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

3.1 Key findings

Box 3.1: Key findings for families/carers of participants from birth to age 14

- In the longitudinal analysis, some significant changes were observed, and the majority of these changes were positive:
  - The percentage of families/carers working in a paid job has increased from 45% at baseline to 48% at review, but is still considerably lower than for Australians without caring responsibilities (76%)[15].
  - The percentage of families/carers in a paid job who work 15 hours or more has increased from 79% to 81%. The percentage working less than 30 hours per week has decreased from 57% to 55%, but is still much higher than the 26% of Australians working on a part-time basis as at 30 June 2018[16].
  - Families and carers report increased levels of support to care for their child with disability. The percentage who feel that their child gets the support he/she needs increased from 27% to 53%, and the percentage who think that the services and supports have helped them to better care for their child with disability increased from 31% to 71%.
  - Families and carers report increasing ability and confidence in helping their children develop and learn. The percentage of families/carers who know what they can do to support their child’s learning and development has increased from 42% at baseline to 50% at review. The percentage who know what specialist services are needed to support this development has also increased (from 40% to 48%). The percentage who say they get enough support to feel confident in parenting their child has increased from 45% to 49%.
  - The percentage feeling more confident about the future of their child with disability under the NDIS has improved (from 51% to 68%).
  - Some deterioration was observed in self-rated health, with the percentage rating their health as good, very good or excellent falling from 73% to 69%. For Australians aged 25 to 64, the corresponding percentage is 87%[17]. Families and carers were also more likely to perceive the situation of their child with disability as a barrier to working more (88% to 91%) and to engaging socially more (91% to 93%).
- Participant age had an impact on family/carer outcomes, with both baseline and longitudinal change tending to be better for families and carers of younger participants.

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[15] ABS Survey of Disability, Ageing and Carers (SDAC) 2015, non-carers aged 15 to 64. https://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0

[16] Australian Bureau of Statistics. 2018. 6202.0 Labour force, Australia, Jun 2018. 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 26%.

[17] ABS National Health Survey (NHS) 2014-15. Families/carers of 0 to 14 year olds are likely to be towards the younger end of the 25-64 age range.

Box 3.1: Key findings for families/carers of participants from birth to age 14 (continued)

- Baseline indicators and longitudinal change for some indicators tended to be worse for families and carers of participants from CALD backgrounds. This may be due to more difficulty in accessing information and lack of support networks.
- Families and carers with poorer self-rated health tended to have worse outcomes, both baseline and longitudinal.
- In one-way analyses, baseline outcomes for families and carers of participants with hearing impairment tended to be better, and those for families and carers of participants with a psychosocial disability tended to be worse, than average.
- Families and carers who have sufficient information and support, know what supports their child needs and can access them, and feel confident in parenting their child, tend to have more favourable outcomes at baseline, and tend to experience greater improvement longitudinally.
- Opinions on whether the NDIS has helped after one year in the Scheme vary by domain, from only 38% who think that the NDIS has helped with health and wellbeing (including employment and social participation) to 69% who think that the NDIS has improved their capacity to help their child develop and learn. Results tended to be more positive for families and carers of participants who are younger, have higher baseline plan utilisation, and are from less intensive streaming categories. Families and carers with sufficient knowledge, support, access to services, and confidence in parenting their child were also more likely to respond positively.

3.2 Results overview

3.2.1 Outcomes framework questionnaire domains

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

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

The LF for families and carers of participants aged 0 to 14 also includes four questions on whether families/carers understand their children's 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.

3.2.2 Baseline indicators – aggregate

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.

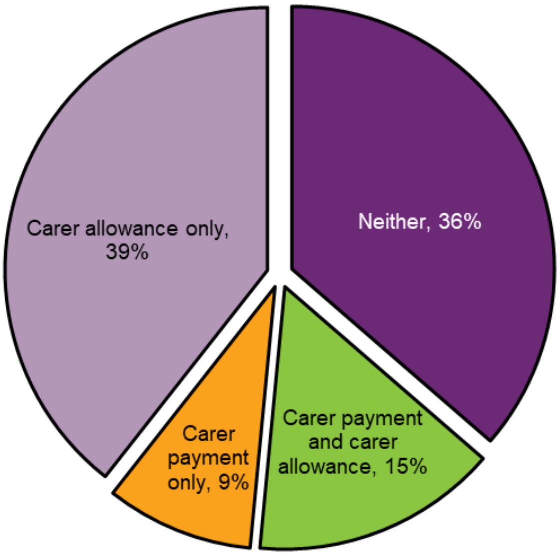
Carer Allowance is an income supplement available to carers who provide daily care in a private home for someone with a long-term disability (or someone who is frail aged). Before 20 September 2018 it was neither income nor assets tested, but from that date a $250,000 family income test threshold was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

As at 30 June 2018, 274,414 Australians were receiving Carer Payment and about 2.3 times as many, 622,423, were receiving Carer Allowance.

