# Longitudinal outcomes for NDIS Participants

30 June 2020



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### **Executive summary**

### Background

Fundamentally, the National Disability Insurance Scheme (NDIS) was set up to allow people with disability to live "an ordinary life": to fully realise their potential, to participate in and contribute to society, and to have a say in their own present and future – just as other members of Australian society do.

These aims are embedded in the legislation which established the Scheme, the National Disability Insurance Scheme Act 2013<sup>1</sup> (the NDIS Act), and included in the National Disability Insurance Agency (NDIA) Corporate Plan 2020-2024<sup>2</sup>.

The NDIS Act underscores the Scheme objectives:

- To support the independence and social and economic participation of people with disability;
- To enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports;
- To maximise independent lifestyles and full inclusion in the community; and
- To facilitate greater community inclusion of people with disability.

### **The NDIS Outcomes Framework questionnaires**

The NDIS Act further indicates that the Scheme adopts an insurance-based approach. An insurance-based approach considers the lifetime cost of participants (including early investment), and the outcomes achieved across participants' lifetimes. Measurement of outcomes and costs (both to the NDIS and other mainstream service systems) is critical in understanding the success of the NDIS and is a legislative requirement.<sup>3</sup>

Measurement of outcomes encompasses a wide range of areas, ranging from participants' progress towards achievement of their own individual goals, to the broad economic and societal benefits that are expected to emerge from the Scheme in the longer term.

The NDIS Outcomes Framework questionnaires have been developed to measure progress towards a common set of accepted goals for each participant, so that the results can be aggregated to provide a picture of how and where the Scheme is making a difference. In addition, a common set of goals allows benchmarking to Australians without disability and to other OECD countries.

### This report

This report summarises longitudinal outcomes for participants who have been in the Scheme for one year or more at 30 June 2020. A separate report covers baseline results for NDIS

<sup>&</sup>lt;sup>1</sup> <u>http://www.comlaw.gov.au/Details/C2019C00332/Download</u>

<sup>&</sup>lt;sup>2</sup> https://www.ndis.gov.au/about-us/publications/corporate-plan

<sup>&</sup>lt;sup>3</sup> Further, the National Disability Insurance Scheme forms part of the broader National Disability Strategy 2010-2020. The strategy is a commitment from all governments to a shared vision of an inclusive Australian society that enables people with disability to fulfil their potential as equal citizens. In particular, the strategy emphasises the need for improved performance of mainstream services in delivering outcomes for people with disability.

participants entering the Scheme during the four year period from 1 July 2016 to 30 June 2020. Two previous reports have covered both baseline and longitudinal experience, as at 30 June 2018 and 30 June 2019.<sup>4</sup>

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

The global COVID-19 pandemic that took hold from early 2020 is likely to have had an impact on at least some participant outcomes, such as community participation, and for older age groups, employment. This report investigates effects of the pandemic on outcomes via multiple regression models that allow for discontinuities in indicator levels, as well as different time trends, pre- and post-onset of the pandemic.

### **Baseline versus progress**

It is important to recognise that, with respect to how they are going in different areas of their lives, participants do not enter the Scheme on an equal footing. A whole range of individual and external factors will impact on the experiences of participants at baseline, including the nature and severity of their disability, where they live, and the extent of support they receive from family and friends.

An example of this baseline variability is provided by young adult participants with a psychosocial disability. These participants were found to have consistently poorer baseline outcomes, across all life domains. On the other hand, participants with a hearing impairment generally experience better baseline outcomes.

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

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

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

### A lifespan approach

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

Reflecting this lifespan approach, the report is organised with separate chapters for each participant age cohort<sup>5</sup>.

<sup>&</sup>lt;sup>4</sup> <u>https://data.ndis.gov.au/reports-and-analyses/outcomes-and-goals/participant-outcomes-report</u>

<sup>&</sup>lt;sup>5</sup> Participants from birth to before starting school, participants from starting school to age 14, participants aged 15 to 24, and participants aged 25 and over.

### Participants from birth to before starting school

Outcome indicators for children in the birth to before starting school age group measure the extent to which participants are gaining functional, developmental and coping skills appropriate to their ability and circumstances; showing evidence of autonomy in their everyday lives; accessing early intervention specialist services; and participating meaningfully in family and community life.

#### **Overall results**

- In the longitudinal analysis, significant **improvements** were observed across a number of indicators, for participants who have been in the Scheme for one, two and three years. Areas of particular note were:
  - Social, community and civic participation:
    - For participants who have been in the Scheme for three years, the percentage of parents/carers who say their child feels welcomed or actively included when they participate in age appropriate community, cultural or religious activities increased by 11.1% between baseline and third review, from 63.7% to 74.8%. The improvement was slightly stronger on an age-adjusted basis (11.7%). However, this indicator did not change significantly over the latest year. Additionally, the percentage of children who have friends they enjoy playing with has increased by 21.9% over three years, including a 2.2% increase in the latest year.
    - For participants who have been in the Scheme for two years, there was a two year improvement of 5.1% in the percentage of parents/carers who say their child feels welcomed or actively included when they participate in age appropriate community, cultural or religious activities, from 64.7% to 69.9%, with no significant change over the most recent year. Additionally, the percentage of children who have friends they enjoy playing with has increased by 12.5% over two years in the Scheme, from 42.4% to 54.9%, including a significant increase of 4.2% over the most recent year.
    - For participants who have been in the Scheme for one year, there was a one year improvement of 3.6%, from 63.4% to 67.1%, for the percentage of parents/carers who say their child feels welcomed or actively included when they participate in age appropriate community, cultural or religious activities. The percentage of children who have friends they enjoy playing with has increased by 8.4% over the one year in the Scheme, from 41.7% to 50.1%.
  - Specialist services:
    - For participants who have been in the Scheme for three years, the use of specialist services increased by 24.2% between baseline and third review, from 71.9% to 96.2%. The percentage of parents/carers who say specialist services support them in assisting their child increased by 12.9%, from 86.0% to 98.9%. Furthermore, the percentage of parents/carers who say specialist services help their child gain the skills they need to participate in everyday life increased by 12.9% (8.4% age adjusted) between baseline and third review, from 85.7% to 98.5%.
    - For participants who have been in the Scheme for two years, the use of specialist services increased by 21.8% two years after Scheme entry. The percentage of parents/carers who say specialist services support them in assisting their child increased by 5.1%, from 92.9% to 98.0%, and the percentage who say specialist

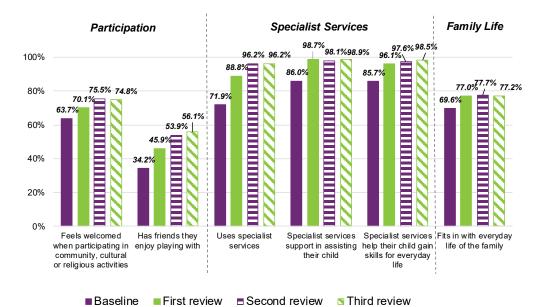
services help their child gain the skills they need to participate in everyday life increased by 5.7%, from 92.5% to 98.2%. Further, the percentage who say the services they use assist staff at their child's day care, pre-school, or community activities to support their child has increased by 34.1% over two years in the Scheme, from 45.5% to 79.5%.

