

Appendix C – Families/Carers 25 and over

Box C.1: Key Findings

- In the longitudinal analysis, significant improvements were observed across the following indicators:
 - Access to and quality of services: An 11.7% improvement in the families/carers who say that services meet the needs of the participant and family (from 23.8% at baseline to 35.6% at review), and a 26.1% improvement in families/carers who say services and supports have helped them better care for their family member (from 42.0% to 68.1%).
 - Feeling supported: A 4.7% improvement in the families/carers who said they could ask for support for the family member with a disability (from 34.2% to 38.9%), and for emotional support (49.7% to 54.4%).
 - Succession planning: A 5.4% improvement in the families/carers who have made or started making succession plans (from 32.1% to 37.5%).
- Baseline outcomes tended to be better for families and carers of participants with higher level of function and lower annualised baseline plan cost (which is correlated with level of function).
- Baseline outcomes for the families and carers of participants from a CALD background were worse across all domains. This may be due to more difficulty in accessing information and lack of support networks.
- Families and carers of Indigenous participants generally had worse baseline outcomes compared to families/carers of non-Indigenous participants.
- There was a higher rate of positive responses for families and carers of participants with hearing impairments with respect to health and feeling supported. They also had the lowest rate of receipt of government benefits compared to the families/carers of participants with other disability types.
- Opinions on whether the NDIS has helped varied by domain. Most agreed that the NDIS has helped with level of support for the family (66%), access to services, programs and the community (62%), and the ability to advocate (53%). Responses were lower for succession planning (41%) and health and wellbeing (33%). Families and carers of participants with a lower level of function and/or higher levels of baseline plan utilisation were more likely to have a positive response across all areas surveyed.

Appendix C.1 – Baseline indicators for SF and LF – aggregate

Summary

Government benefits (Carer Payment and Carer Allowance)

In the baseline SF questionnaire, 45% of families/carers of adult participants report that they are receiving a government benefit for their caring responsibilities. 22% of families/carers receive the Carer Allowance only, 9% receive the Carer Payment only, and 14% receive both of the carer government benefits.

Rights and advocacy

The LF asks families and carers if they understand their rights and the rights of their family member with disability, to which the majority (77%) answered in the affirmative at baseline. Similarly, in the SF most families and carers reported that they are able to advocate for their family member and speak up if they have issues accessing support (70%).

On the other hand, only 46% of families/carers reported in the baseline SF that they are able to identify the needs of their family member with a disability and know how to access the services and support that the family member needs. For this question, 36% of families/carers reported that they had some difficulty, and 16% had great difficulty.

Families feel supported

At baseline, most families/carers of adult participants reported that they did not feel supported across all relevant questions in the SF. Less than half (48%) said they have family and friends that they see as often as they like. In terms of being able to ask for support as often as needed, 61% could not ask for practical help, 52% could not ask for emotional support and 70% could not ask for support for the family member with a disability.

In the LF, 59% of families/carers reported that they had as much contact with other families of people with a disability as they would like.

Families are able to gain access to desired services, programs, and activities in their community

At baseline, 21% of families/carers said that the services the participant and the family receives meets their needs. Furthermore, the majority of families/carers reported that they have difficulty feeling in control when selecting services and supports that meet the needs of the family and participant, with 41% having some difficulty and 17% facing a great deal of difficulty.

On the other hand, at baseline 68% of families/carers reported that the services they and their family member with a disability use listen to them (SF), and 62% said that the services they received helped them plan for the future (LF).

Succession planning

At baseline, the majority of respondents (61%) said they had not made plans for when they are no longer able to care for their family member with a disability, and 26% said they had begun making preparations. For the families/carers who reported that they had asked for assistance, the most common sources of assistance were the participant's siblings (43%), service providers (40%), extended family (30%) and professionals (29%). Families and carers were the least likely to ask for assistance from their friends (13%) or friends of their family members (7%).

Health and wellbeing

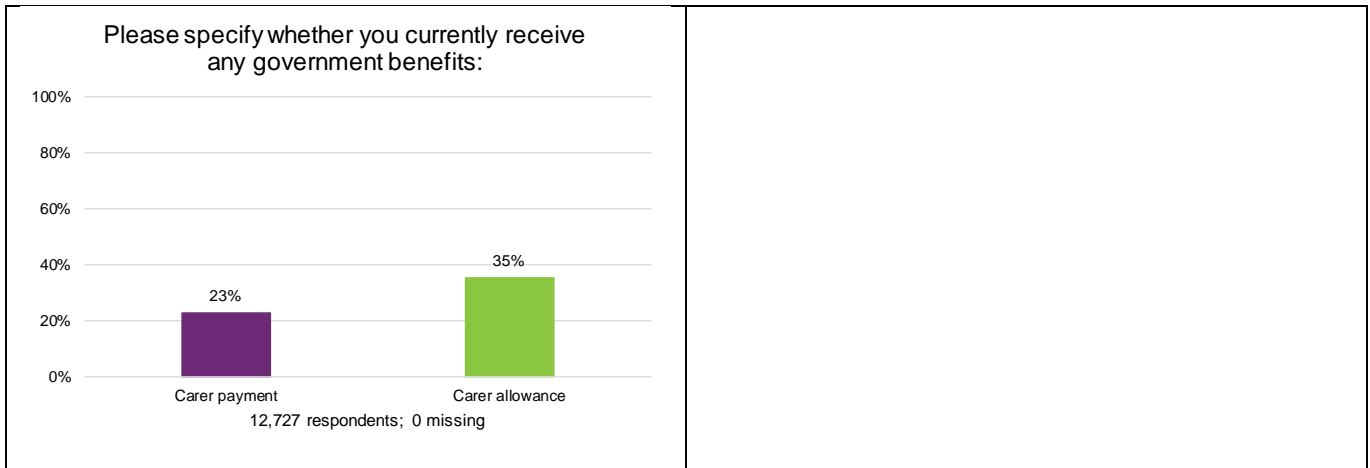
59% of families/carers rate their health as good, very good or excellent at baseline. This is lower than the results for the other participant age groups, likely reflecting the older age of this cohort. 53% of families/carers disagreed or strongly disagreed that their family member with disability gets the support that they need at baseline.

Regarding employment, only 59% of families and carers say that the family who provide informal care to the participant are able to work as much as they want. The main barriers to working more were the situation of the family member with a disability (89%), insufficient flexibility of jobs (22%), and availability of jobs (13%).

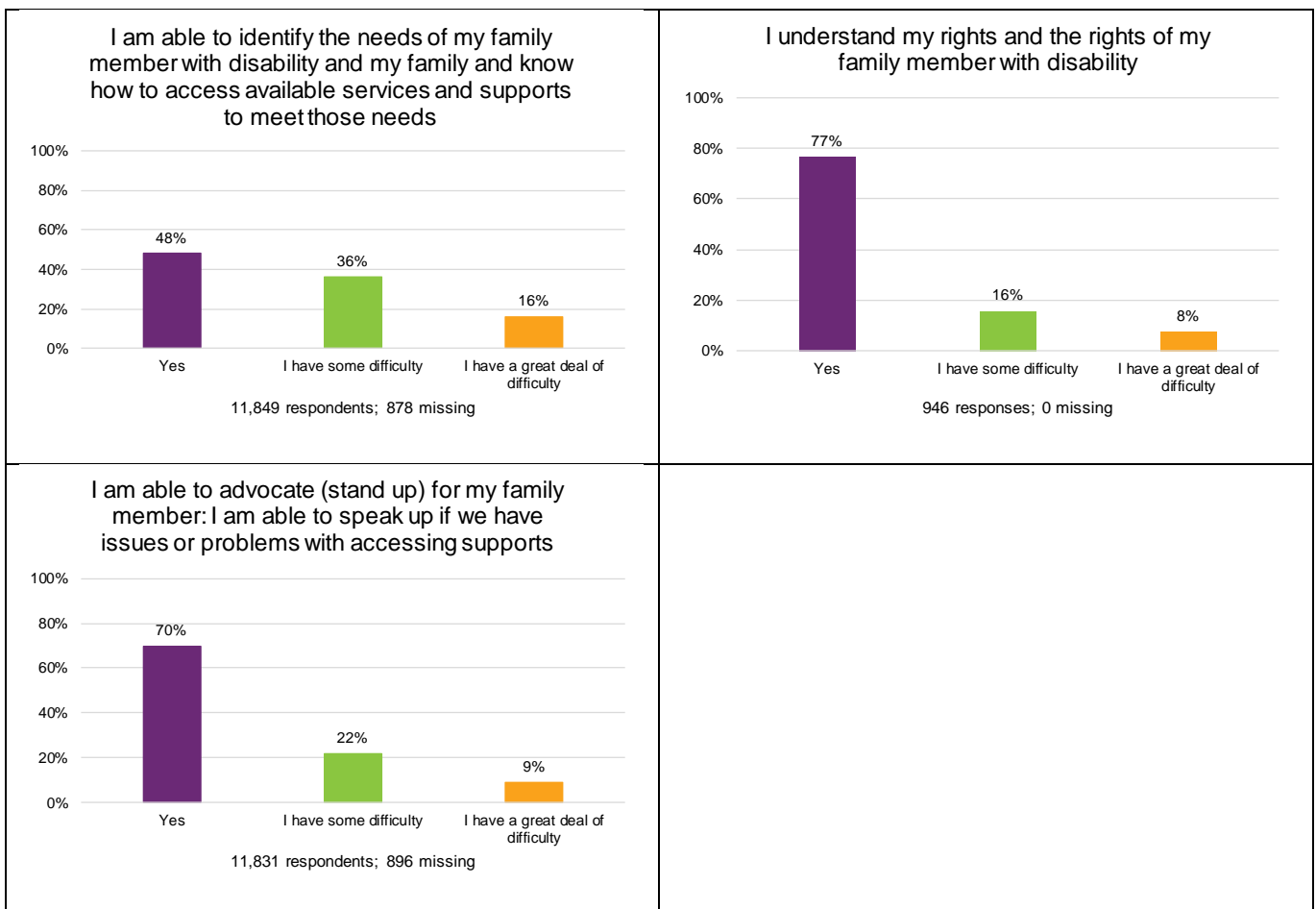
Several additional questions are included in the LF regarding the wellbeing of families and carers and their outlook on life generally. For the question on their own expectations for the future, 47% of families/carers answered positively, 36% had mixed feelings and 10% answered negatively (7% did not know). With respect to the family member with a disability, most families/carers responded neutrally when asked whether they feel more confident about their future under the NDIS (53%), while 40% agreed or strongly agreed.

