# 2. Families/carers of participants from birth to age 14: overview of results

## 2.1 Key findings

**Box 2.1: Overall findings for families/carers of participants from birth to age 14, who joined the Scheme between 1 July 2016 and 30 June 2017**

- For participants entering the Scheme in 2016-17, the longitudinal analysis revealed significant improvements across a number of family/carer indicators, with trends in the first year generally continuing into the second year of Scheme experience.

- The percentage of families/carers working in a paid job has increased by 3.5% over the first year in the Scheme, with a further increase of 1.8% over the second year (5.3% overall), from 46.4% at baseline to 51.7% at second review. However, this is still considerably lower than for Australians without caring responsibilities (77.7%).[10]

- The percentage of families/carers in a paid job who work 15 hours or more per week has increased by 4.8% over two years, from 79.1% at baseline to 83.9% at second review. The percentage working less than 30 hours per week has decreased by 7.2%, from 60.6% to 53.3%, but is still much higher than the 25.8% of Australians working on a part-time basis as at 30 June 2019.[11]

- The percentage who say that they (and/or their partner) are able to work as much as they want has not changed materially (39.7% at baseline and 38.5% at second review). Looking at barriers to working more, the percentage who say that the situation of their child with disability is a factor has increased by 4.8% between baseline and second review, from 88.3% to 93.1%, and the percentage who say insufficient flexibility of jobs is a factor increased by 7.9%, from 39.4% to 47.4%.

- Families and carers report increasing ability and confidence in helping their children develop and learn. The percentage of families/carers who know what specialist services are needed to promote their child’s learning and development increased by 11.7% between baseline and second review, from 40.6% to 52.3%. Similarly, the percentage of respondents who know what they can do to support their child’s learning and development increased by 10.8%, from 42.0% to 52.8%. The percentage who say they get enough support to feel confident in parenting their child has increased by 5.3%, from 44.3% to 49.6%.

- Improvements in interacting with services have been observed. The percentage of families/carers who say their relationship with services is good or very good has increased by 9.9%, from 78.8% at baseline to 88.7% at second review.

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[10] Australian Bureau of Statistics. 2019. 6202.0 Labour force, Australia, Jun 2019. Employment to population ratio.

[11] Australian Bureau of Statistics. 2019. 6202.0 Labour force, Australia, Jun 2019. ABS defines part time work as less than 35 hours per week, so the percentage of the general population working less than 30 hours per week would likely be lower than 25.8%.

### Box 2.1: Overall findings for families/carers of participants from birth to age 14, who joined the Scheme between 1 July 2016 and 30 June 2017 (continued)

- Some deterioration was observed in self-rated health for families/carers, with the percentage rating their health as excellent, very good or good decreasing by 7.9%, from 74.0% at baseline to 66.1% at second review.
- There has also been some deterioration in informal supports for families/carers, with reductions over two years in the percentages who have: friends they can see as often as they like (4.4% decrease); people they can ask for practical help as often as they need (3.8% decrease); people they can ask for childcare as often as they need (3.6% decrease). However, the percentage who have someone they can talk to for emotional support as often as they need increased by 2.3%.
- Families and carers are also less likely to say they are able to engage in social interactions and community life as much as they want (a decrease of 3.0%, from 27.1% at baseline to 24.1% at second review). For those who are unable to engage as much as they want, the percentage who say the situation of their child with disability is a barrier to engaging more has increased by 4.0%, from 90.7% at baseline to 94.7% at second review.

### Box 2.2: Overall findings for families/carers of participants from birth to age 14, who joined the Scheme between 1 July 2017 and 30 June 2018

- Trends observed for families and carers of participants entering the Scheme in 2017-18 were generally similar to those observed for families and carers of 2016-17 entrants.
- The percentage of families/carers working in a paid job has increased by 2.0% over the first year in the Scheme, from 48.2% at baseline to 50.1% at first review. As for 2016-17 entrants, there has also been an increase in the percentage working 15 hours or more per week, from 77.4% at baseline to 79.9% at first review (a 2.5% increase).
- The percentage who say that they (and/or their partner) are able to work as much as they want has not changed materially (39.3% at baseline and 38.5% at first review). However,for those unable to work as much as they want, there have been increases in the percentage who perceive their child's disability as a barrier to working more (a 2.7% increase, from 86.9% to 89.5%), and the percentage who say insufficient flexibility of jobs is a barrier to working more (a 4.0% increase, from 39.0% to 43.0%).
- The percentage of families/carers who say their relationship with services is good or very good has increased by 8.3%, from 77.1% at baseline to 85.4% at first review.
- Improvements were observed across all indicators related to families/carers helping their child develop and learn. Most notably, the percentage of respondents who know what specialist services are required to promote their child's learning and development increased by 8.1%, from 40.7% at baseline to 48.9% at first review. Similarly, the percentage of families/carers who know what they can do to support their child's development increased by 6.9%, from 41.7% at baseline to 48.6% at first review.
- As for 2016-17 entrants, there has been some deterioration in self-rated health. The percentage of families/carers who rate their health as excellent, very good or good fell by 3.3%, from 71.8% at baseline to 68.5% at first review.
- Of those unable to engage in the community as much as they want, the percentage who say the situation with their child is a barrier to engaging in more social interactions increased by 2.3%, from 88.6% at baseline to 90.9% at first review.

## Box 2.3: Outcomes by key characteristics for families/carers of participants from birth to age 14

- Families/carers of participants with a hearing or visual impairment generally experience better outcomes, both baseline and longitudinal. In contrast, respondents for participants with autism or an intellectual or psychosocial disability tend to fare worse.
- Families/carers of older participants tend to exhibit worse outcomes, both at baseline and in the longitudinal analysis, particularly with respect to advocacy, feeling supported, and health and wellbeing. As health tends to decline with age, some deterioration in the health rating is expected.
- Baseline outcomes for families/carers of participants who are from a CALD background tend to be worse than those for families/carers of non-CALD participants, particularly regarding advocacy and independence.
- Baseline results for families/carers of Indigenous participants are mixed. They are less likely to be in paid employment or to report that the services they use listen to them, but are more likely to have access to required services.
- For the majority of indicators in all domains, baseline and longitudinal outcomes are better for families/carers of participants with a high level of function. A similar trend was observed for families/carers of participants with a lower annualised plan budget.
- Families/carers living in New South Wales and Victoria had worse outcomes at baseline across all domains. By contrast, those from South Australia and the Australian Capital Territory had better baseline outcomes. Outcomes for families/carers from Queensland tended to improve the most after spending time in the Scheme, while families/carers from Victoria were less likely to improve.
- Families/carers of participants with self-managed plans (fully or partly) experience more positive outcomes in the domains of advocacy, feeling supported and helping their child develop and learn at both baseline and subsequent review periods.
- Outcomes tend to be more positive across all domains for families/carers of participants living in a private home owned by their family, both at baseline and longitudinally.

### Box 2.4 Has the NDIS helped? – families/carers of participants from birth to age 14

- The percentage of families/carers reporting that the NDIS has helped after two years in the Scheme was higher across almost every domain (except health and wellbeing) than the percentage of families/carers reporting that the NDIS helped after one year in the Scheme.
- Opinions on whether the NDIS helped after one year in the Scheme vary by participant/carer characteristics. Results tended to be more positive for families/carers of participants who are younger, have higher baseline plan utilisation and higher plan budget, have higher level of function, have self-managed plans, and need less support with planning from the NDIA.
- Outcomes at first review tended to be better for families/carers of participants with global developmental delay or developmental delay. On the other hand, outcomes tended to be worse for families/carers of participants with an intellectual disability or Down syndrome.
- Outcomes for families/carers of participants with higher plan utilisation were more likely to improve between first and second review, across almost all domains. On the other hand, outcomes for families/carers of older participants, or those families/carers that changed employment status from permanent to casual, were more likely to deteriorate between first and second review.
- The percentage of families/carers reporting that the NDIS improved the level of support for their family increased by 4.1%, from 62.8% at first review to 66.9% at second review. Families/carers of participants with global developmental delay or developmental delay, or those with higher annualised funding, were least likely to deteriorate on this outcome between first and second review.
- Similarly, the percentage of families/carers reporting that the NDIS improved their access to services, programs and activities in the community increased from 66.0% at first review to 69.7% at second review. This outcome was less likely to deteriorate for families/carers of participants who are not Indigenous.

## 2.2 Results overview

### 2.2.1 Outcomes framework questionnaire domains

For families/carers of participants aged from birth to 14 years, the outcomes framework seeks to measure the extent to which they:

- Know their rights and advocate effectively for their child with a disability (RA domain)
- Feel supported (SP)
- Can gain access to desired services, programs and activities in their community (AC)
- Are able to help their children develop and learn (DV)
- Enjoy health and wellbeing (HW).

The LF contains an extra domain, measuring the extent to which families/carers:

- Understand their children's strengths, abilities and special needs (UN)

The LF also includes a number of extra questions in other domains, particularly the health and wellbeing domain.

### 2.2.2 Baseline indicators – across all participants

#### Government benefits (Carer Payment and Carer Allowance)

The two main government benefits available to eligible carers are Carer Payment and Carer Allowance.

Carer Payment is an income replacement benefit for carers who are unable to work in substantial paid employment because they provide full-time daily care for someone with a severe long-term disability (or someone who is frail aged). Carer Payment is subject to income and assets tests and is paid at the same rate as other social security pensions.

Carer Allowance is an income supplement available to carers who provide daily care in a private home for someone with a long-term disability (or someone who is frail aged). Before 20 September 2018 it was neither income nor assets tested, but from that date a $250,000 family income test threshold was introduced, affecting an estimated 1% of carers who were previously eligible.[12]

As at June 2019, 282,097 Australians were receiving Carer Payment and about 2.2 times as many, 620,396, were receiving Carer Allowance.[13]

The outcomes framework questionnaires ask families/carers of NDIS participants whether they are currently receiving any government benefits (Carer Payment, Carer Allowance, or other benefits). At baseline, 22.8% of families/carers said they were receiving Carer Payment and 51.6% said they were receiving Carer Allowance. The ratio of Carer Allowance to Carer Payment (2.3) is similar to the 2.2 observed for the total populations in receipt of these benefits.

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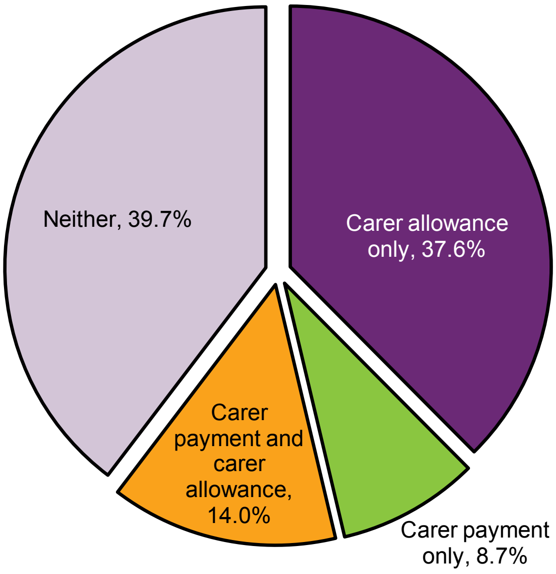
[12] Fact Sheet – New services for carers, Commonwealth of Australia (Department of Social Services) 2018 https://www.dss.gov.au/sites/default/files/documents/04_2018/fact_sheet_-_new_services_for_carers.pdf

[13] Annual report 2018-19, Commonwealth of Australia (Department of Social Services) 2019, https://www.dss.gov.au/sites/default/files/documents/10_2019/d19-1139120-dss-annual-report-2018-19.pdf

Figure 2.1 shows the percentages of family/carer respondents who say they are receiving Carer Payment and/or Carer Allowance at baseline.

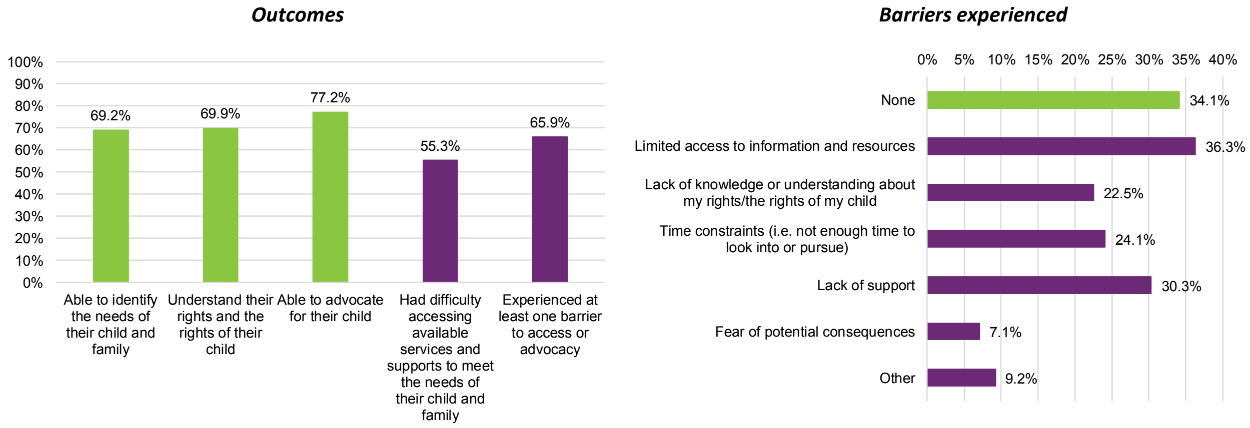
**Figure 2.1 Receipt of Carer Payment and Carer Allowance, families/carers of participants aged 0 to 14**[14]



## Rights and advocacy

Figure 2.2 shows selected outcomes in the Rights and Advocacy domain for families/carers of participants aged 0 to 14. At baseline, 69.2% of families/carers were able to identify the needs of their child and family, 69.9% understood their rights and the rights of their child (LF question), and 77.2% were able to advocate for their child. However, 55.3% had some difficulty or a great deal of difficulty in accessing available services and supports to meet the needs of their child and family. 65.9% of families/carers identified at least one barrier to access or advocacy, the most common being limited access to information and resources (36.3%) and lack of support (30.3%).

**Figure 2.2 Rights and advocacy for families/carers of participants aged 0 to 14**



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[14] Note that this is self-report data.

