Longitudinal outcomes for families and carers of NDIS participants

30 June 2020

Contents

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Executive summary

Background

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

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

Separate reports on baseline and longitudinal outcomes for NDIS participants at 30 June 2020 have also been prepared.[1]

The NDIS Outcomes Framework questionnaires

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

This report

This report summarises longitudinal outcomes for families and carers of participants who have been in the Scheme for one year or more at 30 June 2020. A separate report covers baseline results for families and carers of NDIS participants entering the Scheme during the four year period from 1 July 2016 to 30 June 2020. Two previous reports have covered both baseline and longitudinal experience, as at 30 June 2018 and 30 June 2019.[2]

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

The global COVID-19 pandemic that took hold from early 2020 is likely to have had an impact on at least some participant and family/carer outcomes, such as employment and social and community participation. This report investigates effects of the pandemic on

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[1] Subsequently referred to as "the participant outcomes reports".

[2] Family and carer outcomes report | NDIS

outcomes via multiple regression models that allow for discontinuities in indicator levels, as well as different time trends, pre- and post-onset of the pandemic.

Baseline versus progress

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

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

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

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

A lifespan approach

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

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

Recognising these differences, family/carer questionnaires have been developed for three different *participant* age groups: 0 to 14, 15 to 24, and 25 and over. This report is organised with separate sections for each of these participant age groups. Since the role of the family or carer in the participant's life is most crucial during childhood, the report puts greater emphasis on the 0 to 14 participant age group, followed by the 15 to 24 age group. For the 25 and over age group, where a smaller amount of data is available (particularly longitudinally), and the relationship between participants and families/carers tends to be less close, a briefer presentation of results is given.

Families/carers of participants from birth to age 14

Overall results

In the longitudinal analysis, significant changes were observed across a number of indicators, for families and carers of participants who have been in the Scheme for one, two and three years. Areas of particular note were:

- ***Employment:***
  - For participants who have been in the Scheme for three years:
    - Overall, the percentage of families/carers working in a paid job has increased by 8.2% over three years, from 44.9% at baseline to 53.0% at third review, including a 1.6% increase in the latest year. Taking into account the respondent's relationship to the participant, the large majority of responses included in the longitudinal analysis for families/carers of participants aged 0 to 14 (around 94%) are from the mother of the participant, with around 6% being from the father. Whilst the percentage in a paid job is lower for mothers than fathers, there has been a stronger three-year increase for mothers (+8.4%, from 43.8% to 52.2%), compared to fathers (+4.3%, from 61.2% to 65.5%). Some of this change may be attributed to the participant being one year older and likely more independent, allowing their families/carers to work more, although a comparison to the Household, Income, and Labour Dynamics in Australia (HILDA) survey[3] suggests a slightly stronger increase for families/carers of NDIS participants aged 0 to 14. The percentages are still considerably lower compared to Australian population figures of 73.2% for females and 84.6% for males.[4]
    - For those in a paid job, the percentage working 15 hours or more per week has increased by 6.3% over three years, from 79.0% at baseline to 85.2% at third review. The percentage working 30 hours or more per week has also increased, from 36.1% to 48.9% overall. Looking at responses separately for mothers and fathers of NDIS participants, the percentage working 30 or more hours per week increased by 10.4% for mothers, from 34.7% to 45.1%, and by 4.6% for fathers, from 82.2% to 86.8%. Population figures for full-time work are 60.2% for females and 88.6% for males.[5] Hence for working 30 hours or more per week, the difference to the general population is larger for mothers (compared to Australian females) than fathers (compared to Australian males).
    - At baseline, 39.5% of families and carers said that they were able to work as much as they want, but this percentage has declined gradually, by 1.8% over three years, to 37.7%. Of those unable to work as much as they want, each of the potential barriers to working more is being cited more frequently by families and

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

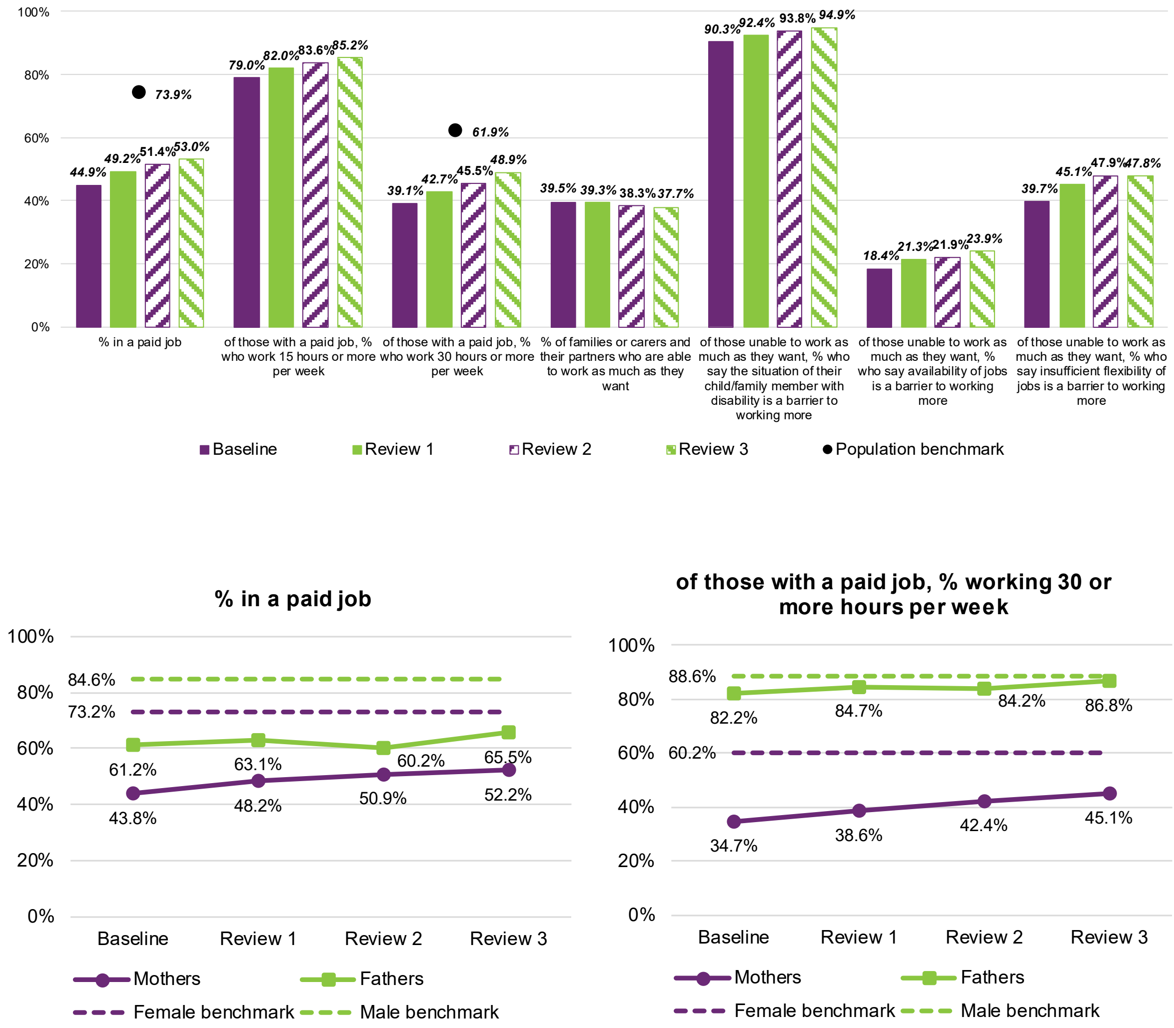
[4] Labour Force, Australia, Detailed, January 2021 | Australian Bureau of Statistics (abs.gov.au) Original series, as at 30 June 2020, age range 25 to 49. The actual ages of families/carers are not reliably known, but mothers and fathers of participants aged 0 to 14 are likely to be in this age range.

[5] Labour Force, Australia, Detailed, January 2021 | Australian Bureau of Statistics (abs.gov.au) Original series, as at 30 June 2020, age range 25 to 49. Employed full-time to employed total. The ABS defines full-time work as 35 hours or more per week, so the percentage of the general population working more than 30 hours per week would likely be higher than the figures quoted.

    carers. The percentage who see the situation of their child with disability as a barrier has increased by 4.6% over three years (from 90.3% to 94.9%, including a 1.0% increase in the latest year), the percentage citing availability of jobs has increased by 5.5% (from 18.4% to 23.9%, including a 1.9% increase in the latest year), and the percentage citing insufficient flexibility of jobs has increased by 8.0% (from 39.7% to 47.8%, with negligible change in the latest year).

- For participants who have been in the Scheme for two years:
    - The percentage of families/carers working in a paid job has increased by 3.6% over two years, from 47.4% at baseline to 51.0% at second review, including a 0.7% increase in the latest year. As for the families and carers of participants who have been in the Scheme for three years, the percentage working 15 or more hours per week has increased, by 5.6% over two years, from 77.4% to 83.0%, including a 2.4% increase in the latest year. The percentage working 30 hours or more per week has also increased, from 40.6% to 47.1% over two years.
    - At baseline, 38.5% of families and carers were able to work as much as they want, and this percentage has remained constant (38.3% at first review and 38.4% at second review). For those unable to work as much as they want, the percentage who see the situation of their child with disability as a barrier to working more increased by 4.4%, from 88.5% to 92.9%, including a 1.9% increase in the latest year. Increases over two years were also observed for the percentages citing availability of jobs (by 4.2%, from 19.0% to 23.1%) and insufficient flexibility of jobs (by 6.3%, from 39.8% to 46.0%).
- For participants who have been in the Scheme for one year:
    - 47.9% of families and carers were working in a paid job at baseline, and this increased by 1.8%, to 49.7%, at first review. Similar increases were observed for the percentage working 15 or more hours per week (from 79.2% to 81.2%, a 2.0% increase), and the percentage working 30 or more hours per week (from 42.2% to 44.5%, a 2.3% increase).
    - At baseline, 39.9% of families and carers were able to work as much as they want, and this was unchanged after one year (39.8%). Of those unable to work as much as they want, the percentage who see the situation of their child with disability as a barrier to working more increased by 1.9%, from 88.8% at baseline to 90.8% at first review. Increases were also observed for the percentages citing availability of jobs (by 2.0%, from 16.6% to 18.6%) and insufficient flexibility of jobs (by 3.3%, from 36.1% to 39.4%).