The outcomes framework questionnaires ask families and carers of NDIS participants whether they are currently receiving any government benefits (Carer Payment, Carer Allowance, or other benefits). At baseline, 25% of families and carers said they were receiving Carer Payment and 55% said they were receiving Carer Allowance. The ratio of Carer Allowance to Carer Payment (2.2) is similar to the 2.3 observed for the total populations in receipt of these benefits.

Figure 3.1 shows percentages of families/carers receiving Carer Payment and/or Carer Allowance.

Figure 3.1 Receipt of Carer Payment and Carer Allowance, families and carers of participants aged 0 to 14



The NDIA has also established a data linkage agreement with the Department of Human Services (DHS), with the long-term aim of measuring the wider economic impact of the NDIS. Investigation into the numbers of family members and carers of NDIS participants receiving Carer Payment and Carer Allowance from this source has commenced, and results will be reported once the analysis is completed.

Rights and advocacy

At baseline, 72% of families and carers were able to identify the needs of their child and family, 70% understood their rights and the rights of their child (LF question), and 78% were able to advocate for their child. However, 55% had some difficulty or a great deal of difficulty in accessing available services and supports to meet the needs of their child and family. 64% of families and carers identified at least one barrier to access or advocacy, the most common being limited access to information and resources (40%) and lack of support (33%).

Families feel supported

At baseline, most families and carers said they lacked sufficient support and social connections. 55% were unable to see friends and family as often as they like, 59% said they could not get as much practical help as they would like, and 72% said they could not get childcare as often as they need. However, 60% of families and 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 78% of families and carers have good (43%) or very good (35%) relationships with their services.

Families help their children develop and learn

At baseline, the SF reveals that 41% of families and carers know what they can do to support their child's learning and development, with a further 51% saying they have some degree of knowledge. A similar pattern is exhibited with regards to specialist services: 40%

of families and carers know what specialist services are needed and 52% have some degree of knowledge. 44% of family and carers agree that they get enough support to feel confident in parenting their child with disability, and a further 41% agree to some extent. 86% feel very confident (28%) or somewhat confident (58%) 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 and carers perceive the strengths and abilities of their child with disability, and how their child is progressing. 84% of families and carers can recognise their child's strengths and abilities and 78% can see how their child is progressing.

Health and wellbeing

At baseline, only 41% of families and carers say that they (and their partner) are able to work as much as they want. 45% say that they themselves would like to work more and 9% say that both they and their partner would like to work more. Of the families and carers who do not work as much as they like, 87% identified the situation of their child with disability as a barrier to working more, and 39% said that insufficient flexibility of jobs was a barrier.

Only 28% of families and carers say that they (and their partner) engage in social and community life as much as they like. Of those who do not, 90% identified the situation of their child with disability as a barrier to engaging more, and 46% said time constraints were a barrier.

From the SF, 72% of families/carers rate their health as good, very good or excellent, compared to 87% of Australians aged 25 to 64 overall.[18] Figure 3.2 compares the distribution of responses for families and carers to the population benchmark.

The LF includes a number of extra questions asking about the wellbeing of families and carers and their outlook on life generally, and for their child in particular. Families and carers most commonly had "mixed" feelings about the future generally (47%), although more answered positively (45%) than negatively (8%)[19]. The 45% responding positively is much lower than the 77% for Australians aged 25 to 64 overall[20], and is lower than for participants aged 25 and over (52%). Response distributions for families/carers and the general population are compared in Figure 3.3.

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[18] ABS National Health Survey (NHS) 2014-15. Families/carers of 0 to 14 year olds are likely to be towards the younger end of the 25-64 age range.

[19] Excluding "don't know" and missing.

[20] 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.

