

Family and carer outcomes | Executive summary To 30 June 2021

ndis

National Disability Insurance Agency

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- NDIS outcomes framework

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Results for each age cohort include:

- Notable changes in indicators over one, two, three and four years in the Scheme
- Perceptions of whether the NDIS has helped

Summary of findings



Background

This report



This report summarises longitudinal outcomes for families and carers of participants entering the Scheme from 1 July 2016, and who have been in the Scheme for one year or more at 30 June 2021, using data available as at that date.

The purpose of the report is to provide a picture of how the families and carers of participants are progressing, based on information provided by them in interviews conducted using the NDIS outcomes framework questionnaires.

The report summarises the number, extent and nature of changes across key outcome indicators. The results are intended to provide insight into how the Scheme is making a difference for families and carers, and point to any areas where improvements may be required.

The present report builds on the work of previous reports:

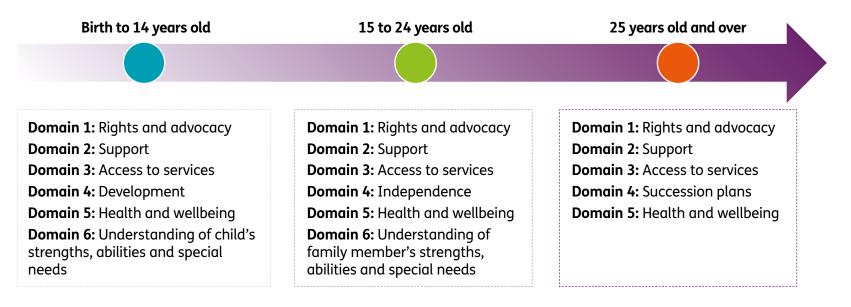
https://data.ndis.gov.au/reports-and-analyses/outcomes-and-goals/family-and-carer-outcomes-report

Outcomes framework



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

Lifespan approach: three cohorts, based on participant age:



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).

Short Form (SF) and Long Form (LF)



The **Short Form (SF)** outcomes questionnaire is completed by all participants, and a family member or carer where available, and contains questions useful for planning as well as key indicators to monitor and benchmark over time. The **Long Form (LF)** outcomes questionnaire is completed for a subset of participants, and a family member or carer where available, and includes some additional questions allowing more detailed investigation of participant and family/ carer experience, and additional benchmarking. For both the SF and the LF questionnaires, participants and their families and carers are interviewed at baseline (Scheme entry), and approximately annually thereafter. Following the same group longitudinally over time allows within-individual changes in outcomes to be investigated.

Progression towards better outcomes



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

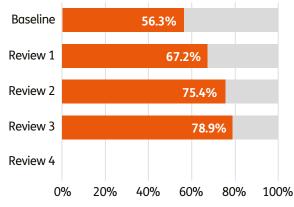
Whilst some outcomes should improve relatively quickly (for example, access to services), others may take some years to improve (for example employment). Family/carer baseline outcomes vary by a number of factors, such as:

- the nature of the participant's disability and how it affects their life
- the extent of support received from family and friends
- how inclusive their community is
- their health and other personal traits.

Families and carers of participants

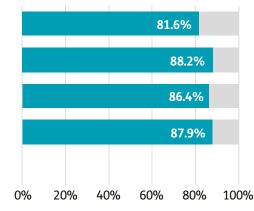
aged 25 and over

who strongly agree or agree that services and supports have helped them to better care for their family member with disability



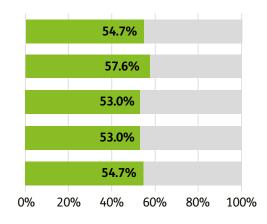
aged 0 to 14

% who say their relationship with services is good or very good



aged 15 to 24

who are in a paid job



Note: Review 4 not shown due to small numbers for the first two questions (Long Form)

Longitudinal cohorts



Longitudinal results for outcome indicators are considered separately for four cohorts, namely families and carers of participants who at 30 June 2021 have been in the Scheme for:

- Four years (C4 cohort)
- Three years (C3 cohort)
- Two years (C2 cohort)
- One year (C1 cohort)

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

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

COVID-19 pandemic

Also of key note is the global pandemic that took hold from early 2020, which is likely to have had an impact on at least some outcomes, such as employment and community participation.