In the baseline LF, 55% of families/carers agreed or strongly agreed that having a family member with disability has made it more difficult to meet everyday costs of living, while 28% disagreed or strongly disagreed (17% were neutral). For the question on whether families/carers felt that services and supports had helped them better care for the participant, 43% answered positively, 36% were neutral and 11% had a negative response.

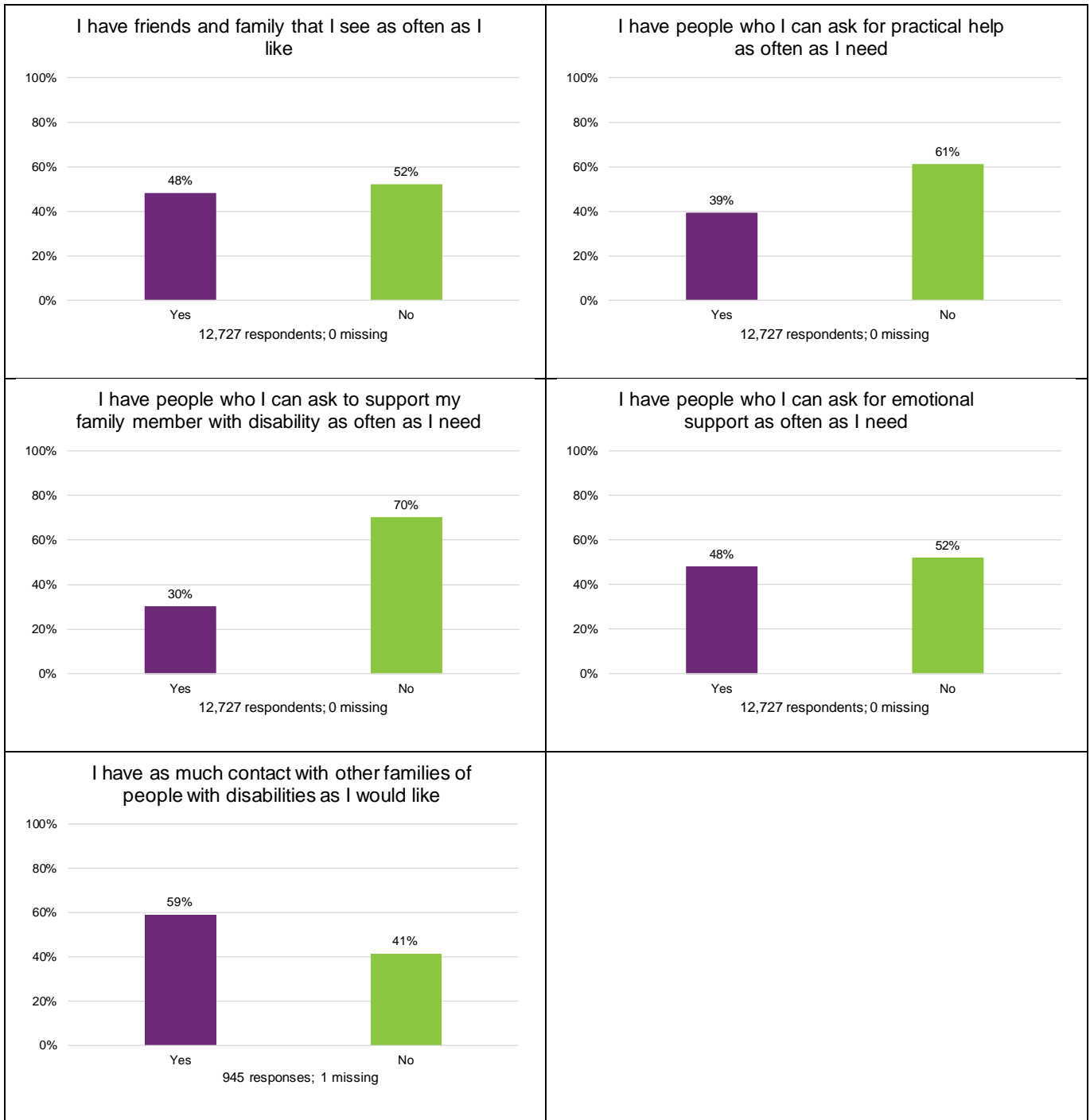
Appendix C.1.1 – Government Benefits



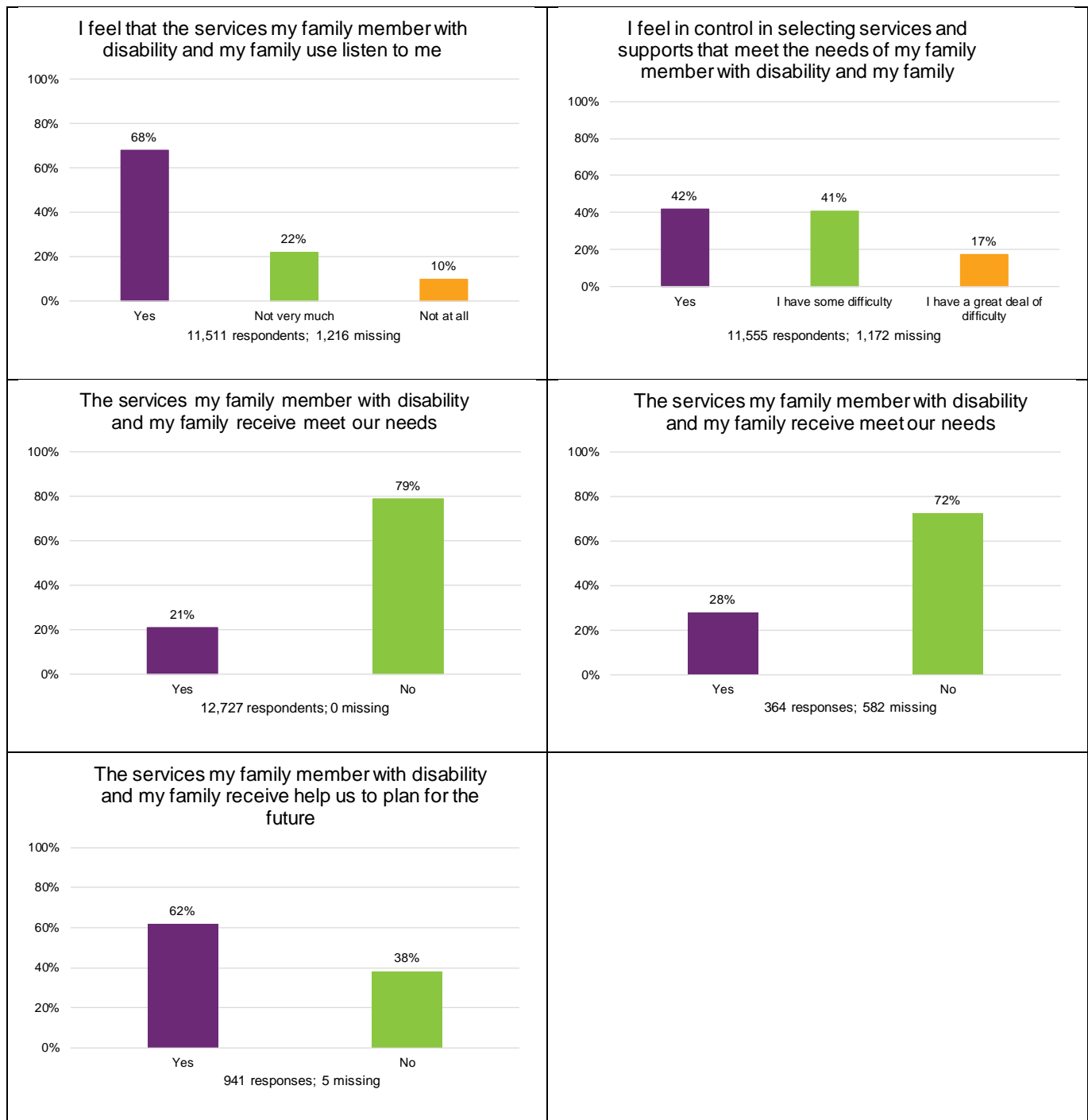
Appendix C.1.2 – Rights and Advocacy



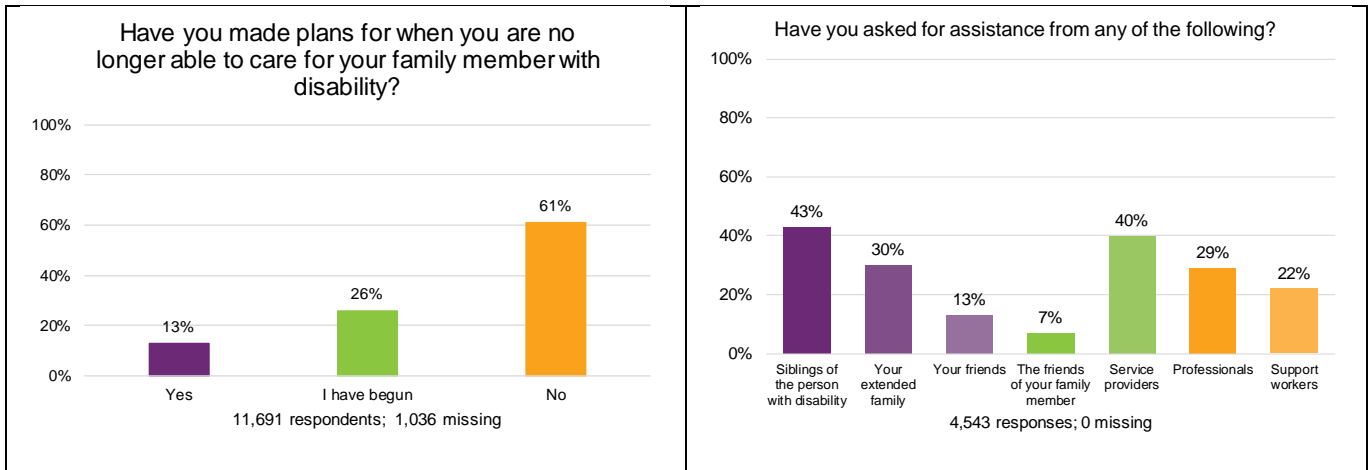
Appendix C.1.3 – Families feel Supported



