Family and carer outcomes

To 30 June 2022

National Disability Insurance Agency

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Measuring progress and change

How have outcomes changed?

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

In total, 58% of indicators (35 out of 60) showed significant and material change.

- Of these, the birth to 14 participant age group has the largest proportion of family and carer indicators with significant and material changes, at 88%, followed by 64% for the 25 and over age group, and 47% for the 15 to 24 age group. Almost half (47%) of indicators that related to all age groups showed significant and material change.
- Of these indicators with significant and material change, the 25 and over participant age group has the highest proportion of indicators showing improvement, at 64%, followed by 56% and 47% for the 15 to 24, and the birth to 14 age groups, respectively. Seventy-one per cent of indicators that related to all age groups, and had significant and material change, showed improvement.

In what areas has the NDIS impacted positively?

Overall, there is an increasing trend in the percentage of positive responses with time in Scheme, for all domains and across all cohorts.

- 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, improving access to services, and families feeling supported.
- For the 15 and over participant age group, families and carers are most positive about the Scheme’s role in helping them feel supported and assisting them to access services.
- There appears to be a cohort effect (particularly in the younger two age groups), with those entering the Scheme later in time responding more positively than those entering the Scheme earlier.
- 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%.

Summary of findings

Outcomes that are improving for families and carers[1]

Improvements were observed in the areas of employment, feeling supported, access to services, rights and advocacy, and health and wellbeing. Families/carers of younger participants help their child develop and learn, and become more independent. Families/carers of older participants get support for succession planning.

Employment

Improvements in employment outcomes (having a paid job, working 15 or more hours per week, and being employed in a permanent position) have been observed for families and carers of participants aged 0 to 14, and to a slightly lesser extent, those aged 15 to 24.	• 55.3% in paid employment (9.7 percentage point (pp) increase) • Of those in a paid job, 87.3% are working 15 or more hours per week (8.4 pp increase). This is approaching the Australian population benchmark of 87.8%

Families and carers feel supported

Respondents have as much contact with other families of people with disability as they would like.	• 69.7% have as much contact with other families of people with disability as they would like (23.6 pp increase)
Families/carers are getting the services and supports they need to care for their family member with disability. This is higher than average for the 0 to 14 participant age group.	• 9.3 pp increase to 20.3%
Families and carers continue to report that they have someone to talk to for emotional support. This is highest for the 0 to 14 age participant age group.	• 59.1% have people they can talk to for emotional support (0.9 pp increase) • 62.1% for 0–14 participant age group

Access to services

Increasingly, families/carers across all participant age groups are reporting that services used are listening to them and are meeting their needs.	• 75.7% report that services used are listening to them (11.6 pp increase) • 34.0% report that services used are meeting their needs (15.0 pp increase)

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[1] Unless otherwise stated, changes are over five years. Where numbers are too small to show five year results, changes are for four years, as noted.

Summary of findings

Outcomes that are improving for families and carers[1]

Rights and advocacy

More families/carers of participants aged 0–14 report no boundaries to access or advocacy, and more families/carers of participants aged 15 and over report that they have no difficulties understanding their rights and the rights of their family member with disability.

- 38.3% experience no boundaries (1.9 pp increase)
- 78.4% understand their rights (16.2 pp increase)

Health and wellbeing

Increasing percentages of families and carers feel that services and supports have helped them to better care for their family member with disability.

- 54.6 pp increase to 81.3%

Respondents are more confident about the future of their family member with disability under the NDIS.

- 34.2 pp increase to 75.0%

Supporting learning and development

More families and carers of participants aged 0 to 14 report knowing what they can do to support, and what services are needed to promote, their child's learning and development.

- 49.0% know what they can do to support their child's learning and development (7.5 pp increase)
- 51.7% know what specialist services are needed (9.6 pp increase)

Recognising strengths, abilities and progress

Families/carers of participants aged up to 24 increasingly report being able to recognise the strengths and abilities of their family member with disability, and seeing them progressing.

- 88.2% have no difficulties in recognising strengths and abilities (9.2 pp increase)
- 82.9% have no difficulties seeing progress (5.3 pp increase)

Succession planning

Families and carers of participants aged 25 and over are getting support for succession planning, and more feel that service providers, professionals and support workers help them to plan for the future, and that their family member gets the support they need.

- 16.0% have made plans for when they are no longer able to provide care (3.0 pp increase over four years)
- 71.8% have asked for help from service providers, professionals or support workers (11.1 pp increase over four years)

[1] Unless otherwise stated, changes are over five years. Where numbers are too small to show five year results, changes are for four years, as noted.

Summary of findings

Areas of concern/deterioration[1]

Self-rated health

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

- 13.1 pp decrease to 58.1%

Rights and advocacy

Some outcomes related to rights and advocacy for families/carers of participants aged 0 to 14 are deteriorating, particularly in terms of respondents being able to identify the needs of their child/ family and access services to meet those needs. In terms of being able to advocate for their family member with disability, the 15 and over age group showed decreases over time, while the younger age group is fairly stable.

- 67.5% able to identify the needs of their child and family (6.0 pp decrease)
- 73.1% able to advocate (3.8 pp decrease)

Families and carers feel supported

There are some poorer outcomes over time relating to families feeling supported, particularly: having friends they can see as often as they'd like; having people they can ask for practical help as often as they need; and having people they can ask for childcare as often as they need.

- 38.8% have friends they can see as often as they'd like (5.6 pp decrease)
- 31.8% who have people they can ask for practical help (8.6 pp decrease)
- 21.0% have people they can ask for childcare (7.7 pp decrease)

Social and community involvement

For families and carers of participants aged 0 to 14 there has been deterioration in social and community involvement, with a decrease in the percentage of families/ carers who are able to engage in social interactions and community life as much as they want. In addition, there has been an increase (deterioration) in respondents who say that one of the barriers is the situation with their child.

- 8.9 pp decrease to 19.2% in being able to engage socially as much as they want
- 5.4 pp increase to 96.6% in saying the situation with their child is a barrier

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1 Unless otherwise stated, changes are over five years. Where numbers are too small to show five year results, changes are for four years, as noted.

Summary of findings

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.

Longitudinal improvements in the percentage of respondents (overall) working 15 hours or more per week mean that this indicator has almost reached the Australian population benchmark (87.8%), while the 15 to 24 age group has surpassed the benchmark (approximately 89% at latest review for cohorts 3 to 5).

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 2022, providing a picture of how family and carers are progressing under the NDIS.

For this year's report, a new approach has been taken to dealing with responses from families and carers of participants who transition to an older age group. This approach increases the amount of data included in the analysis, and allows a continuous longitudinal view of family/carer outcomes at different life stages and durations within the Scheme.

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

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 2022, 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.

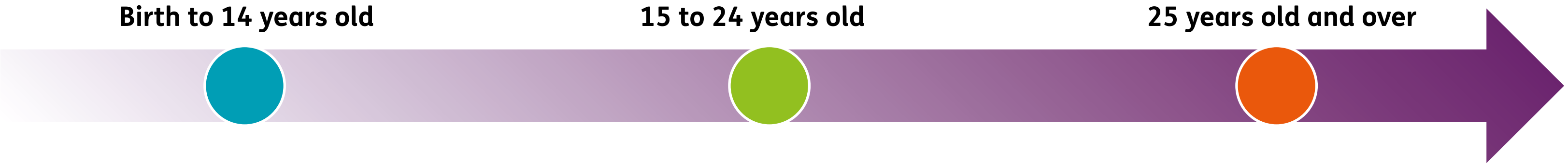
The report summarises the number, extent and nature of changes across key outcome indicators. The results are intended to provide insight into how the Scheme is making a difference for families and carers, and point to any areas where improvements may be required.

> 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



Birth to 14 years old

Domain 1: Rights and advocacy
Domain 2: Support
Domain 3: Access to services
Domain 4: Development
Domain 5: Health and wellbeing
Domain 6: Employment
Domain 7: Strengths, abilities and special needs

15 to 24 years old

Domain 1: Rights and advocacy
Domain 2: Support
Domain 3: Access to services
Domain 4: Independence
Domain 5: Health and wellbeing
Domain 6: Employment
Domain 7: Strengths, abilities and special needs

25 years old and over

Domain 1: Rights and advocacy
Domain 2: Support
Domain 3: Access to services
Domain 4: Succession plans
Domain 5: Health and wellbeing
Domain 6: Employment

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 and Long Form

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.

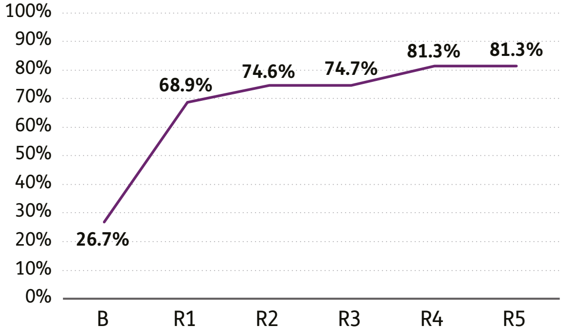
Whilst some outcomes should improve relatively quickly (for example, access to services, feeling listened to), others may take some years to improve (e.g. employment).

Family/carer baseline outcomes vary by a number of factors, such as:

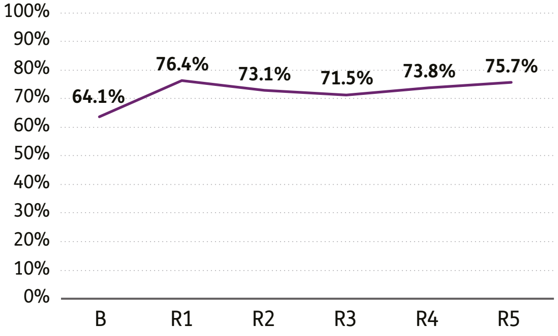
- the nature of the participant's disability and how it affects their life
- the extent of support received from family and friends
- how inclusive their community is
- their health and other personal traits.

Families and carers of participants – over five years

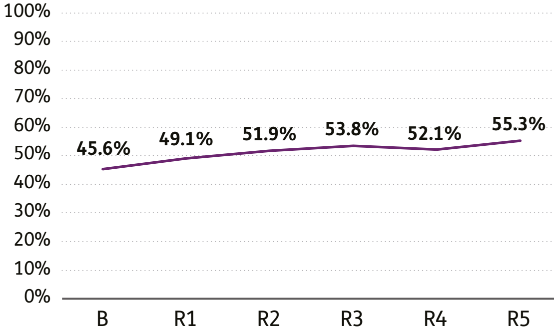
% who strongly agree or agree that services and supports helped them better care for the participant



% who feel services listen to them



% in paid work



Age group transitions

Moving to a different survey form

- Previous annual outcomes reports were structured with separate sections for families/carers in each of three participant age groups.
- Families/carers were tracked in the age group to which the participant belonged when they entered the Scheme until they left that age group, after which they were excluded from the analysis.
- This year's report has been restructured in order to increase the amount of data included in the analysis.
- This is done by moving from an analysis by age group, to an analysis by indicator.
- The approach effectively relaxes the strict segregation by participant age group, enabling progress to be viewed across the wider life course.
- In this report, results are presented by family/carer life domain, and by participant age group within domain where appropriate

Refer to the Appendix for further details of the age transition approach.

Age group transitions

Graphical presentation of results

Results are presented in this report using two key types of graphs:

> a) One that is broken down by cohort or years since baseline

> b) Another that provides additional detail in the form of an age group breakdown.

For those graphs presented by age group, age transition information is shown in the legend as follows:

Age group	Description
0–14	Family/Carer has ONLY answered the F0to14 form since the Participant entered the Scheme
0–14/15–24	Family/Carer has MOVED UP into the F15to24 form since the Participant entered the Scheme
15–24	Family/Carer has ONLY answered the F15to24 form since the Participant entered the Scheme
15–24/25+	Family/Carer has MOVED UP into the F25plus form since the Participant entered the Scheme
25+	Family/Carer has ONLY answered the F25plus form since the Participant entered the Scheme

COVID-19 pandemic

As noted in the previous two years' reports, the global pandemic that took hold from early 2020 is likely to have had an impact on at least some outcomes, such as community participation and employment.

> For more information on the potential impact of the COVID-19 pandemic 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

> The impact of the COVID-19 pandemic has also been considered as part of the analysis of employment outcomes at 31 December 2020:
>
> https://data.ndis.gov.au/reports-and-analyses/outcomes-and-goals/employment-outcomes-participants-their-families-and-carers

Number of respondents

The table[1] below summarises the number of total respondents by question type in each longitudinal cohort, for both SF and LF.

Forms covered (F0to14*, F15to24*, F25plus*)	Short Form (SF)					Long Form (LF)				
	C1	C2	C3	C4	C5	C1	C2	C3	C4	C5
✓✗✗	61,491	33,330	16,627	6,791	1,821	1,808	845	374	142	27
✓✓✗	NA***	NA***	NA***	NA***	NA***	2,108	1,047	499	206	77
✗✓✗	12,431	6,256	3,052	1,163	291	NA****	NA****	NA****	NA****	NA****
✗✓✓	24,425	12,056	6,382	2,424	353	899	448	168	46	<20**
✗✗✓	12,244	5,550	2,899	1,006	49	NA****	NA****	NA****	NA****	NA****
✓✓✓	83,119	45,472	24,754	11,178	3,278	2,595	1,252	590	224	77

[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.

* F0to14=families and carers of participants aged from 0 to 14; F15to24=families and carers of participants aged from 15 to 24; F25plus=families and carers of participants aged 25 and over.