For more information on the potential impact of COVID-19 on outcomes to 30 June 2020, see:

https://data.ndis.gov.au/reports-and-analyses/outcomes-and-goals/covid-19-impact-participant-and-familycarer-outcomes-30-june-2020

Families and carers of participants from birth to age 14

Families and carers of participants from birth to age 14



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

- Know their rights and advocate effectively for their child with disability
- Feel supported
- Are able to gain access to desired services, programs and activities within the community
- Help their children develop and learn
- Enjoy health and wellbeing
- Participate in employment
- Participate in social and community activities
- Understand their child's strengths, abilities and special needs

Number of family/carers in each longitudinal cohort¹:

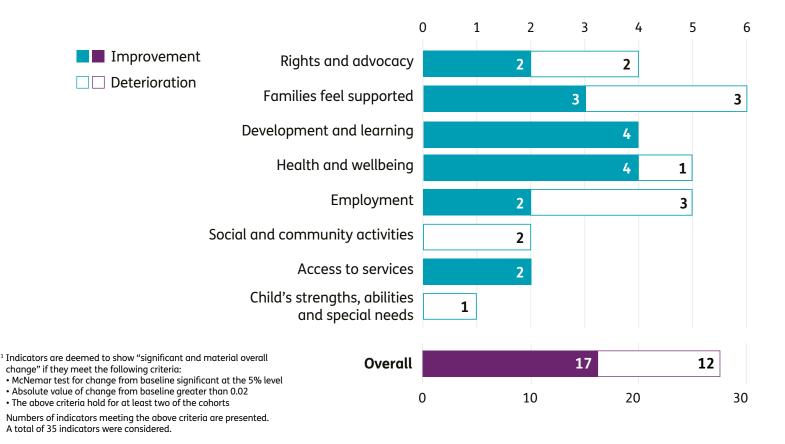
Form	C1	C2	С3	C4
SF	60,447	26,438	11,526	2,718
LF	1,378	620	198	N/A

¹ The table shows the potential number of respondents, however, not all of them responded to each question. The number of missing responses is small and varies by indicator. Only C1-C3 cohorts are shown for the LF, due to small numbers available in C4.

Families and carers of participants from birth to age 14



Number of indicators with significant and material overall change by domain¹



Families and carers of participants from birth to age 14 **Employment**

30%

20%

0%



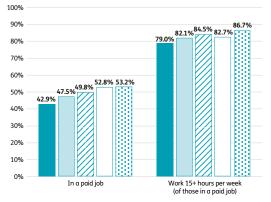
Employment outcomes have improved across all four cohorts.

The percentage of family and carers who are in a paid job has increased with each additional year in the Scheme. Of those with a paid job, the percentage who work 15 or more hours per week has also increased.

For participants in the Scheme four years, increases between baseline and fourth review were:

- 10.3 percentage points for having a paid job
- 7.7 percentage points for working 15 or more hours per week.

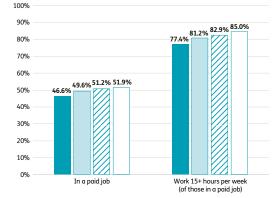




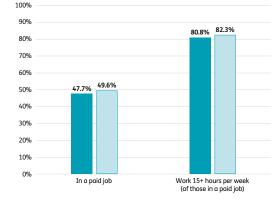


In a paid job

Three years in the Scheme



One year in the Scheme



🗖 Baseline 🛛 Review 1 💋 Review 2 🗌 Review 3 🚺 Review 4

Work 15+ hours per week

(of those in a paid job)

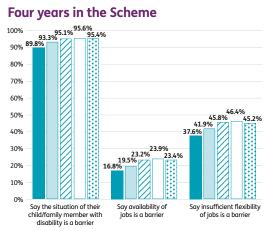
Families and carers of participants from birth to age 14 **Employment**



For families and carers unable to work as much as they want, the percentages who say that one of the barriers is:

- the situation of their child/family member with disability
- availability of jobs
- insufficient flexibility of jobs

all increase with time in the Scheme, by 5.6, 6.6, and 7.6 percentage points, respectively, after participants have been in the Scheme for four years.



41.0% 42.8%

Say insufficient flexibility

of jobs is a barrier

37.4%

19.6% 21.0%

Say availability of

jobs is a barrier

Baseline

173%

Two years in the Scheme

90.9% 92.5%

Say the situation of their

child/family member with

disability is a barrier

88.9%

100%

90% 80%

70% 60%

50%

40%

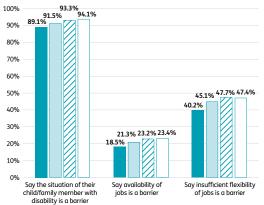
30%

20%

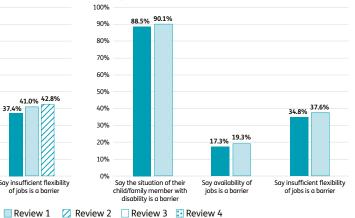
10%

0%

Three years in the Scheme



One year in the Scheme



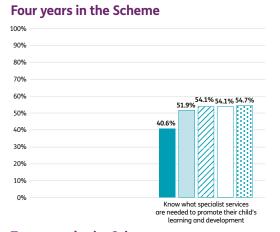
Families and carers of participants from birth to age 14 Access to services



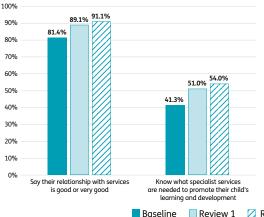
The percentages of family and carers who:

- say their relationship with services is good or very good
- know what specialist services are needed to promote their child's learning and development

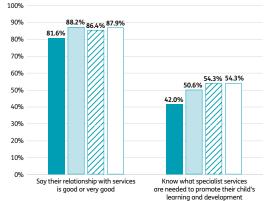
generally increase the longer participants are in the Scheme, with improvements of 6.3 percentage points over three years and 14.1 percentage points over four years, respectively.



