# NDIS Family and Carer Outcomes

## 30 June 2019

# Contents

# Executive summary

## Background

The NDIS Outcomes Framework is one of only a few internationally that measures outcomes for both participants and their families and carers.

Families and carers play an important role in supporting NDIS participants. The outcomes for a participant, and for the person who cares for them, are likely to be closely linked. Families and carers of participants who are well supported under the NDIS and who are achieving greater independence and social and economic participation are likely to find the caring role easier and to experience increased wellbeing and greater opportunities for social and economic participation themselves. The improved situation for families and carers should in turn translate into further improvement in outcomes for participants.

A separate report on participant outcomes at 30 June 2019 has also been prepared.[1] That report discusses the aims of the NDIS and how those aims are embedded in the legislation[2] and the NDIA Corporate Plan 2019-2023[3].

## The NDIS Outcomes Framework questionnaires

The participant outcomes report discusses the insurance principles on which the Scheme is based. An insurance-based approach considers the lifetime cost of participants (including early investment), and the outcomes achieved across participants' lifetimes. In view of the link with participant outcomes, monitoring family and carer outcomes contributes to an assessment of how successfully the insurance-based approach is working. Monitoring of family and carer outcomes is also important from a broader perspective, for example, increased economic participation of families and carers will have wider benefits for the Australian economy.

This report is the second annual report on family and carer outcomes, and analyses:

- The results of the baseline outcomes framework questionnaires for families and carers of participants who entered the Scheme in 2016-17, 2017-18 and 2018-19 (referred to as "baseline" as the NDIS has not influenced the outcomes of participants or their families and carers at this point).
- One year longitudinal changes in outcomes for families and carers of participants who entered the Scheme in 2016-17 and 2017-18 (have been in the Scheme for at least one year).
- Two year longitudinal changes in outcomes for families and carers of participants who entered the Scheme in 2016-17 (have been in the Scheme for two years).

This year's report adds a second year of longitudinal experience to the analysis, compared to last year's report. Two years is still not a lot of time to measure success – however, importantly this report builds on last year's analysis and continues the conversation on what factors are driving good outcomes, and indicates that the NDIS is continuing to improve the lives of many families and carers of NDIS participants.

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[1] Subsequently referred to as "the participant outcomes report".
[2] https://www.legislation.gov.au/Series/C2013A00020
[3] https://www.ndis.gov.au/about-us/publications/corporate-plan

## Baseline versus progress

As also noted in the participant outcomes report, baseline outcomes for participants and their families and carers will differ by a range of individual and external factors, including the nature and severity of the participant's disability, the extent of support networks, local community inclusiveness, and general health.

Consequently, the success of the Scheme should be judged not on baseline outcomes, but on how far participants and their families and carers have come since they entered the Scheme, acknowledging their different starting points.

It is also important to note that whilst some of the benefits of the Scheme should be quick to emerge (for example, assistance with daily living), others are much more long-term in nature (for example, employment), and measurable progress may take some years to emerge.

Finally, it should be recognised that some of the domains included in the outcomes framework (for example, health) are not the primary responsibility of the NDIS, but are nevertheless included in order to provide a fuller picture of the circumstances of participants and their families and carers.

## A lifespan approach

Leveraging research conducted by the NDIS Independent Advisory Council (IAC), the outcomes framework takes a lifespan approach to the measurement of outcomes, recognising that different milestones are important for different participant age groups.

Many of the issues faced by families and carers are similar regardless of participant age (for example, being able to work as much as they want), however there are some differences (for example, families and carers of young children will be focussed on helping their child's early development and learning, whereas families and carers of young adults will want to help their family member to become as independent as possible).

Recognising these differences, family/carer questionnaires have been developed for three different *participant* age groups: 0 to 14, 15 to 24, and 25 and over. This report is organised with separate sections for each of these participant age groups, synthesising analyses from all data sources[4]. Since the role of the family or carer in the participant's life is most crucial during childhood, and since completion of the family/carer questionnaire is not compulsory where the participant is an adult, the report puts greater emphasis on the 0 to 14 participant age group, followed by the 15 to 24 age group. For the 25 and over age group, where a smaller amount of data is available (particularly longitudinally), and the relationship between participants and families/carers tends to be less close, a briefer presentation of results is given.

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[4] The Short Form (SF) outcomes framework and the Long Form (LF) outcomes framework, baseline and longitudinal information.

# Families/carers of participants from birth to age 14

## Overall results

- In the longitudinal analysis, significant **improvements** were observed across a number of indicators, both from baseline to first review, and from baseline to second review, particularly in the areas of:
  - ***Employment:***
    - For participants who joined the Scheme in 2016-17, 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 aged 25 to 64 (77.7%).[5] For those in a paid job, the percentage working 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 30 hours or more has also increased, from 39.4% at baseline to 46.7% at second review, but is still much lower than the 74.2% of Australians working on a full-time basis as at 30 June 2019.[6]
    - For participants entering in 2017-18, 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 the families and carers of 2016-17 entrants, there have been increases in the percentages working 15 hours or more per week, from 77.4% at baseline to 79.9% at first review, and 30 hours or more per week, from 41.4% to 44.0%.
  - ***Development and learning***:
    - For participants entering in 2016-17, 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%.
    - For participants entering in 2017-18, 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.

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

[6] Australian Bureau of Statistics. 2019. 6202.0 Labour force, Australia, Jun 2019. Employed full-time to employed total. The ABS defines full-time work as 35 hours or more per week, so the percentage of the general population working more than 30 hours per week would likely be higher than 74.2%.

- ***Interaction with services***:
    - For participants entering in 2016-17, 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.
    - For participants entering in 2017-18, 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.

**Figure 1 Changes in indicators over two years for families/carers of participants aged 0 to 14 who entered the Scheme in 2016-17**

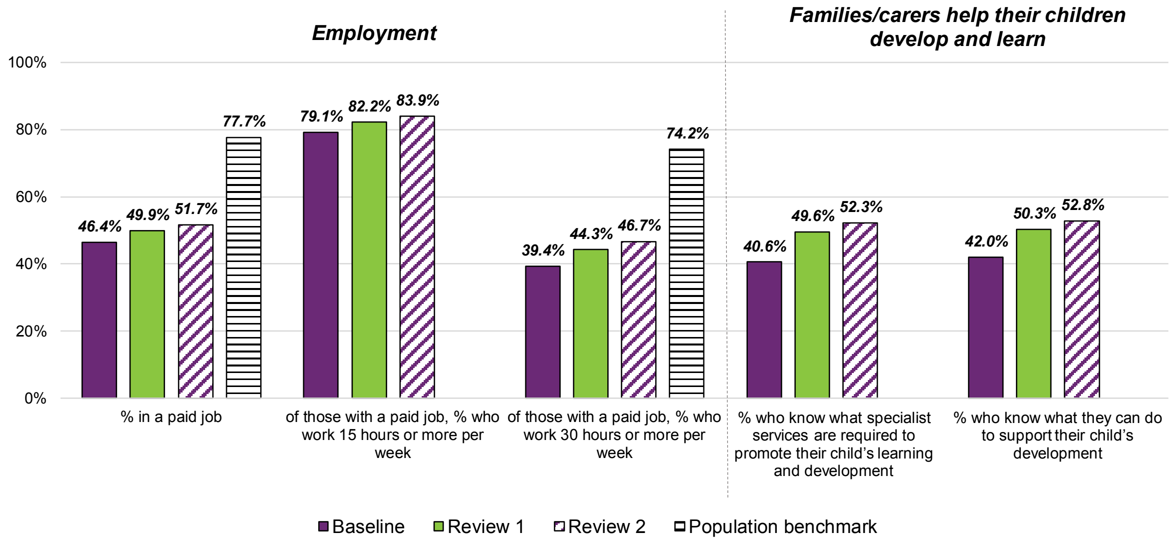
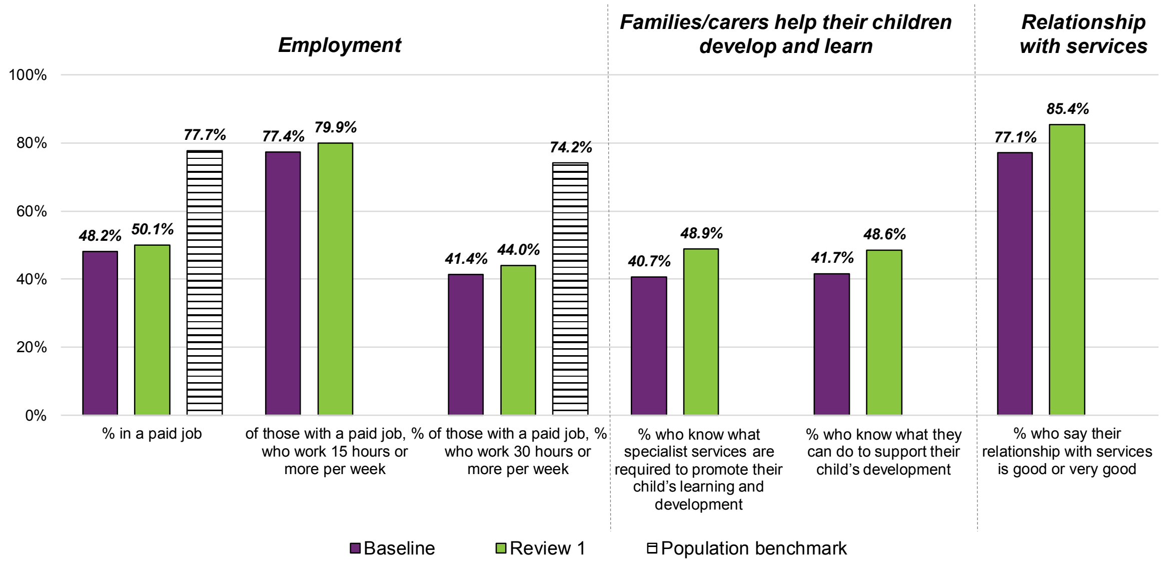
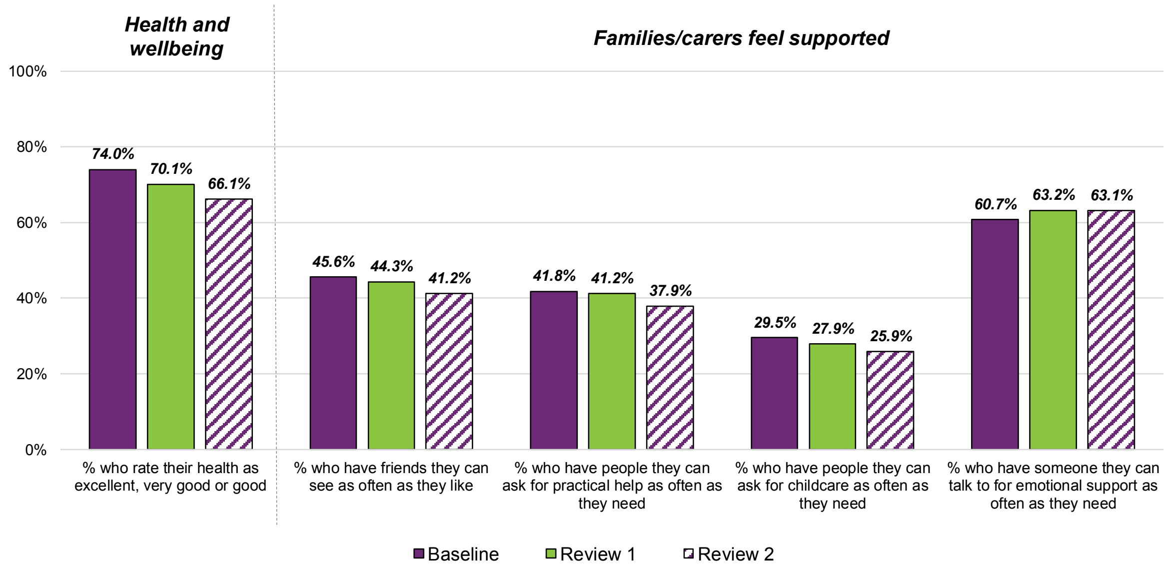


**Figure 2 Changes in indicators over one year for families/carers of participants aged 0 to 14 who entered the Scheme in 2017-18**

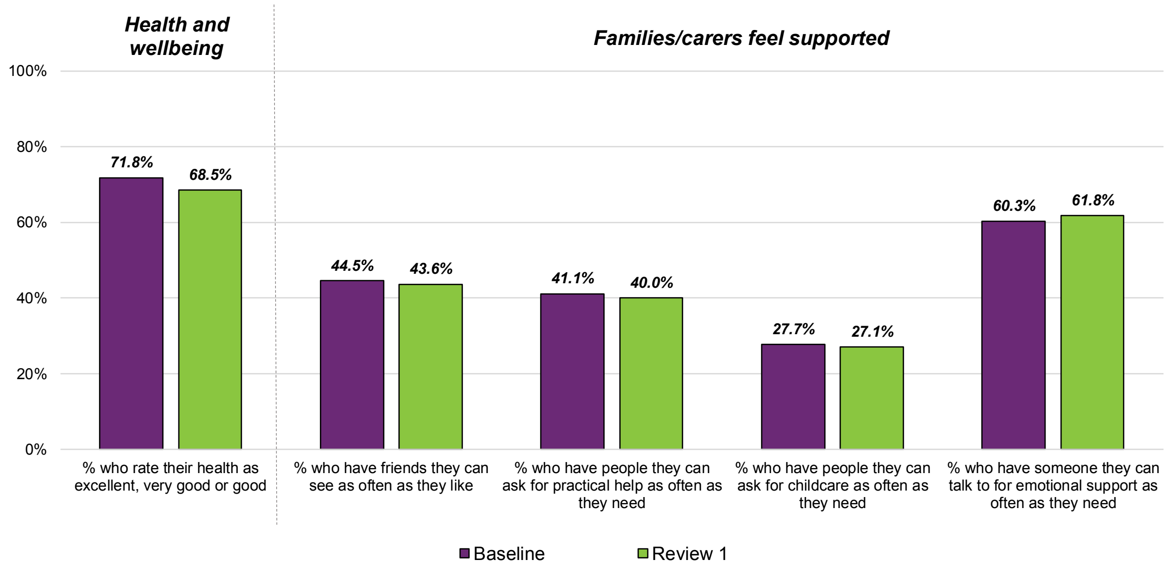


- Changes in some other areas were less positive, reflecting the difficulties faced by families/carers of children with disability.
    - ***Health and wellbeing:***
        - For participants entering in 2016-17, some deterioration was observed in self-rated health for families/carers, with the percentage rating their health as excellent, very good or good decreasing by 7.9%, from 74.0% at baseline to 66.1% at second review.
        - For participants entering in 2017-18, 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.
    - ***Informal supports:***
        - For participants entering in 2016-17, there were 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); and 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%.
        - For participants entering in 2017-18, changes were in the same direction as for those entering in 2016-17, but the one year changes were of smaller magnitude (around 1%).
    - ***Social interactions***:
        - For participants entering in 2016-17, the percentage of families/carers who say they are able to engage in social interactions and community life as much as they want decreased by 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.
        - For participants entering in 2017-18, 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.

## Figure 3 Changes in indicators over two years for families/carers of participants aged 0 to 14 who entered the Scheme in 2016-17



## Figure 4 Changes in indicators over one year for families/carers of participants aged 0 to 14 who entered the Scheme in 2017-18



- Family/carer's baseline and longitudinal outcomes vary significantly with their primary disability, age, cultural background, Indigenous status, level of function, location, plan type and living situation:
    - 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.
- Opinions on whether the NDIS has helped are generally positive for this cohort:
  - 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 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 were who are not Indigenous.

## Families/carers of participants aged 15 to 24

### Overall results

- ***Employment:*** some small positive changes were observed in employment indicators for families/carers of participants aged 15 to 24, however, with one exception (the percentage of families/carers of participants entering the Scheme in 2016-17 working 15 hours or more per week) they were either not statistically significant or of magnitude less than 2%.
    - For participants who joined the Scheme in 2016-17, there was an increase of 2.1% over two years in the percentage of families/carers working in a paid job, from 51.8% to 53.9%. This increase was significant at the 10% level but not at the 5% level. For those with a paid job, there was a significant (at the 5% level) and larger increase of 5.3% in the percentage working 15 hours or more per week, from 82.7% to 88.0%.
    - For participants entering in 2017-18, there was a significant but small increase of 1.6% over one year in the percentage of families/carers working in a paid job, from 51.7% to 53.3%. For those with a paid job, there was a significant but small increase of 1.7% in the percentage working 15 hours or more per week, from 84.5% to 86.2%.
- In the longitudinal analysis for other domains, significant **improvements** were observed across a number of indicators, both from baseline to first review, and from baseline to second review, particularly in the areas of:
    - ***Access to services:***
        - For participants who joined the Scheme in 2016-17, the percentage of families/carers who said that the services they receive for their family member with disability meets their needs increased from 18.0% at baseline to 37.5% at second review. The percentage of families/carers who felt that the services they use for their family member with disability listen to them increased from 66.5% at baseline to 73.8% at second review.
        - For participants who entered in 2017-18, the percentage of families/carers who said that the services they receive for their family member with disability meets their needs increased from 17.6% at baseline to 25.0% at first review. A similar improvement was observed in the percentage of families/carers who feel that the services they use for their family member with disability listen to them (62.9% at baseline versus 67.4% at first review).
    - ***Confidence for the future***:
        - For participants who joined the Scheme in 2016-17, the percentage who felt more confident about the future of their family member with disability under the NDIS increased from 52.9% at baseline to 70.6% at second review. The percentage who strongly agree or agree that their family member gets the support he/she needs also increased, from 32.4% at baseline to 51.5% at second review.
        - For participants who entered in 2017-18, the percentage who felt more confident about the future of their family member with disability under the NDIS increased from 46.2% at baseline to 60.8% at first review. The percentage who strongly agree or agree that their family member gets the support he/she needs also increased, from 34.4% at baseline to 51.1% at first review.

**Figure 5 Changes in indicators over two years for families/carers of participants aged 15 to 24 who entered the Scheme in 2016-17**

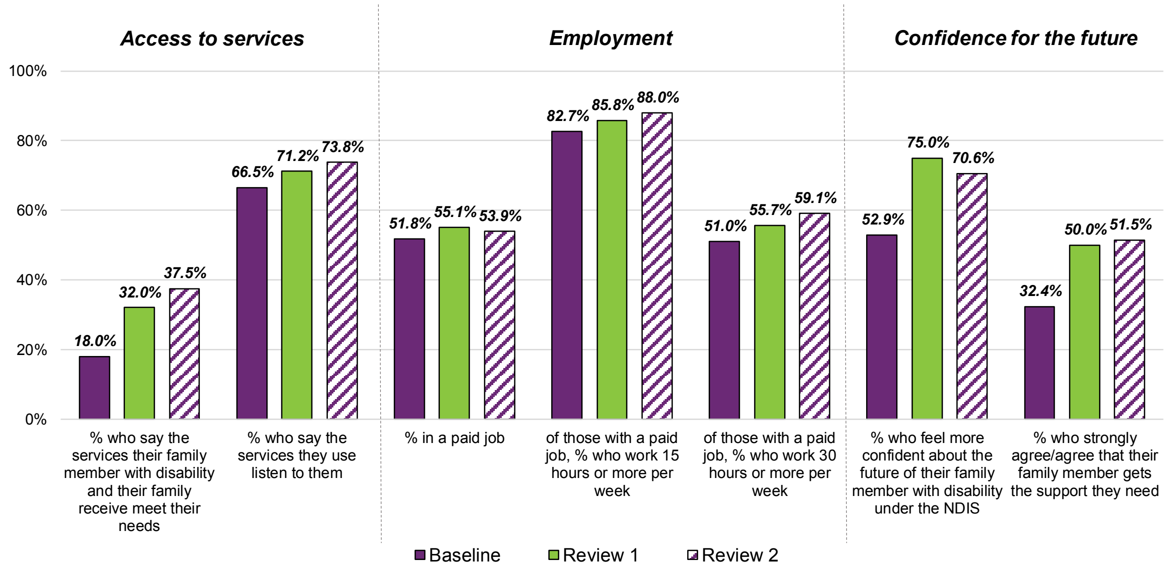
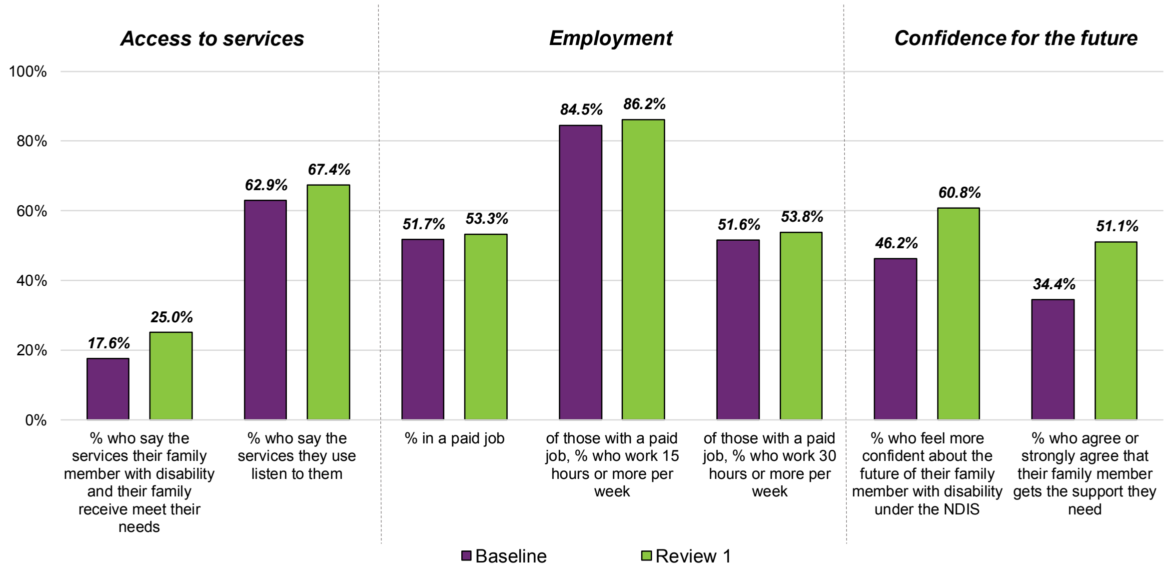


**Figure 6 Changes in indicators over one year for families/carers of participants aged 15 to 24 who entered the Scheme in 2017-18**



- ***Other significant changes*** have been observed for some indicators related to health and wellbeing, and feeling supported.
  - ***Health and Wellbeing***: Outcomes in this domain mostly deteriorated, and can be partially explained by the tendency for health to decline with age. In particular:
    - For participants who joined the Scheme in 2016-17, there was a decline in the percentage of families/carers who rated their health as excellent, very good or good, from 64.6% at baseline to 55.9% at second review. Additionally, of families/carers unable to work as much as they want, the percentage who say the situation of their family member with disability is a barrier to working more increased from 89.2% at baseline to 93.6% at second review.

    - For participants who entered in 2017-18, the percentage of families/carers who rate their health as excellent, very good or good declined from 60.9% at baseline to 57.5% at first review. And of families/carers unable to work as much as they want, the percentage saying that insufficient flexibility of jobs is a barrier to working more increased from 32.4% at baseline to 35.2% at first review.

- Family/carer's baseline and longitudinal outcomes vary significantly with their primary disability, age, cultural background, Indigenous status, level of function, location, plan type and living situation:
  - For the majority of indicators, baseline outcomes are better for families/carers of participants with a high level of function
  - Families/carers of participants with a hearing or visual impairment generally experience better outcomes at baseline. In contrast, families/carers of participants with psychosocial disability tend to fare worse.
  - Baseline outcomes for families/carers of participants from CALD backgrounds tend to be worse, particularly on advocacy and independence. Furthermore, regression modelling of longitudinal outcomes suggests that families/carers from CALD backgrounds are less likely to see improvements in health and wellbeing between baseline and second review.
  - Results for families/carers of Indigenous participants are mixed. This group is less likely to be in paid employment and to report that the services they use listen to them, but more likely to have people who can provide practical help.
  - Families/carers of older participants tend to exhibit better outcomes at baseline, particularly in domains relating to employment and participant independence. However, regression modelling suggests that this group is less likely to see improvements in health and wellbeing.
  - Results for families/carers in regional and remote locations are mixed. This group tends to do better on indicators related to advocacy, feeling supported and helping the participant become more independent. Some employment indicators such as being able to work as much as preferred are also better. However, other employment indicators are worse; in particular, some barriers to working more, such as insufficient flexibility of jobs, are more commonly cited.
  - Families/carers living in Queensland or South Australia are more likely to report improvements in the access to services domain. This is in contrast to families/carers living in New South Wales or Victoria, who are less likely to report improvements.
  - Families/carers with self-managed plans (fully or partly) experience more positive outcomes at baseline on some indicators, namely within the advocacy and feeling supported domains. Moreover, oneway analysis and longitudinal modelling suggest that this group of respondents is more likely to report positive outcomes at first review.
  - Families/carers with strong social connections are more likely to enable their participant to become more independent.
  - Families/carers with higher plan utilisation reported more positive longitudinal outcomes in the employment and access to services domains.