** Exact numbers are not shown for cohorts with less than 20 respondents.

*** There are no questions in the Family/Carer Short Form (SF) that are of this type.

**** There are no questions in the Family/Carer Long Form (LF) that are of these types.

Summary of results

Families and carers of NDIS participants

Outcomes domains by form

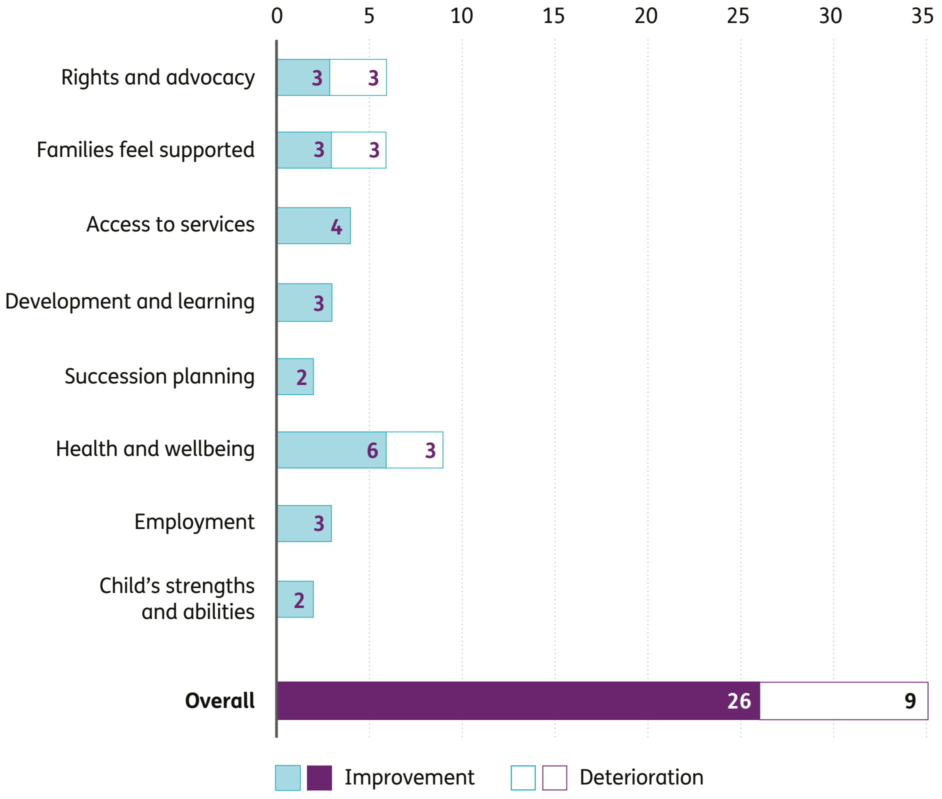
For families and carers of NDIS participants, the outcomes framework seeks to measure the extent to which families/carers:

<table>
<tr><th rowspan="2">Domain</th><th colspan="3">Outcomes for families/ carers of participants aged:</th></tr>
<tr><th>0 to 14</th><th>15 to 24</th><th>25 and over</th></tr>
<tr><td>Domain 1</td><td colspan="3">Know their rights and advocate effectively for their child/ family member with disability</td></tr>
<tr><td>Domain 2</td><td>Feel supported</td><td colspan="2">Have the support they need to care</td></tr>
<tr><td>Domain 3</td><td colspan="3">Are able to gain access to desired services, programs, and activities in their community</td></tr>
<tr><td>Domain 4</td><td>Help their children develop and learn</td><td>Help their young person become independent</td><td>Have succession plans</td></tr>
<tr><td>Domain 5</td><td colspan="3">Enjoy health and wellbeing and participate in social and community activities</td></tr>
<tr><td>Domain 6</td><td colspan="3">Participate in employment</td></tr>
<tr><td>Domain 7</td><td colspan="2">Understand strengths, abilities and special needs (LF only)</td><td>N/A</td></tr>
</table>

Families and carers of NDIS participants

Summary of changes

Number of indicators with significant and material overall change by domain[1]



[1] Indicators are deemed to show "significant and material overall change" if they meet the following criteria:

- McNemar test for change from baseline significant at the 5% level
- Absolute value of change from baseline greater than 0.02
- The above criteria hold for at least two of the cohorts

Numbers of indicators meeting the above criteria are presented. A total of 60 indicators were considered.

Families and carers of NDIS participants

Summary of trend by selected indicators

Domain	Age group	Indicator	Change
Rights and advocacy	15 and over	% who have no difficulties understanding their rights and the rights of their family member with disability	⬆
	0 to 14	% who have experienced no boundaries to access or advocacy	⬆
		% who are able to identify the needs of their child and family	⬇
		% who are able to access available services and supports to meet the needs of their child and family	⬇
	All	% who are able to advocate (stand up) for their family member with disability	⬇
Families feel supported	All	% who have as much contact with other families of people with disability as they would like	⬆
		% who have people they can talk to for emotional support as often as they need	⬆
		% who get the services and supports they need to care for their family member with disability	⬆
		% who have friends they can see as often as they'd like	⬇
		% who say that they have people they can ask for practical help	⬇
	0 to 14	% who have people they can ask for childcare as often as they need	⬇
Relationships	15 and over	% who say that the services their family member with disability and their family receive meet their needs	⬆
		% who feel that the services they use for their family member with disability listen to them	⬆
Development & learning	0 to 14	% who know what specialist services are needed to promote their child's learning and development	⬆
		% who know what they can do to support their child's learning and development	⬆
		% who get enough support in parenting their child	⬆

⬆ Improvement ⬇ Deterioration (decrease in positive indicator) ⬆ Deterioration (increase in negative indicator) 🟧 Context dependent

Families and carers of NDIS participants

Summary of trend by selected indicators

Domain	Age group	Indicator	Change
Succession planning	25 and over	% who have made plans for when they are no longer able to care for their family member with disability	⬆
		Of those families or carers who have begun making plans, the percentage who have asked for help from service providers, professionals or support workers	▬
Health and wellbeing	25 and over	% who feel their family member with disability gets the support they need	⬆
	All	% who strongly agree or agree that services and supports have helped them to better care for their family member with disability	⬆
		% who strongly agree or agree that they feel more confident about the future of their family with disability under the NDIS	⬆
		% who rate their health as excellent, very good or good	⬇
	0 to 14	% who are able to engage in social interactions and community as much as they want	⬇
		Of those unable to engage in the community as much as they want, % who say the situation with their child is a barrier to engaging more	⇧
Employment	All	% who are in a paid job	⬆
		Of those in a paid job, % who work 15 or more hours per week	⬆
		Of those in a paid job, % who are employed in a permanent position	⬆
Strengths and abilities	0 to 24	% who have no difficulties recognising the strengths and abilities of their family member	⬆
		% who have no difficulties seeing their family member progressing	⬆

⬆ Improvement ⬇ Deterioration (decrease in positive indicator) ⇧ Deterioration (increase in negative indicator) ▬ Context dependent

Domain 1:

Families know their rights and advocate effectively for their family member with a disability

For F0to14, analyse by time since first in F15to24, otherwise by time in Scheme

Single group (F0to14), by time in Scheme

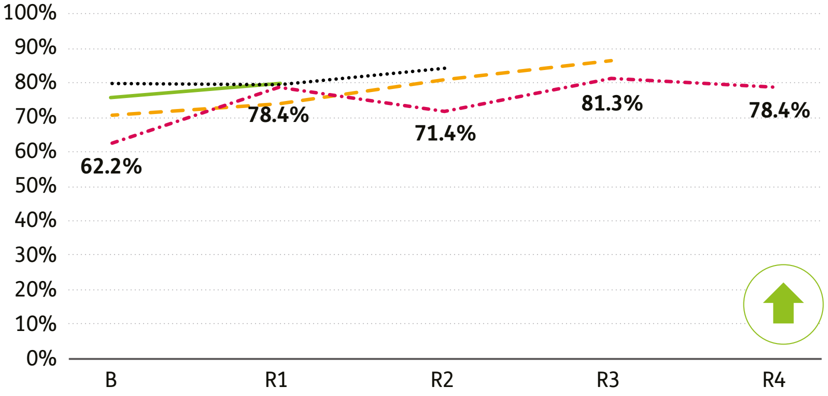
Understanding rights and accessing advocacy

The percentage of families or carers of **participants aged 15 and over** who have no difficulties understanding their rights and the rights of their family member with disability has seen an increasing trend over all cohorts.[1] Improvements have been greater the longer participants are in the Scheme. Over four years there has been a 16.2 percentage point increase from 62.2% at baseline to 78.4% at fourth review. For participants who have been in the Scheme for three years, there has been a 15.8 percentage point increase from 70.5% at baseline to 86.3% at third review. Participants in the Scheme for two years and one year have seen improvements of 4.6 percentage points and 4.0 percentage points, respectively, from baseline to latest review.

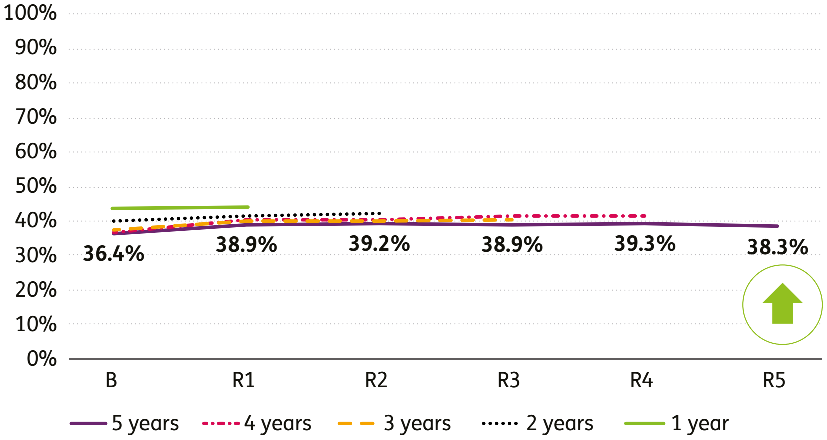
There has been a small increase in the percentage of families or carers of **participants aged 0 to 14** who have experienced no boundaries to access or advocacy between baseline and the latest review period, across all cohorts. The increase is most apparent until the second review, after which the trend levels off. For families or carers of participants in the Scheme for five years, the increase between baseline and fifth review was 1.9 percentage points from 36.4% to 38.3%.

Participants entering the Scheme later in time are also more likely to have experienced no boundaries to access or advocacy at baseline. This baseline percentage has increased from 36.4% (cohort 5) to 43.6% (cohort 1).

% who have no difficulties understanding their rights and the rights of their family member with disability



% of families or carers who have experienced no boundaries to access or advocacy



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[1] Cohort 5 has been omitted as participant numbers are too small.

Domain 1:

Families know their rights and advocate effectively for their family member with a disability

Single group (F0to14), by time in Scheme

Identify needs of child and family and access services/ supports to meet needs

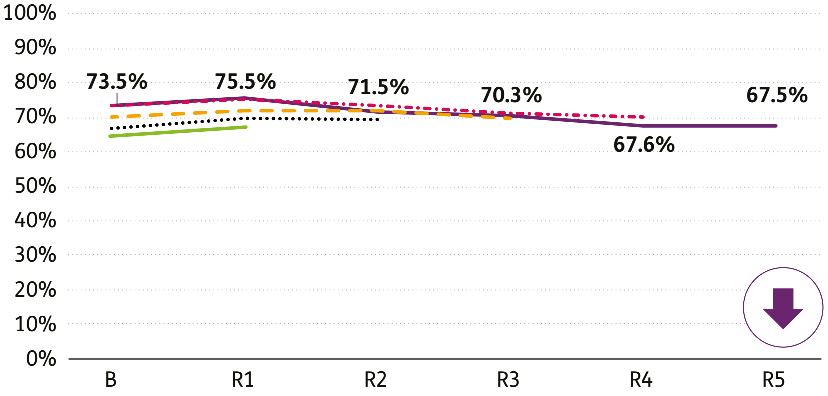
Across the cohorts, in the first year there is a small increase in the percentage of families or carers who are able to identify the needs of their child and family, and who are able to access available services and supports to meet the needs of their child and family. However, following the first year, there is a decreasing trend on these two 0 to 14 age group indicators.

The baseline percentage of families or carers that can identify the needs of their child and family, and have access to services and supports to meet these needs, is also decreasing with calendar time of Scheme entry.

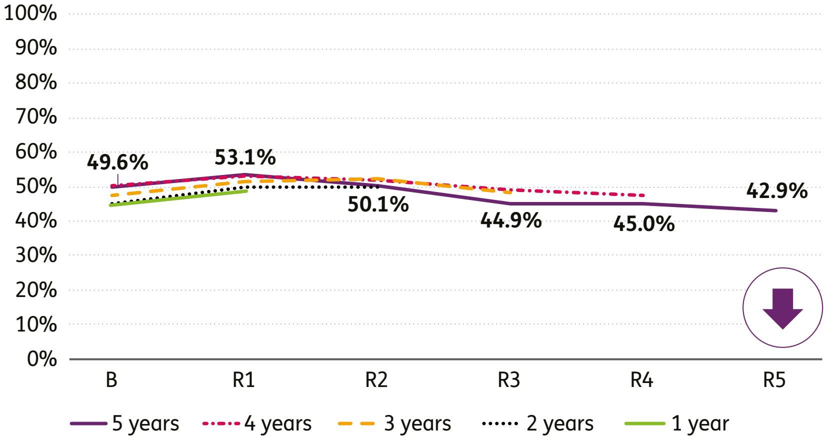
For families or carers of participants that have been in the Scheme for five years, decreases between baseline and fifth review were:

- 6.0 percentage points for those who were able to identify the needs of their child and family
- 6.7 percentage points for those who were able to access services and supports to meet the needs of their child and family.