Figure 1 Changes in employment indicators over three years for families/carers of participants aged 0 to 14 who have been in the Scheme for three years[6]



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[6] Population benchmarks shown in the top chart are a weighted average of female and male benchmarks, reflecting the NDIS percentages of respondents (94% mothers and 6% fathers).

Figure 2 Changes in employment indicators over two years for families/carers of participants aged 0 to 14 who have been in the Scheme for two years[6]

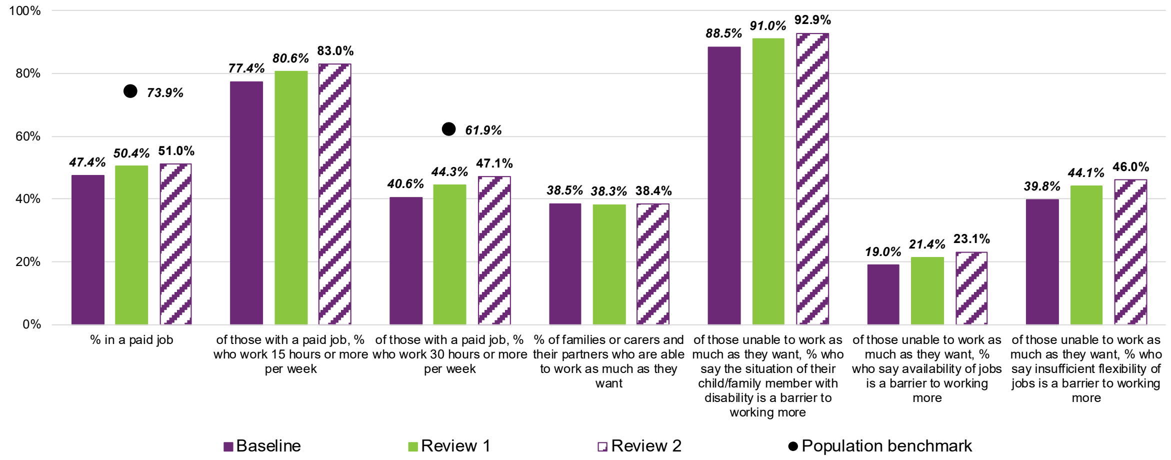
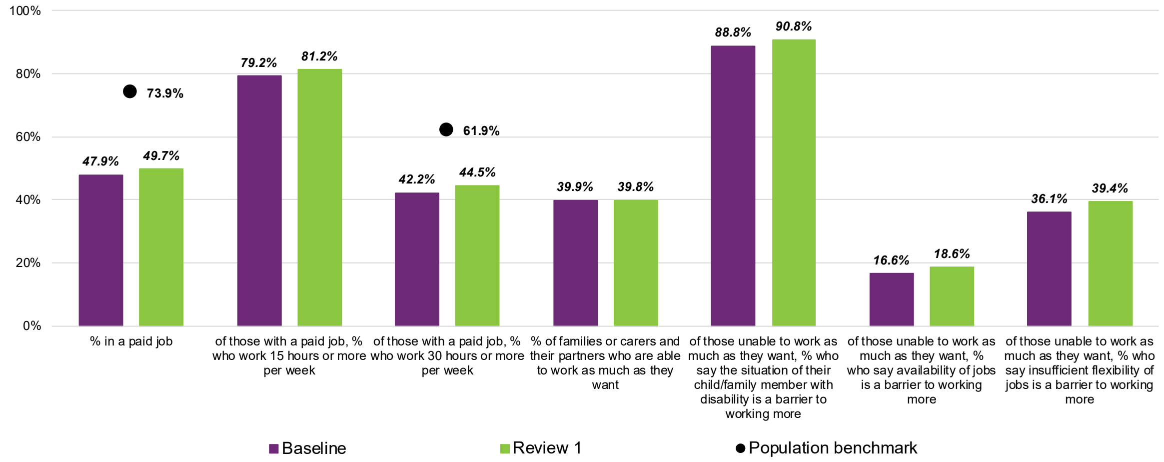


Figure 3 Changes in employment indicators over one year for families/carers of participants aged 0 to 14 who have been in the Scheme for one year Error! Bookmark not defined.



- ***Development and learning:***
  - For participants who have been in the Scheme for three years, the percentage of families/carers who know what specialist services are needed to promote their child's learning and development increased by 11.9% between baseline and second review, from 41.4% to 53.3%. Similarly, the percentage of respondents who know what they can do to support their child's learning and development increased by 9.4%, from 42.5% to 51.9%, and the percentage who get enough support in parenting their child increased by 4.3%, from 44.2% to 48.4%.
    - For participants have been in the Scheme for two years, the percentage of respondents who know what specialist services are needed to promote their child's learning and development increased by 12.3%, from 41.0% at baseline to 53.3% at second review, including a 3.4% increase in the latest year. Similarly,

the percentage of families/carers who know what they can do to support their child’s development increased by 10.0%, from 42.1% at baseline to 52.1% at second review, including a 2.7% increase in the latest year.

    - For participants who have been in the Scheme for one year, the percentage of respondents who know what specialist services are needed to promote their child’s learning and development increased by 8.3%, from 41.2% to 49.5% from baseline to first review. The percentage of families/carers who know what they can do to support their child’s development increased by 7.0%, from 41.6% at baseline to 48.6% at first review.

- ***Relationship with services***:
    - For participants who have been in the Scheme for three years, the percentage of families/carers who say their relationship with services is good or very good has increased by 5.1%, from 85.5% at baseline to 90.6% at third review.
    - For participants have been in the Scheme for two years, the percentage of families/carers who say their relationship with services is good or very good has increased by 13.2%, from 76.3% at baseline to 89.5% at second review.
    - For participants have been in the Scheme for one year, the percentage of families and carers who say their relationship with services is good or very good increased by 7.5%, from 80.6% to 88.1% over one year.
- ***Rights and advocacy:***
    - For participants who have been in the Scheme for three years, the percentage of families/carers who said that they experienced no boundaries to access or advocacy increased by 2.0% over three years overall, from 37.5% to 39.4%, however there has been a 1.2% decline in the latest year.
    - For participants who have been in the Scheme for two years, 35.3% of families and carers said that they experienced no boundaries to access or advocacy at baseline, and this proportion increased by 2.9% to 38.3% at second review.
    - For participants who have been in the Scheme for one year, the percentage who said they experienced no boundaries to access or advocacy increased slightly over one year, from 38.1% to 39.1% (an increase of 0.9%).

Figure 4 Changes in indicators over three years for families/carers of participants aged 0 to 14 who have been in the Scheme for three years – development and learning and relationship with services

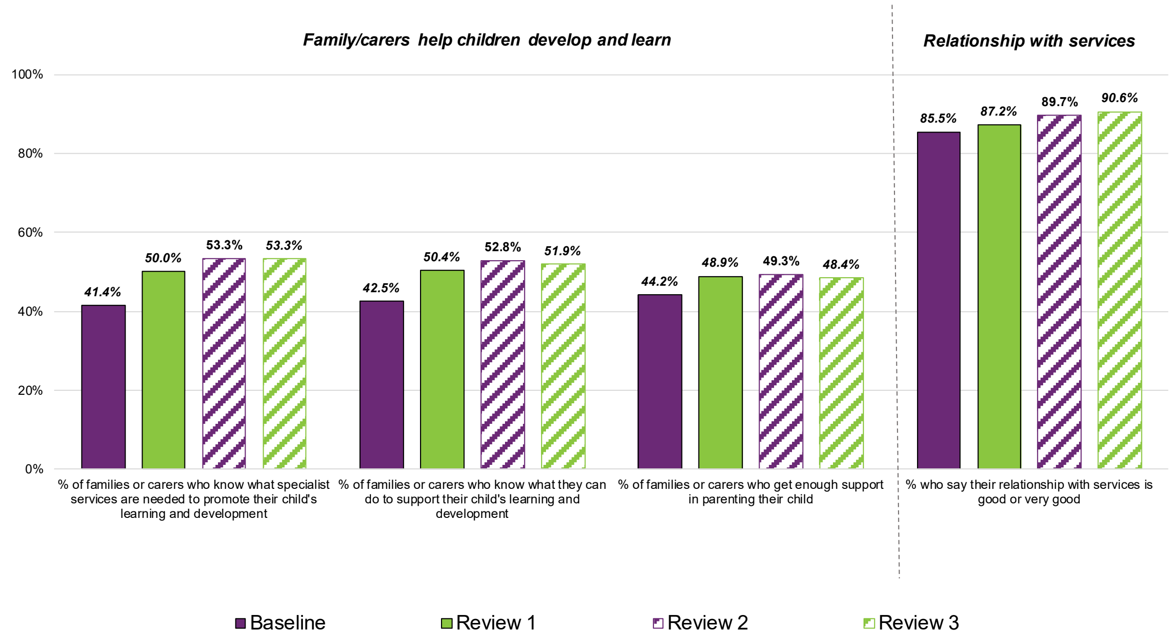


Figure 5 Changes in indicators over two years for families/carers of participants aged 0 to 14 who have been in the Scheme for two years – development and learning and relationship with services

