Family/carer outcomes

To 30 June 2019

National Disability Insurance Agency

Contents

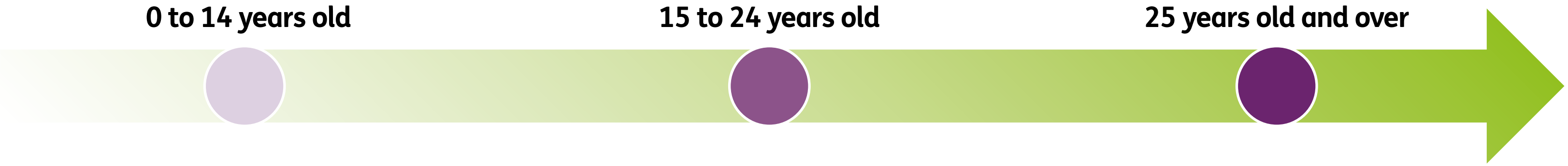
- Family/carer outcomes, and the NDIS outcomes framework
- Baseline versus progress
- Summary of results for families and carers of participants aged from:
  - Birth to age 14
  - 15 to 24
  - 25 and over
- Results for each age cohort include:
  - Notable changes in indicators over one and two years in the Scheme
  - Factors associated with differences in baseline outcomes, and the likelihood of improvement/ deterioration in outcomes over time
  - Perceptions of whether the NDIS has helped, factors associated with positive opinions, and with changes in opinions.

Outcomes framework questionnaires

Outcomes framework

A lifespan approach to measuring participant and family/carer outcomes across main life domains has been used.

Lifespan approach: three cohorts, based on participant age:



0 to 14 years old	15 to 24 years old	25 years old and over
Domain 1: Rights and advocacy	**Domain 1:** Rights and advocacy	**Domain 1:** Rights and advocacy
Domain 2: Support	**Domain 2:** Support	**Domain 2:** Support
Domain 3: Access to services	**Domain 3:** Access to services	**Domain 3:** Access to services
Domain 4: Development	**Domain 4:** Independence	**Domain 4:** Succession plans
Domain 5: Health and wellbeing	**Domain 5:** Health and wellbeing	**Domain 5:** Health and wellbeing
Domain 6: Understanding of child's strengths, abilities and special needs	**Domain 6:** Understanding of child's strengths, abilities and special needs	

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).

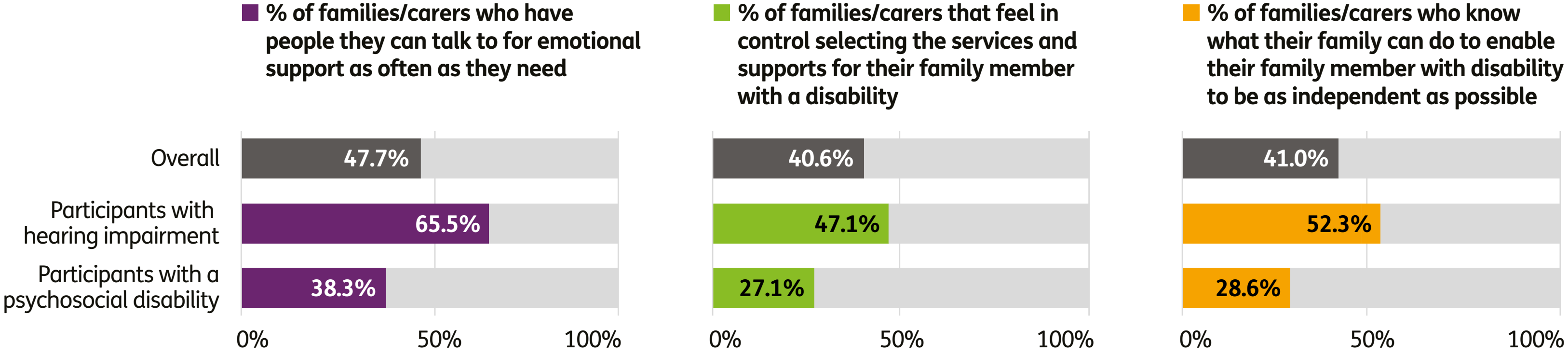
Baseline outcomes

Baseline outcomes for participants and families/carers vary by a number of factors, including:

- the nature and severity of the participant's disability
- the extent of support networks
- local community inclusiveness
- their general health

Example:
Families/carers of participants with a hearing impairment are more likely to experience better baseline outcomes, and families/carers of participants with a psychosocial disability are less likely

Families/carers of participants aged 15 to 24

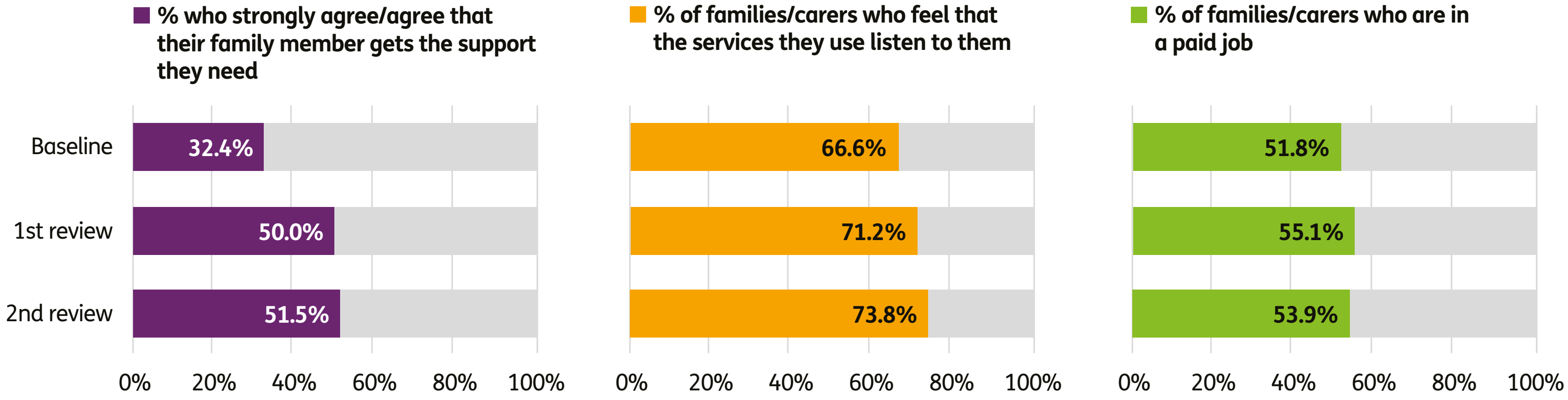


Progression towards better outcomes

Success should be measured on how far participants and their families and carers have come since entering the Scheme, acknowledging different starting points.

Whilst some outcomes should improve relatively quickly (for example, access to services), others are much more long-term in nature (for example, employment), and measurable progress may take some years to emerge.

Families/carers of participants aged 15 to 24



Longitudinal cohorts

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

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

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

The longitudinal analysis is restricted to cases where the same person responded at each of the time points being considered.

Families/carers of participants **from birth to age 14**

Families/carers of participants from birth to age 14

For families/carers of participants aged 0 to 14, the outcomes framework seeks to measure the extent to which:

Families know their rights and advocate effectively for their child with disability (domain RA)

Families feel supported (domain SP)

Families are able to gain access to desired services, programs and activities within the community (domain AC)

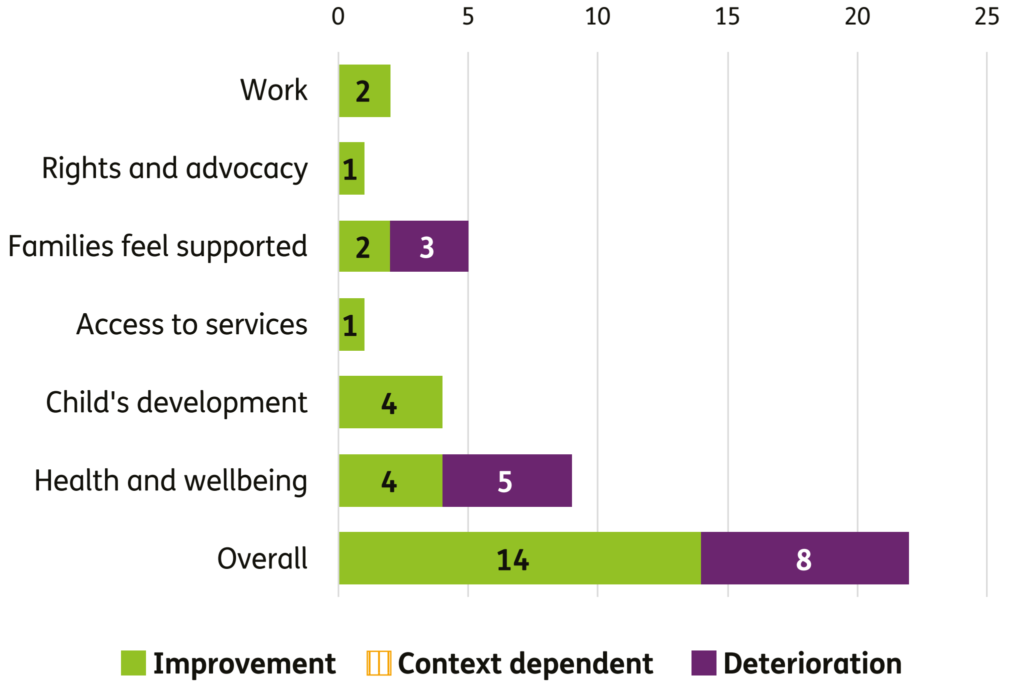
Families help their children develop and learn (domain DV)

