# Disability Dashboard Transcript for Down syndrome

## Insight

This section contains key information about the NDIS participants with Down syndrome in the form of simple charts and commentaries using data as at 30 September 2022:

* A doughnut chart shows that of the 554,917 active participants in the NDIS, 2% (or 11,574) of them have a primary disability of Down syndrome.
* The next doughnut chart shows that 64% (or 7,421) of participants with Down syndrome are aged under 35 years.
* The next doughnut chart shows that 54% (or 6,276) of participants with Down syndrome are male.
* The next doughnut chart shows that 26% (or 2,054) of participants aged 18 years and over with Down syndrome are in supported independent living (SIL). (Supported Independent Living (SIL) is help with and/or supervision of daily tasks to develop the skills of an individual to live as independently as possible).
* A bar chart shows that 95% of access decisions for applicants with Down syndrome resulted in the applicant joining the Scheme in the September 2022 quarter, compared to 77% of access decisions for all applicants.
* The next bar chart shows that NDIS provided $331 million of paid supports to participants with Down syndrome in the September 2022 quarter, compared to $266 million in the September 2021 quarter, representing a year-on-year increase of 17%.
* The next bar chart shows that the average payment for the 12 months to 30 September 2022 for a participant with Down syndrome was $100,400, which is a 9% increase compared to the previous year.
* The next bar chart shows that 81% of participants with Down syndrome aged 15 and over said the NDIS has helped them have more choice and control at their most recent plan reassessment, which is a 10 percentage point increase from their first reassessment at 71%. (The Participant Outcome section compares baseline results when participants entered the Scheme, with results measured at the most recent participant plan reassessment for each respondent. Results are for participants who have been in the Scheme for at least two years and NDIS trial participants are excluded. All outcome results are rounded to the nearest percentage but the percentage point increases or decreases are calculated based on the unrounded results).
* The next bar chart shows that 65% of participants aged 15 and over with Down syndrome said they were actively involved in a community, cultural or religious group in the last 12 months, which is a 15 percentage point increase compared to baseline at 51%. (The Participant Outcome section compares baseline results when participants entered the Scheme, with results measured at the most recent participant plan reassessment for each respondent. Results are for participants who have been in the Scheme for at least two years and NDIS trial participants are excluded. All outcome results are rounded to the nearest percentage but the percentage point increases or decreases are calculated based on the unrounded results).
* The weighted average satisfaction rate for participants with Down syndrome over the 4 stages of Scheme pathway was 71% in the September 2022 quarter.

## Section 1: Participants

**Overview**

Of the 11,574 active participants with a primary disability of Down syndrome at 30 September 2022:

* A doughnut chart shows that 54% (or 6,276) were male, compared to 61% (or 341,220) for all participants
* Another doughnut chart shows that 3% (or 402) identified themselves as First Nations people, compared to 7% (or 40,842) for all participants
* Another doughnut chart shows that 8% (or 877) identified as Culturally and Linguistically Diverse (CALD) compared to 9% (or 50,968) for all participants.

In the twelve months to 30 September 2022:

* A bar chart shows that the number of active participants with Down syndrome has remained at a similar level from 11,466 to 11,574
* Another bar chart shows that the number of participants with Down syndrome who identify as First Nations people has increased from 392 to 402, an increase of 3%
* Another bar chart shows that the number of participants with Down syndrome who identify as CALD has increased from 829 to 877, an increase of 6%.

**Access**

In the quarter to 30 September 2022:

* A doughnut chart shows that 95% of access decisions for applicants with Down syndrome resulted in the applicant joining the Scheme, compared to 77% of access decisions for all applicants
* Another doughnut chart shows that 74 access decisions have been made in the quarter for applicants with Down syndrome, of which 70 participants met access and are still active.

The following section contains 5 charts comparing different demographic make-up of participants with Down syndrome and the make-up of the overall Scheme.

**State/Territory**

Distribution of active participants by State/Territory

A chart represents the percentage of active participants with Down syndrome residing in each State/Territory, and compares that to the distribution of all participants in the Scheme.