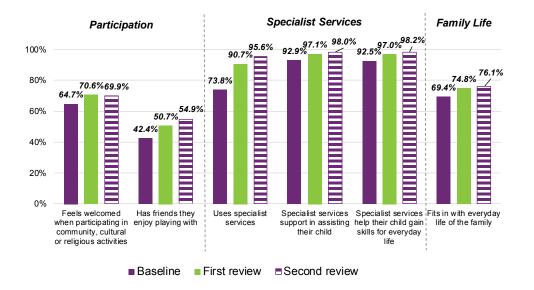
For participants who have been in the Scheme for one year, the use of specialist services increased by 17.7% after one year in the Scheme. In the same time frame, the percentage of parents/carers who say specialist services support them in assisting their child increased by 4.4%, from 91.6% to 96.0%, and the percentage who say specialist services help their child gain the skills they need to participate in everyday life increased by 5.5%, from 90.2% to 95.7%.

#### • Participating in family life:

- For participants who have been in the Scheme for three years, the percentage of parents/carers who say their child fits in with the everyday life of the family increased by 7.7% between baseline and third review, from 69.6% to 77.2%. On an age-adjusted basis the improvement was stronger (11.9%).
- For participants who have been in the Scheme for two years, the percentage of parents/carers who say their child fits in with the everyday life of the family increased by 6.7% between baseline and second review, from 69.4% to 76.1%. On an age-adjusted basis the improvement was stronger (10.7%). In addition, the percentage who say that their child gets along with his or her brothers or sisters has increased by 2.2% (3.3% on an age-adjusted basis), from 84.3% to 86.5%.
- For participants who have been in the Scheme for one year, the percentage of parents/carers who say their child fits in with the everyday life of the family increased by 5.4% between baseline and first review, from 67.8% to 73.2%. On an age-adjusted basis the improvement was stronger (7.4%). In addition, the percentage who say that their child gets along with his or her brothers or sisters has increased by 2.8% (3.7% on an age-adjusted basis), from 80.6% to 83.4%.

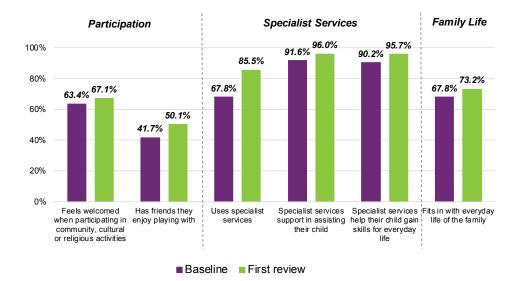
### Figure 1 Changes in indicators over three years for birth to starting school participants who have been in the Scheme for three years





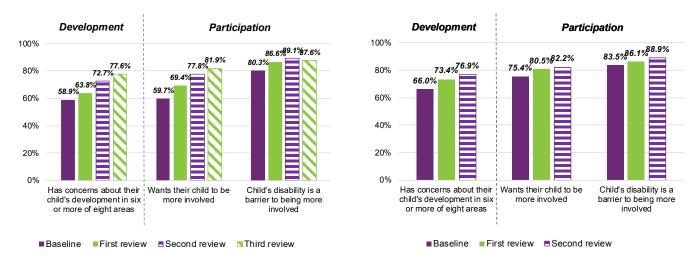
# Figure 2 Changes in indicators over two years for birth to starting school participants who have been in the Scheme for two years

# Figure 3 Changes in indicators over one year for birth to starting school participants who have been in the Scheme for one year



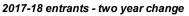
- Improved access to specialist services improves families' knowledge about their child's disability or developmental delay, which can lead to increased concerns and expectations for their child, particularly for families who have had little or no access to services prior to the Scheme.
  - Understandably, their *child's progress in major developmental areas* is a key concern of parents and carers. From the longitudinal analysis, the proportion of parents/carers expressing concern about their child's development in six or more of eight areas surveyed has increased:

- For participants who have been in the Scheme for three years, by 18.6% between baseline and third review, from 58.9% to 77.6%. However, on an age-adjusted basis, the increase was lower (8.2%).
- For participants who have been in the Scheme for two years, by 10.9% between baseline and second review, from 66.0% to 76.9%. However, on an age-adjusted basis, the increase was slightly lower (7.5%).
- For participants who have been in the Scheme for one year, by 5.7% between baseline and first review, from 67.6% to 73.2%. However, on an age-adjusted basis, the increase was slightly lower (4.0%).
- Social inclusion and interaction for children with a disability is another key concern, and the proportion of parents/carers who wanted their child to be more involved in community activities has increased:
  - For participants who have been in the Scheme for three years, by 22.2% between baseline and third review, from 59.7% to 81.9%. There was also a 7.3% increase in the percentage of parents/carers who say their child's disability is one of the barriers to being involved in community activities, from 80.3% at baseline to 87.6% at third review.
  - For participants who have been in the Scheme for two years, by 6.8% between baseline and second review, from 75.4% to 82.2%. There was also a 5.4% increase in the percentage of parents/carers who say their child's disability is one of the barriers to being involved in community activities, from 83.5% at baseline to 88.9% at second review.
  - For participants who have been in the Scheme for one year, by 4.6% between baseline and first review, from 74.0% to 78.7%. There was also a 3.0% increase in the percentage of parents/carers who say their child's disability is one of the barriers to being involved in community activities, from 84.2% at baseline to 87.3% at first review.

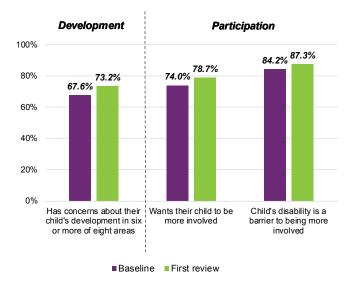


#### Figure 4 Changes in indicators for birth to starting school participants

#### 2016-17 entrants - three year change



2018-19 entrants - one year change



- Participants' longitudinal outcomes vary significantly with their level of function, primary disability, geographic remoteness and cultural background:
  - Longitudinal outcomes vary with participant level of function. Participants with a higher level of function tend to exhibit higher rates of improvement than those with a lower level of function.
  - Participants with a hearing impairment generally experience better longitudinal outcomes than those with other disabilities.
  - Participants from regional and remote locations, compared to those from major cities, show more positive longitudinal results on some indicators. For example, parents/carers of children in regional or remote areas more likely to improve with regard to having concerns in six or more developmental areas from baseline to first review, than children living in major cities.
  - Indigenous status was not strongly associated with longitudinal change: only one multiple regression model found a significant difference between Indigenous and non-

Indigenous participants. This model found that Indigenous children were more likely to deteriorate on the indicator "my child participates in age-appropriate community, cultural or religious activities" from baseline to second review.