  - Outcomes in the access to services and health and wellbeing domains, for families/carers of participants who rate their own health as fair or poor, tend to deteriorate between baseline and first review.
  - Carers who reduced their hours of work were less likely to show improvements in outcomes, across most domains.
- Opinions on whether the NDIS has helped are slightly less positive for this cohort than for families/carers of participants aged 0 to 14. Key findings include:
  - The percentage of families/carers reporting that the NDIS helped after two years in the Scheme was higher across all domains than the percentage of families/carers reporting that the NDIS helped after one year in the Scheme.
  - After one year in the Scheme, families/carers of older participants or those with higher baseline plan utilisation were more likely to say that the NDIS has helped. Similarly, families/carers of participants in self-managed plans or with a higher annualised plan budget were more likely to report positive outcomes at first review. On the other hand, families/carers of participants who required a higher level of NDIA support were less likely to report positive outcomes.
  - Families/carers of participants with autism or Down syndrome were more likely to say that the NDIS helped at first review. In contrast, families/carers of participants with a visual impairment were less likely to respond positively.
  - The percentage of families/carers reporting that the NDIS improved the level of support for their family increased 5.3%, from 58.0% to 63.3% between first and second review. Families/carers of participants with higher baseline plan utilisation were most likely to report improvements.
  - The percentage of families/carers stating that the NDIS improved their access to services, programs and activities in their community increased from 55.9% at first review to 62.2% at second review. Families/carers of younger participants or those with higher baseline plan utilisation were most likely to report improvements in this domain.
  - The percentage of families/carers reporting that the NDIS helped them know their rights and advocate effectively improved 4.3%, from 46.0% at first review to 50.3% at second review. Responses of families/carers were more likely to improve for participants from Queensland or South Australia, while responses were less likely to improve for families/carers of participants with a lower level of function.

# Families/carers of participants aged 25 and over

## Overall results

- ***Employment:*** changes in employment indicators for families/carers of participants aged 25 and over were mostly small and not significant. It should be noted that families/carers of participants aged 25 and over are more likely to be of retirement age compared to families carers of participants aged under 25, and as such are less likely to be in a paid job.
    - For participants who joined the Scheme in 2016-17, there was a small and not statistically significant decline of 1.1% over two years in the percentage of families/carers working in a paid job, from 24.2% to 23.1%. For those with a paid job, there was a larger but again not statistically significant increase of 5.6% in the percentage working 15 hours or more per week, from 83.3% to 88.9%.
    - For participants entering in 2017-18, there was a small and not statistically significant decline of 0.5% over one year in the percentage of families/carers working in a paid job, from 33.8% to 33.3%. For those with a paid job, there was a small and not statistically significant increase of 0.3% in the percentage working 15 hours or more per week, from 85.1% to 85.4%.
- Only a small number of 2016-17 entrants contributed to the two-year longitudinal analysis. Nevertheless, significant changes were observed for five indicators. For the larger group of 2017-18 entrants, the number of significant changes was larger. Improvements were observed particularly in the areas of:
    - ***Interaction with services:***
        - For participants who joined the Scheme in 2016-17, three positive changes were observed related to satisfaction with services. The percentage of families/carers who say that the services their family member with disability and their family receive meet their needs improved from 23.1% at baseline to 40.7% at second review. The percentage who said they had no difficulties working in partnership with professionals and service providers to meet the needs of their family member with disability increased from 62.1% to 89.7% over two years, and the percentage who said the services helped them to plan for the future increased from 44.8% to 75.9%.
        - For participants entering in 2017-18, the percentage of families/carers who said that the services their family member with disability receives meet their needs increased from 21.5% at baseline to 30.3% at first review. The percentage who say the services they use listen to them increased from 67.8% to 71.3%, and the percentage who say the services help them to plan for the future increased from 64.1% to 73.7%.
    - ***Health and wellbeing:***
        - For participants who joined the Scheme in 2016-17, several of the family/carer health and wellbeing indicators showed similar trends to those for 2017-18 entrants, although none was significant at the 5% level. For example, the percentage who strongly agree or agree that services and supports have helped them to better care for their family member with disability increased from 43.3% at baseline to 70.0% at second review (significant at the 10% level).

- For participants entering in 2017-18, the percentage of families/carers who felt their family member with disability gets the support they need rose from 27.5% at baseline to 35.7% at first review, and the percentage who strongly agree or agree that services and supports have helped them to better care for their family member with disability increased from 55.4% to 65.8%. Families/carers also felt more positive about the future, with the percentage feeling more confident about the future of their family with disability under the NDIS increasing from 34.7% at baseline to 56.2% at first review, and the percentage feeling delighted, pleased or mostly satisfied when thinking about last year and what they expect for the future increasing from 44.1% to 55.9%.

**Figure 7 Changes in indicators over two years for families/carers of participants aged 25 and over who entered the Scheme in 2016-17**

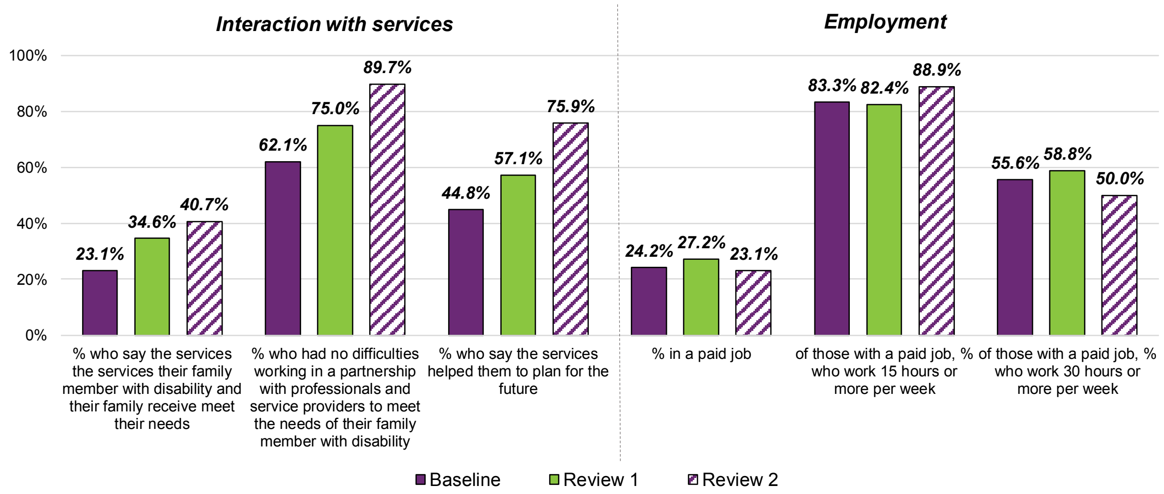
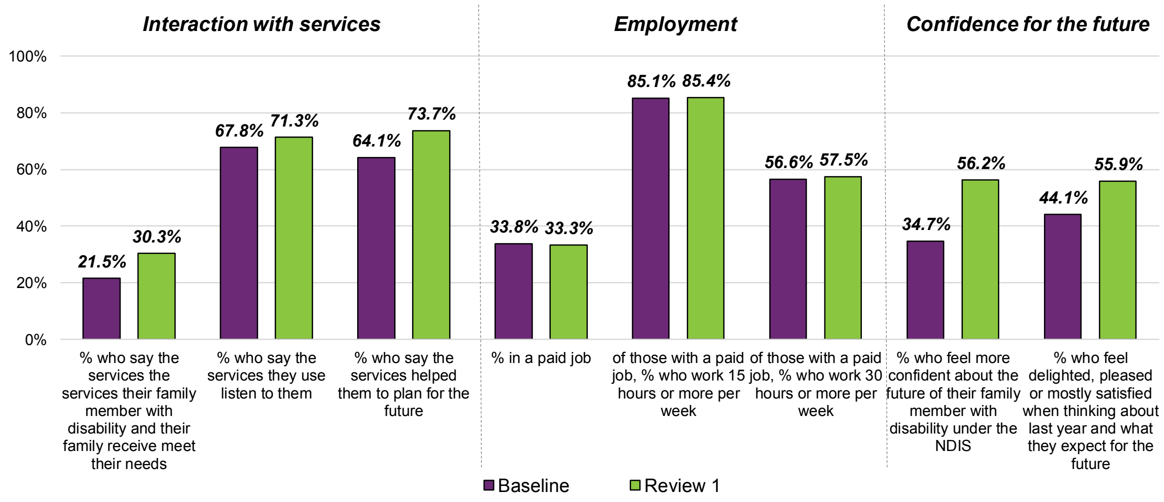


**Figure 8 Changes in indicators over one year for families/carers of participants aged 25 and over who entered the Scheme in 2017-18**



- Some less positive trends were also observed in the health and wellbeing domain, for participants entering the Scheme in 2017-18. The percentage rating their health as excellent, very good or good has declined by 3.9% over one year, and the percentage who say insufficient flexibility of jobs is a barrier to working more increased by 2.3%.

- Family/carer's baseline and longitudinal outcomes vary significantly with participant characteristics such as primary disability, age, cultural background, Indigenous status, level of function, and some plan characteristics:
  - For the majority of indicators, baseline outcomes are better for families/carers of participants with a high level of function.
  - Controlling for other factors, baseline outcomes for families/carers of participants with a CALD background were less likely to be positive. For example, families/carers of CALD participants were less likely to be able to advocate for their family member, were less likely to feel in control when selecting services and supports, and were less likely to be able to work as much as they want.
  - Baseline outcomes for families/carers of participants from Indigenous backgrounds were generally worse than those for families/carers of non-Indigenous participants, especially in the domains relating to access to services and health and wellbeing.
  - At baseline, families/carers of participants with hearing impairments were the least likely to cite the situation of their family member with disability as a barrier to working more. This group also exhibited the best health and wellbeing outcomes at baseline and were most likely to feel supported.
  - Baseline modelling indicates that, like the 15 to 24 cohort, outcomes for families/carers of participants aged 25 or older generally become more positive with increasing participant age, especially in the support and access to services domains. However, the health and wellbeing of families/carers of older participants tends to deteriorate (likely reflecting the positive relationship between participant and family/carer age). This group is also more likely to cite the situation of their family member with disability or insufficient flexibility of jobs as barriers to working more.
  - Longitudinal modelling indicates that families/carers of participants with a higher annualised plan budget are more likely to agree that the services their family member with disability and their family receive meet their needs. A similar trend was observed for families/carers of participants with fully self-managed plans or those with a lower level of NDIA support.
  - Families/carers with a higher score on the Index of Economic Resources are more likely to display improvement in their opinion of whether their family member with disability gets the support they need. In contrast, families/carers of participants with a higher level of NDIA support are more likely to deteriorate in this area.
- Family/carer's opinions on whether the NDIS has helped vary by domain:
  - The most positive responses were for improving access to services, programs and activities in the community (60.1% after one year, increasing to 68.6% after two years) and for improving the level of support for the family (65.1% after one year, increasing to 69.2% after two years). In the health and wellbeing domain, positive response rates increased from 37.1% at first review, to 41.2% at second review. Responses were less positive for the "Has the NDIS helped you with preparing for the future support of your family member" question (37.3% at first review and 36.4% at second review).
  - Improvements in positive response rates between first and second review were observed across all domains except succession planning.
  - After one year in the Scheme, families/carers of participants with higher baseline plan utilisation were more likely to say that the NDIS has helped.

    - Longitudinal modelling of the change in responses between first and second review did not show any significant relationships, primarily due to the small number of respondents completing both the first and second reviews.

# 1. Introduction

## 1.1 Background

Families and carers play an important role in supporting NDIS participants. Improved outcomes for participants under the NDIS can be expected to facilitate this caring role, leading to improved outcomes for families and carers also.

This report is the second annual report on outcomes for families and carers of NDIS participants, including baseline and longitudinal change up to 30 June 2019 for families and carers of participants entering the Scheme since 1 July 2016. The previous report summarised experience to 30 June 2018[7].

The purpose of this report is to provide a picture of how the families and carers of NDIS participants are progressing, based on information provided by them in interviews conducted as part of the NDIS outcomes framework questionnaires. The results are intended to provide insight into how the Scheme is making a difference for families and carers, and point to any areas where improvements may be required.

Separate reports on participant outcomes at 30 June 2018 and at 30 June 2019 have been prepared, and those reports should be consulted for further information on the ways in which the NDIA is measuring outcomes more broadly, as well as general background to the development and implementation of the outcomes framework.

## 1.2 Overview

The remaining sections of the report present results from analysing the outcomes framework data available as at 30 June 2019. Results are organised with separate sections for each questionnaire version, synthesising analyses from all data sources (SF and LF, baseline and longitudinal). Specifically:

- Sections 2 and 3 contain results for families/carers of participants from birth to age 14.
- Sections 4 and 5 contain results for families/carers of participants aged 15 to 24.
- Sections 6 and 7 contain results for families/carers of participants aged 25 and over.

More detailed results contained in the appendices[8] include:

- Appendix A: Families/carers of participants aged 0 to 14
- Appendix B: Families/carers of participants aged 15 to 24
- Appendix C: Families/carers of participants aged 25 and over

Appendices A to C contain the following information:

1. Baseline indicators – aggregate
2. Baseline indicators – by participant characteristics

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[7] NDIS Family and Carer Outcomes Report 2018, National Disability Insurance Scheme 2020, https://data.ndis.gov.au/reports-and-analyses/family-and-carer-outcomes-report

[8] Appendix B of the participant outcomes report also contains information on response rates and representativeness for the LF family/carer survey.

3. Longitudinal change in indicators over one year for families/carers of participants entering the Scheme in 2017-18 – aggregate
4. Longitudinal change in indicators over one year for families/carers of participants entering the Scheme in 2017-18 – by participant characteristics
5. Longitudinal change in indicators over one and two years for families/carers of participants entering the Scheme in 2016-17 – aggregate
6. Longitudinal change in indicators over two years for families/carers of participants entering the Scheme in 2016-17 – by participant characteristics
7. Perceptions of whether the NDIS has helped after one year in the Scheme – aggregate
8. Perceptions of whether the NDIS has helped after one year in the Scheme – by participant characteristics
9. Perceptions of whether the NDIS has helped after two years in the Scheme – aggregate
10. Perceptions of whether the NDIS has helped after two years in the Scheme – by participant characteristics.

## 1.3 Questionnaires

Table 1.1 sets out the questionnaire versions and domains, including letter codes used in the report.

**Table 1.1 Outcomes framework versions and domains for families/carers**

| Domain | Participants aged 0 to 14 | Participants aged 15 to 24 | Participants aged 25 and over |
|---|---|---|---|
| **Families/carers know their rights and advocate effectively for their family member with disability (RA)** | ✓ | ✓ | ✓ |
| **Families/carers feel supported (SP)** | ✓ | ✓ | ✓ |
| **Families/carers are able to gain access to desired services, programs and activities in their community (AC)** | ✓ | ✓ | ✓ |
| **Families/carers enjoy health and wellbeing (HW)** | ✓ | ✓ | ✓ |
| **Families/carers help their child develop (DV)** | ✓ | | |
| **Families/carers help their young person become independent (IN)** | | ✓ | |
| **Families/carers have succession plans (SC)** | | | ✓ |
| **Families/carers understand their child's strengths, abilities and special needs (UN) (LF only)** | ✓ | ✓ | |

The report also includes information not included in any of the specific domains, on employment (WK) and receipt of government benefits (GB).

## 1.4 Cohorts used in the longitudinal analysis

Longitudinal results for outcome indicators are considered separately for two cohorts of families/carers:

- Families/carers of participants entering the Scheme in the first year of transition (1 July 2016 to 30 June 2017), for whom a record of outcomes is available at Scheme entry (baseline), and approximately two years after Scheme entry (second review). The large majority of these families/carers also responded at one year after Scheme entry (first review). This cohort is referred to as the "B,R1,R2" cohort.
- Families/carers of participants entering the Scheme in the second year of transition (1 July 2017 to 30 June 2018), for whom a record of outcomes is available at Scheme entry (baseline), and approximately one year after Scheme entry (first review). This cohort is referred to as the "B,R1" cohort.

These two cohorts are distinct (that is, a family/carer contributing to the longitudinal analysis belongs to one cohort only).

It should also be noted that the longitudinal analysis is restricted to cases where the same person responded at each of the time points being considered.[9]

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[9] As far as can be ascertained from their relationship to the participant.

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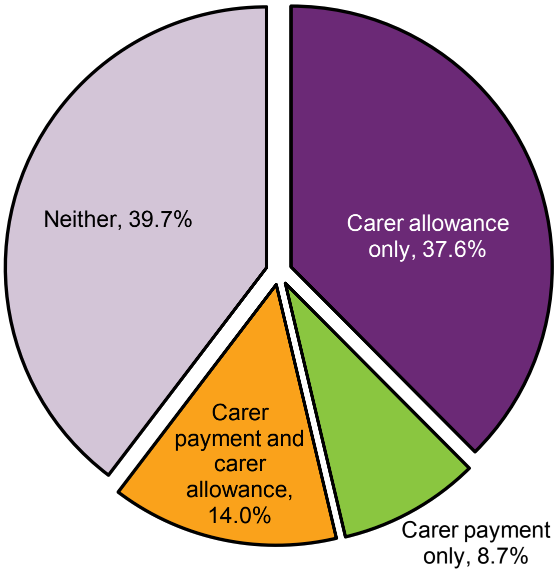
[12] Fact Sheet – New services for carers, Commonwealth of Australia (Department of Social Services) 2018 https://www.dss.gov.au/sites/default/files/documents/04_2018/fact_sheet_-_new_services_for_carers.pdf

[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.

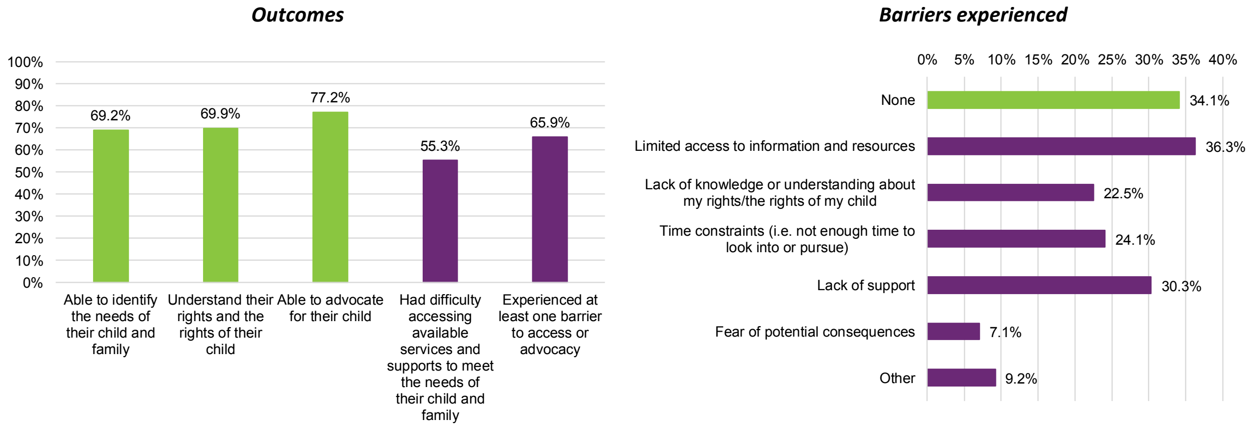
**Figure 2.1 Receipt of Carer Payment and Carer Allowance, families/carers of participants aged 0 to 14**[14]



## 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**

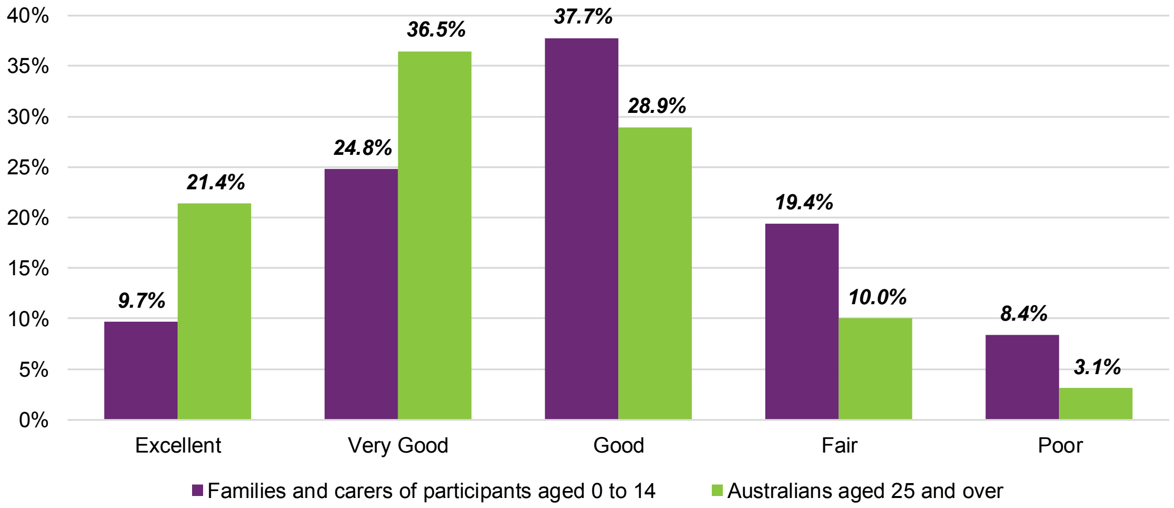
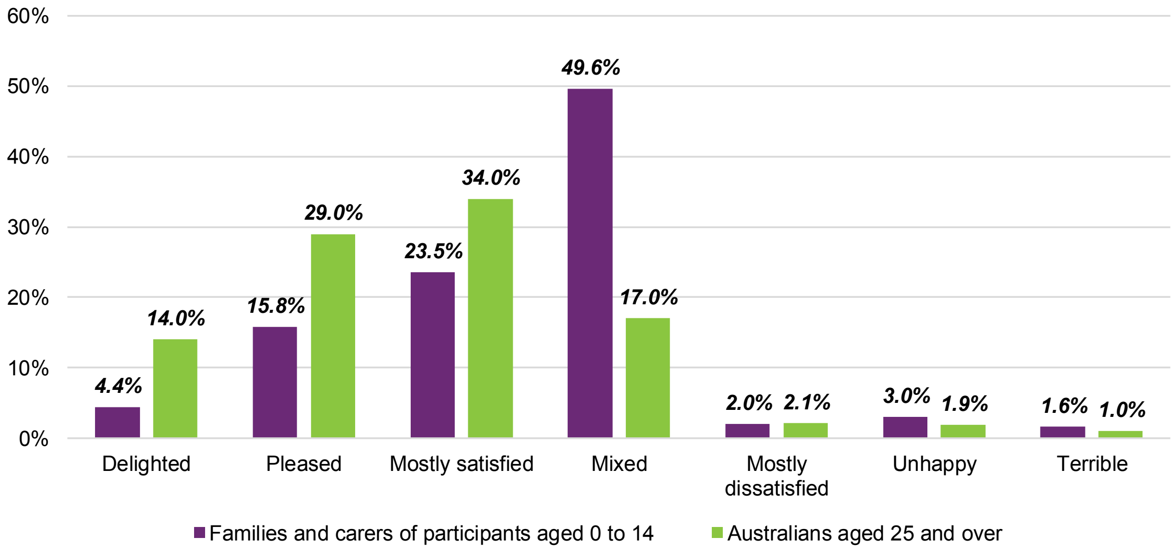


**Figure 2.4 Outlook for the future, families/carers of participants aged 0 to 14**



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**

| | Participant primary disability | | | | |
|---|---|---|---|---|---|
| **Outcome** | **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:**

| | Variable | | |
|---|---|---|---|
| Outcome | 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<br>Relationship with likelihood of | | Baseline to Second Review<br>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<br>Relationship with likelihood of | | Baseline to Second Review<br>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<br>Relationship with likelihood of | | Baseline to Second Review<br>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<br>Relationship with likelihood of | | Baseline to Second Review<br>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 | | Baseline to Second Review | |
|---|---|---|---|---|
| | Relationship with likelihood of | | 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 | ⬆ | | | |
| 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<br>Improvement | <br><br>Deterioration | Baseline to Second Review<br>Relationship with likelihood of<br>Improvement | <br><br>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 | | Baseline to Second Review | |
|---|---|---|---|---|
| | Relationship with likelihood of | | 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 | | Baseline to Second Review | |
|---|---|---|---|---|
| | Relationship with likelihood of | | 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<br>Improvement | <br><br>Deterioration | Baseline to Second Review<br>Relationship with likelihood of<br>Improvement | <br><br>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 | | Baseline to Second Review | |
|---|---|---|---|---|
| | Relationship with likelihood of | | 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<br>Relationship with likelihood of | | Baseline to Second Review<br>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 | | Baseline to Second Review | |
|---|---|---|---|---|
| | Relationship with likelihood of | | 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.

