

5. Families/carers of participants from age 15 to 24: Has the NDIS helped?

5.1 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 5.1 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 5.1 Percentage who think that the NDIS has helped with outcomes related to each domain³⁰

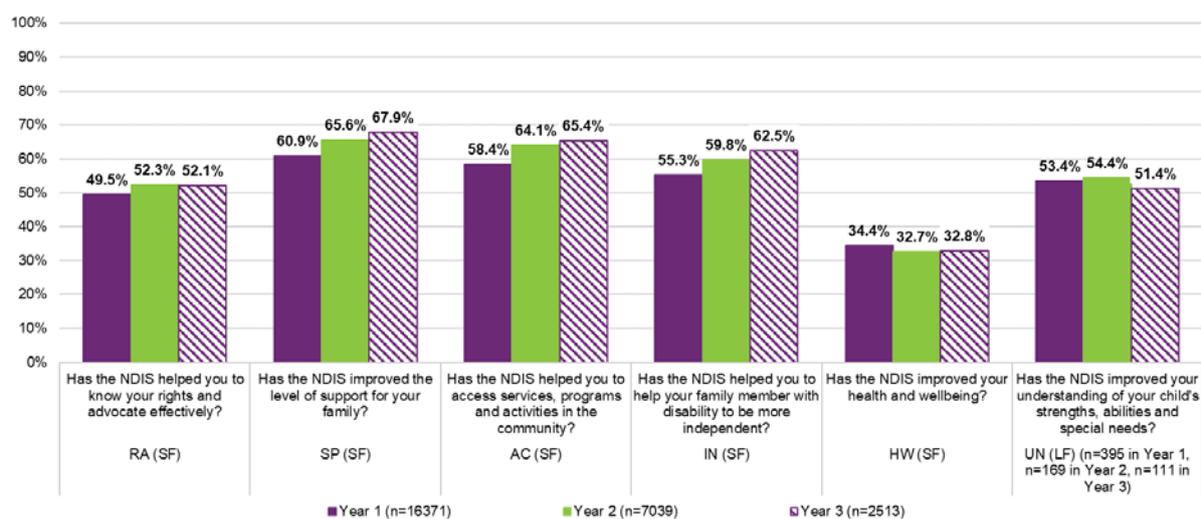


Figure 5.1 shows the movement in the percentage of families and carers saying the NDIS has helped improve outcomes across various domains. In most domains, positive response rates range between 50% and 70%, and overall outcomes improve gradually over time.

In the domains of the NDIS improving family/carer's level of support for their family, access to services, programs and activities in the community, and helping their family member with disability to become more independent, outcomes appears to be improving consistently, by 4-6% over the participant's second year in the Scheme, and another 1-3% over their third year in the Scheme. These two increments result in overall increases of 7.0% (60.9% to 67.9%), 7.0% (58.4% to 65.4%) and 7.2% (55.3% to 62.5%) for the three domains, respectively.

Opinions on whether the NDIS improved the family or carer's knowledge of rights and advocacy improved by 2.8% over the participant's second year in the Scheme, followed by a negligible decrease of 0.2% over their third year in the Scheme.

³⁰ Includes responses from all participants who responded in each review year (not all participants have responded in all three years).

In relation to health and wellbeing, 34.4% agreed that the NDIS had helped after one year in the Scheme, decreasing to 32.7% after two years, and essentially unchanged at 32.8% after three years.

For the LF domain on whether the NDIS improved the family or carer’s understanding of their child’s strengths, abilities and special needs, 53.4% thought that the NDIS had helped after one year. This percentage increased slightly to 54.4% after two years but decreased to 51.4% after three years. There is more variability in these results due to smaller sample sizes.

5.2 Results by participant and family/carer characteristics

5.2.1 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 5.1 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 5.1 Relationships of participant/carer characteristics with the likelihood of positive family/carer responses³¹

Reference	Characteristic	Relationship with				
		Has the NDIS helped				
		RA	SP	AC	ID	HW
N/A	Lower level of function		↑	↑	↑	↑
N/A	Higher annualised plan budget	↑	↑	↑	↑	↑
N/A	Higher baseline utilisation	↑	↑	↑	↑	↑
Autism	Disability is cerebral palsy			↓		
Autism	Disability is a visual impairment		↓	↓		
Autism	Disability is spinal cord injury or other		↓	↓		
Received State/Territory supports	Participant received services from Commonwealth systems before entering the NDIS				↓	

³¹ 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); ability to help their child/family member become more independent (ID); family/carer health and wellbeing (HW).