Families enjoy health and wellbeing (domain HW)

Families understand their child's strengths, abilities and special needs (domain UN)

Families/carers of participants from birth to age 14

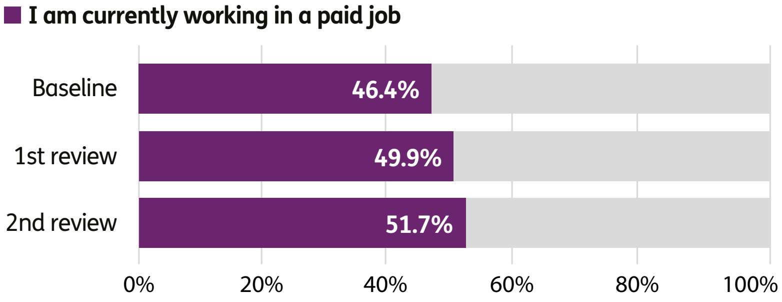
Number of indicators with significant and material overall change by domain

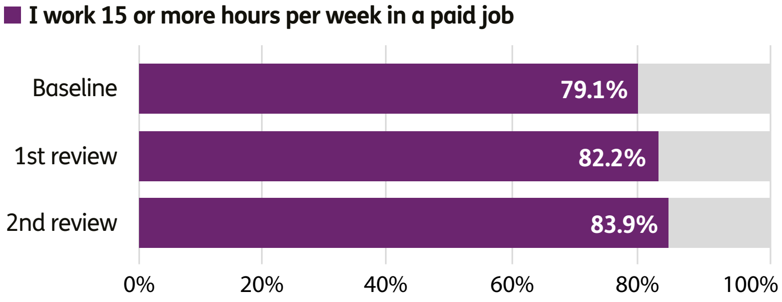


Families/carers of participants from birth to age 14:

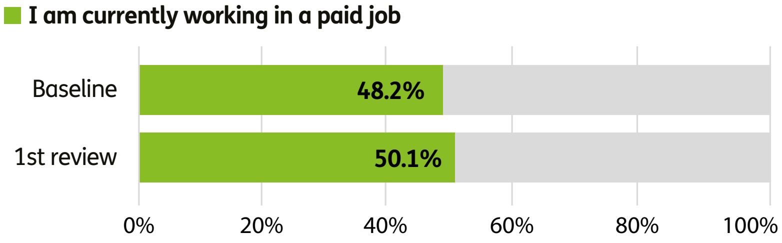
Employment

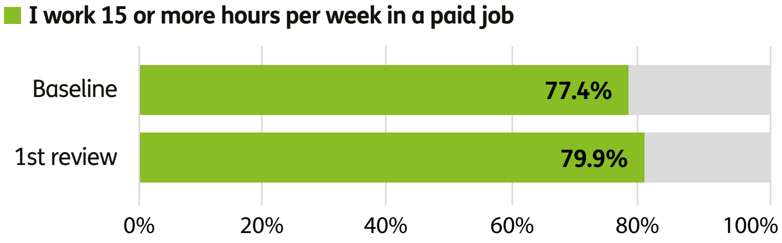
For families/carers of participants entering in 2016-17, the percentage working in a paid job increased by 5.3% between baseline and second review. The percentage of families/carers who work 15 or more hours per week in a paid job increased by 4.8%.





For families/carers of participants entering in 2017-18, the percentage working in a paid job increased by 1.9% in the year following Scheme entry. The percentage who work 15 or more hours per week in a paid job increased by 2.5%.

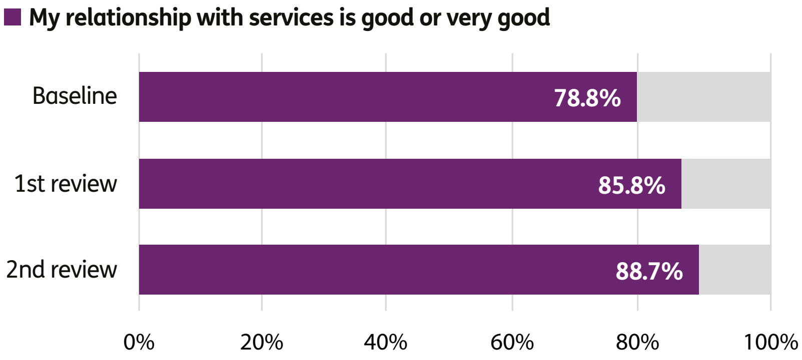




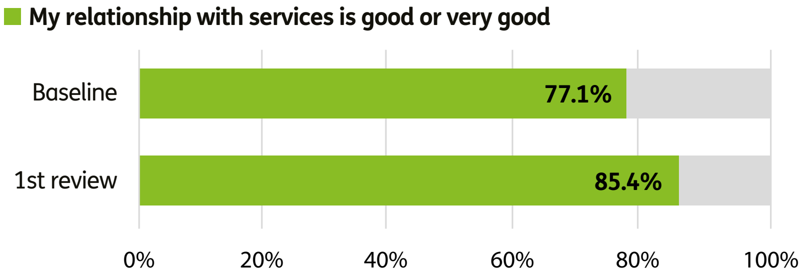
Families/carers of participants from birth to age 14:

Access to services

For families/carers of participants who joined the Scheme in 2016-17, the percentage of parents/carers who say their relationship with services is good or very good increased by 9.9% between baseline and second review, from 78.8% to 88.7%.



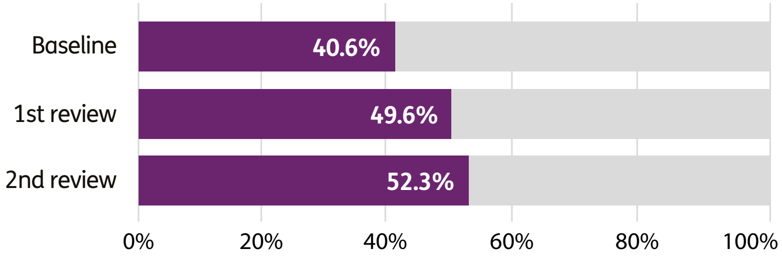
For families/carers of participants entering in 2017-18, there was a one year improvement of 8.3% in the percentage of families/carers who have a good or very good relationship with services, from 77.1% to 85.4%.



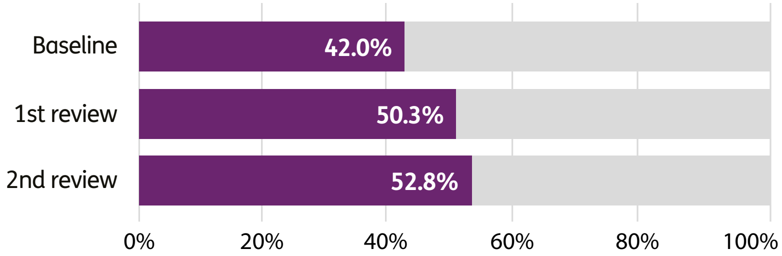
Families/carers of participants from birth to age 14:
Development

For families/carers of participants entering in 2016-17, the percentage who know what specialist services are needed to promote their child’s learning and development increased by 11.7% between baseline and second review. The percentage who know what their family can do to support their child’s learning and development increased by 10.8%.