### Families feel supported

At baseline, most families/carers said they lacked sufficient support and social connections. 56.4% were unable to see friends and family as often as they like, 60.1% said they could not get as much practical help as they would like, and 72.6% said they could not get childcare as often as they need. However, 58.4% of families/carers said they have people they can talk to for emotional support as much as they like.

### Families are able to gain access to desired services, programs, and activities in their community

The LF survey reveals that 79.7% of families/carers have good (42.8%) or very good (36.8%) relationships with their services.

### Families help their children develop and learn

At baseline, the SF reveals that 41.1% of families/carers know what they can do to support their child's learning and development, with a further 51.8% saying they have some degree of knowledge. A similar pattern is exhibited with regards to specialist services: 40.0% of families/carers know what specialist services are needed and 52.1% have some degree of knowledge. 43.8% of family and carers agree that they get enough support to feel confident in parenting their child with disability, and a further 42.3% agree to some extent. 85.6% feel very confident (26.9%) or somewhat confident (58.7%) in supporting their child's development.

### Families understand their children's strengths, abilities and special needs

The LF includes an additional domain concerned with how families/carers perceive the strengths and abilities of their child with disability, and how their child is progressing. 82.8% of families/carers can recognise their child's strengths and abilities and 76.2% can see how their child is progressing.

### Health and wellbeing

At baseline, only 40.3% of families/carers say that they (and their partner) are able to work as much as they want. 45.5% say that they themselves would like to work more and 8.7% say that both they and their partner would like to work more. Of the families/carers who do not work as much as they like, 86.8% identified the situation of their child with disability as a barrier to working more, and 36.4% said that insufficient flexibility of jobs was a barrier.

Only 27.0% of families/carers say that they (and their partner) engage in social and community life as much as they like. Of those who do not, 88.4% identified the situation of their child with disability as a barrier to engaging more, and 42.7% said time constraints were a barrier.

From the SF, 72.2% of families/carers rate their health as good, very good or excellent, compared to 86.6% of Australians aged 25 to 64 overall.[15] Figure 2.3 compares the distribution of responses for families/carers to the population benchmark.

The LF includes a number of extra questions asking about the wellbeing of families/carers and their outlook on life generally, and for their child in particular. Families/carers most commonly had "mixed" or unknown feelings about the future (49.6%), although more

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[15] ABS National Health Survey (NHS) 2017-18. Families/carers of 0 to 14 year olds are likely to be towards the younger end of the 25-64 age range.

answered positively (43.8%) than negatively (6.6%). The 43.8% responding positively is much lower than the 77.0% for Australians aged 25 to 64 overall[16], and is lower than for families/carers of participants aged 25 and over (46.4%). Response distributions for families/carers and the general population are compared in Figure 2.4.

**Figure 2.3 Self-rated health, families/carers of participants aged 0 to 14**

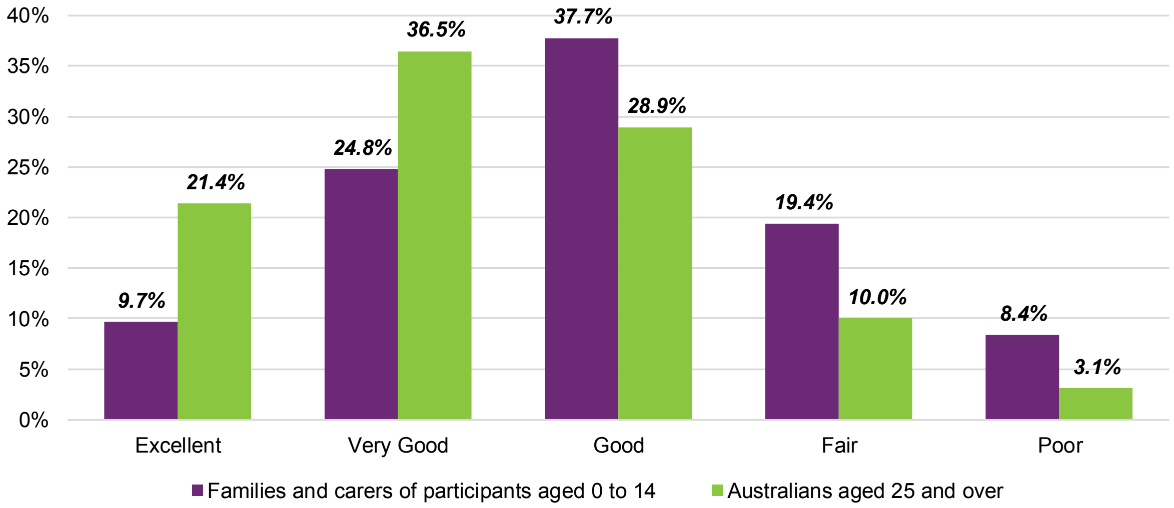
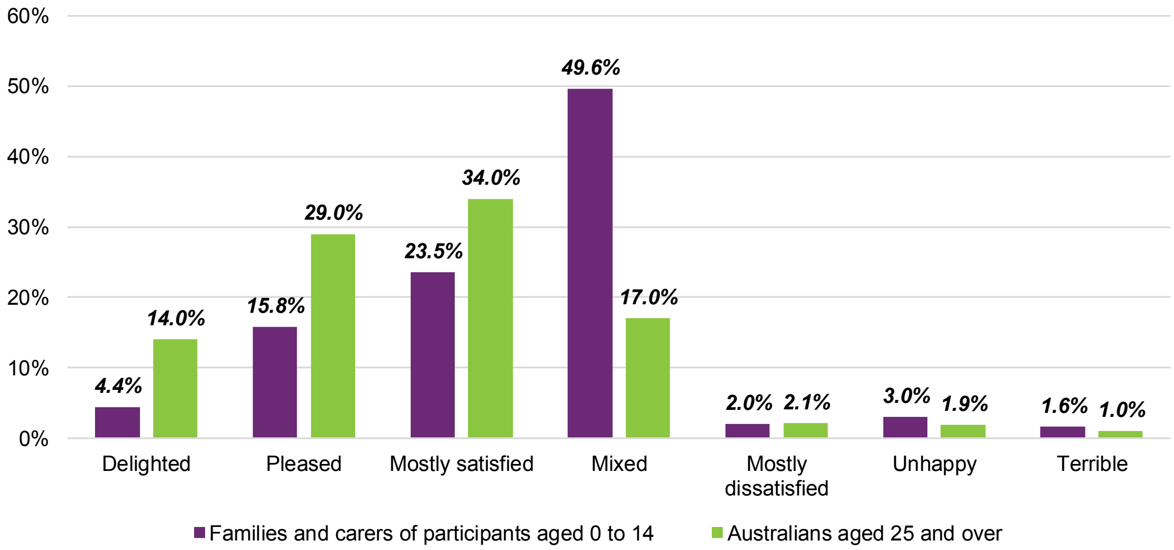


**Figure 2.4 Outlook for the future, families/carers of participants aged 0 to 14**



With regard to their child with disability, 73.9% agreed or strongly agreed that having a child with disability has made it more difficult to meet everyday costs of living. 59.9% agreed or strongly agreed that they feel confident about the future of their child with disability under the NDIS, with 36.2% feeling neutral about this statement and only 3.9% expressing a negative opinion. The percentages agreeing or strongly agreeing that their child gets the support they need (38.7%), or that the services and supports help them to better care for their child

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[16] ABS General Social Survey (GSS) 2010. For GSS 2014 the question changed from using seven descriptive categories to a rating on a 0 to 10 scale.

(45.3%), are both lower. For these last two statements, the most common response was again "neutral" (39.0% and 42.4%, respectively).

### 2.2.3 Baseline indicators – participant characteristics

Baseline indicators have been analysed by participant and family/carer characteristics using one-way analyses and multiple regression modelling.

Across most domains, the participant's primary disability type, their living situation, age, annualised plan budget and who manages their plan are the characteristics most predictive of family/carer outcomes in the multiple-regression models, which control for other factors.

Key findings for each characteristic are summarised below. Tables summarising the direction of the effect for selected characteristics, in the regression models for selected outcomes, are also included. Table 2.1 provides a key to aid interpretation of the arrow symbols used in these tables, including some examples.

**Table 2.1 Definition of symbols used in baseline key driver tables**

| Symbol | Meaning | Impact | Example |
|---|---|---|---|
| ⬆ | **More likely to respond "Yes" to the question** | **Positive** | Families/carers of participants with a hearing impairment being their primary disability are more likely to be in a paid job |
| ⬇ | **Less likely to respond "Yes" to the question** | **Negative** | Families/carers of participants with a lower level of function are less likely to be able to engage in social interactions and community life as much as they want |
| ⬆ | **More likely to respond "Yes" to the question** | **Negative** | Families/carers of older participants who are also unable to work as much as they want are more likely to say the situation of their child/family member with disability is a barrier to working more |
| ⬇ | **Less likely to respond "Yes" to the question** | **Positive** | Families/carers of CALD participants who are also unable to work as much as they want are less likely to say insufficient flexibility of jobs is a barrier to working more |
| ⬆ | **More likely to respond "Yes" to the question** | **Depends on context** | Families/carers of Indigenous participants are more likely to be receiving carer payment |
| ⇩ | **Less likely to respond "Yes" to the question** | **Depends on context** | Families/carers of participants living in a remote or very remote area are less likely to be receiving carer allowance |

#### Participant primary disability type

There is a significant relationship between participant primary disability type and family/carer outcomes. Typically, for a given disability type, the direction (positive or negative) of the relationship with outcomes is consistent for all domains. Compared to the average[17],

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[17] The unweighted average of the outcomes indicators for all disability types

outcomes are worse across all domains for families/carers of participants with autism, intellectual disability, psychosocial disability[18] or another neurological disability, while almost all outcomes are better for families/carers of participants with a hearing impairment, a visual impairment or another physical disability.

Families/carers of participants with Down syndrome, or a sensory or speech disability, tend to have mixed outcomes relative to the average, and those of participants with cerebral palsy or an acquired brain injury are typically somewhat better than average.

Families/carers of participants with Down syndrome were much more likely to be in receipt of Carer Allowance (68.6% compared to 51.6% overall, on a one-way basis), whereas families/carers of participants with another sensory/speech disability or developmental delay were less likely to be receiving both Carer Payment and Carer Allowance. Controlling for other factors, families/carers of participants with hearing impairment were significantly more likely to have people they could ask for practical help as often as they need (62.7% versus 39.9% overall, on a one-way basis).

Table 2.2 shows baseline family/carer outcomes for which participant primary disability type is a significant ($p<0.05$) predictor in the multiple-regression model.

**Table 2.2 Relationship of disability type with the likelihood of selected outcomes**

| Outcome | Participant primary disability | | | | |
|---|---|---|---|---|---|
| | Autism | Hearing impairment | Intellectual disability | Psychosocial disability | Visual Impairment |
| **Being in a paid job** | | ⬆ | ⬇ | | ⬆ |
| **For family/carers with a paid job, the paid job being a permanent position** | ⬇ | | | | |
| **For family/carers with a paid job, working 15 or more hours per week** | ⬇ | ⬆ | | | |
| **Receiving carer payment** | ⬆ | ⇩ | ⬆ | | ⇩ |
| **Receiving carer allowance** | ⬆ | ⇩ | ⬆ | | ⇩ |
| **Currently studying** | ⬆ | | | | |
| **Being able to identify the needs of their family member with disability** | ⬇ | ⬆ | ⬇ | ⬇ | |

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[18] Based on a small number of participants (241) with a psychosocial disability in this age group.

| Outcome | Participant primary disability | | | | |
|---|---|---|---|---|---|
| | Autism | Hearing impairment | Intellectual disability | Psychosocial disability | Visual Impairment |
| Being able to access available services and supports to meet the needs of their child and family | ↓ | ↑ | ↓ | ↓ | ↑ |
| Being able to advocate for their child if they have issues or problems | ↓ | | ↓ | ↓ | |
| Having experienced no barriers to access and/or advocacy | ↓ | ↑ | | ↓ | |
| Having friends they can see as often as they'd like | ↓ | ↑ | | ↓ | ↑ |
| Having people they can ask for practical help as often as needed | ↓ | ↑ | ↓ | ↓ | ↑ |
| Having people they can ask for childcare as often as needed | ↓ | ↑ | ↓ | ↓ | ↑ |
| Having people they can talk to for emotional support as often as needed | ↓ | ↑ | ↓ | ↓ | ↑ |
| Knowing what specialist services are needed to promote their child's learning and development | | | ↓ | ↓ | ↓ |
| Knowing what their family can do to support their child's learning and development | ↓ | ↑ | ↓ | ↓ | |
| Getting enough support to feel confident in parenting their child | ↓ | ↑ | ↓ | ↓ | ↑ |
| Feeling confident in supporting their child's development | ↓ | ↑ | ↓ | ↓ | |
| Rating their health as excellent, very good or good | ↓ | ↑ | | ↓ | ↑ |
| Being able to work as much as they want | ↓ | ↑ | | ↓ | ↑ |

| Outcome | Participant primary disability | | | | |
|---|---|---|---|---|---|
| | Autism | Hearing impairment | Intellectual disability | Psychosocial disability | Visual Impairment |
| **For those unable to work as much as they want, the situation of their child/family member with disability being a barrier to working more** | ⬆ | ⬇ | | ⬆ | ⬇ |
| **For those unable to work as much as they want, the availability of jobs being a barrier to working more** | | ⬆ | | | |
| **For those unable to work as much as they want, the insufficient flexibility of jobs being a barrier to working more** | ⬆ | | ⬆ | ⬇ | |
| **Being able to engage in social interactions and community life as much as they want** | ⬇ | ⬆ | ⬇ | ⬇ | ⬆ |
| **For those unable to engage in the community as much as they want, the situation of their child/family member with disability being a barrier to engaging more** | ⬆ | ⬇ | ⬆ | ⬆ | ⬇ |

## Participant age

In many cases, baseline outcomes for families/carers tend to be worse for those with older children.[19] This is apparent from the one-way analyses and is confirmed by the multiple regression modelling.