Reference	Characteristic	Relationship with				
		Has the NDIS helped				
		RA	SP	AC	ID	HW
Received State/Territory supports	Participant did not previously receive services from Commonwealth or State/Territory programs	↑	↑	↑	↑	↑
NSW	Participant lives in ACT					↑
NSW	Participant lives in NT	↑	↑			
NSW	Participant lives in QLD	↑	↑	↑	↑	↑
NSW	Participant lives in SA	↑	↑		↑	↑
NSW	Participant lives in VIC	↑				↑
NSW	Participant lives in WA	↑	↑	↑	↑	↑
Agency-managed	Plan is managed by a plan manager		↑		↑	
Agency-managed	Plan is fully self-managed	↑	↑	↑	↑	↑
Agency-managed	Plan is partly self-managed	↑	↑	↑	↑	↑
Self-rated health is Good	Participant rated their health as fair or poor	↓	↓	↓	↓	↓
Self-rated health is Good	Participant rated their health as excellent or very good		↑	↑	↑	↑
0-75% capacity building support	75-95% of supports are capacity building supports		↓	↓	↓	
0-75% capacity building support	95-100% of supports are capacity building supports	↓	↓	↓	↓	
Non-SIL	Participant is in Supported Independent Living (SIL)	↓	↓	↓		
Safe	Participant feels unsafe at home	↓	↓	↓	↓	↓
Safe	Participant feels neither safe nor unsafe at home	↓	↓	↓	↓	↓
Not in paid work	Participant is in paid work		↑		↑	
Not in an unpaid job	Participant works in an unpaid job				↑	
Medium level of NDIA support	Lower level of NDIA support		↑			

Reference	Characteristic	Relationship with				
		Has the NDIS helped				
		RA	SP	AC	ID	HW
Medium level of NDIA support	High level of NDIA support					↑
Medium level of NDIA support	Very high level of NDIA support		↓	↓	↓	
N/A	General time trend	↑	↑			
2016/17	Participant entered the Scheme in 2018/19				↑	
Major cities	Participant lives in a regional area		↓			↓
Major cities	Participant lives in a remote/very remote area	↓	↓	↓	↓	
Male	Participant is female		↑	↑	↑	
N/A	Participant is older		↑	↑	↑	↑
Private-owned	Participant lives in other accommodation			↓		
Private-owned	Participant lives in private rented public accommodation			↓		

Annualised plan budget

Family and carers of participants with higher annualised plan budget are more likely to say the NDIS has helped across all five domains.

For example, 42.3% of families and carers of participants with less than \$15,000 annualised plan budget said the NDIS had improved their capacity to advocate for their family member, compared to 55.9% of families and carers of participants who have \$50,000 or more annualised plan budget.

Level of function

Families and carers of participants with lower levels of function tended to be more likely to say that the NDIS had helped in all domains except for rights and advocacy. For example, 66.6% of families and carers of participants of low level of function said that the NDIS helped improved their level of support for their families, compared to 60.6% for those with medium level of function and 51.3% for those with high level of function.

Level of NDIA support

Families and carers of participants with a very high level of NDIA support³² are less likely to say that the NDIS has improved the level of support for their family, helped them to access services, programs and activities in the community, and helped them to help their family member to become more independent.

Utilisation

Family and carers of participants with higher utilisation are more likely to say the NDIS has helped across all five domains.

For example, 30.8% of the families and carers of participants who used less than 20% of their plan budget said the NDIS had improved their capacity to advocate for their family member, compared to 58.6% of participants who used more than 80% of their plan budget.

State and Territory

Families and carers of participants living in Queensland and Western Australia are more likely to say the NDIS has helped after one year across all five domains.

Plan management

Families and carers of participants who self-manage are most likely to respond positively across all five domains after one year. For example, 66.2% of the families and carers of participants who fully self-managed said the NDIS has helped them to help their family member with disability to be more independent, compared to 56.0% of those who use a plan manager and 49.7% of those whose plans are agency-managed.

