT has provided benefits for care recipients (these are identified further in the *NDIS and Carers Survey Report*) and their carers. Survey outcomes also indicate that the NDIS transition has provided significant challenges for most carers who responded to this survey.

Carers ACT believes that urgent consideration about how to improve outcomes for carers through the NDIS in several areas is required by the NDIA through its planning and delivery processes, and in NDIS policy development by the Australian Government Department of Social Services and other agencies.

These include:

1. That the contribution of carers is valued and respected by the NDIA, particularly in the development and review of a participant's NDIS plan. Survey findings indicate the strong correlation between how valued and respected carers felt during the NDIS planning and other NDIS outcomes.
2. That a carer's current capacity or desire to continue caring, the amount of care they provide and their own goals are considered during the development and review processes of a participant's NDIS plan. This includes the carer's awareness of their right to provide a Carer Statement to the NDIA planner.
3. That carers are better supported to self-manage a participant's NDIS plan if they choose to do this, including sufficient awareness of the impact of self-management on a carer's time and its potential to reduce their capacity to engage in other activities.
4. That the need for carers to have a break or time out from caring is recognised and respite and support services that provide replacement care in line with the NDIS legislation and guidelines are incorporated into a participant's NDIS plan.

Carers ACT welcomes the opportunity to further discuss the outcomes from the NDIS and Carer Survey with the ACT NDIA and relevant organisations.

Acknowledgement

Carers ACT acknowledges and thanks the ACT carers who responded to the NDIS and Carers Survey and the many carers who share their caring experience and knowledge to inform our policy advice to government and other organisations.

PART A — ABOUT THE NDIS AND CARERS SURVEY

Introduction

The National Disability Insurance Scheme (NDIS) commenced as a trial site in the ACT on 1 July 2014, with transition to the full scheme from September 2016. As at June 2016 there were 5,229 NDIS participants in the ACT. Of these, 4,098 had approved participant plans.¹⁶

The NDIS aims to provide people under the age of 65 who have a permanent and significant disability a way to access the reasonable and necessary supports they require to enjoy an ordinary life.¹⁷ It provides eligible participants with funded NDIS participant plans and the flexibility to manage their supports to help them achieve their goals. Another aim of the NDIS is to provide people with disability, their carers and families with information, referrals and linkages to existing support services in the community.¹⁸

An anticipated outcome of the NDIS was the flow-on benefit to unpaid carers¹⁹ and caring families by reducing their caring responsibilities and the time they spent caring for the NDIS participants they support.

The NDIS and Carers Survey was conducted by Carers ACT to assess the impact of the ACT NDIS trial site implementation on carers in the ACT who care for a person or people with a physical (including intellectual, cognitive, genetic and sensory) or psychosocial disability (including mental illness) who were assessed for an NDIS participant plan.

The objectives of this survey were to identify:

- if the introduction of the NDIS in the ACT improved caring outcomes for carers of participants with an NDIS participant plan;
- the level of carer engagement in the NDIS planning process, and if the carers' contributions were considered;
- if supports included in the NDIS participant plan met the needs of the care recipient;
- if the design of the NDIS participant plan provided carers with more time away from caring to undertake other activities e.g. employment or education;
- if the carer was provided with support by services included in the NDIS participant plan to provide a break from caring; and
- the number of participants assessed as eligible for an NDIS participant plan.

Survey design and distribution

Carers ACT contracted the Nous Group to co-design a short online survey to discover the above information. The NDIS and Carers Survey was designed so carer respondents could complete it

¹⁶ National Disability Insurance Scheme (2016) *COAG Disability Reform Council Quarterly Report, October 2016*. Note: there is a time lag from when a participant is assessed as eligible for the NDIS and approval of their NDIS participant plan.

¹⁷ National Disability Insurance Scheme, *What is the NDIS?* Accessible at <https://www.ndis.gov.au/about-us/what-ndis>

¹⁸ National Disability Insurance Scheme, Information and referral webpage. Accessible at <https://www.ndis.gov.au/people-disability/information-and-referral.html>

¹⁹ Unpaid carers are family or friend carers who care for an individual with a disability, a chronic condition, an alcohol or drug dependency, a mental health issue, a terminal illness or who is frail aged. A care worker, often referred to as a carer, is a person who is employed to provide formal age or community services.

within 10-15 minutes. This restricted inclusion of additional questions related to carers, as well as the data collected for comparative analysis. For example, questions about the carer's age, the length of their caring role, or their own health and wellbeing prior to the commencement of an NDIS participant plan were not included.

Questions about the gender of the carer and care recipient, and their ethnicity were not included.

The survey focussed on four areas:

1. About you and the person you care for and NDIS eligibility
2. Your engagement with the NDIS
3. Your self-management experiences
4. The impact of the NDIS on you as a carer

It also included options for additional comments.

Information on the survey and a survey link were emailed to 1,698 Carers ACT members who cared for people with a disability. A small number were distributed in hard copy if the carer did not have internet or email access, with a reply-paid envelope to return survey responses to Carers ACT. A total of 120 responses were received.

Survey distribution, data collection and data analysis occurred during October to December 2016. Statistical consultant Stacy Vueti undertook the survey analysis.

If carers experienced discomfort when completing the survey, they were encouraged to call the Carer Information and Advisory Line (1800 242 636) to discuss their concerns and to receive appropriate support.

See Attachment A for a copy of the NDIS and Carers Survey.

PART B — SURVEY ANALYSIS

The survey was designed using a Multichoice closed answer Questionnaire on SurveyGizmo software. Respondents were asked to select one answer to each question that best reflected their experience. Questions in the survey's first section "About you and the person you care for" asked for specific details about the person with a disability, and the data collected in this section was comparative data for the responses in the next three sections of the survey.

The number of respondents for each question in the survey varies, as carers had the option not to answer questions if this was their preference. They also had the option not to complete the survey.

SECTION 1 – ABOUT YOU AND THE PERSON YOU CARE FOR

In this section carers were asked to provide details about the person(s) they cared for – their age, their disability type, if they had been assessed for and if they were eligible for an NDIS participant plan. If the person with a disability had not been assessed or was ineligible for an NDIS participant plan the carer was not required to complete the rest of the survey.

They also had an option to provide comments about their experience of the NDIS assessment process.

How old is the person that you care for?

The survey sought to identify if the age of the person with a disability affected the impact of the NDIS on carers. If respondents cared for more than one person, their response was listed as “Various” and they were analysed as a separate group.

The average age of care recipients was 27 years, with a minimum age of four years and a maximum age of 65 years.²⁰ Most people who received care were children or young people.

