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Appendix B – Families and carers of participants aged 15 to 24

Box B.1: Key Findings

- In the longitudinal analysis, significant improvements were observed across a number of indicators, particularly in the areas of:
 - Feeling supported: all SF indicators have increased by at least 2%. For example, more respondents can see family and friends as often as they like, and more have people they can ask for practical and emotional support. The improvements appear to be driven by better supports put in place over the time spent in the Scheme.
 - Access to services: the percentage of respondents who feel that the services used by the participant and family meet their needs has increased by 13%. Feedback in relation to other aspects of service delivery has been more positive. In particular, respondents are more likely to feel in control in selecting services and supports, and to report that services listen to them. Baseline plan utilisation was found to be a significant predictor of improvement in these indicators.
 - Families and carers help their young family member to become more independent: the respondents appear to have gained more capacity to support their family member with disability to be more independent in decision-making (increased by 2.5%) and in their interactions with non-family members (increased by 2%). Multiple regression analysis suggests that the greatest improvement in this area was achieved for the respondents who were able to identify the needs of the participant and access supports and services to meet those needs.
- For the majority of indicators, baseline outcomes are better for family and carers of participants with higher level of function.
- Respondents for participants with a hearing impairment or visual impairment generally experience better outcomes at baseline. In contrast, respondents for participants with psychosocial disability tend to fare worse.
- Baseline outcomes for respondents for participants from a CALD backgrounds tend to exhibit worse outcomes, particularly on advocacy and independence.
- Results for respondents for Indigenous participants are mixed. This group of respondents are less likely to be in paid employment, but more likely to have people who can provide practical help.
- Results for respondents in regional and remote locations are mixed. This group tends to do better on indicators related to advocacy and feeling supported. However, some employment indicators are worse; in particular, some barriers to working more, such as availability of jobs and insufficient flexibility are more commonly cited.
- Respondents with self-managed plans (fully or partly) experience more positive outcomes on some indicators, particularly on rights and advocacy.
- Results tend to be less positive for families and carers of participants streamed as intensive or super intensive. In particular, these respondents are less likely to have necessary social supports, including being able to see family and friends as often as they like and have people who they can ask for practical help or emotional support. The indicators related to helping the participant become more independent are less likely to be positive compared to other types of streaming.

- Most families say they lack social connections and support. Less than half, 45%, had friends and family that they saw as often as they liked. However, according to one-way analysis and multiple regression, results tend to be better for the respondents who are socially well connected. These respondents are more likely to be able to help the participant becomes more independent. In addition, they are also more likely to be in better health and work as much as they want – both factors could be either a consequence of better social support or be driving it.
- The percentage of respondents who rate their health as good, very good, or excellent has decreased slightly from 65% at baseline to 62% at review. As health tends to decline with age, some decrease in the health rating over the year is expected. In multiple regression analysis, lack of emotional support was found to be correlated with deterioration in health.
- The percentage working in a paid job has increased from 48% at baseline to 51% at review, and the percentage working 15 hours or more has also increased from 83% to 86%. Some of these changes may be attributed to the participant being one year older and likely more independent, allowing their parents/carers to work more.
- Around half of respondents rated the NDIS positively on domains 1 to 4 of the SF. The remaining SF question on respondent's health and wellbeing (domain 5) and the LF question on the understanding of the participant's strengths, abilities and special needs were rated lower, at 33%. The level of satisfaction increased with baseline plan utilisation across all SF domains. According to multiple regression analyses, the satisfaction rates tended to be higher for respondents with higher plan costs, those who are able to identify the needs of the participant, and those who receive services that meet their needs.

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

Summary

Government benefits (Carer Payment and Carer Allowance)

For families and carers of participants aged 15 to 24, 28% were receiving Carer Payment and 51% were receiving Carer Allowance at baseline.

Rights and advocacy

48% of families and carers were able to identify the needs of the participant and family and knew how to access available services and supports to meet those needs. Furthermore, the majority (72%) was able to advocate (stand up) for the participants in case of issues or problems with accessing supports.

Families feel supported

As with families and carers for participants from birth to age 14, most families say they lack sufficient support or social connections. In the SF, 45% had friends and family that they saw as often as they liked. A slightly higher percentage of respondents (49%) had someone who they could ask for emotional support as often as they needed. The percentage of parents/carers who had people they could ask for practical help as often as they needed was lower – only 38%. Similarly, 31% had people they could ask to support the participant as often as they needed. However, having family and friends that the respondent could see as often as they liked increased the likelihood of receiving emotional and practical support.

