6. Families/carers of participants aged 25 and over: Outcome indicators

6.1 Key findings

Box 6.1: Overall findings for C3 cohort (families/carers of participants aged 25 or older, who have been in the scheme for 3 years)[33]

- For the small number of families/carers of participants aged 25 and over entering the Scheme in 2016-17 who contributed to the longitudinal analysis, there were significant and material changes for five indicators.
- Four positive changes were observed related to satisfaction with services. The percentage of families/carers who say that the services their family member with disability and their family receive meets their needs improved from 23.8% at baseline to 36.3% at third review. The percentage who said that the services and supports have helped them to better care for their family member with disability increased from 36.4% to 77.3% over three years, and the percentage who said the services helped them to plan for the future increased from 40.9% to 72.7%.
- The percentage who say they receive Carer Allowance increased from 31.3% at baseline to 41.3% at third review.

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[33] Note that this is a small group of less than 150 respondents for the SF, and smaller again for the LF (less than 30), so results should be interpreted with caution.

Box 6.2: Overall findings for C2 cohort (families/carers of participants aged 25 or older, who have been in the scheme for 2 years)[34]

- Significant improvements were observed in the access to services domain. The percentage of families/carers who said that the services their family member with disability receives meets their needs increased from 21.3% at baseline to 33.6% at second review, the percentage who say the services they use listen to them increased from 68.3% to 74.8%, and the percentage who say the services help them to plan for the future increased from 63.6% to 74.7%.
- There were also some positive results in the health and wellbeing domain. The percentage of families/carers who felt their family member with disability gets the support they need rose from 26.6% at baseline to 40.9% at second review, and the percentage who strongly agree or agree that services and supports have helped them to better care for their family member with disability increased from 54.6% to 73.6%. Additionally, of families/carers who provide informal care to their family member with disability, the percentage that are able to work as much as they want increased from 58.0% at baseline to 61.2% at second review.
- However, the percentage rating their health as excellent, very good or good has declined by 6.5% over the two years from 58.5% to 52.0%, and the percentage who say insufficient flexibility of jobs is a barrier to working more increased by 4.5% from 21.8% to 26.3%.

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[34] Around 3500 respondents for the SF, and 160 for the LF.

Box 6.3: Overall findings for C1 cohort (families/carers of participants aged 25 or older, who have been in the scheme for one year)[35]

- Significant improvements were observed in the access to services domain. The percentage of families/carers who said that the services their family member with disability receives meets their needs increased from 20.0% at baseline to 27.0% at first review, the percentage who say the services they use listen to them increased from 68.5% to 71.8%, and the percentage who say the services help them to plan for the future increased from 66.5% to 73.8%.
- There were also some positive results in the health and wellbeing domain. The percentage of families/carers who felt their family member with disability gets the support they need rose from 26.4% at baseline to 34.7% at first review, and the percentage who strongly agree or agree that services and supports have helped them to better care for their family member with disability increased from 48.1% to 69.9%. Families/carers also felt more positive about the future, with the percentage feeling more confident about the future of their family with disability under the NDIS increasing from 48.1% to 66.7% at first review, and the percentage feeling at least mostly satisfied when thinking about last year and what they expect for the future increasing from 47.6% at baseline to 58.7%.
- However, the percentage rating their health as excellent, very good or good has declined by 4.6% over one year from 58.5% to 53.9%, and the percentage who are able to advocate for their family member with disability declined by 1.6% from 69.0% to 67.4%.

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[35] Around 12000 respondents for the SF, and 400 for the LF.

Box 6.4: Outcomes by key characteristics for families/carers of participants aged 25 or older

- Families and carers of participants who feel safe in their home, and of participants whose self-rated health improves, are more likely to improve and/or less likely to deteriorate in several outcomes.
- Family/carer employment status is also a significant factor for some outcomes. For example, families/carers who remain in paid work are more likely to improve and less likely to deteriorate in rating their health as excellent, very good or good.
- Families/carers of participants living in States/Territories other than Victoria tended to have more positive longitudinal outcomes. For example, they were more likely to improve in the latest year in thinking that the services they receive meet their needs.
- Families/carers of CALD participants were less likely to improve in thinking that their family member with disability gets the support they need.
- Families/carers of older participants had some more favourable longitudinal outcomes, for example, they were more likely to improve in thinking that the services they receive meet their needs.
- Higher plan utilisation was associated with being more likely to improve in thinking that the services they and their family member receive meet their needs, and that their family member gets the support they need.
- Participants living outside a major city were more likely to improve in the latest year in thinking that the services they receive meet their needs, and in thinking that their family member gets the support they need.
- Families/carers of participants with lower level of function were more likely to deteriorate in rating their health as excellent, very good or good.

