# Disability Dashboard Transcript for Down Syndrome

## Insights

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 June 2023:

* A doughnut chart shows that of the 610,502 active participants in the NDIS, 2% (or 11,617) of them have a primary disability of Down syndrome.
* The next doughnut chart shows that 64% (or 7,397) of participants with Down syndrome are aged under 35 years.
* The next doughnut chart shows that 54% (or 6,288) of participants with Down syndrome are male.
* The next doughnut chart shows that 27% (or 2,131) of participants with Down syndrome aged 18 years and over are in Supported Independent Living (SIL).
* A bar chart shows that, in the year ending 30 June 2023, 99% of access decisions for applicants with Down syndrome aged 18 and under resulted in the applicant joining the Scheme, compared to 81% of access decisions for those aged over 18 years.
* The next bar chart shows that NDIS provided $1.30 billion of paid supports to participants with Down syndrome in the year ending 30 June 2023, compared to $1.11 billion in the year ending 30 June 2022, representing a year-on-year increase of 17%.
* The next bar chart shows that the average payment in the year ending 30 June 2023 for a participant with Down syndrome was $112,600, representing a year-on-year increase of 16% compared to $96,900 in the previous year.
* The next bar chart shows that 81% of participants with Down syndrome aged 15 and over indicated the NDIS had helped to improve their choice and control at their latest plan reassessment, which is an 11 percentage point increase from their first review at 71%. (The Participant Outcome section compares baseline results when participants entered the Scheme or at their first plan 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. 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 65% of participants aged 15 and over with Down syndrome indicated they had engagement in social and community activities, a 14 percentage point increase compared to baseline at 51%.
* The weighted average satisfaction rate for participants with Down syndrome over the 4 stages of Scheme pathway was 69% in the year ending 30 June 2023.

A photo shows a woman holding a young child, each smiling at the other.

Quote: “We are forever grateful for the impact the NDIS has had and continues to have on enriching Adam’s life opportunities.” By the mother of NDIS participant, Adam.

## Section 1: Participants

### Active Participant Trend

The number of participants with Down syndrome has increased by 1% and 1% in the last two years.

A bar chart shows there were 11,617 active participants with a primary disability of Down syndrome at 30 June 2023.

* The number of active participants with Down syndrome was 11,551 at June 2022 and 11,414 at June 2021.
* The number of active participants with Down syndrome has increased by 1% between June 2021 and June 2022 and 1% between June 2022, and June 2023.

### Access

In the year ending 30 June 2023:

A doughnut chart shows that 94% of access decisions for applicants with Down syndrome resulted in the applicant joining the Scheme, compared to 76% of access decisions for all applicants.

The next doughnut chart shows that 279 access decisions have been made in the year for applicants with Down syndrome, of which 263 participants met access and are still active.

A bar chart shows the percentage of participants with Down syndrome by age band of those who met access and are still active. Of the 263 participants who joined the scheme in the year ending 30 June 2023, 79% (or 208) were aged 18 years and under.

* 65% were aged 0 to 6.
* 9% were aged 7 to 14.
* 6% were aged 15 to 18.
* 3% were aged 19 to 24.
* 17% were aged 25 and over.

The following section contains 6 bar charts comparing different demographic make-up of participants with Down syndrome and the make-up of the overall Scheme.

### Gender

Distribution of active participants by gender

A bar chart shows the percentage of active participants with Down syndrome by gender and compares that to the distribution of all participants in the Scheme.

As at 30 June 2023, the percentage of participants with Down syndrome who identified as:

* Male was 54%, compared to 61% for all participants.
* Female was 45%, compared to 37% for all participants.
* Other was 1%, compared to 1% for all participants.

Commentary in the text box: The majority of participants with Down syndrome are male (54%).

### State/Territory

Distribution of active participants by State/Territory

A bar chart shows 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.

As at 30 June 2023, the percentage of participants with Down syndrome who resided in:

* NSW was 32%, 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 10%, 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 shows the percentage of active participants with Down syndrome by age band and compares that to the distribution of all participants in the Scheme.

As at 30 June 2023, 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 8%, compared to 9% for all participants.
* 19 to 24 was 11%, 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 5% for all participants.

Commentary in the text box: The majority of participants with Down syndrome are aged under 35 years (64%).

### Reported Level of Function

Distribution of active participants by reported level of function

A chart shows 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.

