



# Family and Carer Outcomes

## Summary Report

At 30 June 2024

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# 1. Overview

This paper presents a summary of the longitudinal outcomes for families and carers of participants entering the Scheme from 1 July 2016, who have been in the Scheme for one year or longer at 30 June 2024, using data available as at that date.

The purpose of the document is to provide a picture of how the families and carers of participants are progressing, based on information provided by them in interviews conducted using the National Disability Insurance Scheme (NDIS) outcomes framework questionnaires.

The paper provides a summary of the number, extent and nature of changes across key outcome indicators. The results are intended to provide insight into how the Scheme is making a difference for families and carers and point to any areas where improvements may be required.

## 2. Background

### 2.1 A life course approach

A life course approach to measuring participant and family/ carer outcomes across main life domains has been used. This lifespan approach aligns key outcomes and life domains to key life stages.

Many of the issues faced by families and carers are similar regardless of participant age – for example, being able to work as much as they want. Nevertheless, there are some differences – such as, families and carers of young children will tend to be focused on helping their child’s early development and learning, whereas families and carers of young adults will tend focus more on helping their family member to become as independent as possible.

For families and carers, the outcomes framework seeks to measure the extent to which families and carers are reaching the following domain level outcomes:

- Knowing their rights and advocate effectively for their child/ family member with disability
- Feeling supported and having the support they need to care
- Gaining access to desired services, programs, and activities in their community
- Helping their child or young person develop, learn and become independent
- Planning for the future
- Enjoying health and wellbeing
- Participating in social and community activities
- Participating in employment
- Understanding strengths, abilities and special needs (Long Form only for 0 to 24 participant age group).

## 2.2 Short Form and Long Form

The Short Form (SF) outcomes questionnaire is completed by all participants, and a family member or carer, where available. It contains questions useful for planning, as well as key indicators to monitor and benchmark over time.

The Long Form (LF) outcomes questionnaire is completed for a subset of participants, and a family member or carer, where available. It includes some additional questions allowing more detailed investigation of participant and family/carer experience, and additional benchmarking.

For both the SF and the LF questionnaires, participants and their families and carers are interviewed at baseline (Scheme entry), and approximately annually thereafter. Following the same group longitudinally over time allows within-individual changes in outcomes to be investigated.

## 3. Summary of findings

Sixty-seven per cent of indicators (i.e. 41 out of 61) showed significant and material change. Key findings by participant age group are as follows:

- The 0 to 14 participant age group had the largest proportion of family and carer indicators with significant and material changes, at 74%
- Fifty-five per cent of family and carer indicators in the 15 and over participant age group showed significant and material changes
- Three quarters (75%) of indicators that related to all age groups showed significant and material change.

Of the indicators with significant and material change, the percentage showing improvement was:

- Forty-seven per cent for the 0 to 14 participant age group
- Eighty-three per cent for the 15 and over participant age group. However, it is noted that there are fewer questions in the 15 to 24 and 25+ age groups, compared to the 0 to 14 age group.
- Sixty-seven per cent for the indicators that related to all age groups.

## 4. Outcomes that are improving for families and carers

As shown in Table 1 below, improvements were evident across several family/carers outcome domains.