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

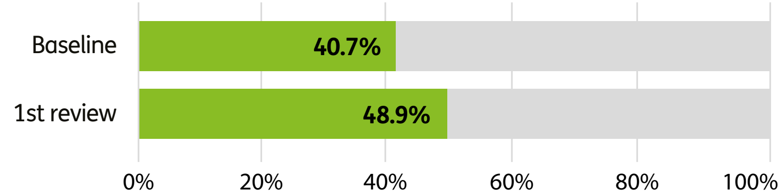


■ I know what my family can do to support my child's learning and development

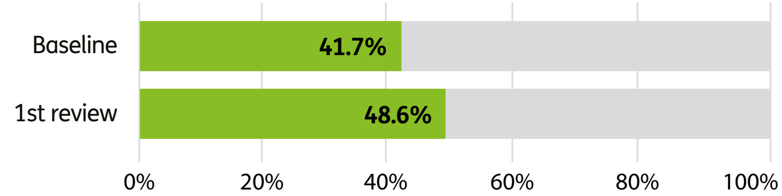


For families/carers of participants entering in 2017-18, the percentage who know what specialist services are needed to promote their child’s learning and development increased by 8.2% in the year following Scheme entry. The percentage who know what their family can do to support their child’s learning and development increased by 6.9%.

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



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

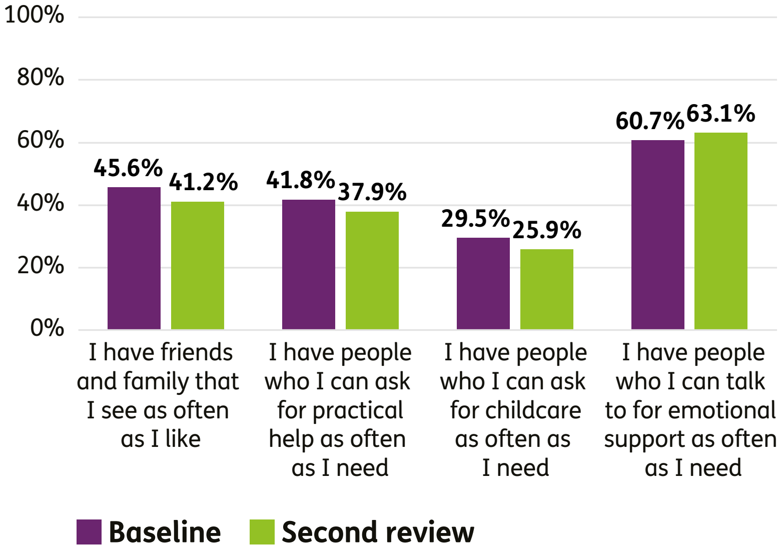


Families/carers of participants from birth to age 14:

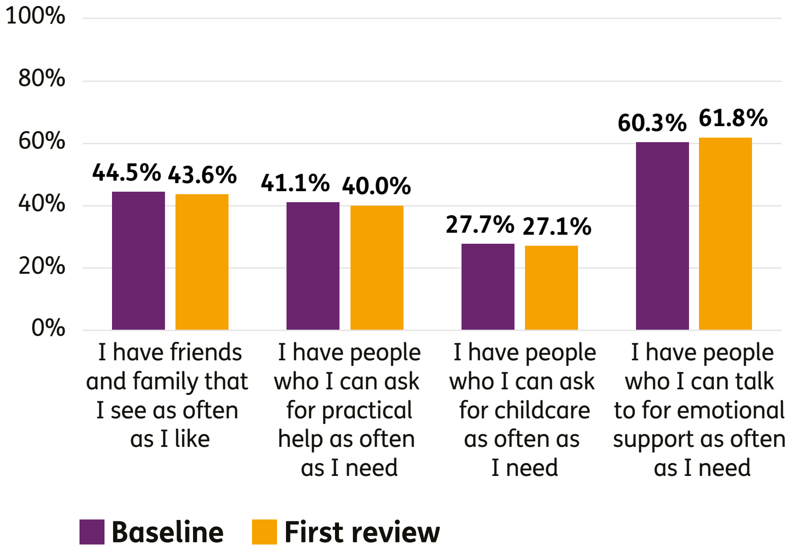
Support

For families/carers of participants entering in both 2016-17 and 2017-18, there has been a decrease in the percentage who have friends or family they can see as often as they like. The percentages who have people they can talk to for practical help or ask for childcare as often as they need have also decreased. However, families/carers are more likely to say that they have people who they can talk to for emotional support as often as they need.

2016-17 entrants – two year change



2017-18 entrants – one year change

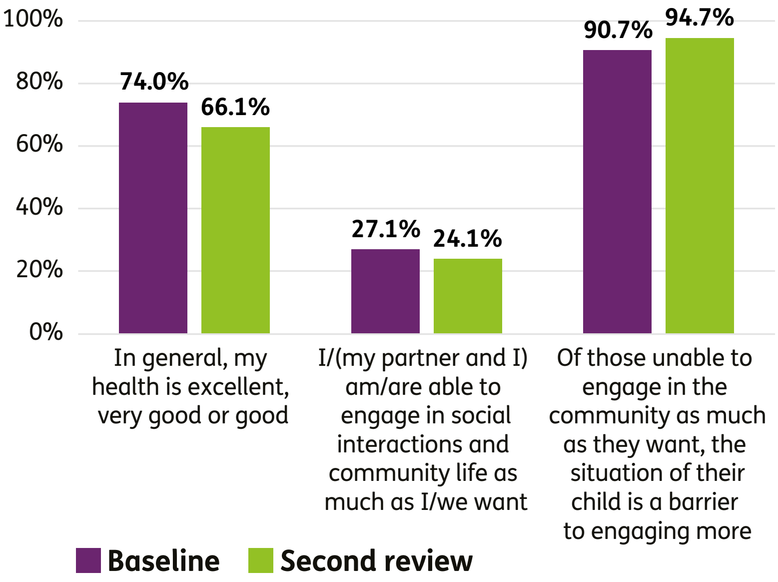


Families/carers of participants from birth to age 14:

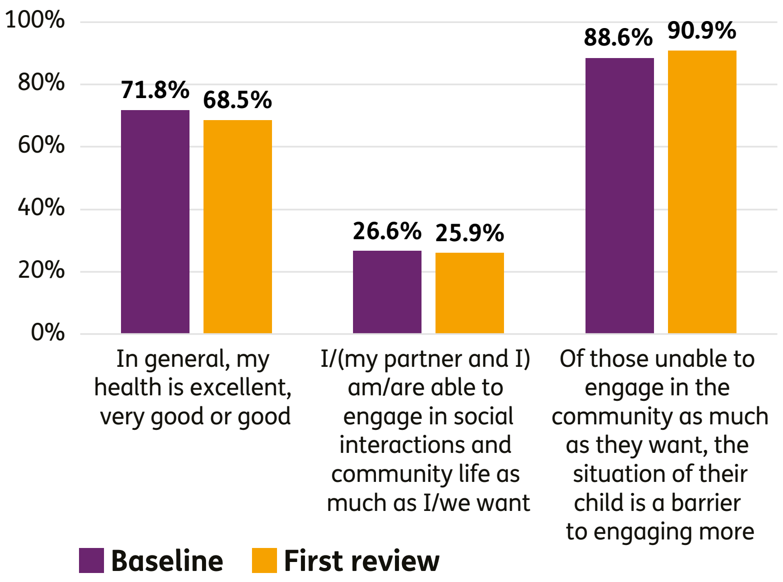
Health and wellbeing

For families/carers of participants entering in both 2016-17 and 2017-18, there has been a deterioration in the percentage of families/carers who rate their health as excellent, very good or good. The percentage who are able to engage in social interactions and community life as much as they want also decreased. Of those unable to engage in the community as much as they want, the percentage who say the situation of their child with disability is a barrier to engaging within the community more has increased.

2016-17 entrants – two year change



2017-18 entrants – one year change



Families/carers of participants from birth to age 14:

Outcomes by participant and plan characteristics

Families/carers' baseline and longitudinal outcomes vary significantly with their primary disability, age, cultural background, Indigenous status, level of function, plan budget and living situation.

Primary disability: Families/carers of participants with a hearing or visual impairment generally experience better outcomes, both baseline and longitudinal.

Age: Families/carers of older participants tend to exhibit worse outcomes, both at baseline and in the longitudinal analysis, particularly with respect to advocacy, feeling supported, and health and wellbeing.

CALD status: Baseline outcomes for families/carers of participants who are from a CALD background tend to be worse than those for families/carers of non-CALD participants, particularly regarding advocacy and independence. Families/carers of CALD participants do better on some longitudinal indicators and worse on others.

Indigenous status: Baseline results for families/carers of Indigenous participants are mixed. They are less likely to be in paid employment or to report that the services they use listen to them, but are more likely to have access to required services.