# 3. Families/carers of participants from birth to age 14: Has the NDIS helped?

## 3.1 Aggregate results

For participants entering the Scheme between 1 July 2016 and 30 June 2018, Figure 3.1 shows the percentage of families/carers who reported that the NDIS has helped with outcomes related to each of the six domains, after one year in the scheme (first review) and after two years in the scheme (second review).

**Figure 3.1 Percentage of families/carers who think that the NDIS has helped with outcomes**

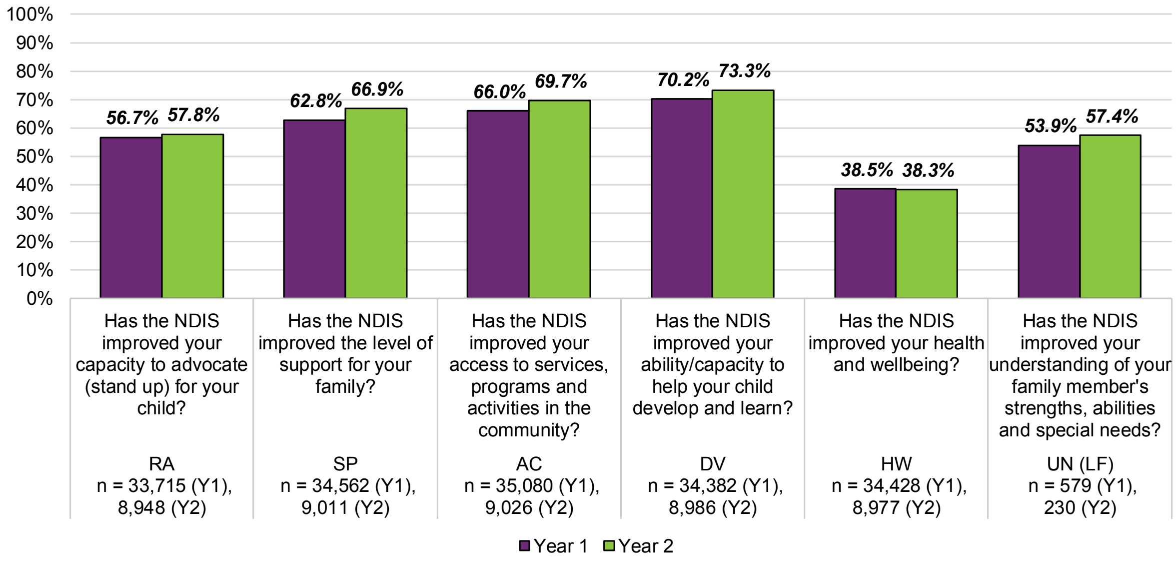


Figure 3.1 shows that opinions on whether the NDIS has helped vary considerably by domain for families/carers of participants aged 0 to 14. After approximately one year in the Scheme, there is widespread agreement that the NDIS has helped in areas related to the family/carer's capacity to help their child develop and learn (70.2%), and that the NDIS helped improve access to services, programs and activities in the community (66.0%). A slightly smaller percentage (62.8%) feel that the NDIS improved the level of support for their family, with 56.7% saying the NDIS improved their capacity to advocate for their child and 53.9% feeling the NDIS improved their understanding of their child's strengths, abilities and special needs. However, only 38.5% of families/carers felt that the NDIS helped improve their health and wellbeing.

Across all domains except health and wellbeing (HW), the percentage who think the NDIS helped is slightly higher for participants who have been in the Scheme for two years, compared to those who have been in the Scheme for one year.

**Figure 3.2 Percentage of families/carers who are satisfied with the amount of say they had about their child's NDIS plan**

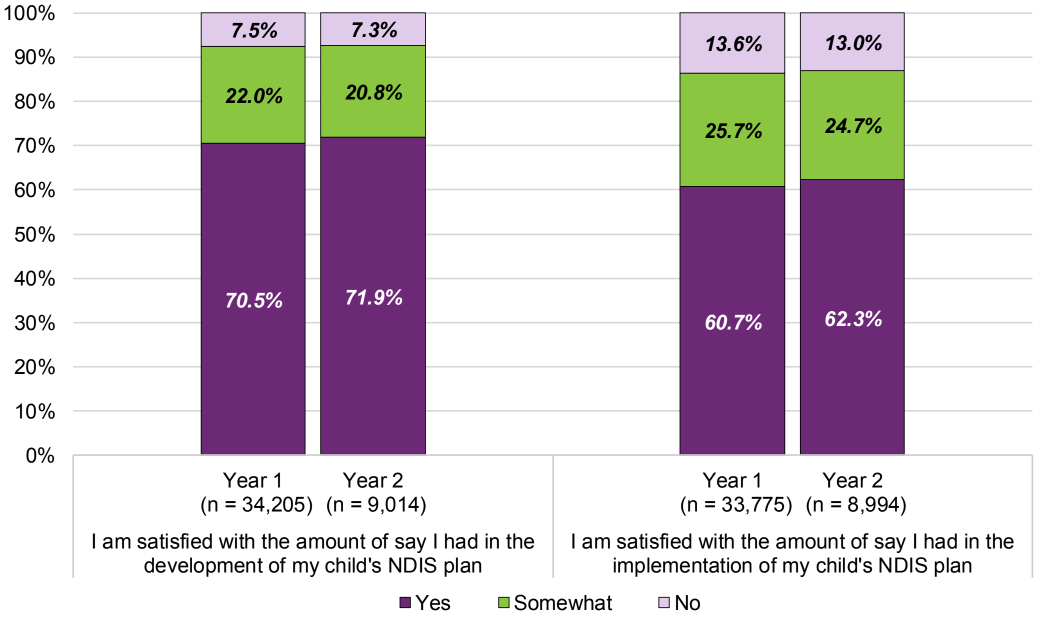


Figure 3.2 shows that families/carers tended to be more satisfied with the development of their child's plan (92.7% satisfied or somewhat satisfied after two years in the Scheme) than with its implementation (87.0% satisfied or somewhat satisfied after two years in the Scheme). The percentage of families/carers who said they were satisfied increased slightly between year one and year two for both questions, and fewer families/carers said they were somewhat satisfied.

## 3.2 Results by participant and family/carer characteristics

### 3.2.1 Year 1 'Has the NDIS Helped?' indicators – characteristics

Year 1 (first review) indicators have been analysed by participant and family/carer characteristics using one-way analysis and multiple regression.

Table 3.1 shows the relationship of different participant and carer characteristics with the likelihood of families/carers saying that the NDIS has helped, and with the likelihood that they are satisfied with the amount of say they had in the development and implementation of their family member's plan. A characteristic is included in the table if it has a significant relationship with at least two of the 'Has the NDIS Helped?' questions or one of the satisfication questions, and all significant relationships are in the same direction (for example, a characteristic with two significant and positive relationships with 'Has the NDIS Helped?' questions will be included, but a characteristic with three significant positive relationships and one significant negative relationship will not be).

**Table 3.1 Relationships of participant/carer characteristics with the likelihood of positive family/carer responses:**

| Characteristic | Relationship with: | |
|---|---|---|
| | Saying the NDIS has helped | Satisfaction with level of say about plan |
| Participant is older | ↓ | ↓ |
| Participant has a higher level of function | ↑ | ↑ |
| Higher annualised plan budget | ↑ | ↑ |
| Higher plan utilisation | ↑ | ↑ |
| Participant is CALD | ↑ | ↓ |
| Participant's disability is cerebral palsy or another neurological disability | ↓ | |
| Participant's disability is global developmental delay or developmental delay | ↑ | ↑ |
| Participant's disability is an intellectual disorder or Down syndrome | ↓ | ↓ |
| Participant's disability is autism | ↑ | ↓ |
| Participant received State/Territory supports before entering the NDIS | ↓ | |
| Participant had not received services from Commonwealth or State/Territory systems before entering the NDIS | ↑ | |
| Lives in NSW | ↓ | ↓ |
| Lives in QLD | ↑ | ↑ |
| Lives in SA | ↑ | |
| Lives in VIC | ↓ | ↓ |
| Lives in ACT, NT, TAS or WA | ↓ | |
| Plan is agency managed | ↓ | ↑ |
| Plan is self-managed | ↑ | ↑ |

| Characteristic | Relationship with: | |
|---|---|---|
| | Saying the NDIS has helped | Satisfaction with level of say about plan |
| **Plan is managed by a plan manager** | ⬇ | ⬇ |
| **Participant lives in a major city** | ⬆ | ⬇ |
| **Participant lives in a remote or very remote area** | ⬇ | |
| **Participant has a higher level of NDIA support** | ⬇ | ⬇ |
| **Participant lives in a private home owned by themselves or family** | | ⬆ |
| **Participant lives in a private home rented from a private landlord** | ⬇ | |
| **Participant lives in a private home rented from a public authority** | ⬇ | |
| **Less than 75% of supports are capacity building supports** | ⬇ | ⬇ |
| **More than 95% of supports are capacity building supports** | ⬆ | ⬆ |
| **Higher Index of Education and Occupation** | ⬆ | ⬇ |
| **Higher Index of Economic Resources** | ⬆ | ⬆ |
| **Carer remained in permanent employment** | ⬆ | ⬆ |
| **Carer's employment status changed from permanent to casual** | | ⬇ |
| **Participant entered the Scheme in 2016/17** | ⬇ | ⬇ |
| **Participant entered the Scheme in 2017/18** | ⬆ | ⬆ |

### Participant age

After controlling for other factors, families/carers of younger participants are more likely to think that the NDIS had helped, across all domains. One-way analysis shows a steep decrease in the positive response rate to all 'Has the NDIS helped?' questions at age 6, and steady decreases from ages 7 to 14. Key findings from the one-way analysis are as follows:

- Satisfaction with the amount of say in the implementation of their child's plan is significantly higher for families/carers of younger participants (74.3% for families/carers of participants aged 4, decreasing to 45.0% for families/carers of participants aged 14 or older)

- The percentage agreeing that the NDIS had improved their capacity to help their child develop and learn decreased significantly with participant age (from 88.8% for families/carers of participants aged 4 to 51.6% for families/carers of participants aged 14 or older)
- The percentage agreeing that the NDIS had improved their health and wellbeing was significantly higher for families/carers of participants aged 4 (53.0%) than for families/carers of older participants (30.7% for participants aged 14 or older).

### Level of function

Families/carers of participants with a higher level of function were more likely to agree that the NDIS had helped or that they were satisfied with the amount of say they had in the development or implementation of their child's plan.

The percentages of families/carers who are satisfied with the amount of say they had in the development and implementation of their child's NDIS plan exhibit the largest differences between participants with low and high levels of function. 63.3% of families/carers of participants with a low level of function are satisfied with the amount of say they had in the development of their child's NDIS plan, compared to 75.5% of families/carers of participants with a high level of function. 52.4% of families/carers of participants with a low level of function are satisfied with the amount of say they had in the implementation of their child's NDIS plan, compared to 66.2% of families/carers of participants with a high level of function.

Similarly, the percentage of families/carers who say the NDIS improved their capacity to help their child develop and learn is 63.3% for families/carers of participants with low levels of function compared to 74.2% for those of participants with high levels of function. Although not as pronounced, all other domains exhibit a similar trend. For example, the percentage who say the NDIS improved their capacity to advocate for their child is 7.6% higher for families/carers of participants with high levels of function (59.9%) than those of participants with low levels of function (52.3%). Likewise, the percentage of families/carers saying that the NDIS improved the level of support for their family is 7.5% higher for families/carers of participants with high levels of function (66.0%) than those of participants with low levels of function (58.5%).

### Plan budget

Multiple regression analysis indicates that, after controlling for other characteristics, families/carers of participants with a higher annualised plan budget were more likely to say that the NDIS had helped across all domains, and that they were satisfied with the development and implementation of their child's NDIS plan.

### Plan utilisation

Baseline plan utilisation was one of the most statistically significant predictors in six out of seven multiple regression models. Except for satisfaction with the development of their child's plan, families/carers of participants with higher plan utilisation were more likely to respond positively across all other domains.

One-way analyses are consistent with the regression modelling. Families/carers of participants with a plan utilisation rate of 80% were more likely to say that the NDIS improved their access to services (73.6%), their capacity to help their child develop and learn (79.2%), their health and wellbeing (43.5%), and their level of satisfaction with the amount of say they had in the implementation of their child's plan (65.1%). These percentages are markedly higher than those families/carers with a plan utilisation rate of 20% or lower (33.9%, 34.4%, 19.9% and 45.5%, respectively).

### CALD status

Both multiple regression analysis and one-way analysis shows that families/carers of participants from a CALD background are more likely to say that the NDIS has improved their capacity to advocate for their child, and has improved their health and wellbeing. However, they were less likely to be satisfied with the amount of say they had in the development and implementation of their child's NDIS plan.

61.6% of families/carers of CALD participants said the NDIS improved their capacity to advocate for their child, compared with 56.4% of families/carers of non-CALD participants. Similarly, 45.6% of families/carers of CALD participants said the NDIS improved their health and wellbeing, compared with 38.1% of families/carers of non-CALD participants.

Conversely, families/carers of CALD participants were less likely to be satisfied with the level of say they had in the development of their child's plan (64.8%, compared to 70.9% for families/carers of non-CALD participants), as well as the level of say they had in the implementation of their child's plan (56.4%, compared to 61.0% for families/carers of non-CALD participants).

### Disability type

After allowing for other factors, families/carers of participants with a developmental delay or a global developmental delay were consistently the most likely to say the NDIS had helped across all domains. 77.8% said the NDIS improved the level of support for their family (compared to 62.8% overall), 79.3% said the NDIS improved their access to services (66.0% overall), 86.6% said the NDIS improved their capacity to help their child develop and learn (70.2% overall), and 72.1% stated that the NDIS improved their capacity to advocate for their child (56.7% overall). This was also the only primary disability group for which a majority of families/carers found the NDIS improved their health and wellbeing (51.9% compared to 38.5% overall). They were also the most likely to be satisfied with the amount of say they had in the development (82.0% compared to 70.5% overall) and implementation (76.3% compared to 60.7% overall) of their child's NDIS plan.

Controlling for other factors, families/carers of participants with autism are similarly more likely to agree that the NDIS improved their capacity to advocate for their child and that the NDIS improved their ability to support their child's learning and development.

In comparison, families/carers of participants with cerebral palsy or another neurological disability tend to be less likely to think the NDIS has helped, with only 51.1% (56.7% overall) saying that the NDIS improved their capacity to advocate for their child, 57.9% (62.8% overall) saying the NDIS improved their level of support, 60.5% (66.0% overall) feeling the NDIS improved their access to services, and 34.1% (38.5% overall) feeling that the NDIS improved their health and wellbeing. Families/carers of participants with Down syndrome or an intellectual disability were less likely to be satisfied with the amount of say they had in the development (65.6% compared to 70.5% overall) or implementation (54.5% compared to 60.7% overall) of their child's NDIS plan.

One-way analysis also shows that a consistently lower percentage of families/carers of participants with visual impairment say the NDIS has helped, across all domains.

### Remoteness

Controlling for other factors, families/carers of participants living in major cities are more likely to agree that the NDIS has helped with their capacity to advocate for their child, has improved the level of support for their family, and has improved their access to services, programs and activities. Families/carers living in remote or very remote areas are less likely to agree (on a one-way basis: 43.8%, 50.3% and 50.3%, respectively, compared to 56.7%, 62.8% and 66.0% overall).

However, families/carers living in major cities are less likely to be satisfied with the amount of say in the implementation of their child's NDIS plan, with 60.0% responding positively to this question, compared to 63.2% of families/carers living in remote or very remote areas.

### Entry type

Families/carers of participants who were not receiving disability supports prior to entering the NDIS (were not a part of an existing State/Territory or Commonwealth scheme upon entry to the NDIS) tended to respond more positively when asked whether the NDIS helped. 75.5% of families of participants who did not receive disability supports prior to entering the NDIS said the NDIS improved their capacity to help their child develop and learn and 71.9% stated that the NDIS improved their access to services and programs within the community, compared to 65.2% and 61.3% respectively for families of participants who received services from State/Territory systems before entering the NDIS. Results for families/carers of participants who had previously received other Commonwealth disability supports were generally between results for those who are new and those who had previously received State/Territory supports.

### State/Territory

Families/carers of participants living in Queensland and South Australia tended to report more positive outcomes across all domains than those in New South Wales and Victoria.

For example, 71.1% of families/carers in Queensland reported that the NDIA helped improve their access to services, programs and activities in their community, while 63.0% of families living in New South Wales reported positively. Additionally, 79.4% of families/carers living in Queensland reported that they were satisfied with the level of say they had in developing their child's plan, compared to 67.6% of families/carers living in NSW.

### Plan management type

In multiple regression and one-way analysis, families/carers of participants with fully self-managed plans are more likely to be satisfied with the amount of say they had in the development and implementation of their child's plan, and are more likely to say that the NDIS had helped, across all domains. Meanwhile, families/carers of those with plan-managed or agency-managed plans were less likely to respond positively.

The largest differences between these two groups were for families feeling that the NDIA improved their capacity to help their child's learning and development (78.5% for families/carers of participants with fully self-managed plans, as opposed to 61.8% for families/carers of participants with plan-managed or agency-managed plans), and being satisfied with their level of say in the implementation of their child's plan (70.0% for families/carers of participants with fully self-managed plans, as opposed to 50.8% for families/carers of participants with plan-managed or agency-managed plans).

### Entry year

Families/carers of participants who entered the Scheme in 2017/18 were more likely to agree that the NDIS helped than those who entered the Scheme in 2016/17. In particular, families/carers of participants who entered later were more satisfied with the amount of say they had in development (72% for 2017/18 participants versus 67% for 2016/17 participants) and implementation (63% for 2017/18 participants versus 56% for 2016/17 participants) of their child's plan.

### Other characteristics

Families/carers of participants with a lower level of NDIA support with planning are more likely to say the NDIS has helped, and to be satisfied with the level of say they had about the development and implementation of their child's NDIS plan, whereas families/carers of participants with a higher level of NDIA support are less likely to respond positively.

A higher Index of Education and Occupation (IEO) is associated with more positive responses for most 'Has the NDIS helped' questions. However, a higher score on the IEO index was linked with lower satisfaction for families/carers with the level of say they had in the development and implementation of their child's plan.

A higher score on the Index of Economic Resources (IER) is associated with a higher likelihood of saying the NDIS helped with support for families/carers, saying the NDIS improved their capacity to support their child's development and that they are satisfied with their level of say in the development of their child's plan.

Families/carers who remained in permanent employment between baseline and first review were more likely to agree that the NDIS helped than those whose employment status changed from permanent to casual.

### Other responses – Supports and Services

Satisfaction rates were found to be correlated with responses to other questions, particularly those regarding supports and services. Figure 3.3 and Figure 3.4 show the difference to the population average "Yes" rate given responses to other selected outcomes framework questions. For example, 56.7% of all families/carers answered "Yes" to the question "Has the NDIS improved your capacity to advocate (stand up) for your child?". However, the positive response rate for those who were able to access available services and supports was 66.4%, 9.7% higher than the overall average. Conversely, the positive response rate for those who answered "No" to the question was 47.7% (9.0% lower than the overall average).

Shown in the figures are the supports and services outcomes that are most correlated with responses to the "Has the NDIS helped?" questions, as follows:

**Q1:** I am able to access available services and supports to meet the needs of my child and family

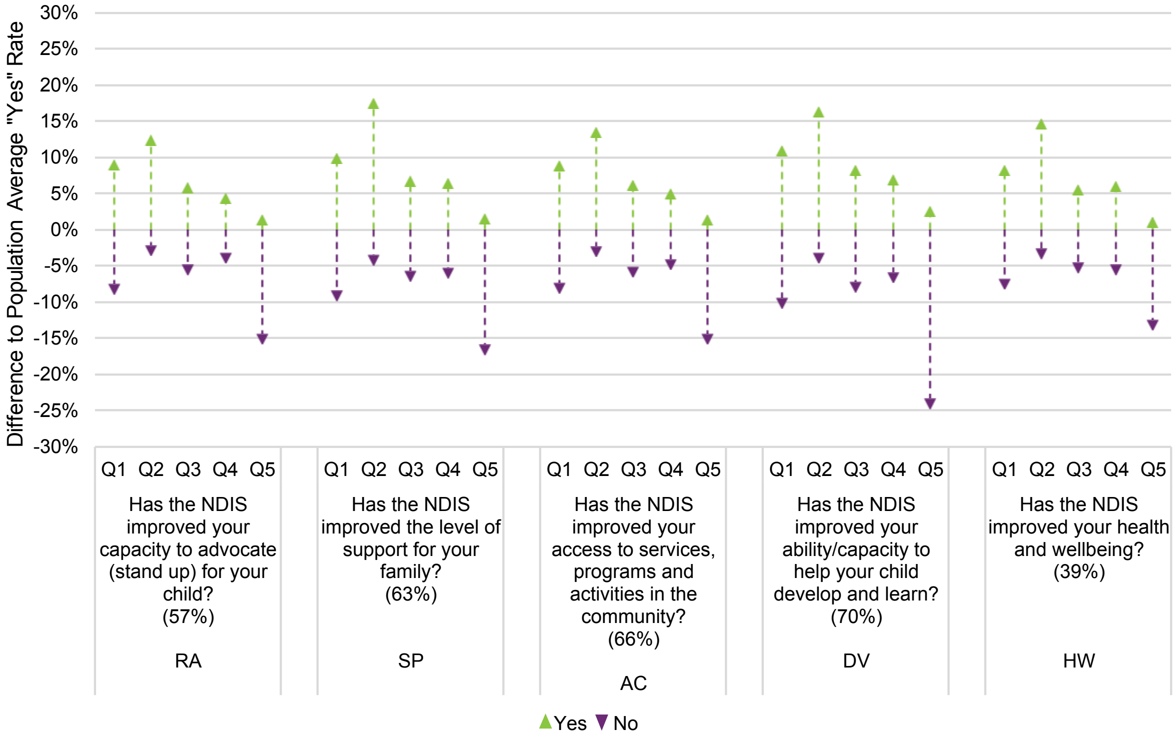
**Q2:** I get the services and supports I need to care for my child with disability

**Q3:** I know what specialist services are needed to promote my child's learning and development

**Q4:** I get enough support to feel confident in parenting my child

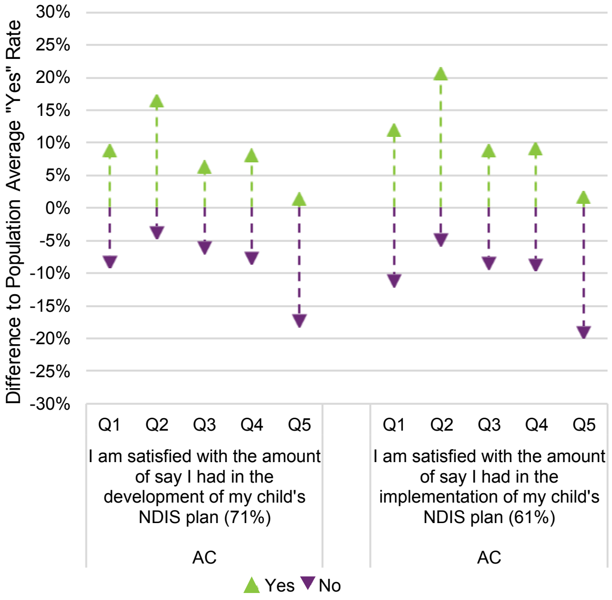
**Q5:** I am confident in supporting my child's development.

**Figure 3.3 Relationship between “Has the NDIS helped?” and other outcomes framework questions (see note below)**



**Note:** In the graphs above and below, the arrow pairs indicate the difference to the population average “yes” rate for the helped questions if the respondent has answered positively (green) or negatively (purple) to Q1 to Q5 as labelled above.