**Table 1: Outcomes that are improving for families and carers**

<b>Rights and advocacy</b>	
More families/carers of participants aged 0–14 report no barriers to access or advocacy, and more families/carers of participants aged 15 and over report that they have no difficulties understanding their rights and the rights of their family member with disability.	<ul style="list-style-type: none"> <li>• 45.1% (0 to 14 group) experience no barriers (6.7 percentage-point increase).</li> <li>• 91.1% (15 and over group) understand their rights (11.1 percentage-point increase over six years).</li> </ul>
<b>Access to services</b>	
Increasingly, families/carers across all participant age groups are reporting that services used are listening to them and are meeting their needs.	<ul style="list-style-type: none"> <li>• 21.7 percentage-point increase to 47.1% (services meeting needs).</li> <li>• 13.6 percentage-point increase to 81.3% (services listening).</li> </ul>
<b>Supporting learning and development</b>	
More families and carers of participants aged 0 to 14 reported knowing what they can do to support, and what services are needed to promote their child's learning and development.	<ul style="list-style-type: none"> <li>• Around 5 percentage-point increase to around 50% for both indicators.</li> </ul>
Increasing percentages get enough support parenting their child for those in the Scheme for 1 to 4 years.	<ul style="list-style-type: none"> <li>• 1.5 percentage point increase to 46.5% after four years in Scheme.</li> </ul>
<b>Plans for the future</b>	
Respondents are more confident about the future of their family member with disability under the NDIS.	<ul style="list-style-type: none"> <li>• 35.3 percentage-point increase to 82.4%.</li> </ul>
Increasing percentages of families/carers say that they receive help to plan for the future.	<ul style="list-style-type: none"> <li>• 24.4 percentage-point increase over six years to 84.4%.</li> </ul>
More families and carers of participants aged 25 and over are seeking assistance with succession planning, and more have asked help from service providers, professionals and support workers.	<ul style="list-style-type: none"> <li>• 34.8% have made plans for when they are no longer able to provide care (8.7 percentage-point increase).</li> <li>• 71.4% of these have asked for help from service providers, professionals or support workers (14.3 percentage-point increase over six years).</li> </ul>

Health and wellbeing	
Families and carers increasingly feel delighted, pleased or mostly satisfied when thinking about what happened last year and what they expect for the future.	<ul style="list-style-type: none"> <li>• 14.2 percentage-point increase to 50.0% after six years.</li> </ul>

Employment	
Strong improvements in employment outcomes (having a paid job, working 15 or more hours per week, and being employed in a permanent position) have been <u>observed</u> for families and carers of participants aged 0 to 14, and to a slightly lesser extent, those aged 15 to 24.	<ul style="list-style-type: none"> <li>• 59.4% in paid employment (12.4 percentage-point increase).</li> <li>• 89.2% working 15 or more hours per week (9.0 percentage-point increase).</li> <li>• 84.0% are employed in a permanent position (5.8 percentage-point increase).</li> </ul>

Recognising strengths, abilities and progress	
Families/carers of participants aged up to 24 increasingly report being able to recognise the strengths and abilities of their family member with disability and seeing them progressing.	<ul style="list-style-type: none"> <li>• 88.4% have no difficulties in recognising strengths and abilities (16.3 percentage-point increase).</li> <li>• 95.3% have no difficulties seeing progress (18.6 percentage-point increase).</li> </ul>

## 5. Areas of concern or deterioration

There are opportunities for improvement across four key areas. These are summarised in Table 2 below.

**Table 2: Outcomes that are of concern/deteriorating for families and carers**

Rights and advocacy	
Some outcomes related to rights and advocacy for families/carers of participants aged 0 to 14 have deteriorated, particularly in terms of respondents being able to identify the needs of their child/ family and access to services to meet their needs. In terms of being able to advocate for their family member with disability, the 15 and over age group shows decreases over time, while the younger age group is fairly stable.	<ul style="list-style-type: none"> <li>• 66.5% able to identify the needs of their child/family (8.1 percentage-point decrease).</li> <li>• 43.5% able to access services/supports to meet needs (11.1 percentage-point decrease).</li> <li>• 69.1% able to advocate (9.4 percentage-point decrease).</li> </ul>