- CALD participants were less likely to improve in making friends with people outside the family from baseline to first review and from baseline to second review. Parents/carers of CALD participants were also less likely to change their response from "Yes" to "No" for the indicator "I would like my child to be more involved in community activities".
- o Moving to a new LGA tends to have a negative impact for some transitions.
- Opinions on whether the NDIS has helped are generally positive for this cohort:
  - There is widespread agreement that the NDIS has helped in areas related to the child's development (91.2% after one year in the Scheme, 95.4% after two years in the Scheme, and 94.9% three years in the Scheme) and access to specialist services (90.5% after one year in the Scheme, increasing to 93.2% after two years and 93.8% after three years in the Scheme). Higher plan utilisation is strongly associated with a positive response after one year in the Scheme, across all five areas surveyed.
  - Parents/carers of participants whose plans are fully self-managed were significantly more likely to think that the NDIS has helped after one year in the Scheme than those of participants with agency-managed plans, across all domains except access to specialist services (where there was no significant difference).
  - Across all domains, the percentage who think the NDIS has helped is slightly higher for participants who have been in the Scheme for two years compared to those who have been in the Scheme for one year. However, opinions on whether the NDIS has helped remained relatively unchanged between the second and third review.
  - Overall, comparing three year responses with one year responses, the percentage responding positively increased slightly for all domains (by 1-4%, depending on the domain). The likelihood of improvement/ deterioration varied by some participant characteristics:
    - Participants who entered the Scheme due to disability (s24) are more likely to deteriorate between first and second review than those entering for early intervention (s25)
    - Participants who have used a higher percentage of their total supports, and in particular of their capacity building supports, are generally more likely to improve and less likely to deteriorate between first review and later reviews
    - Participants with higher annualised plan budget are less likely to improve
    - Parents/carers of Indigenous participants are more likely to deteriorate in thinking the NDIS has improved their child's access to specialist services.

### Participants from starting school to age 14

This age group includes children who are commencing school, up to the early teenage years. Typically these years of a child's life are characterised by increasing independence and development of relationships inside and outside the family.

#### **Overall results**

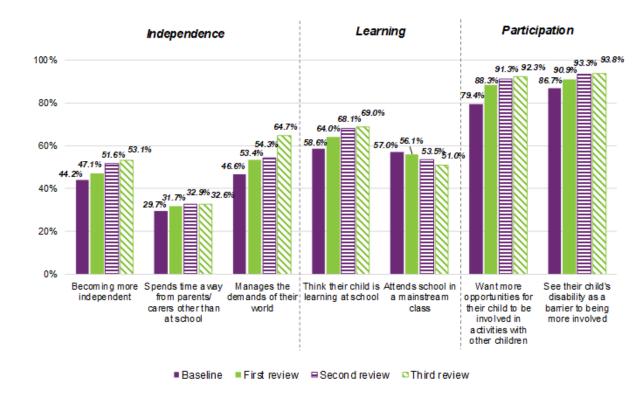
- In the longitudinal analysis, significant *improvements* were observed in areas related to growth in independence and lifelong learning:
  - Growth in independence:
    - For participants who have been in the Scheme for three years, the percentage of parents/carers who say their child is becoming more independent increased by 9.0% between baseline and third review, from 44.2% to 53.1%. On an age-adjusted basis the improvement was stronger (16.6%). The percentage of children who spend time away from parents/carers other than at school increased by 2.9% (2.3% age-adjusted) over three years in the Scheme, from 29.7% to 32.6%, although there has been no significant change in the most recent year. In addition, the percentage of children who manage the demands of their world has increased by 18.1% over three years (10.3% in the latest year).
    - For participants who have been in the Scheme for two years, the percentage of parents/carers who say their child is becoming more independent increased by 8.2% (13.6% after adjusting for age) between baseline and second review, from 41.7% to 49.9%. This includes a 3.4% increase in the latest year. The percentage of children who spend time away from parents/carers other than at school increased by 1.8%, from 30.4% to 32.2%, with a slight increase of 0.4% in the latest year.
    - For participants who have been in the Scheme for one year, the percentage of parents/carers who say their child is becoming more independent increased by 6.4% (7.8% age-adjusted) between baseline and first review, from 39.0% to 45.4%, while the percentage of children who spend time away from parents/carers other than at school increased by 1.5%, from 27.0% to 28.5%. In addition, the percentage of children who manage the demands of their world has increased by 7.1% over one year.

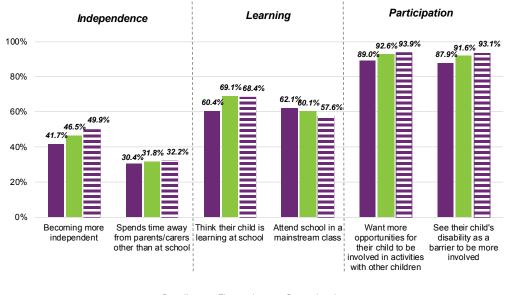
#### • Lifelong learning:

- For participants who have been in the Scheme for three years, the percentage who think their child is learning at school has increased, by 10.4% over three years, from 58.6% to 69.0%. However, the percentage of children who attend school in a mainstream class decreased by 6.0% between baseline and third review, from 57.0% to 51.0%.
- For participants who have been in the Scheme for two years, the percentage of parents/carers who think their child is learning at school increased by 8.0% over two years, from 60.4% to 68.4%. The percentage of children who attend school in a mainstream class decreased by 4.5% between baseline and second review, from 62.1% to 57.6%.
- For participants who have been in the Scheme for one year, the percentage of children who attend school in a mainstream class decreased by 2.1% between baseline and first review, from 65.9% to 63.8%.

- Children in this age group typically are developing a wider range of social skills and have moved from the home environment into school. For indicators of *social interaction and inclusion*, observed changes include:
  - Social, community and civic participation:
    - For participants who have been in the Scheme for three years, the percentage of parents/carers who say they would like their child to have more opportunities to be involved in activities with other children has increased by 12.9%, from 79.4% to 92.3%, between baseline and third review. Of those who would like their child to be more involved in activities with other children, the percentage who see their child's disability as a barrier increased by 7.1%, from 86.7% at baseline to 93.8% at third review.
    - For participants who have been in the Scheme for two years, the percentage of parents/carers who say they would like their child to have more opportunities to be involved in activities with other children increased by 4.9% between baseline and second review, from 89.0% to 93.9%. Of those who would like their child to be more involved in activities with other children, the percentage who see their child's disability as a barrier increased by 5.2% between baseline and the second review, from 87.9% to 93.1%.
    - For participants who have been in the Scheme for one year, the percentage of parents/carers who say they would like their child to have more opportunities to be involved in activities with other children increased by 6.3% between baseline and first review, from 79.4% to 85.7%. Of those who would like their child to be more involved in activities with other children, the percentage who see their child's disability as a barrier increased by 3.4% between baseline and the first review, from 88.2% to 91.6%.