**Figure 3.4 Relationship between “Satisfaction with the amount of say” and other outcomes framework questions (see note above)**



### 3.2.2 Longitudinal ‘Has the NDIS Helped?’ indicators – participant and family/carer characteristics

Longitudinal change by participant and family/carer characteristics has been analysed in two ways:

1. A comparison of the percentage reporting that the NDIS has helped after two years in the Scheme with the percentage reporting that the NDIS had helped after one year in the Scheme. The difference (percentage after two years minus percentage after one year) is compared for different subgroups.
2. Multiple regression analyses modelling the likelihood of improvement/deterioration over the participant’s second year in the Scheme.

This section only considers families/carers who responded at both review 1 and review 2, and who have the same relationship to the participant at both time points. For example, if the respondent at review 1 is the participant’s mother, but the respondent at review 2 is the participant’s father, both responses are excluded from this analysis. Given this, the results and statistics presented below may differ slightly from those in previous sections.

#### “Has the NDIS helped?” by domain

Table 3.2 presents a summary of movements in family/carer responses to the “Has the NDIS helped?” questions, showing improvements and deteriorations, as well as net movements, between year one and year two.

**Table 3.2 Breakdown of net movement in family/carer responses to ‘Has the NDIS helped?’ outcome-based indicators**

| | Number of first review responses | | Improvements: No to Yes | | Deteriorations: Yes to No | | |
|---|---|---|---|---|---|---|---|
| **The NDIS has improved** | No | Yes | Number | % | Number | % | Net Movement |
| **My Capacity to advocate for my child (RA)** | 3,268 | 3,967 | 697 | 21.3% | 429 | 10.8% | +3.7% |
| **The level of support for my family (SP)** | 2,808 | 4,620 | 865 | 30.8% | 446 | 9.7% | +5.6% |
| **My access to services, programs and activities in the community (AC)** | 2,622 | 4,943 | 885 | 33.8% | 487 | 9.9% | +5.3% |
| **My ability/capacity to help my child develop and learn (DV)** | 2,162 | 5,245 | 597 | 27.6% | 342 | 6.5% | +3.4% |
| **My health and wellbeing (HW)** | 4,586 | 2,804 | 614 | 13.4% | 552 | 19.7% | +0.8% |

The percentage of families/carers whose response improved is higher than the percentage whose response deteriorated across all domains except health and wellbeing.

**Table 3.3 Relationships of characteristics with the likelihood of improvement and deterioration in helped responses (statistically significant for more than 2 transitions).**

| | Relationship with | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | Improvement in helped question domain | | | | | Deterioration in helped question domain | | | | |
| Characteristic | RA | SP | AC | DV | HW | RA | SP | AC | DV | HW |
| Participant is older | ⬇ | ⬇ | ⬇ | ⬇ | ⬇ | | | | ⬆ | |
| Higher plan utilisation | ⬆ | ⬆ | ⬆ | ⬆ | ⬆ | ⬇ | | | ⬇ | |
| Participant lives in: | | | | | | | | | | |
| NSW | | | | | | | ⬆ | ⬆ | | ⬆ |
| VIC | | | ⬇ | ⬇ | | | | | | |
| QLD | | ⬆ | ⬆ | ⬆ | | ⬆ | | ⬇ | | |
| SA | ⬆ | ⬆ | | ⬆ | | | | ⬆ | | ⬆ |
| Other | ⬇ | ⬇ | | ⬇ | | | | ⬇ | | |
| Carer's employment status: | | | | | | | | | | |
| Remained permanent | | | | | | | | ⬇ | ⬇ | |
| Remained casual | | | | | | | ⬇ | ⬇ | ⬇ | ⬇ |
| Changed from permanent | | | | | | | ⬆ | | ⬆ | ⬆ |
| Participant has a higher level of function | ⬆ | | | | | ⬇ | ⬇ | | | |
| Higher Index of Education and Occupation | | ⬆ | | ⬆ | | ⬇ | | | | ⬇ |
| Prior to entering the NDIS, the participant: | | | | | | | | | | |
| Received Commonwealth supports | | ⬇ | ⬇ | | | | | | | |
| Received State/Territory supports | | ⬆ | ⬆ | | | | | | ⬇ | |
| Did not receive Commonwealth or State/Territory supports | | | | | | | | | ⬆ | |
| Participant's plan is: | | | | | | | | | | |
| Fully self-managed | | | ⬇ | | | | | | | |
| Managed by a plan manager | | | | ⬆ | | | | | ⬇ | ⬇ |
| Fully agency-managed | | | | ⬇ | | | | ⬆ | ⬆ | ⬆ |

Commonly observed themes across most questions are:

- Families/carers of participants with higher baseline plan utilisation were more likely to improve and were less likely to deteriorate
- Families/carers of younger participants were more likely to improve and less likely to deteriorate
- Families/carers that changed employment status from permanent to casual were more likely to deteriorate

Characteristics other than those in Table 3.3 that were found to be significant to specific questions are described below.

### *The NDIS has improved my capacity to advocate for my child*

The percentage of families/carers reporting that the NDIS improved their capacity to advocate for their child increased by 3.7%, from 54.8% to 58.5%, between the first and the second review.

Responses of families/carers who started paid work were more likely to deteriorate.

### *The NDIS has improved the level of support for my family*

The percentage of families/carers reporting that the NDIS improved the level of support for their family increased by 5.6%, from 62.2% to 67.8%, between the first and the second review.

Responses were less likely to deteriorate for:

- Families/carers of participants with a higher annualised plan budget
- Families/carers of participants with global developmental delay or developmental delay disabilities

Conversely, responses were more likely to deteriorate for:

- Families/carers of participants with cerebral palsy or another neurological disability

### *The NDIS has improved my access to services, programs and activities in the community*

The percentage of families/carers reporting that the NDIS improved their access to services, programs and activities in the community increased by 5.3%, from 65.3% to 70.6%, between the first and second review.

Responses for families/carers of participants whose plans contain more than 95% capacity building supports were less likely to deteriorate, while responses from family/carers of participants with plans with less than 75% capacity building supports were more likely to deteriorate. Responses for families/carers of non-Indigenous participants were also less likely to deteriorate.

### *The NDIS has improved my ability/capacity to help my child develop and learn*

The percentage of families/carers reporting that the NDIS improved their ability/capacity to help their child develop and learn increased by 3.4%, from 70.8% to 74.3%, between the first and second review.

Families/carers of participants with a global developmental delay or developmental delay disability were more likely to improve their response, while families/carers of participants with autism, an intellectual disability or Down syndrome were less likely to improve.

### *The NDIS has improved my health and wellbeing*

The percentage of families/carers reporting that the NDIS improved their health and wellbeing increased by 0.8%, from 37.9% to 38.8%, between the first and second review.

Responses from families/carers of participants with plans with higher total annualised funding or plans with more than 95% of supports that are capacity building supports were more likely to improve. Conversely, responses from families/carers of participants with plans with more than 5% of supports that are capital supports were less likely to improve.

Responses from families/carers of Indigenous participants were more likely to deteriorate compared to those from families/carers of non-Indigenous participants.

Responses from families/carers of participants living in regions with a higher Index of Economic Resources (IER) were more likely to deteriorate.

## Satisfaction with the amount of say in the development/implementation of child's plan

Table 3.4 presents a summary of movements in family/carer satisfaction with the development and implementation of their child's plan, showing improvements, deteriorations and net movements between first and second review. The statistics in Table 3.4 are for the cohort with responses at both first and second review, and thus differ slightly from those in Figure 3.1. Table 3.5 shows the relationships of participant characteristics with the likelihood of improvement and deterioration in family/carer satisfaction with the amount of say in the development and implementation of the participant's plan. Characteristics are included when they are significant ($p<0.05$) predictors in the multiple-regression model.

**Table 3.4 Breakdown of net movement in family/carer satisfaction with the amount of say in the development and implementation of the participant's plan**

| Satisfaction with amount of say in | Number of first review responses | | Improvements: No to Yes | | Deteriorations: Yes to No | | Net Movement |
|---|---|---|---|---|---|---|---|
| | No | Yes | Number | % | Number | % | |
| **The development of my child's NDIS plan** | 2,378 | 5,049 | 914 | 38.4% | 511 | 10.1% | +5.4% |
| **The implementation of my child's NDIS plan** | 3,059 | 4,276 | 922 | 30.1% | 503 | 11.8% | +5.7% |

**Table 3.5 Relationships of characteristics with the likelihood of improvement and deterioration in family/carer satisfaction with the amount of say in the development and implementation of the participant's plan**

| | Relationship with | | | |
|---|---|---|---|---|
| | Improvement in satisfaction with amount of say in | | Deterioration in satisfaction with amount of say in | |
| Characteristic | Development | Implementation | Development | Implementation |
| Participant has a higher level of function | ↑ | ↑ | ↓ | ↓ |
| Participant is older | ↓ | ↓ | | |
| Higher plan utilisation | | ↑ | | ↓ |
| Participant is CALD | ↓ | ↓ | | |
| Participant lives in: | | | | |
| NSW | | | ↑ | ↑ |
| VIC | ↓ | ↓ | | |
| QLD | ↑ | ↑ | | |
| SA | | | ↑ | |
| Other | | | ↓ | |
| Plan has supports that are: | | | | |
| More than 95% capacity building | | ↑ | | |
| Less than 75% capacity building | ↓ | ↓ | | |
| Participant lives in: | | | | |
| A major city | | | ↑ | |
| Participant's plan is: | | | | |
| Fully self-managed | | ↑ | | |
| Fully agency-managed | | ↓ | | |

Commonly observed themes for family/carer satisfaction with the amount of say in the development and implementation of the participant's plan are:

- Families/carers of participants with higher levels of function were more likely to improve and less likely to deteriorate
- Families/carers of younger participants are more likely to improve
- Families/carers of participants with higher baseline plan utilisation were more likely to improve their level of satisfaction with the amount of say they had in the implementation of their child's plan
- Families/carers of CALD participants were less likely to improve

# 4. Families/carers of participants from age 15 to 24: overview of results

## 4.1 Key findings

**Box 4.1: Overall findings for families/carers of participants from age 15 to 24, 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.
- Some large improvements were seen in families/carers’ satisfaction with services. The percentage of families/carers who said that the services they receive for their family member with disability meet their needs increased from 18.0% at baseline to 37.5% at second review, while the percentage of families/carers who felt that the services they use listen to them increased from 66.5% at baseline to 73.8% at second review. The percentage who say that the services help them to plan for the future increased from 63.5% at baseline to 68.3% at second review.
- Improvements were also observed in families/carers’ ability to promote the independence of their family member with disability. The percentage of families/carers who enable their family member with disability to make more decisions increased from 58.6% at baseline to 62.1% at second review.
- Families/carers expressed increased confidence about the future of their family member with disability under the NDIS, from 52.9% at baseline to 70.6% at second review. The percentage who strongly agree or agree that their family member gets the support he/she needs also increased, from 32.5% at baseline to 51.5% at second review.
- The percentage of families/carers in a paid job increased from 51.8% at baseline to 53.9% at second review.
- The percentage of families/carers in a paid job who work 15 hours or more has increased from 82.7% at baseline to 88.0% at second review.
- There was a decline in the percentage of families/carers who rated their health as excellent, very good or good, from 64.6% at baseline to 55.9% at second review.
- Of families/carers unable to work as much as they want, the percentage who say the situation of their family member with disability is a barrier to working more increased from 89.2% at baseline to 93.6% at second review.

### Box 4.2: Overall findings for families/carers of participants from age 15 to 24, who joined the scheme between 1 July 2017 and 30 June 2018

- Significant improvements were observed in the access to services domain. The percentage of families/carers who said that the services they receive for their family member with disability meets their needs increased from 17.6% at baseline to 25.0% at first review. A similar improvement was observed in the percentage of families/carers who feel that the services they use for their family member with disability listen to them (62.9% at baseline versus 67.4% at first review). The percentage who say that the services help them to plan for the future increased from 54.6% at baseline to 73.0% at first review.
- Families/carers were more confident about the future of their family member with disability under the NDIS, from 46.2% at baseline to 60.8% at first review. The percentage who strongly agree or agree that their family member gets the support he/she needs also increased, from 34.4% at baseline to 51.1% at first review.
- Family/carer outcomes in the health and wellbeing domain deteriorated. In particular, the percentage of families/carers who rate their health as excellent, very good or good declined from 60.9% at baseline to 57.5% at first review. As with the 0 to 14 cohort, since health tends to decline with age, some deterioration in the health rating is expected.
- The percentage of families/carers in a paid job increased from 51.7% at baseline to 53.3% at first review, and the percentage working 15 hours or more per week increased from 84.5% to 86.2%.
- Of families/carers unable to work as much as they want, the percentage saying that insufficient flexibility of jobs is a barrier to working more increased from 32.4% at baseline to 35.2% at first review.

### Box 4.3: Outcomes by key characteristics for families/carers of participants from age 15 to 24

- For the majority of indicators, baseline outcomes are better for families/carers of participants with a high level of function
- Families/carers of participants with a hearing or visual impairment generally experience better outcomes at baseline. In contrast, families/carers of participants with psychosocial disability tend to fare worse.
- Baseline outcomes for families/carers of participants from CALD backgrounds tend to be worse, particularly on advocacy and independence. Furthermore, regression modelling of longitudinal outcomes suggests that families/carers from CALD backgrounds are less likely to see improvements in health and wellbeing between baseline and second review.
- Results for families/carers of Indigenous participants are mixed. This group is less likely to be in paid employment and to report that the services they use listen to them, but more likely to have people who can provide practical help.
- Families/carers of older participants tend to exhibit better outcomes at baseline, particularly in domains relating to employment and participant independence. However, regression modelling suggests that this group is less likely to see improvements in health and wellbeing.
- Results for families/carers in regional and remote locations are mixed. This group tends to do better on indicators related to advocacy, feeling supported and helping the participant become more independent. Some employment indicators such as being able to work as much as preferred are also better. However, other employment indicators are worse; in particular, some barriers to working more, such as insufficient flexibility of jobs, are more commonly cited.
- Families/carers living in Queensland or South Australia are more likely to report improvements in the access to services domain. This is in contrast to families/carers living in New South Wales or Victoria, who are less likely to report improvements.
- Families/carers with self-managed plans (fully or partly) experience more positive outcomes at baseline on some indicators, namely within the advocacy and feeling supported domains. Moreover, oneway analysis and longitudinal modelling suggest that this group of respondents is more likely to report positive outcomes at first review.
- Families/carers with strong social connections are more likely to enable their participant to become more independent.
- Families/carers with higher plan utilisation reported more positive longitudinal outcomes in the employment and access to services domains.
- Outcomes in the access to services and health and wellbeing domains, for families/carers of participants who rate their own health as fair or poor, tend to deteriorate between baseline and first review.
- Carers who reduced their hours of work were less likely to show improvements in outcomes, across most domains.

## Box 4.4: Has the NDIS helped families/carers of participants from age 15 to 24?

- The percentage of families/carers reporting that the NDIS helped after two years in the Scheme was higher across all domains than the percentage of families/carers reporting that the NDIS helped after one year in the Scheme.
- After one year in the Scheme (first review), families/carers of older participants or those with higher baseline plan utilisation were more likely to say that the NDIS has helped. Similarly, families/carers of participants with self-managed plans or with a higher annualised plan cost were more likely to report positive outcomes at first review. On the other hand, families/carers of participants who required a higher level of NDIA support were less likely to report positive outcomes.
- Families/carers of participants with autism or Down syndrome were more likely to say that the NDIS helped at first review. In contrast, families/carers of participants with a visual impairment were less likely to respond positively.
- The percentage of families/carers reporting that the NDIS improved the level of support for their family increased 5.3%, from 58.0% to 63.3% between first and second review. Families/carers of participants with higher baseline plan utilisation were most likely to report improvements.
- The percentage of families/carers stating that the NDIS improved their access to services, programs and activities in their community increased from 55.9% at first review to 62.2% at second review. Families/carers of younger participants or those with higher baseline plan utilisation were most likely to report improvements in this domain.
- The percentage of families/carers reporting that the NDIS helped them know their rights and advocate effectively improved 4.3%, from 46.0% at first review to 50.3% at second review. Responses of families/carers were more likely to improve for participants from Queensland or South Australia, while responses were less likely to improve for families/carers of participants with a lower level of function.

## 4.2 Results overview

### 4.2.1 Outcomes framework questionnaire domains

For families/carers of participants aged 15 to 24, the outcomes framework seeks to measure the extent to which they:

- Know their rights and advocate effectively for their family member 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 young person to become independent (IN)
- Enjoy health and wellbeing (HW).

The LF survey for families/carers of participants aged 15 to 24 also includes 4 questions on whether families/carers understand their family members strengths, abilities and special needs, and includes several additional questions on health and wellbeing that focus on their outlook for the future and ability to meet costs of everyday living.

### 4.2.2 Baseline indicators – aggregate

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

For families/carers of participants aged 15 to 24, 27.7% were receiving Carer Payment and 50.9% were receiving Carer Allowance at baseline.

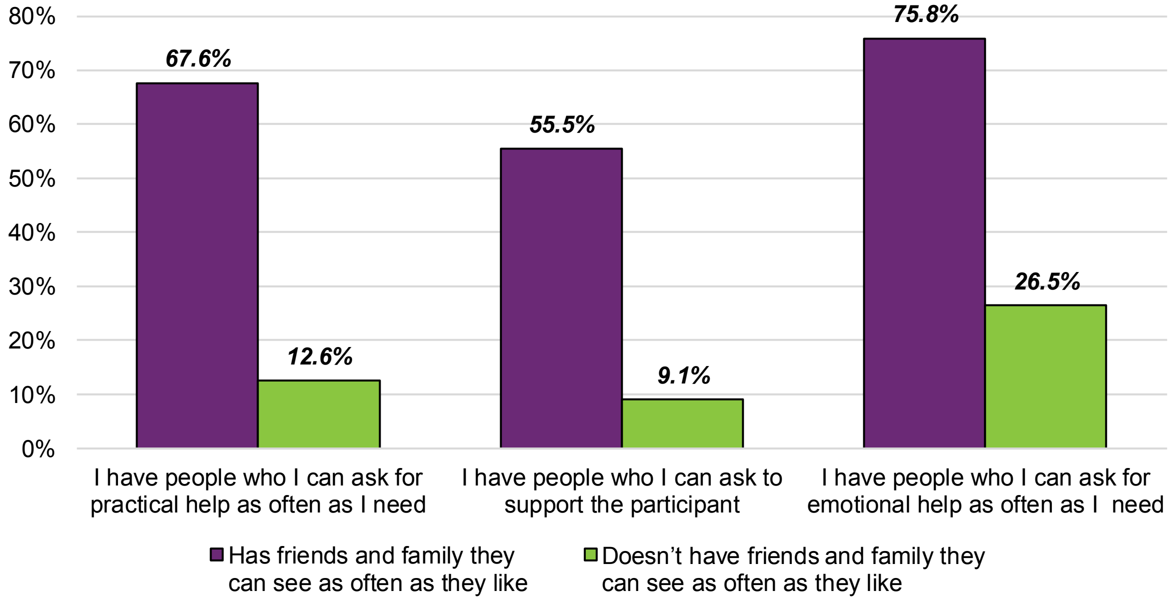
#### Rights and advocacy

47.1% of families/carers were able to identify the needs of the participant and family and knew how to access available services and supports to meet those needs. Furthermore, the majority (70.8%) was able to advocate (stand up) for the participant in case of issues or problems with accessing supports.

#### Families feel supported

As with families/carers for participants from birth to age 14, most families say they lack sufficient support or social connections. In the SF, 42.9% had friends and family that they saw as often as they liked. A slightly higher percentage of families/carers (47.7%) had someone who they could ask for emotional support as often as they needed. The percentage of families/carers who had people they could ask for practical help as often as they needed was lower, at 36.2%. Similarly, 29.0% had people they could ask to support the participant as often as they needed. However, having family and friends that the respondent could see as often as they liked increased the likelihood of receiving emotional and practical support. This relationship is illustrated in Figure 4.1.

**Figure 4.1 Feeling supported outcomes for families/carers of participants aged 15 to 24**



## Access to Services

40.6% of families/carers felt in control in selecting services and supports for their family member with disability. The percentage who felt that services listened to them was higher, at 64.5%. Rating services on the whole, at baseline 18.3% stated that the services met their needs.

## Independence of family member with disability

41.0% of families/carers knew what their family could do to enable the participant to become as independent as possible. 45.3% of families/carers enabled the participant to interact and develop strong relationships with non-family members, while 57.2% enabled their family member with disability to make more decisions in their life.

## Families understand the strengths, abilities and special needs of their family member

The LF includes an additional domain concerned with how families/carers perceive the strengths and abilities of their family member with disability, and how their family member is progressing. 85.4% of families/carers can recognise the strengths and abilities of the participant and 74.8% can see how the participant is progressing.

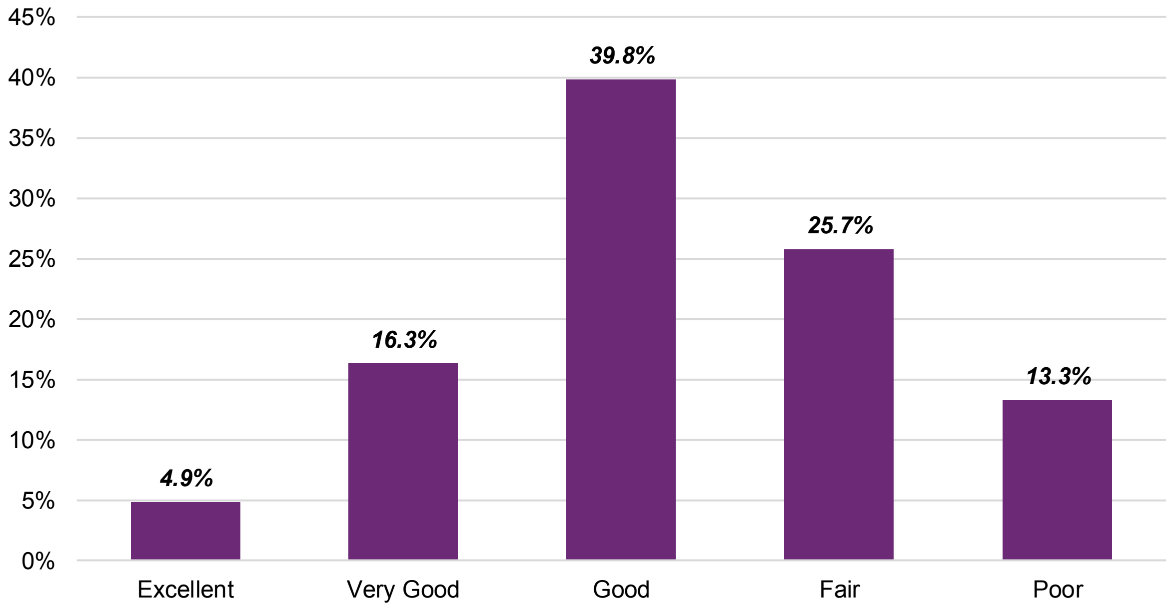
## Employment

At baseline, 49.3% of families/carers are in a paid job and 46.5% of families/carers say that they are able to work as much as they want. Of the families/carers who do not work as much as they want, 89.8% identified the situation of their family member with disability as a barrier to working more, and 29.1% said that insufficient flexibility of jobs was a barrier.

## Health and wellbeing

At baseline, 61.0% of families/carers rate their health as good, very good or excellent, considerably lower compared to 86.6% of Australians aged 25 to 64 overall[31]. Figure 4.2 shows how the respondents rated their health at baseline.

**Figure 4.2 Distribution of family/carer self-rated health ratings at baseline**



The LF includes a number of extra questions asking about the wellbeing of families/carers and their outlook on life generally, and for their family member with disability in particular. The results are slightly worse than those of the families/carers of participants from birth to age 14. Respondents most commonly had "mixed" feelings about the future (44.5%), although more answered positively (44.0%) than negatively (11.5%)[32]. The 44.0% responding positively is much lower than the 77% for Australians aged 25 to 64 overall[33], and is lower than for families/carers of participants aged 25 and over (50.3%).

With regard to their family member with disability, 71.8% agreed or strongly agreed that having a child with disability made it more difficult to meet everyday costs of living. 53.8% agreed or strongly agreed that they feel more confident about the future of their family member with disability under the NDIS, with 40.7% feeling neutral about this statement and only 5.6% expressing a negative opinion. 34.7% agreed or strongly agreed that the family member gets the support he/she needs, and 36.9% responded neutrally. A slightly higher percentage of respondents agreed or strongly agreed that the services help them to better care for their family member with disability (38.5%), and 44.4% responded as "neutral".