At 30 September 2022, the percentage of participants with Down syndrome who resided in:

* NSW was 33%, compared to 30% for all participants
* VIC was 24%, compared to 27% for all participants
* QLD was 21%, compared to 21% for all participants
* WA was 9%, compared to 9% for all participants
* SA was 7%, compared to 9% for all participants
* TAS was 3%, compared to 2% for all participants
* NT was 1%, compared to 1% for all participants
* ACT was 2%, compared to 2% for all participants

**Age Band**

Distribution of active participants by age band

A chart represents the percentage of active participants with Down syndrome by age band, and compares that to the distribution of all participants in the Scheme.

At 30 September 2022, the percentage of participants with Down syndrome who were in the age band:

* 0 to 6 was 10%, compared to 16% for all participants
* 7 to 14 was 15%, compared to 26% for all participants
* 15 to 18 was 7%, compared to 8% for all participants
* 19 to 24 was 12%, compared to 8% for all participants
* 25 to 34 was 20%, compared to 9% for all participants
* 35 to 44 was 16%, compared to 8% for all participants
* 45 to 54 was 12%, compared to 9% for all participants
* 55 to 64 was 7%, compared to 11% for all participants
* 65 and over was 1%, compared to 4% for all participants

Commentary in the text box: The majority of the participants with Down syndrome are aged 25 to 34 years (20%) and 35 to 44 years (16%).

**Reported Level of Function**

Distribution of active participants by reported level of function

A chart represents the percentage of active participants with Down syndrome by reported level of function, and compares that to the distribution of all participants in the Scheme.

At 30 September 2022, the percentage of participants with Down syndrome who had:

* a reported level of function of “High” was 13%, compared to 29% for all participants
* a reported level of function of “Medium” was 38%, compared to 46% for all participants
* a reported level of function of “Low” was 48%, compared to 25% for all participants

Commentary in the text box: The majority of the participants with Down syndrome have a low reported level of function (48%).

**Remoteness**

Distribution of active participants by remoteness

A chart represents the distribution of active participants with Down syndrome by remoteness, and compares that to the distribution of all participants in the Scheme.

At 30 September 2022, the percentage of participants with Down syndrome who resided in:

* Major cities was 66%, compared to 68% for all participants
* Population greater than 50,000 was 11%, compared to 11% for all participants
* Population of 15,000 to 50,000 was 10%, compared to 8% for all participants
* Population of 5,000 to 15,000 was 5%, compared to 5% for all participants
* Population less than 5,000 was 7%, compared to 6% for all participants
* Remote was 1%, compared to 1% for all participants
* Very Remote was 0%, compared to 1% for all participants.

**SEIFA score (using Index of Education and Occupation)**

Distribution of active participants by SEIFA score. (The Australian Bureau of Statistics SEIFA Index of Education and Occupation (IEO) is used by NDIA to classify participants into socio-economic deciles, with decile one representing participants in the lowest socio-economic decile, and decile ten representing participants in the highest socio-economic decile. SEIFA deciles are allocated based on the Statistical Area 1 (SA1) that a participant lives in).

A chart represents the percentage of active participants with Down syndrome by SEIFA score, and compares that to the distribution of all participants in the Scheme. Socio-Economic Indexes for Areas (SEIFA) is a product developed by the ABS that ranks areas in Australia according to relative socio-economic advantage and disadvantage.

At 30 September 2022, the percentage of participants with Down syndrome who reside in areas with:

* SEIFA scores of 1 was 11%, compared to 14% for all participants
* SEIFA scores of 2 was 11%, compared to 12% for all participants
* SEIFA scores of 3 was 11%, compared to 12% for all participants
* SEIFA scores of 4 was 11%, compared to 11% for all participants
* SEIFA scores of 5 was 11%, compared to 10% for all participants
* SEIFA scores of 6 was 11%, compared to 10% for all participants
* SEIFA scores of 7 was 10%, compared to 9% for all participants
* SEIFA scores of 8 was 9%, compared to 8% for all participants
* SEIFA scores of 9 was 8%, compared to 7% for all participants
* SEIFA scores of 10 was 6%, compared to 5% for all participants

Commentary in the text box: There is a greater proportion of participants with Down syndrome who reside in areas with a mid-to-low socioeconomic score.

## Section 2: Payments

In the September 2022 Quarter, the NDIS provided $311 million of paid supports to participants with Down syndrome.