When asked whether the NDIS had improved the level of support for their family, families and carers of participants with agency-managed plans (54.3%) are significantly less likely to respond positively compared to those who use a plan manager (62.9%), self-manage partly (65.0%), or self-manage fully (69.5%).

Receiving support before the NDIS

Families and carers of participants who did not receive services from State/Territory or Commonwealth programs prior to joining the NDIS are more likely to say that the NDIS has helped across all five domains.

Safe at home

Families and carers of participants who said they feel safe at home are more likely to say that the NDIS has helped across all five domains. For example, based on one-way analysis, 50.0% of families and carers for participants feeling safe or very safe said that the NDIS improved their knowledge of rights and advocacy, compared to 46.5% of families and carers of participants who feel neither safe nor unsafe, and 46.2% for those feeling unsafe or very unsafe.

Participant age

Families/carers of older participants are more likely to say the NDIS helped at first review, across all domains except rights and advocacy.

³² The level of NDIA support a participant requires as they move along the participant pathway, having regard to the complexity of their situation.

Disability type

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.

Self-rated health

Families and carers of participants who have better self-rated health are more likely to say that the NDIS improved their level of support, access to services and programs in the community, health and wellbeing and in helping them to help their family member with disability become more independent. For example, for “Has the NDIS helped you to help your family member with disability to be more independent”, 59.5% of families and carers of participants who rated their health as “Very Good” or “Excellent” responded that the NDIS has helped, compared to 55.8% who rated their health as “Good”, and 51.1% who rated their health “Fair” or “Poor”.

Remoteness

Compared to families and carers living in the major cities, those living in remote/very remote areas are less likely to say the NDIS has helped in improving their capacity to advocate for their child, improving the level of support for their family, access to services and helping their child/family member become more independent. Those living in regional areas are also less likely to say the NDIS has helped to improve the level of support for their family, and to improve their health and wellbeing.

Types of supports in plan

Families and carers of participants with a higher percentage of supports in capacity building are less likely to say that the NDIS has helped with advocacy, support, access to services, and independence.

Participant’s paid and unpaid work

Families and carers of participants who are in paid work are more likely to say that the NDIS has improved their family members level of support and helped them to help their family member to be more independent, compared to families and carers of participants who are not working in a paid or unpaid job.

For participants in a paid job, 61.9% of families and carers said that the NDIS improved their level of support for families, compared to 60.9% for those who do not have a paid job; 60.9% of families and carers of participants in paid jobs said that the NDIS helped their family member with disability become more independent, compared to 54.6% of those not in a paid job.

Families and carers of participants in unpaid work are also more likely to say that the NDIS has helped them to help their family member to become more independent. Based on one-way analysis, 64.1% of families or carers of participants working in an unpaid job said that the NDIS helped, compared to 54.6% of participants who are not in an unpaid job.

5.2.2 Longitudinal ‘Has the NDIS helped?’ indicators – participant characteristics

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

The NDIS has improved my capacity to advocate for my family member with disability

The percentage of families and carers of participants aged 15 to 24 who said the NDIS has improved their capacity to advocate for their family member increased significantly by 7.1% between the first review and second review, and by 9.8% between first review and third review.

Table 5.2 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	2187	1782	469	21.4%	187	10.5%	+7.1%
Review 1 to Review 3	554	409	163	29.4%	69	16.9%	+9.8%

Family/carer 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 5.3 below.

Table 5.3 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 utilisation % of capacity building supports	↑			
N/A	General time trend		↓		
Did not relocate	Participant relocated to a new Local Government Area (LGA)		↑		
NSW	Participant lives in ACT, NT, TAS or WA		↓		
NSW	Participant lives in QLD	↑			
NSW	Participant lives in VIC	↑			
N/A	Participant lives in an area with a higher average unemployment rate				↑

Key findings from the multiple regression analysis are:

- Between first and second review:
 - Families and carers of participants who used a higher percentage of their capacity building supports are more likely to improve (change their response from “No” to “Yes”).
 - Compared to participants who live in New South Wales, families and carers of participants living in Victoria and Queensland are more likely to improve in their response, while families and carers of participants living in the State/Territory group Australian Capital Territory, Northern Territory, Tasmania and Western Australia are less likely to deteriorate.
 - Compared to participants who have not relocated to a different Local Government Area (LGA), families and carers of participants who have relocated are more likely to deteriorate in their responses.
- Between first year and third year review:
 - Living in an area with higher unemployment is associated with higher likelihood of deterioration.