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[31] ABS National Health Survey (NHS) 2017-18.

[32] Excluding "don't know" and missing responses.

[33] 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.

### 4.2.3 Baseline indicators – key characteristics

Baseline indicators have been analysed by key characteristics of the participant and the family member/carer using one-way analyses and multiple logistic regression modelling. Key findings from these analyses include:

#### Participant disability type

Families/carers of participants with a hearing or visual impairment are more likely to report positive outcomes across all domains compared to participants with other disabilities. For example, 65.5% of families/carers of participants with a hearing impairment and 55.9% of families/carers of participants with a visual impairment have people who they can ask for emotional help as often as they need. By contrast, 45.3% and 38.3% of families/carers of participants with autism and psychosocial disability, respectively, have people who they can ask for emotional help as often as they need.

A similar pattern is shown in Figure 4.2 regarding having people to ask for practical help as often as needed.

**Figure 4.2 Percentage of families/carers who have people they can ask for practical help as often as they need by participant disability type**

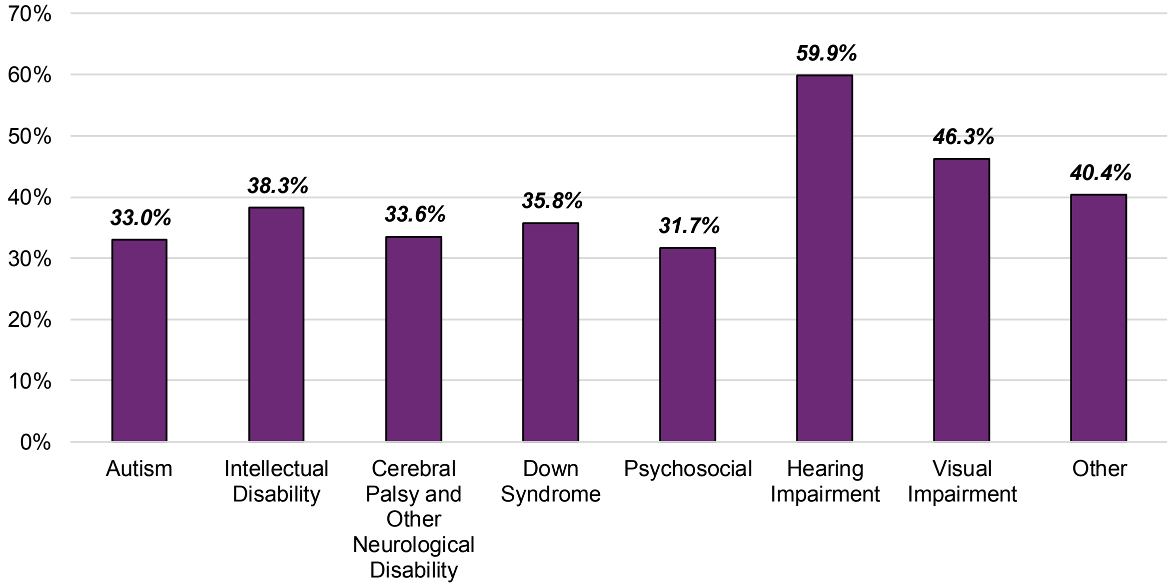

Figure 4.2 shows that 31.7% of families/carers of participants with a psychosocial disability have people who they can ask for practical help as often as they need, lower than the overall average of 36.2%. In addition to the outcomes highlighted above, the percentage who feel in control selecting the services and supports for their family member with disability is lower than average (27.1% compared with 40.6% overall).

The health and wellbeing of families/carers also varies by the participant's disability type. The percentage of families/carers of participants with a hearing or visual impairment who rate their health as excellent, very good or good is higher than the average (74.7% and 69.1% compared with 61.0% overall). By contrast, only 55.8% of families/carers of participants with psychosocial disability and 58.4% of families/carers of participants with autism rate their health as excellent, very good or good.

A higher percentage of families/carers of participants with a hearing impairment or a visual impairment say they enable and support their family member with a disability to make more decisions in their lives (69.7% and 68.8%, respectively). This is considerably higher than the percentage of families/carers of participants with autism or psychosocial disability (55.2% and 46.8%, respectively).

Table 4.1shows baseline family/carer outcomes for which selected participant primary disability types are significant ($p<0.05$) predictors in the multiple-regression model.

**Table 4.1 Relationship of disability type with the likelihood of selected outcomes**

| Outcome | Participant primary disability | | | | |
|---|---|---|---|---|---|
| | Autism | Hearing impairment | Intellectual disability | Psychosocial disability | Cerebral palsy |
| Being in a paid job | | | ⬇ | | |
| 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 the family and family member with disability | ⬇ | | ⬇ | ⬇ | |
| 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 to support their family member with disability as often as needed | ⬇ | ⬆ | ⬇ | ⬇ | |
| Having people they can talk to for emotional support as often as needed | ⬇ | ⬆ | ⬇ | ⬇ | |
| Feeling the services they and their family member with disability use listen to them | ⬇ | ⬆ | ⬇ | ⬇ | ⬇ |

| Outcome | Participant primary disability | | | | |
|---|---|---|---|---|---|
| | Autism | Hearing impairment | Intellectual disability | Psychosocial disability | Cerebral palsy |
| **Feeling in control of selecting the services and supports that meet the needs of their family member with disability** | ⬇ | | ⬇ | ⬇ | ⬆ |
| **Saying the services for them and their family member with disability meet their needs** | ⬇ | ⬆ | ⬇ | ⬇ | |
| **Knowing what they can do to enable their family member with disability to become more independent** | ⬇ | ⬆ | ⬇ | ⬇ | ⬆ |
| **Enabling and supporting their family member with disability to make more decisions in their life** | ⬇ | | ⬇ | ⬇ | ⬆ |
| **Enabling and supporting their family member with disability to develop strong relationships with non-family members** | ⬇ | | ⬇ | ⬆ | |
| **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** | | ⬇ | | | |

### Participant age

Most family/carer outcomes tend to vary with participant age, particularly relating to education and employment. Generally, outcomes are better for families/carers of older participants, especially after controlling for other factors (see Table 4.2 below).

On a one-way basis the percentage who are able to work as much as they want increases from 42.9% for families/carers of participants aged under 18, to 48.5% for families/carers of participants aged 18 to 21, and 51.3% for families/carers of participants aged 22 to 24. For those who are facing barriers to working more, the percentage who see job flexibility as a barrier declines from 32.6% for families/carers of participants aged under 18 to 24.0% for families/carers of participants aged 22 to 24. On the other hand, the percentage who are currently studying declines from 7.5% for family/carers of participants aged under 18 to 4.5% for family/carers of participants aged 22 to 24.

As the ability to be independent becomes more important with age, the support of family/carers to help the participant develop necessary skills increases. In particular, families/carers of older participants are more likely to know what their family can do to enable the participant to become as independent as possible (39.1% for family/carers of participants aged under 18, 41.4% for family/carers of participants aged 18 to 20, and 44.6% for family/carers of participants aged 21 to 24).

Table 4.2 shows baseline family/carer outcomes of which participant age is a significant (p<0.05) predictor in the multiple-regression model. Table 4.2 is located at the end of the 'CALD status' section below.

### CALD status

Families/carers of participants from CALD backgrounds are less likely to work (42.0% versus 49.8% for those from non-CALD backgrounds), however they are more likely to be undertaking study (8.3% versus 6.2%). This group of respondents exhibits worse outcomes on advocacy and independence. In particular, the percentage who are able to advocate (stand up) for the participant if they have issues or problems accessing supports is 46.5%, compared to 72.4% for non-CALD respondents. Also, the percentage who enable the participant to make more decisions in their life is considerably lower (40.6% versus 58.0%).

Table 4.2 shows baseline family/carer outcomes for which participant CALD status is a significant (p<0.05) predictor in the multiple-regression model.

**Table 4.2 Relationship of participant age and CALD status with the likelihood of selected baseline outcomes**

| | Variable | |
|---|---|---|
| **Outcome** | **Participant is older** | **Participant is CALD** |
| **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 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 the family and family member with disability** | | ⬇ |
| **Having friends they can see as often as they'd like** | ⬆ | ⬇ |

| Outcome | Variable | |
|---|---|---|
| | Participant is older | Participant is CALD |
| Having people they can ask for practical help as often as needed | ⬆ | ⬇ |
| Having people they can ask to support their family member with disability as often as needed | ⬆ | ⬇ |
| Having people they can talk to for emotional support as often as needed | ⬆ | ⬇ |
| Feeling the services they and their family member with disability use listen to them | ⬆ | |
| Feeling in control of selecting the services and supports that meet the needs of their family member with disability | ⬆ | ⬇ |
| Saying the services for them and their family member with disability meet their needs | ⬆ | ⬇ |
| Knowing what they can do to enable their family member with disability to become more independent | ⬆ | ⬇ |
| Enabling and supporting their family member with disability to make more decisions in their life | ⬆ | ⬇ |
| Enabling and supporting their family member with disability to develop strong relationships with non-family members | ⬆ | ⬇ |
| 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 insufficient flexibility of jobs being a barrier to working more | ⬇ | ⬇ |

## Indigenous status

After controlling for other factors, participant Indigenous status was a significant factor in only one of 24 regression models of family/carer baseline outcomes (more likely to have people they can ask for practical help as often as needed). This may be partly due to small numbers.

On a one way basis, families/carers of Indigenous participants are less likely to be the parents of the participant (76.5% for Indigenous compared to 93.5% for non-Indigenous). In employment related indicators, they are less likely to be working in a paid job (33.8% compared to 50.5%) and of those who want to work more, they are more likely to say the situation of their family member with a disability is a barrier (90.5% compared to 86.4%), and that available jobs do not have sufficient flexibility (34.6% compared to 28.1%).

Outcomes in the support domain, on a one way basis, are slightly better for families/carers of Indigenous participants. In particular, the percentage who have people they can ask for practical help is 41.8%, compared to 35.3% for families/carers of non-Indigenous participants. On the other hand, fewer families/carers of Indigenous participants feel that the services they use listen to them (59.3% compared to 65.6%).

### Participant level of function and annualised plan budget

For the majority of indicators, outcomes are better for families/carers of participants with a higher level of function. The likelihood of families/carers being able to work as much as they want increases with participant level of function, from 34.1% for families/carers of participants with low level of function, to 49.9% for families/carers of participants with medium level of function, and 59.8% for families/carers of participants with high level of function. Additionally, the social connection and support that families/carers receive tend to vary considerably with level of function. For example, the percentage who have friends that they see as often as they like increases from 28.3% where the participant has low level of function, to 46.9% for medium level of function, and 59.3% for high level of function. Furthermore, the percentage of family members/carers who have people they can ask for emotional support, practical help, and to support the participant increases with participant level of function. The indicators related to helping the participant become more independent also differ by level of function. Families/carers are more likely to know what their family can do to enable the participant to become as independent as possible for participants with higher level of function.

Outcomes for families/carers of participants with lower annualised plan budgets were similar to the families/carers of participants with higher level of function, especially in the support and health and wellbeing domains.[34] The percentage of families/carers who have people they can talk to for emotional support decreases from 60.0% for those with an annualised plan budget less than $15,000 to 38.3% for those with an annualised plan cost over $50,000. With regard to work, 57.7% of families/carers of participants with an annualised plan cost of $15,000 or less were able to work as much as they wanted, in comparison to 36.4% of families/carers of participants with an annualised plan budget greater than $50,000.

Table 4.3 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.

**Table 4.3 Relationship of participant level of function and annualised plan budget with the likelihood of selected baseline outcomes**

| | Variable | |
|---|---|---|
| **Outcome** | **Higher level of function** | **Lower annualised plan budget** |
| **Being in a paid job** | ⬆ | ⬇ |
| **Receiving carer payments** | ⇩ | ⇩ |
| **Receiving carer allowance** | ⇩ | ⇩ |

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[34] 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.

| Outcome | Variable | |
|---|---|---|
| | Higher level of function | Lower annualised plan budget |
| **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** | ↑ | |
| **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 to support their family member with disability as often as needed** | ↑ | ↑ |
| **Having people they can talk to for emotional support as often as needed** | ↑ | ↑ |
| **Feeling in control of selecting the services and supports that meet the needs of their family member with disability** | ↑ | |
| **Saying the services for them and their family member with disability meet their needs** | ↑ | |
| **Knowing what they can do to enable their family member with disability to become as independent as possible** | ↑ | |
| **Enabling/supporting their family member with disability to make more decisions in their life** | ↑ | |
| **Enabling/supporting their family member with disability to develop strong relationships with non-family members** | ↑ | |
| **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** | ↑ | ↓ |

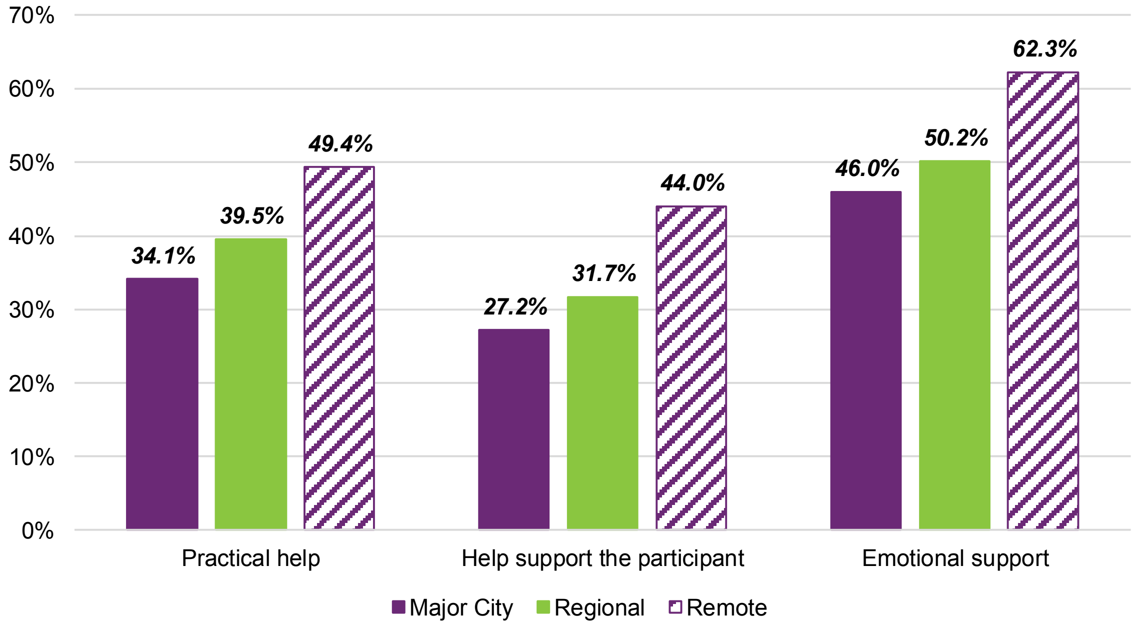
### Remoteness

Outcomes for families/carers of participants living in regional and remote locations are more positive on some indicators. On a one-way basis, the percentage who are able to advocate for the participant if they have issues or problems with accessing supports is higher – 72.3% for remote/very remote areas, compared with 68.5% in major cities. Also of note are results on the indicators related to having necessary supports to care for the participant. Compared with major cities, families/carers in regional and remote areas are more likely to have people they can ask for practical help (37.9-49.4% in regional/remote areas compared with 34.1% in major cities), emotional support (48.0-62.3% in regional/remote areas compared with 46.0% in major cities) or to support the participant as often as they need (29.7-44.0% in regional/remote areas compared with 27.2% in major cities). This relationship is illustrated in Figure 4.3.

Controlling for other factors, families/carers of participants living in remote areas are less likely to feel the services they and their family member with disability use listen to them, and are less likely to feel in control of selecting the services and supports that meet their needs.

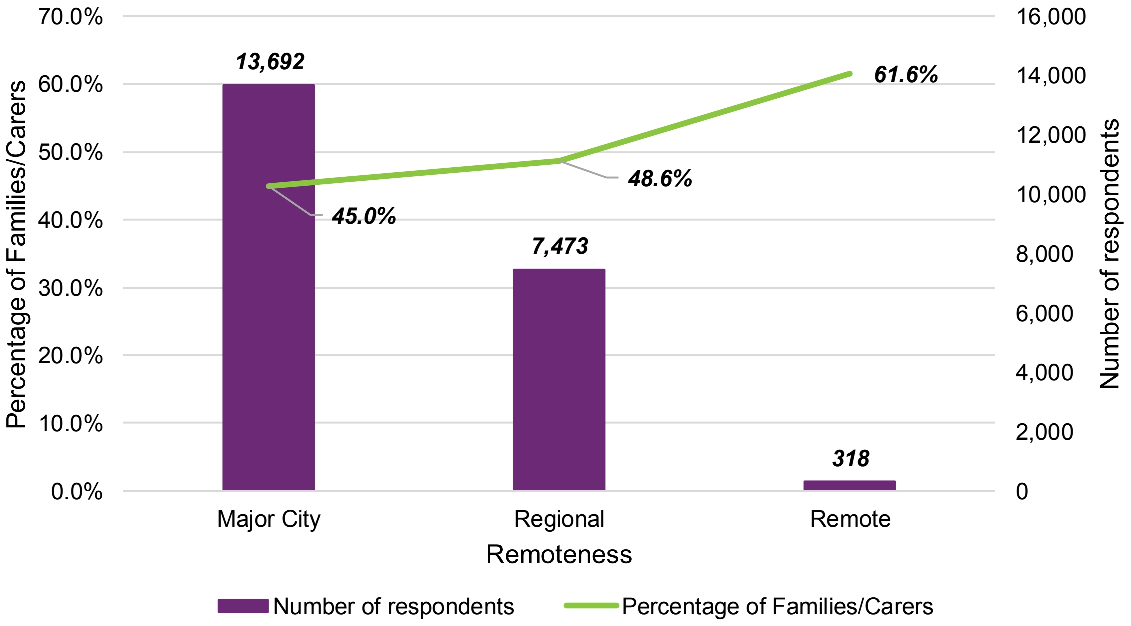
The indicators related to supporting the participant to become more independent show more positive results for families/carers from regional and remote locations. For example, the percentage who know what their family can do to enable the participant to become as independent as possible is higher for those in regional and remote locations (42.3-45.9% compared with 39.0% for major cities).

**Figure 4.3 Percentage of families/carers who are able to ask for different types of help and support as often as they need, by remoteness**

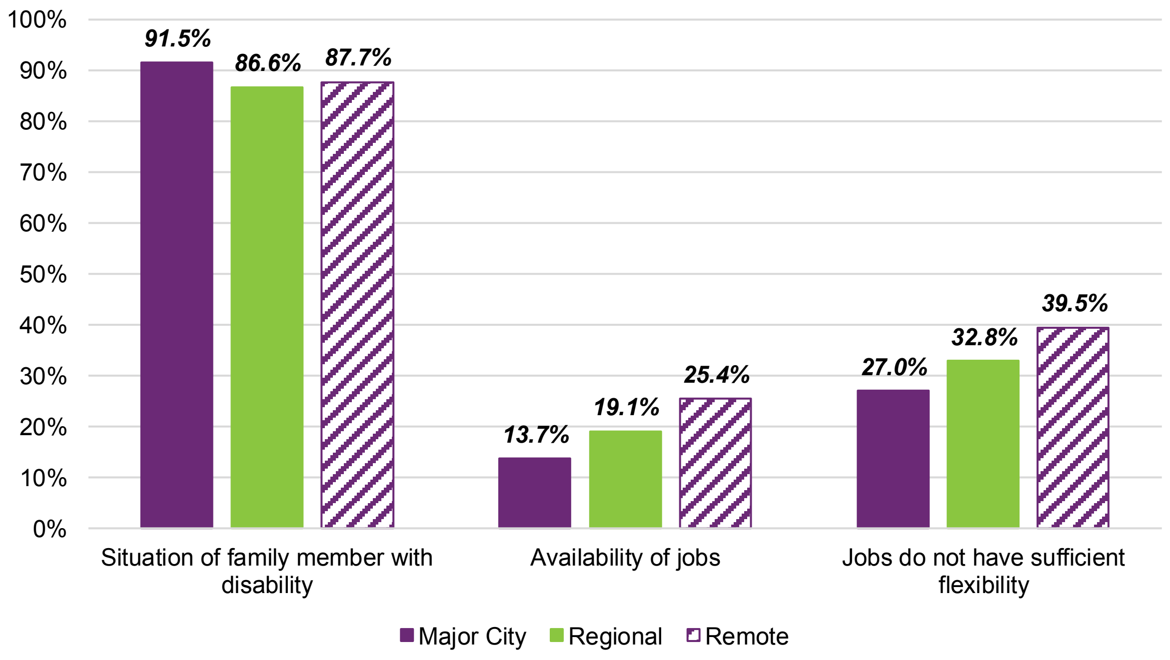


Results on employment in regional and remote locations are mixed. The percentage in paid employment is higher in major cities (50.4%) than in regional locations (45.5%-47.9%). On the other hand, the percentage who are able to work as much as they want increases with remoteness: from 45.0% in major cities, to 61.6% in remote/very remote locations. Of those who are not able to work as much as they want, the percentage of families/carers who see the situation of the participant as a barrier to working more decreases with remoteness: 91.5% for major cities and 87.7% for remote/very remote locations. However, other barriers such as insufficient flexibility of jobs seem to be more of a problem in remote locations (39.5% in remote locations compared with 27.0% in major cities). Figure 4.4 and Figure 4.5 highlight these employment outcomes, by region.

## Figure 4.4 Percentage of families/carers who can work as much as they want, by remoteness



## Figure 4.5 For those who are unable to work as much as they want, the percentage of families/carers with different barriers to working more, by region



### Plan management type

Families/carers of participants with self-managed plans (fully or partly) have better outcomes on the majority of indicators, particularly for the advocacy domain.[35] They are more likely to be able to identify the needs of the participant and to know how to access available services and supports to meet those needs (54.5-59.9% for partly/fully self-managed plans compared with 46.1% for agency-managed plans). Furthermore, families/carers of participants with self-managed plans are more likely to be able to speak up if they have issues accessing supports (76.7-83.0% for partly/fully self-managed plans compared with 69.2% for agency-managed plans). In addition, the percentage who feel in control in selecting services that meet the needs of the participant and their family is higher for families/carers with self-managed plans (48.0-52.2% for partly/fully self-managed plans compared with 40.4% for agency-managed plans).

In contrast, families/carers of participants with a plan managed by a plan manager are slightly less likely to report positive results. In particular, the percentages are lower for the indicators related to having necessary supports to care for participant. For example, families/carers of participants with a plan managed by a plan manager are less likely to have friends and family they can see as often as they like (35.3% compared with 47.9% for fully agency-managed plans), have people they can ask for practical help (28.4% compared with 40.8% for agency-managed plans), emotional support (40.3% compared with 50.3% for agency-managed plans) and to support the participant as often as they need (21.3% compared with 33.6% for agency-managed plans).

### Level of NDIA support

Families/carers of participants with lower level of NDIA support through the participant pathway tended to report better outcomes at baseline, across all domains, than families/carers of participants with a higher level of NDIA support. For example, families/carers of participants with a lower level of NDIA support were more likely to be able to identify the needs of their family member with disability, have people they can ask for practical help or emotional support as often as they like, know what they can do to enable their family member with disability to become as independent as possible, and be able to work as much as they want. They are also more likely to feel in control in selecting services and supports for their family member with disability, and say that the services they and their family member with disability use listen to them. Figure 4.6 illustrates the outcomes for families/carers for select indicators in the advocacy and support domains, by level of NDIA support.

