What is there for carers in the NDIS?

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Carers NSW

The peak non-government organisation for people in New South Wales (NSW) who provide informal care and support to a family member or friend who has a disability, mental illness, drug or alcohol dependency, chronic condition, terminal illness or who is frail.

Our vision is an Australia that values and supports all carers. Our goals are to:

- Work with carers to improve their health, wellbeing, resilience and financial security
- Have caring recognised as a shared responsibility of family, community and government
Outline

1. Background
2. Carers and the NDIS
3. Survey findings
4. Research to results
In 2012:

- 81 per cent of Australians with a reported disability who were in need of assistance with at least one activity received support from an informal carer.

- 91 per cent of Australians with a profound or severe core activity limitation (i.e. needing assistance with self-care, mobility and/or communication) received support from an informal carer.

Carers and the NDIS

Policy framework

• *NDIS Act 2013*, NDIS Rules and NDIS Operational Guidelines recognise:
  o The important role carers have in the lives of people with disability
  o The need to assess what support is reasonable for carers to provide
  o The need to strengthen and sustain carers in their caring roles

• Carers can:
  o Participate in the planning process, with the participant’s agreement
  o Provide a Carer Statement
  o Support the participant to access the NDIS and implement their plan
  o Benefit indirectly from funded supports in the participant’s plan

• **Carers cannot receive an NDIS plan or funded supports in their own right**
Carers and the NDIS

Carer research

• NDIS Evaluation and NDIA Quarterly Reports to COAG

• NDIS Outcomes Framework Pilot

• Carers NSW issues paper, *The NDIS one year in*:
  • Informal consultation
  • Policy analysis

• Carers Australia NDIS Carer Capacity Building Project
  • Focus groups in trial sites
  • Online survey

• Carers NSW 2014 and 2016 Carer Surveys
Many carers were already having positive experiences

Many were having difficulty understanding and engaging with the NDIS

Many were having difficulty supporting participants to prepare and implement their plans

The recognition of carers in NDIS policy framework was promising but limited

The future of carer support was uncertain
Carer respondents generally

- Felt positive about their current lives and their family member’s future under the NDIS

- Felt confident identifying the needs of the person they were caring for and accessing relevant services

- Felt confident understanding and advocating for the rights of the person they were caring for
  - This was lower for carers of participants aged 25 years and over and for carers living in disadvantaged areas
Some key issues for carers included:

- Inadequate social and informal support
- Inadequate time with friends and family
- Lack of succession planning
- Difficulty meeting the costs of everyday living
- Desire to work more
  - Lack of flexible work options
Respondent profile

- 92 valid responses from carers in a range of trial sites across Australia
- Variety of disabilities and plan commencement times
- 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.

Most respondents were:
- Female
- Aged 35 to 54
- Caring for someone under 25 years of age
- Living with the person they cared for
- Providing more than 40 hours per week of care
One in four carers felt prepared for the NDIS

One in four still had little or no understanding after the participant had received their NDIS plan

Nearly one in four carers were unaware that carer supports could be included in an NDIS plan

Three quarters of carers wanted more information about supports they could receive as a carer through the NDIS

The most popular source of information was the NDIS website
Carer involvement

Most carers had helped the participant:
• Apply for the NDIS (88 per cent)
• Prepare for the planning meeting (83 per cent)
• Engage with service providers (71 per cent)

Common ways carers had prepared for the planning meeting included:
• Developing lists of current supports and potential changes (77 per cent)
• Speaking with service providers (45 per cent)
• Obtaining information from the NDIS website (43 per cent)
• Speaking with the NDIA (40 per cent)
• Helping complete the NDIS planning workbook (40 per cent)
• Speaking to other carers who care for an NDIS participant (36 per cent)
Carer involvement (2)

• Around one in four carers thought their caring role was taken into consideration by the planner.

• Just over three quarters of carers were unaware that they could provide a Carer Statement.
  o Of those who were not aware, most would have liked to have the opportunity to submit a Carer Statement.