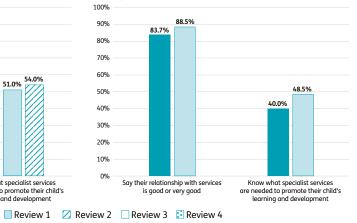




Three years in the Scheme



One year in the Scheme



Note: for the first indicator, cohort 4 has been omitted as there is not enough data (long form question)

Families and carers of participants from birth to age 14

Families and carers of participants from birth to age 14 Social and community involvement

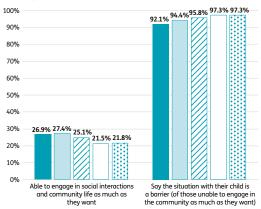


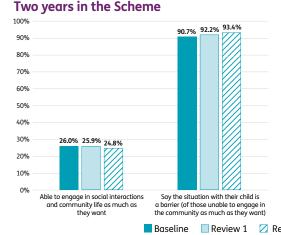
For family/carers of participants who have been in the Scheme for more than one year, the percentage who are able to engage in social interactions and community life as much as they want has declined significantly from baseline (for example, by 5.1 percentage points over four years).

For all cohorts, of those unable to engage socially or in the community as much as they want, the percentage who say the situation of their child with disability is a barrier to engaging more has increased (for example, by 5.2 percentage points over four years).

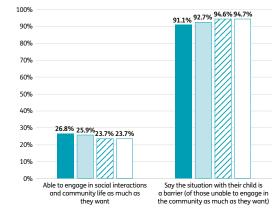
The child getting older is likely having an impact on these indicators.

Four years in the Scheme

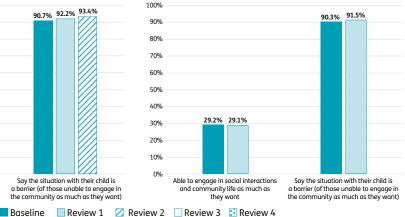




Three years in the Scheme



One year in the Scheme



Families and carers of participants from birth to age 14 Health, practical and emotional support

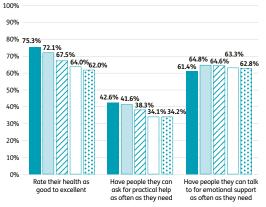


The percentage of family and carers who rate their health as good, very good or excellent has deteriorated, for example, by 13.2 percentage points over four years.

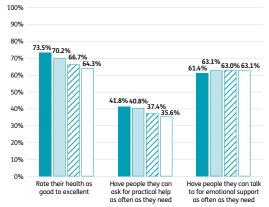
For family/carers of participants in the Scheme longer than one year, the percentage who have people they can ask for practical help has also declined (8.4 percentage points over four years).

However, the percentage who have people they can talk to for emotional support has tended to increase slightly.

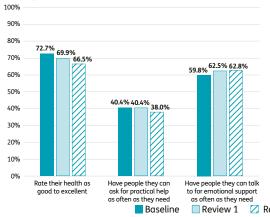




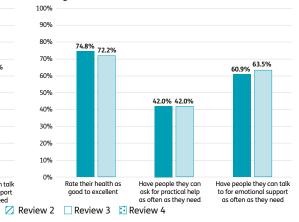
Three years in the Scheme



Two years in the Scheme



One year in the Scheme



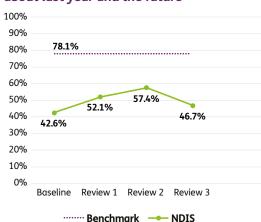
Families and carers of participants from birth to age 14 **Comparison to benchmark: employment and health** Participants in the Scheme for three or four years



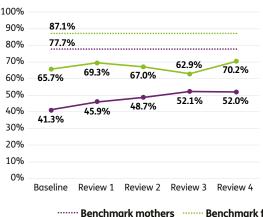
Comparing baseline to latest review, the percentage of mothers (92% of respondents) and fathers (8% of respondents):

- in a paid job improves by 10.7 and 4.5 percentage points, respectively
- who rate their health as good, very good or excellent deteriorates by 13.7 and 8.6 percentage points, respectively
- who felt delighted, pleased or mostly satisfied about last year and the future improves by 4.1 percentage point for the combined group.

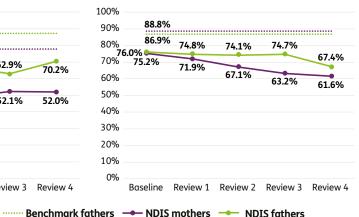
All indicators are considerably below the benchmark Australian population¹ figures.



In a paid job



Rate their health as good, very good or excellent



¹ Population benchmark figures are from:

• Employment: Australian Bureau of Statistics (ABS), Australian labour force data as at June 2021, standardised to NDIS family and carers age distribution.