Access to Services

40% of respondents felt in control in selecting services and supports. The percentage who felt that services listened to them was higher, at 63%. Rating services on the whole, at baseline 18% stated that the services met their needs.

Independence of family member

42% of families and carers knew what their family could do to enable the participant to become as independent as possible. Moreover, 46% enabled/supported the participant to interact and develop strong relationships with non-family members.

Families understand the strengths, abilities and special needs of their family member

The LF includes an additional domain concerned with how families and carers perceive the strengths and abilities of their family member with disability, and how their family member is progressing. 86% of families and carers can recognise the strengths and abilities of the participant and 76% can see how the participant is progressing.

Health and wellbeing

At baseline, 47% of families and carers say that they are able to work as much as they want. Of the families and carers who do not work as much as they like, 92% identified the situation of their family member with disability as a barrier to working more, and 33% said that insufficient flexibility of jobs was a barrier.

From the SF, 61% of families/carers rate their health as good, very good or excellent, considerably lower compared to 87% of Australians aged 25 to 64 overall¹.

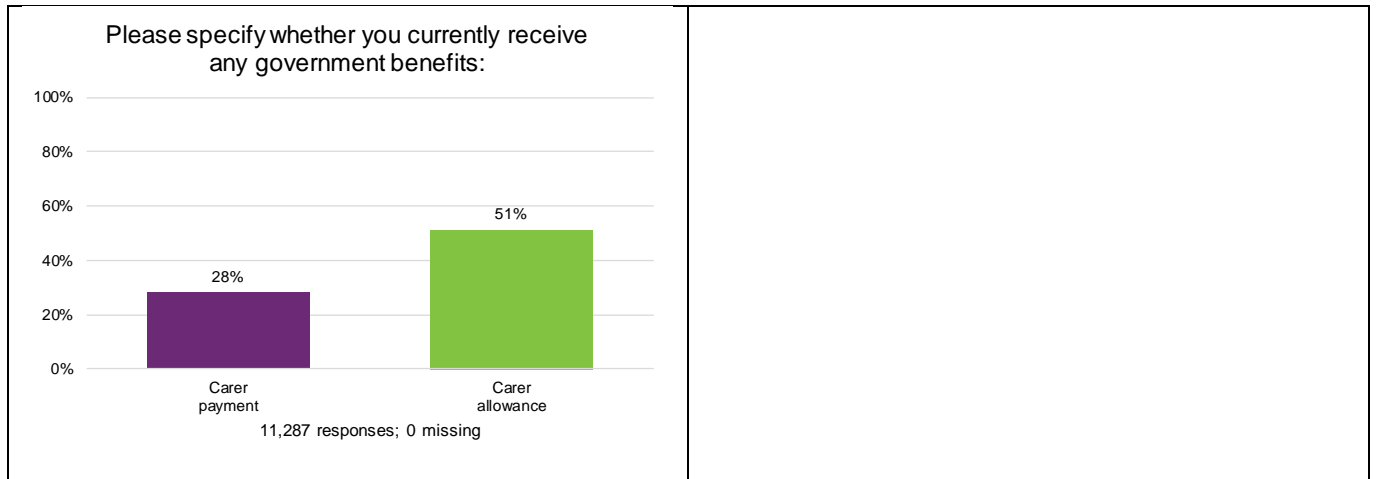
¹ ABS National Health Survey (NHS) 2014-15.

The LF includes a number of extra questions asking about the wellbeing of families and carers and their outlook on life generally, and for their family member with disability in particular. The results are similar to those of the families and carers of participants from birth to age 14 cohort. The respondents most commonly had “mixed” feelings about the future generally (42%), although more answered positively (40%) than negatively (17%). The 40% responding positively is much lower than the 77% for Australians aged 25 to 64 overall², and is lower than for participants aged 25 and over (52%).