# Figure 5 Changes in indicators for starting school to age 14 participants who have been in the Scheme for three years

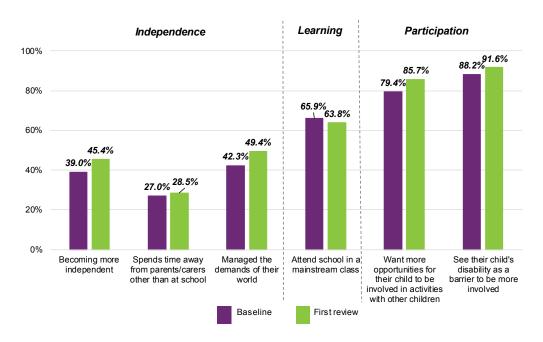




# Figure 6 Changes in indicators for starting school to age 14 participants who have been in the Scheme for two years

Baseline First review Second review

# Figure 7 Changes in indicators for starting school to age 14 participants who have been in the Scheme for one year



- Participants' longitudinal outcomes vary significantly with their level of function, primary disability, geographic remoteness and cultural background:
  - Longitudinal outcomes vary with participant level of function. Participants with higher level of function tend to exhibit higher rates of improvement than those with lower level of function.
  - Participants with a sensory disability generally experience better outcomes than those with other disabilities.
  - Participants from regional and remote locations, show more positive results on some indicators compared to those from major cities. For example, they are more likely to be gaining in independence, and are less likely to move out of a mainstream class at school.
  - CALD participants tend to be less likely to improve on a number of the independence indicators, such as having a genuine say in decisions about themselves, and are less likely to move into a mainstream class at school. However, they are more likely to improve and less likely to deteriorate in getting along with their siblings.
  - Indigenous participants who attend school in a mainstream class are more likely than non-Indigenous participants to move out of a mainstream class between first and second review.
  - Relocating to a new LGA was generally associated with less favourable transitions, with participants being less likely to improve and/or more likely to deteriorate.
- Opinions on whether the NDIS has helped vary by domain for the starting school to 14 cohort:
  - The percentage responding positively is lowest for access to education (39.9% after one year in the Scheme and essentially unchanged after two years and three years in the Scheme) and highest for independence (60.5% after one year in the Scheme, increasing to 65.4% after two years in the Scheme and 68.5% after three years in the Scheme). For education, however, the mainstream education system has a much bigger role in ensuring successful outcomes than the NDIS.
  - Higher plan utilisation is a strong predictor of a positive response across all four areas surveyed, after one, two and three years in the Scheme. In particular, those with very low utilisation (below 20%) are much less likely to say that the NDIS has helped. The fact that utilisation tends to be lowest for the starting school to 14 cohort may contribute to the observed lower levels of satisfaction across all domains, compared to participants in other age groups.
  - Participants who self-manage fully, those who did not receive services from State/Territory or Commonwealth programs before entering the NDIS, and those with a higher annualised plan budget were more likely to respond positively after one year in the Scheme. By contrast, Indigenous participants, those with lower level of function, and those living in regional or remote areas were less likely to respond positively.
  - The percentage who think that the NDIS has helped increased by 4-9% between first and third review across all domains except for access to education, where there was little change (1%). The likelihood of improvement/deterioration varied by some participant characteristics:

- Participants with higher utilisation of capacity building supports were more likely to improve and less likely to deteriorate across all domains
- Participants who self-manage (either fully or partly) were more likely to improve across all domains except in relation to access to education
- Participants who relocated to a different LGA tended to be more likely to deteriorate
- CALD participants were more likely to improve and less likely to deteriorate in relation to access to education
- Female participants were more likely to improve and less likely to deteriorate between baseline and third review in the Relationship domain
- Participants who did not receive Commonwealth or State/Territory support services prior to joining the NDIS were less likely to deteriorate than those who previously received State/Territory support services.

### Participants aged 15 to 24

Participants aged 15 to 24, the young adult cohort, are characterised by increasing levels of independence and participation in community. They are also likely to be impacted by major life events such as moving out of the family home, and transitioning from school to employment or further study.

#### **Overall results**

- Overall, significant *improvements* were observed across a number of indicators, particularly in the areas of Choice and Control, Work, and Social, Community and Civic Participation.
  - Choice and control:
    - For participants who have been in the Scheme for three years, the percentage of participants who make more decisions in their life than they did two years ago increased by 7.5%, from 58.9% at baseline to 66.4% at third review. The percentage who choose who supports them increased by 3.6%, from 31.1% to 34.7%, and the percentage who make most decisions in their life increased by 5.1%, from 24.9% to 30.0%.
    - For participants who have been in the Scheme for two years, the percentage of participants who make more decisions in their life than they did two years ago increased by 6.9%, from 56.7% at baseline to 63.6% at second review. The percentage who choose who supports them increased by 2.2%, from 32.9% to 35.1%, and the percentage who make most decisions in their life increased by 3.8%, from 25.4% to 29.2%.
    - For participants who have been in the Scheme for one year, the percentage of participants who make more decisions in their life than they did two years ago increased by 4.9%, from 54.8% at baseline to 59.6% at first review.

#### • **Work**:

- For participants who have been in the Scheme for three years, the percentage of participants in a paid job increased by 11.8%, from 12.7% at baseline to 24.5% at third review. The percentage of participants working 15 hours or more per week increased by 19.2% from 33.1% at baseline to 52.3% at third review.
- For participants who have been in the Scheme for two years, the percentage of participants in a paid job increased by 6.4%, from 15.3% at baseline to 21.7% at second review. The percentage of participants working 15 hours or more per week increased by 12.7% from 40.5% at baseline to 53.2% at second review.
- For participants who have been in the Scheme for one year, the percentage of participants in a paid job increased by 2.4%, from 17.7% at baseline to 20.1% at first review. The percentage of participants working 15 hours or more per week increased by 4.6% from 40.9% at baseline to 45.5% at first review.

#### • Lifelong learning:

 For participants who have been in the Scheme for three years, the percentage who get opportunities to learn new things increased by 2.7%, from 62.4% at baseline to 65.1% at third review. The percentage who have post-school qualifications increased by 5.2% from 19.1% at baseline to 24.3% at third review.

- For participants who have been in the Scheme for two years, the percentage who get opportunities to learn new things increased by 3.5%, from 60.7% at baseline to 64.2% at second review. The percentage who have post-school qualifications increased by 3.3% from 19.8% at baseline to 23.1% at second review.
- For participants who have been in the Scheme for one year, the percentage who get opportunities to learn new things increased by 2.6%, from 57.6% at baseline to 60.2% at first review. The percentage who have post-school qualifications increased by 1.2% from 21.1% at baseline to 22.3% at first review.

#### • Social, community and civic participation:

- For participants who have been in the Scheme for three years, the percentage actively involved in a community, cultural or religious group in the previous 12 months increased by 14.0%, from 31.1% at baseline to 45.1% at third review. The percentage who spend their free time doing activities that interest them increased 6.6%, from 76.1% to 82.7% at third review. The percentage who know people in their community increased 7.0% from 51.6% to 58.6%.
- For participants who have been in the Scheme for two years, the percentage actively involved in a community, cultural or religious group in the previous 12 months increased by 10.7%, from 32.4% at baseline to 43.1% at second review. The percentage who spend their free time doing activities that interest them increased 4.8%, from 75.5% to 80.2% at second review. The percentage who know people in their community increased 5.4% from 55.2% to 60.5%.
- For participants who have been in the Scheme for one year, the percentage actively involved in a community, cultural or religious group in the last 12 months increased by 5.4%, from 34.9% at baseline to 40.4% at first review. The percentage who spend their free time doing activities that interest them increased 4.2%, from 73.1% to 77.3% at first review. The percentage who know people in their community increased 3.2% from 50.6% to 53.8%.