Box 6.5: Has the NDIS helped families/carers of participants aged 25 and over?

- Improvements in positive response rates were observed over the participant's second year across all domains, however there was minimal change or a slight decline (for access to services and succession planning) over the third year.

After one year in the Scheme:

- Higher baseline plan utilisation, and higher annualised plan budget, were associated with a higher likelihood of responding positively.
- Families/carers of older participants are more likely to say the NDIS helped for the domains rights and advocacy, support for family, and succession planning.
- Families/carers of participants living in QLD or WA were more likely than families/ carers of participants living in NSW to think that the NDIS has helped, across all domains.
- Compared to families/carers of participants who live in a major city, families/ carers of participants who live in regional areas are more likely to respond positively, and families/carers of those living in remote/very remote areas are less likely to respond positively, across all domains except health and wellbeing.
- Families/carers of participants with better self-rated health, and of participants who feel safe in their home, are more likely to respond positively.
- Families/carers of participants who work in a paid or unpaid job are more likely to think the NDIS has helped with level of support, succession planning, and health and wellbeing.

Looking at changes over time:

- Higher plan utilisation (and particularly utilisation of core supports), and higher annualised plan budget, were generally associated with a higher likelihood of improvement and/or lower likelihood of deterioration.
- Families/carers of participants living outside a major city were more likely to improve in thinking the NDIS has helped with level of support, access to services, and succession planning.
- Families/carers of participants with lower level of function were more likely to deteriorate in thinking the NDIS has helped with rights and advocacy, and less likely to improve for succession planning, however, they were less likely to deteriorate for health and wellbeing.

6.2 Outcomes framework questionnaire domains

For families/carers of participants aged 25 and over, 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)
- Have succession plans (SC)
- Enjoy health and wellbeing (HW).

The LF contains a number of extra questions for the adult cohorts, across all domains, but particularly in the health and wellbeing domain.

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 25 plus family and carer cohort comprises families and carers of participants who are aged from 25 when they enter the Scheme, and includes responses at all review time points.

6.3 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 6.1 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[36] and had an absolute magnitude greater than 0.02 for at least one entry year cohort.

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[36] McNemar's test at the 0.05 level.

Table 6.1 Selected longitudinal indicators for families/carers of participants aged 25 and over

Domain (Form)	Indicator	Cohort	Indicator at:				Change		Significant	
			Baseline	Review 1	Review 2	Review 3	Latest year	Overall	Latest year	Overall
Improvement										
SP (SF)	% of families or carers who get the services and supports they need to care for their family member with disability	C3	12.0%	22.7%	4.2%	20.0%	15.8%	8.0%		
		C2	11.5%	13.1%	16.5%		3.4%	4.9%	**	**
		C1	11.9%	14.7%			2.8%	2.8%	**	**
AC (SF)	% of families or carers who feel that the services they use for their family member with disability listen to them	C3	67.6%	77.3%	56.5%	75.7%	19.2%	8.1%		
		C2	68.3%	72.4%	74.8%		2.4%	6.6%	*	**
		C1	68.5%	71.8%			3.3%	3.3%	**	**
AC (SF)	% of families or carers who say that the services their family member with disability and their family receive meet their needs	C3	23.8%	40.4%	44.4%	36.3%	-8.2%	12.5%		*
		C2	21.3%	31.6%	33.6%		1.9%	12.2%	**	**
		C1	20.0%	27.0%			7.0%	7.0%	**	**
SC (SF)	% of families or carers who have made plans for when they are no longer able to care for their family member with disability	C3	8.0%	4.5%	20.0%	14.7%	-5.3%	6.7%		
		C2	10.6%	12.0%	13.4%		1.3%	2.8%	**	**
		C1	11.1%	12.8%			1.6%	1.6%	**	**
SC (SF)	of those who made or have begun making plans, % of families or carers who have asked for help from service providers, professionals or support workers	C3	58.8%	37.5%	50.0%	58.8%	8.8%	0.0%		
		C2	60.5%	61.3%	66.5%		5.3%	6.1%	*	**
		C1	56.9%	61.0%			4.1%	4.1%	**	**
AC (LF)	% whose family member with disability and family receive help to plan for the future	C3	40.9%	50.0%	72.7%	72.7%	0.0%	31.8%		*
		C2	63.6%	79.0%	74.7%		-4.3%	11.1%		*
		C1	66.5%	73.8%			7.3%	7.3%	*	*