Across most domains, there are significant differences in outcomes indicators by participant age. One of the largest is the percentage of families/carers who say they are able to access available services and supports to meet the needs of their child and family, which ranges from 52.4-57.2% where the child is aged 6 or younger to 32.1% where the child is aged 14 (the overall percentage is 44.7%). There are also step-changes in a large number of outcomes indicators between ages 6 and 7. The largest step-decreases are observed in the percentage of families/carers who are able to access available services and supports to meet the needs of their family and child (10.6% decrease), who have friends they can see as

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[19] The age of the family member/carer is expected to be correlated with participant age, and may be driving some of the trends (for example, health).

often as they like (10.1% decrease), and who have people they can ask for practical help as often as they need (9.7% decrease).

Families/carers of older participants are also significantly more likely to cite limited access to information and resources amongst other factors as a barrier to access or advocacy: increasing from 57.9% where their child is aged 0 to 2, to 72.1% where their child is aged 14 (the overall percentage is 65.9%). Strong support networks also appear to be less common for families/carers with an older child, for example the percentage of families/carers with enough emotional support decreases from 71.9% where their child is aged 0 to 2 to 47.8% where their child is 14 (58.4% overall). Self-rated health, and the ability to participate socially, also tend to be worse for families/carers of older participants, while work outcomes tend to be better. Additionally, being in receipt of the Carer Payment or Carer Allowance is significantly more common for families/carers of older participants.

Table 2.3 shows baseline family/carer outcomes for which participant age is a significant ($p<0.05$) predictor in the multiple-regression model.

### Culturally and linguistically diverse (CALD) status

Baseline outcomes for families/carers of participants from CALD backgrounds tend to be worse than those from non-CALD backgrounds. Controlling for other factors, those from CALD backgrounds were less likely to feel able to advocate for their child (58.6% compared to 78.6% for non-CALD on a one-way basis) and more likely to cite limited access to information and resources as a barrier to access or advocacy (74.5% compared to 65.6% on a one-way basis). They were also less likely to have people to ask for practical help (30.7% versus 40.6%) and emotional support (46.8% versus 59.3%), and less likely to be able to work as much as they want (36.8% versus 40.5%).

Table 2.3 shows baseline family/carer outcomes for which participant CALD status is a significant ($p<0.05$) predictor in the multiple-regression model.

### Indigenous status

Some baseline outcomes are better and some are worse for families/carers of Indigenous participants compared to families/carers of non-Indigenous participants. Respondents for Indigenous participants are less likely to be the parents of the participant (83.3% versus 96.6%). Families/carers of Indigenous participants are less likely to be working in a paid job (29.3% versus 48.3%) and consequently more likely to be receiving Carer Payment (31.6% versus 21.5%). However, families/carers of Indigenous participants appear to have better informal support networks at baseline, for example, having friends they can see as often as they like, and people they can ask for practical help as often as needed.

Table 2.3 shows baseline family/carer outcomes for which participant Indigenous status is a significant ($p<0.05$) predictor in the multiple-regression model.

**Table 2.3 Relationship of participant age, CALD status and Indigenous status with the likelihood of selected outcomes:**

| | Variable | | |
|---|---|---|---|
| Outcome | Participant is older | Participant is CALD | Participant is Indigenous |
| **Being in a paid job** | ⬆ | ⬇ | ⬇ |

| Outcome | Variable | | |
|---|---|---|---|
| | Participant is older | Participant is CALD | Participant is Indigenous |
| For family/carers with a paid job, the paid job being a permanent position | | ⬇ | |
| For family/carers with a paid job, working 15 or more hours per week | ⬆ | | ⬆ |
| Receiving carer payment | ⬆ | ⇩ | ⬆ |
| Receiving carer allowance | ⬆ | ⇩ | |
| Currently studying | ⬆ | ⬆ | |
| Being able to identify the needs of their family member with disability | | ⬇ | |
| Being able to access available services and supports to meet the needs of their child and family | | ⬇ | |
| Being able to advocate for their child if they have issues or problems | | ⬇ | ⬆ |
| Having experienced no barriers to access and/or advocacy | ⬇ | ⬇ | |
| Having friends they can see as often as they'd like | ⬇ | ⬇ | ⬆ |
| Having people they can ask for practical help as often as needed | ⬇ | ⬇ | ⬆ |
| Having people they can ask for childcare as often as needed | ⬇ | ⬇ | ⬆ |
| Having people they can talk to for emotional support as often as needed | ⬇ | ⬇ | ⬆ |
| Knowing what specialist services are needed to promote their child's learning and development | ⬇ | ⬇ | ⬇ |
| Knowing what their family can do to support their child's learning and development | ⬇ | ⬇ | |
| Getting enough support to feel confident in parenting their child | ⬇ | ⬇ | ⬆ |
| Feeling confident in supporting their child's development | ⬇ | ⬇ | ⬆ |
| Rating their health as excellent, very good or good | ⬇ | | ⬆ |

| Outcome | Variable | | |
|---|---|---|---|
| | Participant is older | Participant is CALD | Participant is Indigenous |
| Being able to work as much as they want | ⬆ | ⬇ | ⬆ |
| Having experienced no barriers to access and/or advocacy | ⬆ | | |
| For those unable to work as much as they want, the situation of their child/family member with disability being a barrier to working more | ⬆ | | |
| For those unable to work as much as they want, the availability of jobs being a barrier to working more | ⬆ | ⬆ | ⬆ |
| For those unable to work as much as they want, the insufficient flexibility of jobs being a barrier to working more | ⬆ | ⬇ | |
| Being able to engage in social interactions and community life as much as they want | | | ⬆ |
| For those unable to engage in the community as much as they want, the situation of their child/family member with disability being a barrier to engaging more | ⬆ | | ⬆ |

### Participant level of function and annualised plan budget

Baseline outcomes tended to be better for families/carers of participants with higher level of function, and with lower annualised plan budgets.[20] For example, the percentage experiencing difficulties in accessing available services and supports to meet the needs of their child and family was higher for children with lower level of function. Families/carers of participants with lower level of function also tended to be less likely to have adequate support networks, such as family and friends they see as often as they like, and people to ask for practical and emotional support. Receipt of government benefits increases with decreasing level of function/increasing plan cost.

Table 2.4 shows baseline family/carer outcomes for which participant level of function and/or annualised plan budget are significant ($p<0.05$) predictors in the multiple-regression model.

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[20] Note that variations in baseline outcomes by annualised plan budget reflect characteristics associated with having a higher or lower plan budget, rather than the amount of the plan budget itself, since participants are at the start of their first plan at baseline.

**Table 2.4 Relationship of participant level of function and annualised plan budget with the likelihood of selected outcomes:**

| Outcome | Variable | |
|---|---|---|
| | Lower level of function | Higher annualised plan |
| Being in a paid job | ⬇ | ⬇ |
| For family/carers with a paid job, the paid job being a permanent position | ⬇ | |
| For family/carers with a paid job, working 15 or more hours per week | ⬇ | |
| Receiving carer payment | ⬆ | ⬆ |
| Receiving carer allowance | ⬆ | ⬆ |
| Currently studying | ⇩ | |
| Being able to identify the needs of their family member with disability | ⬇ | ⬇ |
| Being able to access available services and supports to meet the needs of their child and family | ⬇ | ⬇ |
| Being able to advocate for their child if they have issues or problems | ⬇ | ⬇ |
| Having experienced no barriers to access and/or advocacy | ⬇ | ⬇ |
| Having friends they can see as often as they'd like | ⬇ | ⬇ |
| Having people they can ask for practical help as often as needed | ⬇ | ⬇ |
| Having people they can ask for childcare as often as needed | ⬇ | ⬇ |
| Having people they can talk to for emotional support as often as needed | ⬇ | ⬇ |
| Knowing what specialist services are needed to promote their child's learning and development | ⬇ | |
| Knowing what their family can do to support their child's learning and development | ⬇ | ⬇ |
| Getting enough support to feel confident in parenting their child | ⬇ | ⬇ |
| Feeling confident in supporting their child's development | ⬇ | ⬇ |

| Outcome | Variable | |
|---|---|---|
| | Lower level of function | Higher annualised plan budget |
| **Rating their health as excellent, very good or good** | ⬇ | ⬇ |
| **Being able to work as much as they want** | ⬇ | ⬇ |
| **For those unable to work as much as they want, the situation of their child/family member with disability being a barrier to working more** | ⬆ | ⬆ |
| **For those unable to work as much as they want, the availability of jobs being a barrier to working more** | ⬇ | ⬇ |
| **For those unable to work as much as they want, the insufficient flexibility of jobs being a barrier to working more** | ⬇ | |
| **Being able to engage in social interactions and community life as much as they want** | ⬇ | ⬇ |
| **For those unable to engage in the community as much as they want, the situation of their child/family member with disability being a barrier to engaging more** | ⬆ | ⬆ |

### Level of NDIA support

Families/carers of participants receiving a higher level of NDIA support with planning were identified as having poorer baseline outcomes in several of the regression models. For example, families/carers of participants receiving a higher level of NDIA support were more likely to experience difficulties in accessing available services and supports to meet the needs of their child and family, and were less likely to have people they can talk to for emotional support.

### State/Territory

Mixed results were observed by State/Territory. Generally, controlling for other factors, New South Wales and Victoria had the worst baseline outcomes, while South Australia and the Australia Capital Territory had the best.

One-way analyses suggest that families/carers of participants from the Northern Territory tended to experience worse outcomes in relation to advocacy and accessing services and supports. For example, 62.3% responded that they are able to advocate for their child, compared to 77.2% overall, and 35.6% responded that they are able to access available services and supports, compared to 44.7% overall. Both results still hold when controlling for other factors such as remoteness.

On a one-way basis, receipt of government benefits was particularly high in Tasmania, where 38.5% received Carer Payment (compared to 22.8% overall) and 62.6% received Carer Allowance (compared to 51.6% overall).

### Remoteness

Controlling for other factors, families/carers living in major cities tend to report worse baseline outcomes than those living in regional or remote areas.

Controlling for other factors, families/carers living in a remote area are more likely to be in a paid job and working as much as they want, compared to families/carers living in a major city or a regional area. However, on a one-way basis, a larger proportion of families/carers in major cities have a paid job (48.5%, compared to 39.6-44.3% for regional areas and 44.3% for remote areas), indicating that there are other confounding factors driving the results by remoteness (primarily family/carer relationship to the participant, Indigenous status, CALD status, and to a lesser degree, participant age). For those unable to work as much as they want, families/carers living in remote areas are more likely to report that the availability of jobs and the insufficient flexibility of jobs are barriers to working more. Families/carers living in major cities are more likely to report the situation of their child's disability is a barrier to working more.

Ability to access available services tends to be better for families/carers living in major cities and regional areas (on a one-way basis, 45.4% of families/carers in major cities are able to access available services, compared to 40.7-46.4% for regional areas and 34.0% for remote areas). Families/carers living in regional areas are more likely be able to advocate for their child, whereas those living in major cities are less likely to be able to. Families/carers in remote areas are more likely to have experienced barriers to access or advocacy.

Table 2.5 shows baseline family/carer outcomes for which remoteness is a significant ($p<0.05$) predictor in the multiple-regression model.

**Table 2.5 Relationship of remoteness with the likelihood of selected outcomes:**

| Outcome | Variable | | |
|---|---|---|---|
| | Lives in a major city | Lives in a regional area | Lives in a remote or very remote area |
| Being in a paid job | ⬇ | ⬇ | ⬆ |
| For family/carers with a paid job, the paid job being a permanent position | ⬆ | | |
| For family/carers with a paid job, working 15 or more hours per week | | ⬇ | |
| Receiving carer payment | ⬆ | ⬆ | ⇩ |
| Receiving carer allowance | ⬆ | ⬆ | ⇩ |
| Currently studying | | ⬆ | |
| Being able to identify the needs of their family member with disability | ⬇ | | |
| Being able to access available services and supports to meet the needs of their child and family | ⬆ | ⬆ | ⬇ |
| Being able to advocate for their child if they have issues or problems | ⬇ | ⬆ | |

| Outcome | Variable | | |
|---|---|---|---|
| | Lives in a major city | Lives in a regional area | Lives in a remote or very remote area |
| Having experienced no barriers to access and/or advocacy | | ⬆ | ⬇ |
| Having friends they can see as often as they'd like | ⬇ | ⬇ | ⬆ |
| Having people they can ask for practical help as often as needed | ⬇ | | ⬆ |
| Having people they can ask for childcare as often as needed | ⬇ | | ⬆ |
| Having people they can talk to for emotional support as often as needed | ⬇ | | ⬆ |
| Knowing what their family can do to support their child's learning and development | | ⬆ | |
| Getting enough support to feel confident in parenting their child | ⬇ | | ⬆ |
| Feeling confident in supporting their child's development | ⬇ | ⬆ | |
| Rating their health as excellent, very good or good | ⬇ | ⬇ | ⬆ |
| Being able to work as much as they want | ⬇ | ⬇ | ⬆ |
| For those unable to work as much as they want, the situation of their child/family member with disability being a barrier to working more | ⬆ | | |
| For those unable to work as much as they want, the availability of jobs being a barrier to working more | ⬇ | | ⬆ |
| For those unable to work as much as they want, the insufficient flexibility of jobs being a barrier to working more | ⬇ | | ⬆ |
| Being able to engage in social interactions and community life as much as they want | ⬇ | ⬇ | ⬆ |
| For those unable to engage in the community as much as they want, the situation of their child/family member with disability being a barrier to engaging more | ⬆ | ⬆ | ⬇ |

### Plan management type[21]

Families/carers who self-manage their child's plan have better baseline outcomes on some indicators. Those who fully self-manage or partly self-manage are more likely to be working in a paid job (59.6% and 49.2% respectively, compared to 46.6% overall, on a one-way basis). Participants who fully self-manage are more likely to be able to meet the needs of their child and family (75.5% compared to 69.2% overall), to be able to advocate for their child (84.4% compared to 77.2% overall), and to be able to access available services and supports (52.8% compared to 44.7% overall). They also tend to respond more positively to indicators around helping their child develop and learn.

### Family/carer knowledge and support

On a one-way basis, favourable outcomes at baseline were observed for families/carers who:

- Are able to advocate for their child
- Know what they can do to support their child and are able to access available services and supports; and
- Have adequate support networks.

For example, overall, 34.1% of families/carers have experienced no boundaries to access and/or advocacy, but this percentage is higher for those who get enough support in parenting their child (49.5%). Conversely, those unable to meet the needs of their child and family were much less likely to experience no boundaries to access and/or advocacy (18.1%).