• Health rating: Australian Bureau of Statistics (ABS), General Social Survey (GSS) 2020, standardised to NDIS family and carers age distribution.

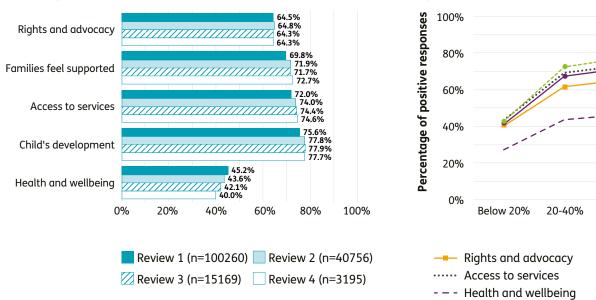
• Life Satisfaction: Australian Bureau of Statistics (ABS), General Social Survey (GSS) 2010, standardised to NDIS family and carers age and gender distribution.

Felt delighted, pleased or mostly satisfied about last year and the future 100%

Families and 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 and carer capacity to help their child develop (75.6% after one year in the Scheme, increasing to 77.7% after four years) and access to services (72.0% after one year in the Scheme, increasing to 74.6% after four years). There have also been improvements for families feeling supported, plan development and implementation domains, but no change for rights and advocacy, and a deterioration for health and wellbeing. Higher plan utilisation is strongly associated with a positive response.



Percentage of positive responses

By plan utilisation rate, outcomes after one year

60-80% 80% and over

Families feel supported

Baseline plan utilisation

---- Child's Independence

40-60%

Families and carers of participants aged 15 to 24

Families and carers of participants aged 15 to 24

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

- Know their rights and advocate effectively for their child with disability
- Feel supported
- Are able to gain access to desired services, programs and activities within the community
- Help their young person become independent
- Enjoy health and wellbeing
- Participate in employment
- Participate in social and community activities

Number of family/carers in each longitudinal cohort¹:

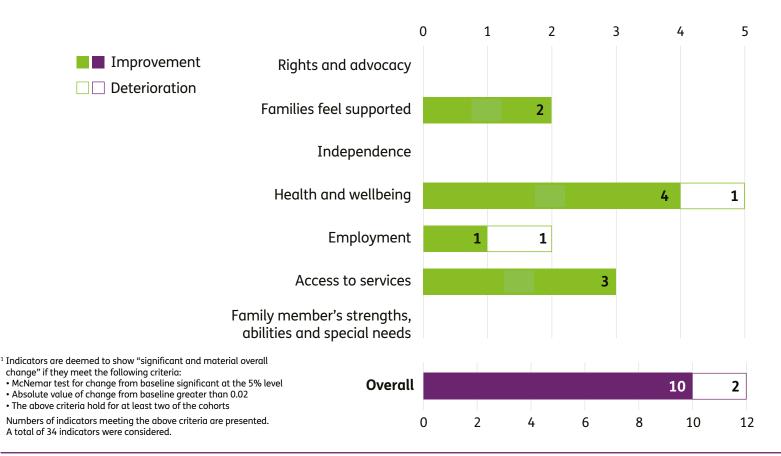
Form	C1	C2	С3	C4
SF	10,568	4,415	1,654	300
LF	358	142	50	N/A

¹ The table shows the potential number of respondents, however, not all of them responded to each question. The number of missing responses is small and varies by indicator. Only C1-C3 cohorts are shown for the LF, due to small numbers available in C4.

Families and carers of participants aged 15 to 24



Number of indicators with significant and material overall change by domain¹



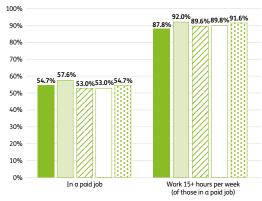
Families and carers of participants aged 15 to 24 **Employment**



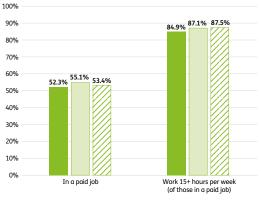
There have been small (but statistically significant) increases from baseline in the percentage with a paid job, for family/carers of participants in the Scheme for one, two or three years (for example, a 2.1 percentage point increase over three years). There has been no change from baseline for those in the Scheme four years.

For those with a paid job, the percentage working 15 hours or more has increased significantly for those in the Scheme less than four years (for example, by 2.6 percentage points for those in the Scheme for two or three years). The increase for those in the Scheme four years was not statistically significant.

