4. Families/carers of participants from age 15 to 24: Outcome indicators

4.1 Key findings

Box 4.1: Overall findings for C3 cohort (families/carers of participants from age 15 to 24, who have been in the Scheme for three years)

- For participants who have been in the Scheme for three years, the longitudinal analysis revealed significant improvements across a number of family/carer indicators.
- Some large improvements were seen in families/carers' satisfaction with services. The percentage of families/carers who said that the services they receive for their family member with disability meet their needs increased from 17.7% at baseline to 36.3% at third review, while the percentage of families/carers who felt that the services they use listen to them increased by 7.9%, from 64.0% at baseline to 72.0% at third review. The percentage who say that the services help them to plan for the future increased from 67.4% at baseline to 72.1% at third review.
- Families and carers report increasing ability and confidence in helping their children develop and learn. The percentage of families/carers who feel that the services they use for their family member with disability listen to them increased by 7.9%, from 64.0% at baseline to 72.0% at third review. Similarly, the percentage of families/carers who say that the services their family member with disability and their family receive meet their needs increased by 18.6%, from 17.7% at baseline to 36.3% at third review.
- The percentage of families/carers in a paid job increased from 49.4% at baseline to 54.4% at third review.
- The percentage of families/carers in a paid job who work 15 hours or more has increased from 85.1% at baseline to 90.2% at third review.
- There was a decline in the percentage of families/carers who rated their health as excellent, very good or good, from 64.9% at baseline to 56.6% at third review.
- The percentage of families/carers who are able to advocate (stand up) for their family member with disability decreased by 3.8%, from 76.9% at baseline to 73.1% at third review.

Box 4.2: Overall findings for C2 cohort (families/carers of participants from age 15 to 24, who have been in the Scheme for two years)

- For families/carers of participants who have been in the Scheme for two years, similar trends as for those who have been in the Scheme for three years were observed.
- Significant improvements were observed in the access to services domain. The percentage of families/carers who said that the services they receive for their family member with disability meets their needs increased from 17.8% at baseline to 30.5% at second review. A similar improvement was observed in the percentage of families/carers who feel that the services they use for their family member with disability listen to them (62.2% at baseline versus 71.1% at second review). The percentage who say that the services help them to plan for the future increased from 58.5% at baseline to 78.0% at first review.
- Families/carers were more confident about the future of their family member with disability under the NDIS, from 50.0% at baseline to 68.6% at second review. The percentage who strongly agree or agree that their family member gets the support he/she needs also increased, from 30.2% at baseline to 59.3% at second review.
- Family/carer outcomes in the health and wellbeing domain deteriorated. In particular, the percentage of families/carers who rate their health as excellent, very good or good declined from 60.9% at baseline to 55.1% at second review. As with the 0 to 14 cohort, since health tends to decline with age, some deterioration in the health rating is expected.
- The percentage of families/carers in a paid job increased from 51.2% at baseline to 53.4% at second review, and the percentage working 15 hours or more per week increased from 84.1% to 86.4%.
- Of families/carers unable to work as much as they want, the percentage saying that the availability of jobs is a barrier to working more increased from 16.0% at baseline to 19.7% at second review.

Box 4.3: Overall findings for C1 cohort (families/carers of participants from age 15 to 24, who have been in the scheme for one year)

- For participants in the Scheme for one year, the longitudinal analysis revealed significant improvements across a number of family/carer indicators.
- Some large improvements were seen in families/carers' satisfaction with services. The percentage of families/carers who said that the services they receive for their family member with disability meet their needs increased from 17.8% at baseline to 24.9% at first review, while the percentage of families/carers who felt that the services they use listen to them increased from 65.5% at baseline to 69.7% at first review. The percentage who say that the services help them to plan for the future increased from 57.4% at baseline to 71.9% at first review.
- Families/carers were more confident about the future of their family member with disability under the NDIS, from 56.1% at baseline to 64.4% at first review. The percentage who strongly agree or agree that their family member gets the support he/she needs also increased, from 32.6% at baseline to 53.0% at first review.
- Family/carer outcomes in the health and wellbeing domain deteriorated. In particular, the percentage of families/carers who rate their health as excellent, very good or good declined from 61.1% at baseline to 58.4% at first review. As with the 0 to 14 cohort, since health tends to decline with age, some deterioration in the health rating is expected.
- The percentage of families/carers in a paid job increased from 51.4% at baseline to 52.7% at first review, and the percentage working 15 hours or more per week increased from 85.2% to 86.7%.
- Of families/carers unable to work as much as they want, the percentage saying that the availability of jobs is a barrier to working more increased from 29.1% at baseline to 31.8% at first review.

Box 4.4: Outcomes by key characteristics for families/carers of participants from age 15 to 24

- Families and carers of participants with autism were more likely to deteriorate in having someone to talk to for emotional support between baseline and first review. Compared to families/carers of participants with autism, families/carers of participants with a psychosocial disability were more likely to improve in self-rated health over the latest year, and in saying their child's disability is a barrier to working more between baseline and first review.
- Families and carers of participants with a lower level of function were less likely to improve and/or more likely to deteriorate across a number of indicators. For example, they were more likely to deteriorate in the latest year and between baseline and second review in thinking that the services they use meet the needs of their family member with disability, and less likely to improve in thinking the situation of their family member with disability is a barrier to working more.
- Families/carers of participants living outside a major city had more positive outcomes in some areas. For example, they were more likely to improve in thinking that the services they use listen to them.
- Higher plan utilisation was a positive factor for some indicators. For example, it was associated with a higher likelihood of improvement and a lower likelihood of deterioration for feeling that the services they use listen to them, and a higher likelihood of improvement in saying that the services they use meet the needs of their family member with disability.
- Families and carers of participants with fully self-managed plans were less likely to deteriorate in thinking the services they use listen to them, and more likely to improve in saying the services meet their needs. Those with plan-managed plans, however, are less likely to improve on the latter indicator.

Box 4.5: Has the NDIS helped families/carers of participants from age 15 to 24?

- The percentage of families/carers reporting that the NDIS helped after three years in the Scheme was higher across all short form domains (except health and wellbeing) than the percentage of families/carers reporting that the NDIS helped after one year in the Scheme.

After one year in the Scheme:

- Family and carers of participants with higher baseline plan utilisation, and of those with higher annualised plan budget, are more likely to say the NDIS has helped, across all five domains.
- Families and carers of participants with a visual impairment or spinal cord injury are less likely to think that the NDIS has helped with level of support or access to services.
- Families and carers whose plans are self-managed, either fully or partly, are more likely than those who agency manage to say that the NDIS helped across all domains.
- Families and carers of participants who live in remote/very remote areas, compared to those who live in major cities, are less likely to say the NDIS has helped across all domains except health and wellbeing.

Looking at changes over time:

- Higher overall plan utilisation, and higher utilisation of capacity building supports, tend to be associated with more positive changes in responses.
- Higher annualised plan budget was associated with a higher likelihood of improvement over the participant’s second year in the Scheme for level of support, access to services, and health and wellbeing.
- Where the participant is working in an unpaid job, families/carers are more likely to improve and less likely to deteriorate in thinking the NDIS has helped them to help the participant become more independent.
- Relocating to a different local government area (LGA) is associated with some more negative changes in responses, for the domains rights and advocacy, access to services, as well as health and wellbeing.
- Families and carers of participants of a lower level of function were less likely to deteriorate in the domains of level of support for family and helping their family member become more independent. They were also more likely to improve with respect to health and wellbeing.