Domain (Form)	Indicator	Cohort	Indicator at:				Change		Significant	
			Baseline	Review 1	Review 2	Review 3	Latest year	Overall	Latest year	Overall
HW (LF)	Thinking about what happened last year, and what they expect for the future, % who are delighted, pleased or mostly satisfied	C3	50.0%	54.5%	54.5%	63.6%	9.1%	13.6%		
		C2	45.4%	52.1%	49.1%		-3.1%	3.7%		
		C1	47.6%	58.7%			11.2%	11.2%	*	*
HW (LF)	% who disagree or strongly disagree that having a family member with a disability has made it more difficult for them to meet the everyday cost of living	C3	13.6%	22.7%	22.7%	36.4%	13.6%	22.7%		
		C2	20.2%	28.8%	32.5%		3.7%	12.3%		*
		C1	21.6%	26.7%			5.1%	5.1%		
HW (LF)	% who strongly agree or agree that they feel more confident about the future of their family with disability under the NDIS	C3	50.0%	45.5%	54.5%	77.3%	22.7%	27.3%		
		C2	39.9%	58.3%	65.0%		6.7%	25.2%		**
		C1	48.1%	66.7%			18.7%	18.7%	**	**
HW (LF)	% who strongly agree or agree that services and supports have helped them to better care for their family member with disability	C3	36.4%	54.5%	59.1%	77.3%	18.2%	40.9%		*
		C2	54.6%	66.9%	73.6%		6.7%	19.0%		*
		C1	48.1%	69.9%			21.8%	21.8%	**	**
HW (SF)	% of families or carers who feel their family member with disability gets the support they need	C3	38.5%	52.2%	42.3%	44.9%	2.6%	6.4%		*
		C2	26.6%	34.2%	40.9%		6.7%	14.3%	**	**
		C1	26.4%	34.7%			8.3%	8.3%	**	**
HW (SF)	% of families or carers who provide informal care to their family member with disability and are able to work as much as they want	C3	59.7%	73.2%	70.8%	62.5%	-8.3%	2.8%		
		C2	58.0%	58.8%	61.2%		2.4%	3.2%	*	**
		C1	57.5%	59.0%			1.6%	1.6%	**	**

Domain (Form)	Indicator	Cohort	Indicator at:				Change		Significant	
			Baseline	Review 1	Review 2	Review 3	Latest year	Overall	Latest year	Overall
Context dependent										
GB (SF)	% of families or carers who are receiving carer allowance	C3	31.3%	48.9%	51.9%	41.3%	-10.6%	10.0%		*
		C2	46.3%	52.5%	50.4%		-2.1%	4.1%		**
		C1	44.7%	48.3%			3.6%	3.6%	**	**
Deterioration										
RA (SF)	% of families or carers who are able to identify the needs of their family and family member with disability and know how to access available services and supports to meet these needs	C3	49.4%	54.3%	53.8%	53.2%	-0.7%	3.8%		
		C2	48.3%	45.5%	46.2%		0.7%	-2.1%		*
		C1	47.8%	46.4%			-1.4%	-1.4%	**	**
RA (SF)	% of families or carers who are able to advocate (stand up) for their family member with disability	C3	72.2%	80.4%	73.1%	73.4%	0.3%	1.3%		
		C2	72.1%	72.0%	69.4%		-2.6%	-2.8%	*	**
		C1	69.0%	67.4%			-1.6%	-1.6%	**	**
SP (SF)	% of families or carers who have people they can ask for practical help as often as they need	C3	46.3%	57.4%	44.4%	45.0%	0.6%	-1.3%	*	
		C2	39.0%	37.6%	36.9%		-0.6%	-2.0%	*	*
		C1	37.4%	37.6%			0.2%	0.2%		
HW (SF)	% of families or carers who rate their health as excellent, very good or good	C3	49.3%	61.4%	66.7%	53.3%	-13.3%	4.0%		
		C2	58.5%	55.9%	52.0%		-4.0%	-6.5%	*	**
		C1	58.5%	53.9%			-4.6%	-4.6%	**	**