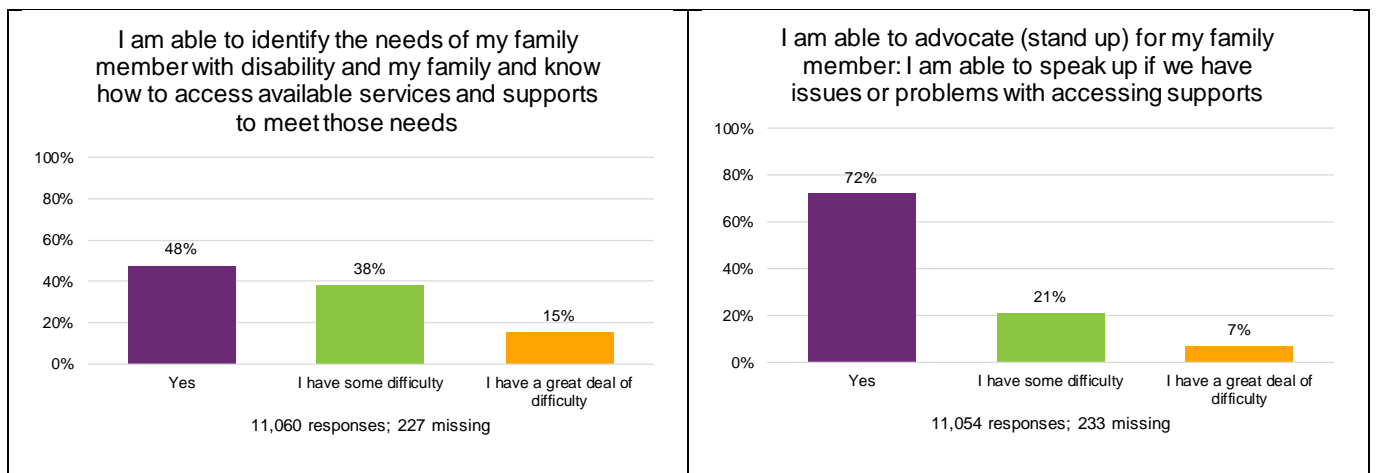
With regard to their family member with disability, 72% agreed or strongly agreed that having a child with disability has made it more difficult to meet everyday costs of living. 48% agreed or strongly agreed that they feel more confident about the future of their family member with disability under the NDIS, with 45% feeling neutral about this statement and only 6% expressing a negative opinion. Furthermore, 35% agreed or strongly agreed that the family member gets the support he/she needs, and 30% responded as “neutral”. A slightly higher percentage of respondents agreed or strongly agreed that the services help them to better care for their family member with disability (41%), and 39% responded as “neutral”.

² ABS General Social Survey (GSS) 2010. For GSS 2014 the question changed from using seven descriptive categories to a rating on a 0 to 10 scale.

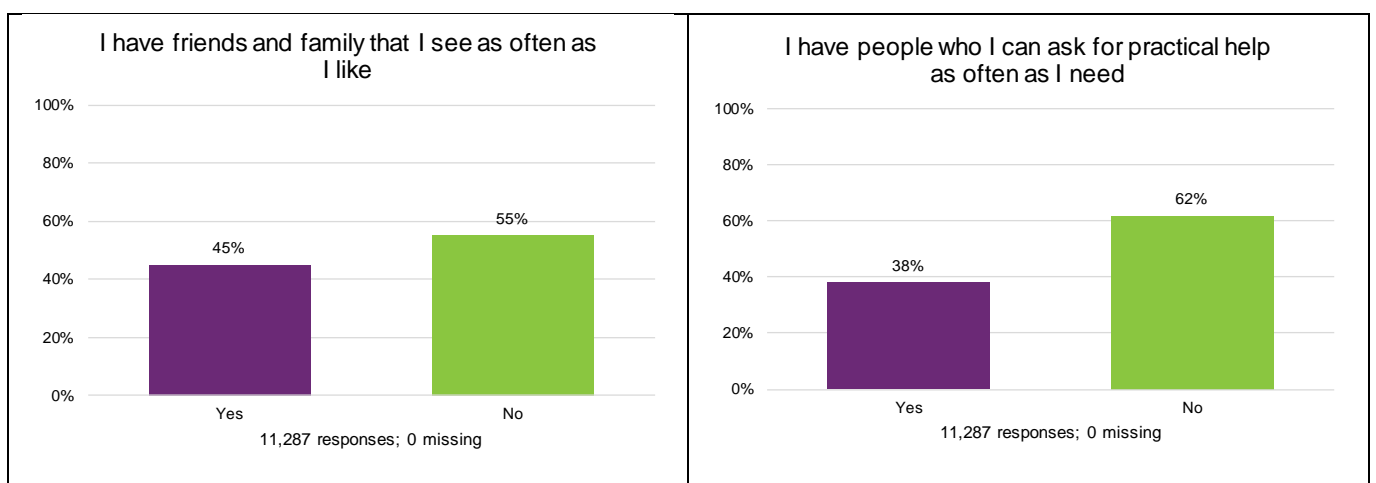
Appendix B.1.1 – Carer Payment and Carer Allowance

