# Outcomes for participants with Autism Spectrum Disorder (ASD)

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## Slide 1: Outcomes for participants with Autism Spectrum Disorder (ASD)

## Slide 2: Outline

This slide talks about the structure of the presentation. The following topics will be covered:

* Introduction
* Key points
* Prevalence estimates, in particular for SDAC and NDIS participants.
* Trends over time and comparisons with other disabilities for NDIS participants with ASD
* The NDIS outcomes framework with findings from baseline outcomes upon entering the scheme, longitudinal outcomes and perceptions on whether the NDIS has helped.

## Slide 3: Introduction

The National Disability Insurance Scheme (NDIS) provides reasonable and necessary funding to people with a permanent and significant disability to access the supports and services they need to live and enjoy their life.

There are a number of pathways potential participants can access the NDIS:

Firstly, Early Childhood Early Intervention (ECEI) helps children aged 0-6 years to access supports and services tailored to the child’s needs prior to becoming a participant of the NDIS. Note: At 30 June 2018, there were approximately 6,800 children supported in the ECEI gateway who had not made a request for access. A further 3,700 had been supported in the gateway and had exited the gateway without needing support from the Scheme.

Secondly, potential participants can make an access request to become a participant of the Scheme. The NDIS makes decisions about whether someone is eligible and, if so, how much funding they will receive in their NDIS plan

Finally, participants can access the Scheme via permanent disability (s24) or early intervention (s25) pathways as set out in the NDIS Act 2013.

This presentation focuses on the final point; participants who have made an access request and received a NDIS plan through the permanent disability (s24) or early intervention (s25) pathways. ECEI is recorded off-system and more analysis will be presented on this as the data moves on-system.

The following sections present information on

* population data compared with NDIS data on the prevalence of Autism Spectrum Disorders,
* trends in participants with ASD, and
* analysis of outcomes for participants with ASD

## Slide 4: Key points

This next section is on the key points of the presentation.

## Slide 5: Key points (1)

ASD is currently the largest primary disability category for the NDIS. As at 31 December 2018, 29% of active participants with an approved plan had a primary disability of ASD, followed by intellectual disability, with 27%. Additionally, about 5% of participants had ASD as a secondary disability, with two-thirds of these having a primary intellectual disability. Note: Since 2017-18 Q1 Developmental Delay and Global Developmental Delay have been reported separately to the Intellectual Disability category. If these were included, the proportion of participants with a primary disability of Intellectual Disability would increase to 33%.

ASD prevalence rates from the ABS Survey of Disability, Ageing and Carers (SDAC) show an increasing trend over time, from 0.3% in 2009 to 0.5% in 2012 and 0.7% in 2015. Note: Autism Spectrum Disorder includes Autistic disorder, Asperger’s disorder, Rett’s Syndrome, Childhood Disintegrative Disorder and Pervasive Developmental Disorder not otherwise stated (PDD-NOS). Includes all those who reported one of these as a long-term condition.

Scheme prevalence rates have also increased over time. For the more mature trial site locations, some trends are:

* All-age prevalence rates range from 0.4% in ACT to 0.7% in SA and the Hunter region.
* Rates generally increase to a peak at around age 8 to 11 before declining.
* For the Hunter and Barwon regions, Scheme prevalence rates are now comparable to SDAC 2015 prevalence rates.

## Slide 6: Key points (2)

Trends in recent quarters reveal some differences between participants with ASD and participants with other disabilities:

1) For access met decisions, quarterly growth rates are higher for ASD than for the group of other disabilities in the age range 7 to 44. Similar results are observed for growth in plan approvals.

2) Ineligibility rates are lower for participants with ASD compared to the group of participants with other disabilities, across all age groups.

3) Compared to the group with disabilities other than ASD, average committed supports for participants with ASD are similar or lower for ages 0 to 24 but higher for ages 25 and over.

Note: differences by age may reflect the different mix of disabilities and also Supported Independent Living.

4) Utilisation for participants aged 18 and under with ASD has shown a slight increasing trend in recent quarters, and is also slightly higher for most age groups compared with other disability groups.

## Slide 7: Key points (3)

Comparing length of time in Scheme for participants with ASD and those with other disabilities; early intervention participants with ASD tend to have been in the scheme for longer than participants with other disabilities; however, the distributions of time in scheme are more similar for disability met participants.

A preliminary comparison of time from access met to first plan approval suggests there has been minimal difference between participants with ASD and participants with other disabilities in recent quarters, however further analysis is being conducted.

Further research into children in the ECEI gateway is also being undertaken.

## Slide 8: Key points (4)

On entering the Scheme, outcomes for participants with ASD are worse in many respects than those for participants with other disabilities.

For example:

* For participants aged 0 to school: participants with ASD are more likely than most other disability groups to experience difficulties in six or more areas of development and are less likely to be able to make friends, to participate in community activities, and to feel welcomed or included when participating.
* For participants aged school to 14: participants with ASD were the least likely to feel happy/ genuinely included at school.
* For participants aged 15 and over: participants with ASD are less likely to choose who supports them, and more likely to have no friends other than family or paid staff.