The importance of strong social networks is highlighted by Table 2.6, which shows how the percentage responding positively to four questions about levels of support and engagement depend strongly on whether the family/carer has friends and family they see as often as they like.

**Table 2.6 Inter-relationships between questions about support networks**

| Question | Percentage responding "Yes" to question where answer to "I have friends and family that I see as often as I like" is: | |
|---|---|---|
| | Yes (43.6%) | No (56.4%) |
| I have people who I can ask for practical help as often as I need | 73.0% | 14.0% |
| I have people who I can ask for childcare as often as I need | 53.0% | 8.0% |
| I have people who I can talk to for emotional support as often as I need | 85.0% | 38.0% |
| I/(my partner and I) am/are able to engage in social interactions and community life as much as I/we want | 37.7% | 17.1% |

Table 2.7 shows the importance of a family/carer's understanding of the situation of their child. It indicates that the percentage responding positively to three questions about

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[21] Note that these baseline differences reflect characteristics of participants whose families/carers choose to self manage, rather than the self-management process itself (since the results are at the start of the participant's first plan).

knowledge and support are linked to whether the family/carer knows what their family can do to support their child's learning and development.

**Table 2.7 Inter-relationships between questions about access to services and supporting the needs of the participant**

| Question | Percentage responding "Yes" to question where answer to "I know what my family can do to support my child's learning and development" is: | |
|---|---|---|
| | Yes (41.1%) | No (58.9%) |
| I am able to access available services and supports to meet the needs of my family and child | 55.3% | 8.5% |
| I know what specialist services are needed to promote my child's learning and development | 47.4% | 13.7% |
| I feel very confident or somewhat confident in supporting my child's development | 90.7% | 65.0% |

## Family/carer's relationship to the participant

Mothers of NDIS participants tend to have worse employment and health and wellbeing outcomes at baseline, and better outcomes in other domains, compared to fathers of NDIS participants. Respondents whose relationship with the participant is "Other" tend to respond the most positively for the majority of non-employment indicators. For participants in this age group, the "Other" category would include a large proportion of grandparents.

## Living arrangements

Families/carers of participants living in a private home they own or that is owned by a family member generally have more favourable baseline outcomes than families/carers of participants living in a private home rented from a private landlord, and significantly more favourable outcomes than families/carers of participants living in private homes rented from a public authority. This likely reflects factors related to income and socio-economic status.

Table 2.8 shows baseline family/carer outcomes for which living arrangements is a significant ($p<0.05$) predictor in the multiple-regression model.[22]

**Table 2.8 Relationship of participant's living situation with the likelihood of selected outcomes for families/carers:**

| Relationship of the variable with the likelihood of: | Variable | | |
|---|---|---|---|
| | Private home owned by family | Private home rented from a private landlord | Private home rented from a public authority |
| **Currently studying** | ⇩ | ⬆ | ⇩ |
| **Being able to identify the needs of their family member with disability** | ⬆ | ⬆ | ⬇ |

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[22] Living arrangements is not included as a predictor for employment outcomes.

| Relationship of the variable with the likelihood of: | Variable | | |
|---|---|---|---|
| | Private home owned by family | Private home rented from a private landlord | Private home rented from a public authority |
| Being able to access available services and supports to meet the needs of their child and family | ⬆ | ⬇ | ⬇ |
| Being able to advocate for their child if they have issues or problems | ⬆ | ⬆ | ⬇ |
| Having experienced no barriers to access and/or advocacy | ⬆ | ⬆ | ⬇ |
| Having friends they can see as often as they'd like | ⬆ | ⬇ | |
| Having people they can ask for practical help as often as needed | ⬆ | ⬇ | ⬇ |
| Having people they can ask for childcare as often as needed | ⬆ | ⬇ | ⬇ |
| Having people they can talk to for emotional support as often as needed | ⬆ | | ⬇ |
| Knowing what specialist services are needed to promote their child's learning and development | ⬆ | | ⬇ |
| Knowing what their family can do to support their child's learning and development | ⬆ | | ⬇ |
| Getting enough support to feel confident in parenting their child | ⬆ | | ⬇ |
| Feeling confident in supporting their child's development | ⬆ | | ⬇ |
| Rating their health as excellent, very good or good | ⬆ | ⬆ | ⬇ |
| Being able to engage in social interactions and community life as much as they want | ⬆ | ⬇ | |
| For those unable to engage in the community as much as they want, the situation of their child/family member with disability being a barrier to engaging more | ⬆ | ⬆ | |

### 2.2.4 Longitudinal indicators – across all participants

Longitudinal analysis describes how outcomes have changed for families/carers of participants during the time the participant has been in the Scheme. Included here are families/carers of participants who entered the Scheme between 1 July 2016 and 30 June 2018, for whom a record of outcomes is available at scheme entry (baseline) and at one or more of the two time points: approximately one year following scheme entry (first review), and approximately two years following scheme entry (second review). The analysis considers how outcomes have changed between baseline and first review, between baseline and second review and between first review and second review.

There have been a number of improvements across all domains for the three periods being considered. The greatest changes occurred when considering family/carer responses from baseline to their second review.

Table 2.9 summarises changes for selected indicators across different time periods. In Table 2.9, cohort "B, R1,R2" includes families/carers responding at baseline, first review and second review[23]. Cohort "B,R1" includes families/carers responding at both baseline and first review (but not at second review, so the cohorts do not overlap). Indicators were selected for the tables if the change was statistically significant[24] and had an absolute magnitude greater than 0.02[25].

**Table 2.9 Selected longitudinal indicators for families/carers of participants aged 0 to 14**

| Domain | Indicator | Cohort | Baseline | Review 1 | Review 2 | Change B-R1 | Change R1-R2 | Change B-R2 | Improvement/ Deterioration |
|---|---|---|---|---|---|---|---|---|---|
| WK (SF) | % of family members / carers working in a paid job | B,R1,R2 | 46.4% | 49.9% | 51.7% | 3.5% | 1.8% | 5.3% | Improvement |
| | | B,R1 | 48.2% | 50.1% | | 2.0% | | | |
| WK (SF) | Of those working in a paid job, % working 15 hours or more | B,R1,R2 | 79.1% | 82.2% | 83.9% | 3.2% | 1.6% | 4.8% | Improvement |
| | | B,R1 | 77.4% | 79.9% | | 2.5% | | | |
| RA (SF) | % of families/carers who have experienced no boundaries to access or advocacy | B,R1,R2 | 33.8% | 36.5% | 38.8% | 2.8% | 2.3% | 5.0% | Improvement |
| | | B,R1 | 33.8% | 37.1% | | 3.3% | | | |

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[23] A small number may be missing a response at the first review

[24] McNemar's test at the 0.05 level

[25] Between baseline and second review for the "B,R1,R2" cohort, and between baseline and first review for the "B,R1" cohort

| Domain (Form) | Indicator | Cohort | Baseline | Review 1 | Review 2 | Change B-R1 | Change R1-R2 | Change B-R2 | Improvement/ Deterioration |
|---|---|---|---|---|---|---|---|---|---|
| SP (SF) | % of families/carers who have someone they can talk to for emotional support as often as they need | B,R1,R2 | 60.7% | 63.2% | 63.1% | 2.5% | -0.1% | 2.3% | Improvement |
| | | B,R1 | 60.3% | 61.8% | | 1.5% | | | |
| SP (LF) | % of families/carers who have as much contact with other parents of children with disability as they would like | B,R1,R2 | 37.2% | 61.9% | 66.2% | 24.7% | 4.3% | 29.0% | Improvement |
| | | B,R1 | 46.0% | 51.2% | | 5.3% | | | |
| AC (LF) | % of families/carers who say their relationship with services is good or very good | B,R1,R2 | 78.8% | 85.8% | 88.7% | 7.1% | 2.8% | 9.9% | Improvement |
| | | B,R1 | 77.1% | 85.4% | | 8.3% | | | |
| DV (SF) | % of families/carers who know what specialist services are needed to promote their child's learning and development | B,R1,R2 | 40.6% | 49.6% | 52.3% | 9.0% | 2.7% | 11.7% | Improvement |
| | | B,R1 | 40.7% | 48.9% | | 8.1% | | | |
| DV (SF) | % of families/carers that know what they can do to support their child's learning and development | B,R1,R2 | 42.0% | 50.3% | 52.8% | 8.3% | 2.5% | 10.8% | Improvement |
| | | B,R1 | 41.7% | 48.6% | | 6.9% | | | |
| DV (SF) | % of families/carers who get enough support in parenting their child | B,R1,R2 | 44.3% | 48.9% | 49.6% | 4.6% | 0.7% | 5.3% | Improvement |
| | | B,R1 | 44.6% | 48.0% | | 3.4% | | | |
| DV (SF) | % of families/carers who feel very confident or somewhat confident in supporting their child's development | B,R1,R2 | 86.5% | 89.3% | 89.0% | 2.8% | -0.3% | 2.5% | Improvement |
| | | B,R1 | 85.9% | 87.9% | | 2.0% | | | |
| UN (LF) | % who have no difficulties recognising their child’s strengths and abilities | B,R1,R2 | 79.2% | 87.9% | 86.6% | 8.7% | -1.3% | 7.4% | Improvement |
| | | B,R1 | 83.6% | 83.2% | | -0.4% | | | |

| Domain (Form) | Indicator | Cohort | Baseline | Review 1 | Review 2 | Change B-R1 | Change R1-R2 | Change B-R2 | Improvement/ Deterioration |
|---|---|---|---|---|---|---|---|---|---|
| HW (LF) | % who felt delighted, pleased or mostly satisfied when thinking about what happened last year and what they expect for the future | B,R1,R2 | 51.5% | 57.6% | 52.8% | 6.1% | -4.8% | 1.3% | Improvement |
| | | B,R1 | 36.9% | 47.8% | | 10.9% | | | |
| HW (LF) | % who feel more confident about the future of their child with disability under the NDIS | B,R1,R2 | 48.3% | 70.0% | 72.6% | 21.7% | 2.6% | 24.3% | Improvement |
| | | B,R1 | 53.1% | 64.4% | | 11.3% | | | |
| HW (LF) | % who feel that their child gets the support he/she needs | B,R1,R2 | 28.4% | 57.2% | 58.1% | 28.8% | 0.9% | 29.7% | Improvement |
| | | B,R1 | 35.5% | 53.8% | | 18.3% | | | |
| HW (LF) | % who feel that the services and supports have helped them to better care for their child with disability | B,R1,R2 | 32.3% | 73.5% | 72.6% | 41.2% | -0.9% | 40.3% | Improvement |
| | | B,R1 | 49.1% | 69.2% | | 20.0% | | | |
| GB (SF) | % of families/carers that are receiving carer allowance | B,R1,R2 | 57.2% | 65.5% | 69.9% | 8.3% | 4.4% | 12.7% | Context dependent |
| | | B,R1 | 55.1% | 62.0% | | 7.0% | | | |
| SP (SF) | % of families/carers who have friends they can see as often as they'd like | B,R1,R2 | 45.6% | 44.3% | 41.2% | -1.2% | -3.1% | -4.4% | Deterioration |
| | | B,R1 | 44.5% | 43.6% | | -0.9% | | | |
| SP (SF) | % of families/carers who have people they can ask for practical help as often as they need | B,R1,R2 | 41.8% | 41.2% | 37.9% | -0.6% | -3.2% | -3.8% | Deterioration |
| | | B,R1 | 41.1% | 40.0% | | -1.1% | | | |
| SP (SF) | % of families/carers who have people they can ask for childcare as often as they need | B,R1,R2 | 29.5% | 27.9% | 25.9% | -1.7% | -2.0% | -3.6% | Deterioration |
| | | B,R1 | 27.7% | 27.1% | | -0.6% | | | |

| Domain (Form) | Indicator | Cohort | Baseline | Review 1 | Review 2 | Change B-R1 | Change R1-R2 | Change B-R2 | Improvement/ Deterioration |
|---|---|---|---|---|---|---|---|---|---|
| HW (SF) | of those unable to work as much as they want, % who say the situation of their child/family member with disability is a barrier to working more | B,R1,R2 | 88.3% | 91.1% | 93.1% | 2.8% | 2.1% | 4.8% | Deterioration |
| | | B,R1 | 86.9% | 89.5% | | 2.7% | | | |
| HW (SF) | of those unable to work as much as they want, % who say insufficient flexibility of jobs is a barrier to working more | B,R1,R2 | 39.4% | 45.1% | 47.4% | 5.7% | 2.3% | 7.9% | Deterioration |
| | | B,R1 | 39.0% | 43.0% | | 4.0% | | | |
| HW (SF) | of those unable to engage in the community as much as they want, % who say the situation with their child is a barrier to engaging in more social interactions within the community | B,R1,R2 | 90.7% | 93.3% | 94.7% | 2.6% | 1.4% | 4.0% | Deterioration |
| | | B,R1 | 88.6% | 90.9% | | 2.3% | | | |
| HW (SF) | % of families/carers and their partners who are able to engage in social interactions and community life as much as they want | B,R1,R2 | 27.1% | 26.3% | 24.1% | -0.8% | -2.2% | -3.0% | Deterioration |
| | | B,R1 | 26.6% | 25.9% | | -0.7% | | | |
| HW (SF) | % of families/carers who rate their health as excellent, very good or good | B,R1,R2 | 74.0% | 70.1% | 66.1% | -3.9% | -4.0% | -7.9% | Deterioration |
| | | B,R1 | 71.8% | 68.5% | | -3.3% | | | |

Some large changes, the majority of them positive, appear in the above table. Significant changes have been observed for:

- Work: the percentage working in a paid job has increased, by 5.3% over two years for 2016-17 entrants and by 2.0% over one year for 2017-18 entrants. Some of this change may be attributed to the participant being one year older and likely more independent, allowing their families/carers to work more. Data from the Household, Income, and Labour Dynamics in Australia (HILDA)[26] survey for wave 18 (2018) shows employment rates averaging around 75% for respondents from households with children aged 0 to 14. There is a large increase of 7% as child's age increases from 0 to 1 (from 64% to 71%), followed by an increase of 2% from age 1 to age 2, then smaller and more stable increases averaging 0.9 percentage points for each one year increase in age for older ages. Overall, the increases for families and carers of participants aged 0 to 14 appear to be slightly higher than for HILDA.
- The percentage working 15 hours or more has also increased, by 4.8% over two years for 2016-17 entrants and by 2.5% over one year for 2017-18 entrants. However, families/carers who are not able to work as much as they want are more

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[26] https://melbourneinstitute.unimelb.edu.au/hilda

likely to perceive the situation of their child as a barrier to working more, and are also more likely to cite insufficient flexibility of jobs as a barrier.