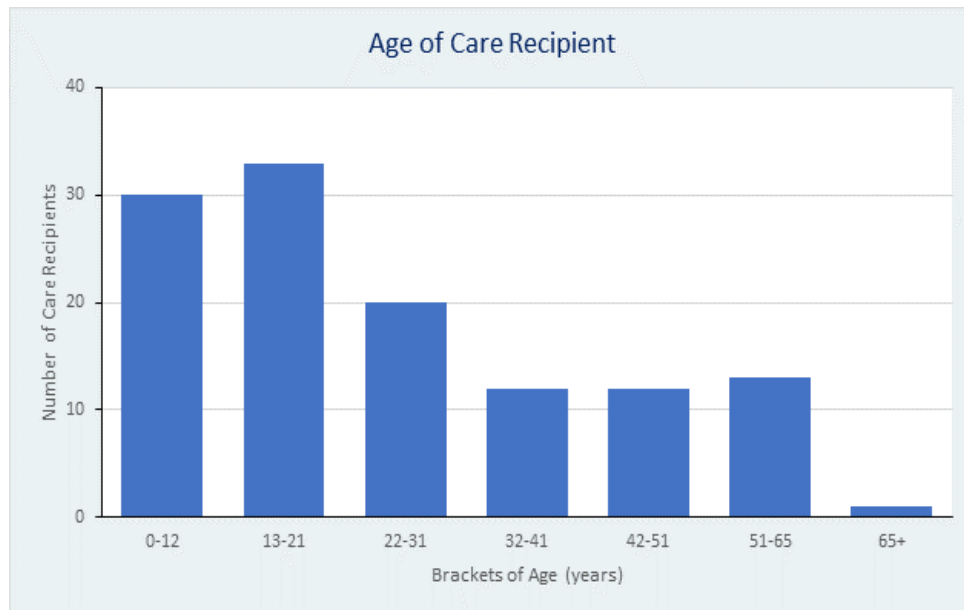


Figure 1 Age distribution of care recipient

Twelve respondents cared for more than one person with disability. There was a wide age range of care recipients when more than one was cared for by the same carer.

Carer and Age in Years of Each Care Recipient					
Carer 1 6, 7	Carer 2 3, 13	Carer 3 8, 9	Carer 4 20, 22, 24	Carer 5 6, 16	Carer 6 18, 20
Carer 7 5, 10	Carer 8 25, 33, 38	Carer 9 11, 13, 50	Carer 10 22, 83	Carer 11 42, 44	Carer 12 26, 34, 37
Total number of care recipients					28

Table 1 Age distribution of care recipients of carers caring for more than one person with disability

²⁰ A participant who is recorded as 65 years at time of the survey would have been assessed for an NDIS participant plan during the transition phase commencing in July 2014 when they were under 65 years and eligible for the NDIS.

What type of disability does the person that you care for have?

There were three response options for the disability type of the person the carer supported. These were, with corresponding response rates: Psychosocial (30%), Physical (31%) and Other (39%).²¹

“Other” had the highest response rate (39%). The response rate for “Physical” and “Psychosocial” disability types varied by 1 per cent.

Disability Type		Number of Care Recipients
Physical		34
Psychosocial		33
Other	More than one disability	14
	Intellectual	12
	ASD	8
	Acquired brain injury	2
	Mental illness	2
	Neurological	2
	Down syndrome	2
	Lewy body dementia	1
Total		110

Table 2 Disability type by number and percentage of care recipients

If “Other” was selected the carer could choose to specify the name of the disability. Of respondents who chose this option, 14 people cared for had more than one disability, 12 had an intellectual disability, eight had Autism Spectrum Disorder, two had an acquired brain injury, two had mental illness, two had a neurological disability, two had Down Syndrome and one had Lewy Body Dementia.

The disability some care recipients identified in “Other” could have been included as a “Physical” or “Psychosocial” disability type. Response data was not adjusted to reflect this.

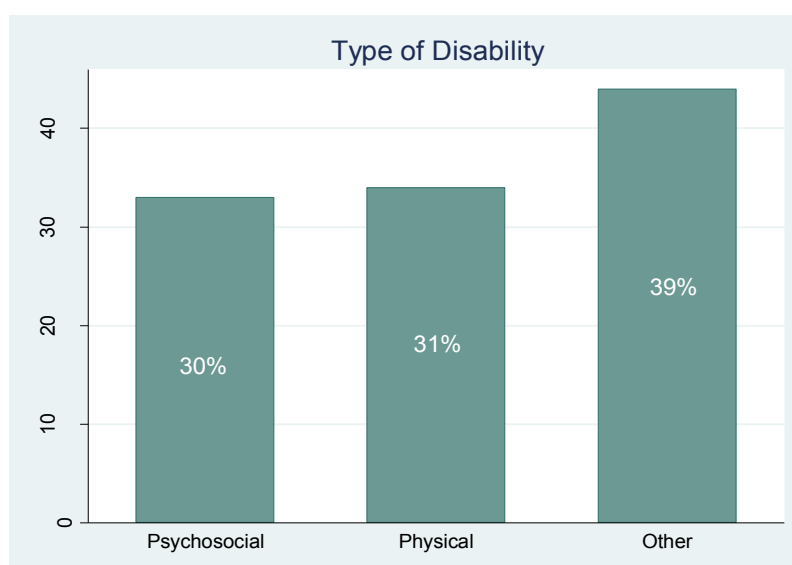


Figure 2 Type of disability of care recipient by number of care recipients

²¹ For the purpose of the survey “Psychosocial” disability includes mental illness. “Physical” disability includes intellectual, cognitive, genetic and sensory disabilities.

Has someone that you care for been through an eligibility assessment for the NDIS?

Of carers who completed this question, 99 had a person assessed for NDIS eligibility. Of carers whose care recipient had not been assessed, one carer hadn't yet applied because they found the process hard, and another because they "weren't aware of the package".

"Haven't applied yet as it is hard. My caring role is hectic. I am in the process of gathering [information] and will apply not expecting much luck."

Was the person that you care for eligible for an NDIS participant plan?

There were 99 respondents to this question. Two respondents cared for a care recipient who was assessed as ineligible for the NDIS. One care recipient had a physical disability and the other had a disability identified as "Other" disability type. Their ages were 6 years and 54 years respectively.

It appears that some carers were unaware of the different ages and stages for people with disability in the ACT's NDIS transition processes.²²

"I was then told that the ACT was only concentrating on the elderly and the young at that stage and to ring back in a couple of years ... Nothing out there for "middle aged" disabled [people]."