## Slide 9: Key points (5)

Results for longitudinal change in outcomes over one year for participants with ASD are largely positive, with improvements seen across a number of the key indicators:

### Participants aged 0 to school:

Significant improvements are observed for the percentage of children with ASD being able to express what they want, and the percentage of children who are welcomed or actively included in community activities.

### Participants aged school to 14:

Changes are less positive than for the youngest children. However, improvements are seen for the percentage of children with ASD becoming more independent, and the percentage welcomed or actively included when they spend time with friends or in community activities.

### Participants aged 15 to 24:

Improvements are observed for the percentage of participants with ASD who have been actively involved in a community, cultural or religious group, and the percentage who have a paid job. However, there has been a deterioration in the percentage with no friends other than family or paid staff.

### Participants aged 25 and over:

Improvements are observed for the percentage of participants with ASD who have been actively involved in a community, cultural or religious group. However, there has been a deterioration in the percentage who choose who supports them, and the percentage who choose that they do each day.

## Slide 10: Key points (6)

Results for longitudinal change in outcomes when comparing participants with ASD with other disabilities, include:

### Participants aged 0 to school:

The improvement in the percentage welcomed when they participate in community activities is slightly greater for participants with ASD, however the percentage with concerns in six or more areas has increased (deteriorated) more for participants with ASD.

### Participants aged school to 14:

Changes tended to be slightly more positive for participants with ASD, particularly the percentage who say their child is becoming more independent, and the percentage welcomed or actively included when they spend time with friends or in community activities.

### Participants aged 15 to 24:

There has been a bigger deterioration in the percentage with no friends other than family or paid staff for participants with ASD. However, participants with ASD are more likely to improve in relation to feeling safe in their home.

### Participants aged 25 and over:

There has been a bigger deterioration in the percentage with no friends other than family or paid staff for participants with ASD. Participants with ASD have also fared worse on the two choice and control indicators: choosing who supports them and choosing what they do each day. However, participants with ASD are more likely to improve in relation to feeling safe in their home.

## Slide 11: Key points (7)

Perceptions of whether the NDIS has helped show:

### Participants aged 0 to school:

Participants with ASD show a small but consistent trend to respond more positively than those with other disabilities.

### Participants aged school to 14:

Participants with ASD respond slightly more positively, except for the education domain where results are similar.

### Participants aged 15 to 24:

There is very little difference between responses for participants with ASD and those with other disabilities.

### Participants aged 25 and over:

Participants with ASD tend to respond slightly more positively for the relationships, home, lifelong learning, work and community participation domains.

Responses tend to be similar to other participants for choice and control and daily living, and very slightly worse for health.

## Slide 12: Prevalence estimates

This following section is on prevalence estimates.

## Slide 13: Survey of Disability, Ageing and Carers (SDAC)

The following section explores the prevalence estimates using the SDAC.

## Slide 14: Background

Autism spectrum disorder (ASD) is “the collective term for a group of neurodevelopmental disorders characterised by persistent deficits in social communication and social interaction and by repetitive patterns of behaviour and restricted interests”. Note: as defined in the report by Whitehouse AJO, Evans K, Eapen V, Wray J. A national guideline for the assessment and diagnosis of autism spectrum disorders in Australia. Cooperative Research Centre for Living with Autism, Brisbane, 2018.

Reported population prevalence of ASD has been increasing worldwide since the 1990s. Explanations put forward include:

* Etiological factors, such as increasing parental age and environmental influences; and
* Non-etiological factors, such as increased awareness and changing diagnostic criteria.

Source: T. May, E. Sciberras, A. Brignell and K. Williams, “Autism spectrum disorder: updated prevalence and comparison of two birth cohorts in a nationally representative Australian sample,” BMJ Open, vol. 7, p. e015549, 2017.

ASD is currently the largest primary disability category for the NDIS. As at 31 December 2018, 29% of active participants with an approved plan had a primary disability of ASD, followed by intellectual disability, with 27%.

## Slide 15: Overall prevalence estimates from the Survey of Disability, Ageing and Carers (SDAC)

The SDAC collects information on disability from a sample of Australian households. The information is collected from interviews and relies on self-report of disability status and type.

Estimated ASD prevalence rates from the 2009, 2012 and 2015 SDAC show an increasing trend. Note: ASD includes Autistic disorder, Asperger’s disorder, Rett’s Syndrome, Childhood Disintegrative Disorder and Pervasive Developmental Disorder not otherwise stated (PDD-NOS). Includes all those who reported one of these as a long-term condition.

This slide includes a graph showing the prevalence rates for males, females and both combined over the years of 2009, 2012 and 2015. Male prevalence rate is about four times the female rate. This is consistent with international studies, e.g. the Centers for Disease Control and Prevention (CDC) found that boys are 4.5 times more likely than girls to be diagnosed with ASD in the US.