Figure 3.2 Self-rated health, families/carers of participants aged 0 to 14

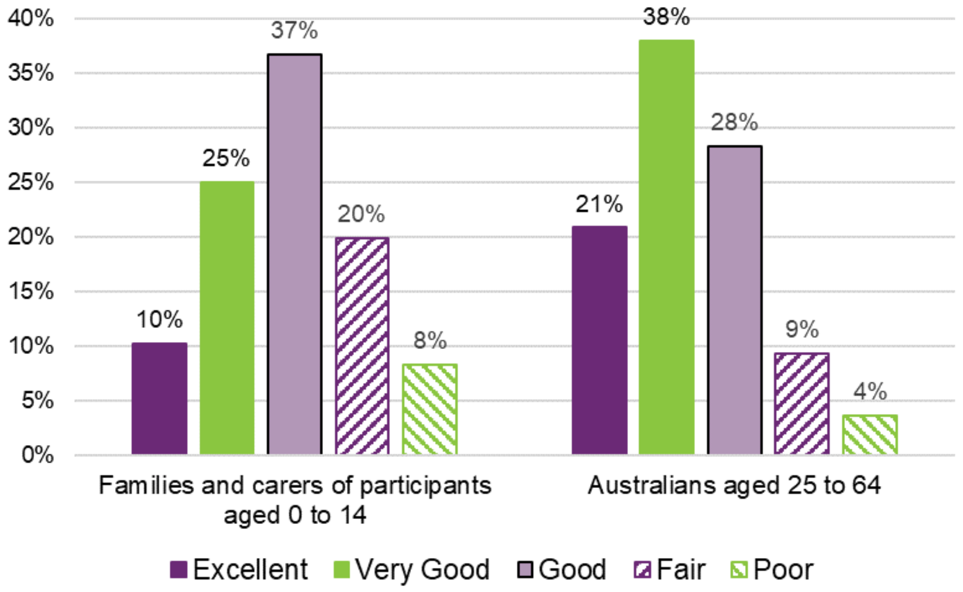
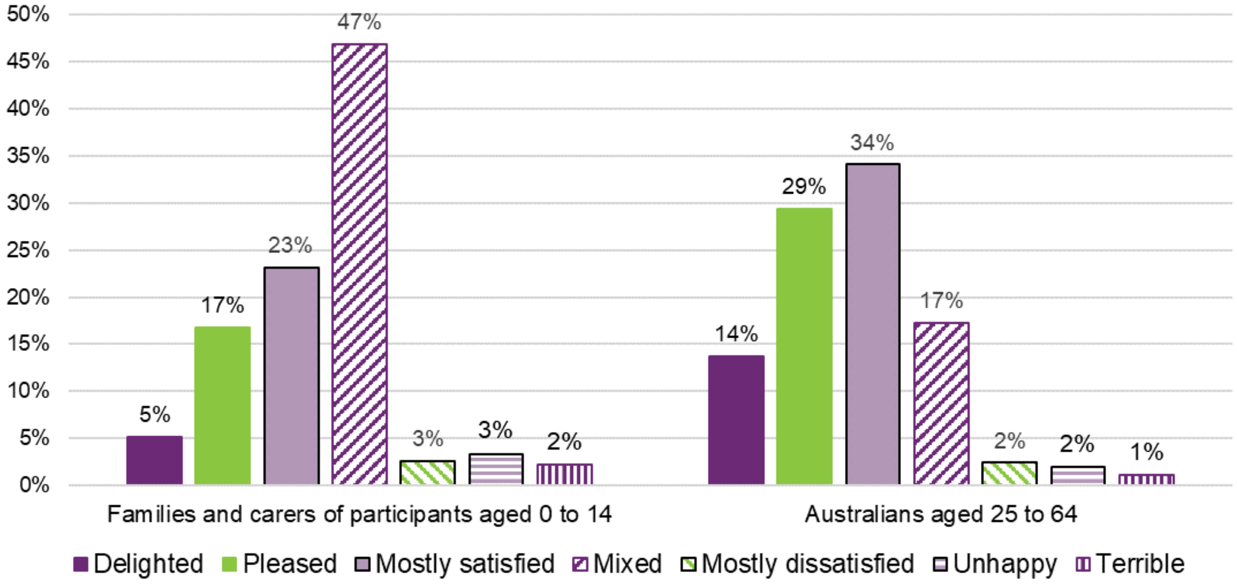


Figure 3.3 Outlook for the future, families/carers of participants aged 0 to 14



With regard to their child with disability, 73% agreed or strongly agreed that having a child with disability has made it more difficult to meet everyday costs of living. 51% agreed or strongly agreed that they feel more confident about the future of their child with disability under the NDIS, with 45% feeling neutral about this statement and only 4% expressing a negative opinion. The percentages agreeing or strongly agreeing that their child gets the support they need, or that the services and supports help them to better care for their child, are lower (34% for both statements). For these last two statements, the most common response was again "neutral" (40% and 42%, respectively).