% of families or carers who are able to identify the needs of their child and family



% of families or carers who are able to access available services and supports to meet the needs of their child and family



Domain 1:

Families know their rights and advocate effectively for their family member with a disability

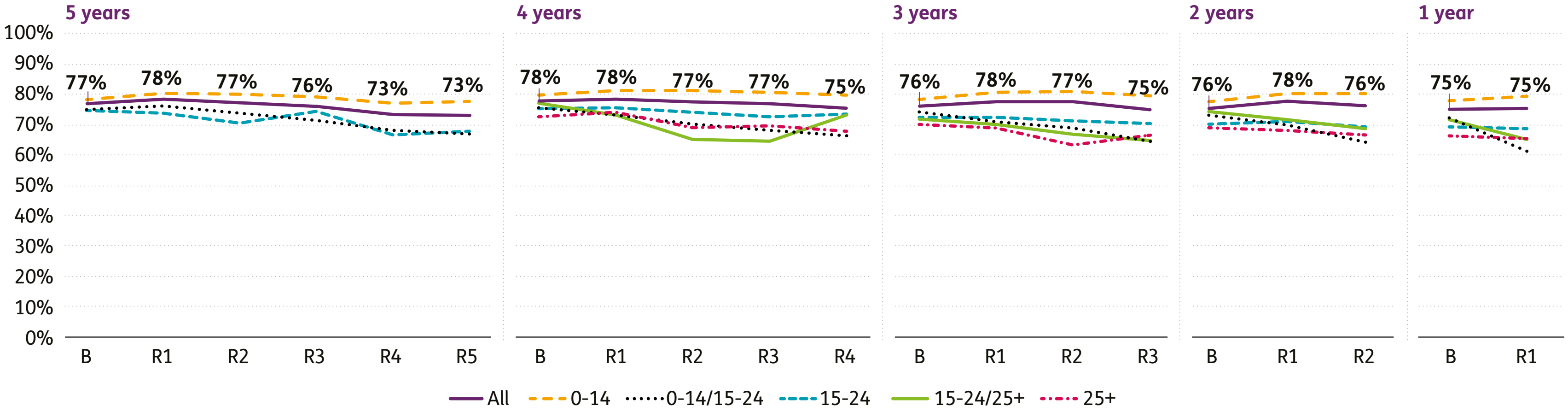
Combined group, by time in Scheme

I am able to advocate (stand up) for my family member with disability

For cohorts 3, 4 and 5, there has been a small decreasing trend in the percentage of families or carers who are able to advocate (stand up) for their family member with disability. The largest decrease between baseline and the latest review was 3.8 percentage points for cohort 5, followed by a decrease of 2.5 percentage points for cohort 4, and the smallest decrease of 1.1 percentage points for cohort 3. Cohorts 1 and 2 were relatively steady between baseline and latest review.

Considering the age group of the participants:

- 0–14 was fairly stable over time in Scheme across all cohorts, with an average of 79.5% of respondents reporting they were able to advocate (stand up) for their family member with disability.
- all other age groups had decreasing trends.
- The largest decrease was associated with the 0–14/15–24 age group of cohort 1, with an 11.2 percentage point difference between baseline (72.3%) and first review (61.1%).



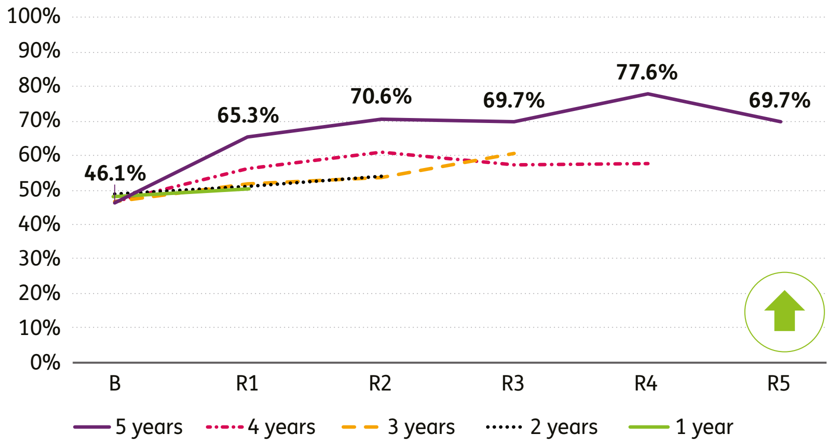
Domain 2:

Families feel supported/have the support they need to care

Combined group, by time in Scheme

% who have as much contact with other families of people with disability as they would like

There has been an increasing trend in the percentage of families or carers who have as much contact with other families of people with disability as they would like, over all cohorts. Improvements have been greatest for families or carers of participants who have been in the Scheme for five years, with an increase of 23.6 percentage points from baseline (46.1%) to latest review (69.7%). However, there was a decline of 7.9 percentage points following the fourth review (77.6%) to the latest review.



Domain 2:

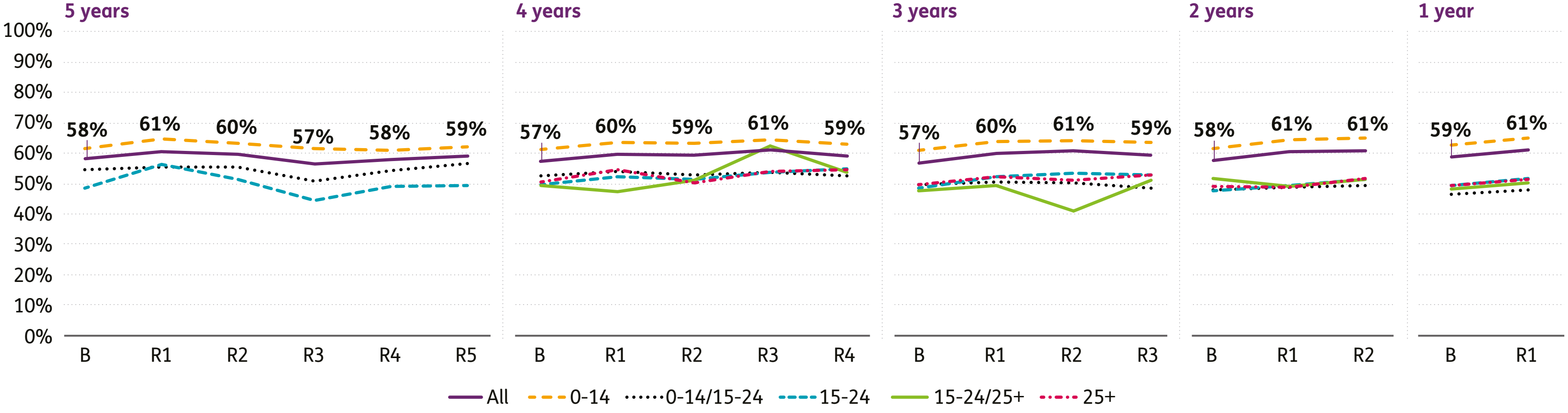
Families feel supported/have the support they need to care

Combined group, by time in Scheme

% of families or carers who have people they can talk to for emotional support as often as they need

Overall, the percentage of families and carers who have people they can talk to for emotional support as often as they need tends to show small improvements the longer the participants are in the Scheme. The improvements range from 0.9 percentage points (cohort 5) to 3.2 percentage points (cohort 2) from baseline to the latest review. For families or carers of participants who have been in the Scheme for five years, 59.1% said they have people they can talk to for emotional support.

The 0–14 age group had the highest percentage of families or carers who reported having people they can talk to for emotional support as often as they need, compared to all other age groups. At review 5, of cohort 5, 62.1% of families or carers of participants aged 0 to 14 have people they can talk to for emotional support.



Domain 2:

Families feel supported/have the support they need to care

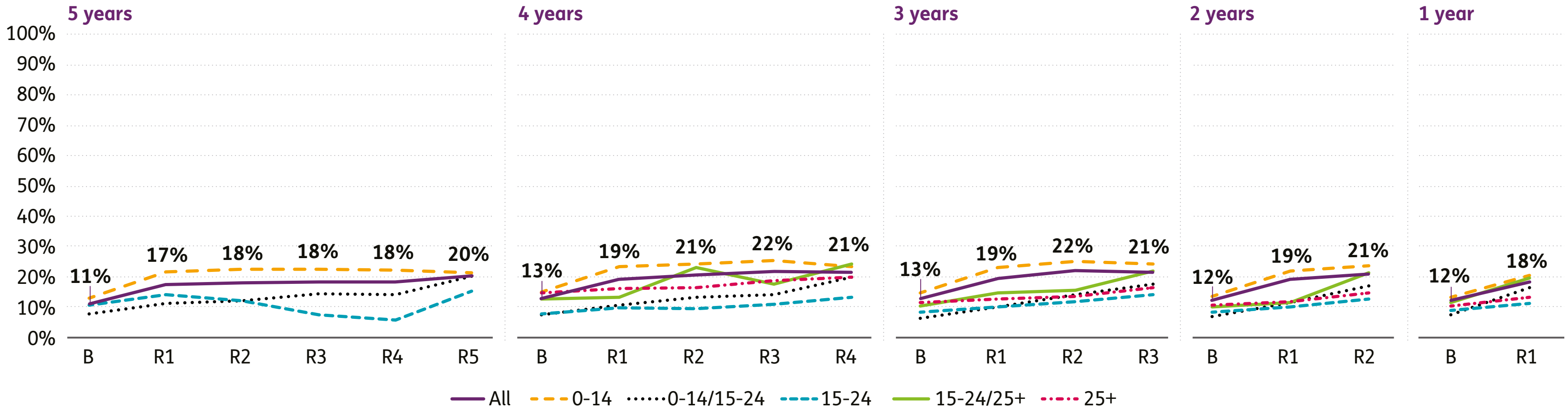
Combined group, by time in Scheme

% of families or carers who get the services and supports they need to care for their family member with disability

There is an increasing trend in the percentage of families and carers who get the services and supports they need to care for their family member with disability. Cohort 5 had the largest increase between baseline and latest review, with a 9.3 percentage point improvement. Overall, all age groups followed an increasing trend across all cohorts.

The 0–14 age group had the largest percentage of families or carers who reported they get the services and supports they need to care for their family member with disability, across all cohorts. The largest percentage of this age group was 24.2% at review three for cohort 3.

Although there have been improvements in this indicator, levels remain generally low. The four response options for this question are “Yes”, “I would like more support”, “I would like different support”, or “I would like support at different times” so not answering “Yes” does not mean the family member/carer receives no support. Most respondents say they would like more support.



Domain 2:

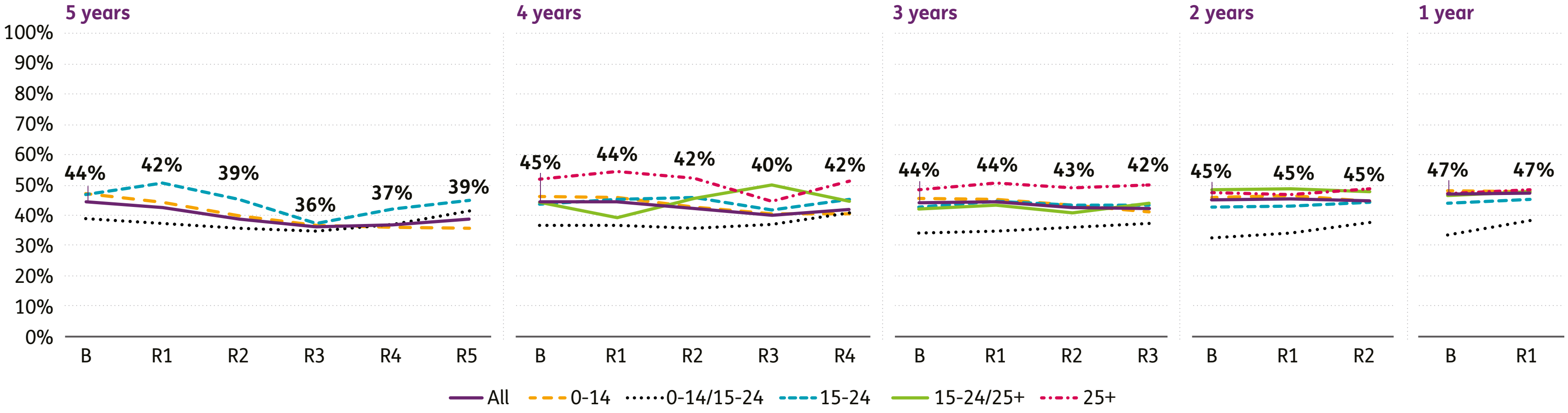
Families feel supported/have the support they need to care

Combined group, by time in Scheme

% of families or carers who have friends they can see as often as they'd like

There is a slight decreasing trend in the percentage of families or carers who have friends they can see as often as they'd like, between baseline and latest review for cohorts 3, 4 and 5, with cohorts 1 and 2 being more stable. For families or carers of participants who have been in the Scheme for five years, 44.5% said they have friends they can see as often as they'd like at baseline, compared to 38.8% at their fifth review, which is a 5.6 percentage point decrease.

There is a similar trend for the 0–14 age group, with a larger decrease of 11.3 percentage points from baseline (47.1%) to fifth review (35.7%). The 0–14/15–24 age group had increases between baseline and latest review across all cohorts (2.7 to 5.2 percentage points).