<b>Families and carers feel supported</b>	
Some outcomes related to families feeling supported have deteriorated, particularly in relation to having support networks to meet different needs.	<ul style="list-style-type: none"> <li>• 41.8% have friends they see as often as they'd like (1.9 percentage-point decrease).</li> <li>• 33.7% have people they can ask for practical help (5.8 percentage-point decrease).</li> <li>• 26.7% have people they can ask for childcare (3.0 percentage-point decrease).</li> </ul>
<b>Self-rated health</b>	
Across all participant age groups, self-rated health of families/ carers has deteriorated over time.	<ul style="list-style-type: none"> <li>• 9.3 percentage-point decrease to 64.2%.</li> </ul>
<b>Social and community involvement</b>	
Families and carers of participants aged 0 to 14 have experienced some deterioration in social and community involvement, with a decline in the percentage of families/ carers who are able to engage in social interactions and community life as much as they want. In addition, there has been an increase in respondents who say that one of the barriers to greater involvement is the situation with their child (deterioration in the indicator).	<ul style="list-style-type: none"> <li>• 4.1 percentage-point decrease to 25.3% in being able to engage socially as much as they want after six years.</li> <li>• 5.0 percentage-point increase to 95.5% in saying the situation with their child is a barrier.</li> </ul>

## 6. Benchmarking against the Australian population

Overall, families and carers of NDIS participants experience poorer outcomes than the Australian population in the areas of employment and health. However, the trend is improving in terms of employment for family and carers of younger participants.

- The percentage in a paid job has increased for families and carers of participants aged under 25. For this combined group, the percentage in a paid job has increased by 12.5 percentage points (over seven years).
- Longitudinal improvement in the percentage of respondents working 15 hours or more per week is strong, reaching 89.2% after seven years. This has almost reached the Australian population benchmark (94.4%).

Self-rated health deteriorates with time in Scheme, possibly due to older age. After seven years, 64.2% of families and carers rated their health as “Excellent”, “Very Good” or “Good”, substantially lower than the Australian population benchmark of 87.4%.

## 7. Has the NDIS helped?

Overall, there is an increasing trend, associated with time in Scheme, in positive perceptions of whether the NDIS has helped, for all domains and across all cohorts.

- For families and carers of participants aged 0 to 14, opinions are most positive in relation to improving family/carer capacity to help their child develop and learn. For the 15 and over participant age group, families and carers are most positive about the Scheme's role in helping them feel supported and assisting them to access services.
- Families and carers of participants aged 0 to 14 tend to be more satisfied with the amount of say they have in plan development than with plan implementation; however, satisfaction with plan development improves faster over time.
- The biggest improvements since first reassessment for families and carers of each participant age group are as follows:
  - Participants aged 0 to 14: rights and advocacy and families feeling supported (22.5 percentage points after 7 years).
  - Participants aged 15 to 24: child's independence (29.0 percentage points after 7 years).
  - Participants aged 25 and over: families feeling supported (43.2 percentage points after 7 years).
- There appears to be a cohort effect (particularly where the participant is aged under 25), with those entering the Scheme more recently responding more positively than those entering the Scheme earlier.

Higher plan utilisation is strongly associated with a positive response after one year in the Scheme. Improvements are typically largest between utilisation bands 0–20% and 20–40%.

It is noted that the NDIA rolled out a new ICT system nationally on 30 Oct 2023. In this new data system, the answer options for the "Has the NDIS helped" questions changed. Previously, 'yes'; 'no' and 'It's my first plan' were the response options available for each helped question. The survey forms in the new system provides the following amended response options: 'yes, a lot', 'yes, a bit', 'no', and 'N/A (I don't need help in this area)'. It is likely that some of the larger-than-usual increases in the percentage responding positively at the latest reassessment (which contains a large proportion of responses from the new data system) can be attributed to this change.

Analysis of latest reassessment responses from the new data system shows that:

- The majority of families and carers needed help in each domain. In particular, over 95% of families and carers needed help in the area of feeling supported, regardless of participant age group.
- Of those needing help, more said the NDIS helped a bit, compared to those saying the NDIS helped a lot, although the percentage responding "yes a lot" tends to be higher for those who have been in the Scheme for longer among families and carers of participants aged 15 and over.



# National Disability Insurance Agency

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