SECTION 2 – YOUR ENGAGEMENT TO DATE WITH THE NDIS

In this section carers were asked about their experience in the development of the participant's NDIS plan, if they felt the NDIA valued and respected their involvement, if the NDIS participant plan met the needs of the care recipient and how long the NDIS participant plan had been in place.

This section also sought to identify the number of carers who chose to self-manage a participant's NDIS plan, and if the NDIA offered carers services to support their caring role.

To what extent were you involved in the development of the participant plan for the person you care for?

Only 3 per cent of respondents were not involved in the development of the participant's NDIS plan. Most carers (76%) were very engaged and 21 per cent were somewhat engaged. The age or the disability type of the NDIS participant didn't influence the level of a carer's involvement.

The survey did not seek to identify the type of involvement a carer had in this process, e.g if they were asked questions about their capacity to continue caring, if they provided a Carer Statement to the NDIA or had a separate meeting with the NDIA planner.

²² Eligible participants were transitioned into the NDIS in the ACT in different ages and stages. Access the schedule here: <https://www.ndis.gov.au/html/sites/default/files/files/TransitioningintotheNationalDisabilityInsuranceSchemeintheACT.pdf>

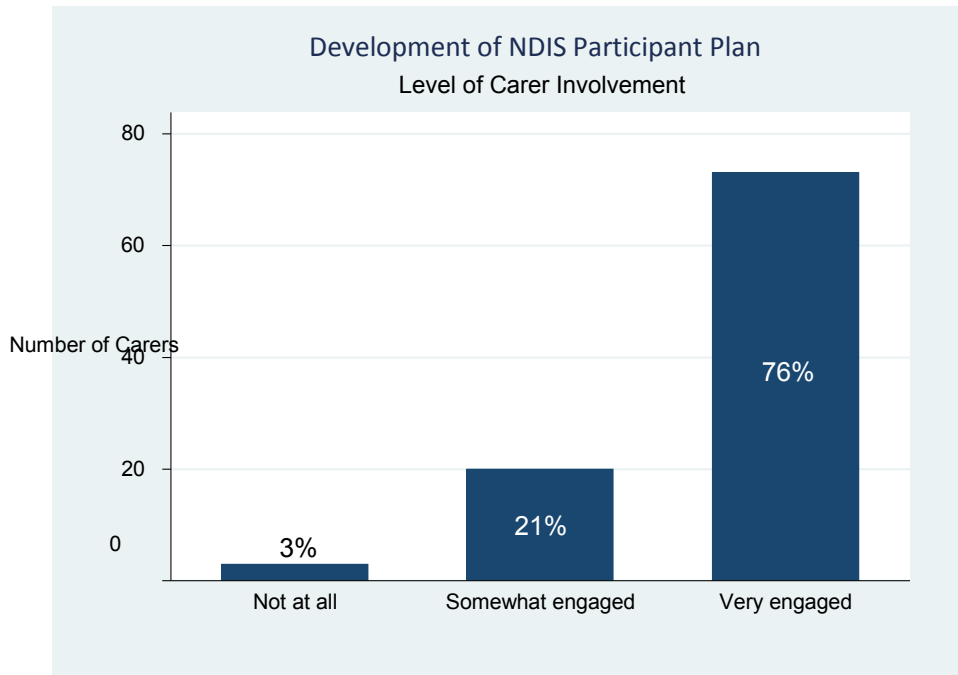


Figure 3 Carer involvement in development of the NDIS participant plan by number and percentage

Did you feel that your input into the development of the participant plan was valued and respected?

Over half (58%) the respondents felt their input was valued and respected. Thirteen per cent felt it was not valued and respected, and 29 per cent felt it was hard to say.

There appears to be no difference in the response pattern based on the age or disability type of the care recipient, or the number of people being cared for by the respondent.

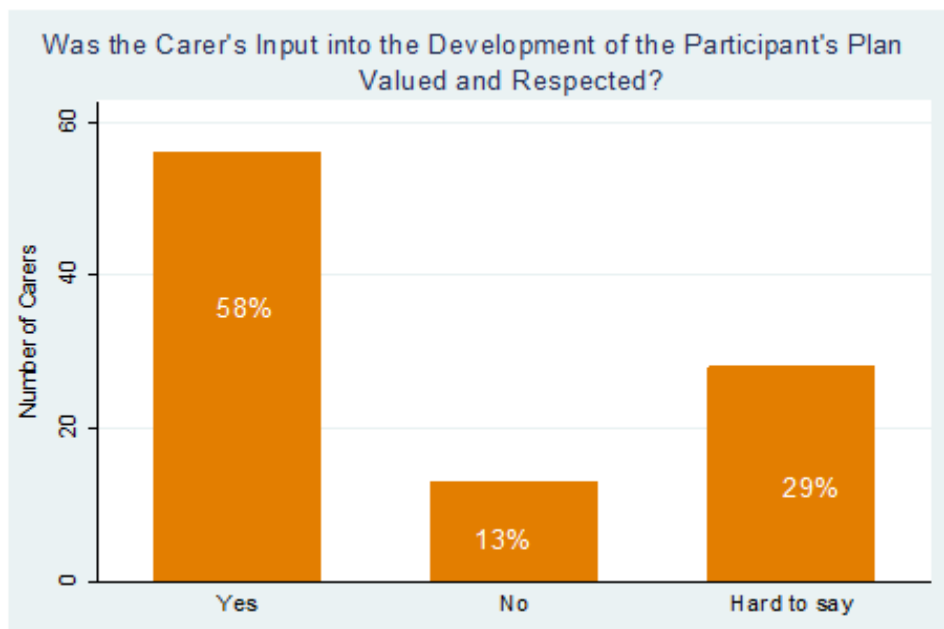


Figure 4 The value and respect for a carer's involvement in the development of the NDIS participant's plan by number and percentage of carers

How would you characterise the NDIS participant plan that was approved for the person that you care for?

Most carers (73%) indicated that the NDIS participant plan would meet all or some of the NDIS participant’s needs. Eighteen per cent indicated that it would meet all their needs, 55 per cent felt that it would meet some, 7 per cent felt it was not aligned and 20 per cent were not sure.

Does the NDIS Participant Plan Meet the Needs of the Person You Care For?	Number	Per cent
It will meet all of their needs	18	18
It will meet some of their needs	53	55
It’s not aligned to their needs	7	7
Not sure yet	19	20
Total	97	100

Table 3 Suitability of the NDIS participant plan by number and percentage of participants

There was a difference in the response pattern about the suitability of the NDIS participant plan based on how much the carer felt their input was valued and respected. If carers felt their input wasn’t valued or respected, then none felt that the NDIS participant plan met all the needs of the person they care for, compared to 26 per cent who felt their input was valued and respected.