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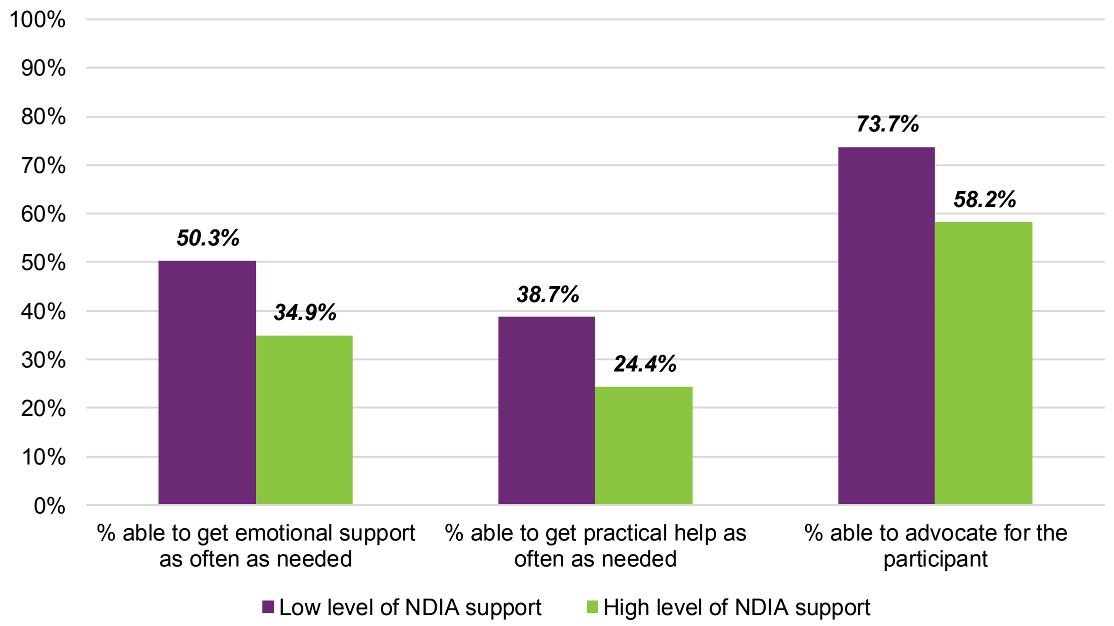
[35] Note that these baseline differences reflect characteristics of participants who choose to self manage, rather than the self-management process itself (since the results are at the start of the participant's first plan).

**Figure 4.6 Family/carer outcomes in the advocacy and support domains, by level of NDIA support**



### Feeling supported

Outcomes at baseline tend to be better for families/carers who are socially well connected. For example, those who have friends and family that they see as often as they like are more likely to enable/support the participant to be more independent, including making more decisions in his/her life (69.0% versus 48.1%) and developing strong relationships with non-family members (57.6% versus 35.8%). Additionally, these families/carers are more likely to be in better health and to work as much as they want – both factors could be either a consequence of better social support or be driving it.

### 4.2.4 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.

Table 4.4 summarises changes for selected indicators across different time periods. Cohort “B,R1,R2” includes families/carers responding at baseline, first review and second review[36]. 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[37] and had an absolute magnitude greater than 0.02[38].

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[36] A small number may be missing a response at the first review
[37] McNemar’s test at the 0.05 level
[38] Between baseline and second review for the “B,R1,R2” cohort

## Table 4.4 Selected longitudinal indicators for families/carers of participants from age 15 to 24

| Domain (Form) | Indicator | Cohort | Baseline | Review 1 | Review 2 | Change B-R1 | Change R1-R2 | Change B-R2 | Improvement/ Deterioration |
|---|---|---|---|---|---|---|---|---|---|
| WK (SF) | % of families/carers that work 15 hours or more per week | B,R1,R2 | 82.7% | 85.8% | 88.0% | 2.8% | 2.1% | 4.9% | Improvement |
| | | B,R1 | 84.5% | 86.2% | | 1.7% | | | |
| AC (SF) | % of families/carers who feel that the services they use for their family member with disability listen to them | B,R1,R2 | 66.6% | 71.2% | 73.8% | 4.6% | 2.6% | 7.2% | Improvement |
| | | B,R1 | 62.9% | 67.4% | | 4.6% | | | |
| AC (SF) | % of families/carers who say that the services for their family member with disability and their family receive meet their needs | B,R1,R2 | 18.0% | 32.0% | 37.5% | 14.0% | 5.5% | 19.5% | Improvement |
| | | B,R1 | 17.6% | 25.0% | | 7.4% | | | |
| IN (SF) | % of families/carers who enable and support their family member with disability to make more decisions in their life | B,R1,R2 | 58.6% | 62.9% | 62.1% | 4.3% | -0.8% | 3.5% | Improvement |
| | | B,R1 | 57.2% | 57.8% | | 0.6% | | | |
| AC (LF) | % who say the service their family member with disability and their family receive help them to plan for the future | B,R1,R2 | 63.5% | 69.8% | 68.3% | 6.3% | -1.6% | 4.8% | Improvement |
| | | B,R1 | 54.6% | 73.0% | | 18.4% | | | |
| HW (LF) | % who strongly agree or agree that they feel confident about the future of their family member the NDIS | B,R1,R2 | 52.9% | 75.0% | 70.6% | 22.1% | -4.4% | 17.6% | Improvement |
| | | B,R1 | 46.2% | 60.8% | | 14.5% | | | |
| HW (LF) | % who strongly agree or agree that their family member gets the support he/she needs | B,R1,R2 | 32.4% | 50.0% | 51.5% | 17.6% | 1.5% | 19.1% | Improvement |
| | | B,R1 | 34.4% | 51.1% | | 16.7% | | | |
| HW (LF) | % who strongly agree or agree that the services and supports have helped them to better care for their family member with disability | B,R1,R2 | 37.9% | 78.8% | 60.6% | 40.9% | -18.2% | 22.7% | Improvement |
| | | B,R1 | 44.1% | 57.5% | | 13.4% | | | |

| Domain (Form) | Indicator | Cohort | Baseline | Review 1 | Review 2 | Change B-R1 | Change R1-R2 | Change B-R2 | Improvement/ Deterioration |
|---|---|---|---|---|---|---|---|---|---|
| GB (SF) | % of families/carers that are receiving carer allowance | B,R1,R2 | 57.3% | 60.9% | 61.4% | 3.6% | 0.5% | 4.1% | Context Dependent |
| | | B,R1 | 54.6% | 56.5% | | 1.8% | | | |
| HW (SF) | % of families/carers who rate their health as excellent, very good or good | B,R1,R2 | 64.6% | 61.2% | 55.9% | -3.4% | -5.3% | -8.7% | Deterioration |
| | | B,R1 | 60.9% | 57.5% | | -3.4% | | | |
| 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 | 89.2% | 92.7% | 93.6% | 3.6% | 0.9% | 4.4% | Deterioration |
| | | B,R1 | 90.8% | 91.9% | | 1.1% | | | |

As with families/carers for participants aged from birth to 14, the majority of significant changes are positive. Key findings include:

- The percentage of families/carers who work 15 hours or more per week has increased, by 4.9% over two years for participants entering in 2016-17.
- More families/carers are enabling or supporting their family member with disability to make more decisions in their life.
- Families/carers feel they are more readily able to access supports. The percentage of families/carers who say the services they use for their family member with a disability listen to them, and the percentage of families/carers who say that the services their family member with a disability and their family receive meet their needs, have both increased.
- Overall, there was a deterioration in the health and wellbeing domain. The percentage of families/carers who rate their health as good, very good or excellent has decreased. Additionally, while there is a greater percentage of families/carers who work 15 hours or more per week, there is also a greater percentage of families/carers who reported that the situation of their family member with disability is a barrier to working more.

### 4.2.5 Longitudinal indicators – key characteristics

Analysis of changes in outcomes by key 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. Multiple regression analyses were performed for the same five SF domains as considered for baseline.

It should be noted that the two types of analysis 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.

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

The percentage of families/carers who worked 15 hours or more per week increased 2.0% between baseline and first review and by 5.3% between baseline and second review. Table 4.5 sets out the breakdown of movements in responses between baseline, first review and the second review.

**Table 4.5 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** | 445 | 2,375 | 86 | 19.3% | 31 | 1.3% | +2.0% |
| **Baseline to Review 2** | 68 | 328 | 30 | 44.1% | 9 | 2.7% | +5.3% |

The main drivers that had a statistically significant effect on the likelihood of improvement or deterioration in the outcome are set out in Table 4.6.

**Table 4.6 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 has 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 has received services from State/Territory systems before entering the NDIS** | | ⬇ | | |
| **Entered the Scheme in 2017/18** | ⬇ | | | |
| **Participant doesn't have SIL supports in their plan** | | | | ⬇ |
| **Access type is early intervention** | | | | ⬆ |

| Variable | Baseline to First Review<br>Relationship with likelihood of |  | Baseline to Second Review<br>Relationship with likelihood of |  |
|---|---|---|---|---|
|  | Improvement | Deterioration | Improvement | Deterioration |
| **Participant feels very safe or safe in their home** |  |  |  | ⬇ |
| **Participant feels very unsafe or unsafe in their home** |  |  |  | ⬆ |
| **Participant is Indigenous** |  |  |  | ⬆ |

Key findings from Table 4.6 include:

- Families/carers of participants who had never received services from State/Territory or Commonwealth schemes before entering the NDIS were less likely to deteriorate between baseline and first review.
- Families/carers of participants who did not receive Supported Independent Living supports were less likely to deteriorate.
- Families/carers of participants who are Indigenous or entered the Scheme through early intervention were more likely to deteriorate between baseline and second review.

### *I feel that the services my family member with disability and my family use listen to me*

The percentage of families/carers who feel that the services they use listen to them increased 4.5% between baseline and first review and by 7.3% between baseline and second review. Table 4.7 sets out the breakdown of movements in responses between baseline, first review and second review.

**Table 4.7 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** | 2,054 | 3,556 | 611 | 29.7% | 357 | 10.0% | +4.5% |
| **Baseline to Review 2** | 266 | 529 | 136 | 51.1% | 78 | 14.7% | +7.3% |

The main drivers that had a statistically significant effect on the likelihood of improvement or deterioration in the outcome are set out in Table 4.8.

**Table 4.8 Key drivers of likelihood of transitions of "I feel that the services my family member with disability and my family use listen to me" response**

| | Baseline to First Review | | Baseline to Second Review | |
|---|---|---|---|---|
| | Relationship with likelihood of | | Relationship with likelihood of | |
| Variable | Improvement | Deterioration | Improvement | Deterioration |
| Higher plan utilisation | ⬆ | ⬇ | | |
| Participant has a higher level of NDIA support | ⬇ | | | |
| Participant has a lower level of function | | | ⬇ | |
| Plan is fully self-managed | | ⬇ | | |
| Plan is fully agency-managed | | ⬆ | | |
| Plan is plan-managed | | ⬆ | | |
| Participant is in unpaid work | | | ⬆ | |
| Participant feels very safe or safe in their home | ⬆ | ⬇ | | |
| Carer's working hours decreased | ⬆ | | | |
| Carer's working hours increased | | ⬆ | | |
| Carer's working hours did not change | ⬇ | | | |
| Participant lives in QLD or SA | ⬆ | | | |
| Participant lives in VIC | ⬇ | | | |
| Participant rates their health as fair or poor | | ⬆ | | |

The findings from Table 4.8 are summarised as follows:

- Families/carers of participants who felt safe or very safe at home were more likely to improve at both first and second reviews. They were also less likely to deteriorate between baseline and the first review.
- Families/carers of participants with a plan-managed or agency-managed plan were more likely to deteriorate at first reviews.
- Families/carers of participants with higher plan utilisation are more likely to improve and less likely to deteriorate between baseline and first review.

### *The services my family member with disability and my family receive meet our needs*

The percentage of families/carers who think the services they receive meet their needs increased by 8.2% between baseline and first review and 19.5% between baseline and second review. Table 4.9 sets out the breakdown of movements in responses between baseline, first review and second review.

**Table 4.9 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** | 4,803 | 1,039 | 679 | 14.1% | 200 | 19.2% | +8.2% |
| **Baseline to Review 2** | 703 | 154 | 209 | 29.7% | 42 | 27.3% | +19.5% |

The main drivers that had a statistically significant effect on the likelihood of improvement or deterioration in the outcome are set out in Table 4.10.

**Table 4.10 Key drivers of likelihood of transitions of "The services of my family member with disability and my family receive meet our needs" response**

| Variable | Baseline to First Review | | Baseline to Second Review | |
|---|---|---|---|---|
| | Relationship with likelihood of | | Relationship with likelihood of | |
| | Improvement | Deterioration | Improvement | Deterioration |
| **Higher plan utilisation** | ⬆ | ⬇ | | |
| **Participant has a higher level of NDIA support** | ⬇ | | ⬇ | |
| **Higher annualised plan budget** | ⬆ | | | |
| **Participant has a lower level of function** | ⬇ | | | |
| **Plan is fully self-managed** | ⬆ | | | |
| **Plan is plan-managed or agency-managed** | ⬇ | | | |
| **Entered the Scheme in 2016/17** | ⬆ | | | |
| **Access type is early intervention** | | | | ⬆ |
| **Carer's working hours increased** | | ⬆ | | |

| 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 or NSW** | ⬇ | | | |
| **Participant rates their health as excellent** | ⬆ | | | |
| **Participant rates their health as poor** | | ⬆ | | |

The findings from Table 4.10 are summarised as follows:

- Higher plan utilisation was associated with a higher likelihood of improvement and lower likelihood of deterioration between baseline and first review.
- Families/carers of participants with a higher level of NDIA support were less likely to improve.
- Families/carers who had increased work hours were more likely to deteriorate between baseline and second review.
- Families/carers of participants who entered the Scheme through early intervention were more likely to deteriorate between baseline and second review.
- Families/carers of articipants who rated their health as poor were more likely to deteriorate at the first review while those who rated their health as excellent were more likely to improve.

### *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 3.4% between baseline and first review and 8.7% between baseline and second review. Table 4.11 sets out the breakdown of movements in responses between baseline, first review and the second review.

**Table 4.11 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** | 2,234 | 3,551 | 251 | 11.2% | 447 | 12.6% | -3.4% |
| **Baseline to Review 2** | 296 | 540 | 53 | 17.9% | 126 | 23.3% | -8.7% |

The main drivers that had a statistically significant effect on the likelihood of improvement or deterioration in the outcome are set out in Table 4.12.

## Table 4.12 Key drivers of likelihood of transitions of "In general, my health is excellent, very good or good" response

| Variable | Baseline to First Review | | Baseline to Second Review | |
|---|---|---|---|---|
| | Relationship with likelihood of | | Relationship with likelihood of | |
| | Improvement | Deterioration | Improvement | Deterioration |
| **Higher plan utilisation** | | ↑ | | |
| **Participant has a higher level of NDIA support** | ↓ | | | |
| **Higher annualised plan budget** | | | | ↑ |
| **Higher Index of Economic Resources (IER)** | | | | ↓ |
| **Participant is not in unpaid work** | | ↓ | | |
| **Carer's working hours did not change** | ↓ | | | |
| **Carer was never in paid work** | ↓ | | | |
| **Carer remained in paid work** | | | | ↓ |
| **Carer started paid work** | ↑ | | | |
| **Carer was always in permanent or casual employment** | | ↓ | | |
| **Carer changed from permanent to casual employment** | | ↑ | | |
| **Participant is not CALD** | | | ↑ | |
| **Participant rates their health as fair** | | ↑ | | |
| **Participant rates their health as very good** | ↑ | | | |
| **Participant rates their health as poor** | ↓ | ↑ | | |
| **Participant is female** | ↑ | | | |
| **Participant is male** | ↓ | | ↓ | |

The findings from Table 4.12 are summarised as follows:

- Families/carers not in unpaid work were less likely to deteriorate between baseline and the first review.
- Families/carers of participants with higher baseline plan utilisation were more likely to deteriorate between baseline and the first review.
- Families/carers who saw no changes to their working hours were less likely to improve between baseline and the first review.
- Improvement in family/carer self-rated health was less likely, and deterioration more likely, when participant health was rated as poor. Conversely, where participant health is very good, family/carer health is more likely to improve.

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

The percentage of families/carers who think that the situation of their family member with disability is a barrier to working more increased by 1.5% between baseline and first review and 4.6% between baseline and second review. Table 4.13 sets out the breakdown of movements in responses between baseline, first review and the second review.

**Table 4.13 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** | 263 | 2520 | 22 | 0.9% | 63 | 24.0% | -1.5% |
| **Baseline to Review 2** | 292 | 75 | 8 | 10.7% | 25 | 8.6% | -4.6% |

The main drivers that had a statistically significant effect on the likelihood of improvement or deterioration in the outcome are set out in Table 4.14.

**Table 4.14 Key drivers of likelihood of transitions of "One of the barriers to working more is the situation of my family member with disability" response**

| 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** | ⬇ | | | |
| **Participant feels neither safe or unsafe** | | | ⬆ | |
| **Participant feels very safe or safe in their home** | | | ⬇ | |
| **Participant lives in a private home owned by self/family** | | ⬇ | | |
| **Participant lives in NSW** | | ⬇ | | |

- Families/carers of participants with a lower level of function were less likely to improve between baseline and first review.
- Families/carers of participants living in a private home owned by self or family were less likely to deteriorate between baseline and first review.
- Families/carers of participants who live in New South Wales were less likely to deteriorate between baseline and first review.

### *One of the barriers to working more is the availability of jobs*

The percentage of families/carers who think that the availability of jobs is a barrier to working more increased by 2.8% between baseline and first review and 6.3% between baseline and second review. Table 4.15 sets out the breakdown of movements in responses between baseline, first review and the second review.

**Table 4.15 Breakdown of net movement in longitudinal responses**

| Longitudinal Period | Number of Responses in cohort | | Improvements: Yes to No | | Deteriorations: No to Yes | | Net Movement (No to Yes) |
|---|---|---|---|---|---|---|---|
| | No | Yes | Number | % | Number | % | |
| **Baseline to Review 1** | 2,310 | 473 | 35 | 7.4% | 112 | 4.8% | -2.8% |
| **Baseline to Review 2** | 292 | 75 | 15 | 20.0% | 38 | 13.0% | -6.3% |

The main drivers that had a statistically significant effect on the likelihood of improvement or deterioration in the outcome are set out in Table 4.16.

**Table 4.16 Key drivers of likelihood of transitions of "One of the barriers to working more is the availability of jobs" 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 has a higher level of NDIA support** | | ⬇ | | |
| **Participant lives in a major city** | | | | ⬇ |
| **Participant lives in a regional area** | | | | ⬆ |
| **Access decision was early intervention** | | ⬆ | | |
| **Carer's working hours increased** | | ⬆ | | |
| **Carer's working hours did not change** | | ⬇ | | |

| Variable | Baseline to First Review<br>Relationship with likelihood of |  | Baseline to Second Review<br>Relationship with likelihood of |  |
|---|---|---|---|---|
|  | Improvement | Deterioration | Improvement | Deterioration |
| **Carer was never in paid work** | ⬇ |  |  |  |
| **Participant lives in QLD** |  | ⬆ |  |  |
| **Participant lives in VIC** |  | ⬇ |  |  |

- Families/carers of participants who entered the Scheme through early intervention were more likely to deteriorate between baseline and first review.
- Families/carers of participants who saw no changes to their working hours were less likely to deteriorate.
- Families/carers who were never in paid work were less likely to improve between baseline and second review.

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

The percentage of families/carers who think that the inflexibility of jobs is a barrier to working more increased by 2.7% between both baseline and first review and 3.0% between baseline and second review. Table 4.17 sets out the breakdown of movements in responses between baseline, first review and the second review.

**Table 4.17 Breakdown of net movement in longitudinal responses**

| Longitudinal Period | Number of Responses in cohort |  | Improvements: Yes to No |  | Deteriorations: No to Yes |  | Net Movement (No to Yes) |
|---|---|---|---|---|---|---|---|
|  | No | Yes | Number | % | Number | % |  |
| **Baseline to Review 1** | 1,857 | 926 | 49 | 5.3% | 124 | 6.7% | -2.7% |
| **Baseline to Review 2** | 226 | 141 | 25 | 17.7% | 36 | 15.9% | -3.0% |

The main drivers that had a statistically significant effect on the likelihood of improvement or deterioration in the outcome are set out in Table 4.18.

### Table 4.18 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's self-rated health improved** | ⬆ | | | |
| **Participant's self-rated did not change** | ⬇ | | | |
| **Participant lives in a major city** | | | | ⬇ |
| **Participant lives in a regional area** | | | | ⬆ |
| **Carer works more than 30 hours a week** | ⬆ | | | |
| **Carer was always in permanent or casual employment** | ⬇ | | | |
| **Carer changed from permanent to casual employment** | ⬆ | | | |
| **Participant lives in VIC** | | ⬇ | | |

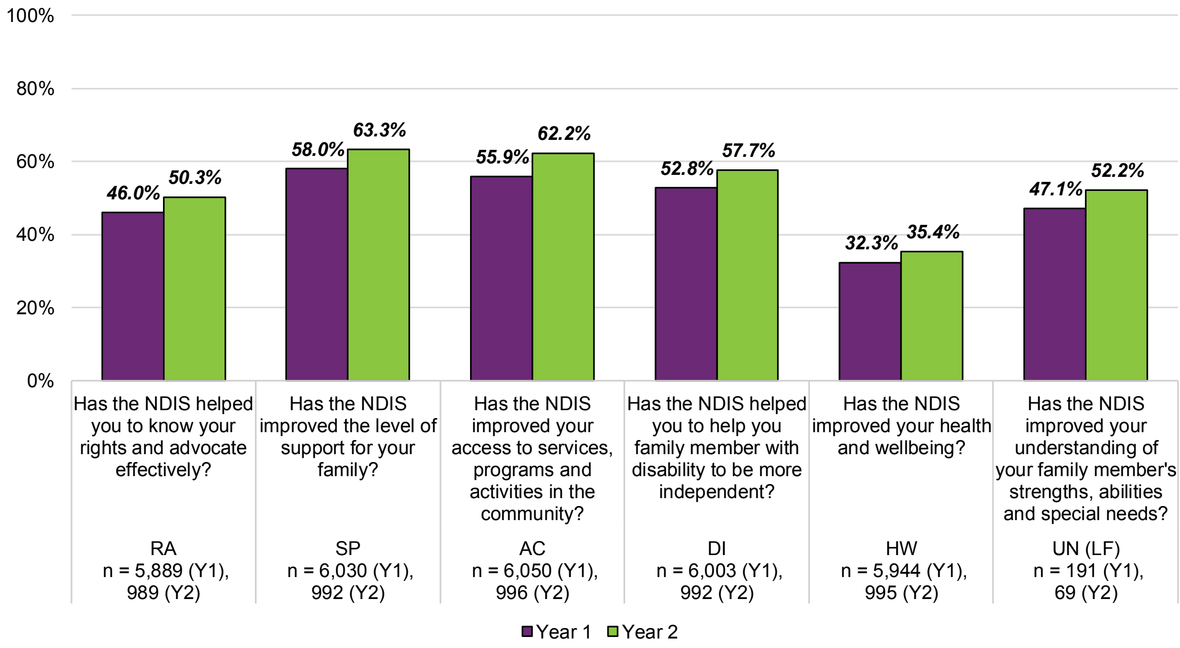
- Families/carers of participants who did not see a change in self-rated health were less likely to improve between baseline and first review. Participants who reported that their health improved were more likely to improve between baseline and first review.
- Families/carers who work more than 30 hours a week were more likely to improve between baseline and first review.
- Families/carers of participants living in Victoria were less likely to deteriorate between baseline and first review.

# 5. Families/carers of participants from age 15 to 24: Has the NDIS helped?

## 5.1 Aggregate results

For participants entering the Scheme between 1 July 2016 and 30 June 2018, and who have been in the Scheme for at least one year as at 30 June 2019, Figure 5.1 shows the percentage of families/carers who reported that the NDIS had helped with outcomes related to each of the five SF domains. Results are also shown for the extra LF domain relating to families' and carers' understanding of their family member's strengths, abilities and special needs.

**Figure 5.1 Percentage who think that the NDIS has helped with outcomes related to each domain**



The percentage of families/carers of participants aged 15 to 24 who said that the NDIS had helped increased between the first and second years in the Scheme, across all domains.

Opinions are slightly less positive compared to the families/carers of participants from birth to age 14. Nevertheless, the majority agree that the NDIS improved the level of support for their family (58.0% after one year in the Scheme, increasing to 63.3% after two years), and helped with access to services, programs and activities in the community (55.9% after one year in the Scheme increasing to 62.2% after two years). Slightly fewer families/carers think the NDIS helped them to help their family member with disability be more independent (52.8% after one year in the Scheme increasing to 57.7% after two years), and to know their rights and advocate effectively (46.0% after one year in the Scheme increasing to 50.3% after two years). The percentage who think the NDIS has improved their health and wellbeing increased from 32.3% after one year in the Scheme, to 35.4% after two years.

After one year in the Scheme, 47.1% of families/carers agreed that the NDIS improved their understanding of their family member's strengths, abilities and special needs, increasing to 52.2% of families/carers after two years (although there were only 69 respondents).