- Support for families/carers in helping their child to develop and learn: families/carers report improved knowledge of what they can do, and the specialist services that are needed, to support their child's learning and development. Family and carers are also more likely to get enough support to feel confident in parenting their child, and report increased levels of confidence in supporting their child's development.
- Families feel supported: the percentage of families/carers who have someone they can talk to for emotional support has increased. However, the percentage who say they have friends they can see as often as they would like has decreased, as has the percentage who have people they can ask for practical help as often as they need.
- Rights and advocacy: the percentage of families/carers who have experienced no boundaries to access or advocacy has increased.
- Health and wellbeing: the percentage rating their health as good, very good or excellent has decreased. There was an increase in the percentage of families/carers who say they are unable to engage in social interactions and community life as much as they want, and these respondents are more likely to say that the situation of their child with disability is a barrier to being more engaged.

### 2.2.5 Longitudinal indicators – key characteristics

Analysis by participant and family/carer characteristics has been examined in two ways:

1. A simple comparison of the percentage meeting the indicator at first or second review with the percentage meeting the indicator at baseline. The difference (review percentage minus baseline percentage) is compared for different subgroups.
2. Multiple regression analyses with separate models for improvement and deterioration in the indicator. That is, for the subset without/with the indicator at baseline, the probability of meeting/not meeting the indicator at first or second review is modelled as a function of participant characteristics[27]. Multiple regression analyses were performed for the same indicators as considered for baseline.

It should be noted that these two analyses can produce different results, particularly where there is a large difference in the indicator at baseline between subgroups.

Some key features of the analyses for selected indicators are summarised below. For each indicator, a table summarising the direction of the effect for each significant predictor in the regression models is included. Table 2.10 provides a key to aid interpretation of the arrow symbols used in these tables, including some examples.

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[27] Modelling of baseline to second review transitions is based on a smaller amount of data, hence these models tend to identify a smaller number of significant predictors

### Table 2.10 Definition of symbols used in longitudinal key driver tables

| Symbol | Meaning | Impact | Example |
|---|---|---|---|
| ⬆ | **More likely to improve** | **Positive** | Families/carers of participants who entered the Scheme in 2016/17 are more likely to start working in a paid job |
| ⬇ | **Less likely to improve** | **Negative** | Families/carers of participants with a higher annualised plan budget are less likely to start seeing friends as often as they like |
| ⬆ | **More likely to deteriorate** | **Negative** | Families/carers of participants with a lower level of function are more likely to deteriorate in their knowledge of what their family can do to support their child's learning and development |
| ⬇ | **Less likely to deteriorate** | **Positive** | Families/carers living in Queensland are less likely to deteriorate in relation to getting enough support to feel confident in parenting their child |

### *Working in a paid job*

The percentage of families/carers with a paid job increased by 2.3% between baseline and first review, and 5.3% between baseline and second review. Table 2.11 sets out the breakdown of the movements in responses between baseline and first review and between baseline and second review.

### Table 2.11 Breakdown of net movement in longitudinal responses

| Longitudinal Period | Number of Responses in cohort[28] | | Improvements: No to Yes | | Deteriorations: Yes to No | | Net Movement (No to Yes) |
|---|---|---|---|---|---|---|---|
| | No | Yes | Number | % | Number | % | |
| **Baseline to Review 1** | 17,154 | 15,715 | 1,855 | 10.8% | 1,110 | 7.1% | +2.3% |
| **Baseline to Review 2** | 4,259 | 3683 | 811 | 19.0% | 389 | 10.6% | +5.3% |

The main drivers that had a statistically significant effect on the likelihood of improvement of deterioration are set out in Table 2.12 below.

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[28] The cohort is selected as all those with non-missing responses at the relevant surveys

### Table 2.12 Key drivers of likelihood of transitions of *“I work in a paid job”* response

| Variable | Baseline to First Review | | Baseline to Second Review | |
|---|---|---|---|---|
| | Relationship with likelihood of | | Relationship with likelihood of | |
| | Improvement | Deterioration | Improvement | Deterioration |
| **Participant is CALD** | | | | ↑ |
| **Entered the Scheme in 2016/17** | ↑ | | | |
| **Higher Index of Education and Occupation (IEO)** | ↑ | ↓ | ↑ | ↓ |
| **Higher Index of Economic Resources (IER)** | ↑ | ↑ | | |
| **Participant is Indigenous** | ↓ | ↑ | ↓ | |
| **Disability is autism** | | ↑ | | |
| **Disability is a sensory impairment** | | ↓ | | |
| **Participant has a lower level of function** | ↓ | ↑ | ↓ | |
| **More than 95% of supports are capacity building supports** | | ↓ | | |
| **Plan is fully agency-managed** | ↓ | ↑ | ↓ | |
| **Plan is fully self-managed** | ↑ | | ↑ | |
| **Plan is partly self-managed** | ↑ | | ↑ | |
| **Plan is managed by a plan manager** | ↓ | | ↓ | |
| **Participant received services from Commonwealth systems before entering the NDIS** | ↑ | | | |
| **Participant has not received services from Commonwealth or State/Territory systems before entering the NDIS** | ↓ | | | |
| **Participant is older** | | ↓ | | ↓ |

| Variable | Baseline to First Review | | Baseline to Second Review | |
|---|---|---|---|---|
| | Relationship with likelihood of | | Relationship with likelihood of | |
| | Improvement | Deterioration | Improvement | Deterioration |
| **Lives in QLD** | ⬆ | | ⬆ | |
| **Lives in SA** | ⬆ | | | |
| **Lives in VIC** | ⬇ | | ⬇ | |
| **Participant has a higher level of NDIA support** | ⬇ | | ⬇ | ⬆ |

- Families/carers from areas with a higher Index of Education and Occupation (IEO) who responded they did not have a paid job at baseline were more likely to have a paid job at both first and second review. Similarly, those who did have a paid job at baseline were more likely to have a paid job at follow-up reviews.
- Families/carers of participants with lower level of function, of Indigenous participants, and of participants with a higher level of NDIA support were less likely to get a job.
- Families/carers of participants who self-manage, either fully or partly, were more likely to get a job.
- For the families/carers who reported they had a paid job at baseline, those caring for older participants were more likely to maintain a paid job at the first review.
- For carers who did not have a paid job at baseline, those living in Queensland were more likely to have a paid job at follow-up reviews, while those in Victoria were less likely.

### *Working 15 hours or more per week*

The percentage of families/carers who work 15 hours or more per week increased by 2.6% between baseline and first review, and 4.8% between baseline and second review. Table 2.13 sets out the breakdown of the movements in responses between baseline and first review and between baseline and second review.

**Table 2.13 Breakdown of net movement in longitudinal responses**

| Longitudinal Period | Number of Responses in cohort | | Improvements: No to Yes | | Deteriorations: Yes to No | | Net Movement (No to Yes) |
|---|---|---|---|---|---|---|---|
| | No | Yes | Number | % | Number | % | |
| **Baseline to Review 1** | 3,118 | 10,911 | 655 | 21.0% | 285 | 2.6% | +2.6% |
| **Baseline to Review 2** | 684 | 2,510 | 263 | 38.5% | 109 | 4.3% | +4.8% |

The main drivers that had a statistically significant effect on the likelihood of improvement of deterioration are set out in Table 2.14 below.

**Table 2.14 Key drivers of likelihood of transitions of *"I work 15 hours or more per week"* response**

| Variable | Baseline to First Review | | Baseline to Second Review | |
|---|---|---|---|---|
| | Relationship with likelihood of | | Relationship with likelihood of | |
| | Improvement | Deterioration | Improvement | Deterioration |
| **Participant is CALD** | | | ↑ | |
| **Higher Index of Economic Resources (IER)** | ↑ | | | |
| **Plan is fully agency-managed** | | ↓ | | |
| **Plan is fully self-managed** | | ↓ | | |
| **Lives in NSW** | ↑ | | | |
| **Lives in QLD** | ↑ | | | |
| **Lives in VIC** | ↓ | | ↓ | |

- Families/carers of participants residing in Victoria who did not work more than 15 hours per week at baseline were less likely to improve at follow-up reviews. Those residing in NSW and Queensland were more likely to improve their response between baseline and first review.
- Family and carers of participants with fully agency-managed and fully self-managed plans and who were working more than 15 hours per week at baseline were more likely to continue working more than 15 hours per week at the first review.

### *Experiencing no barriers to access or advocacy*

The percentage of families/carers who have experienced no boundaries to access or advocacy increased by 3.2% between baseline and first review, and 5.0% between baseline and second review. Table 2.15 sets out the breakdown of the movements in responses between baseline and first review and between baseline and second review.

**Table 2.15 Breakdown of net movement in longitudinal responses**

| Longitudinal Period | Number of Responses in cohort | | Improvements: No to Yes | | Deteriorations: Yes to No | | Net Movement (No to Yes) |
|---|---|---|---|---|---|---|---|
| | No | Yes | Number | % | Number | % | |
| **Baseline to Review 1** | 21,745 | 11,124 | 2,403 | 11.1% | 1,366 | 12.3% | +3.2% |
| **Baseline to Review 2** | 5,261 | 2,681 | 957 | 18.2% | 557 | 20.8% | +5.0% |

The main drivers that had a statistically significant effect on the likelihood of improvement of deterioration are set out in Table 2.16 below.

**Table 2.16 Key drivers of likelihood of transitions of *“I have experienced no barriers to access or advocacy”* response**

| Variable | Baseline to First Review | | Baseline to Second Review | |
|---|---|---|---|---|
| | Relationship with likelihood of | | Relationship with likelihood of | |
| | Improvement | Deterioration | Improvement | Deterioration |
| **Higher annualised plan budget** | | ↑ | ↓ | |
| **Participant is CALD** | | | ↓ | ↑ |
| **Carer reported an increase in working hours between surveys** | ↑ | | | |
| **Carer did not report a change in working hours between surveys** | ↓ | ↓ | | ↓ |
| **Carer reported they were not in paid work at the time of both surveys** | ↓ | ↓ | ↓ | |
| **Carer reported they started paid work between surveys** | ↑ | | | |
| **Carer reported they stopped paid work between surveys** | | ↑ | | |
| **Entered the scheme in 2016/17** | ↑ | ↑ | | |
| **Participant is Male** | | ↓ | | |
| **Higher Index of Education and Occupation (IEO)** | ↓ | | | |
| **Higher Index of Economic Resources (IER)** | ↑ | | | |
| **Participant lives in a major city** | ↑ | ↓ | | |
| **Participant lives in a regional area** | ↑ | ↓ | | |
| **Participant lives in a remote or very remote area** | ↓ | ↑ | | |
| **Disability is autism** | | ↑ | | |

| Variable | Baseline to First Review | | Baseline to Second Review | |
|---|---|---|---|---|
| | Relationship with likelihood of | | Relationship with likelihood of | |
| | Improvement | Deterioration | Improvement | Deterioration |
| **Disability is global developmental delay or developmental delay** | ↑ | | | |
| **Disability is Down syndrome** | | ↑ | | |
| **Disability is a sensory impairment** | ↑ | ↓ | | |
| **Participant has a lower level of function** | ↓ | | | |
| **Less than 75% of supports are capacity building supports** | ↓ | | ↓ | ↑ |
| **More than 95% of supports are capacity building supports** | ↑ | | ↑ | ↓ |
| **Plan is fully agency-managed** | | | ↑ | |
| **Plan is managed by a plan manager** | | | ↓ | |
| **Participant received services from State/Territory systems before entering the NDIS** | | ↑ | | |
| **Participant is older** | ↓ | ↓ | ↓ | ↓ |
| **Lives in NSW** | | ↑ | | |
| **Lives in WA/TAS/ACT/NT** | ↓ | ↓ | ↓ | |
| **Lives in QLD** | ↑ | | ↑ | |
| **Lives in SA** | ↑ | ↑ | ↑ | ↑ |
| **Lives in VIC** | ↓ | ↓ | ↓ | |
| **Participant has a higher level of NDIA support** | ↓ | | | |
| **Higher budget utilisation** | ↑ | | | |

- Family and carers of older participants were less likely to change their baseline answer, being less likely to improve but also less likely to deteriorate.
- Families/carers of participants living in remote or very remote areas were less likely to improve and more likely to deteriorate between baseline and first review compared to those living in regional areas or major cities.
- Families/carers of participants whose plan had more than 95% of supports in capacity building supports were more likely to record favourable responses than those caring for participants with less than 75% capacity building supports in their plan.

### *I have friends and family that I can see as often as I like*

The percentage of families/carers who have friends and family they can see as often as they like decreased by 1.1% between baseline and first review, and decreased by 4.4% between baseline and second review. Table 2.17 sets out the breakdown of the movements in responses between baseline and first review and between baseline and second review.

**Table 2.17 Breakdown of net movement in longitudinal responses**

| Longitudinal Period | Number of Responses in cohort | | Improvements: No to Yes | | Deteriorations: Yes to No | | Net Movement (No to Yes) |
|---|---|---|---|---|---|---|---|
| | No | Yes | Number | % | Number | % | |
| **Baseline to Review 1** | 18,122 | 14,747 | 2,226 | 12.3% | 2,590 | 17.6% | -1.1% |
| **Baseline to Review 2** | 4,322 | 3,620 | 775 | 17.9% | 1,122 | 31.0% | -4.4% |

The main drivers that had a statistically significant effect on the likelihood of improvement or deterioration are set out in Table 2.18 below.