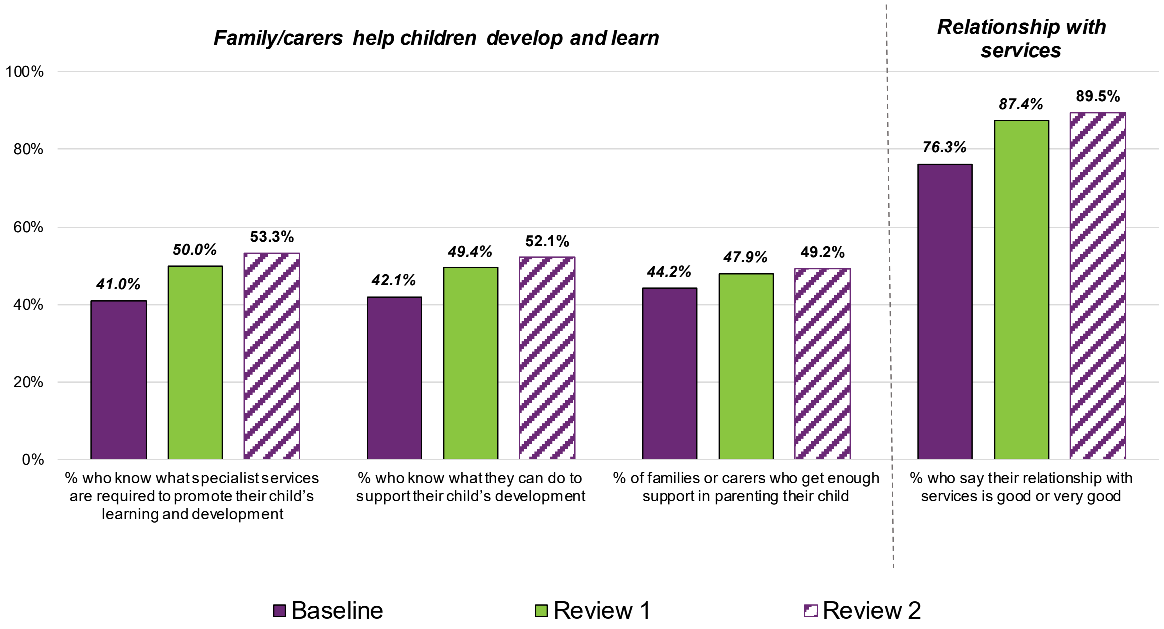
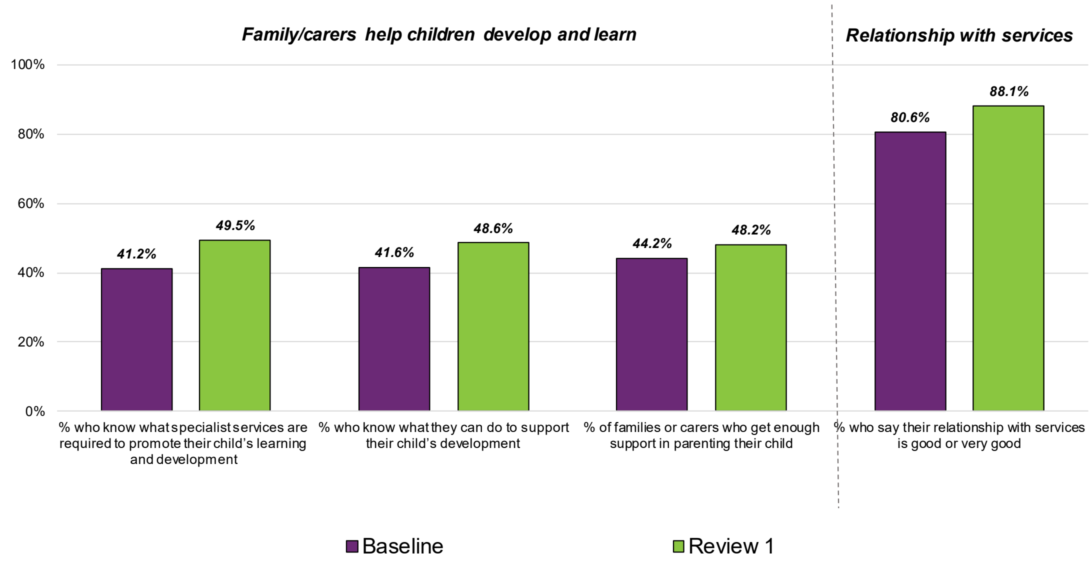


Figure 6 Changes in indicators over one year for families/carers of participants aged 0 to 14 who have been in the Scheme for one year – development and learning and relationship with services



- ***Health and wellbeing:***

  Some deterioration in self-rated health has been observed for families and carers, with the percentage rating their health as excellent, very good or good decreasing by:

  - 9.8% for participants have been in the Scheme for three years, from 74.5% at baseline to 64.7% at third review.
  - 6.7% for participants have been in the Scheme for two years, from 72.4% at baseline to 65.7% at second review.
  - 2.9% for participants who have been in the Scheme for one year, from 72.8% at baseline to 69.9% at first review.

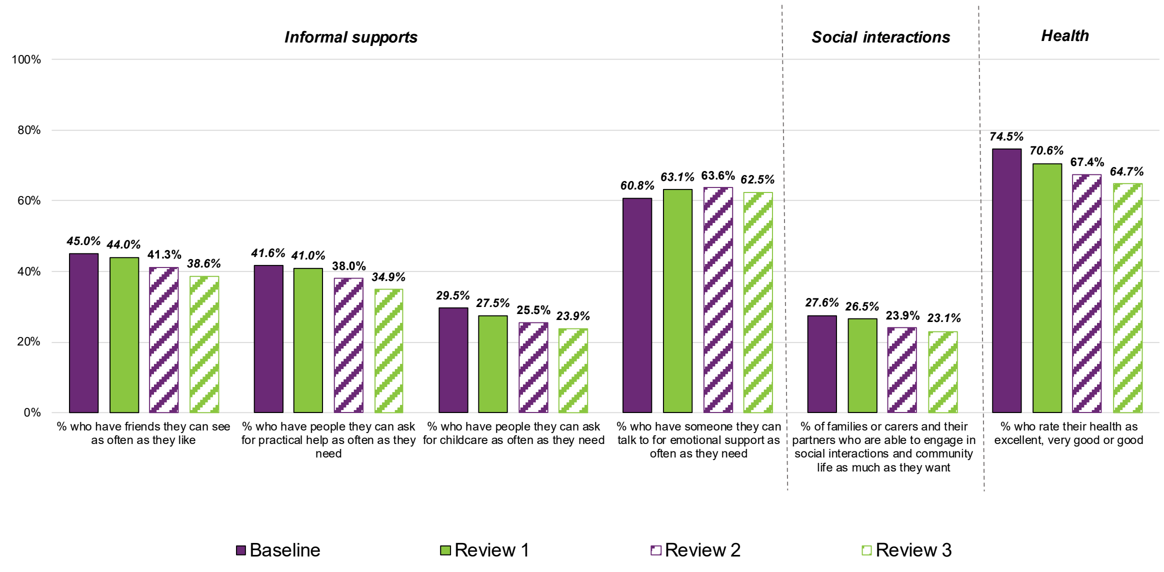
- ***Informal supports:***

  - For participants who have been in the Scheme for three years, there were reductions over three years in the percentages who have: friends they can see as often as they like (6.4% decrease, from 45.0% to 38.6%); people they can ask for practical help as often as they need (6.7% decrease, from 41.6% to 34.9%); and people they can ask for childcare as often as they need (5.6% decrease, from 29.5% to 23.9%). However, the percentage who have someone they can talk to for emotional support as often as they need increased by 1.7% over three years, from 60.8% to 62.5% (although there has been a non-significant decline in the latest year).
  - For participants who have been in the Scheme for two years, there were reductions over two years in the percentages who have: friends they can see as often as they like (3.7% decrease, from 44.8% to 41.2%); people they can ask for practical help as often as they need (3.7% decrease, from 41.2% to 37.5%); and people they can ask for childcare as often as they need (2.1% decrease, from 27.7% to 25.6%). However, the percentage who have someone they can talk to for emotional support as often as they need increased by 1.6% over two years, from 60.9% to 62.5%.

  - For participants who have been in the Scheme for one year, changes in outcomes related to informal supports were negligible and not statistically significant, except that for families/carers who were unable to engage as much as they want in social interactions and community life, the percentage who saw the situation of their child with disability as a barrier to engaging more increased by 1.4% over one year, from 90.6% to 92.0%.

- ***Social interactions:***
  - For participants who have been in the Scheme for three years, the percentage of families/carers who say they have been able to engage in social interactions and community life as much as they want decreased by 4.5%, from 27.6% to 23.1%. Of those unable to engage as much as they want, the percentage who say the situation of their child with disability is a barrier to engaging more has increased by 4.2%, from 92.0% at baseline to 96.2% at third review.
  - For participants who have been in the Scheme for two years, the percentage of families/carers who say they have been able to engage in social interactions and community life as much as they want decreased by 1.8%, from 25.6% to 23.8%. Of those unable to engage as much as they want, the percentage who say the situation of their child with disability is a barrier to engaging more has increased by 2.9%, from 91.0% at baseline to 93.9% at second review.
  - For participants who have been in the Scheme for one year, there was no significant change in being able to engage in social interactions and community life as much as desired. However, for those unable to engage as much as they want, the percentage who say the situation of their child with disability is a barrier to engaging more increased by 1.4%, from 90.6% to 92.0%.

