

7. Families/carers of participants aged 25 and over: Has the NDIS helped?

7.1 Results across all participants and families/ carers

For participants who have been in the Scheme for approximately one, two and three years as at 30 June 2020, Figure 7.1 shows the percentage of families/carers of participants aged 25 and over who think that the NDIS has helped with outcomes related to each of the five SF domains.

Figure 7.1 Percentage of families/carers who think that the NDIS has helped with outcomes related to each domain

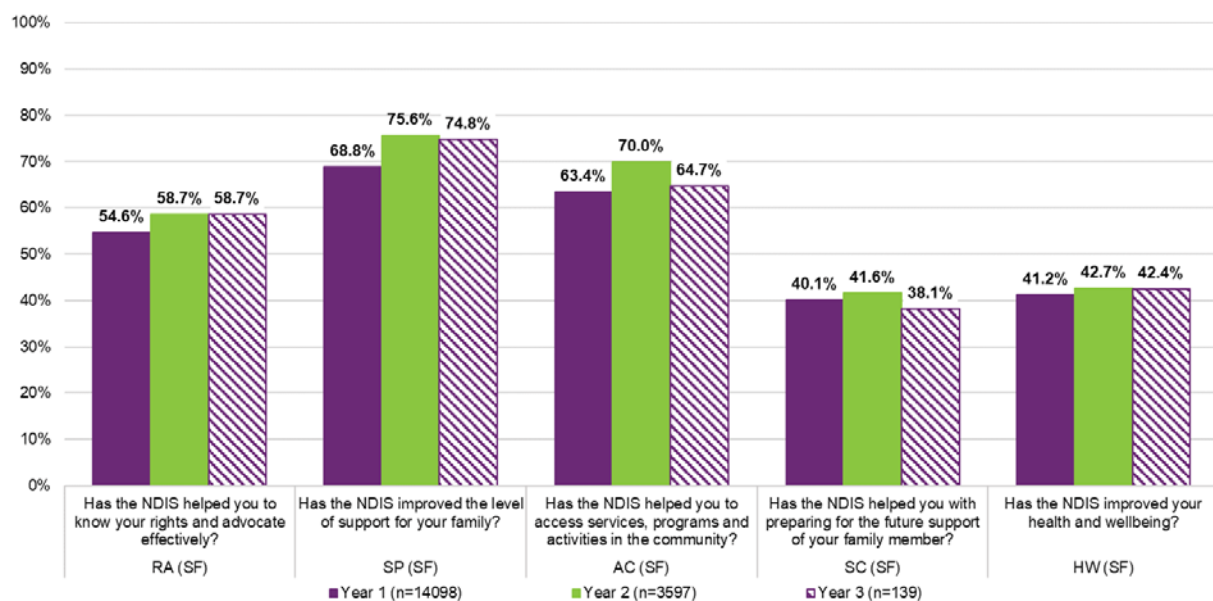


Figure 7.1 shows that most families/carers think that the NDIS has helped with three out of five domains.

After one year, families/carers of participants aged 25 and over were more likely to say that the NDIS has helped than families/carers of participants aged 15 to 24, across all comparable domains. This observation remains consistent at the end of the second year. In the third year, the percentage of families/carers of participants aged 25 and over who say the NDIS helped decreases compared to year 2. In particular, the percentage of families/carers who say the NDIS helped them access services, programs, and activities fell from 70.0% to 64.7%, below the comparable question in the 15 to 24 age group.

This decrease highlights similar movements across the other domains in the third year. While all questions observed an improvement in the percentage of positive responses after the second year, opinions either stagnated or decreased at the third year.

Overall, the percentage of families/carers who say that the NDIS has helped increased over two years in the Scheme (from year 1 to year 3) for all domains except preparing for the future support of their family member (which decreased from 40.1% to 38.1%). Changes between year 1 and year 3 for questions relating to the domains of Rights and Advocacy (RA), Support (SP), and Health and Wellbeing (HW) were 54.8% to 59.7%, 68.7% to 74.8%, and 41.2% to 42.4% respectively.