**Table 2.18 Key drivers of likelihood of transitions of *"I have friends and family that I can see as often as I like"* response**

| Variable | Baseline to First Review Relationship with likelihood of | | Baseline to Second Review Relationship with likelihood of | |
|---|---|---|---|---|
| | Improvement | Deterioration | Improvement | Deterioration |
| **Access type is disability met** | | ⬇ | | |
| **Higher annualised plan budget** | ⬇ | ⬆ | ⬇ | ⬆ |
| **Participant is CALD** | | | ⬆ | |
| **Carer reported a decrease in working hours between surveys** | | ⬆ | | |
| **Carer reported an increase in working hours between surveys** | | | | ⬆ |

| Variable | Baseline to First Review | | Baseline to Second Review | |
|---|---|---|---|---|
| | Relationship with likelihood of | | Relationship with likelihood of | |
| | Improvement | Deterioration | Improvement | Deterioration |
| Carer did not report a change in working hours between surveys | ↓ | ↓ | | ↓ |
| Carer reported that they work more than 30 hours per week | | ↑ | | |
| Carer reported they were not in paid work at the time of both surveys | ↓ | | | |
| Carer reported they were in paid work at the time of both surveys | | ↓ | | |
| Carer reported they started paid work between surveys | ↑ | ↓ | | |
| Carer reported they stopped paid work between surveys | | ↑ | | |
| Entered the scheme in 2016/17 | ↑ | | | |
| Higher Index of Education and Occupation (IEO) | | | ↓ | |
| Higher Index of Economic Resources (IER) | | ↑ | | ↑ |
| Participant is Indigenous | ↑ | | | |
| Participant lives in a regional area | ↓ | | | |
| Disability is autism | ↓ | ↑ | ↓ | ↑ |
| Disability is cerebral palsy or other neurological disorder | | ↓ | | |
| Disability is a sensory impairment | ↑ | ↓ | ↑ | |
| Participant has a lower level of function | ↓ | ↑ | ↓ | ↑ |
| Less than 75% of supports are capacity building supports | ↓ | ↑ | ↓ | ↑ |
| More than 95% of supports are capacity building supports | ↑ | ↓ | ↑ | |

| Variable | Baseline to First Review | | Baseline to Second Review | |
|---|---|---|---|---|
| | Relationship with likelihood of | | Relationship with likelihood of | |
| | Improvement | Deterioration | Improvement | Deterioration |
| **Plan is fully agency-managed** | ↑ | | | |
| **Plan is fully self-managed** | | | | ↓ |
| **Plan is managed by a plan manager** | | | | ↑ |
| **Participant has not received services from Commonwealth or State/Territory systems before entering the NDIS** | | ↓ | | |
| **Participant received services from State/Territory systems before entering the NDIS** | | ↑ | | |
| **Participant is older** | ↓ | | | |
| **Lives in NSW** | ↑ | ↑ | | |
| **Lives in WA/TAS/ACT/NT** | | ↓ | | |
| **Lives in QLD** | | ↑ | | |
| **Lives in SA** | ↑ | ↑ | | |
| **Lives in VIC** | ↓ | ↓ | | |
| **Higher budget utilisation** | ↓ | ↑ | ↓ | ↑ |

- Family and carers who started paid work between baseline and first review were more likely to respond positively between baseline and first review. Carers who saw friends and family as often as they liked at baseline, and who stopped work, were less likely to maintain their favourable response at first review.
- Family and carers of participants with autism were less likely to improve and more likely to deteriorate for this indicator. Conversely, those caring for a participant with a sensory disability were more likely to improve and less likely to deteriorate.
- Family and carers of participants with a higher level of function were more likely to improve and less likely to deteriorate.
- Families/carers of participants whose plan contained less than 75% capacity building supports were less likely to improve and more likely to deteriorate. Conversely, those with a plan with 95-100% capacity building were more likely to improve and less likely to deteriorate.

- A higher plan budget, and higher utilisation, were both associated with a lower likelihood of improvement and a higher likelihood of deterioration.

### *I know what specialist services are needed to promote my child's learning and development*

The percentage of families/carers who know what specialist services are needed to promote their child's learning and development increased by 8% between baseline and first review, and 12% between baseline and second review. Table 2.19 sets out the breakdown of the movements in responses between baseline and first review and between baseline and second review.

**Table 2.19 Breakdown of net movement in longitudinal responses**

| Longitudinal Period | Number of Responses in cohort | | Improvements: No to Yes | | Deteriorations: Yes to No | | Net Movement (No to Yes) |
|---|---|---|---|---|---|---|---|
| | No | Yes | Number | % | Number | % | |
| **Baseline to Review 1** | 19,296 | 13,259 | 4,276 | 22.2% | 1,574 | 11.9% | +8.3% |
| **Baseline to Review 2** | 4,668 | 3,190 | 1,521 | 32.6% | 603 | 18.9% | +11.7% |

The main drivers that had a statistically significant effect on the likelihood of improvement of deterioration are set out in Table 2.20 below.

**Table 2.20 Key drivers of likelihood of transitions of *"I know what specialist services are needed to promote my child's learning and development"* response**

| Variable | Baseline to First Review | | Baseline to Second Review | |
|---|---|---|---|---|
| | Relationship with likelihood of | | Relationship with likelihood of | |
| | Improvement | Deterioration | Improvement | Deterioration |
| **Higher annualised plan budget** | | ↓ | | |
| **Participant is CALD** | | | ↓ | |
| **Carer reported a decrease in working hours between surveys** | ↑ | | | |
| **Carer reported an increase in working hours between surveys** | ↑ | | | |
| **Carer reported they were not in paid work at the time of both surveys** | ↓ | | ↓ | |
| **Carer reported they were in paid work at the time of both surveys** | ↓ | ↓ | | ↓ |

| Variable | Baseline to First Review<br>Relationship with likelihood of<br>Improvement | <br><br>Deterioration | Baseline to Second Review<br>Relationship with likelihood of<br>Improvement | <br><br>Deterioration |
|---|---|---|---|---|
| **Carer reported they started paid work between surveys** | ⬆ | | ⬆ | |
| **Carer reported they stopped paid work between surveys** | ⬆ | ⬆ | | |
| **Entered the scheme in 2016/17** | ⬆ | | | |
| **Higher Index of Economic Resources (IER)** | ⬆ | | ⬆ | |
| **Participant is Indigenous** | ⬇ | | | |
| **Participant lives in a major city** | | ⬆ | | |
| **Disability is cerebral palsy or other neurological disorder** | | ⬇ | | |
| **Disability is Down syndrome** | | ⬆ | | |
| **Participant has a lower level of function** | ⬇ | ⬆ | ⬇ | |
| **Less than 75% of supports are capacity building supports** | ⬇ | ⬆ | ⬇ | |
| **More than 95% of supports are capacity building supports** | ⬆ | ⬇ | ⬆ | |
| **Plan is fully agency-managed** | ⬇ | | | ⬆ |
| **Plan is fully self-managed** | ⬆ | ⬇ | | ⬇ |
| **Plan is partly self-managed** | | ⬇ | ⬆ | |
| **Plan is managed by a plan manager** | ⬇ | | ⬇ | ⬆ |
| **Participant is older** | ⬇ | | ⬇ | ⬆ |
| **Lives in NSW** | | ⬆ | | |
| **Lives in WA/TAS/ACT/NT** | ⬇ | | ⬇ | |
| **Lives in QLD** | ⬆ | | ⬆ | |

| Variable | Baseline to First Review<br>Relationship with likelihood of | | Baseline to Second Review<br>Relationship with likelihood of | |
|---|---|---|---|---|
| | Improvement | Deterioration | Improvement | Deterioration |
| **Lives in SA** | ↑ | ↑ | ↑ | |
| **Lives in VIC** | ↓ | ↓ | ↓ | |
| **Participant has a higher level of NDIA support** | ↓ | | | |
| **Higher budget utilisation** | ↑ | ↓ | ↑ | |

- Families/carers of participants who have a higher level of function were more likely to improve and less likely to deteriorate.
- Families/carers of participants with less than 75% capacity building supports in their plan were less likely to improve and more likely to deteriorate. Conversely, those caring for a participant with 95-100% capacity building supports were more likely to improve and less likely to deteriorate.
- Carers of older participants were generally less likely to improve and more likely to deteriorate.
- Families/carers of participants living in Queensland and SA were more likely to improve.
- Higher plan utilisation was associated with a higher likelihood of improvement.

### *I know what my family can do to support my child's learning and development*

The percentage of families/carers who know what they can do to support their child's learning and development increased by 7.2% between baseline and first review, and 10.8% between baseline and second review. Table 2.21 sets out the breakdown of the movements in responses between baseline and first review and between baseline and second review.

**Table 2.21 Breakdown of net movement in longitudinal responses**

| Longitudinal Period | Number of Responses in cohort | | Improvements: No to Yes | | Deteriorations: Yes to No | | Net Movement (No to Yes) |
|---|---|---|---|---|---|---|---|
| | No | Yes | Number | % | Number | % | |
| **Baseline to Review 1** | 18,927 | 13,599 | 3,892 | 20.6% | 1,561 | 11.5% | +7.2% |
| **Baseline to Review 2** | 4,553 | 3,301 | 1,449 | 31.8% | 602 | 18.2% | +10.8% |

The main drivers that had a statistically significant effect on the likelihood of improvement of deterioration are set out in Table 2.22 below.

## Table 2.22 Key drivers of likelihood of transitions of *“I know what my family can do to support my child’s learning and development”* response

| Variable | Baseline to First Review<br>Relationship with likelihood of | | Baseline to Second Review<br>Relationship with likelihood of | |
|---|---|---|---|---|
| | Improvement | Deterioration | Improvement | Deterioration |
| Participant is CALD | | | 🟪⬇ | |
| Participant is not CALD | | 🟩⬇ | 🟩⬆ | 🟩⬇ |
| Carer reported a decrease in working hours between surveys | | 🟪⬆ | | |
| Carer reported an increase in working hours between surveys | 🟩⬆ | | | |
| Carer did not report a change in working hours between surveys | | 🟩⬇ | | |
| Carer reported they were not in paid work at the time of both surveys | 🟪⬇ | 🟩⬇ | 🟪⬇ | |
| Carer reported they were in paid work at the time of both surveys | 🟪⬇ | | | |
| Carer reported they started paid work between surveys | 🟩⬆ | | 🟩⬆ | |
| Carer reported they stopped paid work between surveys | 🟩⬆ | 🟪⬆ | | |
| Entered the scheme in 2016/17 | 🟩⬆ | | | |
| Higher Index of Education and Occupation (IEO) | 🟪⬇ | | | |
| Higher Index of Economic Resources (IER) | 🟩⬆ | | 🟩⬆ | |
| Participant is Indigenous | | 🟩⬇ | | |
| Disability is autism | | 🟪⬆ | | |
| Disability is cerebral palsy or other neurological disorder | | 🟩⬇ | | |

| Variable | Baseline to First Review | | Baseline to Second Review | |
|---|---|---|---|---|
| | Relationship with likelihood of | | Relationship with likelihood of | |
| | Improvement | Deterioration | Improvement | Deterioration |
| **Disability is global developmental delay or developmental delay** | ⬆ | | | |
| **Disability is Down syndrome** | | ⬆ | | |
| **Participant has a lower level of function** | ⬇ | ⬆ | ⬇ | |
| **Less than 75% of supports are capacity building supports** | ⬇ | | ⬇ | |
| **Between 75% and 95% of supports are capacity building supports** | | | ⬇ | ⬆ |
| **More than 95% of supports are capacity building supports** | ⬆ | | ⬆ | |
| **More than 5% of supports are capital supports** | | | | ⬇ |
| **Plan is fully agency-managed** | ⬇ | | | |
| **Plan is fully self-managed** | ⬆ | ⬇ | | ⬇ |
| **Plan is partly self-managed** | ⬆ | ⬇ | | |
| **Plan is managed by a plan manager** | ⬇ | | ⬇ | ⬆ |
| **Participant is older** | ⬇ | | ⬇ | |
| **Lives in NSW** | ⬆ | ⬆ | | |
| **Lives in WA/TAS/ACT/NT** | ⬇ | | ⬇ | |
| **Lives in QLD** | ⬆ | | ⬆ | |
| **Lives in SA** | ⬆ | ⬆ | ⬆ | |
| **Lives in VIC** | ⬇ | ⬇ | ⬇ | |
| **Participant has a higher level of NDIA support** | ⬇ | | ⬇ | |

| Variable | Baseline to First Review<br>Relationship with likelihood of | | Baseline to Second Review<br>Relationship with likelihood of | |
|---|---|---|---|---|
| | Improvement | Deterioration | Improvement | Deterioration |
| **Higher budget utilisation** | ↑ | ↓ | ↑ | |

- Families/carers of participants who are not from a CALD background were more likely to maintain a positive response at both first and second review, and were more likely to improve between baseline and second review.
- Family and carers who started work between surveys were more likely to improve between baseline and first review, and between baseline and second review.
- Families/carers of participants with self-managed plans (either partially or fully) generally had more favourable follow-up responses than those with agency-managed plans.
- Families/carers of participants with a lower level of function generally responded less favourably.
- Higher plan utilisation was associated with a higher likelihood of improvement.

### *I get enough support to feel confident in parenting my child*

The percentage of families/carers who get enough support in parenting their child increased by 3.7% between baseline and first review, and 5.3% between baseline and second review. Table 2.23 sets out the breakdown of the movements in responses between baseline and first review and between baseline and second review.

**Table 2.23 Breakdown of net movement in longitudinal responses**

| Longitudinal Period | Number of Responses in cohort | | Improvements: No to Yes | | Deteriorations: Yes to No | | Net Movement (No to Yes) |
|---|---|---|---|---|---|---|---|
| | No | Yes | Number | % | Number | % | |
| **Baseline to Review 1** | 17,983 | 14,455 | 3,016 | 16.8% | 1,825 | 12.6% | +3.7% |
| **Baseline to Review 2** | 4,354 | 3,463 | 1,143 | 26.3% | 728 | 21.0% | +5.3% |

The main drivers that had a statistically significant effect on the likelihood of improvement of deterioration are set out in Table 2.24 below.