Domain (Form)	Indicator	Cohort	Indicator at: Baseline	Review 1	Review 2	Review 3	Change Latest year	Overall	Significant Latest year	Overall
HW (SF)	of those unable to work as much as they want, % of families or carers who say availability of jobs is a barrier to working more	C3	28.6%	22.2%	25.0%	23.8%	-1.2%	-4.8%		
		C2	12.5%	15.1%	15.5%		0.4%	3.0%	*	*
		C1	11.1%	11.8%			0.7%	0.7%	*	*
HW (SF)	of those unable to work as much as they want, % of families or carers who say insufficient flexibility of jobs is a barrier to working more	C3	38.1%	33.3%	50.0%	33.3%	-16.7%	-4.8%		
		C2	21.8%	25.4%	26.3%		0.8%	4.4%	*	**
		C1	21.1%	22.6%			1.5%	1.5%	**	**

For families and carers of participants aged 25 and above, the majority of changes between baseline and third review were positive. Noting the smaller volume of respondents for families/carers of participants at third review, and for the LF generally, key findings from Table 6.4 include that between baseline and third review:

- The percentage of families or carers who say that the services their family member with disability and their family receive meet their needs increased by 11.5%.
- The percentage of families or carers who get the services and supports they need to care for their family member with disability increased by 7.8%. Additionally, the percentage of families/carers who strongly agree or agree that the services and supports have helped them to better care for their family member with disability increased by 40.9%.
- The percentage of families or carers who feel that the services they use for their family member with disability listen to them increased by 7.9%, and the percentage who say the services they receive help them to plan for the future increased by 31.8%.
- The percentage of families or carers who have made plans for when they are no longer able to care for their family member with disability increased by 6.5%, noting a low baseline at 7.8%.

6.4 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, and Section 4.4 describes the transitions that have been modelled.

Some key features of the analyses for selected indicators are summarised below.[37]

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

The percentage of families and carers who 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 2.6%, 4.7% and 7.8% from baseline to the first, second and third review, respectively. This was a result of improvements offset by deteriorations as set out in Table 6.2 below.

Table 6.2 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	10,787	1,447	576	5.3%	253	17.5%	+2.6%
Baseline to Review 2	2,456	323	213	8.7%	81	25.1%	+4.7%
Baseline to Review 3	68	9	10	14.7%	4	44.4%	+7.8%

[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 6.3 below.

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

Table 6.3 Key drivers of likelihood of transitions in *“% who get the services and supports they need to care for their family member with disability”* 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.
VIC	Participant lives in QLD	↑							
VIC	Participant lives in SA	↑							
VIC	Participant lives in ACT, NT, TAS, WA	↑							
Non-CALD	Participant is CALD	↓		↓		↓			
Male	Participant is female			↑					
N/A	Participant is older						↓		
N/A	Lower level of function		↑						
N/A	Higher plan utilisation			↓					
N/A	Higher utilisation % of core supports	↑							
N/A	Higher utilisation % of capital building supports								
Non-SIL	Participant is in Supported Independent Living (SIL)			↑			↓		
N/A	Higher Australian Disability Enterprise payments								
N/A	Higher payments to self-managed employment supports			↑					
Agency-managed	Plan is partly self-managed		↓			↑			