Figure 7 Changes in indicators over three years for families/carers of participants aged 0 to 14 who have been in the Scheme for three years – informal supports, social interactions and health



Results by participant and family/carer characteristics

Family/carer’s longitudinal outcomes vary significantly with their primary disability, age, cultural background, Indigenous status, level of function, location, plan type and living situation:

- Families/carers of participants with autism tended to have less positive longitudinal outcomes, particularly in relation to support networks and social and community interactions.
- For the majority of indicators in all domains, longitudinal outcomes are better for families/carers of participants with a high level of function. A similar trend was observed for families/carers of participants with a lower annualised plan budget.
- For most of the indicators modelled, longitudinal outcomes tended to be worse for families/carers of older participants. For example, families/carers of older participants were less likely to improve and more likely to deteriorate in having people they can ask for practical help as often as needed, and in rating their health as excellent, very good or good (which may be partly age related). However, families/carers of older participants were less likely to deteriorate with respect to having a paid job.
- Longitudinal outcomes related to work and health tended to be better when the respondent was the father compared to when the respondent was the mother.
- Families/carers of participants from a CALD background tended to be more likely to improve with respect to having friends they can see as often as they like, and less likely to deteriorate in self-rated health. However, they tended to be less likely to improve and/or more likely to deteriorate across a number of other indicators, in particular related to helping their child develop and learn.
- Indigenous status was significant in a relatively small number of models and results were mixed. For example, families/carers of Indigenous participants tended to be more likely to improve with respect to having friends they can see as often as they like, but were more likely to deteriorate with respect to getting enough support to feel confident in parenting their child.
- Outcomes for families/carers from Queensland tended to be more likely to improve after spending time in the Scheme, while families/carers from Victoria were less likely to improve.
- Some outcomes were better for families/carers of participants living outside a major city. For example, they were generally more likely to improve and less likely to deteriorate with respect to having people they can ask for practical help as much as needed. However, they were less likely to improve with respect to having a paid job.
- Families/carers of participants with self-managed plans (fully or partly) experience more positive outcomes in the domains of work, advocacy and access to services over time.
- Outcomes tend to be more positive across all domains for families/carers of participants living in a private home owned by their family.
- Relocating to a new LGA was associated with worse longitudinal outcomes for a number of indicators, for example, being more likely to deteriorate with respect to being able to engage socially and in the community as much as desired.

Has the NDIS helped?

Opinions on whether the NDIS has helped are generally positive for this cohort:

- The percentage of families/carers reporting that the NDIS has helped has increased gradually over the participant's time in the Scheme, by 2-3% between one and three years, across all five SF domains except for the rights and advocacy domain (no change) and the health and wellbeing domain (a small decrease). The percentages satisfied with the amount of say they had in the development and implementation of their child's plan increased slightly over the participant's second year in the Scheme but were largely unchanged over the third year.

- Opinions on whether the NDIS has helped after **one year** in the Scheme vary by participant/carer characteristics. Key results are as follows:

    - Families and carers of younger participants are more likely to say that the NDIS has helped, across all five outcome domains, and are more likely to be satisfied with the amount of say they had in the development and implementation of their child's plan.
    - Families and carers of participants with developmental delay are more likely to say the NDIS helped, across all five outcome domains. They are also more likely to be satisfied with the amount of say they had in the development and implementation of their child's plan than families/carers of participants with all other disabilities except other sensory/ speech, where there was no significant difference.
    - Families and carers of Indigenous participants are less likely to think that the NDIS has helped improve their ability to help their child develop and learn.
    - Families and carers of participants from a CALD background are more likely to think that the NDIS has helped with health and wellbeing, but less likely to be satisfied with the amount of say they had in the development and implementation of their child's plan.
    - Families and carers of participants with higher level of function are more likely to say that the NDIS helped, across all outcomes domains, and were more likely to be satisfied with the amount of say they had in the development and implementation of their child's plan.
    - Conversely, higher annualised plan budget (generally associated with lower level of function) was associated with a higher likelihood of thinking that the NDIS has helped, and being satisfied with the amount of say the family member/carer had in the development and implementation of their child's plan.
    - Families and carers of participants with higher baseline plan utilisation are more likely to say the NDIS has helped across all five domains. They were also more likely to be satisfied with the amount of say they had in implementing their child's plan, but less likely to say they are satisfied with the amount of say they had in developing their child's plan.
    - Families and carers of participants who are fully self-managing their plan are the most likely to say that the NDIS has helped, and the most likely to be satisfied with the amount of say they had in the development and implementation of their child's plan.
    - Compared to families and carers living in major cities, families and carers of participants living in regional areas are less likely to say that the NDIS has helped across all five domains. Those living in remote/very remote areas are also less likely to say that the NDIS has helped for all domains except for health and wellbeing. However, families and carers living in regional and remote/very remote

areas are more likely to say that they are satisfied with the amount of say they had in the development and implementation of their child’s plan.

- Looking at changes in responses over time (that is, comparing results between first and later reviews), key observations include:
    - Higher utilisation of plan budget in general, and higher utilisation of capacity building supports in particular, is associated with a higher likelihood of improvement and lower likelihood of deterioration in thinking that the NDIS has helped. Higher utilisation of capacity building supports is also associated with a higher likelihood of improvement and lower likelihood of deterioration in being satisfied with the implementation of the child’s plan.
    - Improvement was less likely and deterioration more likely, in general, for families and carers of older participants.
    - Families/carers of CALD participants were less likely to improve in saying they are satisfied with the development and implementation of their child’s plan. They were also more likely to deteriorate in saying they are satisfied with the implementation of their child’s plan.
    - Families/carers of Indigenous participants were more likely to deteriorate in some domains, particularly level of support for the family, health and wellbeing, and being satisfied with the amount of say they had in the implementation of their child’s plan.
    - Self-managing fully was associated with more positive changes in responses for a number of outcome domains, for example, health and wellbeing. However, in multiple regression models, plan management type was not a significant factor in whether families/carers were satisfied with the development and implementation of their child’s plan.
    - Compared to those living in major cities, families and carers of participants living in regional areas were more likely to improve and less likely to deteriorate over the participant’s second year in the Scheme in being satisfied with development of their child’s plan, and were more likely to improve in being satisfied with its implementation.

Families/carers of participants aged 15 to 24

Overall results

- ***Employment***:
    - For participants who have been in the Scheme for three years, there was an increase of 4.9% over three years in the percentage of families/carers working in a paid job, from 49.4% to 54.4% (although there has been a non-significant decline over the latest year, possibly related to the COVID-19 pandemic, which was found to be significantly associated with deterioration in employment outcomes over two and three years). For those with a paid job, over three years, there was an increase of 5.1% in the percentage working 15 hours or more per week, from 85.1% to 90.2%, as well as an increase of 7.1% for those working 30 hours or more per week, from 52.9% to 60.0%.
    - For participants who have been in the Scheme for two years, there was an increase of 2.2% over two years in the percentage of families/carers working in a paid job, from 51.2% to 53.4% (although there has been a non-significant decline in the latest year, again, possibly COVID-19 related). For those with a paid job, there was an increase of 2.3% in the percentage working 15 hours or more per week, from 84.1% to 86.4%. The percentage working 30 hours or more per week increased by 5.2%, from 49.0% to 54.2%.
    - For families and carers of participants who have been in the Scheme for one year, the percentage in a paid job increased by 1.3% over one year, from 51.4% to 52.7%. Of those in a paid job, the percentage working 15 or more hours per week increased by 1.5%, from 85.2% to 86.7%, and the percentage working 30 or more hours per week increased by 2.0%, from 53.1 to 55.1%.

Figure 8 Changes in indicators over three years for families/carers of participants aged 15 to 24 who have been in the Scheme for three years – employment

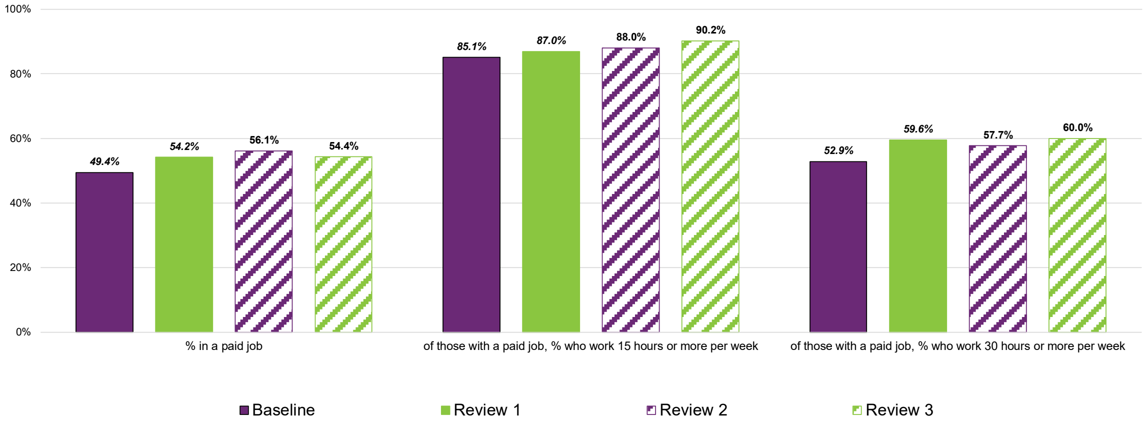


Figure 9 Changes in indicators over three years for families/carers of participants aged 15 to 24 who have been in the Scheme for two years – employment