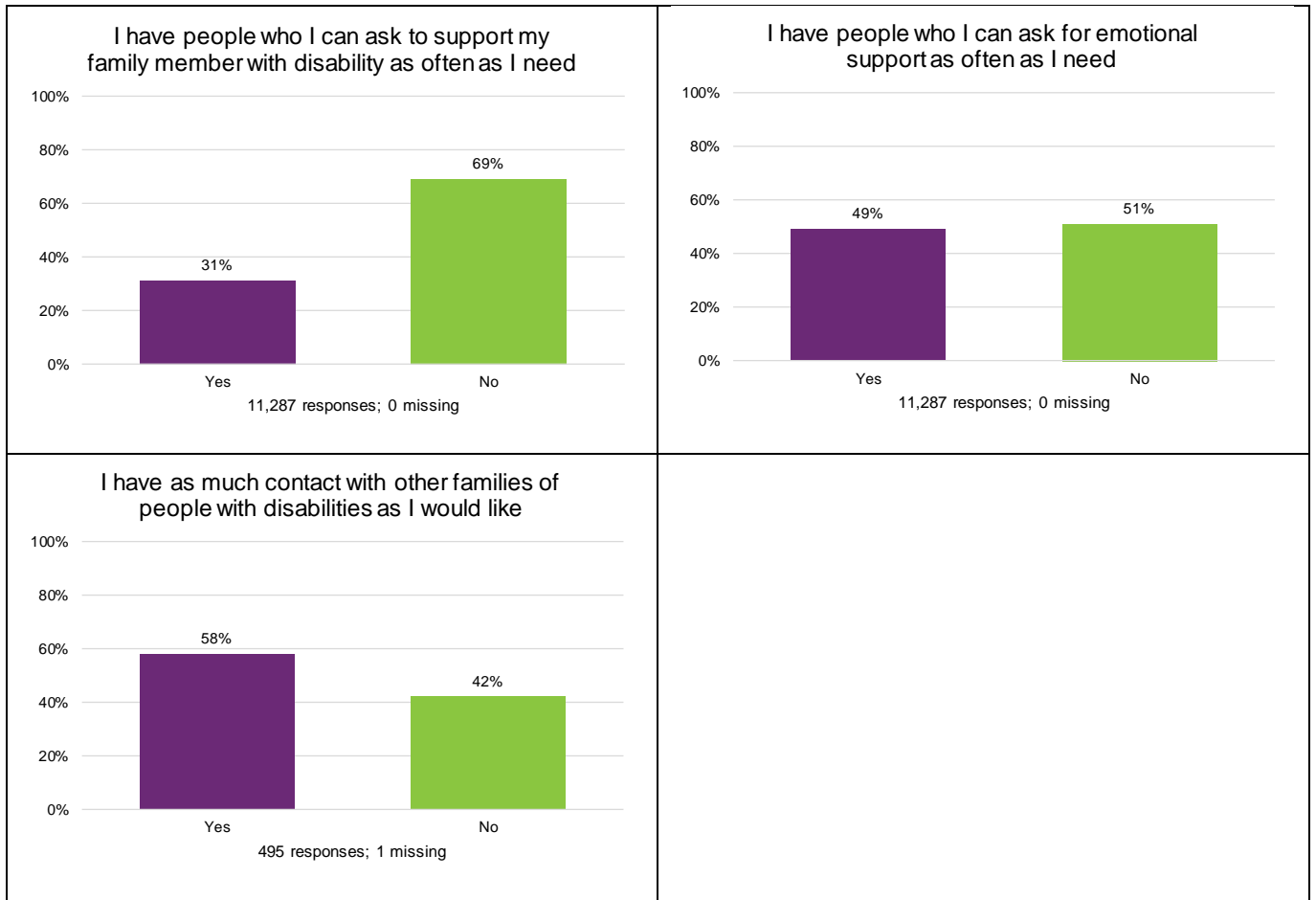


Appendix B.1.2 – Rights and Advocacy