Level of function and plan budget: For the majority of indicators in all domains, baseline and longitudinal outcomes are better for families/carers of participants with a high level of function. A similar trend was observed for families/carers of participants with a lower annualised plan budget.

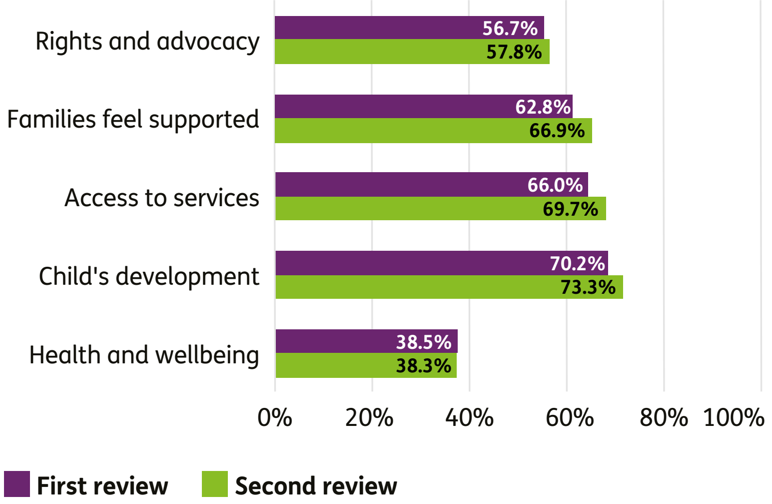
Self-management: Families/carers of participants with self-managed plans (fully or partly) experience more positive outcomes in the domains of advocacy, feeling supported and helping their child develop and learn, at both baseline and subsequent review periods.

Families/carers of participants from birth to age 14:

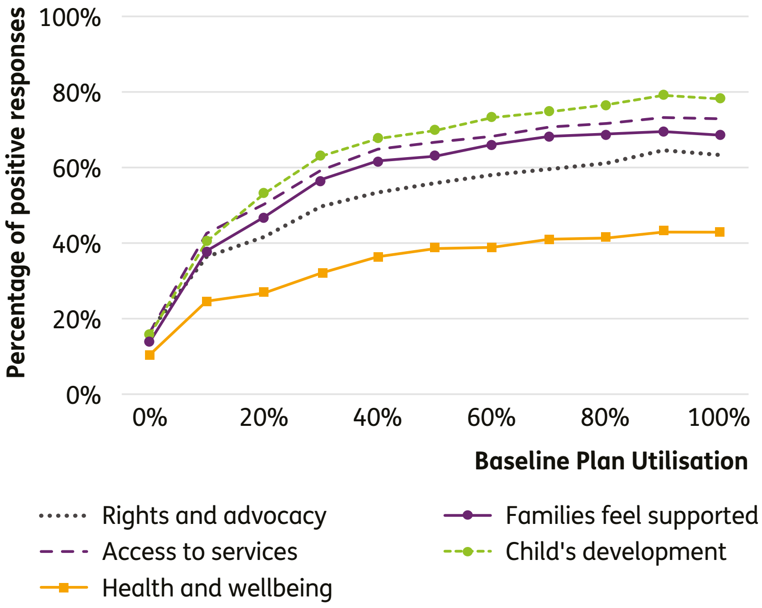
Has the NDIS helped?

Opinions on whether the NDIS has helped vary considerably by domain, being most positive in relation to improving family/carer capacity to help their child develop (70.2% after one year in the Scheme, increasing to 73.3% after two years in the Scheme) and access to services (66.0% after one year in the Scheme, increasing to 69.7% after two years in the Scheme). Higher plan utilisation is strongly associated with a positive response after one year in the Scheme, and also after two years in the Scheme.

Percentage of positive responses



By plan utilisation rate, after one year



Families/carers of participants from birth to age 14:

Has the NDIS helped?

Results tended to be more positive for families/carers of participants who are younger, have higher baseline plan utilisation and higher level of function, have self-managed plans, and need less support with planning from the NDIA.

Change in responses between first and second review

The percentage who think that the NDIS has helped increased (by 1.1 to 4.1%) between first and second review across all domains except for Health and Wellbeing, where there was no change.

The likelihood of improvement/deterioration varied by some participant characteristics, for example:

- Families and carers of participants with higher plan utilisation were more likely to improve across almost all domains
- Families and carers of older participants or those that changed employment status from permanent to casual were more likely to deteriorate between first and second review.

Families/carers of participants **aged 15 to 24**

Families/carers of participants aged 15 to 24

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

Families know their rights and advocate effectively for their child with disability (domain RA)

Families feel supported (domain SP)

Families are able to gain access to desired services, programs and activities within the community (domain AC)

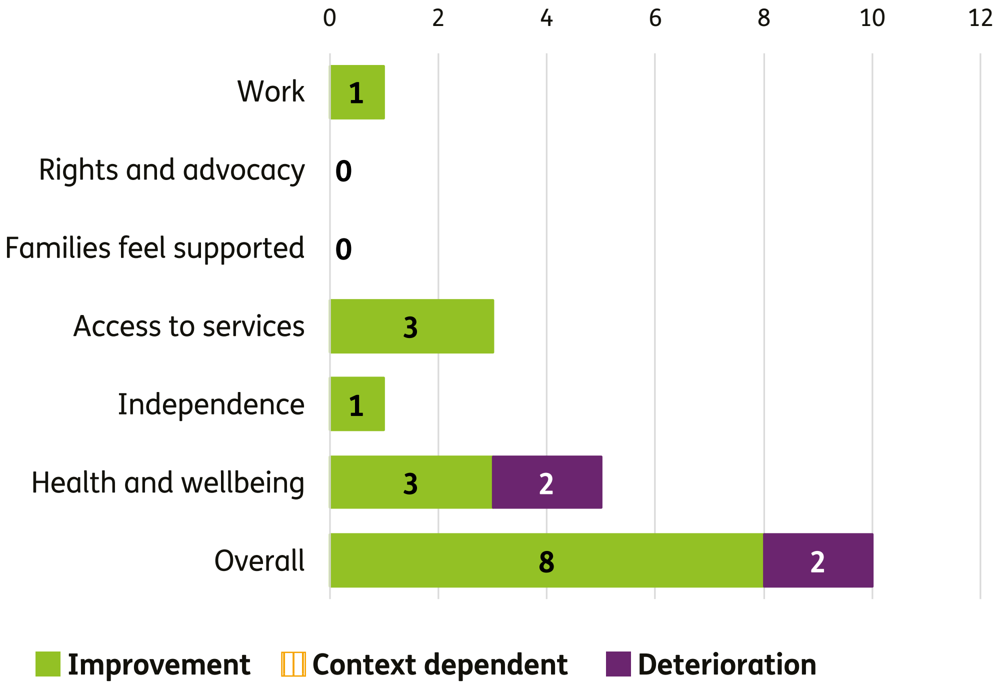
Families help their young person become independent (domain IN)

Families enjoy health and wellbeing (domain HW)

Families understand their child's strengths, abilities and special needs (domain UN)

Families/carers of participants aged 15 to 24

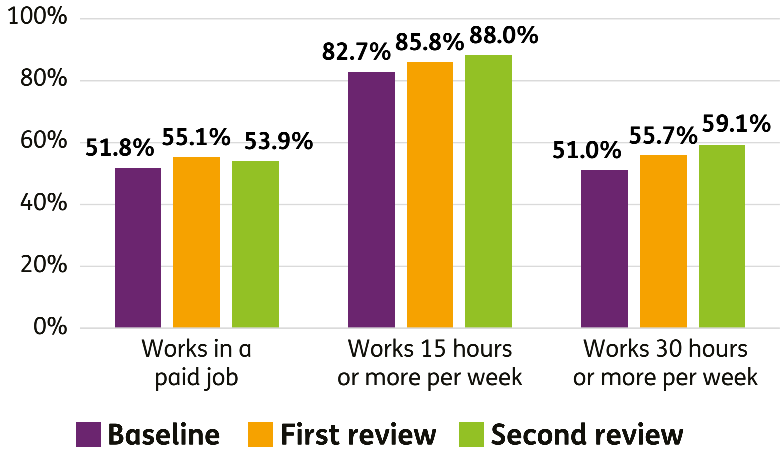
Number of indicators with significant and material overall change by domain