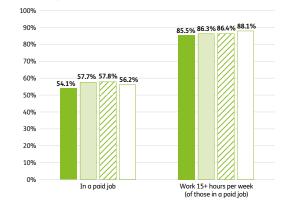
Four years in the Scheme



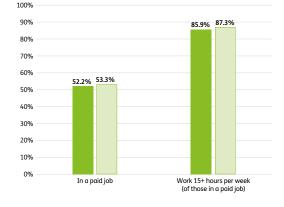




Three years in the Scheme



One year in the Scheme



📕 Baseline 🛛 🔲 Review 1 🛛 Review 2 🗌 Review 3 🗈 Review 4

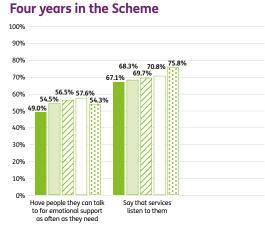
Families and carers of participants aged 15 to 24 Feeling supported and listened to, and support for participant

The percentage of family and carers who:

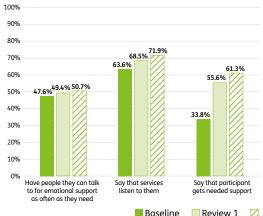
- have people they can talk to for emotional support
- say that services listen to them
- say that their family member with disability gets the support they need

tend to improve the longer the participants are in the Scheme.

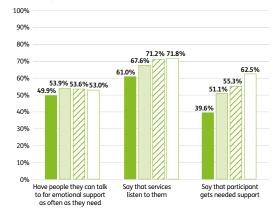
The improvements are 5.3 and 8.7 percentage points from baseline to fourth review for the first two indicators, and 22.9 percentage points from baseline to third review for the third indicator¹.



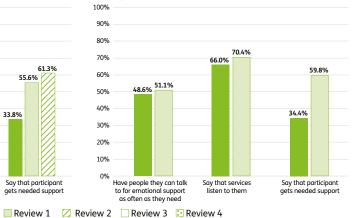




Three years in the Scheme



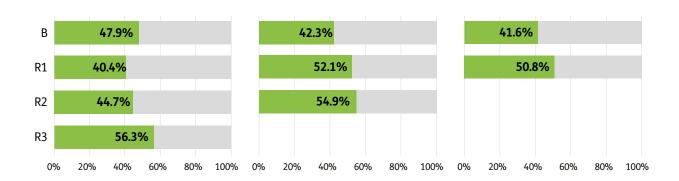
One year in the Scheme



¹ For the third indicator, cohort 4 has been omitted as there is not enough data (long form question).



Families and carers of participants aged 15 to 24 Felt delighted, pleased or mostly satisfied about their life, last year and in the future



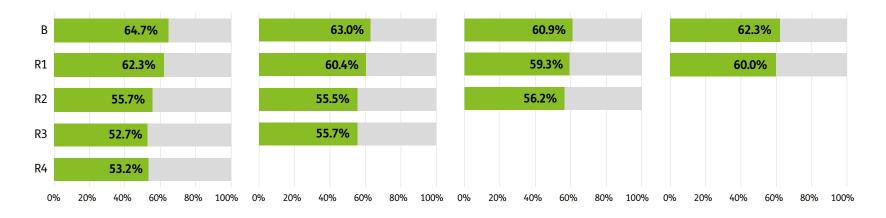
For families and carers of participants who have been in the Scheme for **three years**, there was an improvement of 8.4 percentage points between baseline and third review, from 47.9% to 56.3%. For this cohort the trend is more volatile due to lower volume. For families and carers of participants who have been in the Scheme for **two years**, there was a 12.6 percentage point improvement between baseline and second review, from 42.3% to 54.9%, including a 2.8 percentage points increase in the latest year. For families and carers of participants who have been in the Scheme for **one year**, there was a 9.2 percentage point improvement, from 41.6% to 50.8%.

Note: Cohort 4 is omitted for this long form question due to insufficient numbers of responses.

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Families and carers of participants aged 15 to 24 **Rate their health as good, very good or excellent**





For families and carers of participants who have been in the Scheme for **four years**, there was a deterioration of 11.5 percentage points, from 64.7% to 53.2%. For families and carers of participants who have been in the Scheme for **three years**, there was a 7.3 percentage point deterioration, from 63.0% to 55.7%. For families and carers of participants who have been in the Scheme for **two years**, there was a 4.7 percentage point deterioration, from 60.9% to 56.2%. For families and carers of participants who have been in the Scheme for **one year**, there was a 2.3 percentage point deterioration, from 62.3% to 60%.

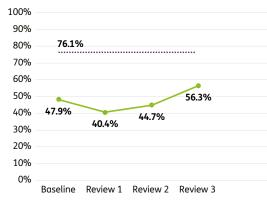
Families and carers of participants aged 15 to 24 **Comparison to benchmark: employment and health** Participants in the Scheme for three or four years

Comparing baseline to latest review, the percentage of NDIS family or carers:

- in a paid job, stays the same at 54.7%
- who felt delighted, pleased or mostly satisfied about last year and the future, improves 8.4 percentage points, from 47.9% to 56.3%
- who rate their health as good, very good or excellent, deteriorates 11.5 percentage points, from 64.7% to 53.2%

All indicators are considerably below the benchmark Australian population¹ figures. (Note males and females are combined due to low volume for males).

