



Carers Australia

**National Disability Insurance Scheme
Carer Capacity Building Project**

Survey Findings

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For information contact:

Ara Cresswell
CEO of Carers Australia
T:02 6122 9900
F:02 6122 9999
acresswell@carersaustralia.com.au

Sue Elderton
Policy Manager
T: 02 6122 9923
F: 02 6122 9999
selderton@carersaustralia.com.au

Carers Australia
Unit 1, 16 Napier Close
DEAKIN ACT 2600
Telephone: 02 6122 9900
Facsimile: 02 6122 9999
Email: carers.ndis@carersaustralia.com.au
www.carersaustralia.com.au

Background

Aims of the Carer Capacity Building project:

The National Disability Insurance Agency (NDIA) has funded Carers Australia to undertake the Carer Capacity Building project. The aims of the Carer Capacity Building Project are to:

1. Increase understanding of the operation of the National Disability Insurance Scheme (NDIS) and the principles which underpin it amongst people with disability, their families and carers.
2. Increase the capacity of people with disability, their families and carers to exercise choice and control in engaging with the NDIS and in purchasing supports in an open market in order to realise their aspirations.
3. Encourage and enable people with disability, their families and carers to move towards greater independence, self-management and community inclusion.

Among the activities identified in the Funding Agreement is to:

- Provide strategic advice to the NDIA on operational issues.

In 2014 and 2015 Carers Australia conducted focus groups and interviews with service providers, carers and families in the NDIS trial sites. A total of 104 carers and 48 service providers attended these focus groups and interviews. The report on the findings from these focus groups was submitted to the NDIA in May 2015.

It was noted by Carers Australia that participants of these focus groups tended to be those at either end of the satisfaction spectrum and, while useful for detailed exchanges on the subject matter, the focus groups alone were not particularly representative of the overall experiences of carers.

For this reason the forums were supplemented with an online survey, which has increased the number of overall responses from carers and helped produce more balanced results.

This report summarises the key findings from the NDIS Carers online survey, which further supports the main operational issues identified in the focus groups, as well as provide some new insight into the experiences carers are having with the NDIS.

NDIS carers online survey

Carers Australia developed an NDIS online survey to reach carers who are caring for someone with an NDIS plan in trial sites. The survey was developed using Survey Monkey and was open from July to October 2015.

Survey respondents and sample bias

149 people responded to the survey, however only 92 of those who responded cared for an NDIS participant and were able to complete the survey.

Carers who completed the survey were from a range of trial sites across Australia. There was a good spread of carers who joined the NDIS at different times across the two year period since the NDIS began in the trial sites.

The carers who participated in the survey cared for people with a variety of disabilities, with intellectual disability being the most common.

In other areas the survey did not reach the variety of carers we had hoped for. Most of the carers who responded were:

- Female (87%; although 70% of primary carers in Australia are female¹),
- Between the ages of 35 to 54 (67%)
- Caring for someone between the ages of 0-24 (60%)
- Living with the person they cared for (86%)
- Providing more than 40 hours per week of care (74%)

It was not surprising that many carers who completed the survey were the parent of the person with disability (52%). Parents are often highly involved in the NDIS process and make decisions on behalf of the participant when they are under the age of 18, and this should be kept in mind when viewing the survey results.

As the survey was online, it suggests that the carers who responded were confident with using a computer and competent in finding information on the internet. This was further supported as half of carers sourced NDIS information from the NDIS website, whereas in the focus groups carers reported that their main source of information was from service providers and through 'word of mouth'. Furthermore, the focus groups found that few carers self-managed NDIS plans, partly due to the perceived difficulty of using the NDIS online portal. However close to a third of carers who participated in the survey self-managed the NDIS plan.

¹ Australian Bureau of Statistics (2013), Disability, ageing and carers, Australia: summary of findings, 2012, ABS Cat No 4430, table 33_1.

NDIS Carer Survey findings

Receiving and understanding NDIS information

“We don’t know what we don’t know” – Carer in the Hunter region (focus group)

Carers reported in the focus groups and interviews that they had been confused about the purpose of the scheme, how to access it and how it relates to the supports that both they and the person they care for currently receive.