Domain 2:

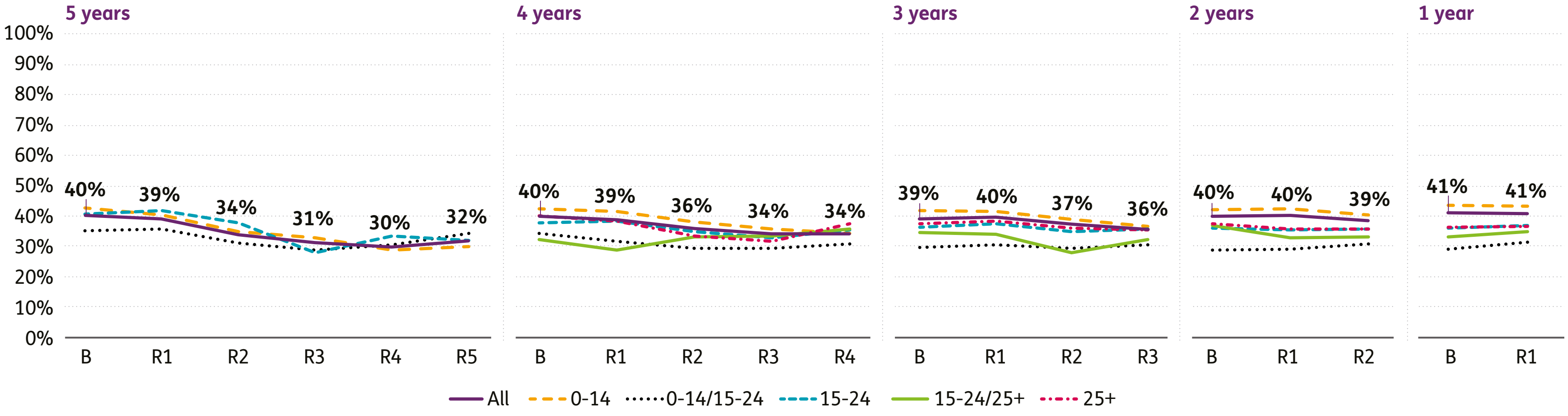
Families feel supported/have the support they need to care

Combined group, by time in Scheme

% of families or carers who have people they can ask for practical help as often as they need

The percentage of family and carers who say that they have people they can ask for practical help has declined across all cohorts. For participants who have been in the Scheme for five years, there has been a decrease of 8.6 percentage points between baseline (40.4%) and fifth review (31.8%). This includes a slight increase of 2.2 percentage points in the latest year, from fourth (29.8%) to fifth (31.8%) review.

There is a similar trend for the 0–14 age group, with a larger decrease of 13.0 percentage points over five years between baseline (42.8%) and fifth review (29.8%). In general, the 0–14 age group had the highest percentages and the 0–14/15–24 age group had the lowest percentages. However, the trend was more favourable for the 0–14/15–24 age group, with small increases in cohorts 1, 2 and 3. The largest increase was 2.3 percentage points for cohort 1, from baseline (29.1%) to first review (31.4%).



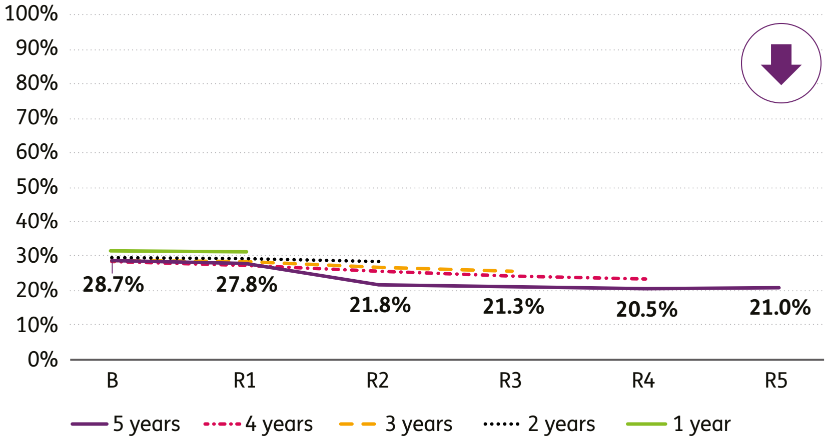
Domain 2:

Families feel supported/have the support they need to care

Single group (F0to14), by time in Scheme

% of families or carers who have people they can ask for childcare as often as they need

There has been a decrease in the percentage of families or carers who have reported that they have people they can ask for childcare as often as they need between baseline and the latest review period, across all cohorts. For families or carers of participants in the Scheme for five years, the decrease between baseline (28.7%) and fifth review (21.0%) was 7.7 percentage points.



Domain 3:

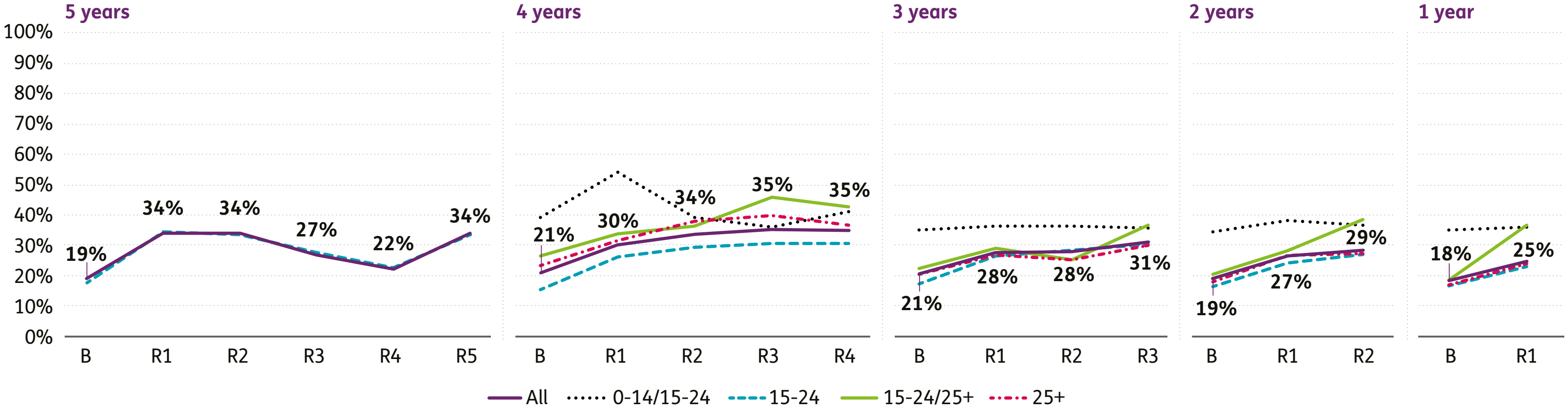
Families are able to gain access to desired services, programs, and activities in their community

For F0to14, analyse by time since first in F15to24, otherwise by time in Scheme

% of families or carers who say that the services their family member with disability and their family receive meet their needs

Overall, there is an improving percentage of families or carers who say that the services their family member with disability and their family receive meet their needs. The percentage increases the longer participants are in the Scheme, with improvements of 6.5 percentage points over one year (cohort 1) to 15.0 percentage points over five years (cohort 5), although there is some volatility in the cohort 5 results due to smaller numbers.

The 15–24/25+ age group had the largest improvements in the percentage of families or carers who reported that services meet their needs from baseline to latest review. For example, for cohort 1, the 15–24/25+ age group had an increase of 18.1 percentage points. This age group also had the highest percentage at latest review, for cohorts 1 to 4, compared to all other age groups. The highest percentage was 42.8% at fourth review (compared to 26.5% at baseline) for cohort 4.



Domain 3:

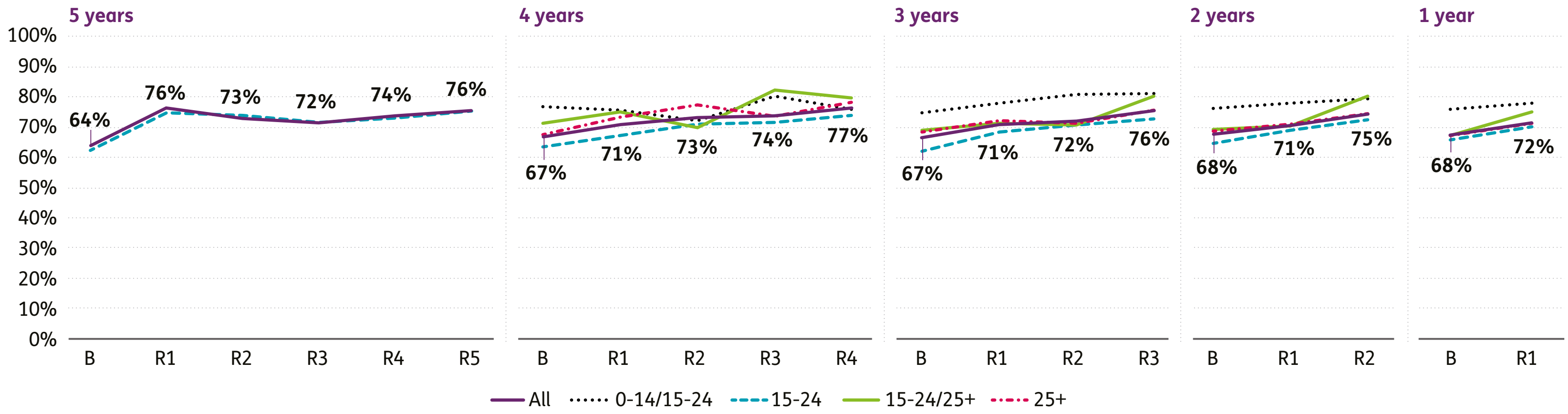
Families are able to gain access to desired services, programs, and activities in their community

For F0to14, analyse by time since first in F15to24, otherwise by time in Scheme

% of families or carers who feel that the services they use for their family member with disability listen to them

The percentage of families or carers who feel that the services they use for their family member with disability listen to them has been increasing, and there tends to be more improvement the longer the participants are in the Scheme. There was an 11.6 percentage point increase from baseline to latest review, for cohort 5, compared to a 4.1 percentage point increase from baseline to latest review, for cohort 1.

For cohorts 1, 2 and 3, the 0–14/15–24 age group had the largest percentage of families or carers who feel the services they use listen to them. For example, at the latest review for cohort 3, the percentage was 81.4% for age group 0–14/15–24, compared to 75.6% for all ages. However, the 15–24/25+ age group showed the largest increases from baseline to latest review for cohorts 1, 2 and 3. The largest increase for this age group was 11.3 percentage points from baseline to latest review in cohort 3.



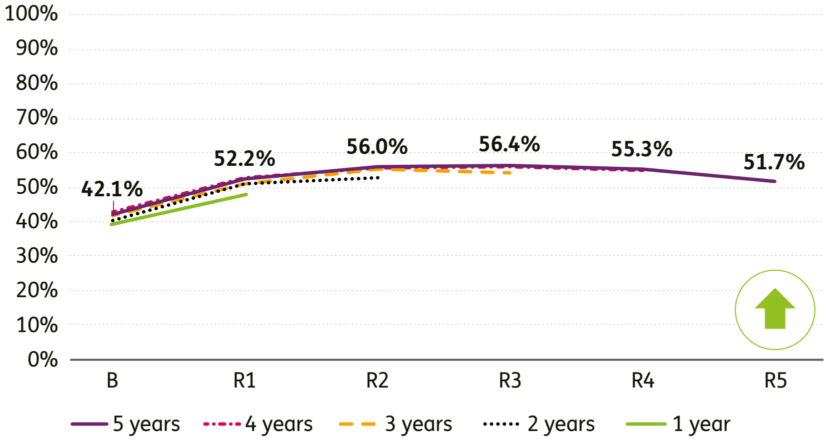
Domain 4:

Families promote development/learning, independence and plan for the future

Single group (F0to14), by time in Scheme

% of families or carers who know what specialist services are needed to promote their child's learning and development

In general, there have been improvements in the percentage of families or carers who know what specialist services are needed to promote their child's learning and development. For families or carers of participants who have been in the Scheme for five years, there have been strong improvements from baseline (42.1%) to the third review (56.4%), with a 14.3 percentage point increase. However, there has been a decline in the fourth (55.3%) and fifth (51.7%) review. This trend is similar for cohorts 3 and 4, both having strong increases followed by declines. Cohorts 1 and 2 are yet to show this experience. The starting baseline percentage has been decreasing over cohorts, from 42.1% (cohort 5) to 39.2% (cohort 1).



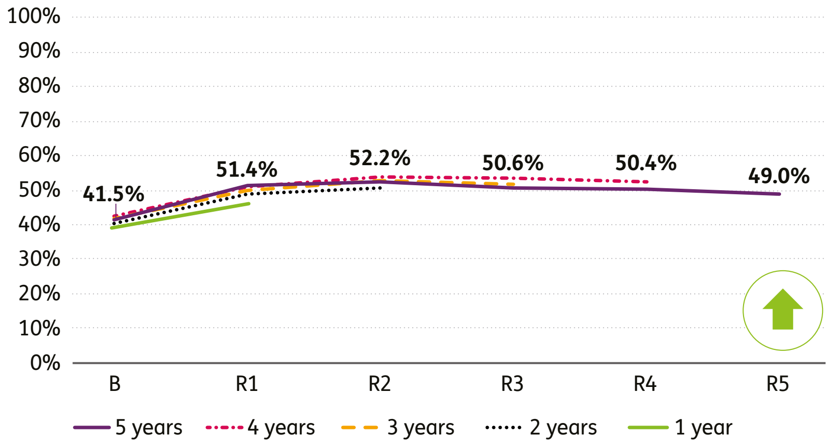
Domain 4:

Families promote development/learning, independence and plan for the future

Single group (F0to14), by time in Scheme

% of families or carers who know what they can do to support their child's learning and development

Overall, the percentage of families or carers who know what they can do to support their child's learning and development has been increasing. For families or carers of participants who have been in the Scheme for five years, there has been a 7.5 percentage point increase from baseline (41.5%) to fifth review (49%). However, following the second review there has been a decreasing trend. This experience has been similar for cohorts 3 and 4. Cohorts 1 and 2 are yet to show this experience. The baseline percentage of families or carers who know what they can do to support their child's learning and development has been decreasing over cohorts, from 41.5% (cohort 5) to 39.2% (cohort 1).