As at 30 June 2023, the percentage of participants with Down syndrome who had:

* a high reported level of function was 14%, compared to 30% for all participants.
* a medium reported level of function was 38%, compared to 46% for all participants.
* a low reported level of function was 48%, compared to 24% for all participants.

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

### Remoteness

Distribution of active participants by remoteness

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

As at 30 June 2023, the percentage of participants with Down syndrome who resided in:

* Major cities was 66%, compared to 68% for all participants.
* A region with a population greater than 50,000 (and not a major city) was 11%, compared to 11% for all participants.
* A region with a population of 15,000 to 50,000 was 9%, compared to 8% for all participants.
* A region with a population of 5,000 to 15,000 was 5%, compared to 5% for all participants.
* A region with a population less than 5,000 (and not a remote of very remote area) was 7%, compared to 6% for all participants.
* Remote areas was 1%, compared to 1% for all participants.
* Very remote areas was less than 1%, 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 bar chart shows 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.

As at 30 June 2023, the percentage of participants with Down syndrome who resided 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 12%, 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 11% 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.

Quote: “The NDIS is supporting us to work towards these outcomes and we are hopeful it will help him live a happy and fulfilling life.” By mother of NDIS participant, Adam.

### First Nations

In the year ending 30 June 2023:

* A bar chart shows that the number of active participants with Down syndrome who identify as First Nations people has increased from 399 to 412, an increase of 3%.

At 30 June 2023:

* A doughnut chart shows that 4% (or 412) of participants with Down syndrome identify as First Nations people, compared to 8% (or 46,694) for all participants.
* A doughnut chart shows that 39% (or 162) of participants with Down syndrome who identify as First Nations people live in a major city, compared to 68% (or 417,206) for all participants.

### Culturally and Linguistically Diverse (CALD)

In the year ending 30 June 2023:

* A bar chart shows that the number of active participants with Down syndrome who identify as CALD has increased from 864 to 910, an increase of 5%.
* At 30 June 2023 a doughnut chart shows that 8% (or 910) of participants with Down syndrome identified as CALD, compared to 9% (or 55,751) for all participants.
* At 30 June 2023 a doughnut chart shows that 92% (or 841) of participants with Down syndrome who identify as CALD live in a major city, compared to 68% (or 417,206) for all participants.

## Section 2: Payments

### Total Payments

* In the year ending 30 June 2023, the NDIS provided $1.30 billion of paid supports to participants with Down syndrome.
* Last year, $1.11 billion of paid supports were provided to participants with Down syndrome.
* This is an increase of 17%.

### Total Payments for Support Category (in $million):

A table shows the total payments to participants with Down syndrome by support category in the last two years. (The sum of the payments by support category may not equal the total payments shown in the table since the total may include payments with a “missing” support category. Daily activity supports include therapies).

* $722.7 million for Core - Daily Activities in the year ending 30 June 2023. This was $646.9 million in the year ending 30 June 2022, which represents a 12% increase from last year.
* $374.0 million for Core - Community in the year ending 30 June 2023. This was $277.1 million in the year ending 30 June 2022, which represents a 35% increase from last year.
* $46.1 million for Core - Consumables & Transport in the year ending 30 June 2023. This was $44.8 million in the year ending 30 June 2022, which represents a 3% increase from last year.
* $88.9 million for Capacity Building - Daily Activities in the year ending 30 June 2023. This was $78.3 million in the year ending 30 June 2022, which represents a 13% increase from last year.
* $53.1 million for Capacity Building - Other in the year ending 30 June 2023. This was $48.1 million in the year ending 30 June 2022, which represents a 10% increase from last year.
* $18.1 million for Capital in the year ending 30 June 2023. This was $16.2 million in the year ending 30 June 2022, which represents a 12% increase from last year.
* $1,302.9 million total payments in the year ending 30 June 2023. This was $1,111.5 million in the year ending 30 June 2022, which represents a 17% increase from last year.

### Total payments by age band (in $million)

A bar chart shows the payments made to participants with Down syndrome by age band for the year ending 30 June 2023.

* $27 million to participants aged 0 to 6.
* $68 million to participants aged 7 to 14.
* $53 million to participants aged 15 to 18.
* $137 million to participants aged 19 to 24.
* $267 million to participants aged 25 to 34.
* $248 million to participants aged 35 to 44.
* $264 million to participants aged 45 to 54.
* $204 million to participants aged 55 to 64.
* $35 million to participants aged 65 and over.