This is further supported by findings in the survey:

- Only a quarter of carers felt prepared when the person they cared for first applied for the NDIS
- 23% of carers still had little or no understanding of the NDIS even after the person they care for had received an NDIS plan.

Carer supports through the NDIS

Both the focus groups and survey found that carers themselves generally do not have a good understanding of the supports specifically available to them under the NDIS, such as training, family group therapy and respite.

The survey found:

- Close to a quarter of carers were unaware that carer supports can be included in an NDIS plan, and another 26% of carers only had some awareness
- 76% of carers would like more information about supports they can receive as a carer through the NDIS
- 57% of carers want more information about respite options.

Source of NDIS information

Carers who completed the survey obtained NDIS information from a range of sources but the most popular source was the NDIS website (49%). The online survey may have created a bias to carers who are confident with using the internet and therefore confident in obtaining information from the NDIS website. Nevertheless this indicates that the NDIS website is a valuable source of information for carers and needs to contain up to date information about carers and the NDIS, particularly what supports they can receive.

Carers who attended the focus groups reported that they gain most of their information about the NDIS from service providers and through ‘word of mouth’. In the survey only 19% of carers obtained information from family and friends and 30% obtained information from service providers. But there is still a reliance on service providers to help prepare for the planning meeting as 45% spoke with a service provider in preparation.

Other popular sources of NDIS information was the NDIA (38%) and advocacy organisations (35%).

Carer involvement in the NDIS

While the aim of the NDIS is to support people with disability, carers play a huge role not only in providing informal support, but helping people join the NDIS and access appropriate supports. The survey found that:

- 88% of carers helped the person they care for apply for the NDIS
- 83% helped prepare for the planning meeting
- 71% engaged with service providers to help the person with disability receive supports.

Preparing for the planning meeting

Carers prepared for the planning meeting in various ways including:

- Developing lists of the supports the person receives and how they could be improved (77%)
- Speaking with service providers (45%)
- Obtaining information from the NDIS website (43%)
- Speaking with the NDIA (40%)
- Helping complete the NDIS planning workbook (40%)
- Speaking to other carers who care for an NDIS participant (36%)

Carers also explained that they did extensive research before the planning meeting and a couple spoke with Local Area Coordinators (LAC). Some examples provided by carers of the work they put into preparing for the planning meeting:

'Gathered reports, assessments and anything else I could in writing to help support my daughter's claim (medical, therapeutic, educational). Spoke with my LAC about the transition - spent hours preparing the workbook and had it reviewed by the service provider for advice - prepared a list of all of the medical and educational equipment and services that she accessed as I wasn't sure what was covered by NDIS.'

'Completed needs assessment with Planner. Spoke with Planner and supervisor around what may be possible. Researched what services are available in our area. Researched self-management of funding. Developed methods for son(s) to have input into their Plans. Advocated for son(s) to ensure that their voice would be heard.'

The survey demonstrates that there is a reliance on carers to help the person they care for receive supports through the NDIS. However, it should be noted that a proportion of carers who completed the survey were parents of a person with disability under the age of 18 and would naturally be involved in these processes.

Carers explaining their role and needs

Carers' circumstances and ability to continue their caring roles should be considered in relation to the participant's support needs. Carers can explain this at the planning meeting with the person they care for or have a separate discussion with the NDIA planner. Carers can also choose to prepare a written Carer Statement and bring this to the planning meeting or submit it to the NDIA. The carer statement can include information about how the caring role affects the carer and whether they are able or willing to sustain this level of care.

The focus groups found that the majority of carers, even if they felt included in the planning process, were unaware of 'carer statements' and their ability to request a separate interview with the planner if they wished.

"I would have asked for one (a carer statement) if I knew, as there are some real sensitivities that need to be addressed" – Carer in Tasmania (focus group)

The survey also found that carers were unaware that they could have a separate conversation with the planner or develop a carer statement and many would have liked to have had this opportunity:

- Only 23% thought their caring role was taken into consideration by the planner
- 78% of carers were unaware that they could provide a Carer Statement
- Out of those who did not know about the carer statement, 69% would have liked to have had the opportunity to submit a statement
- 56% of carers were unaware that they could ask for a separate conversation with the planner
- Out of those who were aware that they could have a separate conversation with the planner, 86% did have this conversation
- Out of those who were not aware that they could have a separate conversation, 56% would have liked to have had one with the planner.