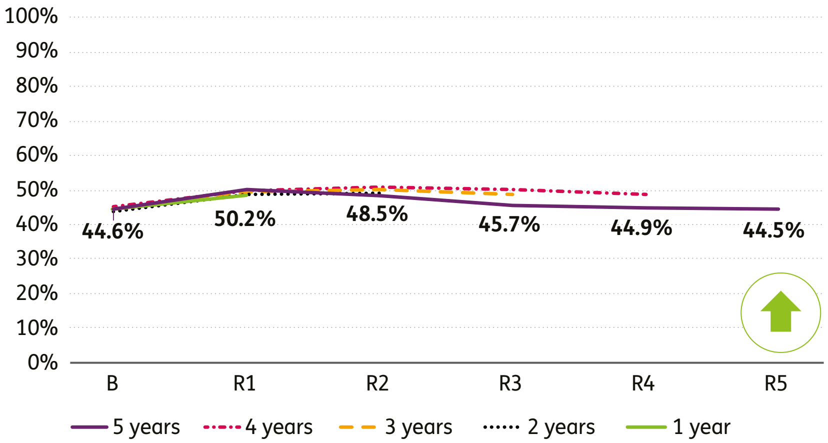
Domain 4:

Families promote development/learning, independence and plan for the future

Single group (F0to14), by time in Scheme

% of families or carers who get enough support in parenting their child

The percentage of families or carers who get enough support in parenting their child saw an increase from baseline to first review, across all cohorts. For families or carers of participants who have been in the Scheme for five years, there was an increase of 5.6 percentage points from baseline (44.6%) to first review (50.2%), which was followed by a decline over the next four reviews, to 44.5% at fifth review, which is a 5.7 percentage point decrease.



Domain 4:

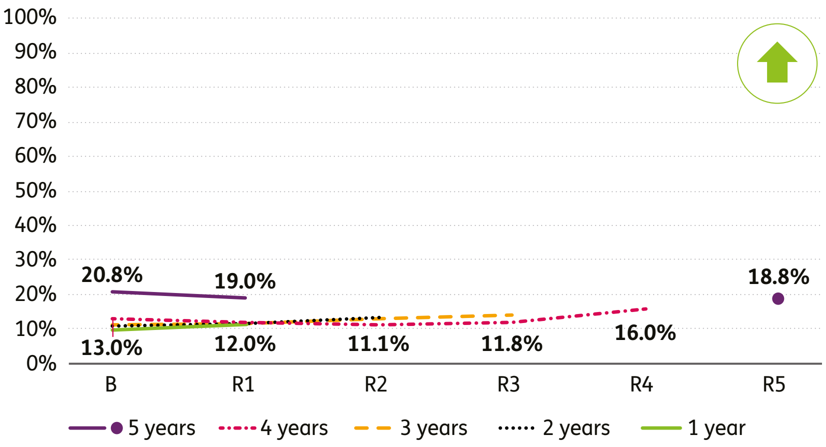
Families promote development/learning, independence and plan for the future

Analyse by time since first in F25plus

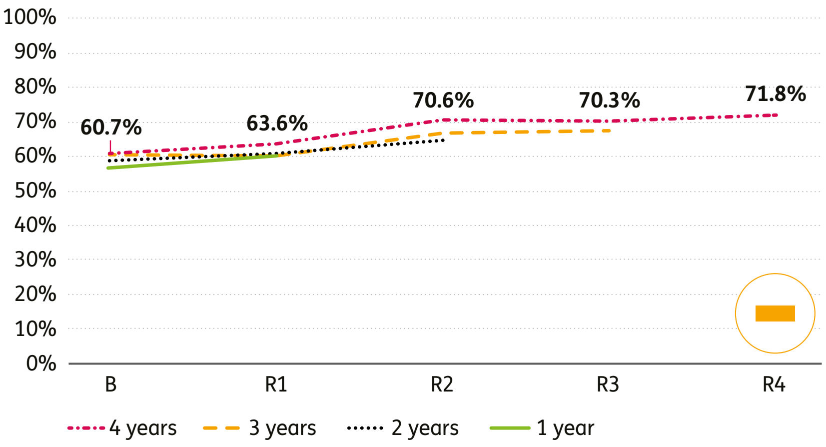
For families or carers who have made plans for when they are no longer able to care for their family member with disability, there was an initial decreasing trend, for cohorts 4 and 5. However, for cohort 4 the trend reversed following the second review (11%), with a 5 percentage point increase to fourth review (16%). Families or carers of participants who have been in the Scheme for 3 years or less have seen an increasing trend, without any initial decrease.

Of those families or carers who have begun making plans, the percentage who have asked for help from service providers, professionals or support workers has been increasing among all cohorts. Families or carers of participants who have been in the Scheme for four years have seen an increase of 11.1 percentage points between baseline (60.7%) and fourth review (71.8%).

% of families or carers who have made plans for when they are no longer able to care for their family member with disability



Of those who made or have begun making plans, % of families or carers who have asked for help from service providers, professionals or support workers



Note: Due to small numbers for C5, R2–R4 omitted for first indicator and all time points omitted for second indicator.

Domain 5:

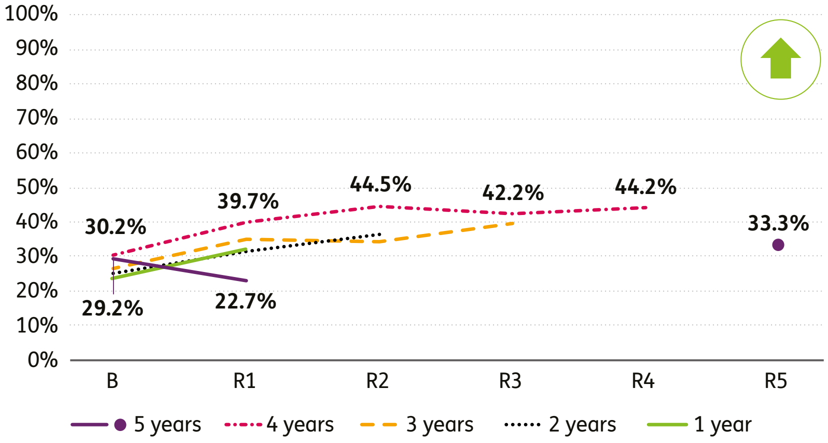
Families enjoy health and wellbeing

Analyse by time since first in F25plus

% of families or carers who feel their family member with disability gets the support they need

Overall, there has been an increasing trend in the percentage of families or carers who feel their family member with disability gets the support they need. For cohort 4 there was a 14 percentage point increase from 30.2% at baseline to 44.2% at fourth review.

The percentage of families or carers who feel their family member with disability gets the support they need at baseline has been decreasing for more recent entrants, from 29.2% (cohort 5) to 23.6% (cohort 1).



Note: For cohort 5, numbers are too small to show R2–R4.

Domain 5:

Families enjoy health and wellbeing

Support to care, and confidence for the future

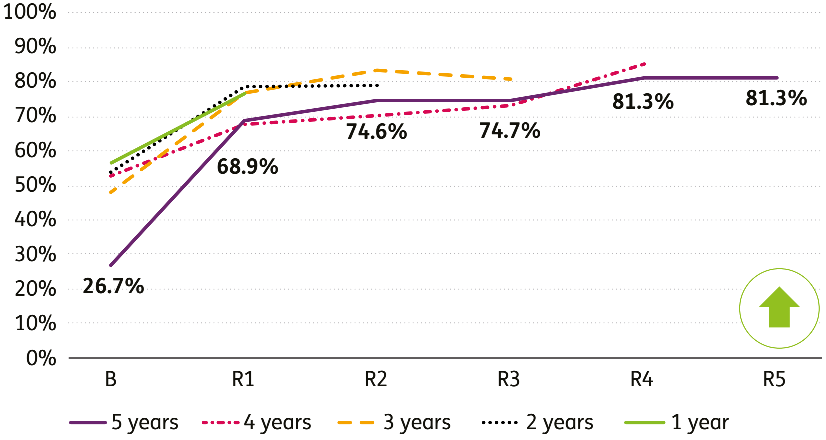
Combined group, by time in Scheme

The percentages of families or carers who strongly agree or agree that:

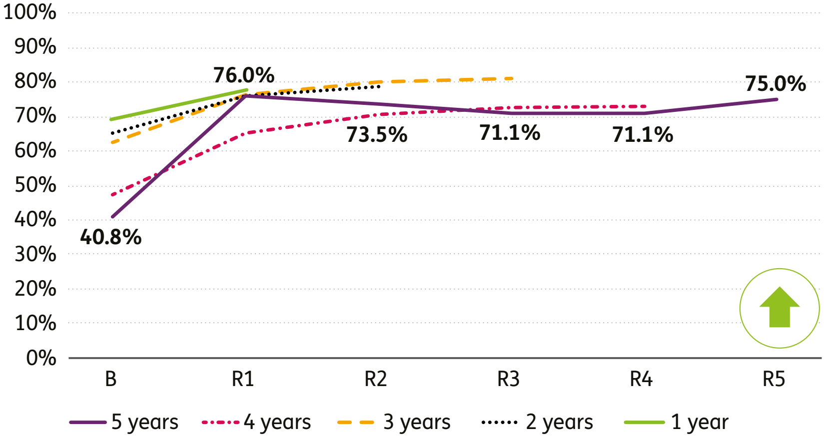
- services and supports have helped them to better care for their family member with disability
- they feel more confident about the future of their family with disability under the NDIS

have increased strongly from baseline to latest review. The extent of improvement increases the longer participants are in the Scheme, with improvements of 54.6 percentage points and 34.2 percentage points, respectively, over five years. The increases are most pronounced between baseline and first review for both of these indicators.

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



% who strongly agree or agree that they feel more confident about the future of their family with disability under the NDIS



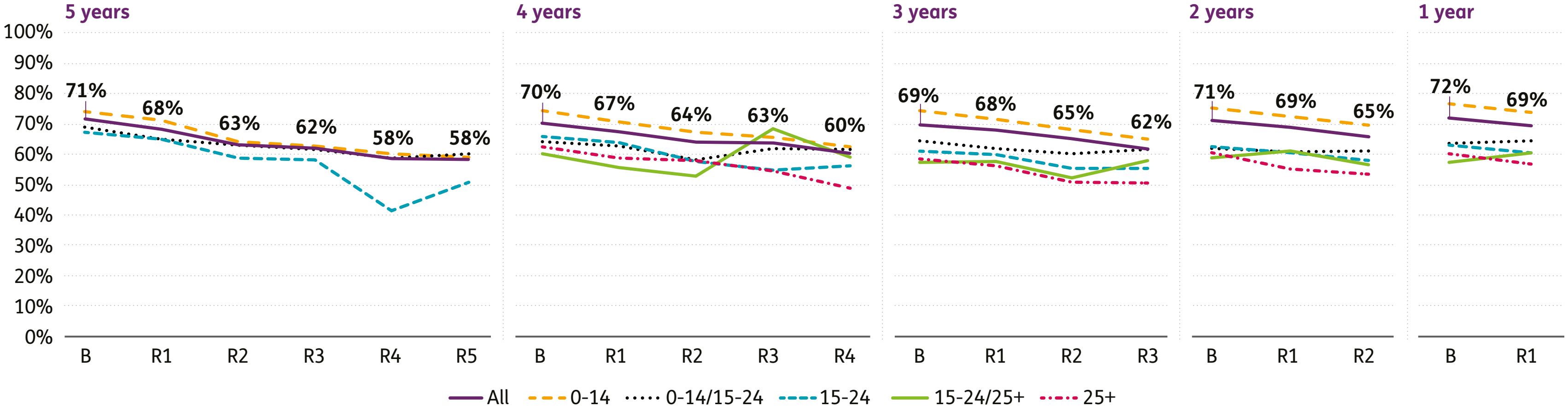
Domain 5:
Families enjoy health and wellbeing

Combined group, by time in Scheme

% of families or carers who rate their health as excellent, very good or good

The percentage of families or carers who rate their health as excellent, very good or good has deteriorated from baseline to latest review, across all cohorts. There was a 13.1 percentage point decrease from baseline (71.2%) to fifth review (58.1%), for families or carers of participants that have been in the Scheme for five years. For cohorts 4, 3, 2 and 1, there were deteriorations of 9.8, 7.8, 5.5 and 2.7 percentage points, respectively.

In general, the 0–14 age group had the highest percentages across all cohorts. For example, the highest reported percentage was 76.2% at baseline in cohort 1 for the 0–14 age group, compared to 71.7% for all ages. For cohort 5, the 15–24 age group had the lowest percentages of families or carers who rate their health as excellent, very good and good, and also had the largest decrease from baseline (66.9%) to latest review (50.4%).



Domain 5:

Families enjoy health and wellbeing

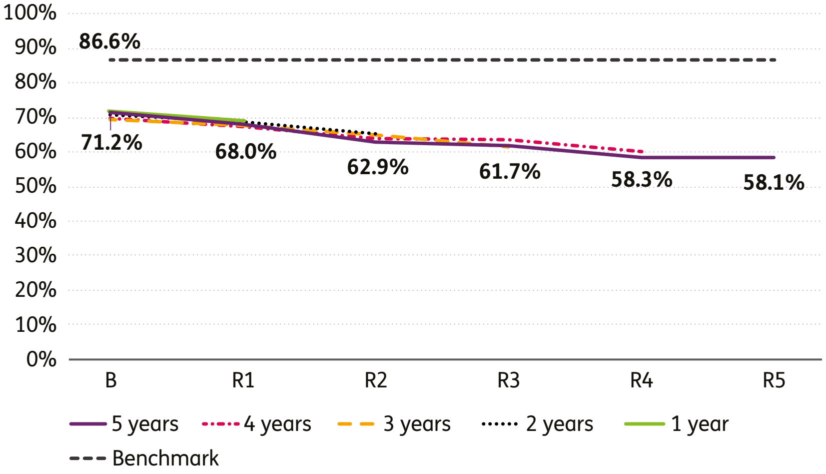
Comparison to benchmark: Health and wellbeing and life satisfaction

Combined group, by time in Scheme

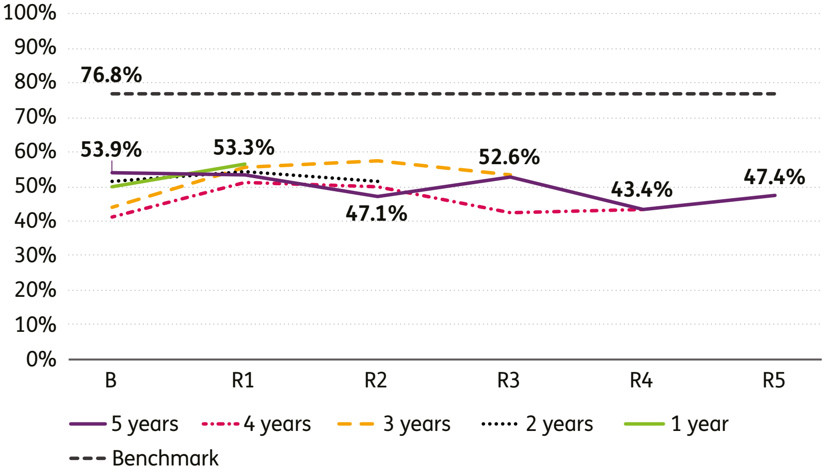
Comparing baseline to review 5, the percentage of families and carers who rate their health as good, very good or excellent deteriorated 13.1 percentage points, from 71.2% to 58.1%. This indicator is considerably below the benchmark for the Australian population[1] (86.6%).