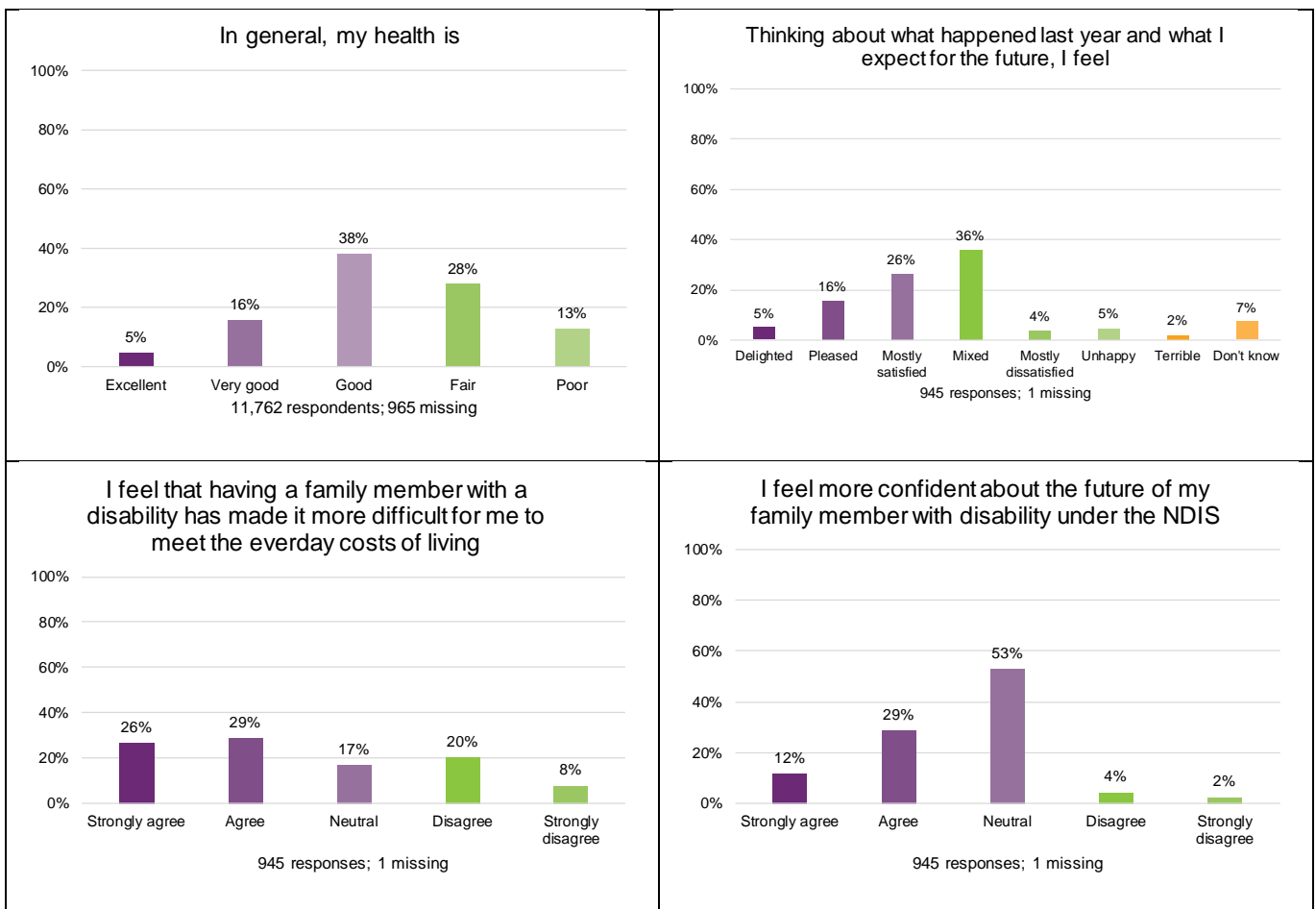
Appendix C.1.4 – Access to Services

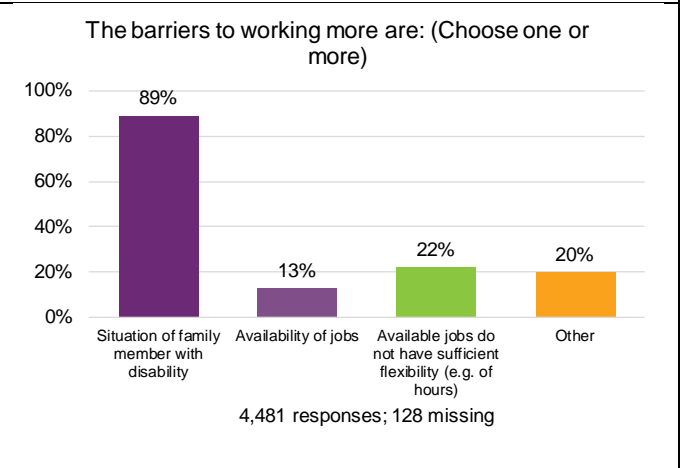
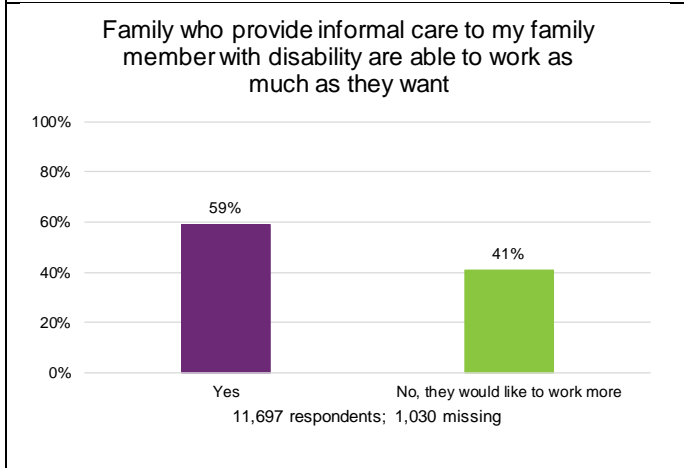
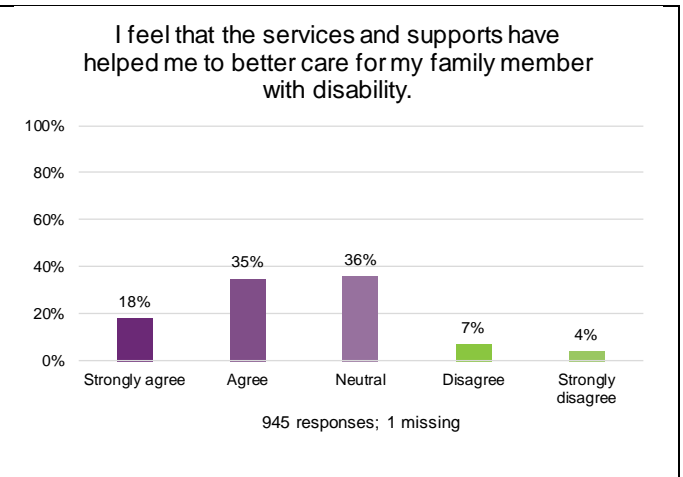
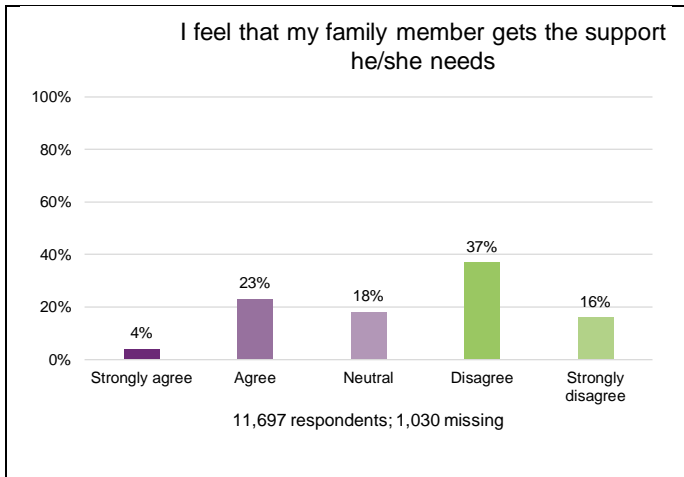


Appendix C.1.5 – Succession Plans

















































Appendix C.1.6 – Health and wellbeing





Baseline indicators for LF

		% who have as much contact with other families of people with disability as I would	
	N	like	
Overall	946		59%
Age group			
34 or younger	243		62%
35 to 44	225		62%
45 to 54	229		57%
55 or over	218		56%
Disability type			
Autism	70		61%
Cerebral Palsy & Other Neurological	125		61%
Intellectual Disability & Down Syndrome	470		61%
Other	250		55%
Sensory	30		53%
Level of Function			
High	105		57%
Medium	422		62%
Low	362		59%
State/Territory			
ACT	66		52%
NSW	444		60%
QLD	71		52%
SA	183		60%
VIC	151		63%
NT & TAS & WA	30		53%
Remoteness			
Inner Regional	381		64%
Major City	474		56%
Outer Regional / Remote / Very Remote	74		57%
Annualised cost of baseline plan			
\$15,000 or less	68		72%
\$15-30,000	157		55%
\$30-40,000	70		56%
\$40-50,000	54		65%
Over \$50,000	535		60%
Aboriginal and Torres Strait Islander Status			
Indigenous	31		61%
Non-Indigenous	904		59%
CALD Status			
CALD	42		60%
Non-CALD	902		59%
Gender			
Female	390		59%
Male	534		58%
Plan Management Type			
Agency-managed	597		61%
Combination	93		59%
Plan-managed	96		57%
Self-managed	25		64%
Access Type			
Benefit from EI	<20		na
Disability Met	937		59%
Reporting Access Entry Type			
Commonwealth	216		56%
New	83		48%
State	646		61%
Plan cost allocation			
Capital 5-100%	174		63%
Capacity Building 0-25%	432		59%
Capacity Building 25-50%	114		61%
Capacity Building 50-75%	109		52%
Capacity Building 75-100%	54		70%