## Table 2.24 Key drivers of likelihood of transitions of *"I get enough support to feel confident in parenting my child"* response

| Variable | Baseline to First Review | | Baseline to Second Review | |
|---|---|---|---|---|
| | Relationship with likelihood of | | Relationship with likelihood of | |
| | Improvement | Deterioration | Improvement | Deterioration |
| **Participant is CALD** | | | | ⬆ |
| **Carer reported a decrease in working hours between surveys** | | ⬆ | | |
| **Carer reported an increase in working hours between surveys** | ⇧ | | | |
| **Carer did not report a change in working hours between surveys** | | ⇩ | | ⇩ |
| **Carer reported they were not in paid work at the time of both surveys** | ⬇ | ⇩ | ⬇ | |
| **Carer reported they started paid work between surveys** | ⇧ | | ⇧ | |
| **Carer reported they stopped paid work between surveys** | ⇧ | | | |
| **Entered the scheme in 2016/17** | ⇧ | | | |
| **Higher Index of Education and Occupation (IEO)** | | ⬆ | | ⬆ |
| **Participant lives in a major city** | | | ⬇ | |
| **Disability is autism** | ⬇ | ⬆ | ⬇ | ⬆ |
| **Disability is cerebral palsy or other neurological disorder** | ⬇ | ⇩ | | |
| **Disability is global developmental delay or developmental delay** | | | | ⇩ |
| **Disability is Down syndrome** | ⬇ | ⬆ | | |
| **Disability is another disability** | ⇧ | | ⇧ | ⬆ |
| **Disability is a sensory impairment** | ⇧ | ⇩ | | ⇩ |

| Variable | Baseline to First Review | | Baseline to Second Review | |
|---|---|---|---|---|
| | Relationship with likelihood of | | Relationship with likelihood of | |
| | Improvement | Deterioration | Improvement | Deterioration |
| **Participant has a lower level of function** | ↓ | ↑ | ↓ | |
| **Less than 75% of supports are capacity building supports** | ↓ | | ↓ | ↑ |
| **More than 95% of supports are capacity building supports** | ↑ | | ↑ | |
| **Plan is fully self-managed** | | | | ↓ |
| **Plan is partly self-managed** | ↑ | | | |
| **Plan is managed by a plan manager** | ↓ | | | ↑ |
| **Participant received services from Commonwealth systems before entering the NDIS** | | | | ↓ |
| **Participant received services from State/Territory systems before entering the NDIS** | | | | ↑ |
| **Participant is older** | ↓ | | ↓ | |
| **Lives in NSW** | | ↑ | | |
| **Lives in WA/TAS/ACT/NT** | ↓ | ↓ | | |
| **Lives in QLD** | ↑ | ↓ | | |
| **Lives in SA** | ↑ | ↑ | ↑ | |
| **Lives in VIC** | ↓ | | ↓ | |
| **Participant has a higher level of NDIA support** | ↓ | | ↓ | |
| **Higher budget utilisation** | ↑ | | | |

- Family and carers of participants with autism were less likely to improve and more likely to deteriorate at both first and second review. This contrasts with the families/carers of participants with sensory disabilities, who were generally more likely to improve and less likely to deteriorate at follow-up reviews.

- Family and carers of participants with lower level of function were generally less likely to respond positively in follow-up reviews.
- Family and carers of participants with less than 75% capacity building supports in their plan were less likely to record an improved response between baseline and first review compared to those with 95-100% capacity building supports.
- Family and carers who maintained a similar level of employment hours between baseline and follow-up reviews and responded “Yes” at baseline were more likely to maintain their favourable response at the follow-up reviews.
- Families/carers who did not feel they had enough support at baseline who started paid work between baseline and first review were more likely to improve their response at first review.
- Families/carers of older participants were less likely to improve.

### *I feel very confident or somewhat confident in supporting my child’s development*

The percentage of families/carers who feel very confident or somewhat confident in supporting their child’s development increased by 2.1% between baseline and first review, and 2.5% between baseline and second review. Table 2.25 sets out the breakdown of the movements in responses between baseline and first review and between baseline and second review.

**Table 2.25 Breakdown of net movement in longitudinal responses**

| Longitudinal Period | Number of Responses in cohort | | Improvements: No to Yes | | Deteriorations: Yes to No | | Net Movement (No to Yes) |
|---|---|---|---|---|---|---|---|
| | No | Yes | Number | % | Number | % | |
| **Baseline to Review 1** | 4,513 | 27,921 | 1,637 | 36.3% | 951 | 3.4% | +2.1% |
| **Baseline to Review 2** | 1,049 | 6,753 | 571 | 54.4% | 379 | 5.6% | +2.5% |

The main drivers that had a statistically significant effect on the likelihood of improvement of deterioration are set out in Table 2.26 below.

**Table 2.26 Key drivers of likelihood of transitions of *“I feel very confident or somewhat confident in supporting my child’s development”* response**

| Variable | Baseline to First Review | | Baseline to Second Review | |
|---|---|---|---|---|
| | Relationship with likelihood of | | Relationship with likelihood of | |
| | Improvement | Deterioration | Improvement | Deterioration |
| **Higher annualised plan budget** | | | ⬇ | |
| **Participant is CALD** | ⬇ | | | ⬆ |
| **Carer did not report a change in working hours between surveys** | ⬇ | ⬇ | | |

| Variable | Baseline to First Review | | Baseline to Second Review | |
|---|---|---|---|---|
| | Relationship with likelihood of | | Relationship with likelihood of | |
| | Improvement | Deterioration | Improvement | Deterioration |
| Carer reported they were not in paid work at the time of both surveys | ⬇ | | ⬇ | ⬆ |
| Carer reported they started paid work between surveys | ⇧ | | | ⇩ |
| Carer reported they stopped paid work between surveys | ⇧ | | | |
| Entered the scheme in 2016/17 | ⇧ | | | |
| Disability is autism | | ⬆ | | |
| Disability is Down syndrome | | ⬆ | | |
| Participant has a lower level of function | ⬇ | ⬆ | ⬇ | ⬆ |
| Less than 75% of supports are capacity building supports | | ⬆ | ⬇ | ⬆ |
| Between 75% and 95% of supports are capacity building supports | | ⬆ | | ⬆ |
| More than 95% of supports are capacity building supports | | ⇩ | ⇧ | ⇩ |
| More than 5% of supports are capital supports | | | | ⇩ |
| Plan is fully agency-managed | ⬇ | | ⬇ | |
| Plan is fully self-managed | ⇧ | ⇩ | | ⇩ |
| Plan is partly self-managed | | | ⇧ | |
| Plan is managed by a plan manager | | ⬆ | ⬇ | ⬆ |
| Participant received services from Commonwealth systems before entering the NDIS | ⬇ | ⇩ | | |
| Participant received services from State/Territory systems before entering the NDIS | | ⬆ | | |

| Variable | Baseline to First Review<br>Relationship with likelihood of | | Baseline to Second Review<br>Relationship with likelihood of | |
|---|---|---|---|---|
| | Improvement | Deterioration | Improvement | Deterioration |
| **Participant is older** | ↓ | | ↓ | |
| **Lives in WA/TAS/ACT/NT** | ↓ | | ↓ | |
| **Lives in QLD** | ↑ | | | ↓ |
| **Lives in SA** | ↑ | | ↑ | |
| **Lives in VIC** | ↓ | | ↓ | |
| **Participant has a higher level of NDIA support** | ↓ | ↑ | | |
| **Higher budget utilisation** | ↑ | | | |

- Of those who did not feel confident in supporting their child's development at baseline, families/carers who reported a change in working circumstances (either starting paid work or stopping paid work) were more likely to feel confident at first review. A similar relationship was also observed for the previous indicators related to knowing what specialist services are needed, and knowing what their family can do, to support their child's learning and development.
- Families/carers of participants with lower levels of function were less likely to improve and more likely to deteriorate in follow-up reviews
- Families/carers of participants with less than 75% capacity building supports in their plan were less likely to respond favourably in follow-up reviews. Family and carers of participants with more than 95% capacity building supports were more likely to respond favourably at follow-up reviews.
- Families/carers of participants with a self-managed plan were more likely to improve and less likely to deteriorate than those of participants with an agency-managed plan
- Families/carers of participants living in Queensland and South Australia generally had more favourable follow-up responses than those living in other states/territories.

### *In general, my health is excellent, very good or good*

The percentage of families/carers who rate their health as excellent, very good or good decreased by 3.5% between baseline and first review, and decreased 7.9% between baseline and second review. Table 2.27 sets out the breakdown of the movements in responses between baseline and first review and between baseline and second review.

**Table 2.27 Breakdown of net movement in longitudinal responses**

| Longitudinal Period | Number of Responses in cohort | | Improvements: No to Yes | | Deteriorations: Yes to No | | Net Movement (No to Yes) |
|---|---|---|---|---|---|---|---|
| | No | Yes | Number | % | Number | % | |
| **Baseline to Review 1** | 8,970 | 23,553 | 1,539 | 17.2% | 2,692 | 11.4% | -3.5% |
| **Baseline to Review 2** | 2,037 | 5,792 | 516 | 25.3% | 1,135 | 19.6% | -7.9% |

The main drivers that had a statistically significant effect on the likelihood of improvement of deterioration are set out in Table 2.28 below.

**Table 2.28 Key drivers of likelihood of transitions of *"In general, my health is excellent, very good or good"* response**

| Variable | Baseline to First Review<br>Relationship with likelihood of | | Baseline to Second Review<br>Relationship with likelihood of | |
|---|---|---|---|---|
| | Improvement | Deterioration | Improvement | Deterioration |
| **Higher annualised plan budget** | | ⬆ | | ⬆ |
| **Carer reported an increase in working hours between surveys** | ⬆ | | | |
| **Carer did not report a change in working hours between surveys** | | ⬇ | | |
| **Carer reported that they work 0 hours per week** | | ⬆ | | |
| **Carer reported that they work 15 to 30 hours per week** | | ⬇ | | |
| **Carer reported they were not in paid work at the time of both surveys** | ⬇ | | ⬇ | ⬆ |
| **Carer reported they were in paid work at the time of both surveys** | | | ⬆ | ⬇ |

| Variable | Baseline to First Review<br>Relationship with likelihood of | | Baseline to Second Review<br>Relationship with likelihood of | |
|---|---|---|---|---|
| | Improvement | Deterioration | Improvement | Deterioration |
| Carer reported they started paid work between surveys | ⬆ | | | |
| Carer reported they stopped paid work between surveys | | ⬆ | | ⬆ |
| Entered the scheme in 2016/17 | ⬆ | | | |
| Participant is Female | | ⬆ | | |
| Higher Index of Education and Occupation (IEO) | | | | ⬇ |
| Disability is autism | | ⬆ | | ⬆ |
| Disability is cerebral palsy or other neurological disorder | ⬆ | | | ⬇ |
| Disability is Down syndrome | ⬆ | | | |
| Disability is another disability[29] | ⬇ | | | |
| Disability is a sensory impairment | | ⬇ | | |
| Participant has a lower level of function | ⬇ | ⬆ | | |
| Less than 75% of supports are capacity building supports | ⬇ | ⬆ | ⬇ | ⬆ |
| More than 95% of supports are capacity building supports | ⬆ | ⬇ | | ⬇ |
| Plan is fully agency-managed | | ⬇ | | |
| Plan is fully self-managed | | ⬇ | | |
| Plan is managed by a plan manager | | ⬆ | | |
| Participant has not received services from Commonwealth | ⬆ | | | |

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[29] Classified as “Other” in the NDIA disability grouping (which comprises 16 named disability groups, with the remaining disabilities grouped as “Other”).

| **Variable** | **Baseline to First Review** |  | **Baseline to Second Review** |  |
|---|---|---|---|---|
|  | **Relationship with likelihood of** |  | **Relationship with likelihood of** |  |
|  | **Improvement** | **Deterioration** | **Improvement** | **Deterioration** |
| **or State/Territory systems before entering the NDIS** |  |  |  |  |
| **Participant received services from State/Territory systems before entering the NDIS** | ⬇ |  |  |  |
| **Participant is older** | ⬇ | ⬆ | ⬇ | ⬆ |
| **Lives in NSW** | ⇧ |  | ⇧ |  |
| **Lives in SA** | ⇧ | ⬆ |  |  |
| **Lives in VIC** | ⬇ | ⇩ | ⬇ |  |
| **Participant has a higher level of NDIA support** | ⬇ |  | ⬇ |  |
| **Higher budget utilisation** | ⬇ | ⬆ | ⬇ | ⬆ |

- Families/carers of younger participants had more favourable responses at follow-up surveys. Those who didn’t rate their health as good or better at baseline were more likely to at first and second review. Those who initially rated their health as good or better were less likely to change their response at follow-up reviews.
- Families/carers of participants with less than 75% capacity building supports in their plan were generally less likely to have a positive response at follow-up reviews compared to those caring for a participant with more than 95% capacity building supports.
- Families/carers of participants with a lower level of function were less likely to record favourable responses at first review.
- Families/carers who remained in paid work between baseline and second review were more likely to have a favourable response at second review compared to those who were not working at baseline or second review. Between baseline and follow-up reviews, carers who had good self-rated health but stopped paid work between baseline and review date were less likely to maintain their response.
- Families/carers of participants with autism who responded positively at their baseline review were less likely to maintain their favourable response at follow-up reviews.

### *One of the barriers to working more is the situation of my child with disability*

The percentage of families/carers who think that the situation of their child with disability is a barrier to working more increased by 2.8% between baseline and first review, and 4.4% between baseline and second review. Table 2.29 sets out the breakdown of the movements in responses between baseline and first review and between baseline and second review.

**Table 2.29 Breakdown of net movement in longitudinal responses**

| Longitudinal Period | Number of Responses in cohort | | Improvements: Yes to No | | Deteriorations: No to Yes | | Net Movement (Yes to No) |
|---|---|---|---|---|---|---|---|
| | No | Yes | Number | % | Number | % | |
| **Baseline to Review 1** | 2,159 | 14,595 | 230 | 1.6% | 691 | 32.0% | -2.8% |
| **Baseline to Review 2** | 446 | 3,341 | 84 | 2.5% | 251 | 56.3% | -4.4% |

The main drivers that had a statistically significant effect on the likelihood of improvement of deterioration are set out in Table 2.30 below.

