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.

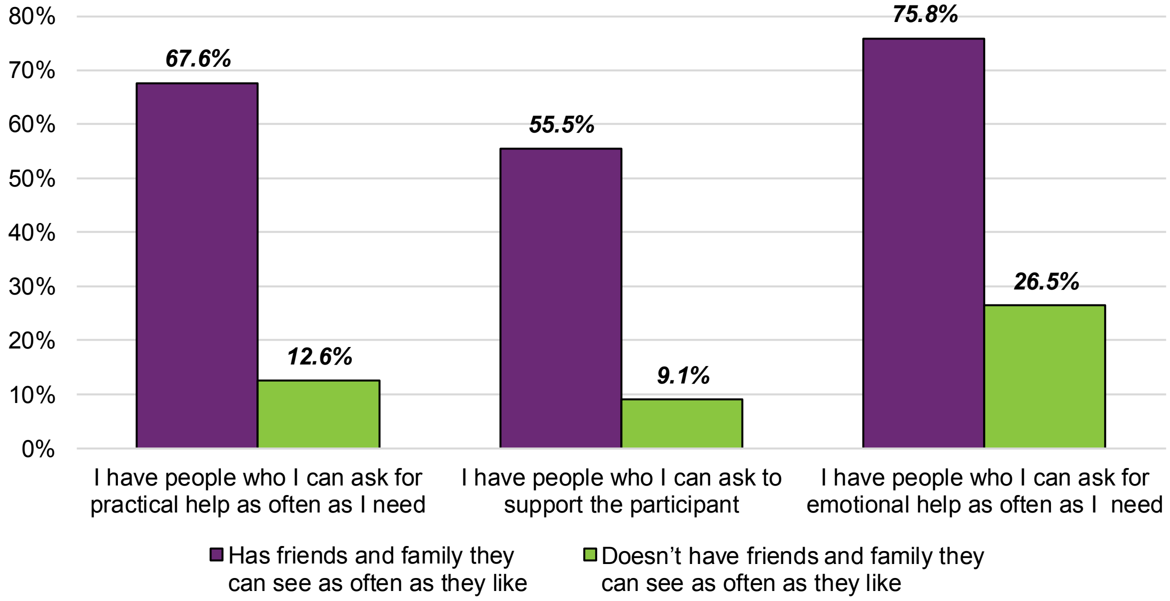
Rights and advocacy

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.