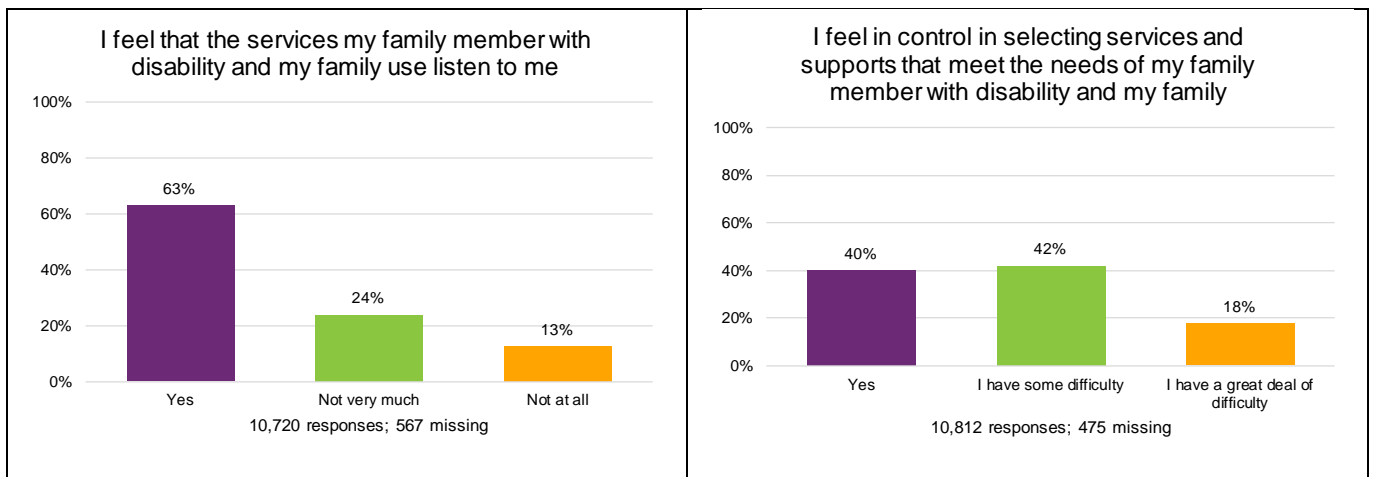


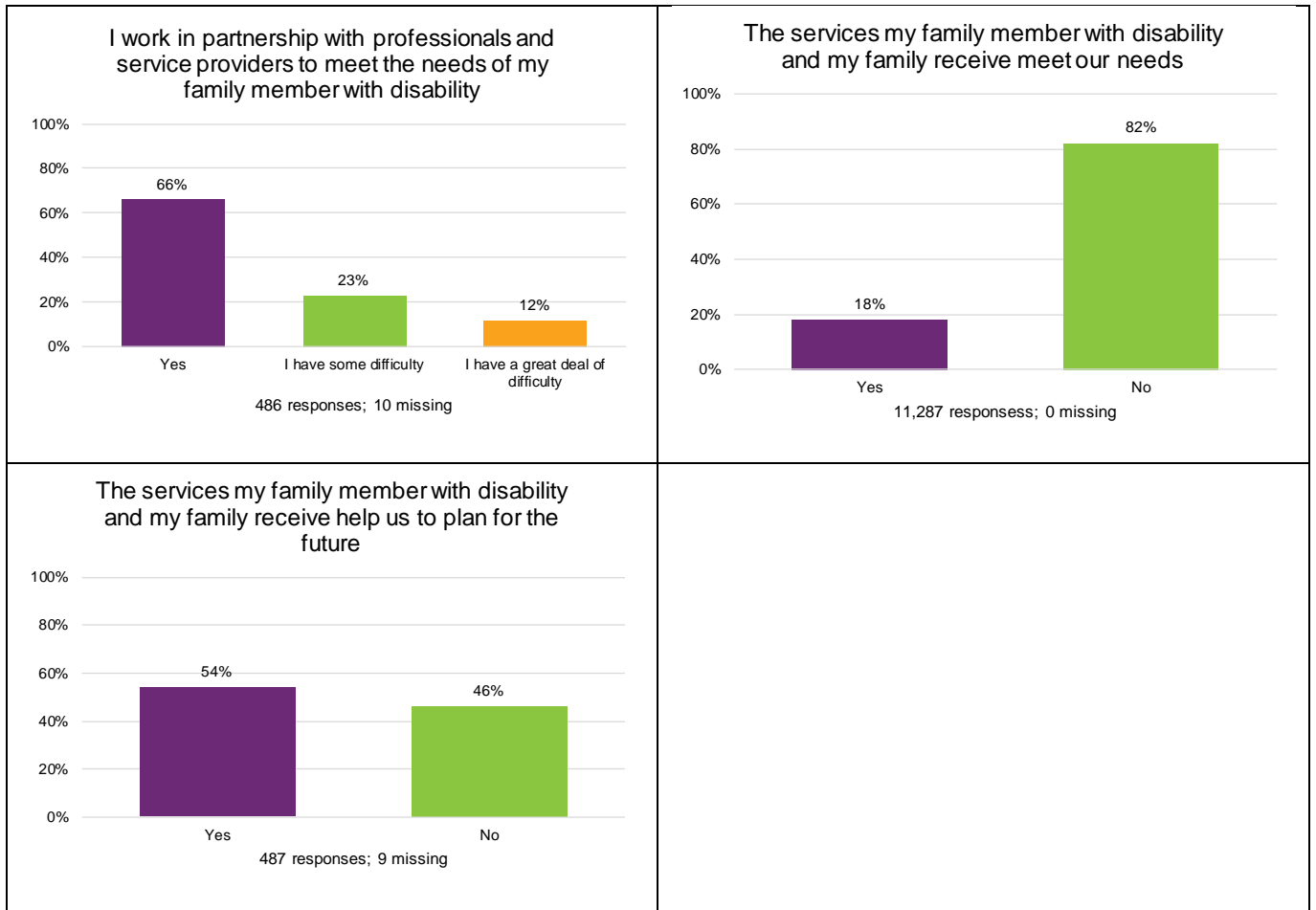