**Table 2.30 Key drivers of likelihood of transitions of *"One of the barriers to working more is the situation of my child with disability"* response**

| Variable | Baseline to First Review<br>Relationship with likelihood of | | Baseline to Second Review<br>Relationship with likelihood of | |
|---|---|---|---|---|
| | Improvement | Deterioration | Improvement | Deterioration |
| **Higher annualised plan budget** | | ⬆ | | ⬆ |
| **Carer reported an increase in working hours between surveys** | ⬆ | | | |
| **Carer reported they were not in paid work at the time of both surveys** | | ⬇ | | |
| **Carer reported they started paid work between surveys** | ⬆ | | | |
| **Higher Index of Economic Resources (IER)** | | ⬆ | | |
| **Disability is autism** | | ⬆ | | |
| **Disability is cerebral palsy or other neurological disorder** | | ⬆ | | |
| **Disability is global developmental delay or developmental delay** | | | ⬆ | |

| Variable | Baseline to First Review | | Baseline to Second Review | |
|---|---|---|---|---|
| | Relationship with likelihood of | | Relationship with likelihood of | |
| | Improvement | Deterioration | Improvement | Deterioration |
| **Disability is another disability[30]** | | ↓ | | |
| **Disability is a sensory impairment** | | | ↑ | |
| **Participant has a lower level of function** | ↓ | | | |
| **Less than 75% of supports are capacity building supports** | | | ↓ | |
| **More than 95% of supports are capacity building supports** | ↑ | | ↑ | |
| **Plan is fully agency-managed** | | | | ↓ |
| **Participant has not received services from Commonwealth or State/Territory systems before entering the NDIS** | | | | ↑ |
| **Participant received services from State/Territory systems before entering the NDIS** | | | | ↓ |
| **Participant is older** | ↓ | ↓ | | |
| **Lives in NSW** | ↑ | ↑ | | ↑ |
| **Lives in WA/TAS/ACT/NT** | | ↓ | | |
| **Lives in SA** | | ↑ | | |
| **Lives in VIC** | ↓ | ↓ | | ↓ |
| **Higher budget utilisation** | ↓ | ↑ | ↓ | |

- Families/carers of participants with higher levels of plan utilisation were less likely to improve, that is, less likely to stop perceiving their child's situation as a barrier to working more between baseline and first review, and between baseline and second review. They were also more likely to keep perceiving their child's situation as a barrier to working more between baseline and first review.

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[30] Classified as "Other" in the NDIA disability grouping (which comprises 16 named disability groups, with the remaining disabilities grouped as "Other").

- Those caring for participants with autism or cerebral palsy were more likely to deteriorate between baseline and first review.
- Families/carers of participants with a developmental delay or sensory impairment were more likely to improve between baseline and second review.

### *One of the barriers to working more is the insufficient flexibility of jobs*

Of the families/carers who are able to work as much as they want, the percentage who say that insufficient flexibility of jobs is a barrier to working more increased by 4.4% between baseline and first review, and 7.6% between baseline and second review. Table 2.31 sets out the breakdown of the movements in responses between baseline and first review and between baseline and second review.

**Table 2.31 Breakdown of net movement in longitudinal responses**

| Longitudinal Period | Number of Responses in cohort | | Improvements: Yes to No | | Deteriorations: No to Yes | | Net Movement (Yes to No) |
|---|---|---|---|---|---|---|---|
| | No | Yes | Number | % | Number | % | |
| **Baseline to Review 1** | 10,206 | 6,548 | 522 | 8.0% | 1,256 | 12.3% | -4.4% |
| **Baseline to Review 2** | 2,302 | 1,485 | 232 | 15.6% | 521 | 22.6% | -7.6% |

The main drivers that had a statistically significant effect on the likelihood of improvement of deterioration are set out in Table 2.32 below.

**Table 2.32 Key drivers of likelihood of transitions of *"One of the barriers to working more is the insufficient flexibility of jobs"* response**

| Variable | Baseline to First Review | | Baseline to Second Review | |
|---|---|---|---|---|
| | Relationship with likelihood of | | Relationship with likelihood of | |
| | Improvement | Deterioration | Improvement | Deterioration |
| **Participant is CALD** | | ⬇ | | |
| **Carer reported a decrease in working hours between surveys** | ⬆ | | ⬇ | ⬆ |
| **Carer reported an increase in working hours between surveys** | ⬇ | ⬆ | ⬆ | |
| **Carer did not report a change in working hours between surveys** | ⬇ | ⬇ | | ⬇ |
| **Carer reported that they work 0 to 8 hours per week** | | ⬆ | | |

| Variable | Baseline to First Review | | Baseline to Second Review | |
|---|---|---|---|---|
| | Relationship with likelihood of | | Relationship with likelihood of | |
| | Improvement | Deterioration | Improvement | Deterioration |
| Carer reported that they work 15 to 30 hours per week | ⬆ | | | |
| Carer reported that they work more than 30 hours per week | ⬆ | | | |
| Carer reported they were in paid work at the time of both surveys | | ⬇ | | |
| Carer reported they stopped paid work between surveys | | ⬆ | | |
| Entered the scheme in 2016/17 | | ⬆ | | |
| Higher Index of Education and Occupation (IEO) | | ⬆ | | |
| Higher Index of Economic Resources (IER) | | | ⬆ | |
| Participant lives in a regional area | ⬇ | | | |
| Less than 75% of supports are capacity building supports | | | | ⬇ |
| More than 95% of supports are capacity building supports | | | | ⬆ |
| Participant received services from Commonwealth systems before entering the NDIS | | | ⬇ | |
| Participant has not received services from Commonwealth or State/Territory systems before entering the NDIS | | | ⬆ | |
| Participant is older | ⬇ | | ⬇ | |
| Lives in NSW | | ⬆ | | ⬆ |
| Lives in WA/TAS/ACT/NT | ⬇ | | ⬇ | |
| Lives in QLD | | ⬆ | ⬆ | ⬆ |
| Lives in SA | ⬆ | | ⬆ | |

| Variable | Baseline to First Review<br>Relationship with likelihood of |  | Baseline to Second Review<br>Relationship with likelihood of |  |
|---|---|---|---|---|
|  | Improvement | Deterioration | Improvement | Deterioration |
| **Lives in VIC** | ⬇ | ⬇ |  | ⬇ |
| **Participant has a higher level of NDIA support** | ⬇ | ⬇ |  |  |

- For the family and carers who reported job flexibility issues at baseline, those who worked 15 or more hours per week at first review were more likely to record an improvement.
- Carers who had job flexibility issues at baseline were more likely to continue having flexibility issues at follow-up reviews if they were caring for a participant of older age.
- Carers in South Australia and Victoria tended to have better outcomes than carers from other states/territories.

### *I am able to engage in social interactions and community life as much as I want*

The percentage of families/carers who are able to engage in social interactions and community life as much as they want decreased by 0.8% between baseline and first review, and 2.9% between baseline and second review. Table 2.33 sets out the breakdown of the movements in responses between baseline and first review and between baseline and second review.

**Table 2.33 Breakdown of net movement in longitudinal responses**

| Longitudinal Period | Number of Responses in cohort |  | Improvements: No to Yes |  | Deteriorations: Yes to No |  | Net Movement (No to Yes) |
|---|---|---|---|---|---|---|---|
|  | No | Yes | Number | % | Number | % |  |
| **Baseline to Review 1** | 23,452 | 8,567 | 1,498 | 6.4% | 1,740 | 20.3% | -0.8% |
| **Baseline to Review 2** | 5,589 | 2,076 | 514 | 9.2% | 738 | 35.5% | -2.9% |

The main drivers that had a statistically significant effect on the likelihood of improvement of deterioration are set out in Table 2.34 below.

### Table 2.34 Key drivers of likelihood of transitions of *“I am able to engage in social interactions and community life as much as I want”* response

| Variable | Baseline to First Review | | Baseline to Second Review | |
|---|---|---|---|---|
| | Relationship with likelihood of | | Relationship with likelihood of | |
| | Improvement | Deterioration | Improvement | Deterioration |
| **Higher annualised plan budget** | ↓ | ↑ | ↓ | ↑ |
| **Participant is CALD** | | ↓ | | |
| **Carer reported a decrease in working hours between surveys** | | ↑ | | ↑ |
| **Carer reported an increase in working hours between surveys** | ↑ | | | |
| **Carer did not report a change in working hours between surveys** | ↓ | ↓ | | ↓ |
| **Carer reported they were not in paid work at the time of both surveys** | ↓ | | ↓ | |
| **Carer reported they were in paid work at the time of both surveys** | | ↓ | | |
| **Carer reported they started paid work between surveys** | ↑ | | | |
| **Carer reported they stopped paid work between surveys** | ↑ | ↑ | | |
| **Entered the scheme in 2016/17** | ↑ | ↑ | | |
| **Higher Index of Education and Occupation (IEO)** | | ↑ | | |
| **Higher Index of Economic Resources (IER)** | ↑ | | | |
| **Participant is Indigenous** | ↑ | ↑ | | |
| **Disability is autism** | ↓ | ↑ | ↓ | ↑ |
| **Disability is cerebral palsy or other neurological disorder** | | ↓ | | |

| Variable | Baseline to First Review | | Baseline to Second Review | |
|---|---|---|---|---|
| | Relationship with likelihood of | | Relationship with likelihood of | |
| | Improvement | Deterioration | Improvement | Deterioration |
| **Disability is global developmental delay or developmental delay** | ⬆ | | | |
| **Disability is Down syndrome** | | ⬆ | | |
| **Disability is a sensory impairment** | ⬆ | ⬇ | | ⬇ |
| **Participant has a lower level of function** | ⬇ | ⬆ | | ⬆ |
| **Less than 75% of supports are capacity building supports** | ⬇ | | ⬇ | |
| **More than 95% of supports are capacity building supports** | ⬆ | | ⬆ | |
| **Plan is fully agency-managed** | ⬆ | | | |
| **Participant is older** | ⬇ | ⬇ | ⬇ | |
| **Lives in NSW** | ⬆ | ⬆ | | |
| **Lives in WA/TAS/ACT/NT** | | ⬇ | | |
| **Lives in QLD** | ⬆ | | | |
| **Lives in SA** | ⬆ | ⬆ | ⬆ | |
| **Lives in VIC** | ⬇ | ⬇ | ⬇ | |
| **Higher budget utilisation** | ⬇ | ⬆ | ⬇ | ⬆ |

- Families/carers of participants with autism were less likely to improve their response and more likely to deteriorate between baseline and follow-up reviews. Those caring for a participant with a sensory disability were generally more likely to have favourable responses at first and second review.
- Families/carers of participants with lower level of function were generally less likely to improve and more likely to deteriorate.
- Families/carers of participants whose plans had 95% or more in capacity building supports were more likely to record improvements between baseline and follow-up reviews compared to those caring for participants with less than 75% capacity building supports in their plans.

- Families/carers whose working circumstances changed between baseline and first review were more likely to improve their response at first review than those were not in paid work at the time of either review.
- A higher plan budget, and higher utilisation, were both associated with a lower likelihood of improvement and a higher likelihood of deterioration.

### *One of the barriers to engaging more in the community is the situation of my child with disability*

Of those unable to engage in the community as much as they want, the percentage of families/carers who say the situation with their child is a barrier to engaging in more social interactions within the community decreased by 2.4% between baseline and first review, and 4.0% between baseline and second review. Table 2.35 sets out the breakdown of the movements in responses between baseline and first review and between baseline and second review.

**Table 2.35 Breakdown of net movement in longitudinal responses**

| Longitudinal Period | Number of Responses in cohort | | Improvements: Yes to No | | Deteriorations: No to Yes | | Net Movement (Yes to No) |
|---|---|---|---|---|---|---|---|
| | No | Yes | Number | % | Number | % | |
| **Baseline to Review 1** | 2,378 | 19,361 | 767 | 4.0% | 256 | 10.8% | +2.4% |
| **Baseline to Review 2** | 485 | 4,596 | 282 | 6.1% | 80 | 16.5% | +4.0% |

The main drivers that had a statistically significant effect on the likelihood of improvement of deterioration are set out in Table 2.36 below.

**Table 2.36 Key drivers of likelihood of transition of "One of the barriers to engaging more in the community is the situation of my child with disability" response**

| Variable | Baseline to First Review | | Baseline to Second Review | |
|---|---|---|---|---|
| | Relationship with likelihood of | | Relationship with likelihood of | |
| | Improvement | Deterioration | Improvement | Deterioration |
| **Access type is early intervention** | ⬇ | | | |
| **Higher annualised plan budget** | | ⬆ | | ⬆ |
| **Participant is CALD** | ⬆ | | | ⬆ |
| **Carer reported an increase in working hours between surveys** | | ⬆ | | |
| **Carer did not report a change in working hours between surveys** | ⬇ | | | |

| Variable | Baseline to First Review | | Baseline to Second Review | |
|---|---|---|---|---|
| | Relationship with likelihood of | | Relationship with likelihood of | |
| | Improvement | Deterioration | Improvement | Deterioration |
| Carer reported they were in paid work at the time of both surveys | | ↓ | | |
| Carer reported they stopped paid work between surveys | | ↑ | | |
| Entered the scheme in 2016/17 | ↑ | ↑ | | |
| Participant is Female | ↑ | | | |
| Higher Index of Economic Resources (IER) | ↑ | | | |
| Disability is autism | ↓ | ↑ | | ↑ |
| Disability is global developmental delay or developmental delay | ↑ | | | |
| Participant has a lower level of function | ↓ | ↑ | ↓ | |
| Less than 75% of supports are capacity building supports | ↓ | | ↓ | |
| More than 95% of supports are capacity building supports | ↑ | | ↑ | |
| Participant received services from Commonwealth systems before entering the NDIS | | | ↓ | |
| Participant has not received services from Commonwealth or State/Territory systems before entering the NDIS | | | ↑ | |
| Participant received services from State/Territory systems before entering the NDIS | | | ↑ | |
| Participant is older | ↓ | | | |
| Lives in WA/TAS/ACT/NT | ↓ | | | |
| Lives in QLD | ↑ | | | |
| Lives in SA | ↑ | | | |

| Variable | Baseline to First Review | | Baseline to Second Review | |
|---|---|---|---|---|
| | Relationship with likelihood of | | Relationship with likelihood of | |
| | Improvement | Deterioration | Improvement | Deterioration |
| **Lives in VIC** | ⬇ | ⬇ | | |
| **Participant has a higher level of NDIA support** | | ⬇ | | ⬇ |
| **Higher budget utilisation** | ⬇ | ⬆ | ⬇ | |

- Family/carers of participants with autism were generally less likely to respond favourably in follow-up reviews
- Those caring for participants with a lower level of function were generally more likely to continue viewing the situation of their child as a barrier to greater engagement in subsequent surveys.
- For the family/carers who wanted more community engagement at baseline but did not cite the situation with their child as a barrier, those caring for participants with a higher annualised plan budget were less likely to maintain their response at follow-up reviews.
- Higher plan utilisation was associated with a lower likelihood of improvement.
- Families/carers of participants with plans with more than 95% of supports being capacity building were more likely to show improvements than those caring for participants with less than 75% capacity building supports in their plans.