In the same quarter last year, $266 million of paid supports were provided to participants with Down syndrome.

* This is an increase of 17%.

The average payment per participant with Down syndrome was $100,400 for the 12 months ending 30 Sep 2022. This was $92,500 for the 12 months ending 30 Sep 2021. (Average payments per participant are calculated using a 12 month period prior to the reporting date).

* This represents a year-on-year increase of 9%.

Participants in SIL comprise 26% of all participants with Down syndrome who were aged 18 and over, and their payments comprise 54% of supports paid to participants with Down syndrome aged 18 and over in this quarter. (Supported Independent Living (SIL) is help with and/or supervision of daily tasks to develop the skills of an individual to live as independently as possible.)

* A year ago, participants with SIL represented 26% of participants with Down syndrome who were aged 18 and over, and their payments were 56% of supports paid to participants with Down syndrome aged 18 and over in that quarter.

A table shows the average payments for the same group of participants with Down syndrome and compares that between this year and last year. (Average payments per participant are calculated using a 12 month period prior to the reporting date). (The average payment for the same group of participants is compared across two different time periods (12 months ending September 2022 vs 12 months ending September 2021). Participants who had an initial plan approved after 30 September 2021 are not included.)

For participants aged under 18 years, the average payments this year was $35,800, compared to last year at $34,100, representing an increase of 5%.

For participants aged 18 years and over not in SIL, the average payments for this year was $80,200, compared to last year at $71,800, representing an increase of 12%.

For participants aged 18 years and over in SIL, the average payments for this year was $280,700, compared to last year at $266,000, representing an increase of 6%.

At an overall level for participants with Down syndrome, the average payments for this year was $101,300, compared to last year at $92,500, representing an increase of 10%.

## Section 3: Participant Outcomes and Satisfaction

The outcome results at 30 September 2022 compare baseline results to latest results for participants with Down syndrome who have been in the Scheme for at least two years. (The Participant Outcome section compares baseline results when participants entered the Scheme or at their first reassessment, with results measured at the most recent participant plan reassessment for each respondent. Results are for participants who have been in the Scheme for at least two years and NDIS trial participants are excluded).

### Outcome: Social and Community Participation

For participants aged 15 years and over with Down syndrome, 65% said at their latest reassessment that they were actively involved in a community, cultural or religious group in the last 12 months. This compares to 43% for the Scheme as a whole.

Comparing responses at the most recent plan reassessment (between two to six years after entry) with responses at Scheme entry, there has been a:

* 15 percentage point increase from 51% to 65% for participants aged 15 years and over
* 14 percentage point increase from 52% to 66% for participants aged 25 years and over.

A chart shows that:

* for participants aged 15 to 24 years there was a 16 percentage point increase from 45% to 61%
* for participants aged 25 to 34 years there was a 15 percentage point increase from 54% to 68%
* for participants aged 35 to 44 years there was a 14 percentage point increase from 52% to 67%
* for participants aged 45 to 54 years there was a 15 percentage point increase from 52% to 67%
* for participants aged 55 to 64 years there was a 10 percentage point increase from 50% to 59%
* for participants aged 65 and over there was a 20 percentage point increase from 48% to 68%.

### Outcome: Participant Employment

For participants aged 15 to 64 years with Down syndrome, 26% reported that they had a paid job at their latest reassessment. This compares to 23% for the Scheme as a whole.

Comparing responses at the most recent plan reassessment (between two to six years after entry) with responses at Scheme entry, there has been a:

* 2 percentage point decrease from 28% to 26% for participants aged 15 to 64 years
* 5 percentage point decrease from 34% to 29% for participants aged 25 to 64 years.

A bar chart shows that:

* for participants aged 15 to 24 years there was a 9 percentage point increase from 7% to 17%
* for participants aged 25 to 34 years there was no material increase from baseline at 33%
* for participants aged 35 to 44 years there was a 4 percentage point decrease from 37% to 33%
* for participants aged 45 to 54 years there was a 10 percentage point decrease from 36% to 26%
* for participants aged 55 to 64 years there was a 11 percentage point decrease from 23% to 12%.