4.2 Outcomes framework questionnaire domains

For families/carers of participants aged 15 to 24, the outcomes framework seeks to measure the extent to which they:

- know their rights and advocate effectively for their family member with a disability (RA)
- feel supported (SP)
- can gain access to desired services, programs and activities in their community (AC)
- are able to help their young person to become independent (IN)
- enjoy health and wellbeing (HW).

The LF survey for families/carers of participants aged 15 to 24 also includes four questions on whether families/carers understand their family members strengths, abilities and special needs, and includes several additional questions on health and wellbeing that focus on their outlook for the future and ability to meet costs of everyday living.

Families and carers of participants answer the outcomes questionnaire applicable to the their family member with disability’s age at the time of interview. For the longitudinal analysis, the 15 to 24 family and carer cohort comprises families and carers of participants who are aged between 15 and 24 when they enter the Scheme, and includes responses at all review time points until the participant turns 25.

4.3 Longitudinal indicators – overall

Longitudinal analysis describes how outcomes have changed for families/carers of participants during the time the participant has been in the Scheme. Included here are families/carers of participants who entered the Scheme between 1 July 2016 and 30 June 2019 for whom a record of outcomes is available at scheme entry (baseline) and at one or more of the two time points: approximately one year following scheme entry (first review), approximately two years following scheme entry (second review) and approximately three years following scheme entry (third review).

For this year’s report, results are shown separately for the three cohorts described in Section 1.4, including the value of the indicator at baseline and each review, as well as the change in the latest year, and the change between baseline and latest review. For example, for the C3 cohort, results at baseline, first review, second review, and third review are shown, as well as the change between second review and third review, and the change from baseline to third review.

Table 4.1 below summarises changes for selected indicators across different time periods. Indicators were selected for the tables if the change, either overall or for the latest year, was statistically significant[24] and had an absolute magnitude greater than 0.02 for at least one entry year cohort.

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[24] McNemar’s test at the 0.05 level.

Table 4.1 Selected longitudinal indicators for families/carers of participants aged 15 to 24

Domain (Form)	Indicator	Cohort	Indicator at:				Change		Significant[25]	
			Baseline	Review 1	Review 2	Review 3	Latest year	Overall	Latest year	Overall
Improvement										
WK (SF)	% of families or carers who are in a paid job	C3	49.4%	54.2%	56.1%	54.4%	-1.7%	4.9%		*
		C2	51.2%	55.1%	53.4%		-1.7%	2.2%		*
		C1	51.4%	52.7%			1.3%	1.3%	**	**
WK (SF)	of those in a paid job, % who are employed in a permanent position	C3	75.7%	76.6%	73.7%	76.0%	2.3%	0.3%		
		C2	73.1%	76.5%	76.0%		-0.5%	2.9%		*
		C1	76.7%	77.8%			1.0%	1.0%	*	*
WK (SF)	of those in a paid job, % who work 15 hours or more per week	C3	85.1%	87.0%	88.0%	90.2%	2.2%	5.1%		*
		C2	84.1%	85.9%	86.4%		0.5%	2.3%	*	*
		C1	85.2%	86.7%			1.5%	1.5%	**	**
SP (SF)	% of families or carers who have people they can talk to for emotional support as often as they need	C3	52.2%	57.2%	58.4%	54.2%	-4.2%	2.0%		*
		C2	48.9%	50.6%	51.2%		0.6%	2.3%	*	*
		C1	47.4%	50.1%			2.7%	2.7%	**	**
SP (SF)	% of families or carers who get the services and supports they need to care for their family member with disability	C3	8.6%	11.9%	13.7%	15.2%	1.5%	6.6%	*	**
		C2	8.8%	11.3%	13.4%		2.1%	4.7%	**	**
		C1	8.9%	10.9%			2.0%	2.0%	**	**

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[25] ** statistically significant, p-value<0.001; * statistically significant, p-value between 0.001 and 0.05.

Domain (Form)	Indicator	Cohort	Indicator at: Baseline	Review 1	Review 2	Review 3	Change: Latest year	Overall	Significant[25]: Latest year	Overall
AC (SF)	% of families or carers who feel that the services they use for their family member with disability listen to them	C3	64.0%	70.3%	73.3%	72.0%	-1.2%	8.1%	*	*
		C2	62.2%	67.7%	71.1%		3.4%	8.9%	**	**
		C1	65.5%	69.7%			4.2%	4.2%	**	**
AC (SF)	% of families or carers who feel in control selecting the services and supports for their family member with disability	C3	41.2%	44.2%	44.4%	46.0%	1.6%	4.8%		*
		C2	40.5%	40.3%	42.3%		2.0%	1.7%		
		C1	40.8%	40.7%			-0.1%	-0.1%		
AC (SF)	% of families or carers who say that the services their family member with disability and their family receive meet their needs	C3	17.7%	31.5%	34.3%	36.3%	2.1%	18.6%		**
		C2	17.8%	26.5%	30.5%		3.9%	12.6%	**	**
		C1	17.8%	24.9%			7.0%	7.0%	**	**
AC (LF)	% who say the service their family member with disability and their family receive help them to plan for the future	C3	67.4%	62.8%	62.8%	72.1%	9.3%	4.7%		
		C2	58.5%	75.6%	78.0%		2.4%	19.5%		*
		C1	57.4%	71.9%			14.4%	14.4%	*	*
IN (SF)	% of families or carers who know what their family can do to enable their family member with disability to be as independent as possible	C3	46.3%	45.5%	46.7%	46.8%	0.1%	0.5%		
		C2	41.5%	40.5%	43.1%		2.6%	1.6%	*	
		C1	40.0%	40.5%			0.6%	0.6%		
IN (SF)	% of families or carers who enable and support their family member with disability to interact and develop strong relationships with non-family members	C3	49.4%	50.0%	52.4%	49.5%	-2.8%	0.2%		
		C2	45.1%	45.1%	47.3%		2.2%	2.2%	*	*
		C1	44.3%	44.8%			0.5%	0.5%	*	*

Domain (Form)	Indicator	Cohort	Indicator at:				Change		Significant[25]	
			Baseline	Review 1	Review 2	Review 3	Latest year	Overall	Latest year	Overall
HW (LF)	% who strongly agree/agree they feel more confident about the future of their family member under the NDIS	C3	50.0%	70.5%	63.6%	75.0%	11.4%	25.0%		*
		C2	50.0%	69.8%	68.6%		-1.2%	18.6%		*
		C1	56.1%	64.4%			8.3%	8.3%	*	*
HW (LF)	% who strongly agree or agree that their family member gets the support he/she needs	C3	40.9%	45.5%	43.2%	70.5%	27.3%	29.5%		*
		C2	30.2%	57.0%	59.3%		2.3%	29.1%		*
		C1	32.6%	53.0%			20.5%	20.5%	**	**
HW (LF)	% who strongly agree or agree that the services and supports have helped them to better care for their family member with disability	C3	38.6%	75.0%	56.8%	65.9%	9.1%	27.3%		*
		C2	42.9%	72.6%	64.3%		-8.3%	21.4%		*
		C1	37.1%	59.1%			22.0%	22.0%	**	**
Context dependent										
GB (SF)	% of families or carers who are receiving Carer Payment	C3	31.5%	29.6%	30.2%	29.5%	-0.7%	-2.0%		*
		C2	28.9%	28.7%	29.8%		1.1%	0.8%		
		C1	27.8%	28.0%			0.2%	0.2%		
GB (SF)	% of families or carers who are receiving Carer Allowance	C3	58.7%	62.9%	63.5%	59.6%	-3.9%	0.9%		
		C2	55.9%	58.6%	58.7%		0.1%	2.8%		*
		C1	53.2%	55.8%			2.6%	2.6%	**	**
Deterioration										
RA (SF)	% of families or carers who are able to advocate (stand up) for their family member with disability	C3	76.9%	77.5%	74.2%	73.1%	-1.0%	-3.7%		*
		C2	72.8%	73.2%	71.6%		-1.6%	-1.2%		*
		C1	71.0%	70.0%			-1.0%	-1.0%	*	*