Appendix C.2.4 – Access to Services

Baseline indicators for SF

	N	% of families or carers who feel that the services they use for their family member with disability listen to them	% of families or carers that feel in control selecting the services and supports for their family member with disability	% of families or carers who say that the services for their family member with disability and their family receive meet their needs
Overall	12,727	68%	42%	21%
Relationship to Participant				
Mother	5,129	69%	42%	23%
Father	993	71%	44%	26%
Spouse/Partner	2,910	64%	40%	16%
Sister	1,030	68%	43%	27%
Brother	405	75%	45%	30%
Other Family	639	65%	42%	23%
Carer	301	65%	39%	21%
Other	812	67%	46%	16%
Age Group				
29 and under	1,748	68%	42%	20%
30 to 34	1,612	66%	42%	23%
35 to 39	1,428	68%	41%	20%
40 to 44	1,348	68%	42%	20%
45 to 49	1,476	67%	40%	22%
50 to 54	1,541	69%	43%	21%
55 to 59	1,697	66%	40%	19%
60 and over	1,877	70%	44%	22%
Disability Type				
ABI	994	66%	39%	19%
Autism	814	70%	43%	22%
Cerebral Palsy	655	64%	44%	20%
Down Syndrome	737	73%	47%	28%
Hearing Impairment	373	66%	47%	21%
Intellectual Disability	3,802	70%	44%	26%
Multiple Sclerosis	596	65%	41%	14%
Other Neurological	1,313	67%	40%	17%
Other Physical	813	65%	46%	20%
Psychosocial Disability	1,400	67%	32%	16%
Spinal Cord Injury	276	65%	49%	21%
Stroke	493	63%	38%	15%
Visual Impairment	461	68%	41%	17%
Level of function				
High	1,627	71%	51%	29%
Medium	6,495	69%	42%	21%
Low	4,605	65%	38%	18%
State				
ACT	84	63%	36%	21%
NSW	5,396	64%	39%	20%
NT	75	46%	16%	12%
QLD	1,438	68%	47%	21%
SA	1,298	72%	51%	28%
TAS	213	73%	48%	33%
VIC	4,114	72%	41%	20%
WA	109	77%	48%	27%
Remoteness				
Major City	7,286	68%	40%	20%
Inner Regional	3,967	68%	43%	21%
Outer Regional / Remote / Very Remote	1,272	68%	46%	26%
Annualised cost of baseline plan				
\$10,000 or less	741	73%	51%	30%
\$10-15,000	501	68%	51%	28%
\$15-20,000	675	71%	51%	29%
\$20-30,000	1,494	69%	42%	22%
Over \$30,000	9,316	67%	40%	19%
Aboriginal and Torres Strait Islander Status				
Indigenous	438	57%	36%	16%
Non-Indigenous	11,568	68%	42%	21%
CALD Status				
CALD	1,422	62%	31%	16%
Non-CALD	11,294	69%	43%	22%
Gender				
Female	5,629	68%	42%	19%
Male	6,927	68%	42%	22%
Plan management type				
Agency-managed	7,549	69%	42%	23%
Self-managed	680	70%	57%	22%
Plan-managed	3,202	65%	35%	16%
Combination	1,248	70%	47%	19%
Access Type				
Benefit from EI	220	69%	36%	16%
Disability Met	12,435	68%	42%	21%
Scheme access				
New	2,985	59%	36%	14%
State	7,969	70%	43%	22%
Commonwealth	1,773	74%	44%	28%
Plan cost allocation				
Capital 5-100%	3,536	65%	42%	19%
Capacity Building 0-75%	8,677	69%	41%	21%
Capacity Building 75-95%	330	76%	56%	38%
Capacity Building 95-100%	174	66%	49%	34%

Baseline indicators for LF

	N	% who work in partnership with professionals and service providers to meet the needs of their family member with disability without difficulty	% whose family member with disability and family receive help to plan for the future
Overall	946	76%	62%
Age group			
34 or younger	243	74%	58%
35 to 44	225	73%	62%
45 to 54	229	79%	64%
55 or over	218	81%	66%
Disability type			
Autism	70	76%	53%
Cerebral Palsy & Other Neurological	125	78%	58%
Intellectual Disability & Down Syndrome	470	78%	66%
Other	250	74%	58%
Sensory	30	70%	70%
Level of Function			
High	105	77%	61%
Medium	422	73%	58%
Low	362	81%	67%
State/Territory			
ACT	66	62%	44%
NSW	444	80%	65%
QLD	71	76%	61%
SA	183	71%	59%
VIC	151	78%	61%
NT & TAS & WA	30	77%	73%
Remoteness			
Inner Regional	381	83%	70%
Major City	474	71%	55%
Outer Regional / Remote / Very Remote	74	77%	64%
Annualised cost of baseline plan			
\$15,000 or less	68	81%	60%
\$15-30,000	157	67%	57%
\$30-40,000	70	66%	50%
\$40-50,000	54	68%	42%
Over \$50,000	535	81%	67%
Aboriginal and Torres Strait Islander Status			
Indigenous	31	77%	58%
Non-Indigenous	904	76%	62%
CALD Status			
CALD	42	68%	51%
Non-CALD	902	77%	62%
Gender			
Female	390	79%	68%
Male	534	75%	57%
Plan Management Type			
Agency-managed	597	78%	65%
Combination	93	78%	67%
Plan-managed	96	79%	55%
Self-managed	25	72%	64%
Access Type			
Benefit from EI	<20	na	na
Disability Met	937	77%	62%
Reporting Access Entry Type			
Commonwealth	216	72%	53%
New	83	68%	51%
State	646	79%	66%
Plan cost allocation			
Capital 5-100%	174	80%	68%
Capacity Building 0-25%	432	80%	65%
Capacity Building 25-50%	114	64%	48%
Capacity Building 50-75%	109	71%	57%
Capacity Building 75-100%	54	74%	57%

Appendix C.2.5 – Succession Plans

Baseline indicators for SF

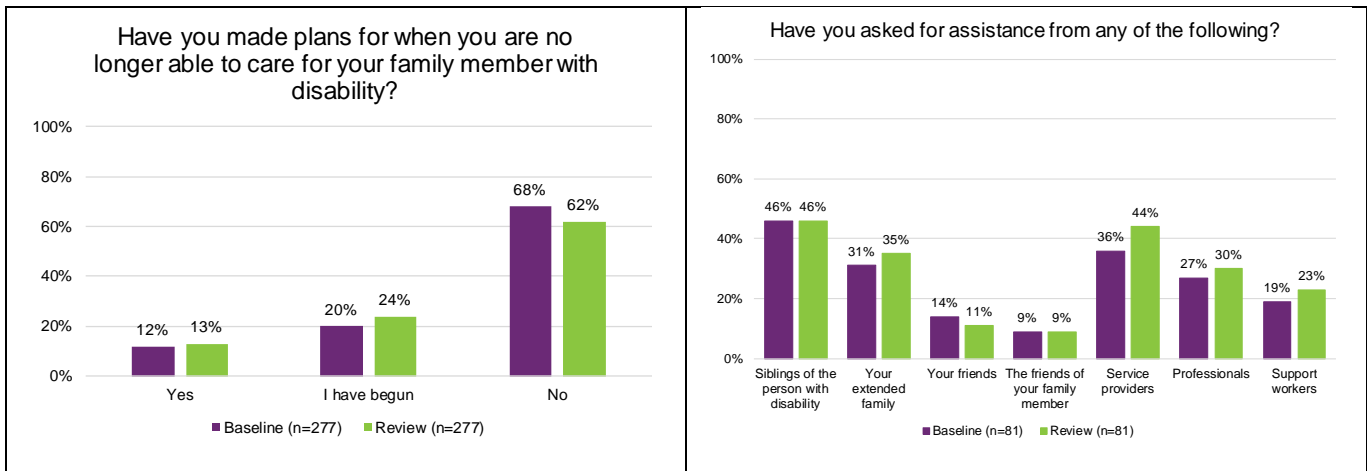
	N	% of families or carers who have made plans for when they are no longer able to care for the family member with disability	% of families or carers who have asked for help from service providers, professionals or support workers
Overall	12,727	13%	61%
Relationship to Participant			
Mother	5,129	14%	60%
Father	993	16%	59%
Spouse/Partner	2,910	6%	67%
Sister	1,030	18%	63%
Brother	405	17%	66%
Other Family	639	17%	62%
Carer	301	12%	71%
Other	812	13%	64%
Age Group			
29 and under	1,748	10%	61%
30 to 34	1,612	13%	59%
35 to 39	1,428	12%	61%
40 to 44	1,348	13%	61%
45 to 49	1,476	14%	63%
50 to 54	1,541	13%	61%
55 to 59	1,697	15%	62%
60 and over	1,877	13%	64%
Disability Type			
ABI	994	13%	66%
Autism	814	13%	63%
Cerebral Palsy	655	13%	62%
Down Syndrome	737	18%	60%
Hearing Impairment	373	12%	43%
Intellectual Disability	3,802	16%	58%
Multiple Sclerosis	596	6%	62%
Other Neurological	1,313	12%	72%
Other Physical	813	7%	59%
Psychosocial Disability	1,400	11%	67%
Spinal Cord Injury	276	7%	67%
Stroke	493	10%	52%
Visual Impairment	461	7%	54%
Level of function			
High	1,627	13%	46%
Medium	6,495	12%	57%
Low	4,605	14%	71%
State			
ACT	84	8%	50%
NSW	5,396	13%	59%
NT	75	10%	100%
QLD	1,438	12%	59%
SA	1,298	10%	60%
TAS	213	37%	72%
VIC	4,114	13%	64%
WA	109	11%	57%
Remoteness			
Major City	7,286	12%	61%
Inner Regional	3,967	14%	62%
Outer Regional / Remote / Very Remote	1,272	13%	60%
Annualised cost of baseline plan			
\$10,000 or less	741	12%	56%
\$10-15,000	501	10%	42%
\$15-20,000	675	12%	44%
\$20-30,000	1,494	12%	47%
Over \$30,000	9,316	13%	65%
Aboriginal and Torres Strait Islander Status			
Indigenous	438	14%	62%
Non-Indigenous	11,568	13%	50%
CALD Status			
CALD	1,422	8%	54%
Non-CALD	11,294	13%	62%
Gender			
Female	5,629	12%	63%
Male	6,927	13%	60%
Plan management type			
Agency-managed	7,549	14%	59%
Self-managed	680	10%	54%
Plan-managed	3,202	12%	66%
Combination	1,248	9%	63%
Access Type			
Benefit from EI	220	7%	67%
Disability Met	12,435	13%	61%
Scheme access			
New	2,985	8%	53%
State	7,969	14%	65%
Commonw health	1,773	17%	52%
Plan cost allocation			
Capital 5-100%	3,536	13%	64%
Capacity Building 0-75%	8,677	13%	61%
Capacity Building 75-95%	330	13%	47%
Capacity Building 95-100%	174	18%	39%