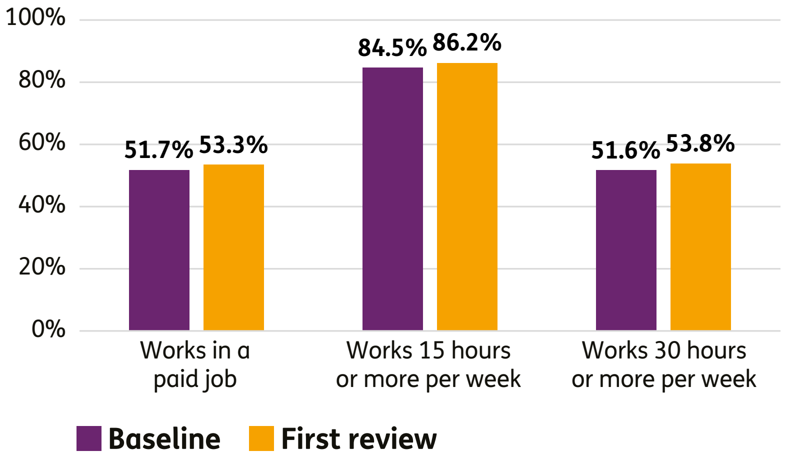
Families/carers of participants aged 15 to 24:
Employment

There were some small positive changes observed in the employment indicators for the families/carers of participants aged 15 to 24. However, with one exception (the percentage of families/carers of participants entering the Scheme in 2016-17 working 15 hours or more per week) they were either not statistically significant[1] at the 5% level or of magnitude less than 2%.

2016-17 entrants – two year change



2017-18 entrants – one year change



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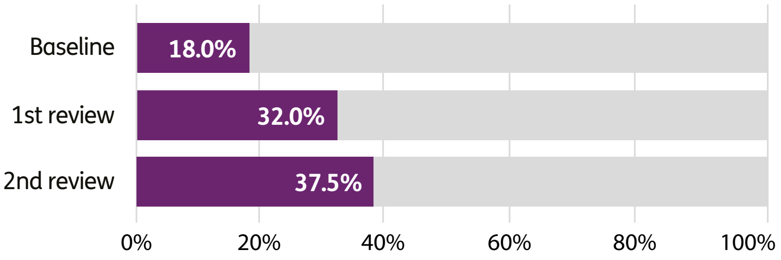
[1] The change in the percentage working in a paid job, for families/carers of participants who joined the Scheme in 2016-17, was significant at the 10% level.

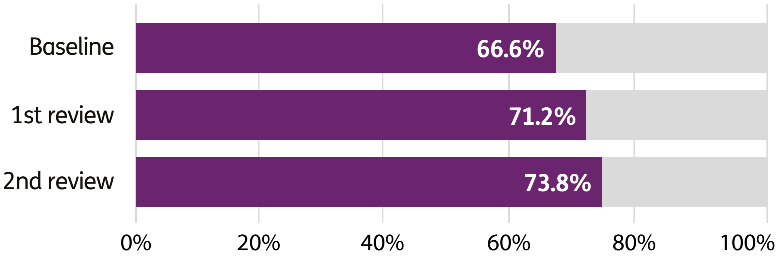
Families/carers of participants aged 15 to 24:
Access to services

For families/carers of participants entering in 2016-17, the percentage who say the services they receive meet their needs increased by 19.5% between baseline and second review. The percentage of families/carers who say the services they use listen to them increased by 7.2%.

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

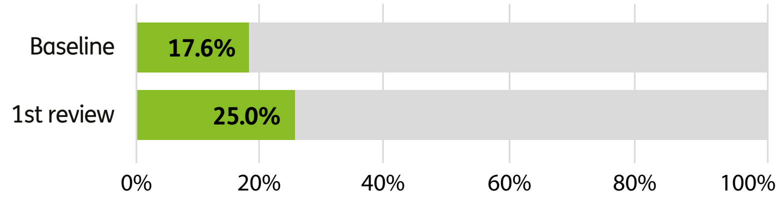


🟪 **I feel that the services my family member with disability and my family use listen to me**

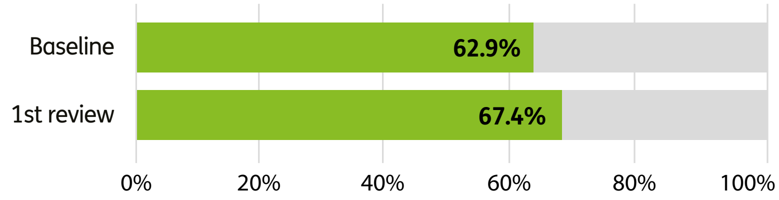


For families/carers of participants entering in 2017-18, the percentage who say the services they receive meet their needs increased by 7.4% in the year following Scheme entry. The percentage who say the services they use listen to them increased by 4.5%.

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



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

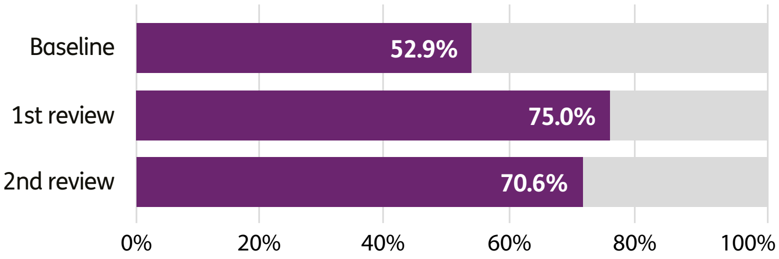


Families/carers of participants aged 15 to 24:

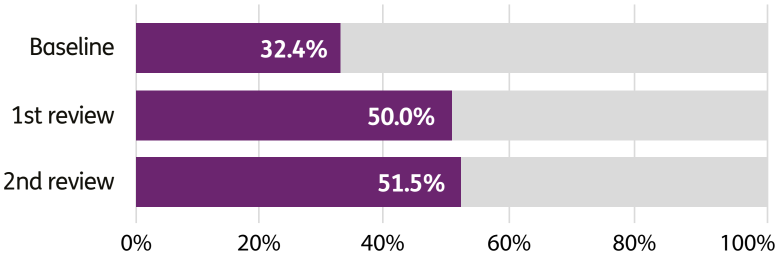
Confidence for the future

For families/carers of participants entering in 2016-17, the percentage who felt more confident about the future of their family member under the NDIS increased by 17.7% between baseline and second review. The percentage of families/carers who strongly agree/agree that their family member gets the support they need increased by 19.1%.

I feel more confident about the future of my family member with disability under the NDIS

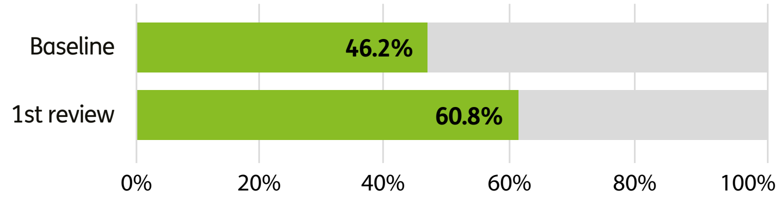


I strongly agree/agree that my family member gets the support they need

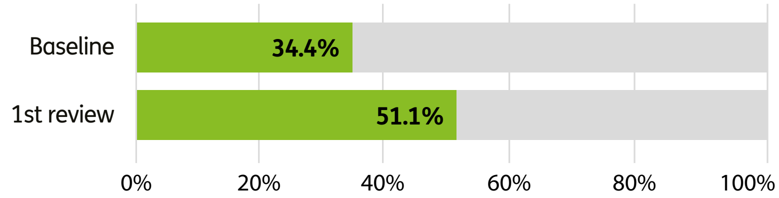


For families/carers of participants entering in 2017-18, the percentage who felt more confident about the future of their family member under the NDIS increased by 14.6% in the year following Scheme entry. The percentage who strongly agree/agree that their family member gets the support they need increased by 16.7%.