Domain (Form)	Indicator	Cohort	Indicator at:				Change		Significant[25]	
			Baseline	Review 1	Review 2	Review 3	Latest year	Overall	Latest year	Overall
IN (SF)	% of families or carers who enable and support their family member with disability to make more decisions in their life	C3	63.7%	65.0%	65.6%	62.0%	-3.6%	-1.7%		
		C2	57.4%	58.8%	60.0%		1.3%	2.6%		*
		C1	56.0%	56.6%			0.6%	0.6%	*	*
HW (SF)	% of families or carers who rate their health as excellent, very good or good	C3	64.9%	61.3%	55.5%	56.6%	1.1%	-8.3%		**
		C2	60.9%	59.0%	55.1%		-3.9%	-5.8%	**	**
		C1	61.1%	58.4%			-2.7%	-2.7%	**	**
HW (SF)	of those unable to work as much as they want, % who say availability of jobs is a barrier to working more	C3	22.7%	25.7%	30.3%	23.8%	-6.5%	1.1%		
		C2	16.0%	19.1%	19.7%		0.6%	3.7%	*	**
		C1	14.9%	17.1%			2.2%	2.2%	**	**

For families and carers of participants aged 15 to 24, the majority of changes have been positive overall. Key findings include the following:

- The percentage of families and carers in a paid job has increased from baseline for all three cohorts: by 4.9% over three years for the C3 cohort, 2.2% over two years for the C2 cohort, and 1.3% over one year for the C1 cohort. However, there were small but non-significant declines over the latest year for the C3 and C2 cohorts.
- The percentage of families and carers working 15 hours or more per week has also increased from baseline for all three cohorts: by 5.1% for the C3 cohort, 2.3% for the C2 cohort, and 1.5% for the C1 cohort.
- There have been increases in the percentages of families/carers reporting positive outcomes in relation to accessing services and supports, and the quality of these interactions. Specifically, for the C3 cohort, respondents reporting that:
    - they received the services and supports they needed to care for their family member with disability, increased by 6.6%
    - the services their family member with disability and family received met their needs, increased by 18.6%
    - the services they used for their family member with disability listened to them, increased by 8.1%
    - they strongly agree or agree that the services and supports have helped them to better care for their family member with disability also increased by 27.3%.
- Families/ carers reported better outcomes in relation to the support that their family member with a disability receives and the level of confidence they have in the future of their family member under the NDIS. For the C3 cohort, the percentage of respondents who strongly agreed or agreed with these items increased by 29.5% and 25.0%, respectively.
- However, deteriorations were observed for a few indicators. For example, the percentage of families/carers who rated their health as excellent, very good, or good decreased by 8.3% over three years for the C3 cohort (although there was a small but not significant increase of 1.1% in the latest year). A drop of 3.7% in the proportion of respondents who were able to advocate for their family member with disability was also observed.

4.4 Longitudinal indicators – participant and family/ carer characteristics

Section 2.4 describes the general methodology used to analyse longitudinal outcomes by participant and family/carer characteristics.

Due to smaller numbers than for the 0 to 14 age group, some transitions have been grouped for the older age groups. Table 4.2 shows the four groups of transitions that have been modelled, and the transitions contributed by each of the C1, C2 and C3 cohorts. Improvements and deteriorations have been considered separately, resulting in eight different models for each indicator.

Table 4.2 Transitions contributing to the models for cohorts C1, C2 and C3*

Cohort	1 year transitions		2 year transitions[26]	3 year transitions
	Baseline to First	Latest Year	Baseline to Second	Baseline to Third
C3	**B → R1**	**R2 → R3**	**B → R2**	**B → R3**
C2	**B → R1**	**R1 → R2**	**B → R2**	
C1	**B → R1**			

*B=baseline, R1=first review, R2=second review. The arrow represents transition between the two time points.

Some key features of the analyses for selected indicators are summarised below. For each indicator, a table summarising the direction of the effect for each significant predictor in the regression models is included.[27] Table 2.3 in section 2.4 provides a key to aid interpretation of the arrow symbols used in these tables, including some examples.

I work 15 hours or more per week

Of those in a paid job, the percentage of families and carers reporting that they work 15 hours or more per week increased significantly from baseline to all reviews, with net increases of 1.5%, 2.5% and 5.1% from baseline to the first, second and third review, respectively. This was a result of improvements offset by deteriorations, as set out in Table 4.3 below.

Table 4.3 Breakdown of net movement in longitudinal responses

Longitudinal Period	Number of Baseline Responses in cohort[1]		Improvements: No to Yes		Deteriorations: Yes to No		Net Movement
	No	Yes	Number	%	Number	%	
Baseline to Review 1	890	5,039	166	18.7%	75	1.5%	+1.5%
Baseline to Review 2	258	1,357	82	31.8%	41	3.0%	+2.5%
Baseline to Review 3	44	251	21	47.7%	6	2.4%	+5.1%

[1] The cohort is selected as all those with non-missing responses at the relevant surveys.

Participant characteristics that had a statistically significant effect ($p<0.05$) on the likelihood of improvement or deterioration in the outcome are set out in Table 4.4 below.

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[26] There is another two-year transition, from first review to third review, however the amount of data for this transition is smaller and to keep the presentation manageable it has not been included. Results from selected models for this transition were generally consistent with baseline to second review (but tended to identify a smaller number of predictors, due to the smaller amount of data).

[27] For models where no variables are identified as significant predictors, the corresponding column in the table is shaded grey.

Table 4.4 Key drivers of likelihood of transitions in *"of those in a paid job, % who work 15 hours or more per week"* response

Reference Category	Variable	1 step transitions				2 step transitions		3 step transitions	
		Baseline to First Review		Latest Year		Baseline to Second Review		Baseline to Third Review	
		Relationship with likelihood of		Relationship with likelihood of		Relationship with likelihood of		Relationship with likelihood of	
		Imp.	Det.	Imp.	Det.	Imp.	Det.	Imp.	Det.
Mother	**Respondent was the father**		⬇						
Mother	**Respondent was the spouse/partner**		⬆						
No change	**Participant's self-rated health improved**	⬆							
Safe	**Participant does not feel safe in their home**				⬆				
Safe	**Participant feels neither safe nor unsafe in their home**				⬆				
N/A	**Higher payments to self-managed employment supports**				⬆				
Pre-COVID	**Review during COVID period**		⬆					⬆	
N/A	**General time trend**							⬇	

Key findings from Table 4.4 include the following:

- The changing self-reported health status of the participant has a significant impact on whether families/ carers were in a paid job and working 15 hours or more per week. Where the participant's self-reported health improved between reviews, families and carers were more likely to improve from baseline to first review, compared to where the participant reported no change in their health status
- There were also differences by respondent, with fathers being less likely to deteriorate than mothers from baseline to first review, whereas spouses/partners were more likely to deteriorate than mothers over the same transition.
- Family and carers of participants who felt unsafe at home or felt neither safe nor unsafe at home, were more likely to deteriorate in their latest year in the Scheme compared with family and carers of participants who feel safe at home.