Similarly, 23 per cent of carers who felt their input wasn’t valued or respected indicated that the NDIS participant plan was not aligned to the needs of the person they care for compared to 4 per cent who felt their input was valued and respected. There was no discernible difference in the response pattern based on the age or disability type of the person being cared for, or the level of carer involvement in the planning process.

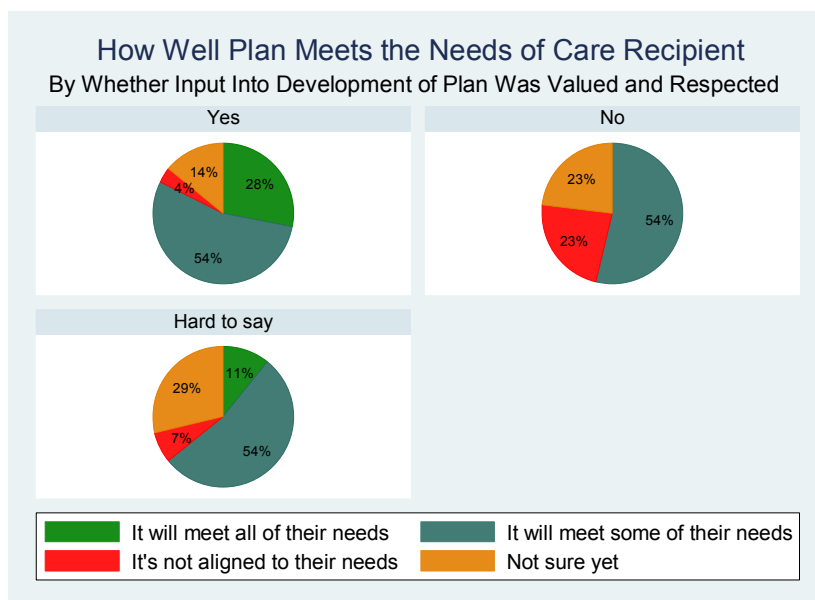


Figure 5 Suitability of an NDIS participant plan by the value and respect for the carer’s involvement in its development

For most carers who weren’t sure yet, the NDIS participant plan had been in place less than a month at the time of the survey.

How long has their NDIS participant plan been in place for?

The average time the NDIS participant plan had been in place was 10 months. Some carers and participants were waiting for the NDIS participant plan to start, while the longest time it had been in place was 30 months. The length of time the NDIS participant plan had been in place decreased as the age of the care recipient increased, which is likely to be attributable to the ACT NDIS transition phasing.²³

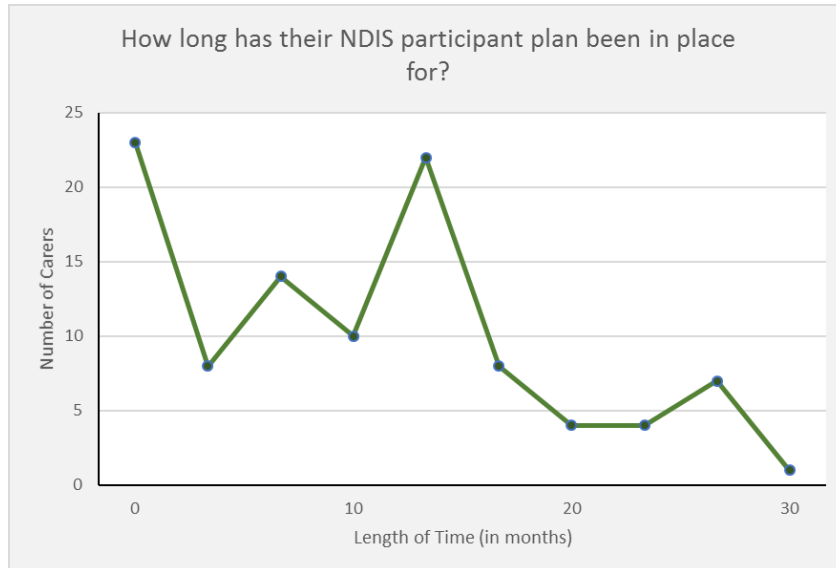


Figure 6 Length of time, in months, the NDIS participant plan has been in place

Has the NDIA offered you any services to support you in your caring role?

The majority (80%) of carers were not offered services to support their caring role, with 20 per cent offered services.

There was no discernible difference in responses based on the age or disability type of the care recipient, or if the carer felt their input into the development of the NDIS participant plan was valued and respected.

Were You Offered any Services to Support You in Your Caring Role?	Number	Per cent
Yes	19	20
No	77	80
Total	96	100

Table 4 Respondents offered support in their caring role by number and percentage of carers

Have you chosen to self-manage the NDIS participant plan?

The majority (59%) of respondents chose not to self-manage the participant’s NDIS plan, while 41 per cent chose to do so. Most carers who cared for NDIS participants aged under 18 years chose to self-manage the NDIS participant plan unless they were caring for more than one person.²⁴

The survey did not seek to identify the level of self-management of the NDIS participant plan.

²³ See 5 above.

²⁴ See 12 above.

Have You Chosen to Self-Manage Your Plan?	Number	Per cent
Yes	41	41
No	58	59
Total	99	100

Table 5 The number of carers who chose to self-manage the NDIS participant plan by number and percentage

SECTION 3 – YOUR SELF-MANAGEMENT EXPERIENCES

This section sought to examine the impact of self-management of the participant’s NDIS plan on carers, how well they coped with self-management and the ease of sourcing supports included in the NDIS participant plan.

What has been the impact on you of self-management of the participant plan?

Only 40 per cent of respondents coped well with self-management of the NDIS participant plan, 55 per cent of carers found it difficult, and 5 per cent couldn’t cope. All respondents who couldn’t cope had children aged under 10 years and one had more than one person to care for.

Three respondents of the 11 carers who cared for more than one person eligible for the NDIS chose to self-manage the NDIS participant plan. All three found it difficult and one carer reported they weren’t coping. It doesn’t appear that the length of time the NDIS participant plan had been in place influenced the impact on the carer.

“I am now doing the work of managing the plan, services, keeping up the with the NDIA and their IT issues, paying invoices on top of my caring role and parenting role etc. that in reality I am doing full-time unpaid work with the stress load increasing health issues.”