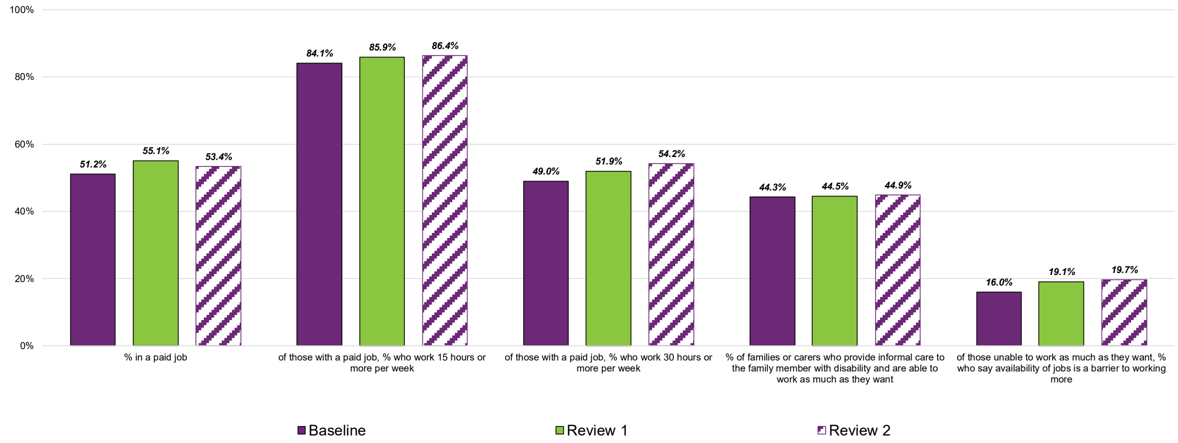
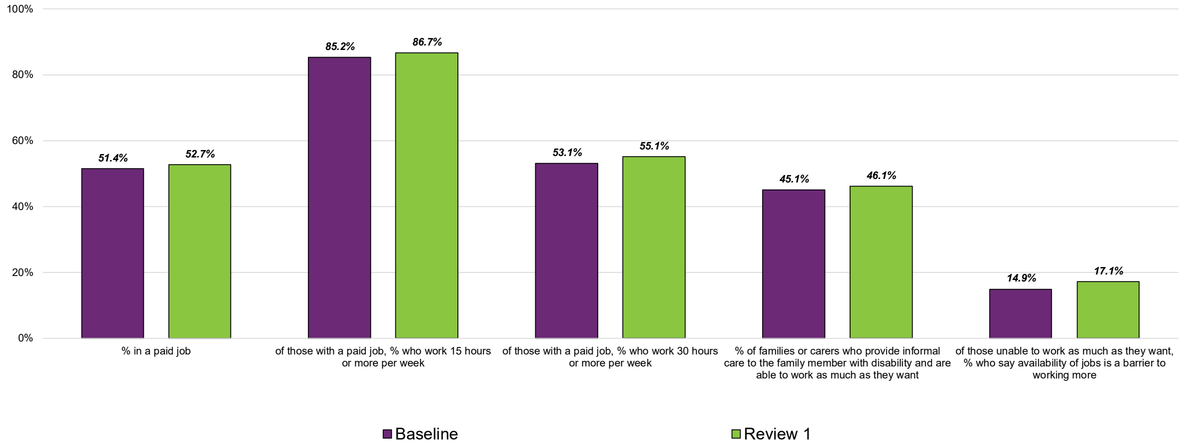


Figure 10 Changes in indicators over three years for families/carers of participants aged 15 to 24 who have been in the Scheme for one year – employment



In the longitudinal analysis for other domains, significant changes were observed across a number of indicators, for families and carers of participants who have been in the Scheme for one, two and three years, particularly in the areas of:

- ***Access to services:***
  - For participants who have been in the Scheme for three years, the percentage of families/carers who said that the services they receive for their family member with disability meet their needs increased from 17.7% at baseline to 36.3% at third review. The percentage of families/carers who felt that the services they use for their family member with disability listen to them increased by 8.1% over three years, from 64.0% at baseline to 72.0% at third review, although there was a 1.2% decline in the latest year. At baseline, 67.4% said that the services they received helped them plan for future, increasing by 4.7% over three years to 72.1%.
  - For participants who have been in the Scheme for two years, the percentage of families/carers who said that the services they receive for their family member with disability meet their needs increased from 17.8% at baseline to 26.5% at first review and 30.5% at second. 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 (62.2% at baseline, 67.7% at first review and 71.1% at second review). The percentage who said that the services helped them plan for the future also increased, by 19.5% overall.

  - For families and carers of participants who have been in the Scheme for one year, the percentage who said that the services they receive for their family member with disability meet their needs increased by 7.0%, from 17.8% at baseline to 24.9% at first review. The percentage saying the services listen to them increased by 4.2%, from 65.5% to 69.7%. In addition, the percentage who said that the services helped them plan for the future increased by 14.4%, from 57.4% to 71.9%.

- ***Confidence for the future***:

  - For participants who have been in the Scheme for three years, the percentage of families/carers who say they feel more confident about the future of their family member with disability under the NDIS increased by 25.0% over three years, from 50.0% to 75.0%. The percentage who strongly agree or agree that their family member gets the support he/she needs also increased, from 40.9% to 70.5%.

  - For participants who have been in the Scheme for two years, the percentage who felt more confident about the future of their family member with disability under the NDIS increased from 50.0% at baseline to 69.8% at first review, but which decreased slightly to 68.6% by the end of second year. The percentage who strongly agree or agree that their family member gets the support he/she needs also increased, from 30.2% at baseline to 59.3% at second review.

  - For participants who have been in the Scheme for one year, the percentage who felt more confident about the future of their family member with disability under the NDIS increased from 56.1% at baseline to 64.4% at first review. The percentage who strongly agree or agree that their family member gets the support he/she needs also increased, from 32.6% at baseline to 53.0% at first review.

Figure 11 Changes in indicators over three years for families/carers of participants aged 15 to 24 who have been in the Scheme for three years – access to services and confidence for the future

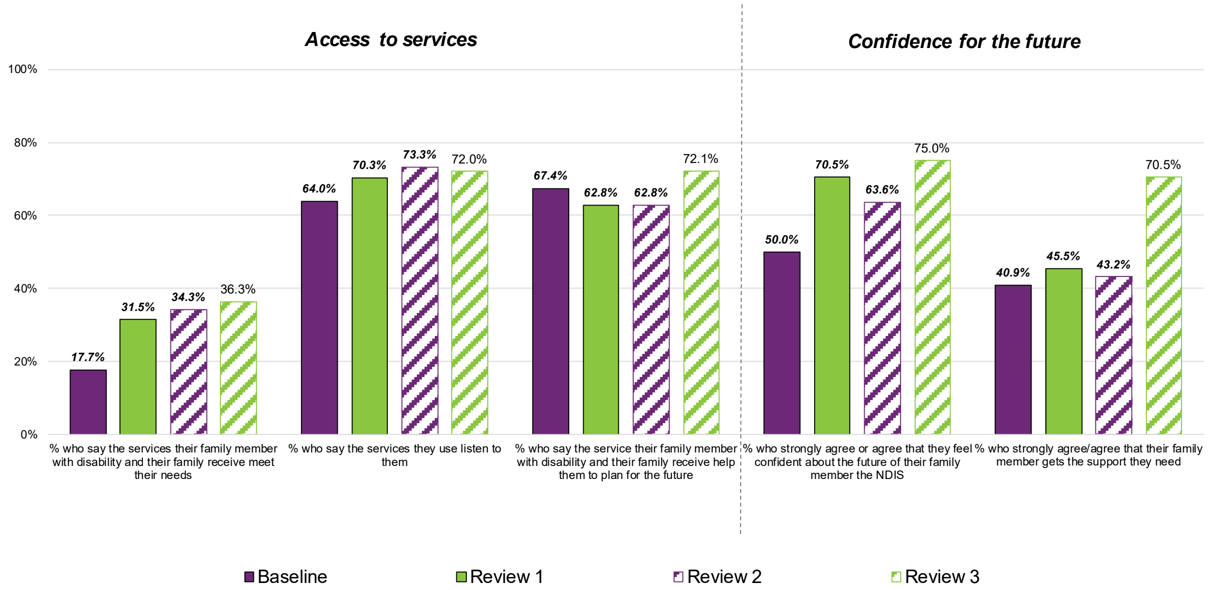


Figure 12 Changes in indicators over two years for families/carers of participants aged 15 to 24 who have been in the Scheme for two years – access to services and confidence for the future