- Families and carers whose latest review response was collected during the COVID period were more likely to show improvement from baseline to third review, however they were also more likely to show deterioration from baseline to first review.

I have people I can talk to for emotional support as often as I need

The percentage of families and carers reporting that they have people they can talk to for emotional support as often as they need has increased significantly from baseline to all reviews, with net increases of 2.5%, 2.6% and 2.3% from baseline to the first, second and third review, respectively. This was a result of improvements offset by deteriorations as set out in Table 4.5 below.

Table 4.5 Breakdown of net movement in longitudinal responses

Longitudinal Period	Number of Baseline Responses in cohort[1]		Improvements: No to Yes		Deteriorations: Yes to No		Net Movement
	No	Yes	Number	%	Number	%	
Baseline to Review 1	6,425	5,920	889	13.8%	586	9.9%	+2.5%
Baseline to Review 2	1,817	1,756	396	21.8%	303	17.3%	+2.6%
Baseline to Review 3	334	360	98	29.3%	82	22.8%	+2.3%

[1] The cohort is selected as all those with non-missing responses at the relevant surveys.

Participant characteristics that had a statistically significant effect ($p<0.05$) on the likelihood of improvement or deterioration in the outcome are set out in Table 4.6 below.

Table 4.6 Key drivers of likelihood of transitions in *"% of families or carers who have people they can talk to for emotional support as often as they need"* response

Reference Category	Variable	1 step transitions				2 step transitions		3 step transitions	
		Baseline to First Review Relationship with likelihood of		Latest Year Relationship with likelihood of		Baseline to Second Review Relationship with likelihood of		Baseline to Third Review Relationship with likelihood of	
		Imp.	Det.	Imp.	Det.	Imp.	Det.	Imp.	Det.
NSW	**Participant lives in QLD**	↑						↑	
Autism	**Disability is cerebral palsy or another neurological disorder**		↓						
Autism	**Disability is Down Syndrome or an intellectual disability**		↓						
Autism	**Disability is a sensory disability**		↓						

Reference Category	Variable	1 step transitions				2 step transitions		3 step transitions	
		Baseline to First Review		Latest Year		Baseline to Second Review		Baseline to Third Review	
		Relationship with likelihood of		Relationship with likelihood of		Relationship with likelihood of		Relationship with likelihood of	
		Imp.	Det.	Imp.	Det.	Imp.	Det.	Imp.	Det.
Autism	**Other disability**		⬇						
2016/17	**Participant entered the Scheme in 2017/18**				⬇	⬇			
N/A	**Lower level of function**								⬆
N/A	**Higher plan utilisation**		⬆						
N/A	**Higher utilisation % of core supports**						⬆		
N/A	**Higher Australian Disability Enterprise payments**	⬆							
Agency managed	**Plan is managed by a plan manager**				⬆		⬆		
Agency managed	**Plan is fully self-managed**		⬇		⬆				
Agency managed	**Plan is partly self-managed**				⬆				
N/A	**General time trend**	⬇	⬇						
Major cities	**Participant lives outside a major city**		⬇			⬆			
Did not relocate	**Participant relocated to a new Local Government Area (LGA)**					⬇			
Entry due to disability	**Participant entered the scheme through Early Intervention**					⬆			
Received State/ Territory supports	**Participant did not previously receive services from Commonwealth or State/Territory programs**					⬆			

Reference Category	Variable	1 step transitions				2 step transitions		3 step transitions	
		Baseline to First Review		Latest Year		Baseline to Second Review		Baseline to Third Review	
		Relationship with likelihood of		Relationship with likelihood of		Relationship with likelihood of		Relationship with likelihood of	
		Imp.	Det.	Imp.	Det.	Imp.	Det.	Imp.	Det.
Medium level of NDIA support	Lower level of NDIA support	⬆							
Medium level of NDIA support	Higher level of NDIA support	⬇				⬇		⬇	
No change	Participant's self-rated health improved	⬆		⬆		⬆			
No change	Participant's self-rated health deteriorated	⬆	⬆				⬆		
Safe	Participant does not feel safe in their home	⬇	⬆	⬇		⬇	⬆		
Safe	Participant feels neither safe or unsafe in their home	⬇	⬆				⬆		⬆
Never in paid work	Carer remained in paid work	⬆	⬇		⬇	⬆	⬇		⬇
Never in paid work	Carer started paid work	⬆				⬆			
Never in paid work	Carer stopped paid work	⬆	⬆						

Key findings from Table 4.6 include the following:

- The level of NDIA support had a significant impact on the percentage of families and carers who reported having people they could talk to for emotional support, as often as they need. Where the participant received a higher level of NDIA support, families and carers were less likely to improve across all transitions from baseline, compared to when to those participants receiving medium level NDIA support. The result reflects the fact that participants who are receiving a higher level of NDIA support through the participant pathway generally have more complex needs.
- The family member or carer remaining in employment between reviews also had an impact. Families/carers who remained in work were less likely to deteriorate and more likely to improve across all transitions, where there were sufficient data

- The family members/carers of participants in Queensland were more likely to improve from baseline to first review and baseline to third review, compared to those from NSW
- The families/carers of participants who felt unsafe at home were less likely to improve and more likely to deteriorate from baseline to first or second review, compared to family members/carers of participants who felt safe at home. They were also less likely to improve in the latest year within the Scheme.

I get the services and supports I need to care for my family member with a disability

The percentage of families and carers reporting that they get the services and supports they need to care for their family member with a disability has increased significantly from baseline to all reviews, with net increases of 2.3%, 4.8% and 6.6% from baseline to the first, second and third review, respectively. This was a result of improvements offset by deteriorations as set out in Table 4.7 below.

Table 4.7 Breakdown of net movement in longitudinal responses

Longitudinal Period	Number of Baseline Responses in cohort[1]		Improvements: No to Yes		Deteriorations: Yes to No		Net Movement
	No	Yes	Number	%	Number	%	
Baseline to Review 1	11,088	1,065	493	4.5%	216	20.3%	+2.3%
Baseline to Review 2	3,200	302	270	8.4%	101	33.4%	+4.8%
Baseline to Review 3	607	57	68	11.2%	24	42.1%	+6.6%

[1] The cohort is selected as all those with non-missing responses at the relevant surveys.

Participant characteristics that had a statistically significant effect ($p<0.05$) on the likelihood of improvement or deterioration in the outcome are set out in Table 4.8 below.