Appendix C.2.6 – Health and wellbeing

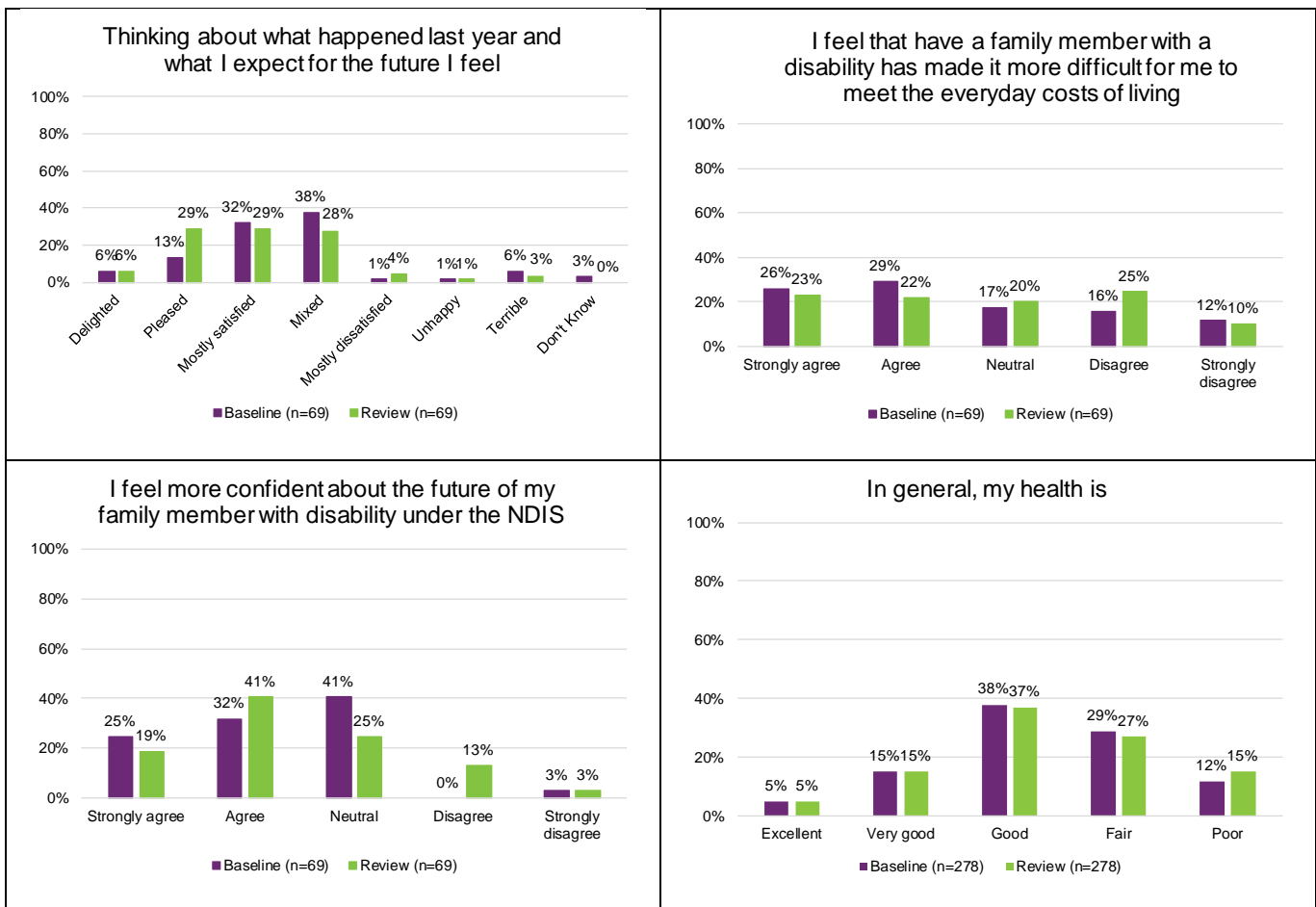
Baseline indicators for SF

	N	% of families or carers who rate their health as excellent, very good or good	% of families or carers who feel their family member with disability gets the support they need	% of families or carers who provide informal care to their family member with disability and are able to work as much as they want	% of families or carers who say the situation with their family member with disability is a barrier to working more	% of families or carers who say flexibility of jobs is a barrier to working more
Overall	12,727	59%	28%	59%	89%	22%
Relationship to Participant						
Mother	5,129	54%	29%	63%	87%	21%
Father	993	56%	31%	67%	87%	20%
Spouse/Partner	2,910	60%	22%	49%	91%	21%
Sister	1,030	73%	33%	62%	90%	22%
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55 to 59	1,697	60%	27%	58%	90%	20%
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Disability Type						
ABI	994	58%	27%	58%	91%	20%
Autism	814	60%	29%	58%	88%	22%
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Stroke	493	63%	23%	46%	94%	21%
Visual Impairment	461	60%	23%	57%	86%	20%
Level of function						
High	1,627	67%	35%	70%	82%	24%
Medium	6,495	61%	28%	63%	87%	22%
Low	4,605	53%	25%	49%	92%	21%
State						
ACT	84	70%	28%	54%	97%	9%
NSW	5,396	59%	27%	58%	90%	23%
NT	75	50%	15%	31%	83%	59%
QLD	1,438	58%	26%	62%	85%	24%
SA	1,298	60%	34%	67%	86%	21%
TAS	213	72%	49%	70%	92%	19%
VIC	4,114	58%	27%	56%	89%	20%
WA	109	74%	44%	62%	85%	21%
Remoteness						
Major City	7,286	58%	27%	56%	89%	19%
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Annualised cost of baseline plan						
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Non-Indigenous	11,568	59%	28%	59%	84%	35%
CALD Status						
CALD	1,422	55%	22%	47%	92%	23%
Non-CALD	11,294	59%	29%	60%	88%	22%
Gender						
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Plan management type						
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Self-managed	680	70%	31%	58%	92%	20%
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Combination	1,248	61%	25%	54%	90%	24%
Access Type						
Benefit from EI	220	59%	20%	48%	94%	19%
Disability Met	12,435	59%	28%	59%	89%	22%
Scheme access						
New	2,985	60%	20%	52%	89%	21%
State	7,969	57%	29%	59%	89%	22%
Commonwealth	1,773	65%	36%	69%	86%	24%
Plan cost allocation						
Capital 5-100%	3,536	59%	26%	55%	91%	21%
Capacity Building 0-75%	8,677	58%	28%	59%	88%	22%
Capacity Building 75-95%	330	66%	48%	77%	69%	20%
Capacity Building 95-100%	174	69%	43%	75%	80%	23%

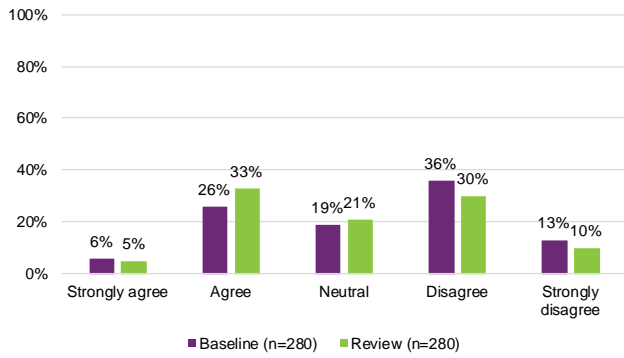
Appendix C.3.5 – Succession Plans



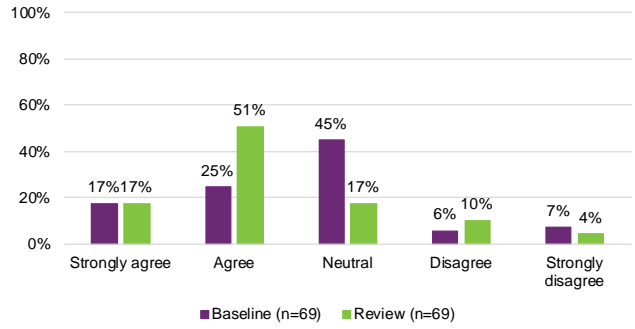
Appendix C.3.6 – Health and wellbeing



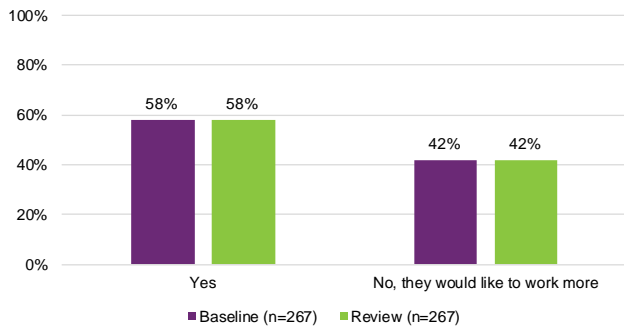
I feel that my family member gets the support he/she needs



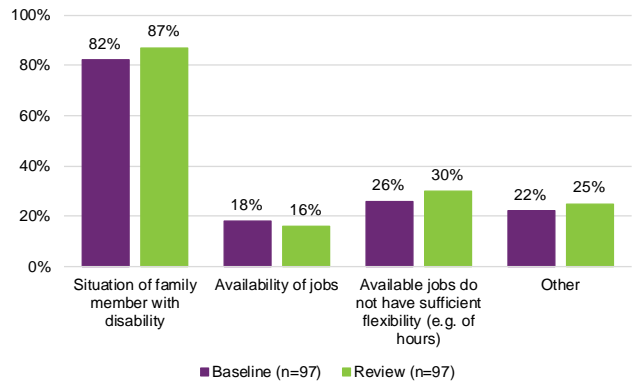
I feel that the services and supports have helped me to better care for my family member with disability



Family who provide informal care to my family member with disability are able to work as much as they want



The barriers to working more are:



Appendix C.4 – Longitudinal change in indicators for SF and LF - participant characteristics