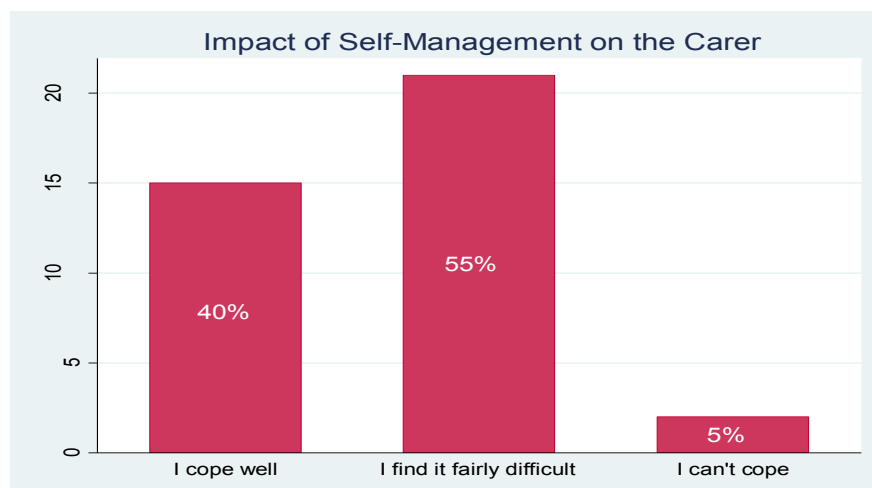


Figure 7 The impact of self-management of the NDIS participant plan on the carer by number and percentage

How easy was it to source services funded under the participant plan?

The majority (77%) of respondents found it challenging sourcing services provided for in the NDIS participant plan, while 23 per cent found it easy. The response pattern didn't discernibly differ based on the age or disability type of the care recipient or the length of time the NDIS participant plan had been in place. All carers who cared for more than one person found it very challenging.

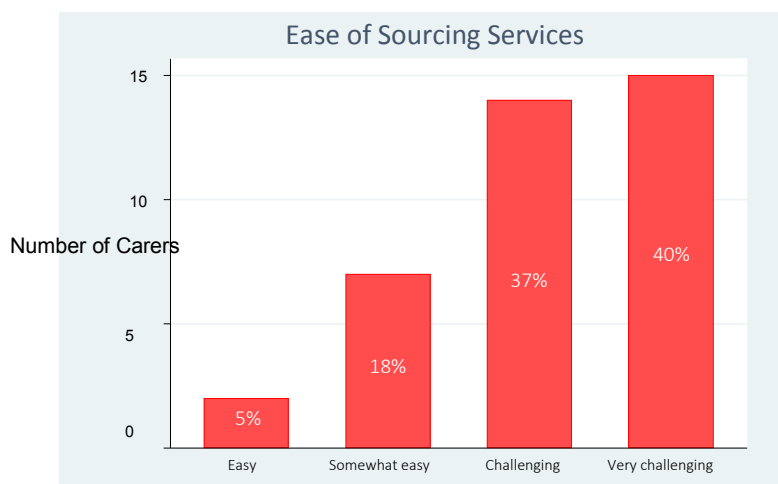


Figure 8 Ease of sourcing supports included in the NDIS participant plan by number and percentage of carers

SECTION 4 – THE IMPACT OF THE NDIS ON YOU AS A CARER

This section sought to examine the impact of the NDIS implementation on carers, particularly if the time a carer spent managing the support needs of the NDIS participant had increased. It also sought to examine if alternate care services provided in a participant's NDIS plan increased carers' capacity to engage in employment or education, if they were offered services to help their caring role, and if they had more time out for themselves.

Carers responding to Sections 2 to 4 also could provide comments about their experience of the NDIS at the end of this section.

Are you spending more time managing the support needs of the person you care for now the NDIS participant plan is in place?

The majority (63%) of respondents felt that the time spent managing the support needs of the person they cared for had increased.

There was no difference in the response pattern based on the age or disability type of the care recipient. The length of time the NDIS participant plan has been in place didn't appear to influence the amount of time spent managing the support needs for the participant.

Carers who self-managed the NDIS participant plan were more likely to indicate an increase in the amount of time spent managing the support needs of the NDIS participant.

"I have to source good service providers, oversee care – both personal, social and community access, design programs of support, train carers, ensure equipment is sourced, ordered, delivered and maintained, and also navigate a portal that has been difficult to access, maintain good financial records, acquit funds and keep a sound audit trail."

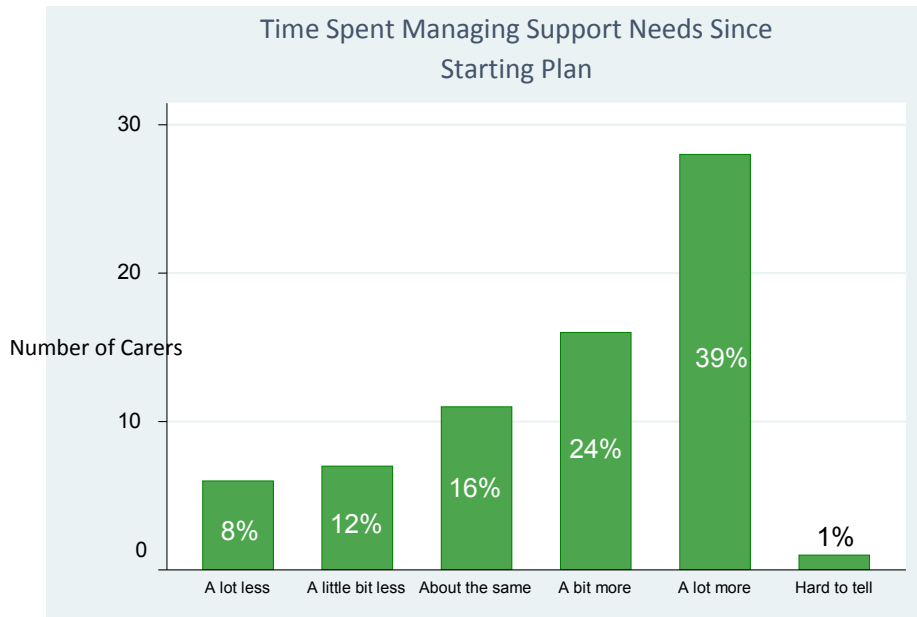


Figure 9 Time spent managing the support needs of the carer since the start of the NDIS participant plan by number and percentage of carers

Has the level of supports provided by the NDIS participant plan changed from the previous supports the person you cared for received?

Most (51%) respondents felt the level of supports was the same or less than those the NDIS participant had previously received, while 49 per cent felt the level of support for the participant was much more under the NDIS.

There was no significant change based on the age or disability type of the care recipient or number of people cared for by the respondent. When an NDIS participant plan was in place for a longer period carers generally reported a higher increase in the level of support included in the participant’s NDIS plan. Respondents who felt their input was respected were more likely to report an increase in the level of support provided by the NDIS.