Felt delighted, pleased or mostly satisfied about last year and the future



In a paid job



Rate their health as good, very good or excellent



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······ Benchmark --- NDIS

¹ Population benchmark figures sources (each standardised to NDIS family and carers age and gender distribution):

• Employment: Australian Bureau of Statistics (ABS), Australian labour force data as at June 2021.

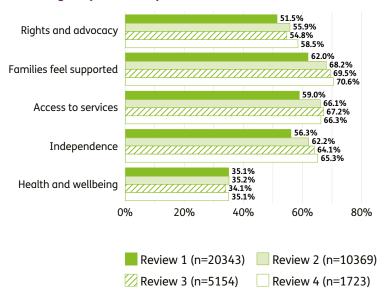
• Health rating: Australian Bureau of Statistics (ABS), General Social Survey (GSS) 2020.

• Life Satisfaction: Australian Bureau of Statistics (ABS), General Social Survey (GSS) 2010.

Families and 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 independence (56.3% after one year in the Scheme, increasing to 65.3% after four years in the Scheme) and families feeling supported (62.0% after one year in the Scheme, increasing to 70.6% after four years in the Scheme) saw the greatest improvement. Higher plan utilisation is strongly associated with a positive response.



Percentage of positive responses



Families and carers of participants aged 25 and over

Families and carers of participants aged 25 and over



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

- Know their rights and advocate effectively for their family member with disability
- Feel supported
- Are able to gain access to desired services, programs and activities within the community
- Have succession plans
- Enjoy health and wellbeing
- Participate in employment
- Participate in social and community activities

Number of family/carers in each longitudinal cohort¹:

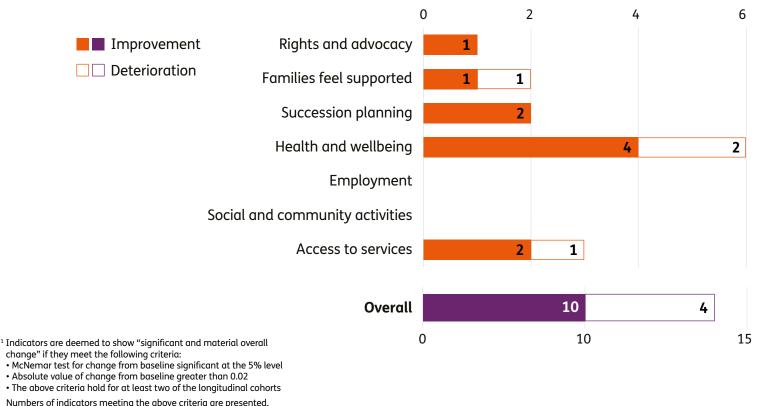
Form	C1	C2	С3	C4
SF	11,770	4,553	1,187	31
LF	422	204	128	N/A

¹ The table shows the potential number of respondents, however, not all of them responded to each question. The number of missing responses is small and varies by indicator. Only C1-C3 cohorts are shown for the LF, due to small numbers available in C4.

Families and carers of participants aged 25 and over



Number of indicators with significant and material overall change by domain¹



A total of 30 indicators were considered.

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

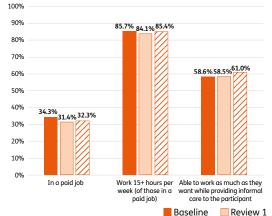


The percentage of family/carers who are in a paid job generally decreases over time (for example, a 3.8 percentage point deterioration over three years in the Scheme). Some of this could be due to retirement, as families and carers of participants aged 25 and over are likely to be older than families and carers of younger participants.

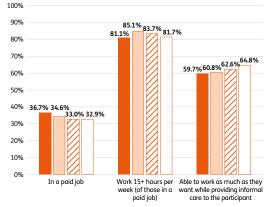
The percentage of family and carers who provide informal care to their family member with disability and are able to work as much as they want tends to increase the longer participants are in the Scheme (a 5.1 percentage point improvement over three years).

Of those family and carers who are in a paid job, the proportion who work 15 or more hours per week has stayed broadly the same over time, and the changes from baseline are not statistically significant.

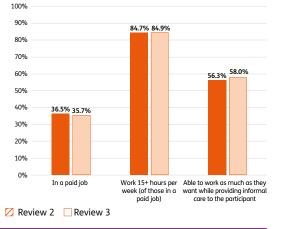
Two years in the Scheme



Three years in the Scheme

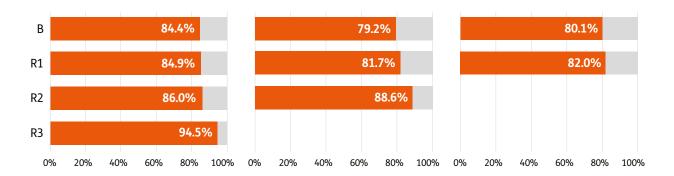


One year in the Scheme



Note: Cohort 4 omitted due to low volume.