## Slide 16: SDAC classification of core activity limitation

SDAC “core activity limitation”: assistance required with at least one of three activities: mobility, communication, self-care. The most common activity restriction for people with autism is communication, followed by mobility.

Limitations are classified as profound, severe, moderate or mild. There appears to have been a shift towards milder levels for autism over time. For example, SDAC 2009 estimated that 68% of people with autism had a profound or severe communication restriction, compared to 51% for SDAC 2015.

## Slide 17: SDAC prevalence estimates by age group

This slide contains a graph showing ASD prevalence estimates according to the SDAC 2009, 2012 and 2015 responses. Rates increase to a peak around 5 to 14 years of age before declining at older ages. Rates have been increasing over time, for all except the oldest age groups. However, increases are pushing into successively older age groups, as the different birth cohorts age.

## Slide 18: NDIS participants

The following section presents prevalence estimates for NDIS participants.

## Slide 19: Scheme prevalence for trial site locations, as at 31 December 2018

This slide contains a graph showing the ASD prevalence rates for NDIS participants, split by participants aged 0 to 14 and participants of all ages in trial site locations, i.e. Newcastle, Hunter, Barwon, SA, Perth Hills and ACT.

Overall prevalence rates for the more mature trial site locations range from 0.4% in ACT to 0.7% in Hunter and SA. Note: In SA, only children aged 13 and under were brought into the scheme during the trial period. During 2016-17, young people up to the age of 17 started to transition. Hence, all age prevalence may be understated.

For ages 0 to 14 only, prevalence rates range from 1.3% in ACT to 2.3% in SA.

## Slide 20: Comparison of Scheme prevalence with SDAC 2015: Hunter and Barwon

This slide contains three graphs: one for Males, Females and All combined. The graphs compare prevalence rate estimates for ASD from the SDAC, and for NDIS participants in the Hunter and Barwon sites.

For males, Hunter and Barwon rates are around 90-115% of SDAC 2015 rates for age groups 5 to 9 and 10 to 14, with lower percentages for other age groups. For females, Hunter and Barwon rates are around 120-150% of SDAC 2015 rates for age group 10 to 14 and 15 to 19. Note: SDAC rates include all those who reported ASD as a long-term condition (had lasted or was likely to last for six months or more).

## Slide 21: Scheme prevalence for trial site locations by age, as at 31 December 2018

This slide has six graphs showing the ASD prevalence rates for males, females and combined, compared for Newcastle, Hunter, Barwon, SA, Perth Hills and ACT.

ACT has lower prevalence rates, with male rates peaking at less than 3.5% and female rates at around 1%.

Rates for Perth Hills are also lower, with male rates peaking at around 4% and female rates at around 1%.

In other sites, male rates generally peak at around 5% to 6% and female rates at around 1% to 2%.

Rates generally increase to a peak at around age 8 to 11 before declining, except in ACT and Perth Hills. The trend for ACT is flatter between ages 8 and 14 while rates for Perth Hills males continue to increase to age 13.

## Slide 22: NDIS participants with ASD by gender

This slide contains a graph showing the gender distribution at 31 December 2018, for participants with an approved plan, comparing Autism with other disabilities. Autism has a higher percentage of males, at 76%, than any other disability type.

## Slide 23: Ratio of Male to Female prevalence rates

This slide contains a graph showing the ASD prevalence rates for age groups 0 to 6 and 7 to 14 for the SDAC 2015, and NDIS trial sites Newcastle, Hunter, Barwon, SA, Perth Hills and ACT.

Ratios are lower for Barwon than for the other trial sites.

Ratios tend to be higher for the 7 to 14 age group compared to the 0 to 6 group (unlike SDAC 2015).

## Slide 24: Increases in prevalence rates over the period from 31 March to 31 December 2018

This slide contains a table showing the increases in the prevalence rates across Newcastle, Hunter, Barwon, Perth Hills and ACT between 31 March 2018 and 31 December 2018.

Increases of 5% (Barwon) to 22% (Perth Hills) have been observed between 31 March 2018 and 31 December 2018.

Higher percentage increases have been observed for females and for older age groups (but off a lower base).

## Slide 25: NDIS participants with ASD – trends over time and comparisons with other disabilities

The following section presents trends over time and comparisons with other disabilities for NDIS participants with ASD.

## Slide 26: Access met (cumulative) by quarter for participants with ASD

This slide contains three charts.

The first chart shows the numbers of access met participants with ASD by Quarter and by State. It shows that VIC, QLD and WA account for a growing % of participants with ASD.

The second chart shows the numbers of access met participants with ASD by Quarter and by age group. It shows that the distributions by age group have remained stable over the most recent six quarters.

The third chart shows the numbers of access met participants with ASD by Quarter and by access decision reason. It shows that the percentage entering due to disability has grown from 68% to 73% over the most recent six quarters.