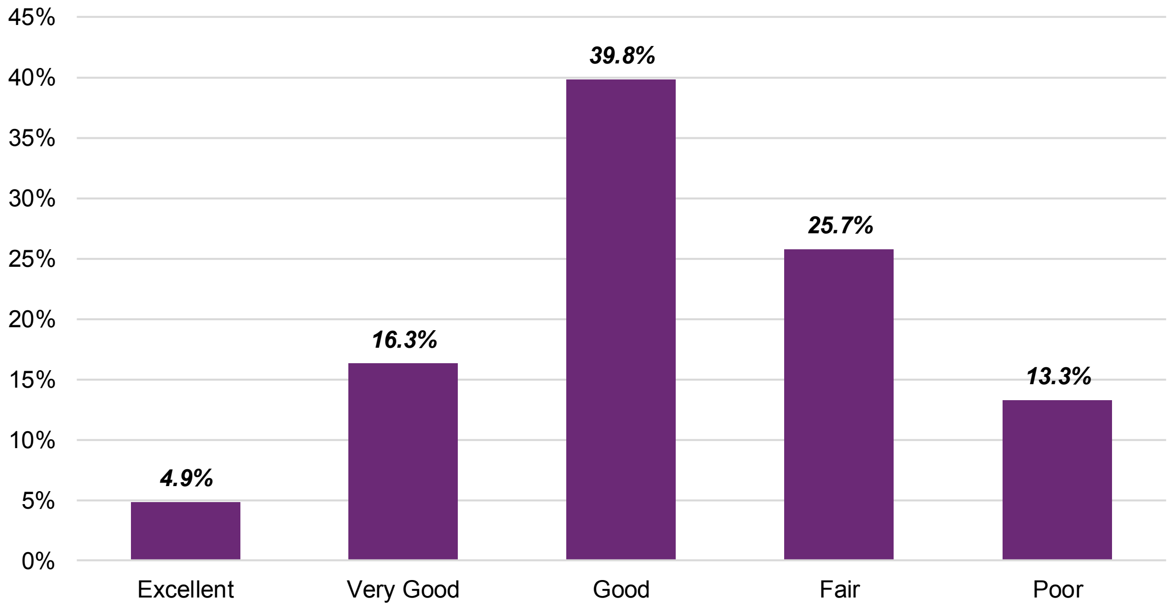
Employment

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

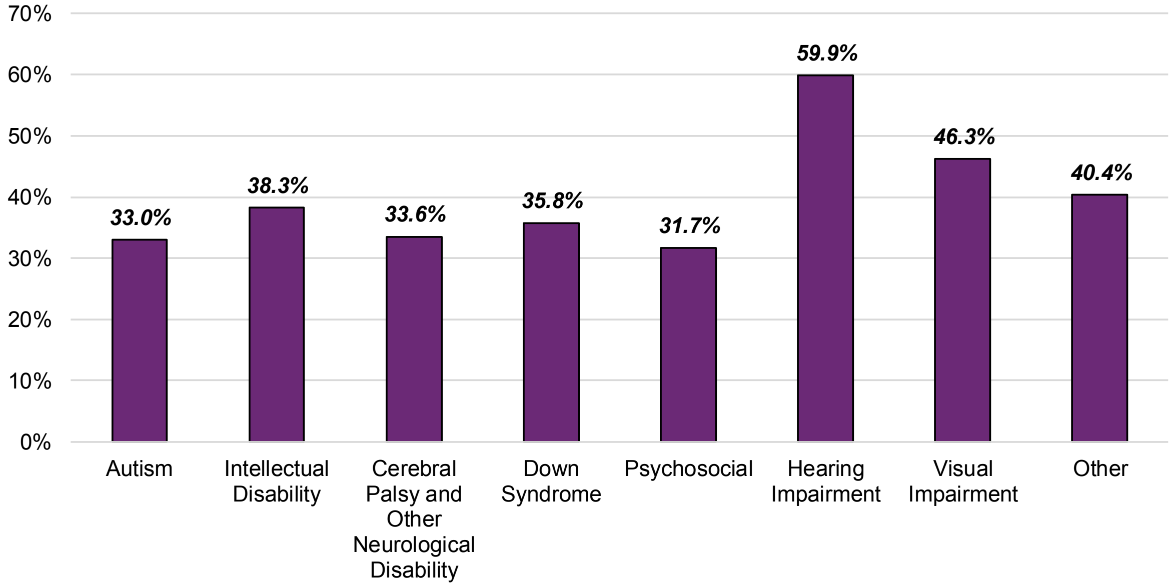

Figure 4.2 shows that 31.7% of families/carers of participants with a psychosocial disability have people who they can ask for practical help as often as they need, lower than the overall average of 36.2%. In addition to the outcomes highlighted above, the percentage who feel in control selecting the 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