The NDIS has improved the level of support for my family

The percentage of families and carers of participants aged 15 to 24 who said the NDIS has improved the level of support for their family increased significantly by 10.2% between first review and second review, and by 12.8% between first review and third review.

Table 5.4 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	1771	2280	593	33.5%	180	7.9%	+10.2%
Review 1 to Review 3	432	537	180	41.7%	56	10.4%	+12.8%

Family/carer 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 5.5 below.

Table 5.5 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	Relationship with likelihood of	Relationship with likelihood of
		Imp.	Det.	Imp.	Det.
N/A	Higher annualised plan budget	↑			

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.
N/A	Higher utilisation % of capacity building supports		↓		
2016/17	Participant entered the Scheme in 2017/18	↑			
Safe or very safe	Participants feels neither safe nor unsafe at home		↑		
Safe or very safe	Participants feels unsafe or very unsafe at home		↑		
Not in an unpaid job	Participant is working in an unpaid job			↑	
Did not relocate	Participant relocated to a new LGA		↑		
N/A	Lower level of function		↓		
NSW	Participant lives in QLD	↑			
NSW	Participant lives in VIC	↑			
N/A	Higher baseline utilisation	↑		↑	↓

Key findings from the multiple regression analysis are as follows:

- Between first and second review:
 - Higher annualised plan budget, and higher utilisation, are associated with an increased likelihood of improvement
 - Families and carers of participants who entered the Scheme in 2017/18 are more likely to improve their responses compared to those entered during 2016/17
 - Compared to participants living in New South Wales, families and carers of participants living in Victoria and Queensland are more likely to improve
 - Responses from families and carers of participants who feel unsafe or very unsafe at home are more likely to deteriorate
 - Relocating to a new LGA is associated with a deterioration in responses.
- Between first and third review:
 - Families/carers of participants using a higher percentage of their plan are more likely to improve and less likely to deteriorate.
 - Families/carers of participants working in an unpaid job are more likely to improve compared to families/carer of participants who are not working.

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

The percentage of families and carers of participants aged 15 to 24 who said the NDIS has improved their access to services, programs and activities in the community increased significantly by 9.0% between first review and second review, and by 9.6% between first review and third review.

Table 5.6 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	1822	2246	564	31.0%	198	8.8%	+9.0%
Review 1 to Review 3	427	551	172	40.3%	78	14.2%	+9.6%

Participant and family/carer 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 5.7 below.

Table 5.7 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	↑			
N/A	Higher utilisation % of capacity building supports				↓
Pre-COVID	Review during COVID period	↑			
N/A	General time trend		↓		
Self-rated health is “Good”	Participant rates his/her own health as “Fair” or “Poor”		↑		
Did not relocate	Participant relocated to a new Local Government Area (LGA)				↓
Major Cities	Participant lives in regional areas	↑			
N/A	Higher plan utilisation	↑	↓	↑	

Key findings from the multiple regression analysis are:

- Between first and second review:
 - Higher likelihood of improvement in response is associated with higher annualised plan budget and higher utilisation of plan budget. Higher utilisation of plan budget is also associated with a lower likelihood of deterioration
 - Compared to participants living in the major cities, families and carers of participants living in regional areas are more likely to improve their responses
 - Families and carers of participants who rate their health as “fair” or “poor” are more likely to deteriorate in their responses compared to families and carers of participants who rate their health as “good”.
 - Families and carers who took the survey during COVID period are more likely to see improvement be
- Between first and third review:
 - Higher overall utilisation is associated with a higher likelihood of improvement in responses between first and third review. Additionally, higher utilisation of capacity building supports is associated with a lower likelihood of deterioration in the two-year period
 - Participants relocating to a different Local Government Area are less likely to improve.

The NDIS has helped me to help my family member become more independent

The percentage of families and carers of participants aged 15 to 24 who said the NDIS has helped them to help their family member become more independent increased significantly by 9.8% between first review and second review, and by 13.3% between first review and third review.