The percentage of families and carers who felt delighted, pleased, or mostly satisfied about last year and the future deteriorated 6.5 percentage points, from 53.9% at baseline to 47.4% at review 5. This indicator is also considerably below the benchmark for the Australian population[1].

Self-rated health



Life satisfaction



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1 Population benchmark figures are from the Australian Bureau of Statistics (ABS), General Social Survey (GSS) 2020, standardised for NDIS family/carer age and gender distribution.

Domain 5:

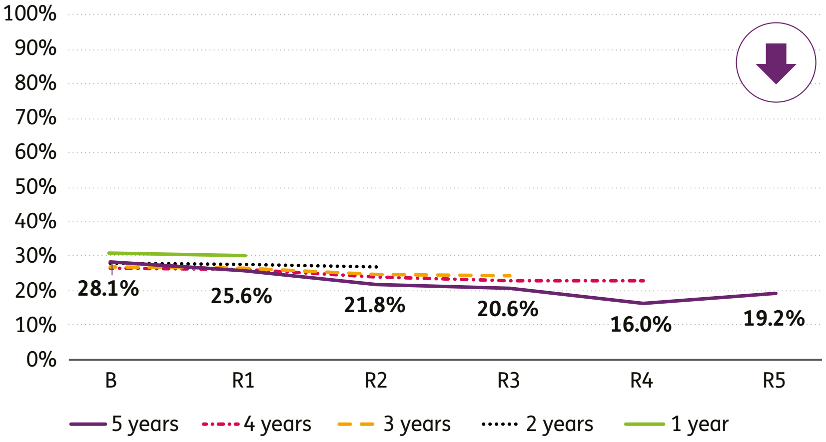
Families enjoy health and wellbeing

Engaging in social interactions and community life, and barriers

Single group (F0to14), by time in Scheme

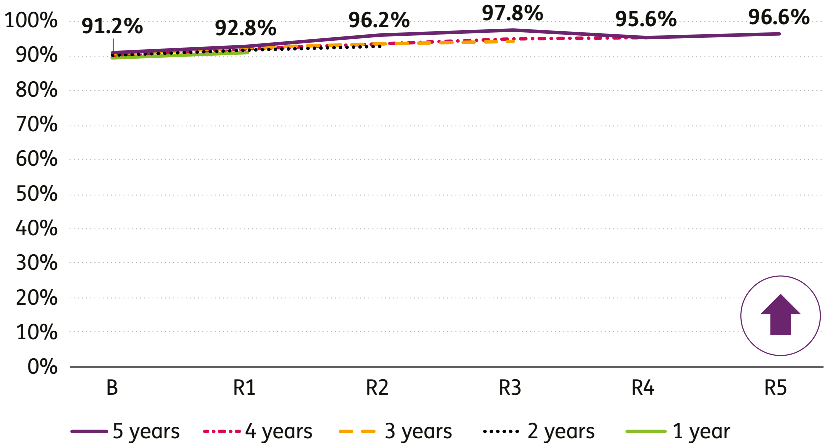
% of families or carers and their partners who are able to engage in social interactions and community life as much as they want

Overall, the percentage of families or carers who are able to engage in social interactions and community as much as they want saw a decreasing trend from baseline to latest review, across all cohorts. For families or carers of participants who have been in the Scheme for five years, there was a decrease of 8.9 percentage points from baseline (28.1%) to fifth review (19.2%). However, there was a 3.2 percentage point increase over the latest year in the Scheme, from 16% to 19.2%.



Of those unable to engage in the community as much as they want, % who say the situation with their child is a barrier to engaging in more social interactions within the community

Of those unable to engage in the community as much as they want, there has been an increasing trend in the percentage who say the situation with their child is a barrier to engaging more, across all cohorts. There has been an increase of 5.4 percentage points from baseline to latest review for families or carers of participants who have been in the Scheme for five years, from 91.2% (baseline) to 96.6% (fifth review).



Domain 6:

Families participate in employment

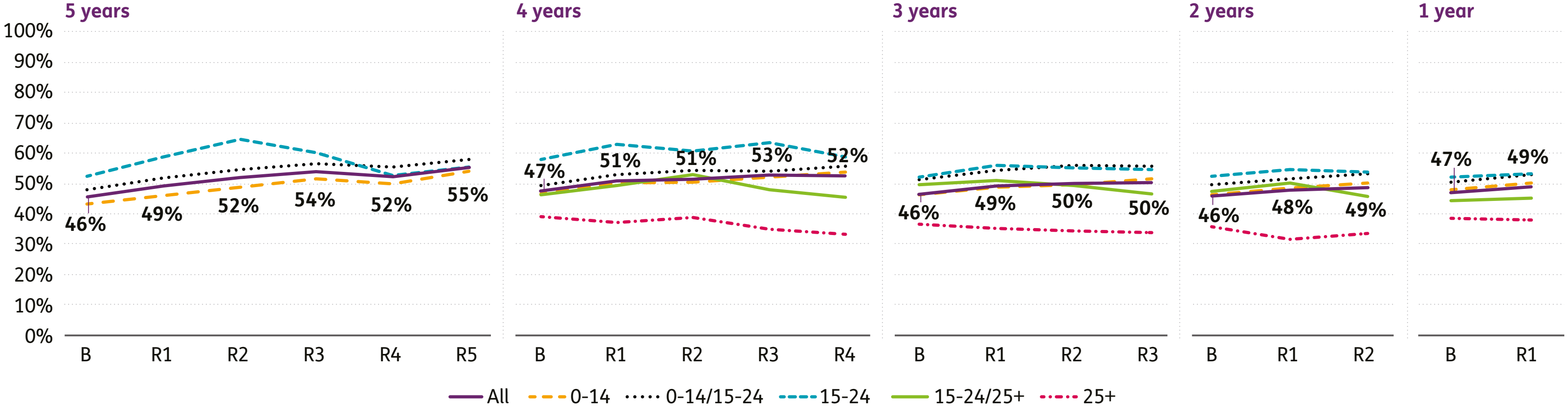
Employment

Combined group, by time in Scheme

% of families or carers who are in a paid job

There have been increases from baseline in the percentage of families or carers who are in a paid job, across all cohorts. Improvements are greater the longer participants have been in the Scheme, with a 9.7 percentage point increase for cohort 5, from 45.6% (baseline) to 55.3% (fifth review). Improvements of between 1.8 and 5.1 percentage points were observed for cohorts 1 to 4.

In cohorts 1 to 4, the 25+ age group has the lowest percentage in a paid job, and this percentage decreased from baseline to latest review. This decline may be partly due to older average age of these respondents, given that family/ carer age tends to be correlated with participant age. Hence these respondents may be more likely to be starting to retire.



Domain 6:

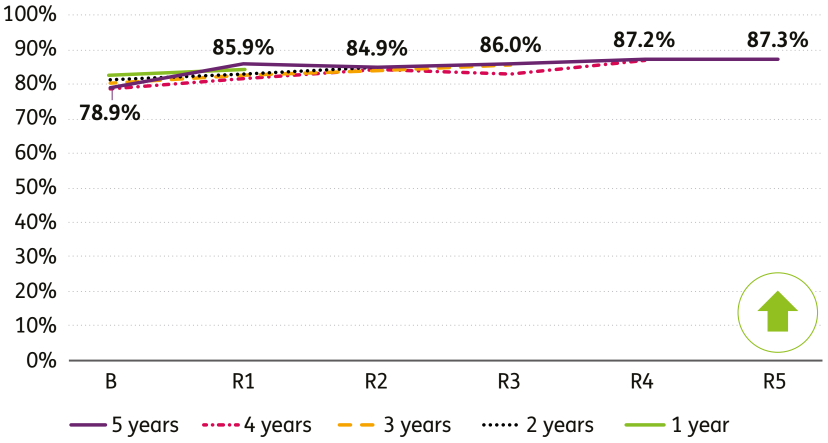
Families participate in employment

Hours worked and type of employment

Combined group, by time in Scheme

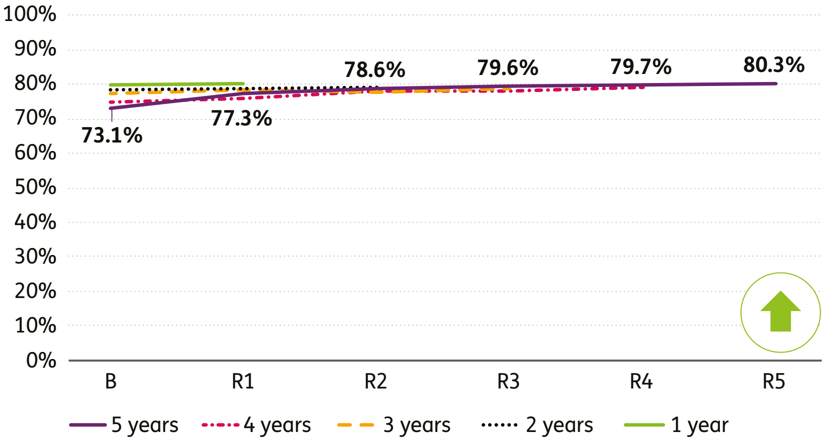
Of those in a paid job, % who work 15 hours or more per week

For those in a paid job, there has been an increasing trend in the percentage of families or carers who work 15 hours or more per week, across all cohorts. For families or carers of participants who have been in the Scheme for five years, there has been an increase of 8.4 percentage points between baseline (78.9%) and latest review (87.3%). For cohorts 1 to 4, improvements ranged from 1.4 to 8.2 percentage points.



Of those in a paid job, % who are employed in a permanent position

For those in a paid job, for cohorts 4 and 5, there have been improvements in the percentage of families or carers who are in a permanent position. For cohort 5, there was a 7.2 percentage point increase from baseline (73.1%) to fifth review (80.3%). Cohort 4 saw an increase of 4.4 percentage points from baseline (74.7%) to fourth review (79.1%). Cohorts 1, 2 and 3 have been relatively steady, showing maintenance or small improvements.



Domain 6:

Families participate in employment

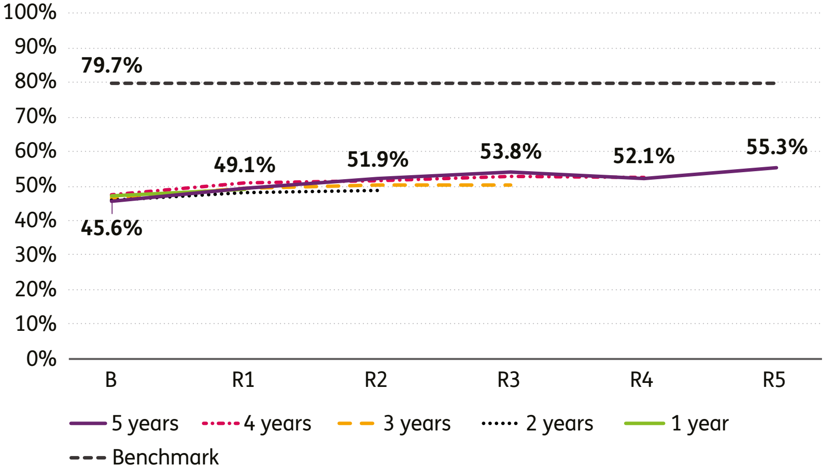
Comparison to benchmark: Employment

Combined group, by time in Scheme

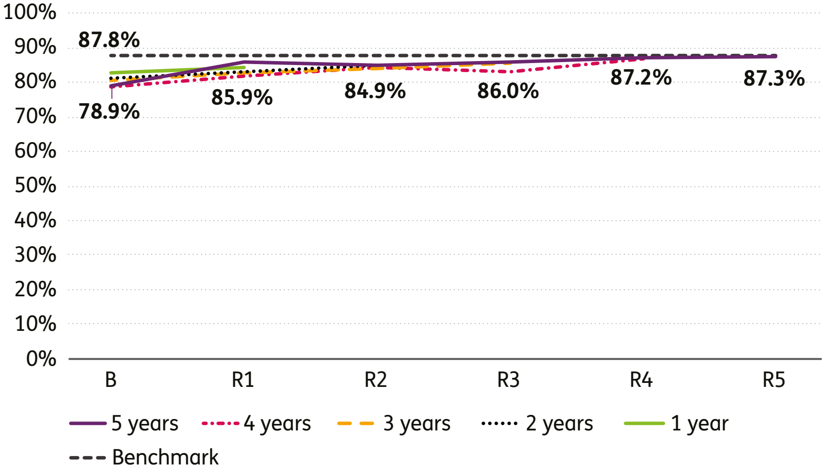
Comparing baseline to latest review, the percentage of families and carers:

- in a paid job improved by 9.7 percentage points, however still remains below the benchmark for the Australian population (79.7%)[1].
- who work 15 hours or more per week improved by 8.4 percentage points and the average (all age groups) at fifth review is only 0.5 percentage points below the Australian population level (87.8%)[1]. In fact, when the group aged 15–24 at latest review is considered separately, the percentage at fifth review is above the benchmark (88.2% for 15–24 and 89.2% for 0–14/15–24).