Families and carers of participants aged 25 and over I understand my rights and the rights of my family member with disability (percentage who have no difficulty)



For participants who have been in the Scheme for **three years**, there was a 10.2 percentage point improvement between baseline and third review, from 84.4% to 94.5%, including an 8.5 percentage point increase in the latest year. For participants who have been in the Scheme for **two years**, there was a 9.4 percentage point improvement between baseline and second review, from 79.2% to 88.6%, including a 6.9 percentage points increase in the latest year. For participants who have been in the Scheme for **one year**, there was a 1.9 percentage point improvement, from 80.1% to 82.0%, however this change was not statistically significant.

Note: Cohort 4 omitted due to low volume

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Families and carers of participants aged 25 and over Feeling supported and listened to, and support for participant

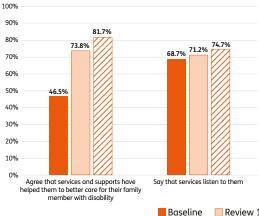
The percentages of family and carers who:

- strongly agree or agree that services and supports have helped them to better care for their family member
- say that services listen to them

tend to increase the longer participants have been in the Scheme.

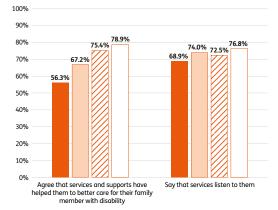
Improvements of 22.6 and 7.9 percentage points, respectively, were observed for family and carers of participants in the Scheme for three years.

Two years in the Scheme

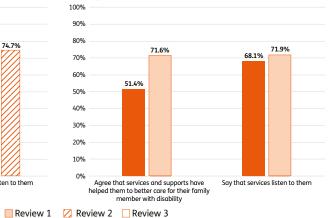




Three years in the Scheme



One year in the Scheme



Note: Cohort 4 omitted due to low volume.

Families and carers of participants aged 25 and over

Families and carers of participants aged 25 and over **Succession plans**



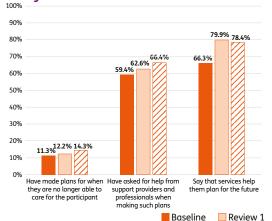
The percentage of families and carers who:

- make plans for when they are no longer able to care for the participant
- ask for help from support providers and professionals when making such plans
- say that services help them plan for the future

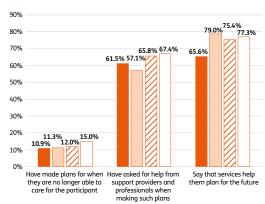
tend to increase the longer participants have been in the Scheme.

Increases of 4.1, 5.9, and 11.7 percentage points, respectively, were observed for participants in the Scheme for three years.

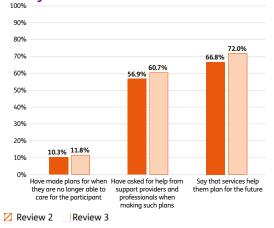




Three years in the Scheme



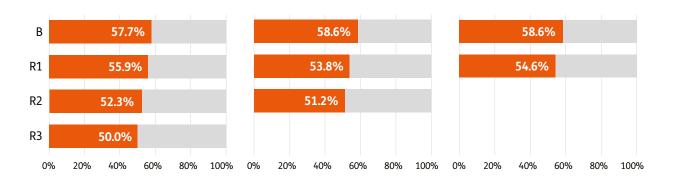
One year in the Scheme



Note: Cohort 4 omitted due to low volume.

Families and carers of participants aged 25 and over

Families and carers of participants aged 25 and over **Rate their health as good, very good or excellent**

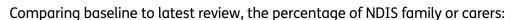


For families and carers of participants who have been in the Scheme for **three years**, there was a 7.7 percentage point deterioration between baseline and third review, from 57.7% to 50.0%. For families and carers of participants who have been in the Scheme for **two years**, there was a 7.4 percentage point deterioration between baseline and second review, from 58.6% to 51.2%. For families and carers of participants who have been in the Scheme for **one year**, there was a 4.0 percentage point deterioration, from 58.6% to 54.6%.

Note: Cohort 4 omitted due to low volume.

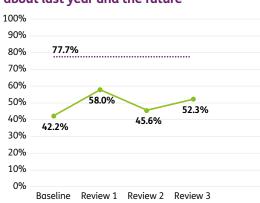
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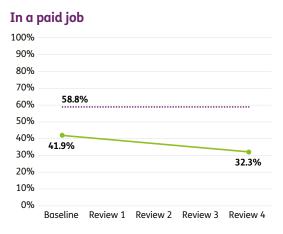
Families and carers of participants aged 25 and over **Comparison to benchmark: employment and health** Participants in the Scheme for three or four years



- in a paid job, or who rate their health as good to excellent, deteriorated by 9.7 percentage points
- who felt delighted, pleased or mostly satisfied about last year and the future, improved by 10.1 percentage points, from 42.2% to 52.3%

All indicators are considerably below the benchmark Australian population¹ figures. Note males and females are combined due to low volume for males. Review figures also not shown if volume is too low.