I feel more confident about the future of my family member with disability under the NDIS



I strongly agree/agree that my family member gets the support they need

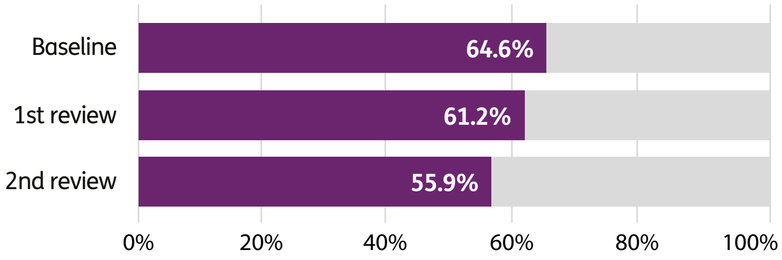


Families/carers of participants aged 15 to 24:

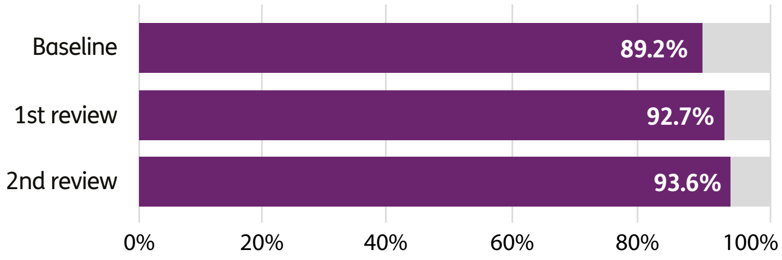
Health and wellbeing

For families/carers of participants entering in 2016-17, the percentage who rated their health as excellent, very good or good decreased by 8.7% between baseline and second review. Of the families/carers who are unable to work as much as they want, the percentage who say the situation of their child is a barrier to working more increased by 4.4%.

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

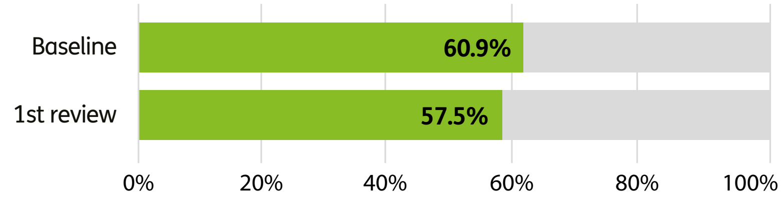


🟪 **Of those unable to work as much as they want, the situation of their child is a barrier to working more**

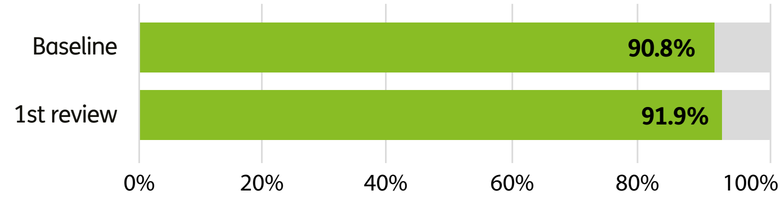


For families/carers of participants entering in 2017-18, the percentage who rated their health as excellent, very good or good decreased by 3.4% in the year following Scheme entry. The percentage who say the situation of their child is a barrier to working more increased by 1.1%.

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



🟩 **Of those unable to work as much as they want, the situation of their child is a barrier to working more**



Families/carers of participants aged 15 to 24:

Outcomes by participant characteristics

Families/carers' baseline and longitudinal outcomes vary significantly with their primary disability, age, cultural background, Indigenous status, level of function and plan type.

Primary disability: Families/carers of participants with a hearing or visual impairment generally experience better outcomes at baseline. Families/carers of participants with psychosocial disability tend to fare worse at baseline.

Age: Families/carers of older participants tend to exhibit better outcomes at baseline, particularly in the employment and participant independence domains. Families/carers of older participants are less likely to see improvements in health and wellbeing.

CALD status: Baseline outcomes for families/carers of participants from CALD backgrounds tend to be worse, particularly on advocacy and independence. They are also less likely to see improvements in health and wellbeing between baseline and second review, but otherwise not significantly different to families/carers of non-CALD participants on longitudinal indicators.

Indigenous status: Families/carers of Indigenous participants are less likely to be in paid employment and to report that the services they use listen to them, but more likely to have people who can provide practical help.

Level of function: Baseline outcomes are better for families and carers of participants with a high level of function.

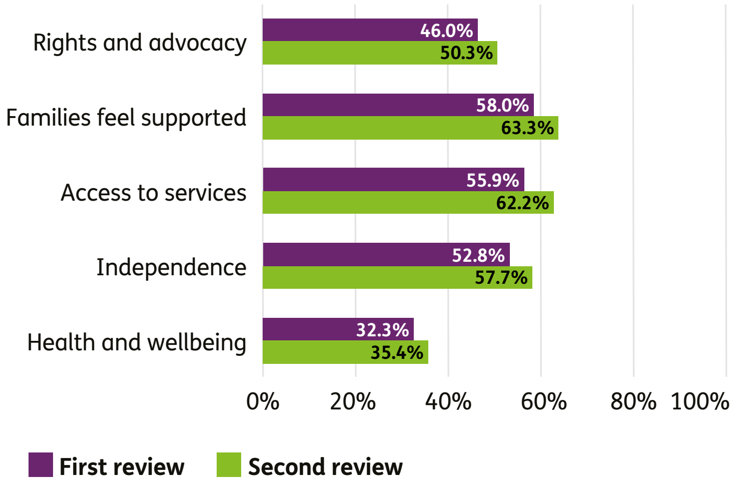
Plan type: Families/carers with self-managed plans (fully or partly) experience more positive outcomes at baseline on some indicators, namely within the advocacy and feeling supported domains. This group is also more likely to report positive outcomes at first review.

Families/carers of participants aged 15 to 24:

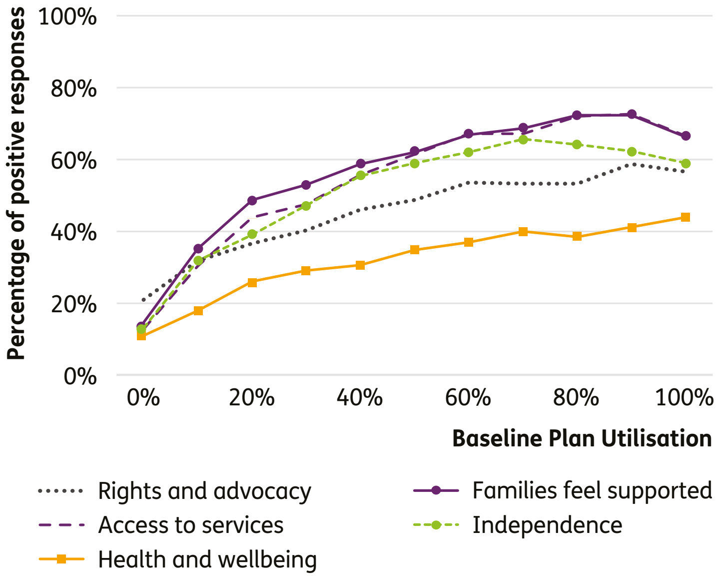
Has the NDIS helped?

Opinions on whether the NDIS has helped tend to be slightly less positive compared to the 0 to 14 cohort. Amongst the five domains, areas relating to families feel supported (58.0% after one year in the Scheme, increasing to 63.3% after two years in the Scheme) and access to services (55.9 % after one year in the Scheme, increasing to 62.2% after two years in the Scheme) observed the greatest improvement. Higher plan utilisation is strongly associated with a positive response after one year in the Scheme, and also after two years in the Scheme.

Percentage of positive responses



By plan utilisation rate, after one year



Families/carers of participants aged 15 to 24:

Has the NDIS helped?

Results tended to be more positive for families/carers of participants who are older, have higher baseline plan utilisation and have self-managed plans. Families/carers of participants who needed more support with planning from the NDIA were less likely to report positive outcomes.

Change in responses between first and second review

The percentage who think that the NDIS has helped increased between first and second review across all domains. The likelihood of improvement/deterioration varied by some participant characteristics, for example:

- Families/carers of participants with higher plan utilisation were most likely to report improvements in relation to the level of support for their family as well as in relation to access to services.
- Families/carers of participants from Queensland or South Australia were more likely to report improvements in relation to rights and advocacy. On the other hand, families/carers of participants with a lower level of function were less likely to improve in the same domain.