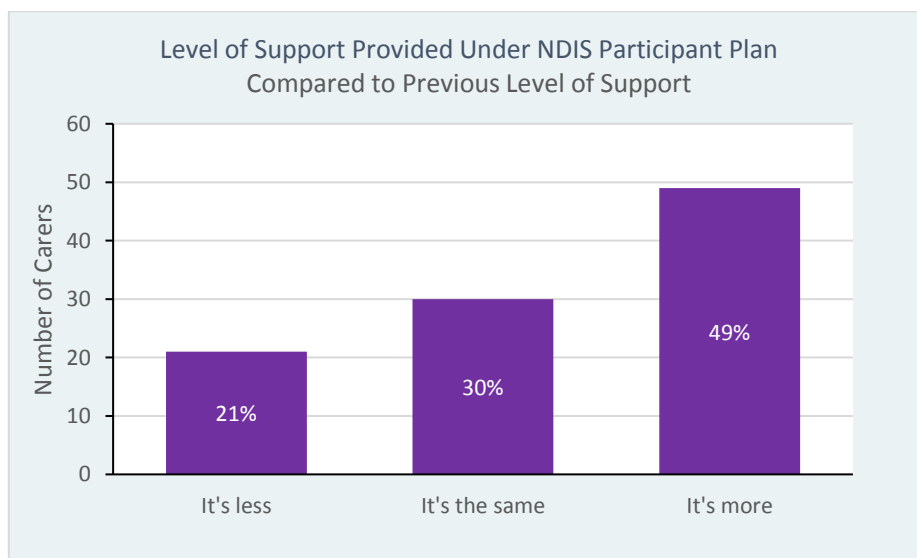


Figure 10 Difference in level of support provided to the care recipient with an NDIS participant plan by number and percentage of carers

How has the NDIS changed your ability to meet existing work commitments or seek new employment?

The largest proportion (35%) of respondents felt that there was no change in their ability to meet existing work commitments or seek new employment since the start of the NDIS. Twenty-seven per cent found it was now harder and 11 per cent found it was now easier.

Carers who found they were spending more time managing the support needs of the NDIS participant, found it harder to meet existing work commitments or to seek new employment compared with those who found they were spending less time. The age or disability type of the care recipient, impact of self-management on the carer or if carers were offered services didn't impact on the response pattern to this question.

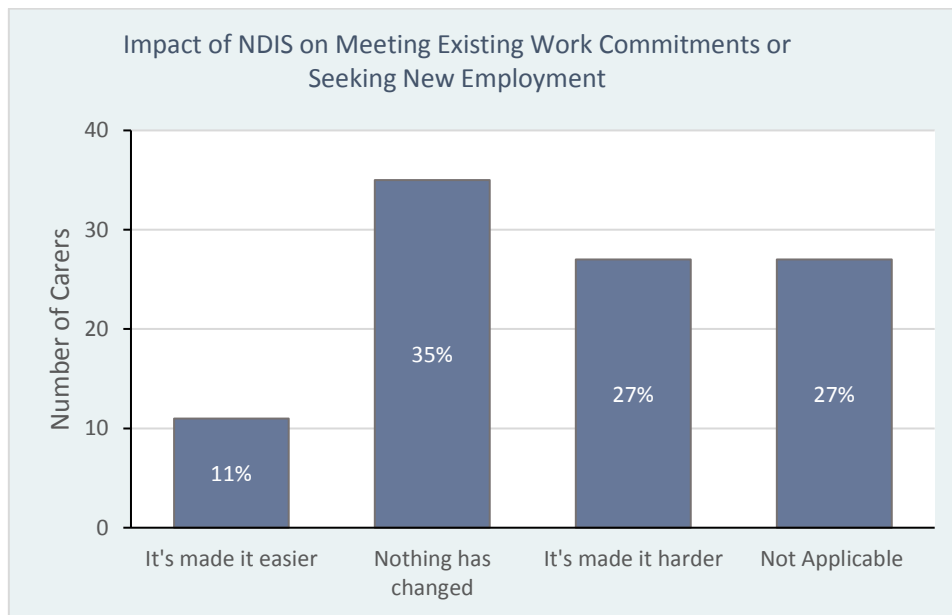


Figure 11 Impact of the NDIS on a carer's ability to meet existing work commitments or seek new employment

How has the NDIS changed your ability to commence some form of education?

Almost half (49%) the respondents felt that this question didn't apply to them. Of the remaining carers, 28 per cent felt nothing had changed, 14 per cent found that it was harder to commence some form of education and 9 per cent found it easier. The greater the reported increase in time spent caring for the NDIS participant, the harder it was to commence some form of education.

The age or disability type of the care recipient, impact of self-management on the carer or if carers were offered services didn't impact on the response pattern to this question.

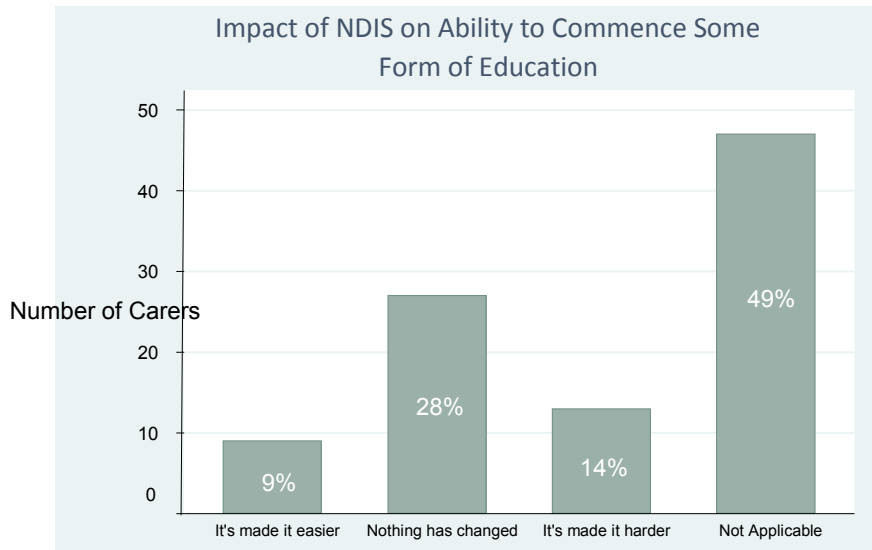


Figure 12 Impact of the NDIS on carers' ability commence some form of education by number and percentage of carers

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

The majority (82%) of respondents reported that their time out from caring had not increased since the NDIS participant plan started, 47 per cent found it was the same, and 35 per cent indicated there was less time out. Only 18 per cent indicated their time out from caring had increased because of the NDIS.