## Slide 27: Access met (cumulative) by quarter for participants with ASD as a proportion of all participants

This slide contains three charts.

The first chart shows access met participants with ASD as a proportion of all participants by Quarter and by State and Territory. The percent of participants with ASD varies by state and has been increasing in every state except for SA and TAS where children phased early.

The second chart shows the number of access met participants with ASD as a proportion of all participants by Quarter and by age group. The proportion of participants with ASD has increased for age groups 7 to 14 and above over the most recent six quarters.

The third chart shows access met participants with ASD as a proportion of all participants by Quarter and by access decision reason. The proportion of participants entering due to disability that have ASD has grown from 23% to 25% over the most recent six quarters.

## Slide 28: Growth in access met by quarter: ASD versus other disabilities

This slide contains a chart showing the growth in access met for participants with ASD compared to other disabilities, by quarter, across all ages.

Overall growth rates are slightly higher for participants with ASD than other disabilities in recent quarters.

However, overall growth rates mask differences between ASD and other disabilities due to different age distributions between the two disability groups.

For age groups 7 to 44, quarterly growth rates are higher for ASD than for other disabilities, as shown on the following slides.

## Slide 29: Growth in access met by quarter and age: ASD versus other disabilities

This slide contains four charts, showing the growth in access met for participants with ASD compared to other disabilities, by quarter, by four age groups. The age groups are 0 to 6 years old, 7 to 14 years old, 15 to 18 years and 19 to 24 years old.

The commentary for these graphs was presented in slide 28.

## Slide 30: Growth in access met by quarter and age: ASD versus other disabilities

This slide contains four charts, showing the growth in access met for participants with ASD compared to other disabilities, by quarter, by four age groups. The age groups are 25 to 34 years old, 35 to 44 years old, 45 to 54 years and 55 to 64 years old.

The commentary for these graphs was presented in slide 28.

## Slide 31: Ineligibility rates by half-year: ASD versus other disabilities

Note: Ineligibility rates are defined as “Access not met” decisions as a percentage of all decisions.

This slide contains a chart showing ineligibility rates by half years, for participants with ASD and for participants with all other disability types.

For Q3-4 2017-18 and Q1-2 2018-19, overall ineligibility rates for participants with disabilities other than ASD were around 2.5 times those for participants with ASD (28% for other disabilities combined compared to 11-12% for participants with ASD).

Ineligibility rates have increased in recent quarters across all disabilities as the number of participants transferring from the existing system has decreases.

Ineligibility rates were higher for all age groups, as shown on the following slides.

## Slide 32: Ineligibility rates by half-year and age: ASD versus other disabilities

Note: Ineligibility rates are defined as “Access not met” decisions as a percentage of all decisions.

This slide contains four charts comparing ineligibility rates by half years, for participants with ASD and for participants with all other disability types. Each graph is for a different age group; 0 to 6, 7 to 14, 15 to 18 and 19 to 24.

Ineligibility rates were higher for all age groups, for other disabilities compared to ASD.

## Slide 33: Ineligibility rates by half-year and age: ASD versus other disabilities

Note: Ineligibility rates are defined as “Access not met” decisions as a percentage of all decisions.

This slide contains four charts comparing ineligibility rates by half years, for participants with ASD and for participants with all other disability types. Each graph is for a different age group; 25 to 34, 35 to 44, 45 to 54 and 55 to 64.

Ineligibility rates were higher for all age groups, for other disabilities compared to ASD.

## Slide 34: Approved plans (cumulative) by quarter for participants with ASD

This slide contains three charts.

The first chart shows the numbers of approved plans for participants with ASD by Quarter and by State. It shows that VIC, QLD and WA account for a growing % of participants with ASD.

The second chart shows the numbers of approved plans for participants with ASD by Quarter and by age group. It shows that the distributions by age group have remained stable over the most recent six quarters.

The third chart shows the numbers of approved plans for participants with ASD by Quarter and by access decision reason. It shows that the percentage entering due to disability has grown from 64% to 71% over the most recent six quarters.

## Slide 35: Approved plans (cumulative) by quarter for participants with ASD as a proportion of all participants

This slide contains three charts.

The first chart shows the number of approved plans for participants with ASD by Quarter and by State. The percent of participants with ASD varies by state and has been increasing in every state except for SA and TAS where children phased early.

The second chart shows the numbers of approved plans for participants with ASD by Quarter and by age group. It shows that the distributions by age group have remained stable over the most recent six quarters.

The third chart shows the numbers of approved plans for participants with ASD by Quarter and by access decision reason. The proportion of participants entering due to disability that have ASD has grown from 23% to 25% over the most recent six quarters

## Slide 36: Growth in approved plans by quarter ASD versus other disabilities

This slide contains a chart showing growth in approved plans by quarter, for participants with ASD compared with other disabilities.

As for access met, differences in plan approval growth rates between ASD and other disabilities occur by age group, but are less apparent overall.