Table 4.8 Key drivers of likelihood of transitions in *"% of families or carers who get the services and supports they need to care for their family member with a disability"* response

Reference Category	Variable	1 step transitions				2 step transitions		3 step transitions	
		Baseline to First Review Relationship with likelihood of		Latest Year Relationship with likelihood of		Baseline to Second Review Relationship with likelihood of		Baseline to Third Review Relationship with likelihood of	
		Imp.	Det.	Imp.	Det.	Imp.	Det.	Imp.	Det.
Mother	**Respondent was the sibling**			↑					
NSW	**Participant lives in QLD**	↑							

Reference Category	Variable	1 step transitions				2 step transitions		3 step transitions	
		Baseline to First Review		Latest Year		Baseline to Second Review		Baseline to Third Review	
		Relationship with likelihood of		Relationship with likelihood of		Relationship with likelihood of		Relationship with likelihood of	
		Imp.	Det.	Imp.	Det.	Imp.	Det.	Imp.	Det.
NSW	Participant lives in SA	⬆							
NSW	Participant lives in ACT, NT, TAS, WA	⬆							
Non-CALD	Participant is CALD	⬇							
2016/17	Entry year is 2017/18	⬇							
2016/17	Entry year is 2018/19	⬇							
N/A	Lower level of function					⬇			
N/A	Higher payments to self-managed employment supports	⬆					⬆		
Agency managed	Plan is managed by a plan manager					⬆			
Agency managed	Plan is fully self-managed	⬆							
Private-owned	Participant lives in supported accommodation			⬆					
Major City	Participant lives outside a major city			⬆		⬆			⬇
Did not relocate	Participant relocated to a new Local Government Area (LGA)	⬇							
Pre-COVID	Review during COVID period							⬆	
N/A	General time trend		⬇					⬇	
Medium level of NDIA support	Higher level of NDIA support						⬇		

Reference Category	Variable	1 step transitions				2 step transitions		3 step transitions	
		Baseline to First Review		Latest Year		Baseline to Second Review		Baseline to Third Review	
		Relationship with likelihood of		Relationship with likelihood of		Relationship with likelihood of		Relationship with likelihood of	
		Imp.	Det.	Imp.	Det.	Imp.	Det.	Imp.	Det.
No change	**Participant's self-rated health improved**	↑				↑	↑		
No change	**Participant's self-rated health deteriorated**		↑		↑		↑		
Never in paid job	**Carer remained in paid job**	↑				↑			
Safe	**Participant does not feel safe in their home**	↓							
Safe	**Participant feels neither safe or unsafe in their home**	↓							
N/A	**Participant lives in an area with a higher average unemployment rate**					↑			

Key findings from Table 4.8 include:

- Families/carers of participants living outside a major city were more likely to improve on this indicator in the latest year, and from baseline to second review, compared to those respondents whose family member with a disability lived in a major city. They were also less likely to deteriorate from baseline to third review
- Families/carers of participants who reported a deterioration in their self-rated health were more likely to deteriorate in all one step transitions and from baseline to second review compared to respondents of participants who reported no change in their self-reported health.
- State/Territory was found to have a significant impact on the percentage of families/carers who received the services and supports they needed to care for their family member with disability. Participants who lived in QLD, SA, or the group ACT, NT, TAS or WA, were more likely to improve from baseline to first review than those living in NSW.
- Families and carers with latest review response collected during the COVID period were more likely to improve from baseline to third review.

I feel that the services I use for my family member with disability listens to me

The percentage of families and carers who feel that the services they use for their family member with disability listen to them has increased significantly from baseline to all reviews, with net increases of 4.5%, 8.6% and 7.9% from baseline to the first, second and third review, respectively. This was a result of improvements offset by deteriorations as set out in Table 4.9 below.

Table 4.9 Breakdown of net movement in longitudinal responses

Longitudinal Period	Number of Baseline Responses in cohort[1]		Improvements: No to Yes		Deteriorations: Yes to No		Net Movement
	No	Yes	Number	%	Number	%	
Baseline to Review 1	4,168	7,695	1,177	28.2%	648	5.5%	+4.5%
Baseline to Review 2	1,264	2,113	578	45.7%	287	13.6%	+8.6%
Baseline to Review 3	228	407	124	54.4%	74	18.2%	+7.9%

[1]The cohort is selected as all those with non-missing responses at the relevant surveys.

Participant characteristics that had a statistically significant effect ($p<0.05$) on the likelihood of improvement or deterioration in the outcome are set out in Table 4.10 below.

Table 4.10 Key drivers of likelihood of transitions in *"% of families or carers who feel that the services they use for their family member with disability listen to them"* response

Reference Category	Variable	1 step transitions				2 step transitions		3 step transitions	
		Baseline to First Review Relationship with likelihood of		Latest Year Relationship with likelihood of		Baseline to Second Review Relationship with likelihood of		Baseline to Third Review Relationship with likelihood of	
		Imp.	Det.	Imp.	Det.	Imp.	Det.	Imp.	Det.
NSW	**Participant lives in VIC**	↓				↓			
NSW	**Participant lives in QLD**	↑							
NSW	**Participant lives in SA**	↑							
N/A	**Participant is older**					↓			
Male	**Participant is female**			↑		↑			
N/A	**Higher plan utilisation**	↑	↓	↑		↑	↓		↓

Reference Category	Variable	1 step transitions				2 step transitions		3 step transitions	
		Baseline to First Review Relationship with likelihood of		Latest Year Relationship with likelihood of		Baseline to Second Review Relationship with likelihood of		Baseline to Third Review Relationship with likelihood of	
		Imp.	Det.	Imp.	Det.	Imp.	Det.	Imp.	Det.
N/A	Higher Australian Disability Enterprise payments					↑			
N/A	Higher utilisation % of capacity building resources	↑	↓					↑	
Agency managed	Plan is fully self-managed		↓				↓		
Major cities	Participant lives outside a major city			↑		↑			
N/A	General time trend	↓	↓	↓					
N/A	General time trend and during COVID period		↓						
State	Participant did not previously receive services from Commonwealth or State/Territory programs	↑							
Medium level of NDIA support	Lower level of NDIA support			↑					
Medium level of NDIA support	Higher level of NDIA support	↓				↓			
No change	Participant's self-rated health improved	↑		↑	↑				
No change	Participant's self-rated health deteriorated	↑	↑	↑	↑		↑		
Safe	Participant does not feel safe in their home	↓	↑			↓			
Safe	Participant feels neither safe or unsafe in their home	↓	↑			↓		↓	↑

Reference Category	Variable	1 step transitions				2 step transitions		3 step transitions	
		Baseline to First Review Relationship with likelihood of		Latest Year Relationship with likelihood of		Baseline to Second Review Relationship with likelihood of		Baseline to Third Review Relationship with likelihood of	
		Imp.	Det.	Imp.	Det.	Imp.	Det.	Imp.	Det.
Never in paid work	**Carer remained in paid work**	↑							
Never in paid work	**Carer started paid work**	↑				↑			
Never in paid work	**Carer stopped paid work**		↑				↑		
N/A	**Participant lives in an area with a higher average unemployment rate**			↓					

Key findings from Table 4.10 include the following:

- The health status of the participant has a significant impact on the percentage of families/carers who feel that the services they use for their family member with disability listen to them. For example, families/carers of participants whose health deteriorated between reviews were more likely to change their response in all one-step transitions and more likely to deteriorate from baseline to second review compared to respondents of participants who experienced no change in self-reported health.
- Families/carers of participants with higher plan utilisation were more likely to improve from baseline to first review, baseline to second review and in the latest year, and were also less likely to deteriorate in all transitions from baseline
- If the family member or carer started or remained in a paid job between reviews, there was a higher likelihood of improvement from baseline to first review and baseline to second review than those who were never in paid work.
- Family members or carers of participants who felt neither safe nor unsafe at home were less likely to improve in all transitions from baseline and more likely to deteriorate from baseline to first review and baseline to third review than family members or carers of participants who felt safe at home.
- Comparing review responses of participants over time, the likelihood of deterioration in response between baseline and first review over time has reduced in the COVID period compared to the pre-COVID period.