# Figure 8 Changes in indicators over three years for participants aged 15-24 who have been in the Scheme for three years – choice and control and employment

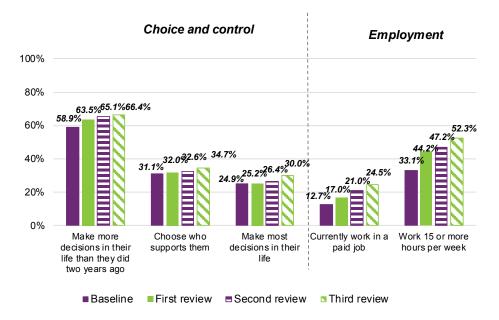
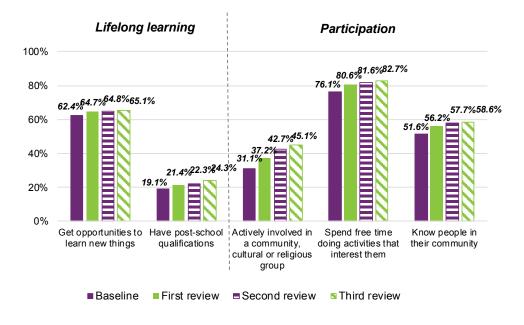


Figure 9 Changes in indicators over three years for participants aged 15-24 who have been in the Scheme for three years – lifelong learning and participation



# Figure 10 Changes in indicators over two years for participants aged 15-24 who have been in the Scheme for two years – choice and control and employment

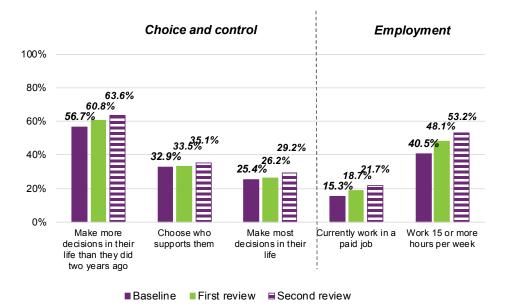


Figure 11 Changes in indicators over two years for participants aged 15-24 who have been in the Scheme for two years – lifelong learning and participation

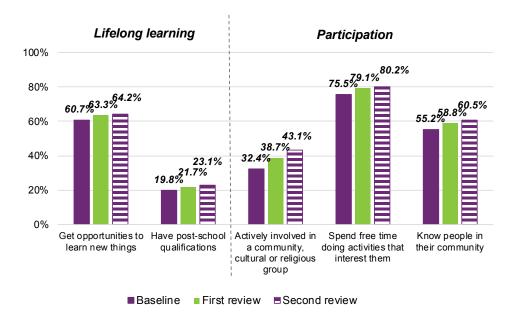
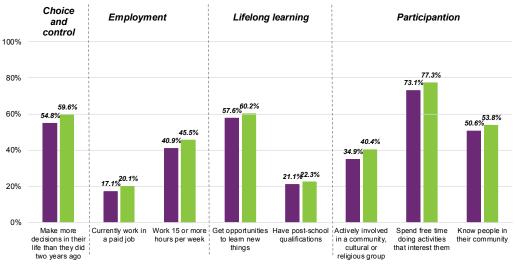


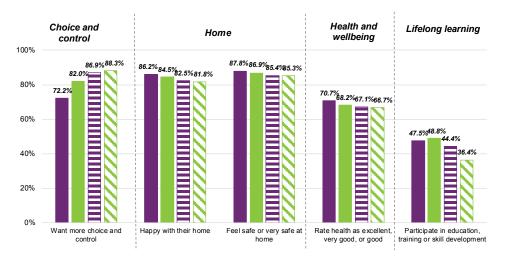
Figure 12 Changes in indicators over one year for participants aged 15-24 who have been in the Scheme for one year – choice and control, employment, lifelong learning and participation



- Baseline First review
- **Other significant changes** have been observed for some indicators in the Choice and Control, Home, Health and Wellbeing and Lifelong Learning domains.
  - Choice and control: While improvements were observed for some choice and control indicators, more participants also expressed a desire for greater choice and control, with the percentage seeking more choice and control increasing:

- By 16.1% over three years for participants who have been in the Scheme for three years, from 72.2% at baseline to 88.3% at third review.
- By 8.6% over two years for participants who have been in the Scheme for two years, from 82.1% at baseline to 90.7% at second review.
- By 4.6% over one year for participants who have been in the Scheme for one year, from 82.6% at baseline to 87.5% at first review.
- *Home*: There have been small but significant reductions in the percentages of participants who are happy with their home and who felt safe or very safe in their home:
  - For participants who have been in the Scheme for three years, the percentage happy with their home decreased by 4.4%, from 86.2% to 81.8% over three years. The percentage feeling safe or very safe in their home decreased by 2.5%, by 87.8% to 85.3%.
  - For participants who have been in the Scheme for two years, reductions over two year were smaller: a 2.1% decrease for the percentage happy with their home, and a 1.6% decrease for the percentage feeling safe or very safe in their home.
  - For participants who have been in the Scheme for one year, the percentage of participants feeling safe or very safe in their home decreased by 1.5% from 84.3% to 82.8%. However, the percentage happy with their home did not change significantly.
- *Health and wellbeing*: The percentage of participants who rated their health as excellent, very good or good has declined:
  - For participants who have been in the Scheme for three years, by 4.0%, from 70.7% at baseline to 66.7% at third review.
  - For participants who have been in the Scheme for two years, by 1.4%, from 68.0% at baseline to 66.5% at second review.
  - For participants who have been in the Scheme for one year, by 2.0%, from 68.9% at baseline to 66.8% at first review.
- Lifelong learning: There has been a reduction in the percentage of participants who participate in education, training or skill development, possibly reflecting the transition from study to work:
  - For participants who have been in the Scheme for three years, a decrease of 11.1% was observed, from 47.5% at baseline to 36.4% at third review.
  - For participants who have been in the Scheme for two years, a decrease of 7.8% was observed, from 48.1% at baseline to 40.4% at second review.
  - For participants who have been in the Scheme for one year, a decrease of 1.6% was observed, from 42.0% at baseline to 40.4% at first review.