Table 5.8 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	2004	2028	561	28.0%	165	8.1%	+9.8%
Review 1 to Review 3	482	490	177	36.7%	48	9.8%	+13.3%

Family/carer 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 5.9 below.

Table 5.9 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 Imp.	Relationship with likelihood of Det.	Relationship with likelihood of Imp.	Relationship with likelihood of Det.
Remained in paid job	The carer has never worked in a paid job		↑		
N/A	Higher utilisation % of capacity building supports			↑	↓
2016/17	Participant entered the Scheme in 2017/18	↑			
Male	Participant is female			↑	
Lives in a privately owned home	Participant lives in a home rented from a public authority	↓			
Pre-COVID	Review during COVID period		↑		
N/A	General time trend		↓		
Self-rated health is "Good"	Participant rates his/her own health as "Very Good"			↑	
Self-rated health is "Good"	Participant rates his/her own health as "Fair"		↑		
Self-rated health is "Good"	Participant rates his/her own health as "Poor"			↓	
Self-rated health improved	Participant's self-rated health deteriorated	↓			
Not in an unpaid job	Participant is working in an unpaid job	↑	↓	↑	
N/A	Lower level of function		↓		
NSW	Participant lives in QLD	↑			
NSW	Participant lives in VIC	↑			
N/A	Higher plan utilisation	↑	↓		

Key findings from the multiple regression analysis are:

- Between first and second review:

- Families/carers of participants working in an unpaid job, and participants using a higher percentage of their plan budget, are more likely to improve and less likely to deteriorate
- A deterioration in the participant's self-rated health is associated with a lower likelihood of improvement over the one year period
- Compared to participants living in NSW, families and carers of participants living in VIC and QLD are significantly more likely to improve in their responses
- Compared to participants who entered during 2016/17, families and carer of participants who entered during 2017/18 are significantly more likely to improve in their responses over the one year period.
- Families and carers who had their later review after COVID are more likely to deteriorate between first and second review.
- Between first and third review:
 - Families and carers of participants who utilise a higher percentage of capacity building supports are more likely to improve in their responses and less likely to deteriorate
 - Responses from families and carers of participants who are female are more likely to improve compared to families and carers of participants who are male
 - Better participant self-rated health is associated with an increased likelihood of improvement, while poorer participant self-rated health is associated with a lower likelihood of improvement.

The NDIS has improved my health and wellbeing

The percentage of families and carers of participants aged 15 to 24 who said the NDIS has improved their health and wellbeing increased slightly by 2.3% between first review and second review, and by 1.8% between first and third review

Table 5.10 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	2765	1223	350	12.7%	259	21.2%	+2.3%
Review 1 to Review 3	666	296	116	17.4%	99	33.4%	+1.8%

Family/carer 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 5.11 below.

Table 5.11 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 Imp.	Relationship with likelihood of Det.	Relationship with likelihood of Imp.	Relationship with likelihood of Det.
N/A	Participant is older		↓		
N/A	Higher annualised plan budget	↑			
Non-CALD	Participant is CALD	↑			
Self-rated health improved	Participant's self-rated health deteriorated		↑		
Agency-managed	Plan is fully self-managed	↑			
Did not relocate	Relocated to a different Local Government Area (LGA)	↓			
N/A	Lower level of function			↑	
NSW	Participant lives in QLD			↑	
N/A	Higher plan utilisation	↑			

Key findings from the multiple regression analysis are:

- Between first review and second review:
 - Families/carers of participants who: have a higher annualised plan budget; are fully self-managing their plan; use a higher percentage of their overall plan budget; or are from a CALD background, are more likely to improve
 - Families/carers of older participants were less likely to deteriorate
 - Families/carers of participants whose self-rated health deteriorated were more likely to deteriorate.
 - Families/carers of participants who relocated to a different LGA were less likely to improve.
- Between first review and third review:
 - Families and carers of participants with lower level of function are more likely to improve
 - Compared to participants living in NSW, families and carers of participants living in QLD are more likely to improve.

Box 5.1 summarises key results from this section.

Box 5.1: Has the NDIS helped? by key characteristics

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.