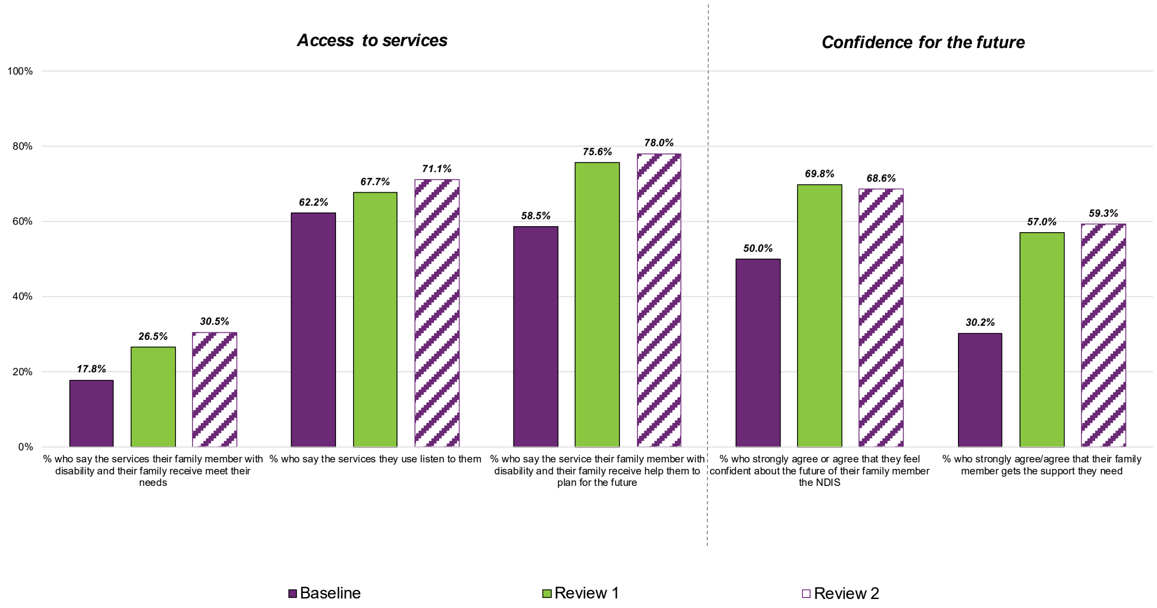
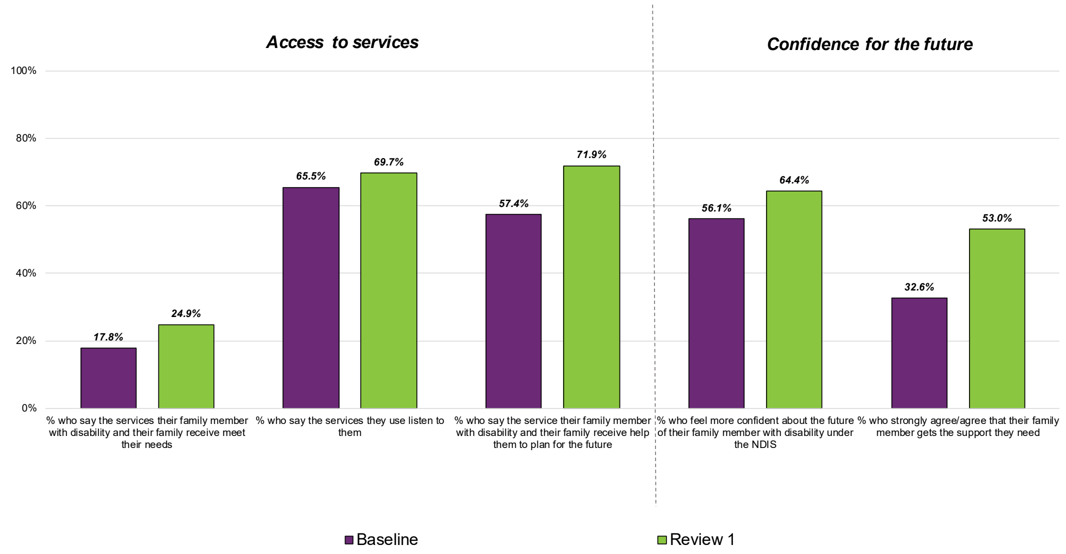
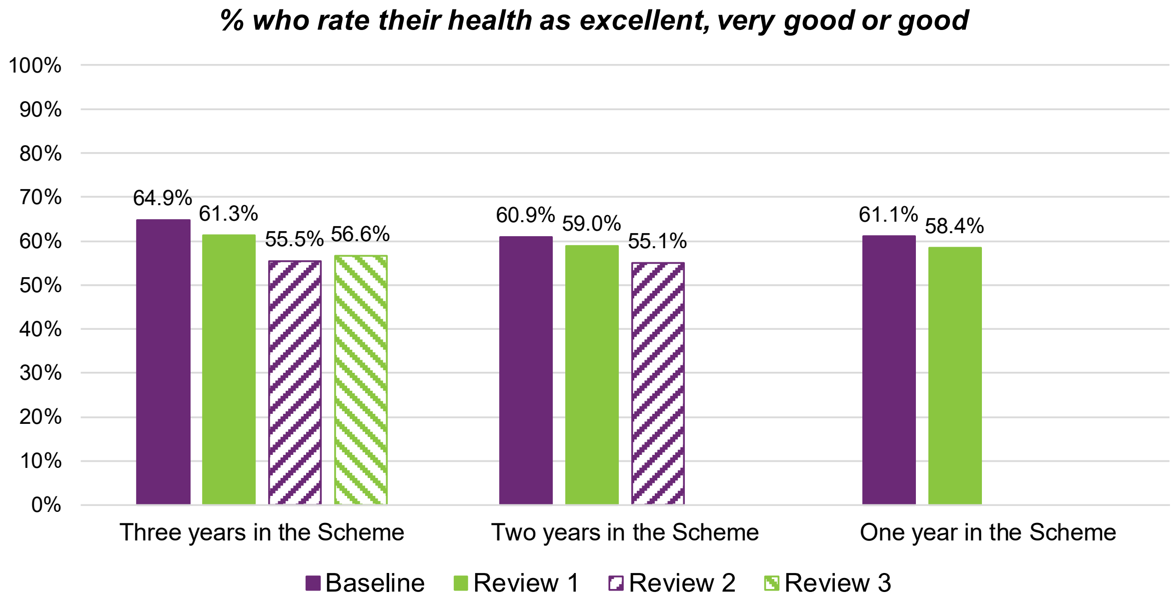


Figure 13 Changes in indicators over one year for families/carers of participants aged 15 to 24 have been in the Scheme for one year – access to services and confidence for the future



- ***Health and Wellbeing***:
  - Outcomes in this domain mostly deteriorated, and this may be partially explained by the tendency for health to decline with age (for this age group, the majority of family members/carers responding to the survey are mothers or fathers, and they will be getting older as the participant gets older). In particular:
    - For participants who have been in the Scheme for three years, there was a decline of 8.3% over three years in the percentage of families/carers who rated their health as excellent, very good or good, from 64.9% to 56.6%.
    - For participants who have been in the Scheme for two years, the percentage of families/carers who rate their health as excellent, very good or good declined from 60.9% at baseline to 55.1% at second review.
    - For those who have been in the Scheme for one year, the percentage of respondents who self-rate their health as excellent, very good or good was 61.1% at baseline, decreasing by 2.7% to 58.4% at first review.

Figure 14 Changes in indicators for families/carers of participants aged 15 to 24 who have been in the Scheme for one, two and three years – health



Results by participant and family/carer characteristics

Family/carer’s longitudinal outcomes vary significantly by a number of participant and family/carer characteristics:

- Families and carers of participants with autism were more likely to deteriorate in having someone to talk to for emotional support between baseline and first review. Compared to families/carers of participants with autism, families/carers of participants with a psychosocial disability were more likely to improve in self-rated health over the latest year, and in saying their child’s disability is a barrier to working more between baseline and first review.
- Families and carers of participants with a lower level of function were less likely to improve and/or more likely to deteriorate across a number of indicators. For example, they were more likely to deteriorate in the latest year and between baseline and second review in thinking that the services they use meet the needs of their family member with disability, and less likely to improve in thinking the situation of their family member with disability is a barrier to working more.
- Families/carers of participants with a higher level of NDIA support through the participant pathway were less likely to improve in thinking that the services they use meet the needs of their family member with disability.
- Family/carer employment status has a significant impact for a number of indicators. For example, families/carers who remained in paid work were more likely to improve and less likely to deteriorate in having someone they can talk to for emotional support.
- Participant self-rated health was also a factor for a number of indicators. For example, where the participant’s health deteriorated between reviews, the family member/carer was more likely to deteriorate in saying that the services they use meet the needs of their family member with disability.

- Some longitudinal outcomes were better when the participant felt safe in their home. For example, improvement was more likely and deterioration less likely for feeling that the services they use listen to them.
- Families/carers of participants living outside a major city had more positive outcomes in some areas. For example, they were more likely to improve in thinking that the services they use listen to them.
- Higher plan utilisation was a positive factor for some indicators. For example, it was associated with a higher likelihood of improvement and a lower likelihood of deterioration for feeling that the services they use listen to them, and a higher likelihood of improvement in saying that the services they use meet the needs of their family member with disability.
- Families/carers of participants living in rented accommodation, compared to those living in a home owned by their family/carer, are more likely to deteriorate in self-rated health.
- Families/carers of participants living in Queensland (QLD) were more likely to improve on a number of indicators, for example, feeling that the services they use listen to them.
- Families and carers of participants with fully self-managed plans were less likely to deteriorate in thinking the services they use listen to them, and more likely to improve in saying the services meet their needs. Those with a plan manager, however, are less likely to improve on the latter indicator.

Has the NDIS helped?

Opinions on whether the NDIS has helped are slightly less positive for this cohort than for families/carers of participants aged 0 to 14. Key findings include:

- The percentage of families/carers reporting that the NDIS helped after three years in the Scheme was higher than the percentage of families/carers reporting that the NDIS helped after one year in the Scheme, across all SF domains except health and wellbeing, where there is a slight deterioration between first and second review.
- Opinions on whether the NDIS helped after **one year** in the Scheme vary by participant and family/carer characteristics. Key results are as follows:
    - Family and carers of participants with higher baseline plan utilisation are more likely to say the NDIS has helped, across all five domains.
    - Families and carers who have higher annualised plan budget are more likely to say the NDIS helped after one year, across all five domains.
    - Families and carers of older participants are more likely to say the NDIS helped at first review, across all domains except rights and advocacy.
    - Families and carers of participants with a visual impairment or spinal cord injury are less likely to think that the NDIS has helped with level of support or access to services.
    - Families and carers of participants with lower level of function are more likely to think the NDIS helped, in all domains except rights and advocacy.
    - Families and carers of participants with a higher percentage of supports in capacity building are less likely to say that the NDIS has helped with advocacy, support, access to services, and independence.