Figure 13 Changes in indicators over three years for participants aged 15-24 who have been in the Scheme for three years – choice and control, home, health and wellbeing and lifelong learning



■Baseline ■First review ■Second review ■Third review

Figure 14 Changes in indicators over one year for participants aged 15-24 who have been in the Scheme for two years – choice and control, home, health and wellbeing and lifelong learning

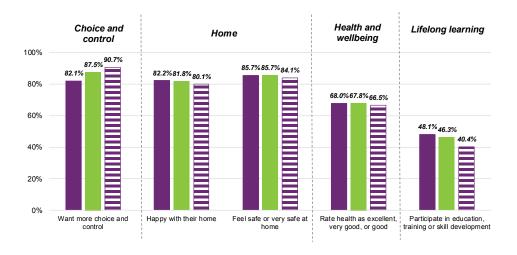
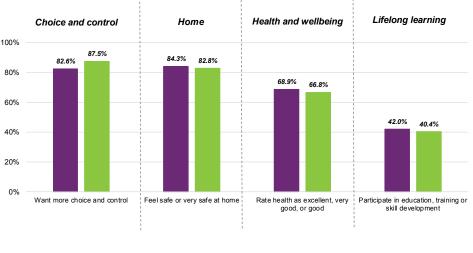




Figure 15 Changes in indicators over one year for participants aged 15-24 who have been in the Scheme for one year – choice and control, home, health and wellbeing and lifelong learning





- Longitudinal outcomes for the 15 to 24 age group vary significantly with participants' level of function, primary disability, geographic remoteness, and cultural background:
  - Longitudinal outcomes vary with participant level of function. Participants with a higher level of function tend to exhibit higher rates of improvement than those with a lower level of function.
  - Participants with a hearing impairment generally experience better outcomes. Additionally, participants with cerebral palsy are less likely to deteriorate with regard to knowing people in their community.
  - Participants from regional areas are more likely to improve over time in knowing people in their community. They were also more likely to want to see their friends more often compared to baseline levels.
  - Participants from a CALD background are more likely to deteriorate over time with respect to making most decisions in life, and knowing people in the community.
  - Indigenous participants were more likely to start wanting more choice and control, and more likely to improve with respect to knowing people in their community.
  - Relocating to a new LGA was significant in a large number of models, with the direction of the effect being mostly negative but sometimes mixed or positive. For example, participants who relocated were more likely to improve on the indicator "I make most decisions in my life". However, they were more likely to deteriorate with respect to having a regular doctor and knowing people in their community.
- Opinions on whether the NDIS has helped vary considerably by domain for the young adult cohort:
  - The percentage who think that the NDIS has helped is lowest for work (18.5% after one year in the Scheme, decreasing to 16.3% after two years in the Scheme and 15.0% after three years in the Scheme), and highest for daily living (60.7% after one year in the Scheme, increasing to 65.4% after two years in the Scheme and 69.5% after three years in the Scheme).

- Higher plan utilisation, and in particular higher utilisation of capacity building supports, is strongly associated with a positive response across most domains, after one, two and three years in the Scheme. Perceptions also tended to improve with increasing participant age. Participants from Western Australia tended to be more positive, and those from Tasmania less positive.
- The percentage who think that the NDIS has helped increased between first and third review across all domains except home and work, where small decreases were observed, and lifelong learning, where there was little change. The likelihood of improvement/deterioration varied by participant characteristics:
  - Higher plan utilisation, and in particular utilisation of capacity building supports, is associated with a higher likelihood of improvement and a lower likelihood of deterioration.
  - Where the plan is self-managed either fully or partly, participants were more likely to improve in the choice and control, daily living, and health and wellbeing domains.
  - For a number of domains, in particular daily living and home, higher annualised plan budget was associated with a higher likelihood of improvement.
  - Female participants were more likely to improve in the lifelong learning domain but less likely to improve in the work domain.

### Participants aged 25 and over

#### **Overall results**

- In the longitudinal analysis, significant *improvements* have been observed for indicators across the relationships, health and wellbeing, lifelong learning, and social, community and civic participation domains.
  - Social, community and civic participation:
    - For participants who have been in the Scheme for three years, the percentage actively involved in a community, cultural or religious group in the last 12 months increased by 12.4% between baseline and third review, from 36.6% to 49.0%. The percentage of participants who spend their free time doing activities that interest them increased by 8.0%, from 69.1% at baseline to 77.1% in third review, and the percentage who know people in their community increased by 8.0%, from 59.2% to 67.2%.
    - For participants who have been in the Scheme for two years, the percentage actively involved in a community, cultural or religious group in the last 12 months increased by 9.1% between baseline and second review, from 36.2% to 45.3%. The percentage of participants who spend their free time doing activities that interest them increased by 6.5%, from 66.0% to 72.5%, and the percentage who know people in their community increased by 4.3%, from 63.1% to 67.3%.
    - For participants who have been in the Scheme for one year, the percentage actively involved in a community, cultural or religious group in the last 12 months increased by 3.4% between baseline and the first review, from 38.1% to 41.5%. Further, the percentage of participants who spend their free time doing activities that interest them increased by 4.3% from 61.6% to 65.9%, and the percentage who know people in their community increased by 2.8%, from 57.5% to 60.3%.
  - *Health and wellbeing*: health indicators suggest an improvement in accessing care, lower rates of hospitalisation, and a more positive outlook on life:
    - For participants who have been in the Scheme for three years, the percentage of participants who had been to the hospital in the last 12 months decreased by 6.1% between baseline and the third review, from 40.2% to 34.1%, the percentage who had no difficulties accessing health services increased by 3.9%, from 70.1% to 73.9%, and the percentage who have a doctor they see on a regular basis increased by 8.9%, from 83.2% to 92.1%.
    - For participants who have been in the Scheme for two years, improvements over two years were also observed for these indicators: hospitalisations declined by 6.2% from 41.4% to 35.2%, the percentage who had no difficulties accessing health services increased by 3.3% from 64.9% to 68.2%, and the percentage who have a doctor they see on a regular basis increased by 4.1%, from 90.7% to 94.8%. In addition, the percentage of participants who felt delighted, pleased, or mostly satisfied about their life increased by 7.2%, from 44.2% to 51.4%.
    - For participants who have been in the Scheme for one year, one year improvements were also observed on these indicators. The percentage of participants who had been to the hospital in the last 12 months decreased by 4.1%, from 41.9% to 37.8%, the percentage of participants who did not have any difficulties accessing health services increased by 1.5%, from 65.0% to 66.5%,

and the percentage who have a doctor they see on a regular basis increased by 2.6%, from 90.1% to 92.7%.

- *Relationships*: improvements in the relationships domain tended to be less consistent across cohorts than those for other domains. However, some statistically significant improvements of note include the following:
  - For participants who have been in the Scheme for two years, the percentage of participants who say they provide care for others but don't get enough assistance decreased by 2.7%, from 80.5% at baseline to 77.8% at second review. There were also small decreases for those who have been in the Scheme for three years and one year, but the changes were not significant.
  - For participants who have been in the Scheme for one year, the percentage of participants who had someone outside their home to call on for practical help increased by 8.0%, from 75.2% at baseline to 83.2% at first review. Further, the percentage of participants who had someone outside their home to call on for emotional support increased by 4.9%, from 76.2% to 81.1%, and the percentage of participants who often felt lonely decreased by 4.5%, from 19.9% to 15.5%.
- Lifelong Learning: More participants are getting opportunities to learn new things, with increases of:
  - 5.0% between baseline (47.1%) and third review (52.2%) for the cohort who have been in the Scheme for three years;
  - 4.2% between baseline (41.9%) and second review (46.1%) for those who have been in the Scheme for two years; and
  - 2.7% between baseline (38.2%) and first review (40.9%) for those who have been in the Scheme for one year.