7.2 Results by participant and family/carer characteristics

7.2.1 Year 1 'Has the NDIS helped?' indicators – participant characteristics

Year 1 (first review) indicators have been analysed by participant and family/carer characteristics using one-way analysis and multiple regression.

Table 7.1 shows the relationship of different participant and carer characteristics with the likelihood of families/carers saying that the NDIS has helped in each domain.

Table 7.1 Relationships of participant characteristics with the likelihood of positive family/carer responses⁴⁰

Reference category	Characteristic	Relationship with				
		Has the NDIS helped				
		RA	SP	AC	SC	HW
N/A	Participant is older	↑	↑		↑	
Non-CALD	Participant is CALD	↓				
Non-Indigenous	Participant is Indigenous		↓	↓		
N/A	Low level of function		↑	↑		↑
N/A	Higher baseline utilisation	↑	↑	↑	↑	↑
N/A	Higher annualised plan budget	↑	↑	↑	↑	↑
Intellectual disability	Disability is autism			↓		
Intellectual disability	Disability is another physical disability			↓		
Intellectual disability	Disability is a psychosocial disability	↑	↑			↑
0-15% capacity building supports	5%-100% of supports are capital supports			↓	↓	
Private-owned	Participant lives in supported accommodation				↑	
Private-owned	Participant lives in aged care				↑	

⁴⁰ Definition of letter symbols in the tables: Has the NDIS improved: family/carer capacity to advocate for their child (RA); level of support for their family (SP); access to services, programs and activities in the community (AC); preparing for the future support of their family member (SC); family/carer health and wellbeing (HW).

Reference category	Characteristic	Relationship with				
		Has the NDIS helped				
		RA	SP	AC	SC	HW
Safe	Participant does not feel safe in their home	↓	↓	↓	↓	↓
Good	Participant rated their health as fair or poor	↓	↓	↓	↓	↓
NSW	Participant lives in ACT			↑	↑	↑
NSW	Participant lives in NT	↑		↑		
NSW	Participant lives in QLD	↑	↑	↑	↑	↑
NSW	Participant lives in SA			↓		
NSW	Participant lives in TAS		↑			
NSW	Participant lives in WA	↑	↑	↑	↑	↑
Agency-managed	Plan is partly self-managed	↑	↑	↑		↑
Agency-managed	Plan is managed by a plan manager	↑	↑			
Received State/Territory supports	Participant received services from Commonwealth programs before joining NDIS			↓		
Received State/Territory supports	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	↑				↑
2016/17	Participant entered the Scheme in 2017/18				↑	
2016/17	Participant entered the Scheme in 2018/19				↑	
30+ hours per week	Carer works for 0 hours per week		↓			
No paid job	Participant works in a paid job		↑		↑	↑
No unpaid job	Participant works in an unpaid job		↑		↑	↑

Reference category	Characteristic	Relationship with				
		Has the NDIS helped				
		RA	SP	AC	SC	HW
Non-SIL	Participant is in Supported Independent Living (SIL)		↓	↓		
Lives in a major city	Lives in a regional area	↑	↑	↑	↑	
Lives in a major city	Lives in a Remote and Very Remote area	↓	↓	↓	↓	
Mother	Respondent was the father				↑	
Mother	Respondent was not a parent					↑

Participant age

Families/carers of older participants are more likely to say the NDIS helped at first review for the domains rights and advocacy, support for family, and succession planning.

CALD status

Controlling for other factors, families and carers of participants from CALD backgrounds are less likely to say that the NDIS helped them understand their rights and to advocate effectively, with 50.4% agreeing to this statement, compared to 54.9% of families and carers of non-CALD backgrounds.

Indigenous status

Families and carers of Indigenous participants are significantly less likely to say that the NDIS improved the level of support for their families (57.7% compared to 69.8% for non-Indigenous), or that the NDIS helped them access services, programs and activities in the community (55.1% versus 64.4%).

Level of function

Families and carers of participants with lower levels of function are more likely to say that the NDIS helped them improve their level of support for their family, their access to services, programs and activities in the community, and their health and wellbeing. For example, 61.8% of families/carers of participants with high level of function responded positively, compared to 68.5% of families/carers of participants with medium level of function and 71.3% of families/carers of participants with low level of function.