Appendix C.4.1 – Government Benefits

Longitudinal change in indicators for SF – participant characteristics

















	N	% of families or carers that are receiving carer payments	% of families or carers that are receiving carer allowance
Overall	298	2%	10%
Relationship to Participant			
Mother	104	-1%	12%
Father	23	9%	13%
Spouse / Partner	79	5%	14%
Other	92	2%	4%
Age Group			
29 and under	38	8%	21%
30 to 34	32	0%	6%
35 to 39	30	3%	3%
40 to 44	43	5%	12%
45 to 49	41	-5%	15%
50 to 54	38	3%	3%
55 to 59	31	6%	10%
60 and over	45	0%	9%
Disability Type			
Autism	<20	na	na
Cerebral Palsy	<20	na	na
Down Syndrome	20	0%	20%
Intellectual Disability	83	-2%	11%
Multiple Sclerosis & Spinal Cord Injury	21	0%	5%
Other	<20	na	na
Other Neurological	43	0%	19%
Other Physical	21	5%	14%
Psychosocial Disability	27	11%	4%
Stroke & Acquired Brain Injury	37	5%	5%
Level of function			
High	53	2%	13%
Medium	141	2%	11%
Low	104	3%	8%
State			
NSW	140	5%	10%
Other	31	6%	13%
QLD	81	0%	9%
VIC	46	-4%	11%
Remoteness			
Major City	158	4%	10%
Inner Regional	88	-2%	14%
Outer Regional / Remote / Very Remote	50	4%	4%
Annualised cost of baseline plan			
\$25,000 or less	77	1%	12%
\$25-50,000	73	3%	10%
\$50-100,000	74	4%	8%
Over \$100,000	74	1%	11%
Aboriginal and Torres Strait Islander Status			
Non-Indigenous	278	1%	11%
Indigenous	<20	na	na
CALD Status			
CALD	32	3%	0%
Non-CALD	266	2%	11%
Gender			
Female	126	4%	11%
Male	170	1%	9%
Plan management type			
Agency-managed	171	3%	10%
Self-managed	<20	na	na
Plan-managed	35	0%	14%
Combination	58	0%	10%
Access Type			
Benefit from EI	<20	na	na
Disability Met	286	2%	10%
Scheme access			
New	101	4%	16%
State	161	2%	7%
Commonwealth	36	0%	8%
Plan cost allocation			
Capacity Building 0-30%	171	2%	12%
Capacity Building 30-100%	76	4%	13%
Capital 5-100%	49	2%	0%

Appendix C.4.2 – Rights and Advocacy

Longitudinal change in indicators for SF – participant characteristics

	N	% of families or carers are able to meet the needs of their family and family member with disability know how to access available services and supports to meet those needs	% of families or carers are able to advocate (stand up) for their family member: who are able to speak up if they have issues
Overall	298	0%	1%
Relationship to Participant			
Mother	104	2%	3%
Father	23	0%	0%
Spouse / Partner	79	0%	-5%
Other	92	-1%	3%
Age Group			
29 and under	38	0%	0%
30 to 34	32	0%	3%
35 to 39	30	0%	3%
40 to 44	43	2%	0%
45 to 49	41	-3%	-3%
50 to 54	38	6%	6%
55 to 59	31	0%	3%
60 and over	45	-2%	-5%
Disability Type			
Autism	<20	na	na
Cerebral Palsy	<20	na	na
Down Syndrome	20	0%	6%
Intellectual Disability	83	6%	6%
Multiple Sclerosis & Spinal Cord Injury	21	-11%	-11%
Other	<20	na	na
Other Neurological	43	2%	-2%
Other Physical	21	0%	-5%
Psychosocial Disability	27	0%	4%
Stroke & Acquired Brain Injury	37	-3%	-5%
Level of function			
High	53	-2%	-2%
Medium	141	5%	2%
Low	104	-4%	1%
State			
NSW	140	-1%	-1%
Other	31	7%	7%
QLD	81	3%	4%
VIC	46	-4%	-4%
Remoteness			
Major City	158	0%	0%
Inner Regional	88	-1%	1%
Outer Regional / Remote / Very Remote	50	4%	2%
Annualised cost of baseline plan			
\$25,000 or less	77	-1%	3%
\$25-50,000	73	0%	-3%
\$50-100,000	74	4%	1%
Over \$100,000	74	-1%	1%
Aboriginal and Torres Strait Islander Status			
Non-Indigenous	278	1%	1%
Indigenous	<20	na	na
CALD Status			
CALD	32	-16%	-13%
Non-CALD	266	2%	2%
Gender			
Female	126	-3%	0%
Male	170	2%	1%
Plan management type			
Agency-managed	171	-2%	-2%
Self-managed	<20	na	na
Plan-managed	35	3%	3%
Combination	58	2%	4%
Access Type			
Benefit from EI	<20	na	na
Disability Met	286	0%	1%
Scheme access			
New	101	6%	6%
State	161	-5%	-4%
Commonwealth	36	9%	6%
Plan cost allocation			
Capacity Building 0-30%	171	1%	1%
Capacity Building 30-100%	76	1%	1%
Capital 5-100%	49	-2%	-2%

Longitudinal change in indicators for LF – participant characteristics

















		% who have no difficulty understanding their rights and the rights of their family member with disability	
	N		
Overall	106		-6%
Age Group			
44 or younger	59		-15%
45 or older	45		7%
Disability Type			
Other	50		11%
Autism & Intellectual Disability & Down Syndrome	44		-18%
Cerebral Palsy & Other Neurological	<20		na
Level of Function			
High	<20		na
Medium	44		-3%
Low	<20		na
State/Territory			
ACT	66		-11%
NSW	36		5%
Other	<20		
Annualised cost of baseline plan			
\$20,000 or less	<20		na
\$20-30,000	24		8%
Over \$30,000	63		-7%
Gender			
Female	45		7%
Male	60		-15%
Entry type			
New	77		2%
State/Commonwealth	28		-32%
Plan cost allocation			
Capital 5-100%	27		-10%
Capacity Building 0-25%	29		16%
Capacity Building 25-50%	<20		na
Capacity Building 50-75%	<20		na
Capacity Building 75-100%	<20		na

Appendix C.4.3 – Families feel supported

Longitudinal change in indicators for SF – participant characteristics

	N	% of families or carers who have friends they can see as often as they'd like	% of families or carers who have people they can ask for practical help as often as they need	% of families or carers who have people they can ask to support my family member with disability as often as they need	% of families or carers who they can talk to for emotional support as often as they need
Overall	298	3%	5%	5%	5%
Relationship to Participant					
Mother	104	0%	12%	11%	8%
Father	23	9%	13%	9%	0%
Spouse / Partner	79	1%	3%	4%	0%
Other	92	5%	-3%	-2%	7%
Age Group					
29 and under	38	5%	5%	3%	11%
30 to 34	32	6%	9%	19%	13%
35 to 39	30	0%	7%	0%	3%
40 to 44	43	-5%	5%	14%	0%
45 to 49	41	2%	2%	2%	7%
50 to 54	38	13%	8%	11%	13%
55 to 59	31	-3%	10%	-3%	3%
60 and over	45	2%	-4%	-7%	-9%
Disability Type					
Autism	<20	na	na	na	na
Cerebral Palsy	<20	na	na	na	na
Down Syndrome	20	10%	10%	15%	15%
Intellectual Disability	83	2%	13%	10%	6%
Multiple Sclerosis & Spinal Cord Injury	21	-5%	0%	-5%	-14%
Other	<20	na	na	na	na
Other Neurological	43	9%	7%	5%	9%
Other Physical	21	0%	14%	14%	0%
Psychosocial Disability	27	7%	4%	4%	4%
Stroke & Acquired Brain Injury	37	8%	-11%	-5%	5%
Level of function					
High	53	8%	8%	8%	8%
Medium	141	5%	8%	4%	1%
Low	104	-3%	-1%	4%	8%
State					
NSW	140	4%	-2%	-1%	4%
Other	31	0%	6%	6%	-3%
QLD	81	5%	12%	12%	11%
VIC	46	-2%	11%	7%	2%
Remoteness					
Major City	158	1%	3%	3%	4%
Inner Regional	88	9%	7%	6%	6%
Outer Regional / Remote / Very Remote	50	-4%	6%	10%	6%
Annualised cost of baseline plan					
\$25,000 or less	77	4%	6%	4%	8%
\$25-50,000	73	7%	11%	8%	8%
\$50-100,000	74	0%	-5%	-3%	-1%
Over \$100,000	74	0%	7%	9%	4%
Aboriginal and Torres Strait Islander Status					
Non-Indigenous	278	3%	5%	5%	4%
Indigenous	<20	na	na	na	na
CALD Status					
CALD	32	-9%	-6%	0%	0%
Non-CALD	266	4%	6%	5%	5%
Gender					
Female	126	-1%	3%	2%	6%
Male	170	5%	6%	6%	4%
Plan management type					
Agency-managed	171	2%	3%	2%	5%
Self-managed	<20	na	na	na	na
Plan-managed	35	3%	11%	9%	9%
Combination	58	7%	5%	10%	3%
Access Type					
Benefit from EI	<20	na	na	na	na
Disability Met	286	3%	5%	5%	5%
Scheme access					
New	101	5%	2%	5%	6%
State	161	0%	6%	4%	2%
Commonwealth	36	8%	6%	8%	11%
Plan cost allocation					
Capacity Building 0-30%	171	0%	5%	6%	7%
Capacity Building 30-100%	76	11%	8%	4%	9%
Capital 5-100%	49	0%	-2%	2%	-10%

Longitudinal change in indicators for LF – participant characteristics

		% who have as much contact with other families of people with disability as I would	
	N	like	
Overall	106		12%
Age Group			
44 or younger	59		-3%
45 or older	45		30%
Disability Type			
Other	50		25%
Autism & Intellectual Disability & Down Syndrome	44		12%
Cerebral Palsy & Other Neurological	<20		na
Level of Function			
High	<20		na
Medium	44		6%
Low	<20		na
State/Territory			
ACT	66		9%
NSW	36		20%
Other	<20		
Annualised cost of baseline plan			
\$20,000 or less	<20		na
\$20-30,000	24		8%
Over \$30,000	63		13%
Gender			
Female	45		17%
Male	60		8%
Entry type			
New	77		12%
State/Commonwealth	28		16%
Plan cost allocation			
Capital 5-100%	27		25%
Capacity Building 0-25%	29		21%
Capacity Building 25-50%	<20		na
Capacity Building 50-75%	<20		na
Capacity Building 75-100%	<20		na