Outcome	Variable	
	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	⬆	⬇

	Variable	
Outcome	**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

Outcome	Variable	
	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	↑	↓

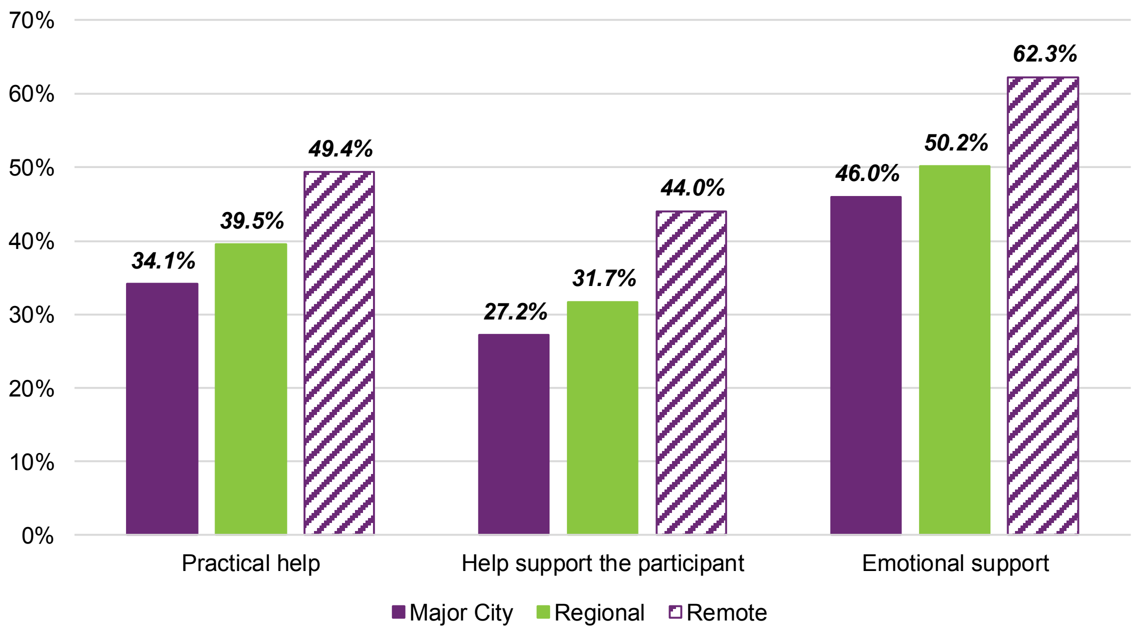
Remoteness

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

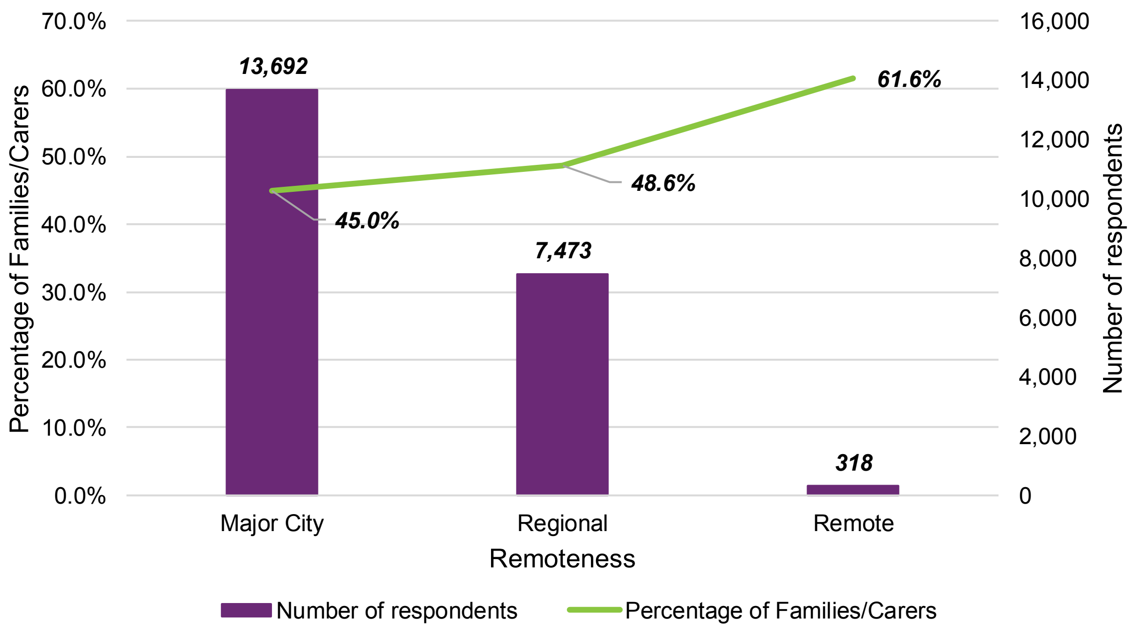
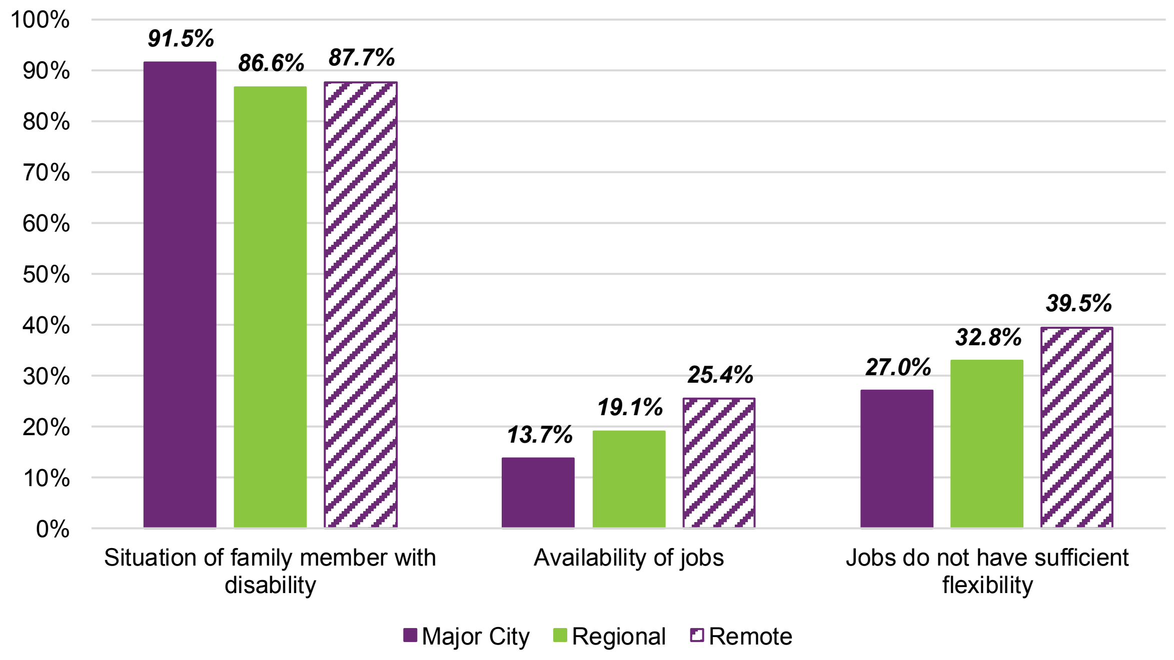