Disability type

Families and carers of participants with autism or other physical disabilities are significantly less likely than families/carers of those with intellectual disability to say that the NDIS improved their access to services, programs and activities in the community.

Families and carers of participants with psychosocial disability are more likely than those with intellectual disability to say that the NDIS improved their understanding of rights and advocacy, their level of support for family, and their health and wellbeing.

Supports in plans

Families/carers of participants whose plans have 5% to 100% of capital supports are significantly less likely to say that the NDIS helped improve their access to services, programs and activities in the community, or helped them prepare for the future support of their family member with disability, relative to those with 0% to 15% of capacity building supports.

For access to services, 58.3% of families/carers of participants whose plans contain 5% to 100% capital supports say that the NDIS helped, compared to 69.0% for families/carers of participants with 0% to 15% capacity building supports in their plans. For preparing for the future support of their family member, these percentages are 37.0% and 43.7%, respectively.

Living situation

Families/carers of participants living in supported accommodation and aged care, relative to those living in privately owned homes, are significantly more likely to say that the NDIS helped them prepare for the future support of their family member. The proportion of positive responses in this domain, for these three living conditions are 37.6%, 43.2% and 11.9%, respectively.

Participant feel safe at home

Families/carers of participants who feel unsafe or very unsafe at home are significantly less likely to say that the NDIS helped across all five domains. For instance, 48.2% of families/carers of participants who feel unsafe/very unsafe responded that the NDIS improved their understanding of rights and advocacy, while 56.0% of families/carers of those feeling safe/very safe agreed to this statement, a 7.8% margin of difference.

Participant self-rated health

Controlling for other factors, families and carers of participants who rate their health as “Fair” or “Poor” instead of “Good”, have a lower probability of saying that the NDIS helped improve their outcomes across all five domains. Positive response rates for families/carers of participants rating their health “Fair” or “Poor” across these domains are 53.1%, 67.4%, 60.7%, 11.1% and 38.8% respectively. These results are significantly lower than for those rating their health as “Good”, where positive response rates were 56.0%, 70.2%, 65.8% 13.3% and 43.2%.

State/Territory

Statistically significant results from multiple regression models include that, compared to NSW, families/carers of participants from:

- QLD and WA are significantly more likely to say the NDIS helped across all five domains of interest
- ACT are more likely to provide a positive response in the domains of access to services, programs and activities in the community, preparing for future support for family and health and wellbeing
- NT are more likely to say the NDIS helped with improving their knowledge of rights and advocacy, as well as access to services, programs and activities in the community
- TAS are more likely to say that the NDIS helped with improving the level of support for family

- SA are less likely to say that the NDIS improved their access to services, programs and activities in the community.

Receiving support before the NDIS

In comparison to families and carers of participants who received support from State/Territory systems prior to joining the NDIS, the families and carers of those who received supports from Commonwealth systems are less likely to say that the NDIS helped improve their level of support for family (69.3% for State/Territory versus 63.5% for Commonwealth). Meanwhile, for those who are former recipients of neither, their families and carers are less likely to say that the NDIS helped with preparing for future support of their family member with disability (41.3% for State/Territory versus 37.4% for neither).

Plan management type

In general, on a one-way basis, families and carers of participants whose plans are managed by a plan manager, or those partly/fully self-managed are more likely to think that the NDIS helped them improve outcomes. However, differences are significant (after examining outputs from multiple regression models) across the following categories and domains:

- Plan-managed versus agency-managed: the NDIS helped improve knowledge of rights and advocacy (55.7% and 51.0%); and level of support for family (70.6% and 64.7%)
- Partly self-managed versus agency-managed: the NDIS helped improve knowledge of rights and advocacy (58.9% and 51.0%); level of support for family (71.9% and 64.7%); access to programs, services and activities in the community (65.4% and 61.2%); and health and wellbeing (44.1% and 38.7%)
- Fully self-managed versus agency-managed: no statistically significant differences. (This may be partly due to the smaller number of participants aged 25 and over who self-manage fully).