• More than half of carers were unaware that they could ask for a separate conversation with the planner.
  o Of those who were aware, most took advantage of this opportunity.
  o Of those who were not aware, most would have liked to.
Effects on carers

• Around half of carers felt that the supports provided though the NDIS had not reduced the hours of care they needed to provide
  o Of those who felt the number of hours had been reduced, nearly half said that the reduction was between 1 and 3 hours

• Most carers did not think the NDIS had made it easier for them to:
  o participate in their own activities and pursue their own goals
  o get or keep paid employment
  o engage in further education or training

• More than one third of carers did not receive any identified carer supports in the participant’s plan. Nearly half received respite-like supports.
About the survey

• Over 2,000 respondents

• Online and hard copy versions

• Results still being cleaned and analysed

• Report due for release in October 2016

• Majority female (83 per cent), median age 57 years

• 1957 respondents completed NDIS section, of whom 109 were caring for NDIS participants
The NDIS has made my own life better as a carer:

- Strongly agree: 18%
- Agree: 34%
- Neither agree nor disagree: 31%
- Disagree: 10%
- Strongly disagree: 5%
Benefits for carers

- Greater access to services and supports (18 respondents)
- Greater affordability / improved financial situation (15 respondents)
- A break / reduced responsibility (9 respondents)
- Reduced stress (6 respondents)
- Greater choice and control (5 respondents)
- Continued or increased engagement with workforce (3 respondents)
- Improved family relationships (2 respondents)
Some quotes from survey respondents

“For thirty years my brother had no access to outside help. NDIS has taken a huge worry off my shoulders. Now we have assistance for him which means someone else visits weekly and some household chores are attended to.”

“It has released some of the financial pressure, my daughter can now attend speech therapy, OT therapy and Art Therapy as well as her psychologist, without worrying about how we are going to feed our family.”

“The NDIS has put in place a support worker for my mother to go out for certain activities so I am able to have a break.”
Some quotes from survey respondents

“NDIS has assisted with providing speech and occupational therapy so it helps my sons language and coping mechanisms a lot which improves me life as he is easier to work with.”

“Because we are self-managing, I have been able to employ support workers who I feel comfortable with, and who value and respect my son enough to work with him as an individual, making respite a genuine option.”

“In addition to traditional day program (community participation), the NDIS has provided funding for personal care supports, 3 hrs a day, twice a week, allowing me to work longer hours.”
Challenges for carers

- More work or stress for the carer (7 respondents)
- System too complex (4 respondents)
- No real change (4 respondents)
- Carers’ needs overlooked (2 respondents)
- Delays (2 respondents)
- Issues with planners (2 respondents)
- Issues with service quality (2 respondents)
Some quotes from survey respondents

“While I agree theoretically that the NDIS has assisted my caring role there is still a lot of follow up needed on my part and it cuts into my day/week.”

“NDIS meetings review etc. only make another thing to have to do. The old system was much, much, much simpler.”

“Nothing much has changed for my disabled daughter.”

“Under the NDIS scheme carers seem to be forgotten about e.g. weekends or short term holidays were previously offered to carers.”

“My planner did not do her job properly so I spent a lot of time chasing things up and calling around to different NDIS offices to get information that my planner forgot (by her own admission) to provide to me.”
Some key findings

- Many carers need more information on the NDIS process, especially on their involvement and entitlements, such as making a Carer Statement.

- Carers of participants aged 25 years and over need particular support to self-advocate and plan for the future.

- Many carers need more social supports in their lives to help them care, and more time with their family and friends.

- Carers need targeted support to be able to use the opportunity make the most of NDIS opportunities and increase their participation in employment and education.
What Carers NSW is doing

- NDIS resources for carers:
  - NDIS web page with links tailored to carers
  - Monthly NDIS Update e-newsletter targeted at carers
  - Fact sheets for carers, including NDIS Checklist

- NDIS workshops for carers
  - Half day, interactive workshops with carers across NSW
  - Broad overview of NDIS, how to support someone to access the NDIS, prepares carers to communicate their own needs

- together program for carer support groups, including regular forums

- Corporate Services – supporting employers and carer employees

- Systemic advocacy
References


Please visit www.carersnsw.org.au/NDIS for more information.
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