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**	⬆							
Private-owned	**Participant lives in aged care**	⬆							
Private-owned	**Participant lives in supported accommodation**	⬆	⬇						
Safe	**Participant feels neither safe or unsafe in their home**	⬇	⬆			⬇			
Safe	**Participant does not feel safe in their home**	⬇				⬇			
Medium level of NDIA support	**Higher level of NDIA support**		⬇						
Received State/ Territory supports	**Participant received services from Commonwealth programs before joining NDIS**						⬇		
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**	⬆				⬆			
N/A	**Participant lives in an area with a higher average unemployment rate**						⬆		

Key findings from Table 6.3 include:

- State/Territory has a significant impact whether families and carers get the supports they need to care for their family member with disability. Where the participant lives in QLD, SA, or the group ACT, NT, TAS or WA, the family member or carer was more likely to improve from baseline to first review than when the participant lived in Victoria.
- Where the participant's self-rated health improved between reviews, families/carers were more likely to improve in all one-step transitions and between baseline and second review, compared to where the participant's self-rated health did not change.
- Where the family member or carer stopped paid work between reviews, they were more likely to improve between baseline and first review and between baseline and second review than those who were never in paid work.
- Families/carers of CALD participants were more likely to deteriorate in all one-step transitions and between baseline and second review than families/carers of non-CALD participants.
- Where the participant feels unsafe in their home, families/carers were less likely to improve from baseline to first review and from baseline to second review than where the participant feels safe.

The services my family member with a disability and my family receive meet our needs

The percentage of families and carers who say that the services their family member with disability and their family receive meet their needs increased significantly from baseline to all reviews, with net increases of 7.3%, 11.9% and 11.5% from baseline to the first, second and third review, respectively. This was a result of improvements offset by deteriorations as set out in Table 6.4 below.

Table 6.4 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	10,033	2,556	1,291	12.9%	372	14.6%	+7.3%
Baseline to Review 2	2,279	617	460	20.2%	114	18.5%	+11.9%
Baseline to Review 3	67	20	16	23.9%	6	30.0%	+11.5%

[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 6.5 below.

Table 6.5 Key drivers of likelihood of transitions in *“% of families or carers who say that the services their family member and their family receive 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.
VIC	Participant lives in NSW	⬆		⬆					
VIC	Participant lives in QLD	⬆		⬆					
VIC	Participant lives in SA			⬆					
VIC	Participant lives in ACT, NT, TAS, WA	⬆		⬆					
Down Syndrome / Intellectual disability	Disability is sensory impairment		⬇						
2016/17	Participant entered the Scheme in 2017/18		⬇						
2016/17	Participant entered the Scheme in 2018/19		⬇						
Non-CALD	Participant is CALD				⬆				
Male	Participant is female						⬆		
N/A	Participant is older			⬆		⬆			
N/A	Lower level of function	⬆							
N/A	Higher plan utilisation	⬆				⬆			
0-15% capacity building supports	15%-30% of supports are capacity building supports	⬇							
0-15% capacity	30%-60% of supports are	⬇							

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.
building supports	capacity building supports								
N/A	Higher Australian Disability Enterprise payments	↑							
Agency-managed	Plan is managed by a plan manager		↑						
Pre-COVID	Review during COVID period	↑							
N/A	General time trend	↓					↑		
Major city	Participant lives outside a major city	↑		↑		↑			
Did not relocate	Participant relocated to a new Local Government Area (LGA)				↑				
Private-owned	Participant lives in other accommodation						↑		
Safe	Participant feels neither safe or unsafe in their home	↓	↑		↑	↓			
Safe	Participant does not feel safe in their home	↓	↑	↓	↑	↓	↑		
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								

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.
Never in paid work	**Carer stopped paid work**	⬆							

Key findings from Table 6.5 include:

- State/Territory has a significant impact whether families and carers get the supports they need to care for their family member with disability. Where the participant lives in NSW, QLD, or the group ACT, NT, TAS or WA, the family member/ carer was more likely to improve in all one-step transitions than those living in Victoria.
- The health status of the participant also has a significant impact. For example, where the participant's self-rated health improved between reviews, families/carers were more likely to report an improvement in all one-step transitions and from baseline to second review than when the participant's health did not change.
- Where there is a higher level of NDIA support, the response was less likely to change (either improve or deteriorate) between baseline and first review and was less likely to improve between baseline and second review than where there is a medium level of NDIA support.[38]
- Where the participant lives outside of a major city, families/carers were more likely to report an improvement in all one-step transitions and from baseline to second review than where the participant lived in a major city.
- Where the participant feels unsafe in their home, families/carers were less likely to improve and more likely to deteriorate across all one-step transitions and from baseline to second review than where the participant feels safe in their home.
- Families and carers who gave their later response during the COVID period were more likely to improve between baseline and first review.