Working in a paid job



Working 15 hours or more per week



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1 Population benchmark figures are from:

- Working in a paid job: Australian Bureau of Statistics (ABS), Labour Force Status June 2022, standardised for NDIS family/carer age and gender distribution.
- Working 15 hours or more per week: ABS, TableBuilder (Employment, Income and Education) 2016, standardised for NDIS family/carer age and gender distribution.

Domain 7:

Strengths and abilities

Recognising strengths, abilities and progress

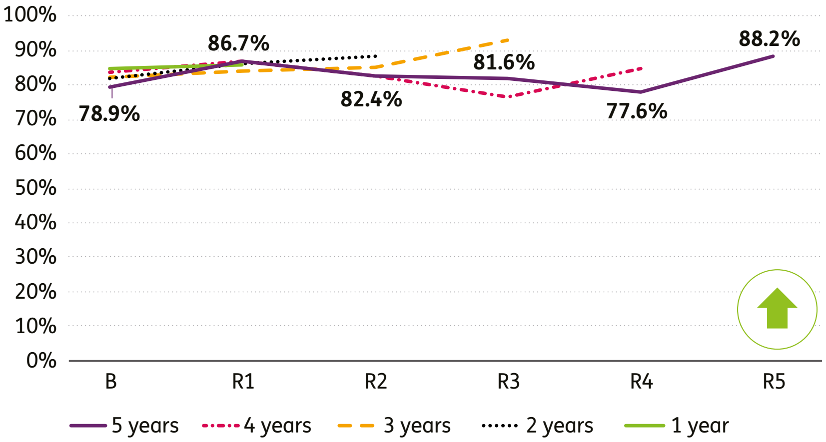
Combined group, by time in Scheme

Overall, the percentages of families or carers of participants aged 0 to 24, who have no difficulties in:

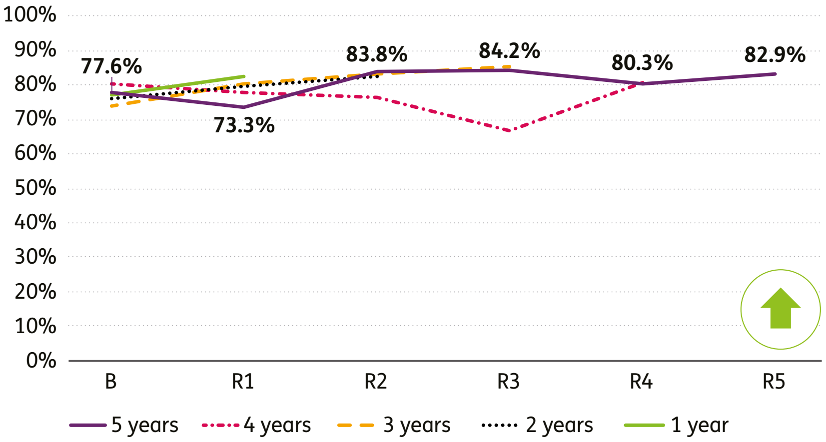
- recognising the strengths and abilities of their family members
- seeing their family member progressing

have seen improvements from baseline to latest review, for all cohorts. There have been increases of 9.3 percentage points and 5.3 percentage points, respectively, over five years (despite some volatility in the results due to small numbers).

% who have no difficulties in recognising the strength and abilities of their family members



% who have no difficulties in seeing their family member progressing



Has the NDIS helped?

Has the NDIS helped?

Families and carers of participants aged 0 to 14

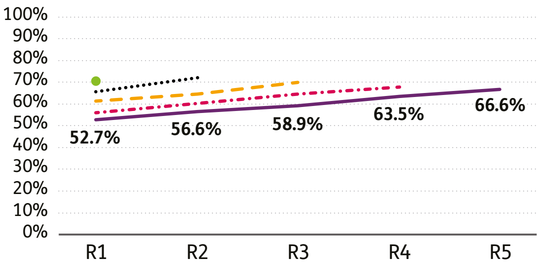
Percentage of positive responses

Opinions are most positive in relation to improving family/carer capacity to help their child develop and learn, followed by access to services, and families feeling supported. Positive opinions are lower for health and wellbeing.

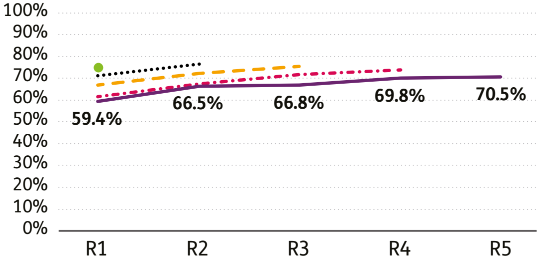
There is an increasing trend in the percentage of positive responses with time in Scheme, for all domains and across all cohorts. For example, for C5, improvements over five years ranged from 3.7 percentage points (health and wellbeing) to 13.9 percentage points (rights and advocacy).

There appears to be a cohort effect for all domains, with those entering the Scheme later in time (e.g. C1) responding more positively than those entering the Scheme earlier (e.g. C5).

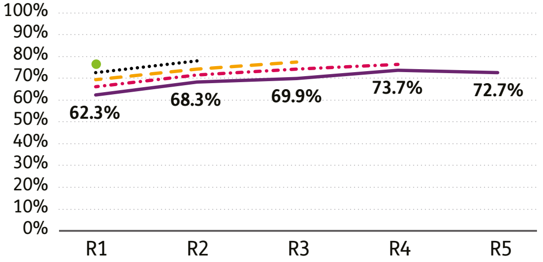
Rights and advocacy



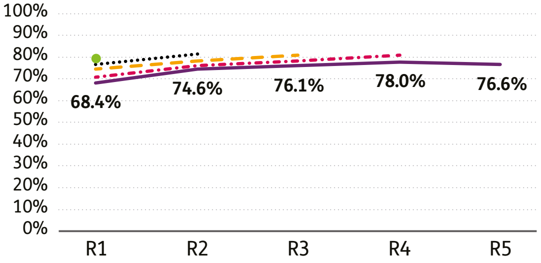
Families feel supported



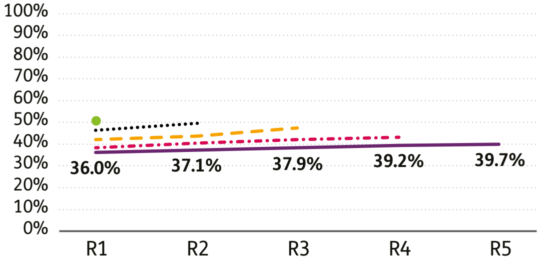
Access to services



Helping children develop and learn



Health and wellbeing



Families and carers of participants aged 0 to 14

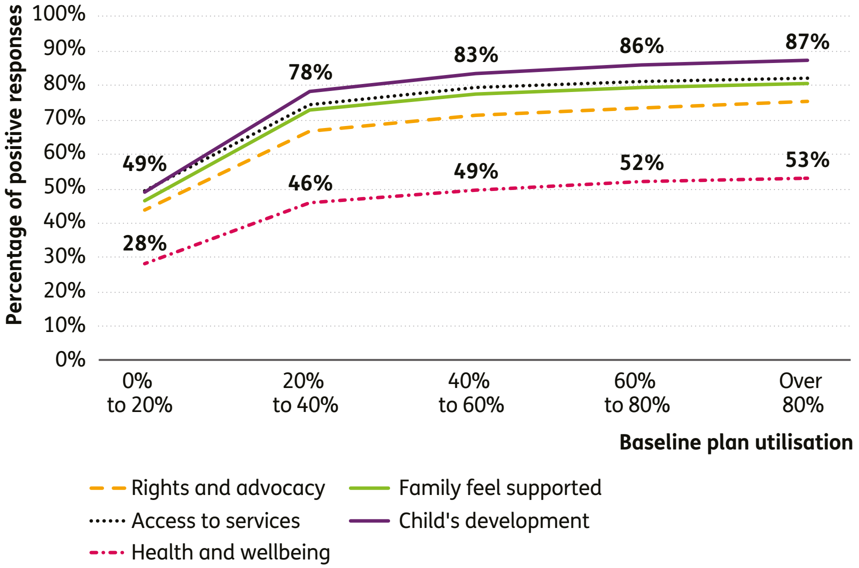
By baseline plan utilisation

By plan utilisation rate, after one year

Higher baseline plan utilisation is strongly associated with a positive response after one year in the Scheme.

The increase is strongest when moving from the 0% to 20% utilisation band to the 20% to 40% utilisation band, although substantial increases are still observed for higher utilisation bands.

For example, in the child development domain, the positive response rate for participants who used 20% to 40% of their funding was 29 percentage points higher than the positive response rate for participants who used 0% to 20%. Comparing the over 80% band with the 20% to 40% band, a further 9 percentage point increase is observed. Hence overall, there is a 38 percentage point increase when comparing the highest and lowest utilisation bands.



Has the NDIS helped?

Families and carers of participants aged 15 to 24

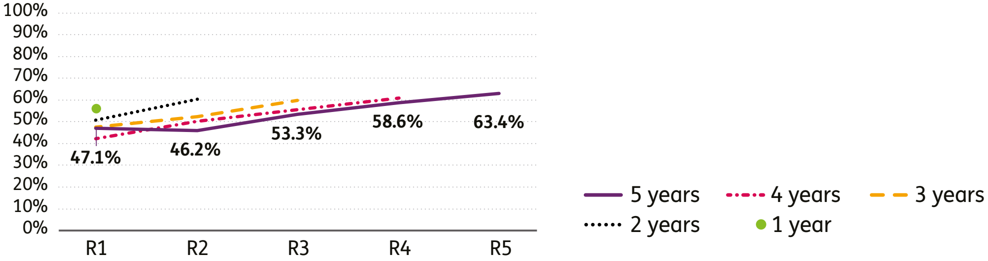
Percentage of positive responses

Opinions are most positive in relation to families feeling supported, and access to services. Positive opinions are lower for health and wellbeing.

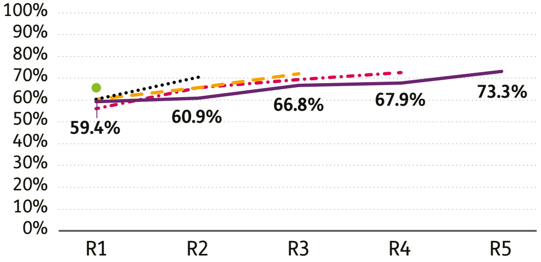
There is an increasing trend in the percentage of positive responses with time in Scheme, for all domains (although less pronounced for health and wellbeing) and across all cohorts. For example, for C5, improvements over five years ranged from 4.5 percentage points (health and wellbeing) to 16.3 percentage points (rights and advocacy).

There appears to be a cohort effect for all domains, with those entering the Scheme later in time (e.g. C1) responding more positively than those entering the Scheme earlier (e.g. C5).

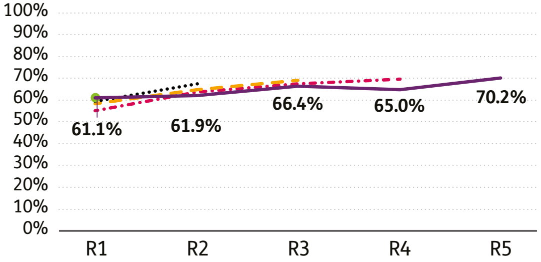
Rights and advocacy



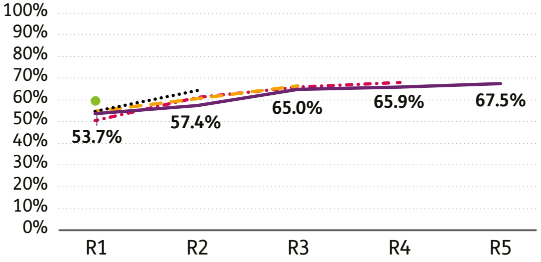
Families feel supported



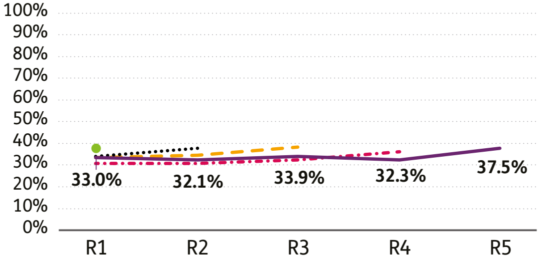
Access to services



Helping young participants become independent



Health and wellbeing



Has the NDIS helped?

Families and carers of participants aged 15 to 24

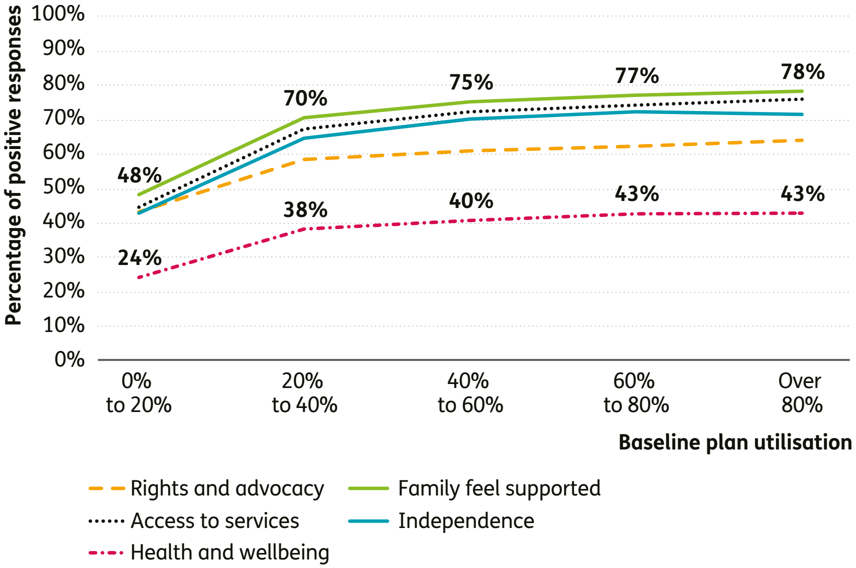
By baseline plan utilisation

By plan utilisation rate, after one year

Higher baseline plan utilisation is strongly associated with a positive response after one year in the Scheme.