Appendix C.4.4 – Access to Services

Longitudinal change in indicators for SF – participant characteristics

		% of families or carers who feel that the services they use for their family member with disability listen to them	% of families or carers that feel in control selecting the services and supports for their family member with disability	% of families or carers who say that the services for their family member with disability and their family receive meet their needs
Overall	298	5%	1%	12%
Relationship to Participant				
Mother	104	10%	4%	20%
Father	23	14%	0%	13%
Spouse / Partner	79	0%	0%	4%
Other	92	0%	0%	9%
Age Group				
29 and under	38	6%	6%	21%
30 to 34	32	16%	6%	28%
35 to 39	30	4%	-3%	3%
40 to 44	43	-5%	-5%	7%
45 to 49	41	3%	-3%	7%
50 to 54	38	16%	15%	13%
55 to 59	31	-4%	-7%	6%
60 and over	45	5%	3%	9%
Disability Type				
Autism	<20	na	na	na
Cerebral Palsy	<20	na	na	na
Down Syndrome	20	-6%	6%	-5%
Intellectual Disability	83	8%	4%	17%
Multiple Sclerosis & Spinal Cord Injury	21	0%	-6%	14%
Other	<20	na	na	na
Other Neurological	43	3%	8%	5%
Other Physical	21	18%	6%	19%
Psychosocial Disability	27	-7%	-4%	4%
Stroke & Acquired Brain Injury	37	21%	0%	14%
Level of function				
High	53	0%	-8%	4%
Medium	141	7%	5%	16%
Low	104	4%	2%	11%
State				
NSW	140	2%	0%	6%
Other	31	0%	-3%	13%
QLD	81	11%	8%	21%
VIC	46	7%	-2%	11%
Remoteness				
Major City	158	6%	3%	9%
Inner Regional	88	1%	-3%	16%
Outer Regional / Remote / Very Remote	50	6%	2%	14%
Annualised cost of baseline plan				
\$25,000 or less	77	0%	-6%	3%
\$25-50,000	73	-2%	-3%	11%
\$50-100,000	74	10%	7%	16%
Over \$100,000	74	10%	7%	18%
Aboriginal and Torres Strait Islander Status				
Non-Indigenous	278	4%	2%	11%
Indigenous	<20	na	na	na
CALD Status				
CALD	32	-4%	-10%	-3%
Non-CALD	266	6%	3%	14%
Gender				
Female	126	1%	0%	13%
Male	170	8%	2%	11%
Plan management type				
Agency-managed	171	6%	-1%	11%
Self-managed	<20	na	na	na
Plan-managed	35	0%	3%	17%
Combination	58	2%	4%	16%
Access Type				
Benefit from EI	<20	na	na	na
Disability Met	286	5%	2%	12%
Scheme access				
New	101	1%	2%	11%
State	161	7%	1%	12%
Commonwealth	36	3%	3%	14%
Plan cost allocation				
Capacity Building 0-30%	171	10%	3%	15%
Capacity Building 30-100%	76	-8%	-4%	5%
Capital 5-100%	49	4%	4%	12%

Longitudinal change in indicators for LF – participant characteristics

		% who work in partnership with professionals and service providers to meet the needs of their family member with disability without difficulty		% whose family member with disability and family receive help to plan for the future	
	N				
Overall	106		0%		9%
Age Group					
44 or younger	59		3%		8%
45 or older	45		-3%		10%
Disability Type					
Other	50		7%		14%
Autism & Intellectual Disability & Down Syndrome	44		-9%		3%
Cerebral Palsy & Other Neurological	<20		na		na
Level of Function					
High	<20		na		na
Medium	44		7%		7%
Low	<20		na		na
State/Territory					
ACT	66		2%		13%
NSW	36		-5%		-5%
Other	<20				
Annualised cost of baseline plan					
\$20,000 or less	<20		na		na
\$20-30,000	24		9%		27%
Over \$30,000	63		-2%		11%
Gender					
Female	45		-10%		10%
Male	60		8%		8%
Entry type					
New	77		0%		4%
State/Commonwealth	28		-5%		21%
Plan cost allocation					
Capital 5-100%	27		0%		15%
Capacity Building 0-25%	29		0%		11%
Capacity Building 25-50%	<20		na		na
Capacity Building 50-75%	<20		na		na
Capacity Building 75-100%	<20		na		na

Appendix C.4.5 – Succession Plans

Longitudinal change in indicators for SF – participant characteristics

	N	% of families or carers who have made plans for when they are no longer able to care for the family member with disability	% of families or carers who have asked for help from service providers, professionals or support workers
Overall	298	1%	3%
Relationship to Participant			
Mother	104	0%	3%
Father	23	5%	9%
Spouse / Partner	79	-1%	0%
Other	92	5%	0%
Age Group			
29 and under	38	0%	0%
30 to 34	32	3%	-11%
35 to 39	30	0%	0%
40 to 44	43	2%	14%
45 to 49	41	3%	9%
50 to 54	38	3%	0%
55 to 59	31	3%	0%
60 and over	45	-2%	0%
Disability Type			
Autism	<20	na	na
Cerebral Palsy	<20	na	na
Down Syndrome	20	11%	13%
Intellectual Disability	83	1%	0%
Multiple Sclerosis & Spinal Cord Injury	21	0%	50%
Other	<20	na	na
Other Neurological	43	3%	0%
Other Physical	21	0%	0%
Psychosocial Disability	27	0%	0%
Stroke & Acquired Brain Injury	37	3%	14%
Level of function			
High	53	0%	0%
Medium	141	2%	3%
Low	104	2%	5%
State			
NSW	140	0%	3%
Other	31	7%	18%
QLD	81	1%	-17%
VIC	46	2%	8%
Remoteness			
Major City	158	1%	10%
Inner Regional	88	3%	-8%
Outer Regional / Remote / Very Remote	50	0%	-8%
Annualised cost of baseline plan			
\$25,000 or less	77	1%	-6%
\$25-50,000	73	2%	20%
\$50-100,000	74	-1%	-8%
Over \$100,000	74	4%	0%
Aboriginal and Torres Strait Islander Status			
Non-Indigenous	278	2%	3%
Indigenous	<20	na	na
CALD Status			
CALD	32	-4%	0%
Non-CALD	266	2%	3%
Gender			
Female	126	3%	4%
Male	170	1%	3%
Plan management type			
Agency-managed	171	1%	7%
Self-managed	<20	na	na
Plan-managed	35	-3%	0%
Combination	58	4%	0%
Access Type			
Benefit from EI	<20	na	na
Disability Met	286	2%	2%
Scheme access			
New	101	2%	5%
State	161	2%	0%
Commonwealth	36	-3%	11%
Plan cost allocation			
Capacity Building 0-30%	171	2%	-5%
Capacity Building 30-100%	76	0%	18%
Capital 5-100%	49	2%	9%

Appendix C.4.6 – Health and wellbeing

Longitudinal change in indicators for SF – participant characteristics

	N	% of families or carers who rate their health as excellent, very good or good	% of families or carers who feel their family member with disability gets the support they need	% of families or carers who provide informal care to their family member with disability and are able to work as much as they want	% of families or carers who say the situation with their family member with disability is a barrier to working more	% of families or carers who say insufficient flexibility of jobs is a barrier to working more
Overall	298	-1%	6%	0%	3%	4%
Relationship to Participant						
Mother	104	-2%	15%	1%	4%	4%
Father	23	0%	-9%	5%	0%	17%
Spouse / Partner	79	-3%	0%	-6%	3%	-3%
Other	92	1%	6%	4%	3%	9%
Age Group						
29 and under	38	3%	17%	3%	7%	13%
30 to 34	32	3%	6%	7%	20%	10%
35 to 39	30	-3%	3%	-7%	0%	0%
40 to 44	43	2%	0%	2%	0%	-9%
45 to 49	41	-11%	3%	-9%	0%	0%
50 to 54	38	-3%	15%	0%	13%	0%
55 to 59	31	0%	3%	7%	0%	18%
60 and over	45	0%	5%	0%	-7%	0%
Disability Type						
Autism	<20	na	na	na	na	na
Cerebral Palsy	<20	na	na	na	na	na
Down Syndrome	20	0%	11%	6%	17%	0%
Intellectual Disability	83	0%	10%	-3%	0%	13%
Multiple Sclerosis & Spinal Cord Injury	21	6%	6%	-12%	13%	0%
Other	<20	na	na	na	na	na
Other Neurological	43	-3%	-5%	0%	0%	-5%
Other Physical	21	0%	16%	0%	0%	0%
Psychosocial Disability	27	-4%	0%	8%	8%	8%
Stroke & Acquired Brain Injury	37	-3%	8%	8%	6%	6%
Level of function						
High	53	6%	-2%	2%	-6%	11%
Medium	141	-4%	8%	-1%	6%	6%
Low	104	-1%	9%	1%	4%	0%
State						
NSW	140	-2%	5%	2%	2%	9%
Other	31	-3%	3%	0%	10%	0%
QLD	81	4%	9%	-1%	4%	0%
VIC	46	-7%	9%	-2%	0%	0%
Remoteness						
Major City	158	-2%	10%	1%	4%	2%
Inner Regional	88	1%	1%	-4%	4%	12%
Outer Regional / Remote / Very Remote	50	-2%	4%	6%	0%	0%
Annualised cost of baseline plan						
\$25,000 or less	77	-4%	-3%	-3%	0%	9%
\$25-50,000	73	-1%	-1%	2%	6%	12%
\$50-100,000	74	0%	8%	8%	6%	-6%
Over \$100,000	74	1%	21%	-6%	0%	8%
Aboriginal and Torres Strait Islander						
Non-Indigenous	278	-1%	7%	0%	3%	4%
Indigenous	<20	na	na	na	na	na
CALD Status						
CALD	32	-7%	-3%	0%	0%	0%
Non-CALD	266	0%	8%	0%	4%	5%
Gender						
Female	126	1%	3%	2%	0%	9%
Male	170	-2%	9%	-1%	6%	0%
Plan management type						
Agency-managed	171	-1%	2%	1%	3%	7%
Self-managed	<20	na	na	na	na	na
Plan-managed	35	0%	18%	-6%	0%	0%
Combination	58	-2%	9%	4%	0%	0%
Access Type						
Benefit from EI	<20	na	na	na	na	na
Disability Met	286	-2%	6%	0%	3%	4%
Scheme access						
New	101	-4%	4%	3%	5%	0%
State	161	0%	8%	-3%	2%	9%
Commonwealth	36	3%	6%	6%	0%	0%
Plan cost allocation						
Capacity Building 0-30%	171	2%	10%	1%	4%	0%
Capacity Building 30-100%	76	-9%	-7%	1%	5%	14%
Capital 5-100%	49	2%	13%	-2%	0%	5%