Figure 16 Changes in indicators over three years for participants aged 25 and over who have been in the Scheme for three years – participation, health and wellbeing, and lifelong learning

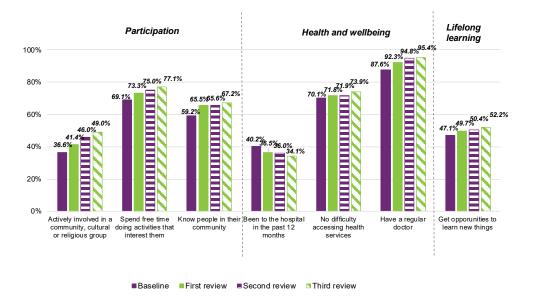
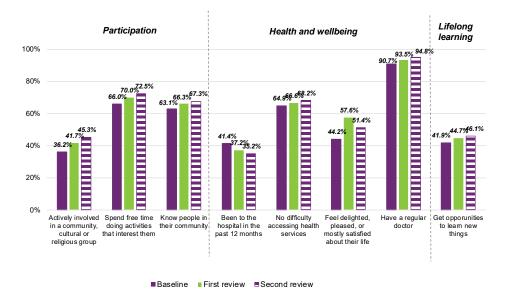
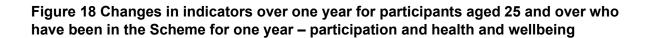
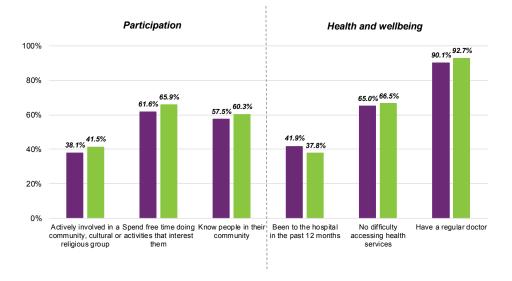


Figure 17 Changes in indicators over two years for participants aged 25 and over who have been in the Scheme for two years – participation, health and wellbeing, and lifelong learning

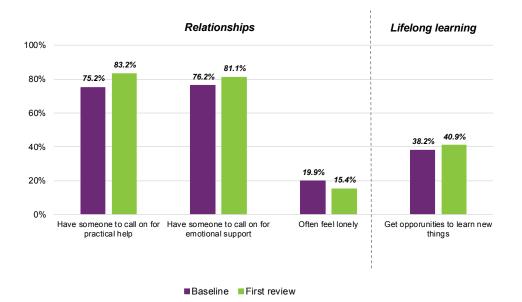






Baseline First review

# Figure 19 Changes in indicators over one year for participants aged 25 and over who have been in the Scheme for one year – relationships and lifelong learning



- **Other significant changes** have been observed in some indicators across choice and control, relationships, home, health and wellbeing, and social, community and civic participation domains.
  - Choice and control:
    - For participants who have been in the Scheme for three years, the percentage wanting more choice and control in their life has increased by 16.0% between baseline and third review, from 65.4% to 81.4%.
    - For participants who have been in the Scheme for two years, the percentage wanting more choice and control in their life has increased by 7.8% between baseline and second review, from 77.8% to 85.6%.
    - For participants who have been in the Scheme for one year, the percentage wanting more choice and control in their life has increased by 3.9% between baseline and first review, from 79.8% to 83.7%.
  - Home:
    - For participants who have been in the Scheme for three years, the percentage who feel safe or very safe at home has decreased by 2.6% from 79.1% at baseline to 76.5% at third review.
    - For participants who have been in the Scheme for two years, the percentage who feel safe or very safe at home has decreased by 1.7% from 75.4% at baseline to 73.7% at second review.
    - For participants who have been in the Scheme for one year, the percentage who feel safe or very safe at home has decreased by 1.4% from 73.1% at baseline to 71.8% at first review.
  - Health and wellbeing: Fewer participants rated their health as excellent, very good or good:

- For participants who have been in the Scheme for three years, the percentage decreased by 5.1%, from 51.2% at baseline to 46.2% at third review.
- For participants who have been in the Scheme for two years, the percentage decreased by 3.2%, from 47.6% at baseline to 44.4% at second review.
- For participants who have been in the Scheme for one year, the percentage decreased by 1.6%, from 45.9% at baseline to 44.3% at first review.

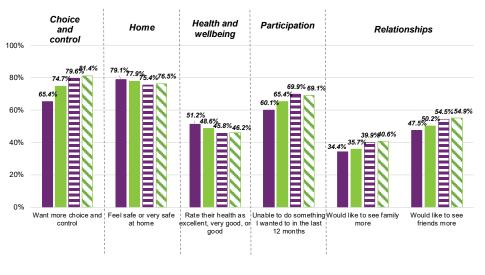
#### • Social, community and civic participation:

- For participants who have been in the Scheme for three years, there was a threeyear increase of 9.0% from 60.1% to 69.1% in the percentage of participants who wanted to do certain things in the last 12 months but could not.
- For participants who have been in the Scheme for two years, there was a two-year increase of 5.1% from 68.0% to 73.0% in the percentage of participants who wanted to do certain things in the last 12 months but could not.
- For participants who have been in the Scheme for one year, there was a one-year increase of 2.9% from 68.5% to 71.4% in the percentage of participants who said there was something they wanted to do in the last 12 months but could not.

#### • Relationships:

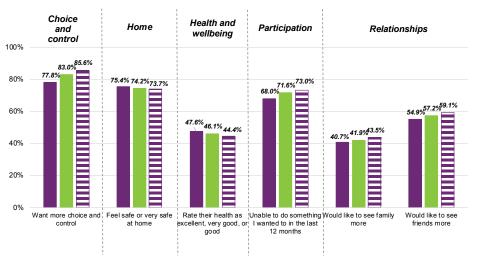
- For participants who have been in the Scheme for three years, there was a 6.1% increase in the percentage of participants who would like to see their family more, from 34.4% at baseline to 40.6% at third review, and an increase of 7.5% in the percentage of participants who would like to see their friends more, from 47.5% at baseline to 54.9% at third review.
- For participants who have been in the Scheme for two years, there were slight increases in the percentage who would like to see their family (2.8%, from 40.7% to 43.5%) and friends (4.2%, from 54.9% to 59.1%).
- For participants who have been in the Scheme for one year, there were also slight increases in the percentage who would like to see their family (1.6%, from 42.3% to 43.9%) and friends (1.6%, from 60.2% to 61.8%).