Families/carers of participants **aged 25 and over**

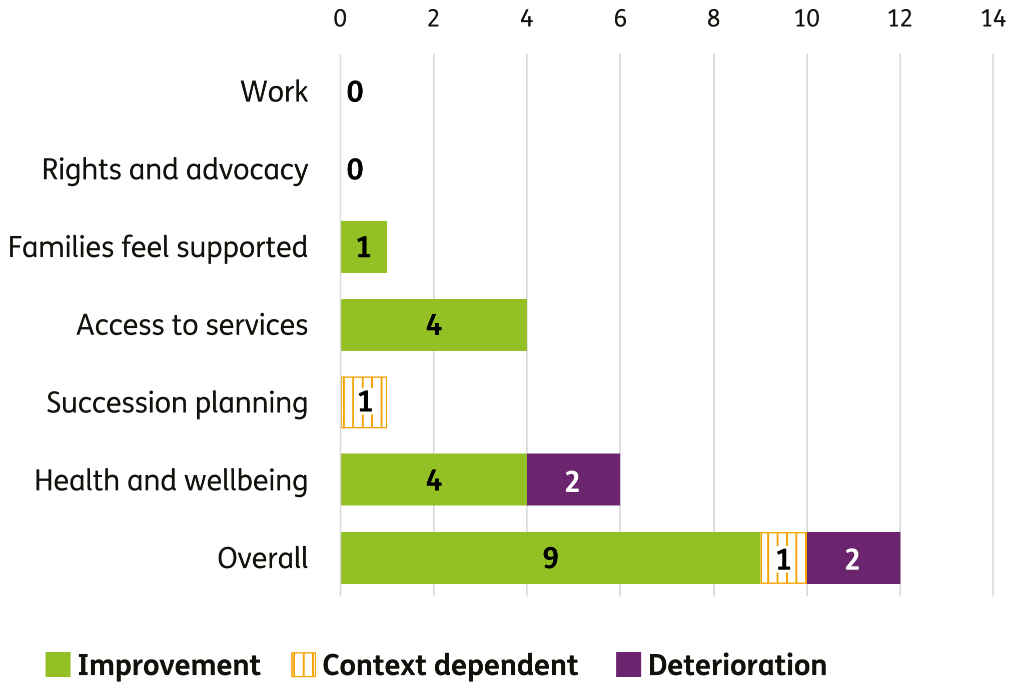
Families/carers of participants aged 25 and over

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

- **Families know their rights and advocate effectively for their child with disability** (domain RA)
- **Families feel supported** (domain SP)
- **Families are able to gain access to desired services, programs and activities within the community** (domain AC)
- **Families have succession plans** (domain SC)
- **Families enjoy health and wellbeing** (domain HW)

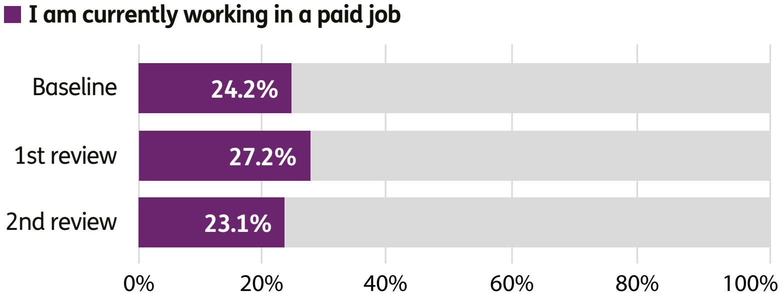
Families/carers of participants aged 25 and over

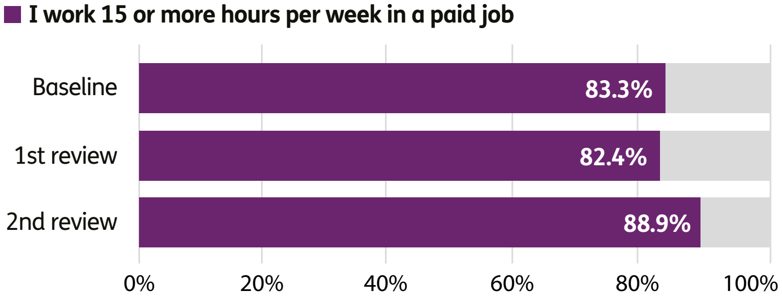
Number of indicators with significant and material overall change by domain



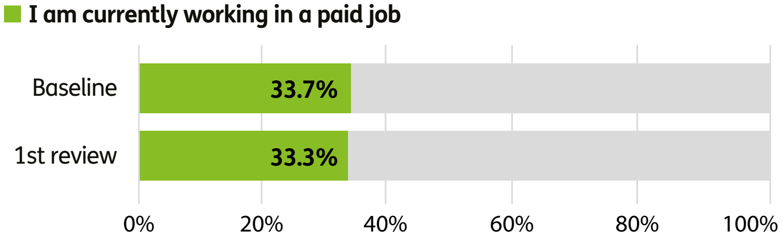
Families/carers of participants aged 25 and over:
Employment

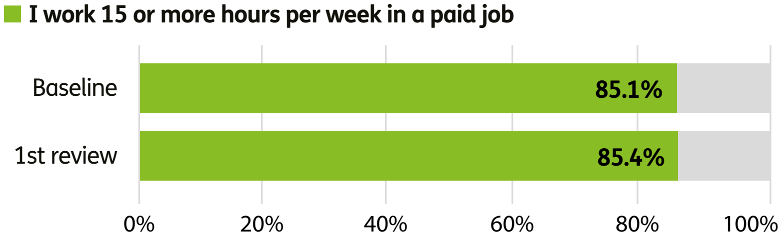
For families/carers of participants entering in 2016-17, the percentage in a paid job declined by 1.1% over two years. Of those in a paid job, the percentage who work 15 or more hours per week increased by 5.6%.[1]





For families/carers of participants entering in 2017-18, the percentage in a paid job decreased by 0.5% in the year following Scheme entry. Of those in a paid job, the percentage who work 15 or more hours per week increased by 0.3%.[1]

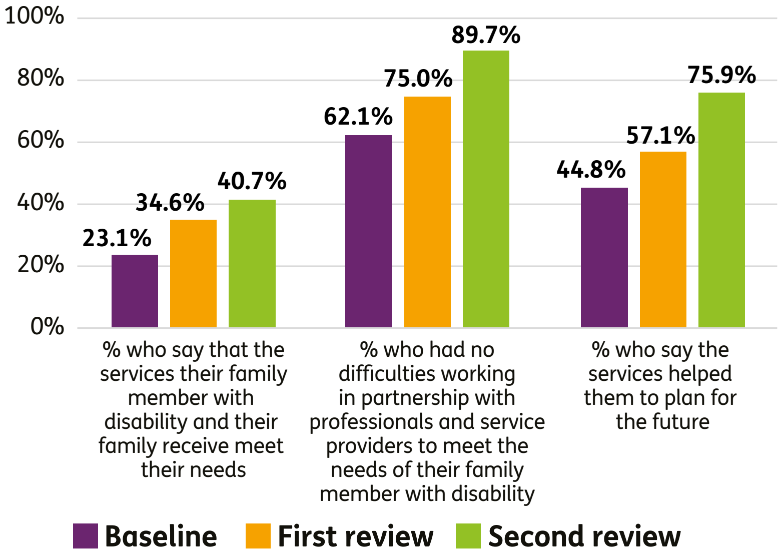


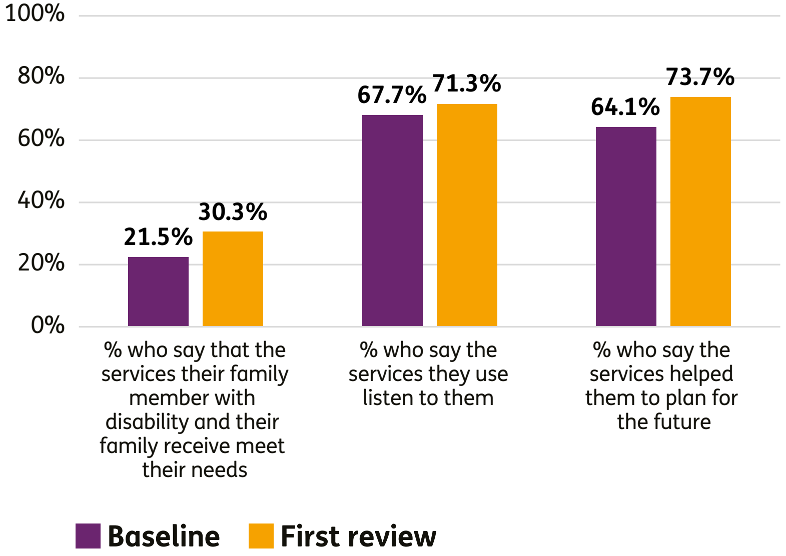


[1] These changes were not statistically significant. Also, families and carers of participants aged 25 and over are likely to be older than families and carers of younger participants, and hence more likely to be approaching retirement.

Families/carers of participants aged 25 and over:

Access to services





For families and carers of participants who joined the Scheme in 2016-17, there have been increases in the percentages who say that: the services they receive meet their needs (17.6% over two years); they had no difficulties working in partnership with professionals and service providers to meet the needs of their family member with disability (27.6%); the services helped them to plan for the future (31.1%).