Those who found they were now spending more time managing the support needs of those they care for had less time out from caring. Similarly, carers of participants whose level of support increased under the NDIS experienced more time out from caring than those whose level of support was less or those whose level of support hadn't changed.

Carers who self-managed the participant's NDIS plan reported less time out from their caring role and less time for themselves. There was no discernible difference in the response pattern based on the age or disability type of the care recipient, or the number of people cared for by a respondent.

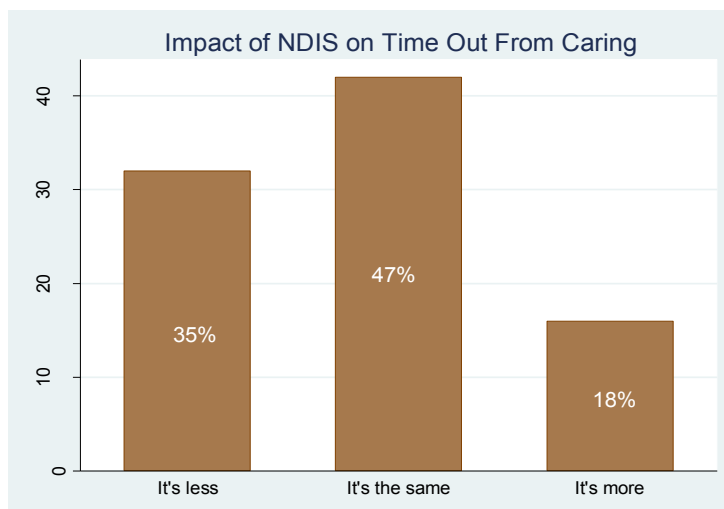


Figure 13 Impact of the NDIS on a carer's time out from caring

Does the NDIS participant's package include specific services to enable you to have a break from your caring role?

The majority (57%) of respondents reported that the NDIS participant plan didn't include services which enabled them to take a break from their caring role. About half as many (29%) cared for an NDIS participant whose NDIS plan included these and 14 per cent weren't sure. There was no apparent difference based on the age and disability type of the participant, or the number of people cared for by the respondent.

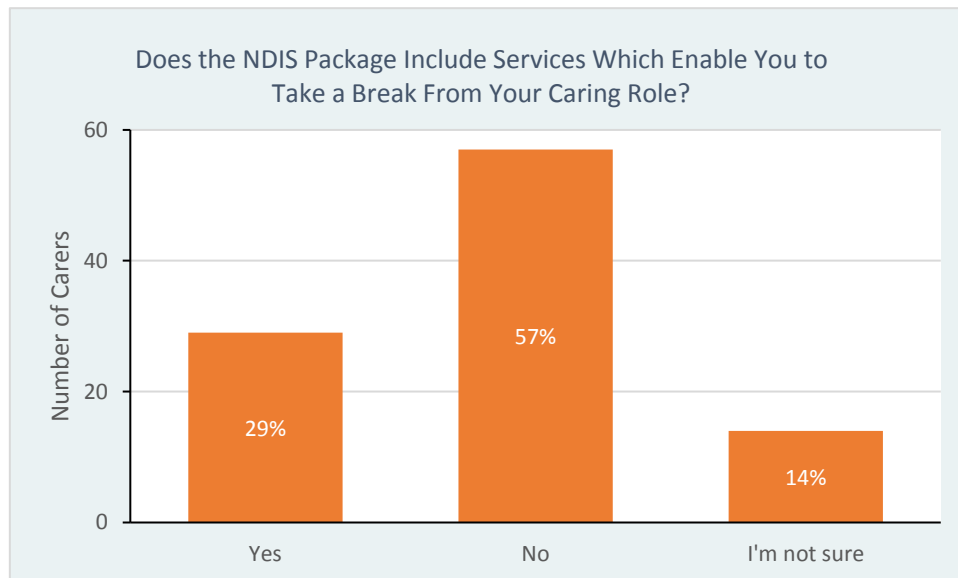


Figure 14 Do services in an NDIS participant plan enable a carer to have a break from caring by number and percentage of carers

The response to this question didn't influence the amount of time out the carer experienced under the NDIS.

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

There were 73 responses to this question. This is equivalent to 67 per cent of carers who answered questions in Sections 2 to 4 of the survey. Of these respondents:

- 55% felt that their role as a carer had become more difficult since the commencement of the NDIS
- 38% reported difficulties with communication and/or navigating the NDIS online portal
- 19% found that there was an increase in the demands placed on them and the time spent caring
- 15% reported having trouble accessing services for the NDIS participant
- 15% felt there was a lack of resources for carers
- 5% reported a negative impact on employment

An analysis of the 73 respondents' answers to other sections in the survey was conducted. There was an even spread of people who self-managed the NDIS participant plan, the age and disability type of the care recipient, and if the respondent felt that their input into the development of the NDIS participant plan was valued and respected.

The reported positive impact on carers due to transition to the NDIS

Some respondents found they spent less time managing the support needs of the person they cared for, and some reported that improved access to community services had opened new opportunities.

“It is a great initiative. I would like to thank those who are involved with this. It saves me time, headache and money.”

“I love the NDIS. Finally given me help as I’m carer to three children. It’s opened doors to us to the community as we were totally home bound. Forever thankful.”

“I am [sic] very happy when NDIS took part in planning for my son’s support for his needs.”

The reported negative impact on carers due to transition to the NDIS

Many carers found that the NDIS was having a negative impact on their lives, with some having to reduce work hours.

Some found that transitioning to the new system was challenging and there was insufficient information and support to help them through the transition.

Some carers indicated that there was insufficient support for carers under the NDIS.

Others have found that the needs of the care recipient are being better provided for, but the needs of the carer have been neglected.

“The NDIS has made the caring role more complicated, difficult and time consuming.”

“The system is administratively difficult and stressful. NDIS doesn’t consider family unpaid carers. Let’s hope NDIS Listens to our small voice and supports carers.”

“There is no direct support for me any longer as a carer, even though I am doing more. I was better off before the NDIS as a carer.”

“Although our son is the recipient of NDIS [participant plan] and we want to support him for as long as possible, perhaps some acknowledgment that the carer needs caring for [is required].”

The impact on carers if they felt their input into the NDIS participants planning process was valued and respected

All respondents who reported that their input into the development of the NDIS participant plan wasn’t valued or respected spoke of a negative experience with the NDIS as did all respondents who felt the NDIS participant plan wasn’t aligned to the participant’s needs.