Longitudinal change in indicators for LF – participant characteristics

		Thinking about what happened last year and the future, % who are delighted, pleased or mostly satisfied	% who disagree or strongly disagree that having a family member with a disability has made it more difficult for me to meet the everyday cost of living	% who agree or strongly agree that they feel more confident about the future of their family with disability under the NDIS	% who strongly agree or agree that services and supports have helped them to better care for their family
Overall	106	13%	7%	3%	26%
Age Group					
44 or younger	59	8%	5%	10%	28%
45 or older	45	20%	10%	-7%	23%
Disability Type					
Other	50	25%	0%	-4%	36%
Autism & Intellectual Disability & Down Syndrome	44	9%	12%	6%	18%
Cerebral Palsy & Other Neurological	<20	na	na	na	na
Level of Function					
High	<20	na	na	na	na
Medium	44	3%	3%	6%	35%
Low	<20	na	na	na	na
State/Territory					
ACT	66	15%	13%	11%	37%
NSW	36	5%	0%	-20%	5%
Other	<20				
Annualised cost of baseline plan					
\$20,000 or less	<20	na	na	na	na
\$20-30,000	24	8%	0%	-8%	8%
Over \$30,000	63	15%	9%	7%	35%
Gender					
Female	45	28%	21%	14%	31%
Male	60	3%	-3%	-5%	23%
Entry type					
New	77	17%	6%	4%	25%
State/Commonwealth	28	0%	0%	0%	21%
Plan cost allocation					
Capital 5-100%	27	20%	15%	20%	35%
Capacity Building 0-25%	29	32%	5%	-11%	26%
Capacity Building 25-50%	<20	na	na	na	na
Capacity Building 50-75%	<20	na	na	na	na
Capacity Building 75-100%	<20	na	na	na	na

Appendix C.5 – Has the NDIS helped?

Summary

Overall results (Appendix C.5.1)

Appendix C.5.1 shows the percentage of families/carers who think that the NDIS has helped with outcomes related to each of the five SF domains after at least one year in the Scheme (i.e. at review).

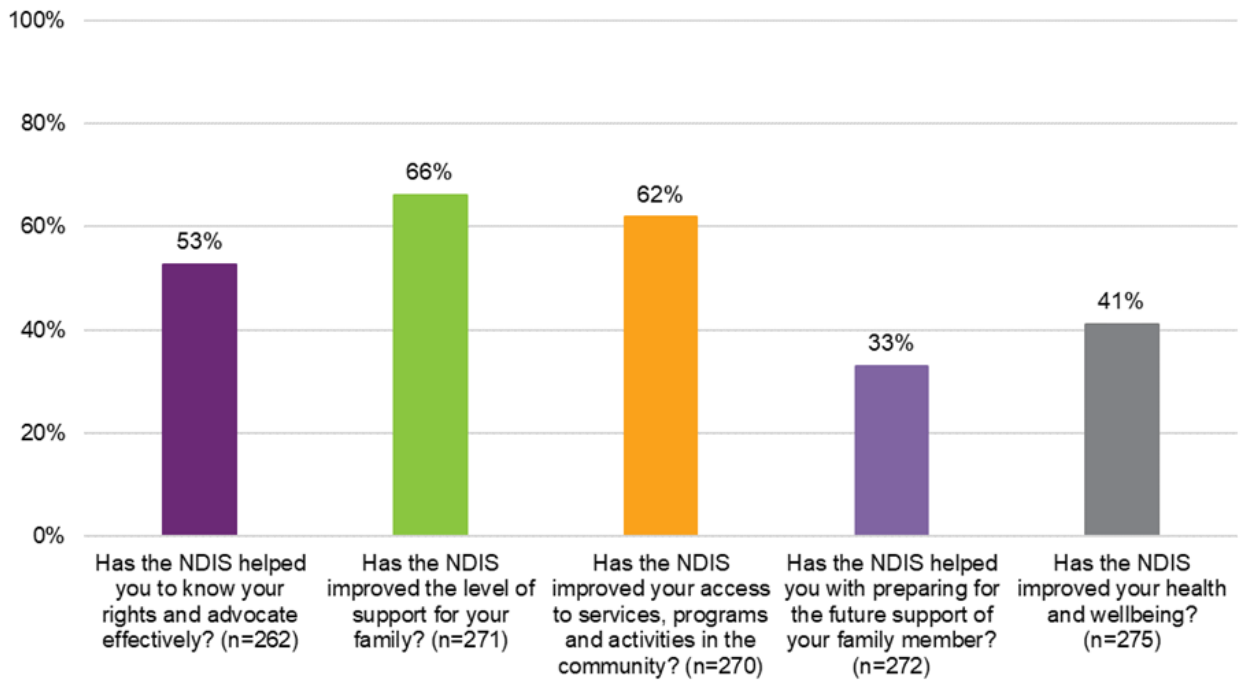
Appendix C.5.1 highlights that most families/carers think that the NDIS has helped with three out of the five SF domains. The most positive responses are for improving the level of support for the family (66%), and improving access to services, programs and activities in the community (62%). However, only 41% felt that the NDIS had improved their health and wellbeing, and only 33% said the NDIS had helped them to prepare for the future support of the participant.

Results by participant characteristics (Appendix C.5.2)

One-way analysis of key participant and family/carer characteristics against the NDIS helped questions suggests the following relationships:

- Participant level of function: Families and carers of participants with a low level of function were more likely to think that the NDIS had helped across all domains in the SF as compared to those with medium and high levels of function. For example:
 - The percentage who said the NDIS had helped them to know their rights and advocate effectively was 44% for high level of function, 46% for medium level of function, and 66% for low level of function.
 - The percentage saying that the NDIS had improved the level of support for their family was highest for participants with low levels of function (73%) as compared to medium (66%) and high (54%).
- Baseline plan utilisation: Families/carers were generally more likely to think that the NDIS had helped as the utilisation of the participant's baseline plan increased. For example, 49% of families/carers with the lowest level of utilisation (<20%) thought that the NDIS had improved their access to services, programs and activities in the community, compared to 79% for the highest level of utilisation (80-100%).
- Culturally and linguistically diverse background and Indigenous status: Families/carers were less likely to say that the NDIS had helped them to prepare for the future support of the participant if the participant was Indigenous, or from a CALD background. However, families and carers of Indigenous participants were more likely to say that the NDIS had improved their health and wellbeing.
- Gender: The families and carers of female participants responded more positively across all domains compared to male participants, with the largest difference being improved access to services, programs and activities in the community (72% females vs 55% males).

Appendix C.5.1 – Summary by domain



Appendix C.5.2 – All domains by participant characteristics

	N	Has the NDIS helped you to know your rights and advocate effectively?	Has the NDIS improved the level of support for your family?	Has the NDIS improved your access to services, programs and activities in the community?	Has the NDIS helped you with preparing for the future support of your family member?	Has the NDIS improved your health and wellbeing?
	298	53%	66%	62%	33%	41%
Relationship to participant						
Mother	104	52%	69%	67%	39%	39%
Father	23	63%	60%	70%	42%	44%
Spouse / Partner	79	57%	74%	56%	22%	45%
Other	92	48%	58%	59%	33%	39%
Age Group						
29 and under	38	47%	64%	64%	42%	40%
30 to 34	32	52%	67%	69%	29%	32%
35 to 39	30	56%	64%	69%	31%	41%
40 to 44	43	49%	62%	61%	42%	40%
45 to 49	41	53%	63%	63%	41%	49%
50 to 54	38	65%	75%	63%	28%	32%
55 to 59	31	45%	62%	48%	24%	43%
60 and over	45	56%	71%	59%	26%	49%
Disability Type						
Autism	<20	na	na	na	na	na
Cerebral Palsy	<20	na	na	na	na	na
Down Syndrome	20	42%	58%	61%	39%	33%
Intellectual Disability	83	41%	58%	63%	33%	36%
Multiple Sclerosis & Spinal Cord Injury	21	53%	70%	45%	37%	35%
Other	<20	na	na	na	na	na
Other Neurological	43	54%	66%	54%	13%	43%
Other Physical	21	67%	63%	65%	33%	47%
Psychosocial Disability	27	50%	71%	72%	52%	35%
Stroke & Acquired Brain Injury	37	67%	66%	64%	29%	44%
Level of Function						
High	53	44%	54%	53%	33%	37%
Medium	141	46%	66%	57%	31%	41%
Low	104	66%	73%	73%	36%	43%
State						
NSW	140	55%	68%	59%	30%	40%
Other	31	37%	46%	56%	28%	47%
QLD	81	51%	72%	64%	44%	47%
VIC	46	60%	62%	72%	28%	28%
Remoteness						
Major City	158	55%	67%	63%	32%	43%
Inner Regional	88	52%	61%	61%	29%	33%
Outer Regional / Remote / Very Remote	50	44%	72%	60%	40%	49%
Annualised cost of baseline plan						
\$25,000 or less	77	42%	55%	49%	32%	39%
\$25-50,000	73	44%	65%	59%	32%	39%
\$50-100,000	74	55%	69%	66%	30%	34%
Over \$100,000	74	68%	75%	75%	38%	52%
Aboriginal and Torres Strait Islander Status						
Indigenous	<20	na	na	na	na	na
Non-Indigenous	278	53%	67%	62%	34%	40%
CALD Status						
CALD	32	52%	69%	62%	23%	40%
Non-CALD	266	53%	66%	62%	34%	41%
Gender						
Female	126	58%	68%	72%	36%	48%
Male	170	49%	65%	55%	31%	36%
Plan Management Type						
Agency-managed	171	53%	68%	62%	33%	39%
Self-managed	<20	na	na	na	na	na
Plan-managed	35	61%	66%	75%	38%	39%
Combination	58	55%	68%	63%	35%	48%
Access Type						
Benefit from EI	<20	na	na	na	na	na
Disability Met	286	53%	66%	62%	33%	41%
Scheme access						
New	101	48%	65%	52%	32%	45%
State	161	56%	67%	68%	31%	38%
Commonwealth	36	50%	63%	60%	46%	44%