Also similar to access, for age groups 7 to 44, quarterly growth rates are higher for ASD than for other disabilities, as shown on the following slides.

## Slide 37: Growth in approved plans by quarter and age ASD versus other disabilities

This slide contains four charts comparing ineligibility rates by quarter, for participants with ASD and for participants with other disability types. Each graph is for a different age group: 0 to 6, 7 to 14, 15 to 18 and 19 to 24.

These graphs show that, by and large, quarterly growth rates are higher for ASD than for other disabilities.

## Slide 38: Growth in approved plans by quarter and age ASD versus other disabilities

This slide contains four charts comparing ineligibility rates by quarter, for participants with ASD and for participants with other disability types. Each graph is for a different age group: 25 to 34, 35 to 44, 45 to 54 and 54 to 64.

These graphs show that quarterly growth rates are generally higher for ASD than for other disabilities for age groups 25 to 44 but on a par for older ages.

## Slide 39: Average committed supports by quarter for participants with ASD

This slide contains two charts.

The first chart shows average committed supports by quarter and by state. Average committed supports for NT have declined over recent quarters. This is reflective of the phasing pattern where clients of Supported Accommodation services phased in earlier than other existing participants.

Slight increases have occurred for SA and TAS in the last three quarters.

The second chart shows average committed supports by quarter and by age group. Increases have been observed for the 65 and over age groups, but the number of plans is relatively small.

## Slide 40: Average committed supports by quarter, ASD versus other disabilities

This slide displays a chart showing average committed supports by quarter for participants with ASD compared with other disability types.

Overall, average committed supports are around twice as high for the group of other disabilities compared to ASD, largely due to the younger age for ASD.

However, the relationship differs considerably by age group, as shown on the following slides:

Firstly, for the 0 to 6 age group, averages are similar for ASD compared to other disabilities.

Secondly, for age groups 7 to 14, 15 to 18, and 19 to 24, the average for ASD is lower than the average for other disabilities.

Thirdly, for older age groups, the average for ASD is higher than the average for other disabilities.

These differences reflect the different mix of disabilities for different age groups.

## Slide 41: Average committed supports by quarter and age: ASD versus other disabilities

This slide contains four charts comparing average committed supports by quarter, for participants with ASD and for participants with other disability types. Each graph is for a different age group: 0 to 6, 7 to 14, 15 to 18 and 19 to 24.

These graphs show that for the 0 to 6 age group, averages are similar for ASD compared to other disabilities and for the age groups 7 to 14, 15 to 18, and 19 to 24 the average for ASD is lower than the average for other disabilities.

## Slide 42: Average committed supports by quarter and age: ASD versus other disabilities

This slide contains four charts comparing average committed supports by quarter, for participants with ASD and for participants with other disability types. Each graph is for a different age group: 25 to 34, 35 to 44, 45 to 54 and 55 to 64.

For older age groups, the average for ASD is higher than the average for other disabilities.

## Slide 43: Utilisation by quarter and age group: ASD versus other disabilities

This slide contains two charts.

The first chart shows plan utilisation rates for participants with ASD by age group and by quarter. The second chart shows plan utilisation rates for participants with other disability types by age group and by quarter.

A gradual increase in utilisation has been observed for the three youngest age groups.

Considering all age groups combined, utilisation has been similar between participants with ASD (63-68% over the five quarters to Sep-18) and other participants (64-66%). However, there are differences by age:

Firstly, utilisation is higher for ASD participants compared to other participants for age groups 0 to 6, and from age 19 onward, with the gap tending to widen for older ages.

Secondly, utilisation is very similar for ASD and other participants for age groups 7 to 14 and 15 to 18.

## Slide 44: Utilisation by quarter and State/Territory: ASD versus other disabilities

This slide contains two charts.

The first chart shows plan utilisation rates for participants with ASD by state and territory and by quarter. The second chart shows plan utilisation rates for participants with other disability types by state and territory and by quarter.

Increases have been observed for NT, and to a lesser extent, NSW and QLD.

Utilisation has been higher for participants with ASD in NT and ACT, but similar in other States and Territories.

## Slide 45: ASD as a secondary disability

This slide contains a chart showing the distribution of primary disability types for participants with their secondary disability as ASD.

10,168, or about 5% of participants currently in the Scheme, have Autism as a secondary disability.

Around two-thirds of these participants have intellectual disability as their primary disability. 6% have a primary psychosocial disability, 5% have Down syndrome, and 5% have cerebral palsy.

## Slide 46: Secondary disabilities for NDIS participants with a primary disability of ASD

This slide contains a chart showing the distribution of secondary disability types for participants with their primary disability as ASD.

24,193, or about 36% of participants who have Autism as a primary disability, have at least one secondary disability.

The most common secondary disabilities are intellectual disability (15%), psychosocial disability (11%), other sensory or speech disability (7%) and other neurological disability (5%).