Participant employment status

Families and carers of participants who are working, whether the job is paid or not, are more likely to say that the NDIS helped them improve the level of support for their families, prepare for the future support of their family member, and with health and wellbeing.

Carer working hours

Compared to carers who work for 30 or more hours per week, carers who do not work at all (0 hours per week) are significantly less likely to say that the NDIS helped them improve the level of support for their families (71.5% (30+ hours) versus 38.9% (0 hours)).

Entry year

Families/carers of participants who entered the scheme in FY 2017-18 or FY 2018-19 are more likely to say that the NDIS helped them prepare for the future support of their family member with disability.

Supported Independent Living arrangement (SIL)

Families and carers of SIL participants are less likely to say that the NDIS helped improve the level of support for their family, as well as access to programs, services and activities in the community.

Respondent's relationship with participant

Fathers responding to the survey are more likely than mothers to say that the NDIS helped them prepare for the future support of their family member with disability (45.1% versus 41.9%). Respondents who are not the participant's parents are more likely to say that the NDIS improved their health and wellbeing, relative to respondents who are mothers of participants (42.9% versus 41.0%).

Level of NDIA support⁴¹

Families and carers of participants who receive a lower or higher level of NDIA support are more likely to say that the NDIS improved their knowledge of rights and advocacy, relative to those with a medium level of NDIA support. For the low level of NDIA support, 53.8% agreed with this statement, as did 59.6% of those in very high NDIA support level, compared to 52.9% of those in the medium support level.

The families and carers of those with a very high level of NDIA support are also more likely than the medium support level to say the NDIS improved their health and wellbeing (46.5% versus 39.3%).

Remoteness

Compared to families and carers who live in the major cities, those living in the regional areas are more likely to say the NDIS has improved their capacity to advocate, the level of support for their family, access to services, and preparing for the future support of their family member. In contrast, families and carers of participants who live in remote and very remote areas are less likely to say that the NDIS has helped in the four domains.

Other characteristics

Families and carers of participants whose plan utilisation percentages are higher, and those whose annualised plan budget are higher, are both more likely to say that the NDIS helped them improve outcomes across all five domains of Table 7.1.

7.2.2 Longitudinal 'Has the NDIS Helped?' indicators – participant and family/carer characteristics

Methodology for longitudinal analysis of "Has the NDIS helped?" questions is described in Chapter 3.

The NDIS has helped me understand my rights and advocate effectively

The percentage of families and carers of participants aged 25 and over who said the NDIS has helped them understand their rights and advocate effectively increased significantly by 7.2% between the first review and second review. There was no significant net change observed between first review and third review.

⁴¹ The level of NDIA support a participant requires as they move along the participant pathway, having regard to the complexity of their situation.

Table 7.2 Breakdown of net movement in family/carer responses to ‘Has the NDIS helped?’ indicators

Longitudinal Period	Number of Baseline Responses in cohort		Improvements: No to Yes		Deteriorations: Yes to No		Net Movement
	No	Yes	Number	%	Number	%	
Review 1 to Review 2	1055	971	210	19.9%	64	6.6%	+7.2%
Review 1 to Review 3	32	37	4	12.5%	5	13.5%	-1.4%

Family/carer characteristics that had a statistically significant effect ($p < 0.05$) on the likelihood of improvement or deterioration in the outcome are summarised below:

Between first year review and second year review, families and carers of:

- Participants who feel unsafe or very unsafe at home are less likely to improve than those who feel safe or very safe
- Participants who receive a high level of NDIA support are more likely to improve than those receiving a low level of NDIA support
- Participants who used a greater percentage of their total supports are more likely to improve
- Participants who have greater annualised plan budget are less likely to deteriorate
- Participants with lower levels of function are more likely to deteriorate
- Participants whose self-rated health deteriorated are more likely to deteriorate.

No significant trends were observed between first review and third review due to small numbers of respondents.

The NDIS has improved the level of support for my family

The percentage of families and carers of participants aged 25 and over who said the NDIS has improved the level of support for their family increased significantly by 11.5% between the first review and second review. The net change between first review and third review was not significant.