    - Families and carers whose plans are self-managed, either fully or partly, are more likely than those who agency manage to say that the NDIS helped across all domains.
    - Families and carers of participants who live in remote/very remote areas, compared to those who live in major cities, are less likely to say the NDIS has helped across all domains except health and wellbeing.
    - Families and carers living in Queensland (QLD) or Western Australia (WA) are more likely to say the NDIS helped compared to those in NSW, across all domains.
    - Families and carers of participants who said they feel safe at home are more likely to say that the NDIS has helped across all five domains.
    - Families and carers of participants who have better self-rated health are more likely to say that the NDIS has helped.
    - Those who did not receive supports from Commonwealth or State/Territory systems prior to entering the NDIS are more likely to say the NDIS has helped across all domains, compared to those previously receiving either State/Territory or Commonwealth services.
    - Families and carers of participants in supported independent living (SIL) are less likely to think the NDIS has helped for the domains of rights and advocacy, families feeling supported, and access to services.
    - Families and carers of female participants are more likely to say the NDIS has helped for the domains of families feeling supported, access to services and independence.
    - Families and carers of participants with lower levels of function tended to be more likely to say that the NDIS had helped in all domains except for rights and advocacy. However, families and carers of participants with a very high level of NDIA support are less likely to say the NDIS helped for the domains of families feeling supported, access to services and independence.

- Looking at changes in responses over time (that is, comparing results between first and later reviews), key observations include:

    - Higher overall plan utilisation, and higher utilisation of capacity building supports, tend to be associated with more positive changes in responses.
    - Higher annualised plan budget was associated with a higher likelihood of improvement over the participant’s second year in the Scheme for level of support, access to services, and health and wellbeing.
    - Where the participant is working in an unpaid job, families/carers are more likely to improve and less likely to deteriorate in thinking the NDIS has helped them to help the participant become more independent.
    - Relocating to a different local government area (LGA) is associated with some more negative changes in responses, for the domains rights and advocacy, access to services, as well as health and wellbeing.
    - Families and carers of participants of a lower level of function were less likely to deteriorate in the domains of level of support for family and helping their family member become more independent. They were also more likely to improve with respect to health and wellbeing.

Families/carers of participants aged 25 and over

Overall results

- ***Employment:***
    - Changes in employment indicators for families/carers of participants aged 25 and over were mostly small and not statistically significant. It should be noted that families/carers of participants aged 25 and over are more likely to be of retirement age compared to families and carers of participants aged under 25, and as such are less likely to be in a paid job.
    - For participants who have been in the Scheme for three years, the percentage of families and carers in a paid job has declined by 2.5% over three years, from 37.5% to 35.0%. (Numbers are too small to report on hours worked).
    - For participants who have been in the Scheme for two years, the percentage of families and carers in a paid job has declined by 1.6% over two years, from 33.5% at baseline to 31.9% at second review. Of those in a paid job, the percentage working 15 or more hours per week remained constant from baseline to second review, at around 85%, and the percentage working 30 or more hours per week remained at around 59%.
    - For participants who have been in the Scheme for one year, the percentage in a paid job decreased by 0.7%, from 34.7% and 34.0%, between baseline and first review. Of those with a paid job, the percentage working 15 hours or more per week remained at around 84%, and the percentage working 30 or more hours per week remained at around 57%.
- ***Interaction with services:***
    - For participants who have been in the Scheme for three years, three positive changes were observed related to satisfaction with services. The percentage of families/carers who say that the services their family member with disability and their family receive meet their needs improved from 23.8% at baseline to 36.3% at third review (although there was a non-significant decline over the latest year). The percentage who said the services helped them to plan for the future increased from 40.9% to 72.7% over three years, and the percentage who agree or strongly agree that the services and supports have helped them to better care for their family member with disability increased from 36.4% to 77.3%.
    - For participants who have been in the Scheme for two years, the percentage of families/carers who said that the services their family member with disability receives meet their needs increased from 21.3% at baseline to 33.6% at second review. The percentage who say the services they use listen to them increased from 68.3% to 74.8%, the percentage who say the services help them to plan for the future increased from 63.6% to 74.7%, and the percentage agreeing or strongly agreeing that services and supports have helped them to better care for family member with disability increased from 54.6% to 73.6% over two years.
    - For participants who have been in the Scheme for one year, the percentage of families/carers who said that the services their family member with disability and their family receive meet their needs increased by 7.0% over one year, from 20.0% to 27.0%. The percentage who said that the services listened to them increased by 3.3%, from 68.5% at baseline to 71.8% at first review. The

    percentage who thought that the services helped them plan for the future increased from 66.5% to 73.8%, and the percentage agreeing or strongly agreeing that the services helped them to better care for their family member with disability increased by 21.8%, from 48.1% to 69.9%.

- ***Health and wellbeing:***
    - For participants who have been in the Scheme for three years, the percentage who think that their family member with disability gets the support they need increased by 6.4%, from 38.5% at baseline to 44.9% at third review.
    - For participants who have been in the Scheme for two years, the percentage who think that their family member with disability gets the support they need increased from 26.6% at baseline to 40.9% at second review. The percentage who say that those who provide informal support to their family member with disability are able to work as much as they want increased by 3.2% over two years, from 58.0% to 61.2%, including a 2.4% increase in the latest year. However, the percentage rating their health as excellent, very good or good declined by 6.5% (4.0% in the latest year), from 58.5% at baseline to 52.0% at second review.
    - For participants who have been in the Scheme for one year, the percentage of families/carers who felt their family member with disability gets the support they need increased by 8.3%, from 26.4% at baseline to 34.7% at first review. However, the percentage rating their health as excellent, very good or good declined by 4.6%, from 58.5% to 53.9%.
- ***Confidence for future:***
    - For participants who have been in the Scheme for two years, the percentage feeling more confident about the future of their family member with disability under the NDIS increased from 39.9% at baseline to 65.0% at second review.
    - For participants who have been in the Scheme for one year, the percentage feeling more confident about the future of their family member with disability under the NDIS increased from 48.1% at baseline to 66.7% at first review, and the percentage feeling delighted, pleased or mostly satisfied when thinking about last year and what they expect for the future increased from 47.6% to 58.7%.
    - These outcomes did not change significantly for families/carers of participants have been in the Scheme for three years.

Figure 15 Changes in indicators over three years for families/carers of participants aged 25 and over who have been in the Scheme for three years – employment and interaction with services

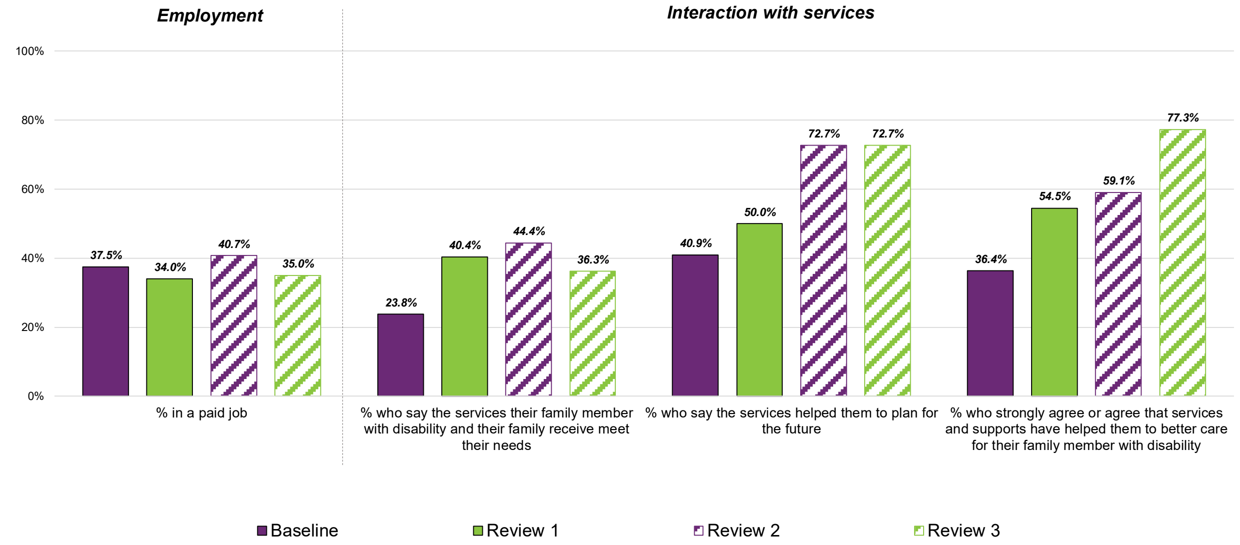


Figure 16 Changes in indicators over two years for families/carers of participants aged 25 and over who have been in the Scheme for two years – employment and interaction with services