I rate my health as excellent, very good or good

The percentage of families and carers who rate their health as excellent, very good or good has decreased significantly from baseline to first and second reviews, with net decreases of 4.5%, 6.3% from baseline to the first and second review, respectively. The percentage has increased by 2.6% from baseline to third review (but the numbers involved were very small). This was a result of improvements offset by deteriorations as set out in Table 6.6 below.

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

Table 6.6 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	5,077	7,222	412	8.1%	963	13.3%	-4.5%
Baseline to Review 2	1,159	1,632	146	12.6%	322	19.7%	-6.3%
Baseline to Review 3	39	38	10	25.6%	8	21.1%	+2.6%

[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 6.7 below.

Table 6.7 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 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 father**		⬇						
Mother	**Respondent was the sibling**		⬇						
Mother	**Respondent was the spouse/partner**		⬇						
2016/17	**Participant entered the Scheme in 2017/18**						⬆		
N/A	**Participant is older**		⬆						
Non-Indigenous	**Participant is Indigenous**		⬆						
N/A	**Lower level of function**		⬆		⬆		⬆		
N/A	**Higher utilisation % of core 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.
Non-SIL	Participant is in Supported Independent Living (SIL)		⇩						
N/A	Higher payments to self-managed employment supports		⬆						
Agency-managed	Plan is fully self-managed		⇩						
Agency-managed	Plan is partly self-managed		⇩						
N/A	General time trend	⬇							
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 authority			⬇					
Safe	Participant feels neither safe or unsafe in their home	⬇	⬆		⬆		⬆		
Safe	Participant does not feel safe in their home	⬇	⬆		⬆		⬆		
Medium level of NDIA support	Higher level of NDIA support	⬇	⇩			⬇	⇩		
No change	Participant's self-rated health improved	⇧		⇧		⇧			

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 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**	⬆	⬇		⬇		⬇		

Key findings from Table 6.7 include the following:

- The health status of the participant has a significant impact on whether families or carers rate their health as excellent, very good or good. For example, where the participant's self-rated health improved between reviews, the family member or carer was more likely to report an improvement in all one-step transitions and from baseline to second review than where the participant's health did not change.
- Families/carers of participants with a lower level of function were more likely to deteriorate in all one-step transitions and from baseline to second review than families/carers of participants with a higher level of function.
- Where there is a higher level of NDIA support, the response was less likely to change (either improve or deteriorate) between baseline and first review and between baseline and second review than where there is a medium level of NDIA support.[39]
- Where the family/carer remained in paid work between reviews, the response was less likely to deteriorate in all one-step transitions and between baseline and second review, and was more likely to improve between baseline and first review.
- Where the participant feels neither safe nor unsafe, or feels unsafe, in their home, families/carers were more likely to deteriorate in all one-step transitions and between baseline and second review, and were less likely to improve between baseline and first review, than where the participant feels safe in their home.

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

I feel my family member with a disability gets the support they need

The percentage of families and carers who feel that their family member with a disability gets the support they need has increased significantly from baseline to all reviews, with net increases of 8.2%, 14.2% and 5.0% from baseline to the first, second and third review, respectively. This was a result of improvements offset by deteriorations as set out in Table 6.8 below.

Table 6.8 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	9,004	3,245	1,603	17.8%	596	18.4%	+8.2%
Baseline to Review 2	2,045	745	571	27.9%	175	23.5%	+14.2%
Baseline to Review 3	49	31	14	28.6%	10	32.3%	+5.0%

[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 6.9 below.