For families and carers of participants who joined the Scheme in 2017-18, there have been increases in the percentages who say that: the services they receive meet their needs (8.8% over one year); these services listened to them (3.6%); the services helped them to plan for the future (9.6%).

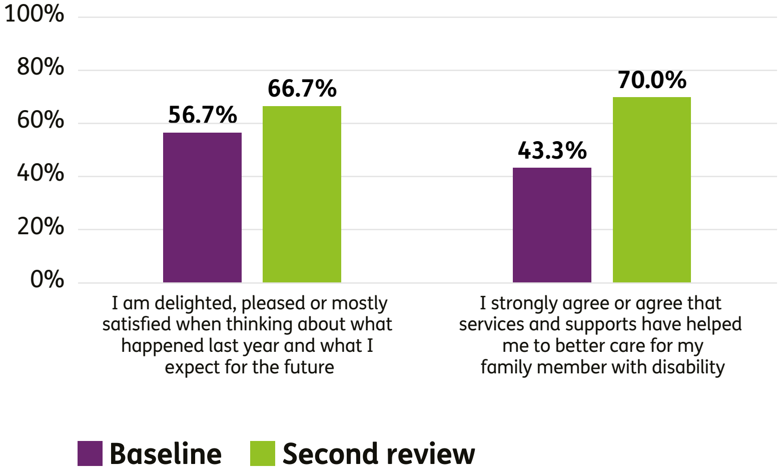
Families/carers of participants aged 25 and over:

Health and wellbeing

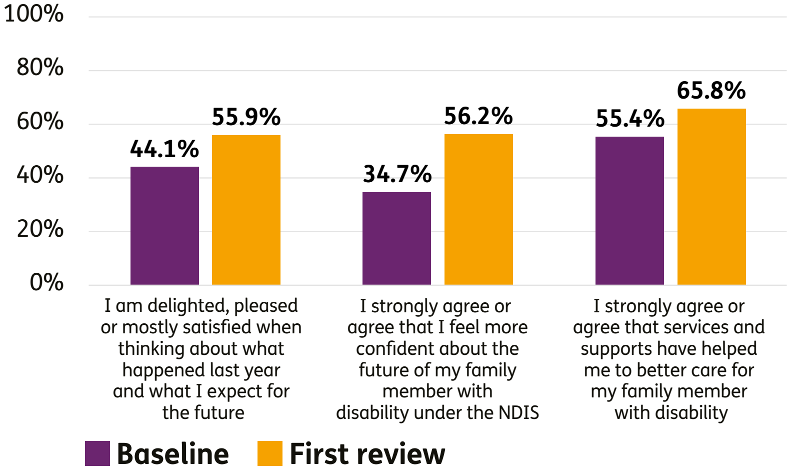
For families/carers of participants entering in both 2016-17[1] and 2017-18, there has been an increase in the percentage who are delighted, pleased or mostly satisfied when thinking about what happened last year and what they expect for the future. The percentage who strongly agree or agree that services and supports have helped them to better care for their family member with disability has also increased.

While there was no significant change in the percentage who strongly agreed or agreed that they feel more confident about the future of their family member with disability under the NDIS among families/carers of participants who entered in 2016-17, there was a large improvement in this percentage among families/carers of participants who entered in 2017-18.

2016-17 entrants – two year change



2017-18 entrants – one year change



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[1] The changes for participants who joined the Scheme in 2016-17 were not statistically significant at the 5% level, but were significant at the 10% level.

Families/carers of participants aged 25 and over:

Outcomes by participant characteristics

Families/carers’ baseline and longitudinal outcomes vary significantly with their primary disability, age, cultural background, Indigenous status, level of function and some plan characteristics. However, longitudinal results are based on small samples for this cohort.

Primary disability: At baseline, families/carers of participants with hearing impairments were least likely to cite the situation of their family member with disability as a barrier to working more. This group also exhibited the best health and wellbeing outcomes at baseline and were most likely to feel supported.

Age: At baseline, families/carers of older participants tend to exhibit better outcomes, especially in the support and access to services domains. However, health and wellbeing outcomes are more likely to deteriorate for older participants.

Level of function: For the majority of indicators in all domains, baseline and longitudinal outcomes are better for families/carers of participants with a high level of function.

Indigenous status: Baseline outcomes for families/ carers of participants from Indigenous backgrounds were generally worse than those for families/carers of non-Indigenous participants, especially in the access to services and health and wellbeing domains. No significant differences were observed longitudinally.

CALD status: At baseline, families/carers with a CALD background were less likely to be able to advocate for their family member, less likely to feel in control when selecting services and supports, and less likely to be able to work as much as they want. No significant differences were observed longitudinally.

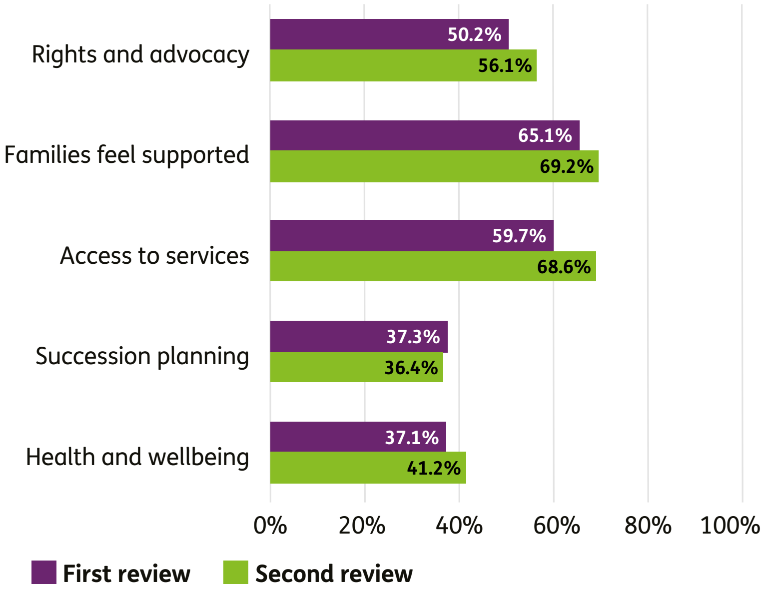
Plan characteristics: Families/carers of participants with a higher annualised plan budget and/or fully self-managed plans are more likely to agree that the services their family member with disability and their family receive meet their needs.

Families/carers of participants aged 25 and over:

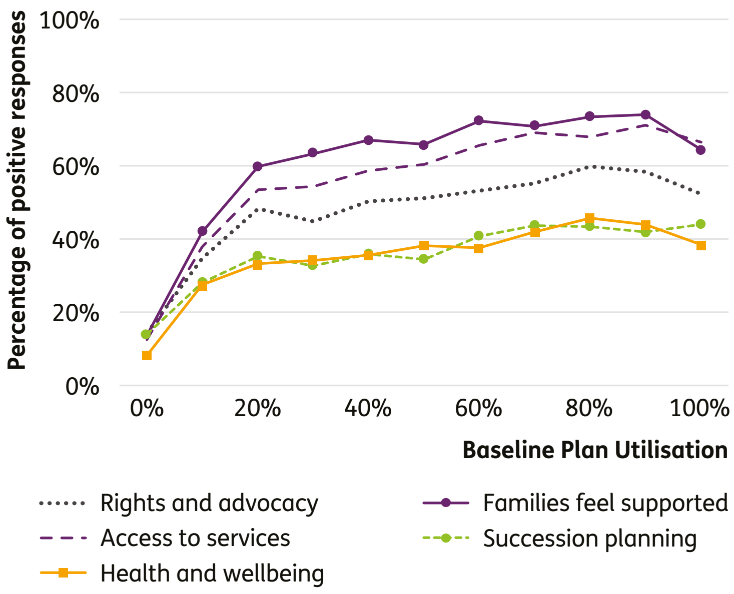
Has the NDIS helped?

Opinions on whether the NDIS has helped vary by domain. The percentage responding positively was lowest for health and wellbeing (37.1% after one year in the Scheme, increasing to 41.2% after two years in the Scheme) and highest for families feeling supported (65.1% after one year in the Scheme, increasing to 69.2% after two years in the Scheme). Higher plan utilisation is strongly associated with a positive response after one year in the Scheme, and also after two years in the Scheme.

Percentage of positive responses



By plan utilisation rate, after one year



Families/carers of participants aged 25 and over:

Has the NDIS helped?

After one year in the Scheme, families/carers of participants with higher baseline plan utilisation were more likely to say that the NDIS has helped.

Change in responses between first and second review

The percentage who think that the NDIS has helped increased significantly between first and second review across all domains with the exception of Succession Planning, which deteriorated between first and second review.

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

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