The increase is strongest when moving from the 0% to 20% utilisation band to the 20% to 40% utilisation band, although substantial increases are still observed for higher utilisation bands.

For example, in the access to services domain, the positive response rate for participants who used 20% to 40% of their funding was 23 percentage points higher than the positive response rate for participants who used 0% to 20%. Comparing the over 80% band with the 20% to 40% band, a further 9 percentage point increase is observed. Hence overall, there is a 31 percentage point increase when comparing the highest and lowest utilisation bands.



Has the NDIS helped?

Families and carers of participants aged 25 and over

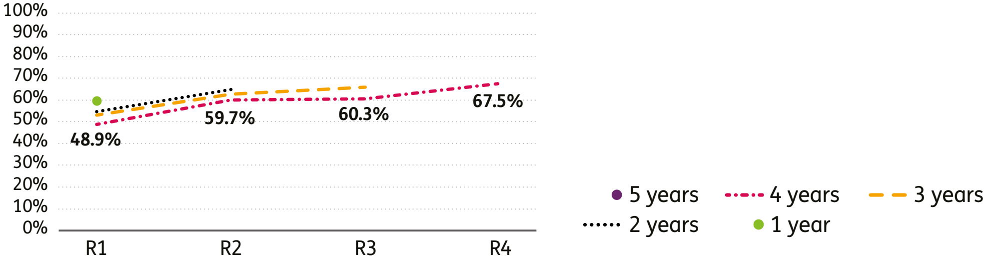
Percentage of positive responses

Opinions are most positive in relation to families feeling supported, and access to services. Positive opinions are lower for health and wellbeing, and succession planning.

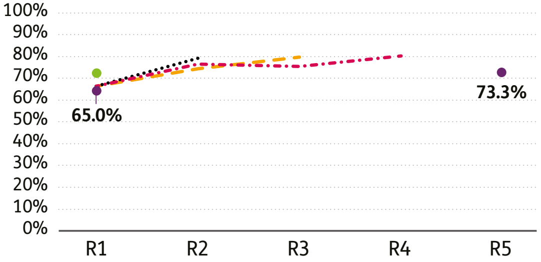
There is an increasing trend in the percentage of positive responses with time in Scheme, for all domains and across all cohorts. For example, for C4[1], improvements over four years ranged from 10.5 percentage points (health and wellbeing) to 18.6 percentage points (rights and advocacy).

Positive response percentages at five years for C5 appear lower than would be expected based on the observed trends. However, the percentages are based on small numbers of respondents.

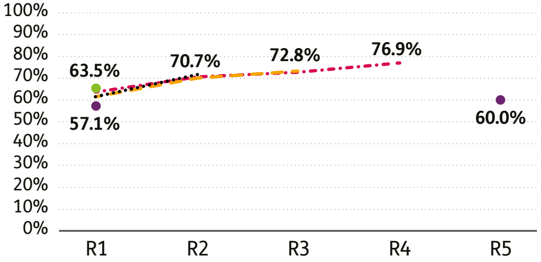
Rights and advocacy[2]



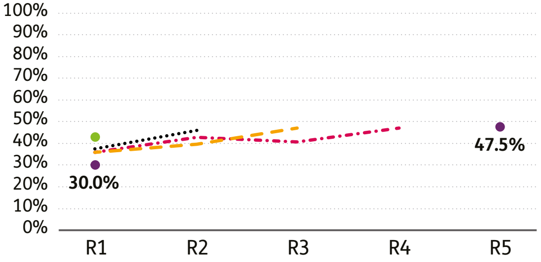
Families feel supported[3]



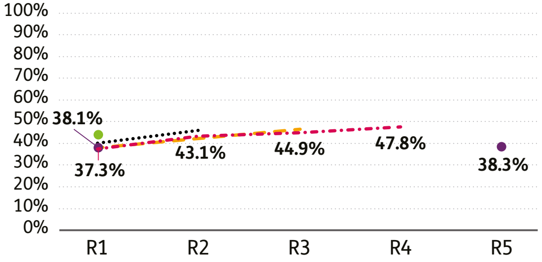
Access to services[3]



Succession planning[3]



Health and wellbeing[3]



[1] C4 used due to small numbers in C5.

[2] Numbers are too small to show cohort 5.

[3] For cohort 5, numbers are too small to show R2–R4.

Has the NDIS helped?

Families and carers of participants aged 25 and over

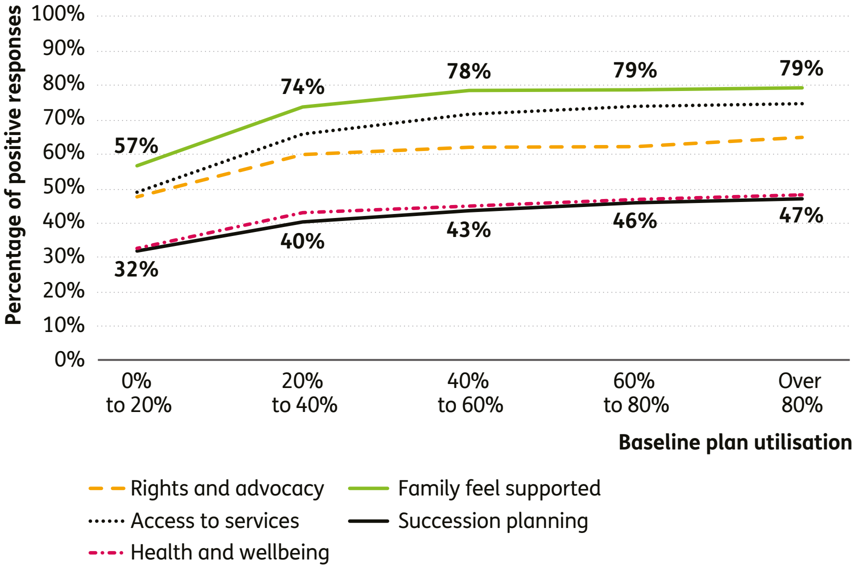
By baseline plan utilisation

By plan utilisation rate, after one year

Higher baseline plan utilisation is strongly associated with a positive response after one year in the Scheme.

The increase is strongest when moving from the 0% to 20% utilisation band to the 20% to 40% utilisation band, although increases are still observed for higher utilisation bands.

For example, in the access to services domain, the positive response rate for participants who used 20% to 40% of their funding was 17 percentage points higher than the positive response rate for participants who used 0% to 20%. Comparing the over 80% band with the 20% to 40% band, a further 9 percentage point increase is observed. Hence overall, there is a 26 percentage point increase when comparing the highest and lowest utilisation bands.



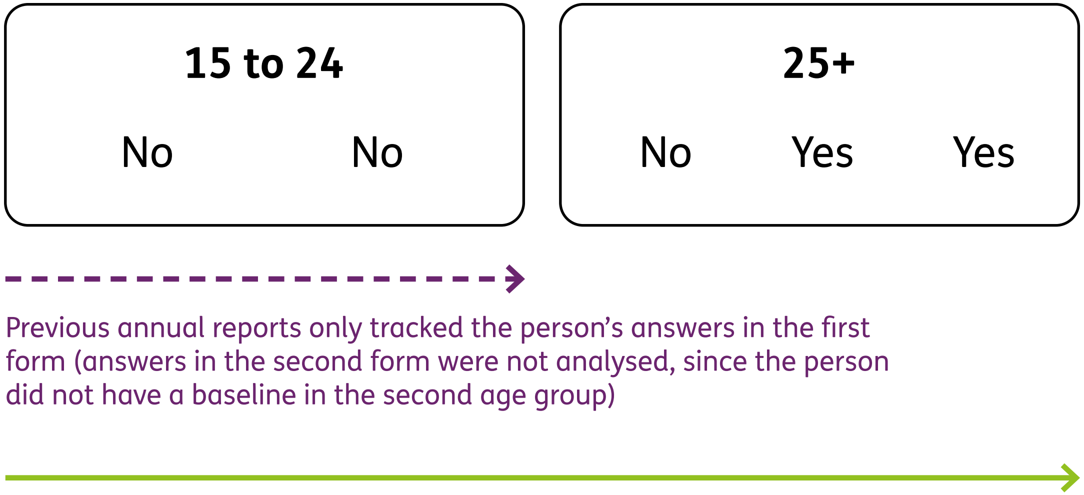
Appendix

Moving up age groups

Questions appearing in both survey forms

If a participant moves up to an older age group, family/carer answers to the **same question** continue to be tracked across the different survey forms.

For example, the item “I feel that the services my family member with disability and my family use listen to me” is included in two survey forms: families/carers of participants aged 15 to 24 and families/carers of participants aged 25+. Suppose a family member/carer responded to a survey twice in the 15 to 24 form and three times in the 25+ form:



15 to 24

No No

25+

No Yes Yes

Previous annual reports only tracked the person’s answers in the first form (answers in the second form were not analysed, since the person did not have a baseline in the second age group)

This report tracks answers to the same question across both forms. Analysis is by “time in Scheme”.

Moving up age groups

Questions only appearing in older age group

If a participant moves up to an older age group, family/carer answers to **questions that are only asked in the older age group** start to be tracked in the new survey form.

For example, the item "I know what my family can do to enable my family member with disability to become as independent as possible" is only included for families/carers of participants aged 15 to 24. Suppose a family member/carer responded to a survey twice in the 0 to 14 form and three times in the 15 to 24 form:

0 to 14

(Question not asked)

15 to 24

No Yes Yes

Previously, the answers to this question were not analysed (since the question is not asked in the first age group, and the person did not have a baseline in the second age group).

This report tracks the person's answers to the question from when they first answer the second form. This is done by "resetting" the baseline at this point, for the purposes of this question. Effectively, this means that the analysis is by "time in age group" rather than "time in Scheme".

The rationale for this approach is that the question was not relevant for family/carers of participants in the younger age group, and so the Scheme was not focussed on improving this particular outcome until they moved to the older age group.

Age group transitions

Summary

The table below summarises the types of questions and how they are treated in the analysis.

Example question	F0to14*	P15to24*	P25plus*	Number of age groups	Type of question	Age group transitioning up**	Treatment in the analysis
I know what specialist services are needed to promote my child's learning and development	1	0	0	1	Non-overlapping	N/A	Single group, by time in Scheme
I recognise the strengths and abilities of my family member	1	1	0	2	Overlapping	N/A	Combined group, by time in Scheme
I know what my family can do to enable my family member with disability to become as independent as possible	0	1	0	1	Non-overlapping	F0to14	Analyse by time since first in F15to24
I feel that the services my family member with disability and my family use listen to me	0	1	1	2	Overlapping	F0to14	For F0to14, analyse by time since first in F15to24, otherwise by time in Scheme
Have you made plans for when you are no longer able to care for your family member with disability?	0	0	1	1	Non-overlapping	F15to24	Analyse by time since first in F25plus
I have friends and family that I see as often as I like	1	1	1	3	Overlapping	N/A	Combined group, by time in Scheme

* F0to14=families/carers of participants aged 0 to 14; F15to24=families/carers of participants aged 15 to 24; F25plus=families/carers of participants aged 25 and over.

** Note this is the oldest group ageing up. Younger groups may eventually age up also. For example, F0to14 ages up to F15to24, and finally to F25plus.

Longitudinal cohorts

For each outcome indicator, longitudinal results are considered separately for five cohorts of families and carers of participants. The cohorts are based on the number of years of experience that the person has contributed to that indicator as at 30 June 2022, in line with the final column of the previous slide. Hence the same person can belong to different cohorts for different indicators. However, for a given indicator, the cohorts are distinct (that is, a person belongs to one cohort only).

The following table shows how cohorts C1–C5 are defined.

Cohort	Number of years of experience contributed to indicator	Possible total number of years in the Scheme
C5	5	5
C4	4	4–5
C3	3	3–5
C2	2	2–5
C1	1	1–5

For example, consider a participant who has been in the Scheme for a total of five years and whose parent responded to the F0to14 questionnaire at baseline and review 1, then to the F15to24 questionnaire at reviews 2 to 5. For the indicator:

- "I know what specialist services are needed to promote my child's learning and development" (only asked in F0to14), the parent would be in cohort C1 (i.e. one review has occurred since baseline where this indicator was asked).
- "I recognise the strengths and abilities of my family member" (asked in both F0to14 and F15to24), the parent would be in cohort C5 (i.e. five reviews for this indicator have occurred since baseline).
- "I know what my family can do to enable my family member with disability to become as independent as possible" (only asked in F15to24), the parent would be in cohort C3 (i.e. the parent first responded to this indicator at review 2 (which becomes the reset baseline) and three reviews have occurred since this reset baseline).

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

Treatment of “Has the NDIS helped?” questions

The final question in each domain asks whether family and carers of participants think that the NDIS has helped with areas related to that domain. In reporting on these questions:

- Only responses at first and subsequent reviews are included, since the Scheme has not had an opportunity to have an impact at baseline.

- All responses from review 1 onwards contribute to the analysis, and responses are allocated to the age group and duration in Scheme applicable at the time of response. For example, family/carer responses for a participant ageing up at review 3 would be included in the new age group from review 3.

- Hence the analysis is cross-sectional by time in Scheme, i.e. results at review ***t*** represent a snapshot of the views of all family/carers when the participant has been in the Scheme for ***t*** years. This is in contrast to the longitudinal (by time in Scheme) presentation for the outcome indicators. The rationale for this difference is that the “Has the NDIS helped” questions measure satisfaction with the Scheme, rather than outcomes of family/carers of participants.

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