3.2.3 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 age**
  In many cases, baseline outcomes for families and carers tend to deteriorate as their child gets older.[21] This is apparent from the one-way analyses and is generally confirmed by the multiple regression modelling. For example, the percentage of families and carers who say they are able to access available services and supports to meet the needs of their child and family decreases significantly with participant age: from 54-58% where the child is aged 6 or younger to 33% where the child is aged 14 (the overall percentage is 45%). Families and carers of older participants are also significantly more likely to cite limited access to information and resources as a barrier to access or advocacy: increasing from 27% where their child is aged 0 to 1, to 46% where they are aged 14 (the overall percentage is 37%). Support networks also appear to deteriorate as the child gets older, for example the percentage of families and carers with enough emotional support decreases from 75% where their child is 0-1 to 51% where their child is 14 (60% overall). Family and carer's self-rated health, and the ability to participate socially, also tend to deteriorate with participant age. Receipt of Carer Payment and Carer Allowance tends to increase with participant age.

- **Culturally and linguistically diverse backgrounds**
  Baseline outcomes for families and carers from CALD backgrounds tend to be worse in many cases 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 (60% compared to 79% 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 (47% compared to 36%). They were also less likely to have people to ask for practical help (32% versus 42%) and emotional support (48% versus 60%), and less likely to be able to work as much as they want (35% versus 41%).

- **Indigenous participants**
  Respondents for Indigenous participants are less likely to be the parents of the participant (82% versus 95%). Families and carers of Indigenous participants are less likely to be working in a paid job (29% versus 48%) and consequently more likely to be receiving Carer Payment (34% versus 24%).

- **Participant level of function and plan cost**
  Baseline outcomes tended to be better for families and carers of participants with higher level of function, and for lower baseline plan costs. 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 and 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.

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[21] 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).

- **Participant streaming intensity**
  Families and carers of participants requiring a higher level of support with planning (as measured by streaming intensity) were identified as having poorer baseline outcomes in several of the regression models. For example, families and carers of participants in the intensive and super intensive streams 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.

- **Family/carer self-rated health**
  In some instances, families and carers with better self-rated health tended to have better baseline outcomes. Controlling for other factors, this trend was observed for the percentage with family and friends they see as often as they like and the percentage with someone to ask for practical help as often as they need. Those with better health were also more likely to say they were able to work as much as they want.

- **Geography**
  Some mixed results were observed by State/Territory and by geographical remoteness. One-way analyses suggest that families and carers of participants from NT, and those in more remote locations, tended to experience worse outcomes in relation to advocacy and accessing services and supports. However, in multiple regression models, families and carers living in more remote locations were more likely to have people to ask for practical help as often as they needed, and more likely to be able to work as much as they want. On a one-way basis, receipt of government benefits was particularly high in Tasmania, where 44% received Carer Payment (compared to 25% overall) and 68% received Carer Allowance (compared to 55% overall).

- **Participant disability**
  The child's disability appears to have an impact on outcomes for families and carers. From the one-way analyses,[22] families and carers of participants with hearing impairment tend to have the best outcomes at baseline, and families and carers of participants with a psychosocial disability tend to have the worst.[23] Families and carers of participants with other sensory disabilities also tend to fare better than average, and families and carers of participants with intellectual disability tend to fare worse. For the health and wellbeing domain, families and carers of participants with autism tend to have poorer outcomes, being less likely to work and engage in social interactions as much as they want, and more likely to cite the situation of their child with disability as a barrier to working or engaging socially more. Families and carers of participants with Down syndrome were much more likely to be in receipt of Carer Allowance (72% compared to 55% overall), whereas families and carers of participants with another sensory/speech disability or developmental delay were less likely to be receiving both Carer Payment and Carer Allowance.

  In multiple regression analyses controlling for other factors, families and carers of participants with hearing impairment were significantly more likely to have people they

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[22] The one-way analyses should be interpreted with caution since age distributions will differ between disabilities. For example, participants with a psychosocial disability in the 0-14 age range would be older than average.

[23] Based on a relatively low number of participants (188) with a psychosocial disability in this age group.

could ask for practical help as often as they need (64% versus 41% overall on a one-way basis).

- **Self-management**

Families and 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 (60% and 52% respectively, compared with 46% overall). Participants who fully self-manage are more likely to be able to meet the needs of their child and family (80% versus 72% overall), to be able to advocate for their child (85% versus 78%), and to be able to access available services and supports (55% versus 45%). They also tend to respond more positively to indicators around helping their child develop and learn.