Rate their health as good to excellent

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······· Benchmark --- NDIS

¹ Population benchmark figures sources (each standardised to NDIS family and carers age and gender distribution):

• Employment: Australian Bureau of Statistics (ABS), Australian labour force data as at June 2021.

• Health rating: Australian Bureau of Statistics (ABS), General Social Survey (GSS) 2020.

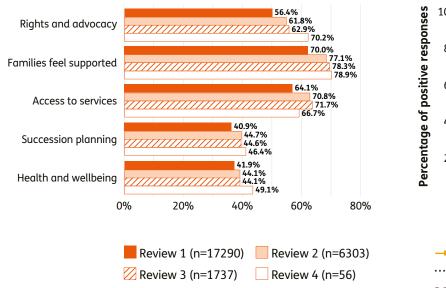
• Life Satisfaction: Australian Bureau of Statistics (ABS), General Social Survey (GSS) 2010.

Felt delighted, pleased or mostly satisfied about last year and the future

Families and carers of participants aged 25 and over **Has the NDIS helped?**

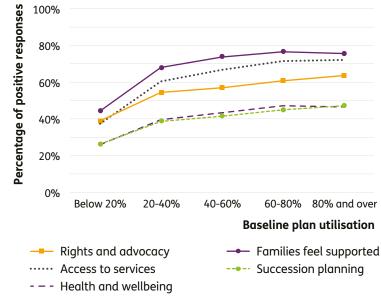


Opinions on whether the NDIS has helped vary by domain. The percentage responding positively was lowest for succession planning (40.9% after one year in the Scheme, increasing to 46.4% after four years) and highest for families feeling supported (70.0% after one year in the Scheme, increasing to 78.9% after four years in the Scheme). Across all domains, the percentage responding positively generally improves at the next review, except for access to services at review 4 and succession planning at review 3. Higher plan utilisation is strongly associated with a positive response.



Percentage of positive responses

By baseline plan utilisation rate, outcomes after one year



Summary of findings

Summary of findings (1)



Measuring progress and change

The report summarises the number, extent and nature of changes across key outcome indicators.

- In total, there are between 30 and 35 indicators for each of the participant age groups.
- Of these, the birth to 14 participant age group has the largest proportion of family and carer indicators with significant and material changes, at 83%, followed by 47% for the 25 and over age group, and 35% for the 15 to 24 age group.
- Of these significant and material changes, the 15 to 24 participant age group has the highest proportion of family and carer indicators showing improvement, at 83%, followed by 71% and 59% for the 25 and over, and the birth to 14 age groups, respectively.

In what areas has the NDIS impacted positively?

- For all three participant age groups, families and carers are increasingly positive about the Scheme's role in helping them feel supported.
- For participants from birth to age 14, there have been positive perceptions of the Scheme's role in improving family and carer capacity to help their child develop and learn, and improving access to services.
- For families and carers of participants aged 15 to 24, positive perceptions of the Scheme's role in helping their young person to become more independent have increased strongly over time.
- For families and carers of participants aged 25 and over, perceptions that the NDIS has helped with rights and advocacy have become increasingly positive over time.
- In most cases, higher plan utilisation is strongly associated with a positive response after one year in the Scheme. Improvements are typically largest between utilisation bands 0-20% and 20-40% (for most domains).

Summary of findings (2)



Outcomes that are improving for families and carers

- Improvements in employment outcomes (having a paid job, and working 15 or more hours per week) have been observed for families and carers of participants aged 0 to 14, and to a lesser extent, those aged 15 to 24.
- More families and carers of participants aged 0 to 14 said that they have good relationships with services, and know what services are needed to promote their child's learning and development.
- Families and carers of participants aged up to 24 more frequently reported having someone to talk to for emotional support.
- Families and carers of participants aged 15 and over were more likely to feel that services listen to them and have helped them to care for their family member, and that their family member gets the support they need.
- Families and carers of older participants (aged 25 and over) are getting support for succession planning, and more feel that services help them to plan for the future. There have also been improvements in understanding their rights and the rights of the participant.

Areas of concern – opportunities for improvement

Across all participant age groups, self-rated health of families and carers has deteriorated over time.

Additionally, for families and carers of participants aged 0 to 14:

- in the area of employment, of families and carers unable to work as much as they want, there are increasing proportions who say that one of the barriers is the situation with their child, job availability, or job flexibility.
- there are also deteriorations in social and community involvement and access to practical help.

Summary of findings (3)



Benchmarking against the Australian population

Overall, families and carers of NDIS participants generally experience poorer outcomes than the Australian population in the areas of employment, health, and life satisfaction.

However, the trend is improving on life satisfaction for families and carers of participants of all ages, and on employment for family and carers of younger participants.

Final remarks

This report summarises longitudinal outcomes for family and carers of participants who entered the Scheme from 1 July 2016, and who have been in the Scheme for one year or more at 30 June 2021, providing a picture of how family and carers are progressing under the NDIS.

The results provide insight into how the Scheme is making a difference and point to areas where improvements may be required.

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