### Average Payments

The average payment per participant with Down syndrome was $112,600 for the year ending 30 June 2023, compared to $96,900 for the year ending 30 June 2022. This was a year-on-year increase of 16%. (Average payments per participant are calculated using a 12 month period prior to the reporting date.)

A separate table compares the average payments for the same group of participants between this year and last year (that is, the 12 months ending 30 June 2023 versus the 12 months ending 30 June 2022). Participants who had an initial plan approved after 30 June 2022 are not included.

* For participants aged under 18 years, the average payment this year was $40,100, compared to $34,700 last year, an increase of 16%.
* For participants aged 18 years and over and not in SIL, the average payment this year was $89,000, compared to $76,200 last year, an increase of 17%.
* For participants aged 18 years and over and in SIL, the average payment this year was $308,900, compared to $275,600 last year, an increase of 12%.
* At overall level for participants with Down syndrome, the average payment this year was $113,600, compared to $96,900 last year, an increase of 17%.

### Participants in Supported Independent Living (SIL)

### Total payments by support category for the year ending 30 June 2023 (in $million)

A table shows the payments by support category made to participants with Down syndrome who were in SIL and not in SIL, in the year ending 30 June 2023.

* $483.3 million of payments for Core - Daily Activities to participants in SIL, compared to $239.4 million for participants not in SIL. This represents a total of $722.7 million for all payments made for Core - Daily Activities supports.
* $109.9 million of payments for Core - Community to participants in SIL, compared to $264.2 million for participants not in SIL. This represents a total of $374.0 million for all payments made for Core - Community supports.
* $8.1 million of payments for Core - Consumables & Transport to participants in SIL, compared to $38.0 million for participants not in SIL. This represents a total of $46.1 million for all payments made for Core - Consumables & Transport supports.
* $15.9 million of payments for Capacity Building - Daily Activities to participants in SIL, compared to $73.0 million for participants not in SIL. This represents a total of $88.9 million for all payments made for Capacity Building - Daily Activities supports.
* $19.7 million of payments for Capacity Building - Other to participants in SIL, compared to $33.4 million for participants not in SIL. This represents a total of $53.1 million for all payments made for Capacity Building - Other supports.
* $12.3 million of payments for Capital to participants in SIL, compared to $5.8 million for participants not in SIL. This represents a total of $18.1 million for all payments made for Capital supports.
* $649.2 million total payments to participants in SIL, compared to $653.7 million to participants not in SIL. This represents a total of $1,302.9 million payments to participants with Down syndrome.

For participants aged 18 years and over with Down syndrome:

* Participants in SIL comprise 27% of all participants with Down syndrome who were aged 18 years and over, and their payments in the year ending 30 June 2023 comprise 56% of payments to participants with Down syndrome aged 18 years and over.
* A year ago, participants in SIL represented 26% of participants with Down syndrome who were aged 18 years and over, and their payments were 55% of payments to participants with Down syndrome aged 18 years and over in that year.

## Section 3: Participant Outcomes and Satisfaction

The Participant Outcome section compares baseline results when participants entered the Scheme or at their first plan 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. All outcome results are rounded to the nearest percentage but the percentage point increases or decreases are calculated based on the unrounded results.

### 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 42% for the Scheme as a whole.

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

* 14 percentage point increase from 51% to 65% for participants aged 15 years and over.
* 14 percentage point increase from 53% to 67% for participants aged 25 years and over.

A bar 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 14 percentage point increase from 54% to 67%.
* for participants aged 35 to 44 years there was a 14 percentage point increase from 53% to 66%.
* for participants aged 45 to 54 years there was a 16 percentage point increase from 52% to 68%.
* for participants aged 55 to 64 years there was a 10 percentage point increase from 51% to 62%.
* for participants aged 65 years and over there was a 22 percentage point increase from 38% to 60%.

### 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 seven years after entry) with responses at Scheme entry, there has been a:

* 2 percentage point decrease from 27% to 26% for participants aged 15 to 64 years.
* 5 percentage point decrease from 34% to 28% for participants aged 25 to 64 years.

A bar chart shows that:

* for participants aged 15 to 24 years there was a 10 percentage point increase from 7% to 16%.
* for participants aged 25 to 34 years there was a less than 1 percentage point decrease from 32% to 31%.
* for participants aged 35 to 44 years there was a 4 percentage point decrease from 38% to 34%.
* for participants aged 45 to 54 years there was a 11 percentage point decrease from 36% to 25%.
* for participants aged 55 to 64 there was a 12 percentage point decrease from 25% to 12%.