- **Family/carer knowledge and support**

Favourable outcomes at baseline were generally observed for families and carers who:

- Are able to identify their child's needs and to advocate for their child;
- Know what services are required to support their child and are able to access those services;
- Have adequate support networks; and
- Feel confident in parenting and supporting their child.

These factors come up as important predictors in multiple regression models. For example, overall 55% of families/carers experience difficulties in accessing available services and supports to meet the needs of their child and family, but this percentage is much higher for those who also had difficulties advocating for their child (90%), and those who cited limited access to information and resources as a barrier to access/advocacy. Conversely, those able to identify the needs of their child and family were much less likely to experience difficulties (14%).

The importance of strong social networks is highlighted by Table 3.1, which shows how the percentage responding positively to three questions about levels of support depends strongly on whether the family/carer has friends and family they see as often as they like.

Table 3.1 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 (45%)	No (55%)
I have people who I can ask for practical help as often as I need	74%	15%
I have people who I can ask for childcare as often as I need	53%	8%
I have people who I can talk to for emotional support as often as I need	85%	39%

3.2.4 Longitudinal indicators – aggregate

Longitudinal analysis describes how outcomes have changed for families and carers of participants during the time the participant has been in the Scheme. Included here are families and carers of participants entering the Scheme in the first year of transition (from 1 July 2016 to 30 June 2017) for whom a record of outcomes is available at two time points: at scheme entry and at approximately one year following scheme entry.[24]

As expected during this relatively short period, many indicators have not changed a great deal. For this summary we select indicators based on a combination of statistical significance and magnitude of change.[25]

Table 3.2 summarises changes for the 16 selected indicators.

Table 3.2 Selected longitudinal indicators for families/carers of participants aged 0 to 14

SF/LF	Domain description	Indicator	Baseline	Review	Change	Improvement/ Deterioration
SF	Work	% working in a paid job	45.2%	48.2%	3.0%	**Improvement**
SF	Work	Of those in a paid job, % working 15 hours or more	79.0%	81.3%	2.3%	**Improvement**
SF	Families feel supported	% who have people who they can talk to for emotional support as often as they need	60.3%	62.6%	2.2%	**Improvement**
LF	Families feel supported	% who have as much contact with other parents of children with disability as they would like	37.8%	56.7%	18.9%	**Improvement**
LF	Access to services	% who describe their relationship with services as Very Good or Good	77.5%	84.8%	7.2%	**Improvement**
SF	Families help their children develop and learn	% who know what specialist services are needed to promote their child's learning and development	40.1%	48.3%	8.2%	**Improvement**
SF	Families help their children develop and learn	% who know what their family can do to support their child's learning and development	42.2%	49.5%	7.3%	**Improvement**
SF	Families help their children develop and learn	% who get enough support to feel confident in parenting their child	45.0%	49.0%	4.0%	**Improvement**
LF	Health and wellbeing	% who feel more confident about the future of their child with disability under the NDIS	50.5%	67.5%	17.1%	**Improvement**
LF	Health and wellbeing	% who feel that their child gets the support he/she needs	26.6%	52.7%	26.1%	**Improvement**
LF	Health and wellbeing	% who feel that the services and supports have helped them to better care for their child with disability	31.0%	71.0%	40.0%	**Improvement**
SF	Government benefits	% receiving Carer Allowance	56.2%	63.9%	7.7%	**Context dependent**

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[24] Only pairs of responses where the person had the same relationship to the participant are included. For example, if the participant's mother responded at baseline and the participant's father responded at review, then the pair of responses would be excluded.

[25] Since there is much more data available for the SF, statistical testing would identify indicators where the magnitude of change is unimportantly small, so we only consider SF indicators where the absolute magnitude of change in the indicator is greater than 0.02 (all of these changes are statistically significant). For the LF, where the quantity of data is much smaller, selection is based on statistical significance.