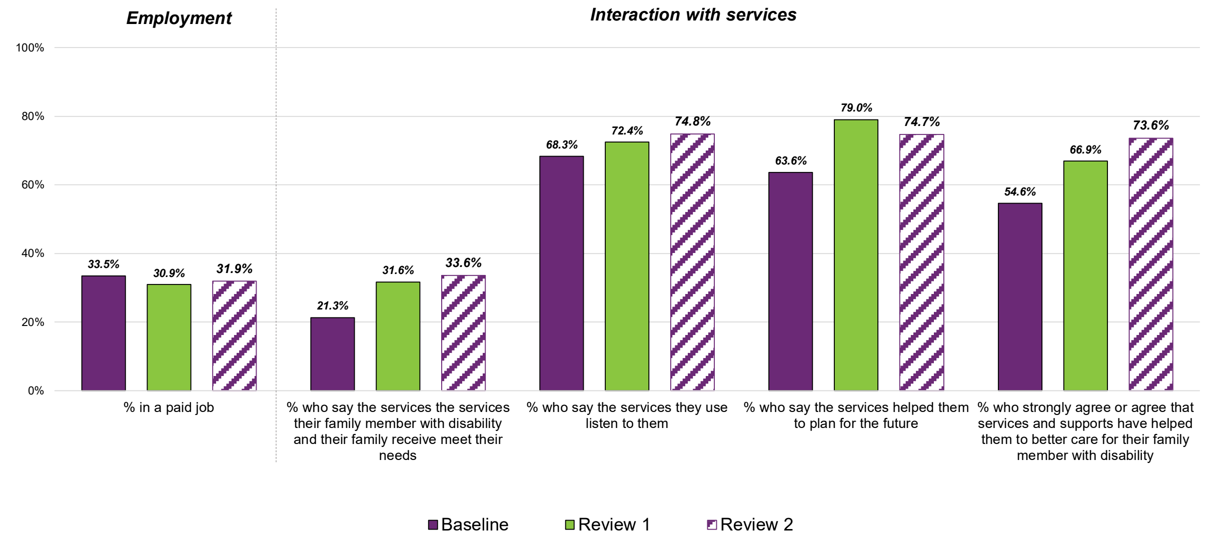
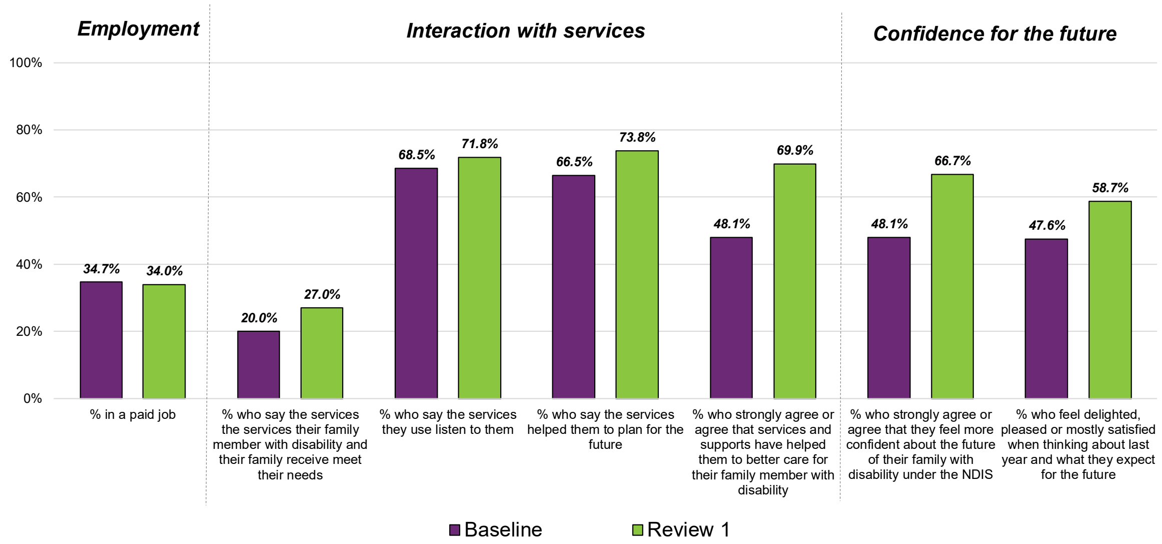


Figure 17 Changes in indicators over one year for families/carers of participants aged 25 and over who have been in the Scheme for one year – employment, interaction with services and confidence for the future



Results by participant and family/carer characteristics

Due to the smaller amount of data for families/carers of participants aged 25 and over, the modelling performed was less extensive. Nevertheless, some participant and family/carer characteristics were identified as being significantly associated with changes in outcomes:

- Families and carers of participants who feel safe in their home, and of participants whose self-rated health improves, are more likely to improve and/or less likely to deteriorate in several outcomes.
- Family/carer employment status is also a significant factor for some outcomes. For example, families/carers who remain in paid work are more likely to improve and less likely to deteriorate in rating their health as excellent, very good or good.
- State/Territory of residence is also a factor. Families/carers of participants living in States/Territories other than Victoria tended to have more positive longitudinal outcomes. For example, they were more likely to improve in the latest year in thinking that the services they receive meet their needs.
- Families/carers of CALD participants were less likely to improve in thinking that their family member with disability gets the support they need.
- Families/carers of older participants had some more favourable longitudinal outcomes, for example, they were more likely to improve in thinking that the services they receive meet their needs.
- Higher plan utilisation was associated with being more likely to improve in thinking that the services they and their family member receive meet their needs, and that their family member gets the support they need.
- Families/carers of participants with lower level of function were more likely to deteriorate in rating their health as excellent, very good or good.

- Participants living outside a major city were more likely to improve in the latest year in thinking that the services they receive meet their needs, and in thinking that their family member gets the support they need.

Has the NDIS helped?

Families' and carers' opinions on whether the NDIS has helped vary by domain:

- Improvements in positive response rates were observed over the participant's second year across all domains, however there was minimal change or a slight decline (for access to services and succession planning) over the third year.

- The likelihood of a positive response after **one year** in the Scheme depended on some participant and family/carer characteristics:
    - Higher baseline plan utilisation, and higher annualised plan budget, were associated with a higher likelihood of responding positively after one year in the Scheme.
    - Families/carers of participants with better self-rated health, and of participants who feel safe in their home, are more likely to respond positively.
    - Families/carers of participants who work in a paid or unpaid job are more likely to think the NDIS has helped with level of support, succession planning, and health and wellbeing.
    - Families/carers of participants in supported independent living (SIL) were less likely to think that the NDIS has helped with level of support and access to services.
    - Families/carers of participants living in QLD or WA were more likely than families/ carers of participants living in NSW to think that the NDIS has helped, across all domains.
    - Compared to families/carers of participants who live in a major city, families/ carers of participants who live in regional areas are more likely to respond positively, and families/carers of those living in remote/very remote areas are less likely to respond positively, across all domains except health and wellbeing.
    - Controlling for other factors, families/carers of participants with partly self-managed plans were significantly more likely than families/carers of those with agency-managed plans to think that the NDIS has helped across all domains except succession planning. However, no significant difference was found for those fully self-managing compared to those agency-managing (this may be partly due to the smaller number of participants aged 25 and over who self-manage fully).

- Looking at changes in responses over time (that is, comparing results between first and later reviews), the smaller amount of longitudinal data for this cohort meant that a smaller number of factors was identified. However, some differences by participant and family/carer characteristics occurred for multiple domains:
    - Higher plan utilisation (and particularly utilisation of core supports), and higher annualised plan budget, were generally associated with a higher likelihood of improvement and/or lower likelihood of deterioration.
    - Families/carers of participants with lower level of function were more likely to deteriorate in thinking the NDIS has helped with rights and advocacy, and less likely to improve for succession planning, however, they were less likely to deteriorate for health and wellbeing.

    - Families/carers of participants living outside a major city were more likely to improve in thinking the NDIS has helped with level of support, access to services, and succession planning.

COVID-19

The global pandemic that took hold from early 2020 is likely to have had an impact on at least some family/carer outcomes, such as employment, and social and community participation.

To investigate which outcomes may have been affected by the pandemic via quantitative modelling, additional time-related terms were included in the regression models.[7] These terms allow for a step change in the probability of families/carers changing their response, and/or a different trend over time, when the later review occurs during the COVID-19 pandemic.

Families and carers of participants from birth to age 14

There were some significant changes to families' and carers' longitudinal outcomes during the pandemic, across all 14 indicators considered. Results were mixed, being favourable for some indicators but unfavourable for others. For example:

- When the later response occurred during the COVID period, deterioration over two years was more likely for having a paid job, and deterioration between second and third review was more likely for working 15 or more hours per week.
- Deterioration was less likely in transitions from baseline for having people to ask for practical help, and for being able to engage in social interactions and community life.
- There was a drop in the likelihood of improvement between baseline and first review with respect to getting enough support to feel confident in parenting their child at the start of the pandemic, however this was accompanied by a favourable change in time trend, with improvement becoming more likely over time during the pandemic.

Families and carers of participants from age 15 to age 24

There were a few significant changes to families' and carers' longitudinal outcomes during the pandemic, and results were mixed, being favourable in some indicators but unfavourable in others. For example:

- Families and carers whose latest response was collected during the COVID period were more likely to show deterioration from baseline to first review in working 15 or more hours per week, however, they were more likely to show improvement from baseline to third review.
- Families and carers are less likely to deteriorate between baseline and first review in thinking that the services they use listen to them when their latest response is given during the COVID period.
- Families and carers who are unable to work as much as they want are more likely to start citing lack of job availability as a reason for not working more between baseline and third review, when the third review happened during the COVID period.

Families and carers of participants aged 25 and over

There were only two indicators where there were significant changes to families' and carers' longitudinal outcomes during the pandemic:

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[7] The methodology and limitations of the approach are discussed in Section 2.5. In particular, the modelling is based on only about three months of experience during the pandemic, and some of the effects detected are only slight.

- Families and carers who gave their later response during the COVID period were more likely to improve between baseline and first review in thinking that the services their family members with disability and their families receive meet their needs.
- Families and carers who had their review during the COVID period were less likely to deteriorate between baseline and first review but less likely to improve between baseline and second review in thinking that their family member gets the support they need.