Table 7.3 Breakdown of net movement in family/carer responses to ‘Has the NDIS helped?’ indicators

Longitudinal Period	Number of Baseline Responses in cohort		Improvements: No to Yes		Deteriorations: Yes to No		Net Movement
	No	Yes	Number	%	Number	%	
Review 1 to Review 2	769	1342	292	38.0%	49	3.7%	+11.5%
Review 1 to Review 3	20	49	6	30.0%	4	8.2%	+2.9%

Family/carer characteristics that had a statistically significant effect ($p < 0.05$) on the likelihood of improvement or deterioration in the outcome are summarised below:

Between first review to second review, families and carers of:

- Participants who living in regional, remote or very remote areas are more likely to improve than those living in major cities
- Participants who feel unsafe or very unsafe at home are less likely to improve than those feeling safe or very safe
- Participants with partly self-managed plans are more likely to improve than those with agency-managed plans
- Participants living in New South Wales (NSW) or Queensland (QLD) are less likely to improve than those living in Victoria (VIC)
- Participants who used a greater percentage of their supports are more likely to improve.

No significant trends were observed between first review and third review due to small numbers of respondents.

The NDIS has improved my access to services, programs and activities in the community

The percentage of families and carers of participants aged 25 and over who said the NDIS has improved my access to services, programs and activities in the community increased significantly by 8.2% between the first review and second review. The net change between first review and third review was not statistically significant.

Table 7.4 Breakdown of net movement in family/carer responses to ‘Has the NDIS helped?’ indicators

Longitudinal Period	Number of Baseline Responses in cohort		Improvements: No to Yes		Deteriorations: Yes to No		Net Movement
	No	Yes	Number	%	Number	%	
Review 1 to Review 2	849	1256	241	28.4%	69	5.5%	+8.2%
Review 1 to Review 3	20	49	3	15.0%	9	18.4%	-8.7%

Family/carer characteristics that had a statistically significant effect ($p < 0.05$) on the likelihood of improvement or deterioration in the outcome are summarised below.

Table 7.5 Relationships of characteristics with the likelihood of improvement and deterioration in helped responses

Reference category	Variable	1 st Review to 2 nd Review Relationship with likelihood of		1 st Review to 3 rd Review Relationship with likelihood of	
		Imp.	Det.	Imp.	Det.
N/A	Higher annualised plan budget	↑		No significant trend observed due to small numbers	
N/A	Higher utilisation % of core supports	↑			
Major Cities	Participant lives in a regional area	↑	↓		

Reference category	Variable	1 st Review to 2 nd Review		1 st Review to 3 rd Review	
		Relationship with likelihood of		Relationship with likelihood of	
		Imp.	Det.	Imp.	Det.
Major Cities	Participant lives in a remote/very remote area	↑			
Privately-owned home	Participant lives in private rented accommodation / public accommodation	↓			
0-15% capacity building supports	30-60% of supports are capacity building supports	↓			
0-15% capacity building supports	More than 5% of supports are capital supports	↓			
Participant self-rated health deteriorated	Participant self-rated health improved	↑			
N/A	Higher plan utilisation		↓		

Between first review to second review, families and carers of:

- Participants who have greater annualised plan budget are more likely to improve
- Participants who use a greater percentage of their core supports are more likely to improve
- Participants who live in regional, remote or very remote areas are more likely to improve
- Participants who have improved in self-rated health are more likely to improve
- Participants who live in regional areas are less likely to deteriorate
- Participants who live in a privately rented home from a private landlord or a public authority are more likely to deteriorate compared to those living in a family owned home
- Participants who use a greater percentage of their total supports are less likely to deteriorate
- Participants who have 30-60% supports in capacity building or 5-100% of support in Capital supports are more likely to deteriorate compared to those who have 0-15% funding in capacity building.

No significant trends were observed between first review and third review due to small numbers of respondents.

This NDIS has helped prepare for the future support of my family member

The percentage of families and carers of participants aged 25 and over who said the NDIS has helped prepare for the future support of my family member increased significantly by 3.9% between the first review and second review, however between first review and third review the net change is zero based on a small number of families and carers responding.