I feel that the services I use for my family member with a disability meet their needs

The percentage of families and carers who felt that the services they used for their family member with a disability met their needs has increased significantly from baseline to all reviews, with net increases of 7.8%, 13.1% and 18.3% from baseline to the first, second and third review, respectively. This was a result of improvements offset by deteriorations as set out in Table 4.11 below.

Table 4.11 Breakdown of net movement in longitudinal responses

Longitudinal Period	Number of Baseline Responses in cohort[1]		Improvements: No to Yes		Deteriorations: Yes to No		Net Movement
	No	Yes	Number	%	Number	%	
Baseline to Review 1	10,154	2,191	1,339	13.2%	382	17.4%	+7.8%
Baseline to Review 2	2,941	632	638	21.7%	169	26.7%	+13.1%
Baseline to Review 3	570	124	169	29.7%	42	33.9%	+18.3%

[1] The cohort is selected as all those with non-missing responses at the relevant surveys.

Participant characteristics that had a statistically significant effect ($p<0.05$) on the likelihood of improvement or deterioration in the outcome are set out in Table 4.12 below.

Table 4.12 Key drivers of likelihood of transitions in *"% of families or carers who feel that the services they use for their family member with disability meet their needs"* response

Reference Category	Variable	1 step transitions				2 step transitions		3 step transitions	
		Baseline to First Review Relationship with likelihood of		Latest Year Relationship with likelihood of		Baseline to Second Review Relationship with likelihood of		Baseline to Third Review Relationship with likelihood of	
		Imp.	Det.	Imp.	Det.	Imp.	Det.	Imp.	Det.
NSW	**Participant lives in QLD**	↑							
NSW	**Participant lives in ACT, NT, TAS, WA**	↑							
Male	**Participant is female**			↑					↓
Non-Indigenous	**Participant is Indigenous**							↑	
N/A	**Lower level of function**				↑		↑		
N/A	**Higher plan utilisation**	↑		↑		↑		↑	
N/A	**Higher Australian Disability Enterprise payments**	↑				↑			

		Baseline to First Review		Latest Year		Baseline to Second Review		Baseline to Third Review	
		Relationship with likelihood of		Relationship with likelihood of		Relationship with likelihood of		Relationship with likelihood of	
		Imp.	Det.	Imp.	Det.	Imp.	Det.	Imp.	Det.
N/A	Higher utilisation % of capacity building resources	⬆							
0-15% capacity building supports	75%-95% of supports are capacity building supports							⬆	
Agency-managed	Plan is managed by a plan manager	⬇		⬇		⬇			
Agency-managed	Plan is fully self-managed	⬆							
Private-owned	Participant lives in a private accommodation rented from a private landlord							⬇	
Private-owned	Participant lives in private accommodation rented from a public landlord								⬆
Major cities	Participant lives in a major city		⬆			⬆			⬇
Did not relocate	Participant relocated to a new Local Government Area (LGA)	⬇	⬆						⬆
N/A	General time trend	⬇				⬇			
State	Participant received services from Commonwealth programs before joining NDIS					⬇			
Medium level of NDIA support	Lower level of NDIA support	⬆						⬆	⬇

Reference Category	Variable	1 step transitions				2 step transitions		3 step transitions	
		Baseline to First Review		Latest Year		Baseline to Second Review		Baseline to Third Review	
		Relationship with likelihood of		Relationship with likelihood of		Relationship with likelihood of		Relationship with likelihood of	
		Imp.	Det.	Imp.	Det.	Imp.	Det.	Imp.	Det.
Medium level of NDIA support	**Higher level of NDIA support**	↓				↓		↓	
No change	**Participant's self-rated health improved**	↑	↑						
No change	**Participant's self-rated health deteriorated**		↑		↑				
Safe	**Participant does not feel safe in their home**	↓				↓			
Safe	**Participant feels neither safe or unsafe in their home**	↓		↓	↑	↓			
Never in paid work	**Carer stopped paid work**						↑		

Key findings from Table 4.12 include:

- Families/carers of participants with higher plan utilisation were more likely to improve.
- The timing of the review had a significant impact on the percentage of families/carers who felt that the services they used for their family member with disability met their needs. Those with a later review were less likely to improve from baseline to first review and from baseline to second review
- There were also differences by plan management type. Families/carers of participants with plans managed by a plan manager were less likely to improve in all one-step transitions and from baseline to second review, compared to families/carers of participants with agency-managed plans
- Family members/carers of participants who relocated to a new LGA were less likely to improve from baseline to first review and baseline to second review compared to those who did not relocate. They were also more likely to deteriorate from baseline to first review.
- Family members/carers of participants who felt neither safe nor unsafe in their home were less likely to improve in all one-step transitions and from baseline to second review and were more likely to deteriorate in the latest year than family members or carers of participants who felt safe at home.

I rate my health as excellent, very good or good

The percentage of families and carers who rated their health as excellent, very good or good has decreased significantly from baseline to all reviews, with net decreases of 2.8%, 6.5% and 8.2% from baseline to the first, second and third review, respectively. This was a result of improvements offset by deteriorations as set out in Table 4.13 below.

Table 4.13 Breakdown of net movement in longitudinal responses

Longitudinal Period	Number of Baseline Responses in cohort[1]		Improvements: No to Yes		Deteriorations: Yes to No		Net Movement
	No	Yes	Number	%	Number	%	
Baseline to Review 1	4,693	7,496	545	11.6%	890	11.9%	-2.8%
Baseline to Review 2	1,348	2,162	238	17.7%	466	21.6%	-6.5%
Baseline to Review 3	234	433	50	21.4%	105	24.3%	-8.2%

[1] The cohort is selected as all those with non-missing responses at the relevant surveys.

Participant characteristics that had a statistically significant effect ($p<0.05$) on the likelihood of improvement or deterioration in the outcome are set out in Table 4.14 below.

Table 4.14 Key drivers of likelihood of transitions in *"% of families or carers who rate their health as excellent, very good or good"* response

Reference Category	Variable	1 step transitions				2 step transitions		3 step transitions	
		Baseline to First Review		Latest Year		Baseline to Second Review		Baseline to Third Review	
		Relationship with likelihood of		Relationship with likelihood of		Relationship with likelihood of		Relationship with likelihood of	
		Imp.	Det.	Imp.	Det.	Imp.	Det.	Imp.	Det.
Mother	**Respondent was the father**	↓	↓						
NSW	**Participant lives in SA**						↑		
Autism	**Disability is cerebral palsy or another neurological disorder**			↑					
Autism	**Disability is a psychosocial disability**			↑					
N/A	**Lower level of function**								↑
N/A	**Higher plan utilisation**		↑						