The impact on a carer’s employment or education ability because of the NDIS transition

There appeared to be a trend between the carer’s overall experience and their ability to meet existing work commitments or seek new employment along with the ability to undertake education. The respondents who found it difficult were more likely to report a negative experience and conversely those who found it easier were more likely to have a positive experience.

For some respondents, self-management of an NDIS participant plan had a negative impact on their employment. This had a financial impact.

“I have had to cut down work from 5 days to 3 due to carer stress. This has put more stress on us as a family financially.”

“I have multiple connections to manage and I am unable to continue to work due to the demands of managing the various aspects of the NDIS.”

“I had to reduce my work since my daughter left school and went on the NDIS, and my family is financially disadvantaged because of this.”

The impact of time out from caring because of the NDIS transition

As the reported amount of time required to provide services to those in their care decreased, the more likely the respondent was to report a positive experience with the NDIS. Similarly, as the reported level of support for the care recipient increased, so did the likelihood of the respondent leaving a positive comment about their experience.

Respondents who found they had less time out from caring were more likely to report a negative overall experience under the NDIS.

The impact of carers and self-management of a participant’s NDIS plan

Some respondents found the system hard to negotiate, and that more information and support is needed for carers who choose to self-manage an NDIS participant plan.

Some respondents had trouble navigating the NDIA portal and some had trouble being reimbursed for money already spent on service provision.

Some carers found that while the NDIS participant plan included funding to access support services, they were having difficulty finding available service providers.

“Although the plan is generous considering we received no support before NDIS ... the reality is that resources are stretched and you cannot find supports.”

“The NDIS has been one of the best things that has happened for people with a disability. However, the onus on carers who are self-managing the funds for the disabled person is quite high.”

“I think now that I know what I am doing the planning and the process is really good. It was a very bumpy start. But I could not be happier for my son.”

Attachment A – Survey

Impact of the NDIS on carers in the ACT



Introduction

Carers ACT wants to know if the introduction of the National Disability Insurance Scheme (NDIS) in the ACT has made a difference to the caring role of people who care for NDIS participants. We hope you are able to complete this survey.

This survey should take you about 10 minutes to complete. You do not have to answer any questions you do not want to. If you care for more than one person with disability who was assessed for an NDIS package you can choose to complete a survey for each or you can choose to complete one survey that illustrates your overall experience with the NDIS assessment process and your satisfaction with the participants' NDIS plans and funded supports. If you choose to complete only one survey for all the people you care for in Q1 about the age of participants enter 'various' and in Q3 about the type of disability choose 'Other' if you are caring for people with different types of disability.

Completing the survey is voluntary, and you may choose not to complete the survey. By submitting a completed survey you are indicating your consent to participate in this research.

You and your answers will remain anonymous, but they will provide us with a better understanding about what has improved for you since the NDIS and the areas that still need improvement. Survey findings will also help us advise the government about changes to the NDIS to improve benefits for participants and caring families in the ACT. Carers ACT will publish a summary of findings of this research.

If you experience any discomfort from completing the survey you are encouraged to call the Carer Line (1800 242 636) to discuss your concerns and to receive appropriate support.

If you have any concerns about this project you are welcome to contact Alex Scetrine, Carers ACT Policy Team, by email at Alexandra.scetrine@carersact.org.au or call (02) 6296 9900.

The closing date for your survey response is **Friday 21 October 2016**.

About you and the person you care for

1) How old is the person that you care for? _____

2) Has someone that you care for been through an eligibility assessment for the NDIS? **Please tick the appropriate box below.**

() Yes

() No

3) What type of disability does the person that you care for have? **Please tick the appropriate box below.**

() Psychosocial

() Physical

() Other: _____

4) Was the person that you care for eligible for an NDIS participant plan? **Please tick the appropriate box below.**

() No

() Yes **[PLEASE GO TO QUESTION 6]**

NDIS eligibility

5) Are there any comments that you would like to make about why the person you care for was not eligible for an NDIS package and the impact on you as their carer?

IF YOU ANSWERED 'NO' TO QUESTION 4 ABOVE YOU DO NOT NEED TO ANSWER THE REMAINING SURVEY QUESTIONS. (See page 5 for information on how to return your survey to Carers ACT.)

Your engagement to date with the NDIS

6) To what extent were you involved in the development of the participant plan for the person that you care for? **Please tick the appropriate box below.**

() Not at all

() Somewhat engaged

() Very engaged

7) Did you feel that your input into the development of the participant plan was valued and respected? **Please tick the appropriate box below.**

() No

() Yes

() Hard to say

8) How would you characterise the NDIS participant plan that was approved for the person that you care for? **Please tick the appropriate box below.**

- It will meet all of their needs
- It will meet some of their needs
- It's not aligned to their needs
- Not sure yet

9) How long has their NDIS participant plan been in place for? _____ months

10) Has the NDIA offered you any services to support you in your caring role? **Please tick the appropriate box below.**

- No
- Yes

11) Have you chosen to self-manage the your NDIS participant plan? **Please tick the appropriate box below.**

- Yes [PLEASE GO TO QUESTIONS 12 and 13]
- No [PLEASE GO TO QUESTION 14]

Your self-management experiences

12) What has been the impact on you of self-management of the participant plan? **Please tick the appropriate box below.**

- I cope well
- I find it fairly difficult
- I can't cope

13) How easy was it to source services funded under the plan? **Please tick the appropriate box below.**

- Easy
- Somewhat easy
- Challenging
- Very challenging

The impact of the NDIS on you as a carer

14) Are you spending more time managing the support needs of the person you care for now the NDIS participant plan is in place? **Please tick the appropriate box below.**

- Too early to tell
- A lot less
- A little bit less

About the same

A bit more

A lot more

15) Has the level of supports provided by the NDIS participant plan changed from the previous supports the person you cared for received? **Please tick the appropriate box below.**

It's more

It's the same

It's less

16) How has the NDIS changed your ability to meet existing work commitments or seek new employment? **Please tick the appropriate box below.**

It's made it harder

Nothing has changed

It's made it easier

Not applicable

17) How has the NDIS changed your ability to commence some form of education? **Please tick the appropriate box below.**

It's made it harder

Nothing has changed

It's made it easier

Not applicable

18) Has the NDIS meant that your time out from caring has increased and that you have more time for yourself? **Please tick the appropriate box below.**

It's more

It's the same

It's less

19) Does the NDIS participant's package include specific services to enable you to have a break from your caring role? **Please tick the appropriate box below.**

Yes

No

I'm not sure

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

Thank You!