Table 6.9 Key drivers of likelihood of transitions in *"% of families or carers who feel their family member with disability gets the support they need"* 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.
VIC	**Participant lives in NSW**	⬆							
VIC	**Participant lives in QLD**	⬆							
VIC	**Participant lives in ACT, NT, TAS, WA**	⬆							
Male	**Participant is female**						⬆		
Non-CALD	**Participant is CALD**	⬇		⬇		⬇			

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	Lower level of function	⬆	⬆						
N/A	Higher plan utilisation	⬆				⬆	⬇		
N/A	Higher utilisation % of capacity building supports	⬆							
N/A	Higher utilisation % or core supports		⬇						
0-15% capacity building supports	30%-60% of supports are capacity building supports	⬇							
0-15% capacity building supports	60-100% of supports are capacity building supports	⬇							
0-5% capital supports	More than 5% of supports are capital supports	⬇							
Non-SIL	Participant is in Supported Independent Living (SIL)		⬇						
N/A	Higher payments to self-managed employment supports	⬆							
Pre-COVID	Review during COVID period		⬇			⬇			
N/A	General time trend	⬇							
Major city	Participant lives outside a major city	⬆		⬆		⬆	⬇		

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.
Did not relocate	**Participant relocated to a new Local Government Area (LGA)**					⬇			
Safe	**Participant feels neither safe or unsafe in their home**	⬇	⬆	⬇		⬇			
Safe	**Participant does not feel safe in their home**	⬇	⬆	⬇		⬇	⬆		
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 stopped paid work**	⇧				⇧			
Never in paid work	**Carer remained in paid work**	⇧							

Key findings from Table 6.9 include:

- State/Territory has a significant impact on whether families and carers get the supports they need to care for their family member with disability. Where the participant lives in NSW, QLD, or the group ACT, NT, TAS or WA, the family member or carer was more likely to improve from baseline to first review than where the participant lived in Victoria.
- The health status of the participant also has a significant impact. For example, where the participant's self-rated health deteriorated between reviews, families/carers were more likely to report a deterioration in all one-step transitions than where there was no change in status.

- Where the participant lives outside a major city, families/carers were more likely to report an improvement in all one-step transitions and from baseline to second review than where they live in a major city. They were also less likely to report a deterioration between baseline and second review.
- Plan utilisation also has a significant impact. Where plan utilisation was higher, families/carers were more likely to report an improvement between baseline and first or second review, and less likely to report a deterioration between baseline and second review.
- Where the participant feels unsafe in their home, families/carers were less likely to report an improvement across all models, and were more likely to report a deterioration between baseline and first or second reviews, than where the participant feels safe in their home.
- Families and carers who had their review during the COVID period were less likely to deteriorate between baseline and first review but less likely to improve between baseline and second review.

Findings from this section are summarised in Box 6.6.

Box 6.6: Summary of findings – longitudinal outcomes by participant and family/ carer characteristics

- Families and carers of participants who feel safe in their home, and of participants whose self-rated health improves, are more likely to improve and/or less likely to deteriorate in several outcomes.
- Family/carer employment status is also a significant factor for some outcomes. For example, families/carers who remain in paid work are more likely to improve and less likely to deteriorate in rating their health as excellent, very good or good.
- Families/carers of participants living in States/Territories other than Victoria tended to have more positive longitudinal outcomes. For example, they were more likely to improve in the latest year in thinking that the services they receive meet their needs.
- Families/carers of CALD participants were less likely to improve in thinking that their family member with disability gets the support they need.
- Families/carers of older participants had some more favourable longitudinal outcomes, for example, they were more likely to improve in thinking that the services they receive meet their needs.
- Higher plan utilisation was associated with being more likely to improve in thinking that the services they and their family member receive meet their needs, and that their family member gets the support they need.
- Participants living outside a major city were more likely to improve in the latest year in thinking that the services they receive meet their needs, and in thinking that their family member gets the support they need.
- Families/carers of participants with lower level of function were more likely to deteriorate in rating their health as excellent, very good or good.

Box 6.6 (continued): Summary of findings – longitudinal outcomes by participant and family/ carer characteristics

- There were only two indicators where there were significant changes to families’ and carers’ longitudinal outcomes during the pandemic: families and carers who gave their later response during the COVID period were more likely to improve between baseline and first review in thinking that the services their family members with disability and their families receive meet their needs; and families and carers who had their review during the COVID period were less likely to deteriorate between baseline and first review but less likely to improve between baseline and second review in thinking that their family member gets the support they need.