## Slide 47: Length of time in scheme by access decision reason: ASD versus other disabilities

This slide contains two charts showing the distribution of length of time spent in the scheme for participants with ASD vs other disabilities. One graph is for participants who entered the scheme due to Early Intervention (s25), the other graph is for participants who entered the scheme due to Disability Met (s24).

Early intervention participants with ASD tend to have been in the scheme for longer than participants with other disabilities.

The distributions of time in scheme are more similar for disability met participants.

## Slide 48: NDIS participants with ASD who received support from HCWA/Better Start – trend

Note: As at 31 December 2018, 98.7% of the “HCWA and Better Start” category is HCWA, 1.1% is Better Start, and 0.2% is both.

Note: Data on HCWA/Better Start are current as at 31 December 2018.

This slide contains two charts.

The first chart shows the number of participants with ASD who receive support from HCWA/Better Start for access met participants, by quarter. As at 31 December 2018, 19,278 participants with ASD (24%) had received HCWA (and/or Better Start).

The second chart shows the number of participants with ASD who receive support from HCWA/Better Start for participants with a plan approved, by quarter. As at 31 December 2018, 15,644 participants with ASD who had an approved plan (23%) had received HCWA (and/or Better Start).

## Slide 49: NDIS participants with ASD who received support from HCWA/Better Start – by age

Note: As at 31 December 2018, 98.7% of the “HCWA and Better Start” category is HCWA, 1.1% is Better Start, and 0.2% is both.

Note: Data on HCWA/Better Start are current as at 31 December 2018.

This slide contains two charts.

The first chart shows the number of participants with ASD who receive support from HCWA/Better Start for access met participants, by age group. As at 31 December 2018: 49%, 60%, and 10% of participants with ASD aged 0 to 6, 7 to 9, and 10 to 12, respectively, had received HCWA (and/or Better Start).

The second chart shows the number of participants with ASD who receive support from HCWA/Better Start for participants with a plan approved, by age group. As at 31 December 2018: 46%, 59%, and 10% of participants with ASD aged 0 to 6, 7 to 9, and 10 to 12, respectively, had received HCWA (and/or Better Start).

## Slide 50: Methodology for analysing outcomes

This next section is on methodology for analysing outcomes.

## Slide 51: Methodology roadmap

### Baseline outcomes:

Measure how participants are going at their point of entry into the NDIS.

### Longitudinal outcomes:

Describe how outcomes have changed for participants during the time they have been in the Scheme.

### Has the NDIS helped?

The outcomes framework includes a question at the end of each domain asking whether the participant thinks that the NDIS has helped in areas related to that domain.

For each of the above, the analysis of outcomes looks at the 0 to before school, school to age 14, ages 15 to 24, and ages 25 and over groups separately, and focuses on indicators specific to each life stage.

## Slide 52: Participants from birth to before starting school

This next section focuses on outcomes for participants from birth to before starting school age.

## Slide 53: Participants from 0 to before starting school: Key indicators at baseline

This slide contains a chart summarising answers to the Outcomes questionnaire for participants at baseline, separately for participants with ASD and participants with other disabilities.

Baseline key indicators tend to be worse for participants with ASD compared to participants with other disabilities (considered as a group). The exception is the percentage of parents/carers who say their child is able to tell them what he/she wants, which is similar for participants with ASD and other disabilities.

Multiple regression modelling confirms that children with autism are more likely than most other disability groups to experience difficulties in six or more areas of development and are less likely to be able to make friends, to participate in community activities, and to feel welcomed or included when participating.

## Slide 54: Participants from 0 to before starting school: concerns in major developmental areas

The first domain of the SF investigates whether pre-school children are gaining functional, developmental and coping skills appropriate to their ability and circumstances.

The first question asks if the parent/carer has any concerns about their child’s development in the areas: Gross motor skills, Fine motor skills, Self-care, Eating/Feeding, Social interaction, Language/Communication, Cognitive development, Sensory processing.

## Slide 55: Participants from 0 to before starting school: concerns in major developmental areas at baseline

This slide contains two charts. The first chart shows the proportion of parents and carers who have any concerns about their child’s development in the following areas: Gross motor skills, Fine motor skills, Self-care, Eating/Feeding, Social interaction, Language/Communication, Cognitive development, Sensory processing. The proportions are reported separately for children with autism and with other disabilities.

The second chart summarises the number of concerns each parent/carer has, separately for children with Autism and with other disabilities.

Parents/carers of participants with ASD are more likely to have concerns in each of the eight areas surveyed except for gross motor skills. The largest differences between parents/carers of children with autism and parents/carers of children with other disabilities occur for sensory processing (93% versus 71%) and social interaction (96% versus 81%).

Parents/carers of participants with ASD have concerns in more areas: 77% have concerns in six or more areas compared to 60% for other disabilities combined.

## Slide 56: Participants from 0 to before starting school: concerns about sensory processing at baseline

Results on the previous slide do not control for differences between participants with ASD and participants with other disabilities, such as differences by age, gender, level of function, CALD and Indigenous status.