# Figure 20 Changes in indicators over three years for participants aged 25 and over who have been in the Scheme for three years



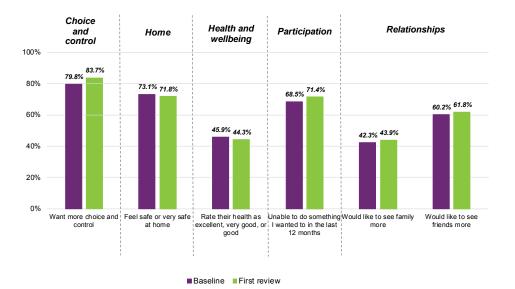
■Baseline ■First review ■Second review ■Third review

# Figure 21 Changes in indicators over two years for participants aged 25 and over who have been in the Scheme for two years



■Baseline ■First review ■Second review

# Figure 22 Changes in indicators over three years for participants aged 25 and over who have been in the Scheme for one year



- Longitudinal changes in outcomes vary significantly with participants' level of function, primary disability, geographic remoteness and cultural background:
  - The impact of disability type on outcomes varies by indicator. In longitudinal analyses, participants with a spinal cord injury or other physical injury were more likely to improve and less likely to deteriorate with regard to being able to advocate for themselves, however they were less likely to improve and more likely to deteriorate with regard to being in the hospital in the last 12 months.
  - Longitudinal outcomes also vary with participant level of function. Participants with a higher level of function tend to exhibit higher rates of improvement than those with a lower level of function.
  - Participants not living in major cities were more likely to improve with regard to being able to advocate for themselves.
  - CALD participants were less likely to improve and more likely to deteriorate with respect to being able to advocate for themselves. They were also less likely to improve getting opportunities to learn new things.
  - Older participants were more likely to change their response from "no" to "yes" with respect to wanting more choice and control in their lives.
  - Participants in supported independent living (SIL) were generally more likely to improve and less likely to deteriorate compared with participants not in SIL. In particular, outcomes were more positive in all models for having been to the hospital in the last 12 months, and SIL participants were more likely to maintain having a regular doctor in all transitions from baseline. However, they were less likely to improve with respect to knowing people in their community between baseline and either first or second review.
  - Relocating to a new LGA was significant in a large number of models, with the direction of the effect being mostly negative but sometimes mixed. In particular, the effect was negative for having been to hospital in the last 12 months, getting the

opportunity to learn new things, saying there were certain things they wanted to do in the last 12 months but could not, and knowing people in their community.

- Opinions on whether the NDIS has helped tend to be slightly more optimistic than the young adult cohort (apart from lifelong learning and work), but generally reflect a similar pattern by domain:
  - The percentage who think the NDIS has helped is highest for daily activities (72.8% after one year in the Scheme, increasing to 79.0% after two years in the Scheme and 82.7% after three years in the Scheme), followed by choice and control (69.2% after one year in the Scheme, increasing to 74.1% after two years in the Scheme and 77.5% after three years in the Scheme). Percentages are lowest for home (30.7% after one year, 29.5% after two years and 31.7% after three years) and work (19.5% after one year, 18.1% after two years and 18.5% after three years).
  - Higher plan utilisation is strongly associated with a positive response across all eight domains, after both one, two and three years in the Scheme. Perceptions also tended to improve with increasing plan budget. Participants from Western Australia and Queensland tended to be more positive, and those from Victoria and South Australia less positive.
  - The percentage who think that the NDIS has helped increased by 1% to 10% between first and third review across all domains except work, where there was a 1% decrease. The likelihood of improvement/deterioration varied by some participant characteristics:
    - Female participants were more likely to improve in the daily living domain but more likely to deteriorate in choice and control.
    - Participants who self-manage were more likely to improve and/or less likely to deteriorate in the choice and control, daily living, and health and wellbeing domains.
    - Older participants were less likely to deteriorate in choice and control, daily living, home and health and wellbeing, however they were less likely to improve and/or more likely to deteriorate in lifelong learning and work.
    - Participants living in a regional area were more likely to improve and/or less likely to deteriorate in daily living, relationships, home, health and wellbeing, lifelong learning and social and community participation.
    - Participants in supported independent living (SIL) were more likely to improve and/or less likely to deteriorate for at least some transitions across all domains.

### COVID-19

The global pandemic that took hold from early 2020 is likely to have had an impact on at least some participant outcomes, such as community participation, and for older age groups, employment.

To investigate which outcomes may have been affected by the pandemic via quantitative modelling, additional time-related terms were included in the regression models.<sup>6</sup> These terms allow for a step change in the probability of a participant changing their response, and/or a different trend over time, when the later review occurs during the COVID-19 pandemic.

#### Participants from birth to before starting school

Results from the modelling were generally negative, with participants being less likely to improve or more likely to deteriorate in their response compared to the pre-COVID period:

- The COVID-19 step-change variable was significant in at least one model for all but one of the nine indicators modelled ("My child fits in with the everyday life of the family"), and had a negative impact for all but one of these models, with responses being less likely to improve or more likely to deteriorate between the two time points when the later time point occurred during the COVID-19 period. For example, participants were less likely to improve between baseline and first or second review with regard to:
  - Participating in age-appropriate community, cultural or religious activities.
  - Being able to make friends with people outside the family.
- The one indicator where there was a positive step change was "My child joins me when I complete tasks at home", where participants were less likely to deteriorate between baseline and first review, when the review occurred during the COVID period.
- There were two indicators where a favourable change in the time trend was observed after the COVID-19 date: "My child fits in with the everyday life of the family" and "My child's disability is a barrier to being more involved" (although the latter indicator was preceded by a negative step change).

#### Participants from starting school to age 14

There were some significant changes to participants' longitudinal outcomes during the pandemic, and results were mixed, being favourable in some models but unfavourable in others. For example:

- For the indicator "My child gets along with his/her siblings", parents/carers were less likely to change their response (either improve or deteriorate) in all one-year transitions, when the later review occurred during the COVID period. In addition, responses were less likely to improve over three years when the third review occurred during the COVID period.
- For the indicator "There is enough time each week for all members of the family to get their needs met", parents/carers were less likely to change their response (either improve or deteriorate) between baseline and first review, and they were less likely to deteriorate between second and third review.

<sup>&</sup>lt;sup>6</sup> The methodology and limitations of the approach are discussed in Section 2.5. In particular, the modelling is based on only about three months of experience during the pandemic, and some of the effects detected are only slight.

- With respect to their child becoming more independent, parents/carers were less likely to change their response (either improve or deteriorate) between baseline and first review, but were less likely to improve between second and third review. There was also a negative change in time trend post-COVID, with improvement becoming less likely over time for some transitions.
- However, parents/carers were less likely to deteriorate with respect to perceiving their child's disability as a barrier to being more involved between baseline and first review, where the review occurred during the COVID period.

#### Participants aged 15 to 24

There were some significant changes to participants' longitudinal outcomes during the pandemic, and results were mixed, being favourable in some models but unfavourable in others. For example:

- Participants were generally less likely to report an improvement between reviews with respect to making more decisions than they did two years ago, when the later review occurred during the pre-COVID period.
- Participants who gave their second response during the COVID period were less likely to change their response from "Yes" (wanting to see their friends more often) to "No" (not wanting to see them) in all transitions from baseline.
- However, participants were less likely to deteriorate between baseline and second review in relation to wanting to do certain things in the last 12 months but being unable to, when the later response occurred during the COVID period.

#### Participants aged 25 and over

There were some significant changes to participants' longitudinal outcomes during the pandemic, and results were mixed, being favourable in some models but unfavourable in others. For example:

- With respect to having a regular doctor, participants were less likely to deteriorate between baseline and second or third review, when the review occurred during the COVID period. There was also a favourable change in time trend post-COVID, with deterioration becoming less likely over time, for the transition from baseline to third review.
- However, participants were less likely to improve with respect to knowing people in their community between baseline and second review, and between second and third review, when the later review took place during the COVID period.
- Participants who gave their second response during the COVID period were less likely to change their response from "Yes" (wanting to see their family more often) to "No" (not wanting to see them) between baseline and first or second review, as well as between first and second review.