### Outcome: Family & Carer Employment

Family/carers of participants with Down syndrome reported an employment rate of 46%, this compares to Scheme average family/carers employment rate of 50%.

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

* 7 percentage point increase from 39% to 46% for participants aged 0 to 14 years.
* 1 percentage point decrease from 47% to 46% for participants aged 15 and over.
* 3 percentage point increase from 43% to 46% for participants across all ages.

### Outcome: Choice & Control

At 30 June 2023, 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 77%.

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

* 11 percentage point increase from 71% to 81% for participants aged 15 years and over.
* 11 percentage point increase from 73% 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 12 percentage point increase from 72% to 84%.
* 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 13 percentage point increase from 70% to 83%.
* for participants aged 55 to 64 years there was an 8 percentage point increase from 73% to 81%.
* for participants aged 65 and over there was a 13 percentage point increase from 75% to 88%.

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

* 95% 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.
* 95% 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 a 11 percentage point increase from the first reassessment.

### Education outcomes

This section contains 4 bar charts demonstrating education outcomes and Australian Disability Enterprise (ADE) employment outcomes for participants with Down syndrome.

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

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

* 37% at baseline.
* 29% at the latest reassessment.

The next chart entitled: "Percentage of participants who have post-school qualification" displays the percentage of participants with Down syndrome who have post-school qualifications and compares the results at the 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 and over.

The next chart entitled: "Percentage of participants who get opportunities to learn new things" displays the percentage of participants with Down syndrome who get opportunities to learn new things and compares the results at the latest plan reassessment and Scheme entry (or baseline).

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

* 69% 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 and over.

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

Of the participants with Down syndrome who are working in a paid job, the chart displays the percentage 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:

* 44% at baseline and 48% at the latest plan reassessment for participants aged 15 to 24 years.
* 70% at baseline and 74% at the latest plan reassessment for participants aged 25 and over.

Quote: “For Adam, the NDIS came in at the right time. He has had support at all the right stages which has made all the difference.” By mother of NDIS participant, Adam.

### Satisfaction

Four bar charts compare the satisfaction responses between participants with Down syndrome and all participants in the year ending 30 June 2023. The NDIA gathers responses at the four primary stages of the participant pathway – access, preplanning, planning and plan reassessment.

The percentage of participants with Down syndrome who rated their experience with the NDIS as good or very good was:

* 85% for the Planning Process, compared to 86% for all participants.
* 68% for the Reassessment Process, compared to 68% for all participants.

Satisfaction results for access and pre-planning are not shown due to the small sample size of responses collected from participants with Down syndrome.

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 69% in the year ending 30 June 2023.

* This was 71% for the year ending 30 June 2022.
* This compares to a satisfaction rate of 75% for all participants.

### Complaints

There were 630 complaints raised by participants with Down syndrome in the year ending 30 June 2023 (or a complaint rate of 5%). (The complaint rate is an annualised rate calculated as the number of complaints in the year divided by the active participant exposure in the year).

* The complaint rate 12 months ago for participants with Down syndrome was 7%.
* This compares to a complaint rate of 6% for all participants.

## Section 4: Providers

This section contains information on service providers supporting participants with Down syndrome in the year ending 30 June 2023, in the form of doughnut charts.

* The first set of three doughnut charts show an overview of all the providers supporting participants with Down syndrome:
* A doughnut charts shows that 20,407 agency or plan managed providers received a payment during the year. 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 52% of these providers were companies or organisations and 48% 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 19,327 providers received a payment during the year. (For each plan management type, a single provider is counted if they received a payment in the year 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 28% of the providers were registered and 72% were 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 $513 million was paid in the year ending 30 June 2023. This makes up 39% 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 3,586 providers received a payment during the year.
* A doughnut chart shows that 100% of providers were registered.
* The next doughnut chart shows that $645 million was paid in the year ending 30 June 2023. This makes up 49% of payments to participants with Down syndrome.

For providers supporting self-managed participants with Down syndrome, $145 million was paid in the year ending 30 June 2023, which is 11% 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.

## Key definitions

Definitions of terms used in this dashboard are consistent with those used in Appendix A of the Quarterly Report to disability ministers published on the NDIS website.