Multiple regression models can be used to control for other factors apart from whether the participant has ASD or another disability.

For example, in a model for the probability of having concerns about sensory processing at baseline, the probability: increases with participant age, increases as participant level of function decreases, is lower for girl participants, is lower for CALD participants, is not significantly different for Indigenous and non-Indigenous participants, remains higher for participants with ASD, after controlling for the above factors.

## Slide 57: Participants from 0 to before starting school: Change in key indicators

Note: at least some of the change may be normal age-related development as children are one year older at review.

This slide contains a chart showing changes in responses to the key indicator questions for participants aged 0 to before starting school, by participants with ASD and participants with other disabilities.

In aggregate, significant improvements were observed for the percentage whose child can tell them what they want, the percentage who can make friends with people outside the family, and the percentage welcomed when they participate in community activities. A significant deterioration (increase) was observed in the percentage with concerns in six or more areas.

Based on a simple comparison of change, differences between participants with ASD and other disabilities are generally slight, although the improvement in the percentage welcomed when they participate in community activities is greater for participants with ASD.

## Slide 58: Participants from 0 to before starting school: % with concerns in six or more areas

Based on a multiple logistic regression model for deterioration in the percentage with concerns in six or more areas (for the subset who did not have concerns in six or more areas at baseline):

Deterioration was more likely for participants with ASD, as well as those with global developmental delay. Deterioration was less likely for those with a hearing impairment.

Deterioration was also more likely for those with lower level of function.

A number of other factors, including age, geography, plan cost and utilisation, as well as the child’s ability to make friends and participate in community activities, were also significant predictors in the model.

## Slide 59: Participants from 0 to before starting school: Has the NDIS helped?

This slide contains a chart showing the percentage responding positively to the “Has the NDIS helped?” questions, by participants with ASD and participants with other disabilities.

Participants with ASD show a small but consistent trend to respond more positively than the group of participants with other disabilities.

## Slide 60: Participants from starting school to age 14

This next section focuses on outcomes for participants from school age to 14.

## Slide 61: Participants from starting school to age 14: Key indicators at baseline

This slide contains a chart showing the responses to the key indicator questions at baseline, by participants with ASD and participants with other disabilities.

Participants with ASD tend to do worse on most baseline indicators than participants with other disabilities.

In particular, participants with ASD are less likely to be able to make friends with people outside the family, and are less likely to be welcomed or actively included when they spend time with friends or in community activities.

However, children with ASD are more likely to attend school in a mainstream class.

## Slide 62: Participants from starting school to age 14: school experiences at baseline

The short form asks parents and carers whether they think their child is happy at school, and the long form asks whether they think their child is genuinely included at school.

Multiple regression models revealed that children with ASD were the least likely to feel happy at school; and children with ASD were the least likely to feel genuinely included at school.

## Slide 63: School experiences of children with ASD: SDAC 2015

This slide contains a chart summarising school experiences of children with ASD in Australia.

Note: This information was sourced from AIHW analysis of ABS SDAC 2015 data, at the weblink: <https://www.aihw.gov.au/reports/disability/autism-in-australia/contents/autism>

From SDAC 2015, 83,700 children and young people (aged 5–20) with ASD and disability were estimated to be living in households and attending school.

28% attended a special school, compared to 21% of school age to 14 NDIS participants with ASD (and 28% of participants with other disabilities).

85% reported difficulty at school, with the five most common types of difficulty shown in the graph. Fitting in socially (63%) and learning difficulties (62%) were the most common.

## Slide 64: Participants from starting school to age 14: Change in key indicators

This slide contains a chart summarising the changes in the key indicators, by participants with ASD and participants with other disabilities.

In aggregate, changes were less positive than for the youngest children. However the changes observed tended to be slightly more positive (or less negative) for participants with ASD compared to the group of participants with other disabilities. This is particularly the case for the percentage who say their child is becoming more independent, and the percentage welcomed or actively included when they spend time with friends or in community activities.

## Slide 65: Participants from starting school to age 14: Has the NDIS helped?

This slide contains a chart summarising the responses to the “Has the NDIS helped?” questions for participants school age to 14, by participants with ASD and participants with other disabilities.

Participants with ASD respond slightly more positively than the group of participants with other disabilities, except for the education domain where results are similar.

## Slide 66: Participants aged 15 to 24

This next section focuses on outcomes for participants aged 15 to 24.

## Slide 67: Participants aged 15 to 24: Key indicators at baseline

This slide contains a chart summarising the responses to the key indicator questions for participants aged 15 to 24, by participants with ASD and participants with other disabilities.

In multiple regression models, participants with ASD are less likely to choose who supports them, and more likely to have no friends other than family or paid staff.

Participants with ASD are more likely to currently attend or to have previously attended school in a mainstream class. They are also slightly more likely to be happy with their home and to rate their health as good, very good or excellent.