Reference Category	Variable	1 step transitions				2 step transitions		3 step transitions	
		Baseline to First Review		Latest Year		Baseline to Second Review		Baseline to Third Review	
		Relationship with likelihood of		Relationship with likelihood of		Relationship with likelihood of		Relationship with likelihood of	
		Imp.	Det.	Imp.	Det.	Imp.	Det.	Imp.	Det.
N/A	Higher payments to self-managed employment supports	↑							
N/A	Higher School Leaver Employment Supports						↑		
N/A	Higher utilisation % of core supports						↑		
Agency-managed	Plan is managed by a plan manager		↑						
Private-owned	Participant lives in a private accommodation rented from a private landlord		↑		↑		↑		
Private-owned	Participant lives in a private accommodation rented from a public landlord		↑		↑		↑		
Private-owned	Participant lives in other accommodation				↑				
Major cities	Participant lives outside a major city			↑					
N/A	Participant lives in an area with a higher average unemployment rate								↑
Medium level of NDIA support	Lower level of NDIA support			↑		↑			
Medium level of NDIA support	Higher level of NDIA support	↓							
N/A	General time trend		↓						

Reference Category	Variable	1 step transitions				2 step transitions		3 step transitions	
		Baseline to First Review Relationship with likelihood of		Latest Year Relationship with likelihood of		Baseline to Second Review Relationship with likelihood of		Baseline to Third Review Relationship with likelihood of	
		Imp.	Det.	Imp.	Det.	Imp.	Det.	Imp.	Det.
No change	Participant's self-rated health improved	↑	↑	↑		↑			
No change	Participant's self-rated health deteriorated	↑	↑			↑	↑		
Safe	Participant does not feel safe in their home	↓	↑						
Safe	Participant feels neither safe or unsafe in their home		↑						
Never in paid work	Carer started paid work			↑		↑			↓
Never in paid work	Carer remained in paid work	↑	↓	↑	↓	↑	↓		↓

Key findings from Table 4.14 include the following:

- The participant's self-rated health had a significant impact on the percentage of families/carers who rated their health as excellent, very good or good. For example, where the participant's self-rated health improved between reviews, the family/carer was more likely to report an improvement in all one-step transitions and between baseline and second review, compared to those who reported no change in self-rated health. They were, however, more likely to report a deterioration between baseline and first review
- The families/carer work status also had an impact. When the family/carer remained in paid work, they were less likely to deteriorate across all transitions than those who were never in paid work. They were also more likely to improve in all one-step transitions and between baseline and second review than those who were never in paid work.
- Where the participant lives in private accommodation rented from either a private or public landlord, the family member/carer was more likely to deteriorate in all one-step transitions and between baseline and second review than those in private-owned accommodation.
- If the respondent was the father, transitions (either improvement or deterioration) between baseline and first review are less likely than where the respondent is the mother.

The situation of my child/family member with a disability is a barrier to working more

Of those who are unable to work as much as they want, the percentage of families and carers reporting the situation of their family member with disability being a barrier to working more has increased significantly from baseline to all reviews, with net increases of 1.1%, 1.8% and 4.1% from baseline to the first, second and third review, respectively. This was a result of improvements offset by deteriorations as set out in Table 4.15 below.

Table 4.15 Breakdown of net movement in longitudinal responses

Longitudinal Period	Number of Baseline Responses in cohort[1]		Improvements: Yes to No		Deteriorations: No to Yes		Net Movement
	No	Yes	Number	%	Number	%	
Baseline to Review 1	390	5,282	29	0.6%	91	23.6%	+1.1%
Baseline to Review 2	105	1,426	13	0.9%	41	39.1%	+1.8%
Baseline to Review 3	18	251	3	1.2%	14	77.8%	+4.1%

[1] The cohort is selected as all those with non-missing responses at the relevant surveys.

Participant characteristics that had a statistically significant effect ($p<0.05$) on the likelihood of improvement or deterioration in the outcome are set out in Table 4.16 below.

Table 4.16 Key drivers of likelihood of transitions in *"of those unable to work as much as they want, % who say the situation of their child/family member with disability is a barrier to working more"* response

Reference Category	Variable	1 step transitions				2 step transitions		3 step transitions	
		Baseline to First Review		Latest Year		Baseline to Second Review		Baseline to Third Review	
		Relationship with likelihood of		Relationship with likelihood of		Relationship with likelihood of		Relationship with likelihood of	
		Imp.	Det.	Imp.	Det.	Imp.	Det.	Imp.	Det.
Autism	**Disability is a psychosocial disability**	↑							
Autism	**Disability is other**	↑							
N/A	**Lower level of function**	↓		↓		↓			
N/A	**Higher plan utilisation**	↓	↑						
N/A	**Higher payments to other employment supports**	↑				↑			

Reference Category	Variable	1 step transitions				2 step transitions		3 step transitions	
		Baseline to First Review		Latest Year		Baseline to Second Review		Baseline to Third Review	
		Relationship with likelihood of		Relationship with likelihood of		Relationship with likelihood of		Relationship with likelihood of	
		Imp.	Det.	Imp.	Det.	Imp.	Det.	Imp.	Det.
Private-owned	**Participant lives in supported accommodation**			↑					
N/A	**Participant lives in an area with a higher average unemployment rate**	↑							
Entry due to disability	**Participants entered the scheme through Early Intervention**		↓	↑		↑			

Key findings from Table 4.16 included the following:

- Disability type had a significant impact on the percentage of families/carers who were unable to work as much as they wanted and who reported that the situation of their child/family member with disability was a barrier to working more. Where the disability is a psychosocial disability, the family or carer was more likely to improve between baseline and first review than respondents with participants whose disability is autism.
- Level of function also had a significant impact, with a lower level of function resulting in the family/carer being less likely to improve in all one-step transitions and from baseline to second review.
- Where the participant entered the Scheme through early intervention (s24), the family member/carer was more likely to improve their response from baseline to second review and in the latest year, and less likely to report a deterioration from baseline to first review, than where the participant entered the Scheme due to disability (s25).
- Higher plan utilisation resulted in the family/carer being less likely to improve and more likely to deteriorate between baseline and first review.

The availability of jobs is a barrier to working more

Of those who were unable to work as much as they want, the percentage of families and carers who reported the availability of jobs as a barrier to working more has increased significantly from baseline to all reviews, with net increases of 2.3%, 4.0% and 1.1% from baseline to the first, second and third review, respectively. This was a result of improvements offset by deteriorations as set out in Table 4.17 below.

Table 4.17 Breakdown of net movement in longitudinal responses

Longitudinal Period	Number of Baseline Responses in cohort[1]		Improvements: Yes to No		Deteriorations: No to Yes		Net Movement
	No	Yes	Number	%	Number	%	
Baseline to Review 1	4,797	875	56	6.4%	189	3.9%	+2.3%
Baseline to Review 2	1,274	257	36	14.0%	97	7.6%	+4.0%
Baseline to Review 3	208	61	12	19.7%	15	7.2%	+1.1%

[1] The cohort is selected as all those with non-missing responses at the relevant surveys.

Participant characteristics that had a statistically significant effect ($p<0.05$) on the likelihood of improvement or deterioration in the outcome are set out in Table 4.18 below.