### Outcome: Family & Carer Employment

Family/carers of participants with Down syndrome reported an employment rate of 46%, which is lower than the Scheme average family/carers employment rate of 50%.

Comparing responses at the most recent plan reassessment (between two to six years after entry) with responses at Scheme entry, there has been a:

* 6 percentage point increase from 40% to 46% for participants aged 0 to 14 years
* 1 percentage point decrease from 47% to 46% for participants aged 15 years and over
* 3 percentage point increase from 44% to 46% for participants across all ages.

### Outcome: Choice & Control

At 30 September 2022, 81% of participants with Down syndrome aged 15 years and over said the NDIS has helped them have more choice and control over their life.

* This is higher than the Scheme average rate at 76%.

Comparing responses at the most recent plan reassessment (between two to six years after entry) with responses at their first plan reassessment, there has been a:

* 10 percentage point increase from 71% to 81% for participants aged 15 years and over
* 10 percentage point increase from 72% to 83% for participants aged 25 years and over.

A chart shows that:

* for participants aged 15 to 24 years there was a 9 percentage point increase from 67% to 76%
* for participants aged 25 to 34 years there was a 11 percentage point increase from 72% to 83%
* for participants aged 35 to 44 years there was a 9 percentage point increase from 75% to 84%
* for participants aged 45 to 54 years there was a 12 percentage point increase from 70% to 81%
* for participants aged 55 to 64 years there was a 9 percentage point increase from 70% to 80%
* for participants aged 65 years and over there was a 14 percentage point increase from 70% to 84%.

### Outcome: For children aged 0 to before starting school:

* 96% of parents and carers for children with Down syndrome thought the NDIS improved their child's development at their most recent plan reassessment, compared to 92% at their first reassessment. This is a 3 percentage point increase from the first reassessment.
* 96% of parents and carers for children with Down syndrome thought the NDIS improved their child's access to specialist services at their latest plan reassessment, compared to 91% at their first reassessment. This is a 5 percentage point increase from the first reassessment.

### Outcome: For children starting school to 14 years:

* 72% of parents and carers for children with Down syndrome felt their child had become more independent as a result of the NDIS at their most recent plan reassessment, compared to 58% at their first reassessment. This is a 14 percentage point increase from the first reassessment.
* 60% of parents and carers for children with Down syndrome felt the NDIS has improved their child's relationship with family and friends at their most recent plan reassessment, compared with 48% at their first reassessment. This is an 11 percentage point increase from the first reassessment.

### Education outcomes

This section contains 4 bar charts demonstrating education outcomes and ADE employment outcomes for participants with Down syndrome.

A chart entitled: “Percentage of children starting school to aged 14 that attend school in a mainstream class.”

This chart illustrates the percentage of school children with Down syndrome (up to 14 years of age) who attend school in a mainstream class, and compares their results at their latest plan reassessment and Scheme entry (or baseline).

The percentage of children starting school to aged 14 with Down syndrome that attend school in the mainstream class were:

* 38% at baseline
* 30% at the latest reassessment.

The next chart is entitled: “Percentage of participants who have post-school qualification”.

This chart displays the percentage of participants with Down syndrome who have post-school qualifications and compares the results at their latest plan reassessment and Scheme entry (or baseline).

The percentage of participants with Down syndrome who have post-school qualification were:

* 7% at baseline and 8% at the latest plan reassessment for participants aged 15 to 24 years
* 19% at baseline and 18% at the latest plan reassessment for participants aged 25 years and over.

The next chart is entitled: “Percentage of participants who get opportunities to learn new things”

This chart displays the percentage of participants with Down syndrome who get opportunities to learn new things and compares the results at their latest plan reassessment and Scheme entry (or baseline).

The percentage of participants with Down syndrome who get opportunities to learn new things were:

* 68% at baseline and 74% at the latest plan reassessment for participants aged 15 to 24 years
* 58% at baseline and 65% at the latest plan reassessment for participants aged 25 years and over.

The next chart is entitled: “Percentage of who are working in Australian Disability Enterprise (of those participants who are working in a paid job)”

Of participants with Down syndrome who are working in a paid job, the chart displays the percentage of them working in Australia Disability Enterprise, and compares the results at their latest plan reassessment and Scheme entry (or baseline).