## Slide 68: Participants aged 15 to 24: Change in key indicators

This slide contains a chart summarising the changes in responses to the key indicator questions for participants aged 15 to 24, by participants with ASD and participants with other disabilities.

In one-way analyses, there has been a bigger deterioration in the percentage with no friends other than family or paid staff for participants with ASD. This is confirmed by a multiple regression model for the subset with no friends other than family or paid staff at baseline, modelling the probability of improvement one year later.

However, participants with autism are more likely to improve in relation to feeling safe in their home.

## Slide 69: Participants aged 15 to 24: Has the NDIS helped?

This slide contains a chart summarising the responses to the “Has the NDIS helped?” questions, by participants with ASD and participants with other disabilities.

For the 15 to 24 cohort, there is very little difference between responses for participants with ASD and responses for the group of participants with other disabilities.

## Slide 70: Participants aged 25 and over

This next section focuses on outcomes for participants aged 25 and over.

## Slide 71: Participants aged 25 and over: Key indicators at baseline

This slide contains a chart summarising responses to the key indicators, by participants with ASD and participants with other disabilities.

Participants with ASD are much less likely to choose who supports them, and to choose what they do each day. They are also more likely to have no friends other than family or paid staff.

Participants with ASD are slightly more likely to be happy with their home and to feel safe there, and more likely to rate their health as good, very good or excellent.

## Slide 72: Participants aged 25 and over: Change in key indicators

This slide contains a chart summarising the changes in responses to the key indicators, by participants with ASD and participants with other disabilities.

There has been a bigger deterioration in the percentage with no friends other than family or paid staff for participants with ASD compared to other disabilities.

Participants with ASD have also fared worse on the two choice and control indicators: choosing who supports them and choosing what they do each day.

Participants with autism are more likely to improve in relation to feeling safe in their home.

## Slide 73: Participants aged 25 and over: Has the NDIS helped?

This slide contains a chart summarising responses to the “Has the NDIS helped questions?”, by participants with ASD and participants with other disabilities.

Participants with ASD tend to respond slightly more positively for the relationships, home, lifelong learning, work and community participation domains. Responses tend to be similar to other participants for choice and control and daily living, and very slightly worse for health.

## Slide 74: Employment among participants aged 15 and over with ASD: % with a paid job at baseline by disability

This slide contains two charts summarising the percentage of participants with a paid job at baseline, by disability. One chart is for participants aged 15 to 24, and the other is for participants aged 25 and over.

15% of participants with ASD aged 15 to 24 have a paid job, slightly lower than the overall average of 17%.

28% of participants with ASD aged 25 and over have a paid job, slightly higher than the overall average of 25%.

## Slide 75: Employment among participants aged 15 and over with ASD: Type of employment by disability

This slide contains two charts summarising the type of employment at baseline, by disability. One chart is for participants aged 15 to 24, and the other is for participants aged 25 and over.

Participants aged 15 to 24 with ASD have the third lowest percentage in open employment at full award wages compared to other disabilities (44% compared to 41% overall).

Participants aged 25 and over with ASD have the third lowest percentage in open employment at full award wages compared to other disabilities (16% compared to 33% overall).

## Slide 76: Employment among participants aged 15 and over with ASD: Employment goals by disability (jobseekers)

This slide contains two charts summarising the percentage of participants with a work goal in their plan, by disability. One chart is for participants aged 15 to 24, and the other is for participants aged 25 and over.

62% of participants aged 15 to 24 with ASD who don’t have a paid job but would like one have a work goal in their plan, higher than most other disabilities and equal to the overall average.

56% of participants aged 25 and over with ASD who don’t have a paid job but would like one have a work goal in their plan, higher than most other disabilities and above the overall average of 52%.

## Slide 77: Employment among participants aged 15 and over: % receiving the DSP by disability

This slide contains a chart summarising the percentage of participants receiving the disability support pension, by disability.

Preliminary data linkage results suggest 67% of participants with ASD are receiving the Disability Support Pension (DSP). This is lower than the overall average of 77%, however this may partly reflect the younger age distribution for ASD participants.

## Slide 78: Employment experiences of 15 to 64 year olds with ASD: SDAC 2015

Note: This information was sourced from AIHW analysis of ABS SDAC 2015 data, at the weblink: <https://www.aihw.gov.au/reports/disability/autism-in-australia/contents/autism>

This slide contains a chart summarising the proportion of persons aged 15 to 64 years with ASD facing five most common employment restrictions; namely, the proportion of those who have difficulty changing jobs or getting a preferred job (50%), who are restricted in type of job (47%), who need ongoing supervision or assistance (30%), who are restricted in the number of hours (29%), and who are permanently unable to work because of the condition(s) (29%).

From SDAC 2015, 29% of people aged 15 to 64 with ASD were permanently unable to work due to their condition or disability.

Difficulty changing jobs or getting a preferred job was the most common employment restriction, experienced by 50%.

## Slide 79: NDIS website [www.ndis.gov.au](http://www.ndis.gov.au)