Figure 4.5 For those who are unable to work as much as they want, the percentage of families/carers with different barriers to working more, by region



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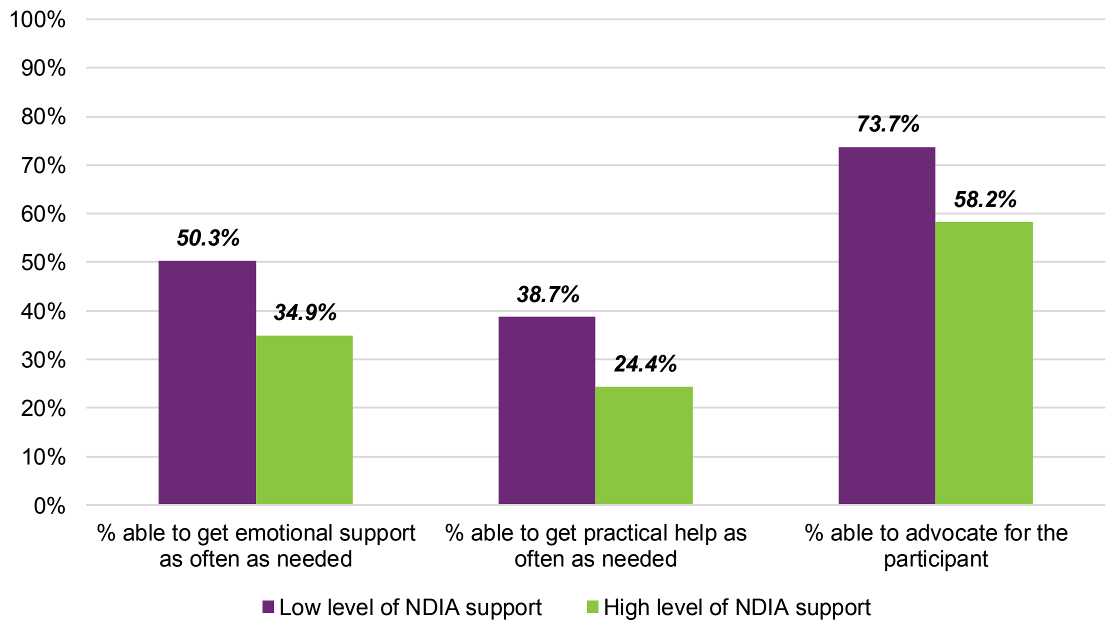
[35] Note that these baseline differences reflect characteristics of participants who choose to self manage, rather than the self-management process itself (since the results are at the start of the participant's first plan).

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 Relationship with likelihood of		Baseline to Second Review 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		Baseline to Second Review	
	Relationship with likelihood of		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 Relationship with likelihood of		Baseline to Second Review 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 Relationship with likelihood of		Baseline to Second Review 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 Relationship with likelihood of		Baseline to Second Review 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 Relationship with likelihood of		Baseline to Second Review 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.