Table 4.18 Key drivers of likelihood of transitions in *"of those unable to work as much as they want, % who say the availability of jobs is a barrier to working more"* response

Reference Category	Variable	1 step transitions				2 step transitions		3 step transitions	
		Baseline to First Review		Latest Year		Baseline to Second Review		Baseline to Third Review	
		Relationship with likelihood of		Relationship with likelihood of		Relationship with likelihood of		Relationship with likelihood of	
		Imp.	Det.	Imp.	Det.	Imp.	Det.	Imp.	Det.
N/A	**Participant is older**						⬇		
N/A	**Higher plan utilisation**		⬇						
N/A	**Higher Australian Disability Enterprise payments**			⬆					
N/A	**Higher School Leaver Employment Supports**		⬆						
N/A	**Higher payments to other employment supports**		⬆						
N/A	**Higher utilisation % of capacity building resources**	⬆							

Reference Category	Variable	1 step transitions				2 step transitions		3 step transitions	
		Baseline to First Review		Latest Year		Baseline to Second Review		Baseline to Third Review	
		Relationship with likelihood of		Relationship with likelihood of		Relationship with likelihood of		Relationship with likelihood of	
		Imp.	Det.	Imp.	Det.	Imp.	Det.	Imp.	Det.
Major city	Participant lives outside a major city		⬆						
Did not relocate	Participant relocated to a new Local Government Area (LGA)			⬆					
Not during COVID	Review during COVID period								⬆
N/A	General time trend		⬇			⬇			
Entry due to disability	Participants entered the scheme through Early Intervention						⬆		
Medium level of NDIA support	Higher level of NDIA support		⬇				⬇		
No change	Participant's self-rated health deteriorated	⬆							
Never in paid work	Carer started paid work	⬆				⬆			
Never in paid work	Carer stopped paid work		⬆		⬆		⬆		
Never in paid work	Carer remained in paid work	⬆	⬇		⬇		⬇		
Safe	Participant feels neither safe or unsafe in their home						⬆		

Key findings from Table 4.18 include:

- The family/carer's work status has a significant impact on the percentage of families or carers who were unable to work as much as they wanted and who identified the availability of jobs is a barrier to being able to work more. For example, if the family member/carer stopped work between reviews, they were more likely to deteriorate in all one-step transitions and between baseline and second review than those who were never in paid work. The reverse was true for those who remained in paid work between reviews

- Where the participant received a high level of NDIA support[28], the family/carer were less likely to report a deterioration between baseline and first review and between baseline and second review.
- Deterioration is more likely between baseline and third review for families and carers whose interview took place after COVID impact.

Insufficient flexibility of jobs is a barrier to working more

Of those who were unable to work as much as they wanted, the percentage of families/carers who reported the inflexibility of jobs as a barrier to working more has increased significantly from baseline to all reviews, with net increases of 2.6%, 3.1% and 1.1% from baseline to the first, second and third review, respectively. This was a result of improvements offset by deteriorations as set out in Table 4.19 below.

Table 4.19 Breakdown of net movement in longitudinal responses

Longitudinal Period	Number of Baseline Responses in cohort[1]		Improvements: Yes to No		Deteriorations: No to Yes		Net Movement
	No	Yes	Number	%	Number	%	
Baseline to Review 1	3,938	1,734	81	4.7%	231	5.9%	+2.6%
Baseline to Review 2	995	536	67	12.5%	114	11.5%	+3.1%
Baseline to Review 3	153	116	21	18.1%	24	15.7%	+1.1%

[1] The cohort is selected as all those with non-missing responses at the relevant surveys.

Participant characteristics that had a statistically significant effect ($p<0.05$) on the likelihood of improvement or deterioration in the outcome are set out in Table 4.20 below.

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[28] The level of NDIA support a participant requires as they move along the participant pathway, having regard to the complexity of their situation.

Table 4.20 Key drivers of likelihood of transitions in *"of those unable to work as much as they want, % who say the inflexibility of jobs is a barrier to working more"* response

Reference Category	Variable	1 step transitions				2 step transitions		3 step transitions	
		Baseline to First Review Relationship with likelihood of		Latest Year Relationship with likelihood of		Baseline to Second Review Relationship with likelihood of		Baseline to Third Review Relationship with likelihood of	
		Imp.	Det.	Imp.	Det.	Imp.	Det.	Imp.	Det.
Mother	Respondent was the sibling	⬆							
N/A	Lower level of function						⬆		
N/A	Higher plan utilisation	⬆							
N/A	Higher Australian Disability Enterprise payments						⬆		
Did not relocate	Participant relocated to a new Local Government Area (LGA)					⬆			
N/A	General time trend		⬇				⬇		
Entered the Scheme for disability	Participant entered the scheme for early intervention	⬆							
Medium level of NDIA support	Higher level of NDIA support		⬇				⬇		
No change	Participant's self-rated health improved		⬆						
No change	Participant's self-rated health deteriorated		⬆						
Never in paid work	Carer started paid work	⬆	⬆						
Never in paid work	Carer stopped paid work				⬆		⬆		

Reference Category	Variable	1 step transitions				2 step transitions		3 step transitions	
		Baseline to First Review Relationship with likelihood of		Latest Year Relationship with likelihood of		Baseline to Second Review Relationship with likelihood of		Baseline to Third Review Relationship with likelihood of	
		Imp.	Det.	Imp.	Det.	Imp.	Det.	Imp.	Det.
Never in paid work	**Carer remained in paid work**						⬇		

Key findings from Table 4.20 include the following:

- The family member/carer work status had a significant impact on the percentage of families or carers who were unable to work as much as they wanted and who reported the inflexibility of jobs as a barrier to working more. For example, if the family/carer stopped paid work, they were more likely to deteriorate in the latest year for one-step transitions, and from baseline to second review, than those who were never in paid work
- Where the participant received a high level of NDIA support[29], the family/carer was less likely to report a deterioration between baseline and first review and between baseline and second review
- If the participant's self-rated health status changed between reviews (either improvement or deterioration), families/carers were more likely to report a deterioration between baseline and first review.

The key findings from this section are summarised in Box 4.6.

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[29] The level of NDIA support a participant requires as they move along the participant pathway, having regard to the complexity of their situation.

Box 4.6: Summary of findings – longitudinal outcomes by participant and family/ carer characteristics

- Families and carers of participants with autism were more likely to deteriorate in having someone to talk to for emotional support between baseline and first review. Compared to families/carers of participants with autism, families/carers of participants with a psychosocial disability were more likely to improve in self-rated health over the latest year, and in saying their child's disability is a barrier to working more between baseline and first review.
- Families and carers of participants with a lower level of function were less likely to improve and/or more likely to deteriorate across a number of indicators. For example, they were more likely to deteriorate in the latest year and between baseline and second review in thinking that the services they use meet the needs of their family member with disability, and less likely to improve in thinking the situation of their family member with disability is a barrier to working more.
- Families/carers of participants living outside a major city had more positive outcomes in some areas. For example, they were more likely to improve in thinking that the services they use listen to them.
- Higher plan utilisation was a positive factor for some indicators. For example, it was associated with a higher likelihood of improvement and a lower likelihood of deterioration for feeling that the services they use listen to them, and a higher likelihood of improvement in saying that the services they use meet the needs of their family member with disability.
- Families and carers of participants with fully self-managed plans were less likely to deteriorate in thinking the services they use listen to them, and more likely to improve in saying the services meet their needs. Those with plan-managed plans, however, are less likely to improve on the latter indicator.
- There were a few significant changes to families' and carers' longitudinal outcomes during the pandemic, and results were mixed. For example, families and carers whose latest response was collected during the COVID period were more likely to show deterioration from baseline to first review in working 15 or more hours per week, however, they are less likely to deteriorate between baseline and first review in thinking that the services they use listen to them.