The percentage of participants with Down syndrome who are working in Australian Disability Enterprise are:

* 46% at baseline and 51% at the latest plan reassessment for participants aged 15 to 24 years
* 69% at baseline and 74% at the latest plan reassessment for participants aged 25 years and over.

### Satisfaction

A bar chart that compares the satisfaction responses between participants with Down syndrome and that of all participants in the September 2022 quarter. The percentage of participants with Down syndrome who rated their experience with the NDIS (The NDIA gathers responses at the four primary stages of the participant pathway – access, preplanning, planning and plan reassessment) as good or very good was:

* 100% for the access process, compared to 81% for all participants (Due to small sample size of responses collected from participants with down syndrome this quarter, the satisfaction results shown here are subject to higher volatility than normal.)
* 50% for the pre-planning process, compared to 80% for all participants (Due to small sample size of responses collected from participants with down syndrome this quarter, the satisfaction results shown here are subject to higher volatility than normal.)
* 76% for the planning process, compared to 85% for all participants.
* 70% for the reassessment process, compared to 69% for all participants.

The weighted average satisfaction result for participants with Down syndrome who rated their experience as good or very good over the 4 stages of the pathway was 71% in the quarter of September 2022.

* This was 72% in the September 2021 quarter
* The overall Scheme weighted average satisfaction rate in the September 2022 quarter was 75%.

### Complaints

There were 182 complaints raised by participants with Down syndrome in the September 2022 quarter (or an annualised complaint rate of 6%). (The complaint rate is an annualised rate calculated as the number of complaints in the quarter divided by the active participant exposure in the quarter).

* The annualised complaint rate 12 months ago for participants with Down syndrome was 6%, which is the same as the current quarter
* This compares to an annualised complaint rate of 7% for all participants.

## Section 4: Providers

This section contains information on service providers supporting participants with Down syndrome in the September 2022 Quarter, in the form of doughnut charts:

The first three doughnut charts show an overview of all the providers supporting participants with Down syndrome:

* A doughnut charts shows that 13,706 providers received a payment during the quarter. (The count of providers is by ABN and includes providers supporting agency-managed participants, participants who use a plan manager and self-managed participants. Note that for self-managed payments, the total number of providers is unable to be determined since it is not a requirement for self-managed participants to provide the ABN at the time of payment).
* The next doughnut chart shows that 12% of payments were received by the top 10 providers
* The next doughnut chart shows that 54% of these providers are companies or organisations and 46% are individuals or sole traders.

The second set of three doughnut charts are for providers supporting participants with Down syndrome who used a plan manager:

* A doughnut chart shows that 12,244 providers received a payment during the quarter. (For each plan management type, a single provider is counted if they received a payment in the quarter for that plan management type. Note that a single provider can receive payments across more than one plan management type so may be included in more than one count.)
* The next doughnut chart shows that 34% of the providers were registered and 66% are unregistered. (A registered provider is an approved person or provider of supports who is registered with the NDIS Quality and Safeguard Commission. While a registered provider can provide supports to all participants, an unregistered provider can only provide supports to participants who use a plan manager or who are self-managed.)
* The next doughnut chart shows that $118 million was paid in the September 2022 quarter (This makes up 38% of payments to participants with Down syndrome).

The last set of three doughnut charts are for providers supporting agency-managed participants with Down syndrome:

* A doughnut chart shows that 2,791 providers received a payment during the quarter
* The next doughnut chart shows that 100% of the providers were registered
* The next doughnut chart shows that $157 million was paid in the September 2022 quarter (This makes up 50% of payments to participants with Down syndrome).

For providers supporting self-managed participants with Down syndrome, $36 millionwas paid in the September 2022 quarter (which is 12%of all payments to participants with Down syndrome). At this time, for self-managed payments, the total number of providers and the registration status of providers is unable to be determined since it is not a requirement for self-managed participants to provide the ABN at the time of payment.

## Additional Information

**Key definitions**

Definitions of terms used in this dashboard are consistent with those used in Appendix A of the Quarterly Report to disability ministers (QRDM) published on the NDIS website. However, note that the QRDM groups participants with Down syndrome recorded as their primary disability together with those with intellectual disability.