## 5.2 Results by participant and family/carer characteristics

### 5.2.1 Year 1 ‘Has the NDIS helped?’ indicators – participant characteristics

Indicators at first review have been analysed by participant and family/carer characteristics using one-way analysis and multiple regression. Table 5.1 shows the relationship of different participant and carer characteristics with the likelihood of families/carers saying that the NDIS has helped. A characteristics is included in the table if it has a significant relationship with at least two of the ‘Has the NDIS Helped?’ questions, and all significant relationships are in the same directions (for example, a characteristic with two significant and positive relationships with ‘Has the NDIS Helped?’ questions will be included, but a characteristic with three significant positive relationships and one significant negative relationship will not be).

**Table 5.1 Relationships of participant/carer characteristics with the likelihood of positive family/carer responses**

| Characteristic | Saying the NDIS has helped |
|---|---|
| **Participant is older** | ⬆ |
| **Higher annualised plan budget** | ⬆ |
| **Higher plan utilisation** | ⬆ |
| **Participant’s disability is autism** | ⬆ |
| **Participant’s disability is Down syndrome** | ⬆ |
| **Participant’s disability is a visual impairment** | ⬇ |
| **Participant had not received services from Commonwealth or State/Territory systems before entering the NDIS** | ⬆ |
| **Lives in NSW** | ⬇ |
| **Lives in QLD** | ⬆ |
| **Plan is agency managed** | ⬇ |
| **Plan is self-managed** | ⬆ |
| **Participant has a higher level of NDIA support** | ⬇ |
| **Participant rates their health as excellent or very good** | ⬆ |

| Characteristic | Saying the NDIS has helped |
|---|---|
| **Participant rates their health as poor** | ⬇ |

## Participant age

Family/carer satisfaction increases with the participant's age in three domains:

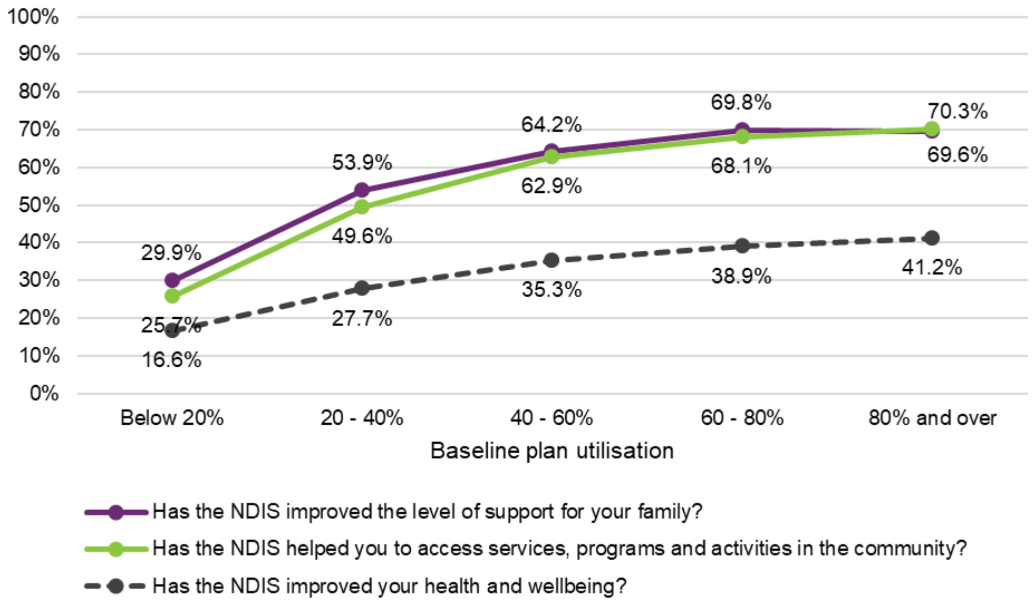
- Level of support
- Access to desired services, programs and activities within the community
- Helping their family member with disability become more independent

For example, 62.6% of families/carers of participants aged 22 or older felt that the NDIS improved their access to services, programs and activities within the community, compared to 53.9% of families/carers with participants aged 17 or younger. Similarly, 57.1% of families/carers of participants aged 22 or older said that the NDIS helped them help their family member with disability become more independent, as opposed to 50.7% of families/carers with participants aged 17 or younger.

## Plan utilisation

The level of satisfaction increases with baseline plan utilisation across all SF domains. In one-way analysis, the percentage of families/carers who agreed that the NDIS helped is significantly higher for those with higher plan utilisation. For example, families/carers of participants with plan utilisation of 80% and above were more likely to agree that the NDIS improved the level of support they have (69.6% compared with 29.9% for families/carers of participants with utilisation below 20%). Figure 5.2 shows the relationship between the positive response rates to the 'has the NDIS helped?' questions and baseline plan utilisation for selected domains.

**Figure 5.2 Percentage of families/carers who think the NDIS has helped by baseline plan utilisation**



### Plan budget

The percentage of families/carers who think the NDIS helped increases with increasing plan budget. The relationship is particularly strong for the “Has the NDIS improved the level of support for your family?” question, with the percentage of families/carers answering “Yes” increasing from 42.9% for plan budgets below $15,000 to 66.6% for plan budgets of $50,000 and higher. A similar trend was observed for the “Has the NDIS improved your access to services, programs and activities in the community?” question, with the percentage of respondents answering “Yes” increasing from 40.6% for plan budgets below $15,000 to 65.8% for plan budgets of $50,000 and higher.

### Disability type

In relation to advocacy, and access to services and programs, families/carers of participants with autism or Down syndrome were more likely to respond positively than families/carers of participants with a visual impairment. For example, 47.1% of families/carers of participants with autism agreed that the NDIS improved their capacity to advocate for their family member with disability, whereas only 26.0% of families/carers of participants with a visual impairment agreed.

### State/Territory

Multiple regression analysis confirms that families/carers from New South Wales were less likely to respond positively than families/carers from Queensland, across all domains. In particular, 51.8% of families/carers from New South Wales feel the NDIS helped their family member with disability become independent, compared to 60.3% from Queensland. Similarly, 44.1% of families/carers from New South Wales reported that the NDIS improved their capacity to advocate for their family member with disability, compared to 52.8% of families/carers from Queensland.

### Plan management type

Multiple regression analysis indicated that families/carers of participants with fully agency-managed plans were less likely to report that the NDIS helped, across all domains. Conversely, families/carers of those with fully self-managed plans were more likely to feel the NDIS helped. For example, 53.2% of families/carers of participants with fully agency-managed plans felt that the NDIS improved the level of support for their family, compared to 65.9% of families/carers of participants with fully self-managed plans.

### Participant health

Multiple regression analysis suggests that a relationship exists between the family/carer’s level of satisfaction with the NDIS and the participant’s self-rated health. In particular, families/carers of participants with better self-rated health were more likely to agree that the NDIS improved access to services and the health and wellbeing of the family member/carer, and helped families/carers to promote the independence of their family member.

### Other characteristics

Families/carers of participants with a lower level of NDIA support were more likely to say that the NDIS improved their level of support and helped their family member with disability become more independent.

Families/carers who did not receive services from State/Territory or Commonwealth systems before joining the NDIS were more likely to say that the NDIS improved their health and wellbeing, and helped them to help their family member with disability become more independent.

### 5.2.2 Longitudinal 'Has the NDIS helped?' indicators – participant characteristics

Longitudinal indicators by participant characteristics were analysed in two ways:

1. A comparison of the percentage of families/carers reporting that the NDIS has helped at second review with the percentage reporting that the NDIS has helped at first review. The difference (percentage at second review minus percentage at first review) is compared for different subgroups.
2. Multiple regression analyses modelling the likelihood of improvement / deterioration over the participant's second year in the Scheme.

Table 5.2 presents a summary of movements in family/carer responses to the 'Has the NDIS helped?' questions, showing improvements, deteriorations, and net movements between first and second review. The statistics in Table 5.2 are for the cohort with responses at both first and second review, and thus differ slightly from those in Figure 5.1.

**Table 5.2 Breakdown of net movement in family/carer responses to 'Has the NDIS helped?' indicators**

| The NDIS has | Number of first review responses | | Improvements: No to Yes | | Deteriorations: Yes to No | | Net Movement |
|---|---|---|---|---|---|---|---|
| | No | Yes | Number | % | Number | % | |
| **Helped me know our rights and advocate effectively (RA)** | 417 | 337 | 83 | 19.9% | 47 | 13.9% | +4.8% |
| **Improved the level of support for my family (SP)** | 340 | 431 | 101 | 29.7% | 40 | 9.3% | +7.9% |
| **Improved my access to services, programs and activities in the community (AC)** | 351 | 445 | 106 | 30.2% | 53 | 11.9% | +6.7% |
| **Improved ability/capacity to help my family member with disability be more independent (IN)** | 373 | 403 | 95 | 25.5% | 40 | 9.9% | +7.1% |
| **Improved my health and wellbeing (HW)** | 503 | 277 | 60 | 11.9% | 66 | 23.8% | -0.8% |

The percentage of families/carers whose response improved is higher than the percentage whose response deteriorated, across all domains, except health and wellbeing. The most commonly observed theme was that responses of families/carers of participants with higher plan utilisation were more likely to improve, as highlighted in Table 5.3.

## Table 5.3 Relationships of characteristics with the likelihood of improvement and deterioration in helped responses

| | Relationship with | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | Improvement in helped question domain | | | | | Deterioration in helped question domain | | | | |
| Characteristic | RA | SP | AC | IN | HW | RA | SP | AC | IN | HW |
| Participant is older | | | ↓ | | | | | | | |
| Higher plan utilisation | ↑ | ↑ | ↑ | | | | | | | |
| Participant lives in: | | | | | | | | | | |
| NSW | | | | | | | | | | |
| VIC | | | | | | | | | | |
| QLD | ↑ | | | ↑ | | | | | | |
| SA | | | | | | | | | | |
| Other | ↓ | | | ↓ | | | | | | |
| Plan has supports that are: | | | | | | | | | | |
| 30-60% capacity building | | | | | | | | | ↑ | |
| Participant has a higher level of function | | | | | | ↓ | | | | |
| Participant engaged in unpaid work | | | | ↑ | | | | | | |
| Participant's self-rated health: | | | | | | | | | | |
| Remained unchanged | | | | | | ↓ | | | | |
| Improved | | | | | | ↑ | | | | |
| Deteriorated | | | | | | | | | | |
| Participant's plan is: | | | | | | | | | | |
| Fully self-managed | | | ↑ | | | | | | | |
| Fully agency-managed | | | ↓ | | | | | | | |
| Higher Index of Education and Occupation | | | | | ↑ | | | | | |

***The NDIS has helped me know our rights and advocate effectively***

The percentage of families/carers reporting that the NDIS improved their capacity to advocate for their family member increased by 4.8%, from 44.7% to 49.5%, between the first and second review.

Responses of families/carers were more likely to improve for:

- Participants with higher plan utilisation
- Participants in Queensland

Responses of families/carers were more likely to deteriorate for:

- Participants whose self-rated health improved between first and second review
- Participants with a lower level of function

***The NDIS has improved the level of support for my family***

The percentage of families/carers reporting that the NDIS improved the level of support increased by 7.9%, from 55.9% to 63.8%, between the first and second review.

Participants with higher plan utilisation were more likely to improve.

***The NDIS has improved my access to services, programs and activities in the community***

The percentage of families/carers reporting that the NDIS improved their access to services, programs and activities in the community increased by 6.7%, from 55.9% to 62.6%, between the first and second review.

Responses of families/carers were more likely to improve for:

- Participants with higher plan utilisation
- Younger participants
- Participants with fully self-managed plans

***The NDIS has helped me to help my family member be more independent***

The percentage of families/carers reporting that the NDIS helped them to help their family member be more independent increased by 7.1%, from 51.9% to 58.4%, between the first and second review.

Responses of families/carers were more likely to improve for:

- Participants living in Queensland
- Participants who engaged in unpaid work

Responses of families/carers of participants with plans in which 30-60% of supports were capacity building were more likely to deteriorate.

***The NDIS has improved my health and wellbeing***

The percentage of families/carers reporting that the NDIS improved their health and wellbeing decreased by 0.8%, from 35.5% to 34.7%, between the first and second review.

Responses from families/carers of participants living in an area with a higher Index of Education and Occupation (IEO) were more likely to improve.

# 6. Families/carers of participants aged 25 and over: overview of results

## 6.1 Key findings

### Box 6.1: Overall findings for families/carers of participants aged 25 or older, who joined the scheme between 1 July 2016 and 30 June 2017[39]

- For the small number of families/carers of participants aged 25 and over entering the Scheme in 2016-17 who contributed to the longitudinal analysis, there were significant and material changes for five indicators.
- Three positive changes were observed related to satisfaction with services. The percentage of families/carers who say that the services their family member with disability and their family receive meets their needs improved from 23.1% at baseline to 40.7% at second review. The percentage who said they had no difficulties working in partnership with professionals and service providers to meet the needs of their family member with disability increased from 62.1% to 89.7% over two years, and the percentage who said the services helped them to plan for the future increased from 44.8% to 75.9%.
- The percentage who say they receive Carer Allowance increased from 40.7% at baseline to 56.0% at second review.

### Box 6.2: Overall findings for families/carers of participants aged 25 or older, who joined the scheme between 1 July 2017 and 30 June 2018[40]

- Significant improvements were observed in the access to services domain. The percentage of families/carers who said that the services their family member with disability receives meets their needs increased from 21.5% at baseline to 30.3% at first review, the percentage who say the services they use listen to them increased from 67.7% to 71.3%, and the percentage who say the services help them to plan for the future increased from 64.1% to 73.7%.
- In the support domain, the percentage of families/carers who have people they can talk to for emotional support as often as the need increased from 50.7% at baseline to 52.7% at first review.
- There were also some positive results in the health and wellbeing domain. The percentage of families/carers who felt their family member with disability gets the support they need rose from 27.5% at baseline to 35.7% at first review, and the percentage who strongly agree or agree that services and supports have helped them to better care for their family member with disability increased from 55.4% to 65.8%. Families/carers also felt more positive about the future, with the percentage feeling more confident about the future of their family with disability under the NDIS increasing from 34.7% at baseline to 56.2% at first review, and the percentage feeling at least mostly satisfied when thinking about last year and what they expect for the future increasing from 44.1% at baseline to 55.9%.

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[39] Note that this is a small group of less than 100 respondents for the SF, and smaller again for the LF (less than 30), so results should be interpreted with caution.

[40] Around 5000 respondents for the SF, and 350 for the LF.

### Box 6.2: Overall findings for families/carers of participants aged 25 or older, who joined the scheme between 1 July 2017 and 30 June 2018 (continued)

- However, the percentage rating their health as excellent, very good or good has declined by 3.9% over one year, and the percentage who say insufficient flexibility of jobs is a barrier to working more increased by 2.3%.

### Box 6.3: Outcomes by key characteristics for families/carers of participants aged 25 or older

- For the majority of indicators, baseline outcomes are better for families/carers of participants with a high level of function.
- Controlling for other factors, baseline outcomes for families/carers of participants with a CALD background were less likely to be positive. For example, families/carers of CALD participants were less likely to be able to advocate for their family member, were less likely to feel in control when selecting services and supports, and were less likely to be able to work as much as they want.
- Baseline outcomes for families/carers of participants from Indigenous backgrounds were generally worse than those for families/carers of non-Indigenous participants, especially with regard to employment and health.
- At baseline, families/carers of participants with hearing impairments were the least likely to cite that the situation of their family member with disability was a barrier to working more. This group also exhibited the best health and wellbeing outcomes at baseline and were most likely to feel supported.
- Baseline modelling indicates that, like the 15 to 24 cohort, outcomes for families/carers of participants aged 25 or older generally become more positive with increasing participant age, especially in the support and access to services domains. However, the health and wellbeing of families/carers of older participants tends to deteriorate (likely reflecting the positive relationship between participant and family/carer age). This group is also more likely to cite the situation of their family member with disability or insufficient flexibility of jobs as barriers to working more.
- Longitudinal modelling indicates that families/carers of participants with a higher annualised plan budget are more likely to agree that the services their family member with disability and their family receive meet their needs. A similar trend was observed for families/carers of participants with fully self-managed plans or those with a lower level of NDIA support.
- Families/carers with a higher score on the Index of Economic Resources are more likely to display improvement in their opinion of whether their family member with disability gets the support they need. In contrast, families/carers of participants with a higher level of NDIA support are more likely to deteriorate in this area.

## Box 6.4: Has the NDIS helped families/carers of participants aged 25 and over?

- Improvements in positive response rates between first and second review were observed across all domains except succession planning.
- After one year in the Scheme, families/carers of participants with higher baseline plan utilisation were more likely to say that the NDIS has helped. Similarly, families/carers of participants with a higher annualised plan budget were more likely to report positive outcomes at first review.
- Longitudinal modelling of the change in responses between first and second review did not show any significant relationships, primarily due to the small number of respondents completing both the first and second reviews.

## 6.2 Results overview

### 6.2.1 Outcomes framework questionnaire domains

For families/carers of participants aged 25 and over, the outcomes framework seeks to measure the extent to which they:

- Know their rights and advocate effectively for their family member with a disability (RA)
- Feel supported (SP)
- Can gain access to desired services, programs and activities in their community (AC)
- Have succession plans (SC)
- Enjoy health and wellbeing (HW).

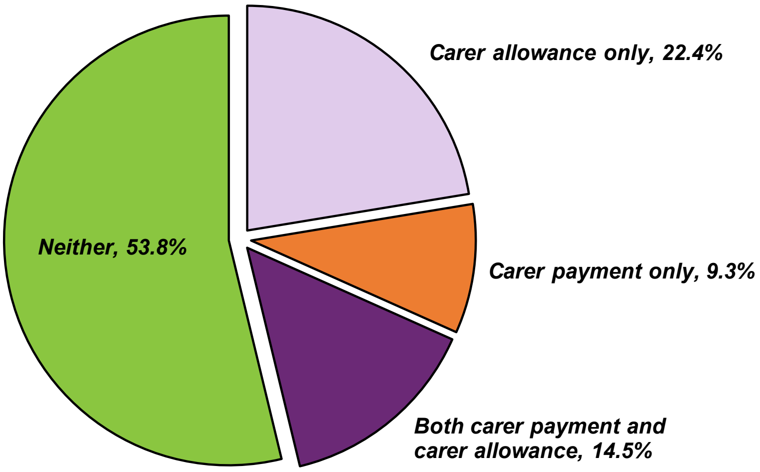
The LF contains a number of extra questions for the adult cohorts, across all domains, but particularly in the health and wellbeing domain.

### 6.2.1 Baseline indicators – aggregate

#### Government benefits (Carer Payment and Carer Allowance) [41]

In the baseline SF questionnaire, 46.2% of families/carers of adult participants report that they are receiving a government benefit for their caring responsibilities. 22.4% of families/carers receive the Carer Allowance only, 9.3% receive the Carer Payment only, and 14.5% receive both of the carer government benefits (Figure 6.1).

**Figure 6.1 Percentage of families/carers of participants aged 25 and over receiving government carer benefits at baseline**



#### Rights and advocacy

The LF asks families/carers if they understand their rights and the rights of their family member with disability, to which the majority (77.4%) answered in the affirmative at baseline. Similarly, in the SF most families/carers reported that they are able to advocate for their family member and speak up if they have issues accessing support (67.9%).

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[41] Families/carers self-report whether they receive carer payment or carer allowance.

On the other hand, only 47.1% of families/carers reported in the baseline SF that they are able to identify the needs of their family member with a disability and know how to access the services and support that the family member needs. For this question, 37.0% of families/carers reported that they had some difficulty, and 15.9% had great difficulty.

### Families feel supported

At baseline, most families/carers of adult participants reported that they did not feel supported across all relevant questions in the SF. Less than half (47.3%) said they have family and friends that they see as often as they like. In terms of being able to ask for support as often as needed, 62.3% could not ask for practical help, 51.9% could not ask for emotional support and 70.9% could not ask for support for their family member with a disability.

In the LF, 55.1% of families/carers reported that they had as much contact with other families of people with a disability as they would like.

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

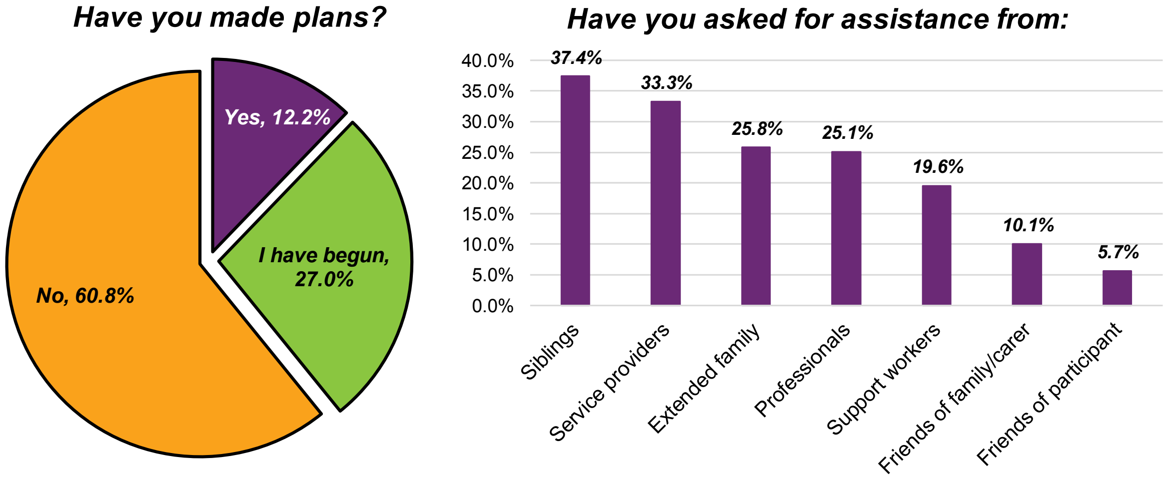
At baseline, 19.7% of families/carers said that the services the participant and their family receives meets their needs. Furthermore, the majority of families/carers reported that they have difficulty feeling in control when selecting services and supports that meet the needs of the family and participant, with 41.4% having some difficulty and 17.7% facing a great deal of difficulty.

On the other hand, at baseline 68.6% of families/carers reported that the services they and their family member with a disability use listen to them (SF), and 63.7% said that the services they received helped them plan for the future (LF).

### Succession planning

At baseline, the majority of families/carers (60.8%) said they had not made plans for when they are no longer able to care for their family member with a disability, and 27.0% said they had begun making preparations. For the families/carers who reported that they had asked for assistance, the most common sources of assistance were the participant's siblings (37.4%), service providers (33.3%), extended family (25.8%) and professionals (25.1%). Families/carers were least likely to ask for assistance from their friends (10.1%) or friends of their family members (5.7%).

**Figure 6.2 Succession planning for families/carers of participants aged 25 and over**



### Employment

At baseline, 34.6% of families/carers are in a paid job, and 58.6% say that the family member who provides informal care to the participant is able to work as much as they want. The main barriers to working more were the situation of the family member with a disability (87.2%), insufficient flexibility of jobs (20.2%), and availability of jobs (12.0%). It is important to note that a higher proportion of families/carers of participants aged 25 and over have reached retirement age, compared to the families/carers of younger participants, which has an impact on the percentage of families/carers in a paid job. However, the percentage who are able to work as much as they want is higher than for other participant age cohorts.

### Health and wellbeing

58.9% of families/carers rate their health as good, very good or excellent at baseline. This is lower than the results for the other participant age groups, likely reflecting the older age of this cohort. 54.5% of families/carers disagreed or strongly disagreed that their family member with disability gets the support that they need at baseline.

Several additional questions are included in the LF regarding the wellbeing of families/carers and their outlook on life generally. For the question on their own expectations for the future, 46.4% of families/carers answered positively, 35.3% had mixed feelings and 10.4% answered negatively (7.9% did not know). With respect to their family member with a disability, 47.7% of families/carers agreed or strongly agreed that they feel more confident about the future of their family member with disability under the NDIS, while 45.5% responded neutrally.

In the LF, at baseline, 57.1% of families/carers agreed or strongly agreed that having a family member with disability has made it more difficult to meet everyday costs of living, while 24.0% disagreed or strongly disagreed (18.9% were neutral). For the question on whether families/carers felt that services and supports had helped them better care for the participant, 48.6% answered positively, 40.8% were neutral and 10.6% had a negative response.

## 6.2.2 Baseline indicators – participant characteristics

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

Key findings from the one-way analyses and regression modelling include:

### Disability type

Families/carers of participants with hearing impairments were the least likely to say that the situation of their family member with a disability was a barrier to working more, and the most likely to rate their health as good, very good or excellent compared to families/carers of participants of all other disability types. They generally also had the highest positive response rate for questions related to whether they feel supported and had the lowest rate of receipt of government benefits (10.8% for Carer Payment, and 11.5% for Carer Allowance).