The findings clearly indicate that carers appreciate the opportunity to provide information about their caring role without the presence of their care recipient.

Accessing supports on the NDIS plan

Participants of the focus groups advised that the person they care for now receives more support on their NDIS plan, however 38% of carers in the survey thought that the supports on the NDIS plan did not meet all the needs of the person with disability and another 36% thought some other supports would be helpful.

Issues and confusion with implementing NDIS plans was a recurring theme that was raised by carers at focus groups. After receiving an NDIS plan many carers felt they were given no information or explanation on the next steps of implementing the plan so the person with disability can receive supports. This was similar to what was found in the survey as 47% of carers wanted more information on how to find the most appropriate services to provide supports in the NDIS plan.

Another plan implementation issue that was raised by carers in the focus groups was that, even if a person receives NDIS funding for a particular support, it does not necessarily mean that the support is available, for example available in the local area. A third of carers who

responded to the survey also indicated that at least one support on the NDIS plan was not accessible for the participant and a further 27% were unsure.

Managing NDIS funds

The focus groups found that few carers self-managed NDIS plans, partly due to the perceived difficulty of using the NDIS online portal. However in the survey:

- Close to a third of carers self-managed the NDIS plan
- Only 19% were managed through the NDIA
- 24% had a combination of the plan management options.

This suggests that quite a few carers who completed the survey were comfortable undertaking self-management. The online survey may have created a bias to carers who were confident in using a computer, and therefore more easily able to access the online NDIS portal and self-manage.

Wait Times

The people we spoke to were daunted by the wait times involved in the planning process. Carers felt that a long time elapses between becoming an approved participant, obtaining a planning meeting and then receiving a plan.

This issue was explored further in the survey, which found:

- 37% of people with disability were accepted to be an NDIS participant in less than 3 weeks of handing in their application form
- It took longer than 2 months for many people with disability to receive services through the NDIS from when they handed in their application form (51%).
- 26% were unsure of the timeframe between applying, becoming a participant and then receiving services through the NDIS.

Effect of the NDIS on carers

Carers who attended the focus groups felt that the package of supports offered to the person they care for had improved both their own lives and that of the person they cared for.

The survey further investigated whether the NDIS had helped carers pursue their own activities and goals. The survey found:

- Just over half of carers felt that the supports provided though the NDIS does not reduce the hours of care they need to provide
- Out of those who felt the NDIS had reduced the number of hours of care they provide, 46% said it had only reduced by 1 to 3 hours
- 62% of carers did not think the NDIS has made it easier for them to participate in their own activities and pursue their own goals
- 65% of carers did not think the NDIS made it easier to get or keep paid employment
- 69% of carers did not think the NDIS has made it easier for them to engage in further education or training.

It is clear that even with the NDIS, many carers are still providing a lot of care that impacts on their ability to participate in their own activities and pursue their own goals.

Supports carers have received through the NDIS

39% of carers did not receive any of the listed supports² provided in the survey that may help carers on the participant's plan.

Respite-like supports³ were the most popular supports that were included on participant's plans that may also help carers (48%). Only 16% of carers received emergency respite on the plan.

Next Steps for the NDIS Carer Capacity Building Project

The findings from the focus groups and survey have been used to inform the development of NDIS resources by Carers Australia through the Capacity Building Project. Resources include:

- NDIS webpage on the Carers Australia website: <http://carersaustralia.com.au/ndis-and-carers/what-is-the-ndis/>
- Videos containing information about various NDIS topics for carers
- Online forums for families and carers
- Resources for Peer Conversation Partners (trained carers who provide peer support to carers new to the NDIS)

² The listed supports in the survey they may help carers included; Respite-like support (e.g. Overnight assistance with self-care, short term accommodation, group-based facilities or in-home support), Group or family therapy, Emergency respite, Training for carers, Counselling, Assistance with decision making, daily planning, budgeting and life/transition planning (e.g. to plan for changing needs and circumstances).

³ Examples of respite-like support provided in the survey included overnight assistance with self-care, short term accommodation, group-based facilities or in-home support.