Table 7.6 Breakdown of net movement in family/carer responses to ‘Has the NDIS helped?’ indicators

Longitudinal Period	Number of Baseline Responses in cohort		Improvements: No to Yes		Deteriorations: Yes to No		Net Movement
	No	Yes	Number	%	Number	%	
Review 1 to Review 2	1364	716	177	13.0%	96	13.4%	+3.9%
Review 1 to Review 3	51	18	4	7.8%	4	22.2%	0.0%

Family/carer characteristics that had a statistically significant effect ($p < 0.05$) on the likelihood of improvement or deterioration in the outcome are summarised below:

Table 7.7 Relationships of characteristics with the likelihood of improvement and deterioration in helped responses

Reference category	Variable	1 st Review to 2 nd Review		1 st Review to 3 rd Review	
		Relationship with likelihood of	Relationship with likelihood of	Imp.	Det.
		Imp.	Det.	Imp.	Det.
N/A	Higher annualised plan budget	↑			
Non-CALD	Participant is CALD	↑			
N/A	Higher utilisation % of core supports	↑	↓		
Major Cities	Participant lives in a regional or remote/very remote area	↑			
Privately-owned home	Participant lives in aged care	↑			
Mother	Respondent was the grandparent	↑			
Mother	Respondent was the spouse/partner	↓			
Non-SIL	Participant is in Supported Independent Living (SIL)	↓			
N/A	Lower level of function	↓			
VIC	Participant lives in NSW	↓			
Participant self-rated health improved	Participant self-rated health deteriorated				↑

No significant trend observed due to small numbers

Reference category	Variable	1 st Review to 2 nd Review		1 st Review to 3 rd Review	
		Relationship with likelihood of Imp.	Relationship with likelihood of Det.	Relationship with likelihood of Imp.	Relationship with likelihood of Det.
Not in an unpaid job	Participant works in an unpaid job		↓		
Never in paid work	Carer remained in paid work		↓		

Between first review to second review, families and carers of:

- Participants who have greater annualised total funding are more likely to improve
- Participants who are from a CALD background are more likely to improve
- Participants who use a greater percentage of the core supports are more likely to improve and less likely to deteriorate
- Participants who live in regional, remote or very remote areas are more likely to improve compared to those live in major cities
- Participants who live in age care are more likely to improve compared to those live in privately owned home
- Participants living in Supported Independent Living are less likely to improve compared to those living in a privately-owned home
- Participants with lower levels of function are less likely to improve
- Participants living in NSW are less likely to improve compared to those living in VIC
- Participants whose self-rated health deteriorated are more likely to deteriorate compared to those whose self-rated health improved
- Participants who are working in an unpaid job is less likely to deteriorate compared to those who are not working in an unpaid job.

Additionally, participants are more likely to improve if the respondent is the grandparent compared to the mother. Participants are less likely to deteriorate if the carer has never worked in a paid job compared to the carer remained in the paid job.

No significant trends were observed between first review and third review due to small numbers of respondents.

The NDIS has improved my health and wellbeing

The percentage of families and carers of participants aged 25 and over who said the NDIS has improved their health and wellbeing increased significantly by 3.7% between the first review and second review. The net change between first review and third review is not statistically significant based on a small number of families and carers responding.

Table 7.8 Breakdown of net movement in family/carer responses to ‘Has the NDIS helped?’ indicators

Longitudinal Period	Number of Baseline Responses in cohort		Improvements: No to Yes		Deteriorations: Yes to No		Net Movement
	No	Yes	Number	%	Number	%	
Review 1 to Review 2	1336	745	183	13.7%	105	14.1%	+3.7%
Review 1 to Review 3	41	29	4	9.8%	7	24.1%	-4.3%

Family/carer characteristics that had a statistically significant effect ($p < 0.05$) on the likelihood of improvement or deterioration in the outcome are summarised below:

Between first review to second review, families and carers of:

- Participants with greater annualised plan budget are more likely to improve
- Participants with lower levels of function are less likely to deteriorate

Between first review to third review, families and carers of:

- Participants who live in a Local Government Area (LGA) with high unemployment rates are less likely to deteriorate.

Box 7.1 summarises key results from this section.

Box 7.1: Has the NDIS helped? by key characteristics

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.