Table 6.1 shows baseline family/carer outcomes for which the participant's primary disability type is a significant ($p<0.05$) predictor in the multiple-regression model.

### Table 6.1 Relationship of disability type with the likelihood of selected outcomes:

| Outcome | Participant primary disability | | | | |
|---|---|---|---|---|---|
| | Autism | Down syndrome | Hearing impairment | Psychosocial disability | Visual Impairment |
| Being in a paid job | | ⬇ | | ⬇ | |
| Receiving carer payments | ⬆ | ⬆ | ⇩ | ⇩ | |
| Receiving carer allowance | ⬆ | ⬆ | ⇩ | ⇩ | ⬆ |
| 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 family member with disability | ⬇ | | | | ⬇ |
| 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 to support their family member with disability as often as needed | ⬇ | ⬆ | | ⬇ | ⬇ |
| Having people they can talk to for emotional support as often as needed | ⬇ | ⬆ | | ⬇ | ⬇ |
| Feeling the services they and their family member with disability use listen to them | | ⬆ | ⬇ | ⬆ | |
| Feeling in control of selecting the services and supports that meet the needs of their family member with disability | | ⬆ | | ⬇ | ⬇ |

| Outcome | Participant primary disability | | | | |
|---|---|---|---|---|---|
| | Autism | Down syndrome | Hearing impairment | Psychosocial disability | Visual Impairment |
| **Saying the services for them and their family member with disability meet their needs** | | ⬆ | | ⬇ | ⬇ |
| **Having made plans for when they are no longer able to care for their family member with disability** | | ⬆ | | | ⬇ |
| **Having asked for assistance from siblings of the person with disability** | | | | ⬆ | |
| **Rating their health as excellent, very good or good** | ⬇ | ⬇ | | | ⬇ |
| **Feeling their family member gets the support they need** | | ⬆ | | ⬇ | ⬇ |
| **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** | | | ⬆ | | |

### Participant age

The percentage of families/carers of participants that are in a paid job is highest for participants aged 34 or younger at 40.9%, and lowest for families/carers of participants aged between 35 and 44, at 28.2%. Family/carer age is positively correlated with participant age, so families/carers of older participants are more likely to have reached retirement age.

The percentage of families/carers who provide informal care for participants and are able to work as much as they want is lowest for respondents of participants aged 34 or younger at 54.3% and highest for respondents of participants aged 35 to 44, at 62.1%. At least 84.5% of family and carers of participants across all age groups say that the situation with their family member with a disability is a barrier to working more.

Table 6.2 shows baseline family/carer outcomes of which participant age is a significant (p<0.05) predictor in the multiple-regression model. Table 6.2 is located after the “Indigenous status” section below.

## CALD status

Controlling for other factors, baseline outcomes for families/carers of participants with a CALD background were less likely to be positive. For example, families/carers of CALD participants were less likely to be able to advocate for their family member, were less likely to feel in control when selecting services and supports, and were less likely to be able to work as much as they want. Table 6.2 shows baseline family/carer outcomes of which participant CALD status is a significant (p<0.05) predictor in the multiple-regression model. Table 6.2 is located after the “Indigenous status” section below.

## Indigenous status

Baseline outcomes for families/carers of participants from Indigenous backgrounds were generally worse than those for families/carers of non-Indigenous participants, especially with regard to employment and health and wellbeing.

Table 6.2 shows baseline family/carer outcomes for which participant Indigenous status is a significant (p<0.05) predictor in the multiple-regression model.

**Table 6.2 Relationship of participant age, CALD status and Indigenous status with the likelihood of selected outcomes:**

| Outcome | Variable | | |
|---|---|---|---|
| | Participant is older | Participant is CALD | Participant is Indigenous |
| 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 advocate for their family member with disability | ⬇ | ⬇ | |
| Having friends they can see as often as they'd like | ⬆ | ⬇ | |
| Having people they can ask for practical help as often as needed | ⬆ | ⬇ | |

| Outcome | Variable | | |
|---|---|---|---|
| | Participant is older | Participant is CALD | Participant is Indigenous |
| Having people they can ask to support their family member with disability as often as needed | ↑ | ↓ | |
| Having people they can talk to for emotional support as often as needed | ↑ | ↓ | |
| Feeling the services they and their family member with disability use listen to them | ↑ | ↓ | |
| Feeling in control of selecting the services and supports that meet the needs of their family member with disability | ↑ | ↓ | |
| Saying the services for them and their family member with disability meet their needs | ↑ | ↓ | |
| Having made plans for when they are no longer able to care for their family member with disability | ↑ | | |
| Having asked for assistance from siblings of the person with disability | ↑ | ↓ | |
| Rating their health as excellent, very good or good | ↓ | | ↓ |
| Feeling their family member gets the support they need | ↑ | ↓ | |
| 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 | ↓ | | |

### Participant level of function and annualised plan budget

Families/carers of participants with higher levels of function or lower annualised plan budgets tended to have better outcomes at baseline. For example, 69.9% of families/carers were able to work as much as they wanted to if the participant had a high level of function, compared to 50.8% if the participant had a low level of function. Families/carers of participants with a low level of function are more likely to ask for help from service providers, professionals or support workers when planning for when they are no longer able to care for their family member with disability, with 68.6% of them doing so compared to 45.0% for families/carers of participants with a high level of function. Furthermore, families/carers of participants with high level of function were more likely to respond positively as compared to participants with low level of function for all questions related to whether the family feels supported. The likelihood of receiving carer payment and carer allowance also increases as the participant’s level of function decreases, but after controlling for other factors, no statistically significant relationship with annualised plan budget was found.

Families/carers of participants with a higher annualised plan budget were particularly likely to respond less positively in the support domain. For example, 57.7% of families/carers of participants with an annualised plan budget below $15,000 reported that they had friends they could see as often as they like, whereas this decreases to 37.8% for families/carers of participants with an annualised plan budget of $100,000 or more. Similarly, 50.3% of families/carers of participants with an annualised plan budget under $15,000 said that they had people they could ask for practical help as often as needed, decreasing to 30.4% of families/carers of participants with an annualised plan budget above $100,000.

Table 6.3 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.

**Table 6.3 Relationship of participant level of function and annualised plan budget with the likelihood of selected outcomes:**

| | Variable | |
|---|---|---|
| Outcome | Higher level of function | Higher annualised plan budget |
| For family/carers with a paid job, working 15 or more hours per week | ⬆ | |
| Receiving carer payment | ⇩ | |
| Receiving carer allowance | ⇩ | |
| Being able to identify the needs of their family member with disability | ⬆ | |
| Being able to advocate for their family member with disability | ⬆ | |
| 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 to support their family member with disability as often as needed | ⬆ | ⬇ |
| Having people they can talk to for emotional support as often as needed | ⬆ | |
| Feeling the services they and their family member with disability use listen to them | ⬆ | |
| Feeling in control of selecting the services and supports that meet the needs of their family member with disability | ⬆ | |

| Outcome | Variable | |
|---|---|---|
| | Higher level of function | Higher annualised plan budget |
| **Saying the services for them and their family member with disability meet their needs** | ↑ | |
| **Having made plans for when they are no longer able to care for their family member with disability** | ↑ | |
| **Having asked for assistance from siblings of the person with disability** | ↓ | |
| **Rating their health as excellent, very good or good** | ↑ | |
| **Feeling their family member gets the support they need** | ↑ | ↓ |
| **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** | ↓ | |

### 6.2.3 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). We consider 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 a respondent's responses from baseline to their second review.

Table 6.4 summarises changes for selected indicators across different time periods. Cohort "B,R1,R2" includes participants responding at baseline, first review and second review[42]. Cohort "B,R1" includes participants responding at both baseline and first review (but not at second review, so the cohorts are mutually exclusive). Indicators were selected for the

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

tables if the change was statistically significant[43] and had an absolute magnitude greater than 0.02[44].

**Table** 6.4 **Selected longitudinal indicators for families/carers of participants aged 25 and over**

| 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 people who they can ask for emotional support as often as they need (*) | B,R1,R2 | 48.4% | 51.9% | 54.9% | 3.5% | 3.1% | 6.6% | Improvement |
| | | B,R1 | 50.7% | 52.7% | | 2.0% | | | |
| AC (SF) | % of families/carers who feel that the services their family member with disability and their family use listen to them (**) | B,R1 | 67.7% | 71.3% | | 3.6% | | | Improvement |
| AC (SF) | % of families/carers who say that the services for their family member with disability and their family receive meet their needs | B,R1,R2 | 23.1% | 34.6% | 40.7% | 11.5% | 6.1% | 17.6% | Improvement |
| | | B,R1 | 21.5% | 30.3% | | 8.8% | | | |
| AC (LF) | % of families/carers who have no difficulties working in partnership with professionals and service providers to meet the needs of their family member with disability | B,R1,R2 | 62.1% | 75.0% | 89.7% | 12.9% | 14.7% | 27.6% | Improvement |
| | | B,R1 | 78.5% | 78.8% | | 0.3% | | | |
| AC (LF) | % of families/carers who say the services their family member with disability and family receive help to plan for the future | B,R1,R2 | 44.8% | 57.1% | 75.9% | 12.3% | 18.7% | 31.0% | Improvement |
| | | B,R1 | 64.1% | 73.7% | | 9.6% | | | |
| HW (LF) | Thinking about what happened last year, and what they expect for the future, % who are delighted, pleased or mostly satisfied (*) | B,R1,R2 | 56.7% | 62.1% | 66.7% | 5.4% | 4.6% | 10.0% | Improvement |
| | | B,R1 | 44.1% | 55.9% | | 11.9% | | | |
| HW (LF) | % who strongly agree or agree that they feel more confident about the future of their family with disability under the NDIS (**) | B,R1 | 34.7% | 56.2% | | 21.5% | | | Improvement |

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[43] McNemar's test at the 0.05 level

[44] 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 people who they can ask for emotional support as often as they need (*) | B,R1,R2 | 48.4% | 51.9% | 54.9% | 3.5% | 3.1% | 6.6% | Improvement |
| | | B,R1 | 50.7% | 52.7% | | 2.0% | | | |
| HW (LF) | % who strongly agree or agree that services and supports have helped them to better care for their family member with disability (*) | B,R1,R2 | 43.3% | 62.1% | 70.0% | 18.7% | 7.9% | 26.7% | Improvement |
| | | B,R1 | 55.4% | 65.8% | | 10.5% | | | |
| HW (SF) | % of families/carers who feel their family member with disability gets the support they need | B,R1,R2 | 29.5% | 38.8% | 48.9% | 9.2% | 10.1% | 19.3% | Improvement |
| | | B,R1 | 27.5% | 35.7% | | 8.2% | | | |
| GB (SF) | % of families/carers that are receiving carer allowance | B,R1,R2 | 40.7% | 51.9% | 56.0% | 11.2% | 4.2% | 15.4% | Context dependent |
| | | B,R1 | 44.1% | 48.3% | | 4.2% | | | |
| SC (SF) | Of those who have begun planning for the future care of their family member, % who have asked for help from service providers, professionals or support workers (**) | B,R1 | 57.3% | 61.2% | | 3.9% | | | Context dependent |
| HW (SF) | % of families/carers who rate their health as excellent, very good or good (**) | B,R1 | 59.4% | 55.5% | | -3.9% | | | Deterioration |
| HW (SF) | For those unable to work as much as they want, % who say insufficient flexibility of jobs is a barrier to working more (**) | B,R1 | 21.3% | 23.6% | | 2.3% | | | Deterioration |

(*) Two year change for B,R1,R2 cohort is not significant at the 0.05 level.
(**) Results for B,R1,R2 cohort not shown due to small numbers

Noting the small volume of respondents to both the survey at second review and the long form questions, the key findings from Table 6.4 include:

- Families/carers express greater satisfaction with services, with a significant increase in the percentage who say that the services that their family member with disability and their family receive meets their needs.
- In the health and wellbeing domain, more families/carers feel their family member with disability gets the support they need.
- For the cohort entering in 2016-17, there were large improvements in the percentage of families/carers who have no difficulties working in partnership with professionals and service providers to meet the needs of their family member with disability. For both cohorts, there were significant improvements in the percentage of

families/carers whose family member with disability and family receive help to plan for their future.
- There has been a considerable increase in the percentage of families/carers who say they receive carer allowance.

### 6.2.4 Longitudinal indicators – key characteristics

Due to small sample sizes for families/carers who responded at both baseline and second review (less than 100), the analysis of longitudinal indicators by key characteristics for families/carers of participants aged 25 and over only covers short form responses between baseline and first review. Baseline to second review short form results are shown in the summary tables only.

***The services my family member with disability and my family receive meet our needs***

Table 6.5 sets out the breakdown of the movements in responses between baseline and first review and between baseline and second review.

**Table 6.5 Breakdown of net movement in longitudinal responses**

| Longitudinal Period | Number of Baseline Responses in cohort | | Improvements: No to Yes | | Deteriorations: Yes to No | | Net Movement |
|---|---|---|---|---|---|---|---|
| | No | Yes | Number | % | Number | % | |
| **Baseline to Review 1** | 4,054 | 1,116 | 624 | 15.4% | 167 | 15.0% | 8.8% |
| **Baseline to Review 2** | 62 | 27 | 23 | 37.1% | 7 | 25.9% | 18.0% |

The following factors had a positive relationship with the response at first review (those exhibiting these factors had a greater likelihood of improving their response):

- Higher level of funding in the participant's plan
- Plan is fully self-managed
- Plan category is 0-15% capacity building
- Participant lives in Queensland
- Participant has a lower level of NDIA support
- Participant has a higher level of plan utilisation

The following factors had a negative relationship (less likely to improve on baseline response):

- Plan category is 30-60% capacity building
- Participant's plan is managed by a plan manager
- Participant has a higher level of NDIA support
- Family/carer's reported employment status did not change between surveys

Of the family and carers who received adequate support at baseline, the following factors increased the likelihood of maintaining the favourable response at first review:

- Higher level of funding in the participant's plan
- Higher level of function
- Participant is in supported independent living.

***I feel that my family member gets the support he/she needs***

Table 6.6 sets out the breakdown of the movements in responses between baseline and first review and between baseline and second review.

**Table 6.6 Breakdown of net movement in longitudinal responses**

| Longitudinal Period | Number of Baseline Responses in cohort | | Improvements: No to Yes | | Deteriorations: Yes to No | | Net Movement |
|---|---|---|---|---|---|---|---|
| | No | Yes | Number | % | Number | % | |
| **Baseline to Review 1** | 3,683 | 1,402 | 684 | 18.6% | 269 | 19.2% | 8.2% |
| **Baseline to Review 2** | 62 | 27 | 23 | 37.1% | 7 | 25.9% | 18.0% |

For the families/carers who did not feel their family member was receiving the support they needed at baseline, the following factors increased the likelihood of an improved response at first review:

- Higher level of funding in the participant's plan
- Participant responded that they feel safe or very safe at home
- Participant lives in Queensland
- Participant has a lower level of NDIA support
- Participant has a higher level of plan utilisation

The following factors decreased the likelihood of an improved response:

- Participant responded that they feel unsafe or very unsafe at home
- Participant lives in Victoria
- Participant has a higher level of NDIA support

At baseline, of the carers who felt their family member received the support they needed, those caring for participants in supported independent living were more likely to maintain their response at first review. Carers whose employment hours increased between baseline and first review were less likely to maintain their positive response.

# 7. Families/carers of participants aged 25 and over: Has the NDIS helped?

## 7.1 Aggregate results

For participants who have been in the Scheme for approximately one or two years as at 30 June 2019, Figure 7.1 shows the percentage of families/carers of participants aged 25 and over who think that the NDIS has helped with outcomes related to each of the five SF domains, after one year in the Scheme and after two years in the Scheme.

**Figure 7.1 Percentage of families/carers who think that the NDIS has helped with outcomes related to each domain**

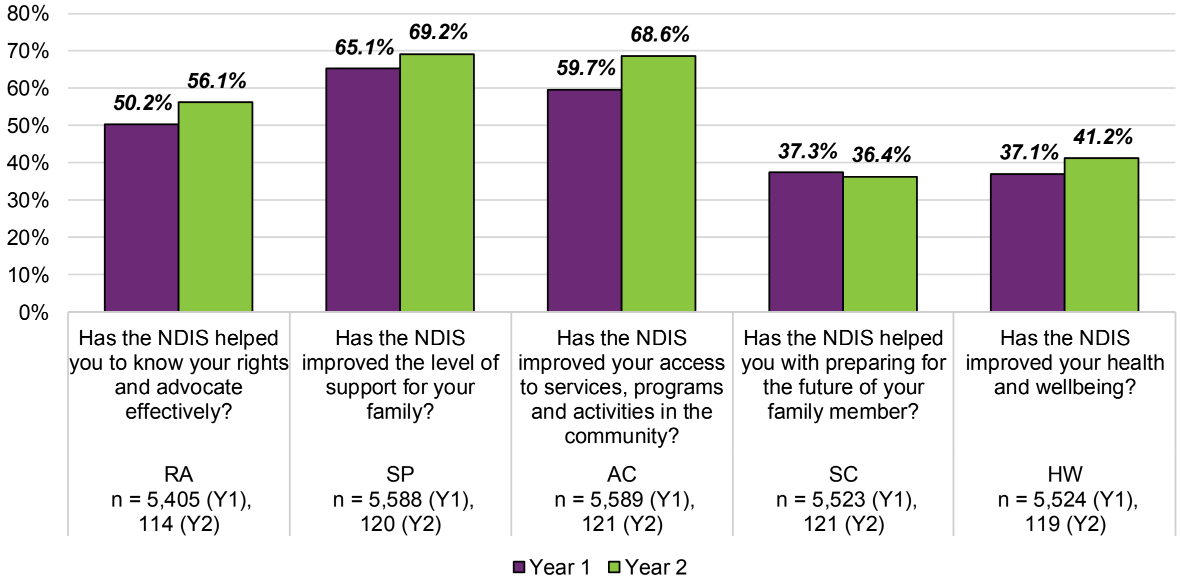

Figure 7.1 shows that most families/carers think that the NDIS has helped with three out of the five SF domains.

Families/carers of participants aged 25 and over were more likely to say that the NDIS has helped than families/carers of participants aged 15 to 24, across all comparable domains. The percentage of families/carers who say the NDIS has helped after two years in the Scheme is generally on par with that of families/carers of participants aged 0 to 14. Out of all the cohorts, families/carers of participants aged 25 and over saw the greatest improvement in the advocacy and access to services domains.

The most positive responses were for improving access to services, programs and activities in the community (59.7% after one year, increasing to 68.6% after two years) and for improving the level of support for the family (65.1% after one year, increasing to 69.2% after two years). In the health and wellbeing domain, positive response rates increased from 37.1% at first review, to 41.2% at second review. Responses were less positive for the “Has the NDIS helped you with preparing for the future support of your family member” question (37.3% at first review and 36.4% at second review). Improvements in positive response rates between first and second review were observed across all domains except preparing for the future of the participant.

## 7.2 Results by participant and family/carer characteristics

### 7.2.1 Year 1 ‘Has the NDIS helped?’ indicators – participant characteristics

Indicators at first review have been analysed by participant and family/carer characteristics using one-way analysis and multiple regression. Table 7.1 shows the relationship of different participant and carer characteristics with the likelihood of families/carers saying that the NDIS has helped. A characteristics is included in the table if it has a significant relationship with at least two of the ‘Has the NDIS Helped?’ questions, and all significant relationships are in the same directions (for example, a characteristic with two significant and positive relationships with ‘Has the NDIS Helped?’ questions will be included, but a characteristic with three significant positive relationships and one significant negative relationship will not be).

**Table 7.1 Relationships of participant characteristics with the likelihood of positive family/carer responses**

| Characteristic | Saying the NDIS has helped |
|---|---|
| **Higher plan utilisation** | ⬆ |
| **Higher annualised plan budget** | ⬆ |
| **Participant’s disability is a hearing impairment** | ⬇ |
| **Participant’s disability is a spinal cord injury** | ⬇ |
| **Participant’s disability is caused by a stroke** | ⬆ |
| **Participant’s disability is a psychosocial disability** | ⬆ |
| **Participant’s disability is another neurological disability** | ⬆ |
| **Participant’s disability is multiple sclerosis** | ⬆ |
| **0-30% of supports are capacity building supports** | ⬆ |
| **60-100% of supports are capacity building supports** | ⬇ |
| **Participant has a higher level of NDIA support** | ⬇ |
| **Higher Index of Economic Resources** | ⬇ |
| **Participant feels unsafe or very unsafe at home** | ⬇ |
| **Participant rates their health as poor** | ⬇ |

| Characteristic | Saying the NDIS has helped |
|---|---|
| **Participant has a higher level of function** | ⬆ |
| **Lives in QLD** | ⬆ |
| **Plan is fully self-managed** | ⬆ |
| **Plan is fully agency-managed** | ⬇ |

### Plan utilisation

Baseline plan utilisation was a significant predictor in all multiple regression models. Families/carers of participants with a higher baseline plan utilisation were more likely to say the NDIS has helped. On a one-way basis, 37.3% of families/carers of participants with utilisation under 20% indicated that the NDIS improved their access to services and programs, compared to 70.3% for families/carers of participants with utilisation of 80% or higher. Similarly, 28.3% of families/carers of participants with utilisation under 20% say the NDIS helped them with preparing for the future support of their family member with disability, compared to 42.9% of families/carers of participants with utilisation of 80% or higher.

### Plan Budget

Families/carers of participants with a higher annualised plan budget were more likely to say that the NDIS had helped, across all domains. For example, the percentage of families/carers who felt that the NDIS improved the level of support for their family increased from 43.2% for those with a plan budget of $15,000 or less to 72.1% for those with a plan budget of $100,000 or more. A similar increase was observed in the percentage of families/carers who said the NDIS improved their access to services (37.7% for those with a plan budget of $15,000 or less compared to 63.3% for those with a plan budget of $100,000 or more).

### Disability Type

Families/carers' perceptions of whether the NDIS helped varied by the participant's disability type and domain. For example:

- Families/carers of participants with autism were less likely to think the NDIS improved their health and wellbeing (31.8%), whereas families/carers of participants with cerebral palsy or another neurological disability were more likely to respond positively (38.6%).
- Families/carers of participants with another neurological disability were more likely to say that the NDIS improved their access to services, programs and activities in the community, compared to families/carers of participants with a spinal cord injury.
- Families/carers of participants who have had a stroke are more likely to feel the NDIS improved the level of support for their family.

### Plan management type

Multiple regression analyses indicates that families/carers of participants with fully self-managed plans were more likely to say that the NDIS has helped, across all but the support and access to services domains. Conversely, families/carers of participants with fully agency-managed plans were less likely to respond positively, across all domains except for the access to services domain.

For example, only 35.9% of families/carers of participants with fully agency-managed plans indicated that the NDIS improved their health and wellbeing, compared to 45.3% of families/carers of participants with fully self-managed plans. Similarly, 48.5% of families/carers of participants with fully agency-managed plans said that the NDIS improved their capacity to advocate for their family member with disability, compared to 55.4% of families/carers of participants with fully self-managed plans.

### Plan category

Both multiple regression and one-way analyses show that families/carers of participants who commit 0-15% of their plan budget to capacity building were more likely to say that the NDIS helped with feeling supported (69.1% compared to 65.1% overall), access to services (65.7% compared to 59.7%) and health and wellbeing (40.0% compared to 37.1%). The analysis also indicates that for these same three domains, families/carers of participants who commit 60-100% of their plan budget to capacity building were less likely to say that the NDIS has helped (49.7%, 47.6% and 28.9%, respectively).

### State/Territory

Residents of Queensland were more likely to say that the NDIS improved their capacity to advocate for their family member with disability and that the NDIS improved the level of support for their family. For example, on a one-way basis, 71.6% of families/carers from Queensland said that the NDIS improved the level of support for their family, compared to 63.9% of families/carers from New South Wales and 64.6% of families/carers from Victoria.

### Other characteristics

Families/carers of participants who live in an area with a higher Index of Economic Resources (IER) were less likely to respond positively when asked whether the NDIS improved their access to services, helped prepare for the future support of their family member, or improved their health and wellbeing.

Families/carers of participants who felt unsafe or very unsafe at home were less likely to respond positively in the domain of advocacy for their family member with disability. Families/carers were also less likely to report that the NDIS improved their health and wellbeing if the participant also rated their health as poor.

Families/carers of participants with higher levels of function were more likely to respond that the NDIS helped with preparation for the future support of their family member and improved their health and wellbeing.

Longitudinal modelling did not show any significant relationships, primarily due to the small number of respondents completing both the first and second reviews.