SF/LF	Domain description	Indicator	Baseline	Review	Change	Improvement/ Deterioration
SF	Work	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	88.2%	90.8%	2.6%	**Deterioration**
SF	Work	Of those unable to work as much as they want, % who say insufficient flexibility of jobs is a barrier to working more	39.5%	45.4%	5.9%	**Deterioration**
SF	Health	% who rate their health as good, very good or excellent	73.4%	68.9%	-4.5%	**Deterioration**
SF	Social and community participation	Of those unable to engage as much as they want, % who say the situation of their child/family member with disability is a barrier to engaging more	90.5%	92.9%	2.4%	**Deterioration**

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 from 45% at baseline to 48% at review, and the percentage working 15 hours or more has also increased. However, parents/carers who are not able to work as much as they want are more 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.
- Families/carers feeling supported: families and carers report increased levels of emotional support and interactions with other families of children with disabilities. The percentages of parents/carers who feel that their child gets the support he/she needs, and that the services and supports have helped them to better care for their child with disability, have increased considerably.
- Support for families/carers in helping their child to develop and learn: families and 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.
- Outlook for their child’s future: the percentage feeling more confident about the future of their child with disability under the NDIS has improved from 51% to 68%.
- Health: the percentage rating their health as good, very good or excellent has decreased.
- Social and community participation: as for work, parents/carers who are not able to engage in social interactions and community life as much as they want are more likely to perceive the situation of their child as a barrier to engaging more.

3.2.5 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 review with the percentage meeting the indicator at baseline. The difference (review-baseline) is compared for different subgroups.
2. Multiple regression analyses modelling improvement (or sometimes deterioration) in the indicator. That is, for the subset without the indicator at baseline, the probability of meeting the indicator at review is modelled as a function of participant and family member/carer characteristics.

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 by domain, and for selected indicators, are summarised below.

Government benefits - Carer Allowance

An 8 percentage point increase in the percentage receiving Carer Allowance has been observed over the year. From the one-way analyses, increases were greater for families and carers of younger participants (13 percentage points for participants aged two or younger decreasing to 6 percentage points for participants aged 14).

Of those who did not receive Carer Allowance at baseline, 24% received it at review. Based on the logistic regression model for receiving the allowance at review, for this cohort:

- Respondents in VIC (17%) were less likely to receive the allowance and those in SA (29%) were more likely to receive it.
- Families and carers of participants with autism (31%) and Down syndrome (41%) were more likely to receive the allowance.

In contrast to the one-way analyses, participant age was not a significant predictor in the model for receiving the allowance at review amongst those who did not receive it at baseline. This difference in results may reflect the fact that families/carers of older participants were more likely to be receiving Carer Allowance at baseline.

Domain 1: Families know their rights and advocate effectively for their child with disability

Whilst aggregate changes in this domain tended to be relatively small, the one-way analyses show a consistent trend towards greater improvement at younger participant ages.

Domain 2: Families feel supported

Families/carers reported improved levels of emotional support, and having as much contact as they want with other parents of children with disability. Improvements appear slightly higher in regional and remote areas compared to major cities.

Domain 3: Families are able to gain access to desired services, programs, and activities in their community

Indicators in this domain relate to satisfaction with the development and implementation of the child’s plan. These questions are similar in nature to the questions about whether the NDIS has helped, and are discussed in Section 4.

Domain 4: Families help their children develop and learn

There were significant improvements of more than two percentage points overall across a number of indicators for this domain. The one-way analyses again suggest that results are more positive for families/carers of younger participants.

I know what specialist services are needed to promote my child's learning and development (overall improvement of .082)

Of those who said they did not know what services were needed at baseline, 22% said they did know at review. Based on the logistic regression model for improvement:

- Improvement was less likely for families/carers of CALD participants (14%).
- Improvement was considerably higher for respondents who knew what their family could do to support their child's learning and development (56%).
- Improvement was positively correlated with family members/carers level of confidence in supporting their child's development (increasing from 6% for those who are not at all confident to 43% for those who are very confident).

I know what my family can do to support my child's learning and development (overall improvement of .073)

Of those who said they did not know what their family could do at baseline, 21% said they did know at review. Based on the logistic regression model for improvement:

- Families/carers who were able to identify the needs of their child and family were more likely to improve (29%), as were those able to advocate for their child (27%).
- Respondents who had friends and family they saw as often as they liked were more likely to improve (28% compared to 17% for those who did not have friends and family they saw as often as they liked).
- Respondents who knew what specialist services were needed to promote their child's learning and development were more likely to improve (57%).

I get enough support to feel confident in parenting my child (overall improvement of .040)

Of those who said they did not get enough support at baseline, 18% said they did get enough support at review. Based on the logistic regression model for improvement:

- Families/carers who had people they could ask for practical help as often as they needed were more likely to improve (32%).
- Respondents who knew what specialist services were needed to promote their child's learning and development were more likely to improve (35%).
- Families and carers who had better levels of self-rated health were more likely to improve.