Appendix B.1.3 – Families feel Supported



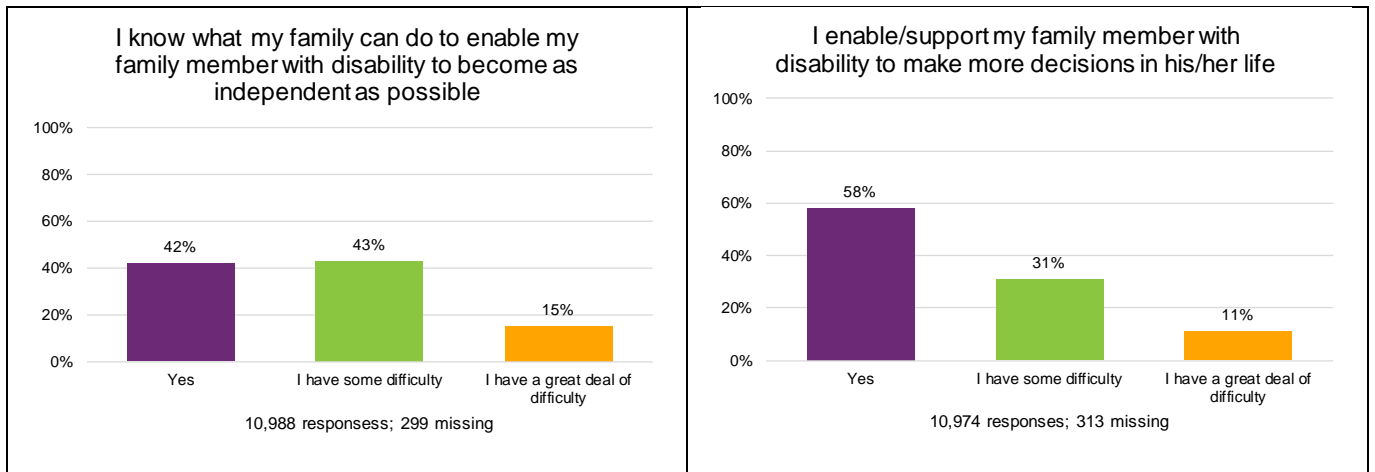


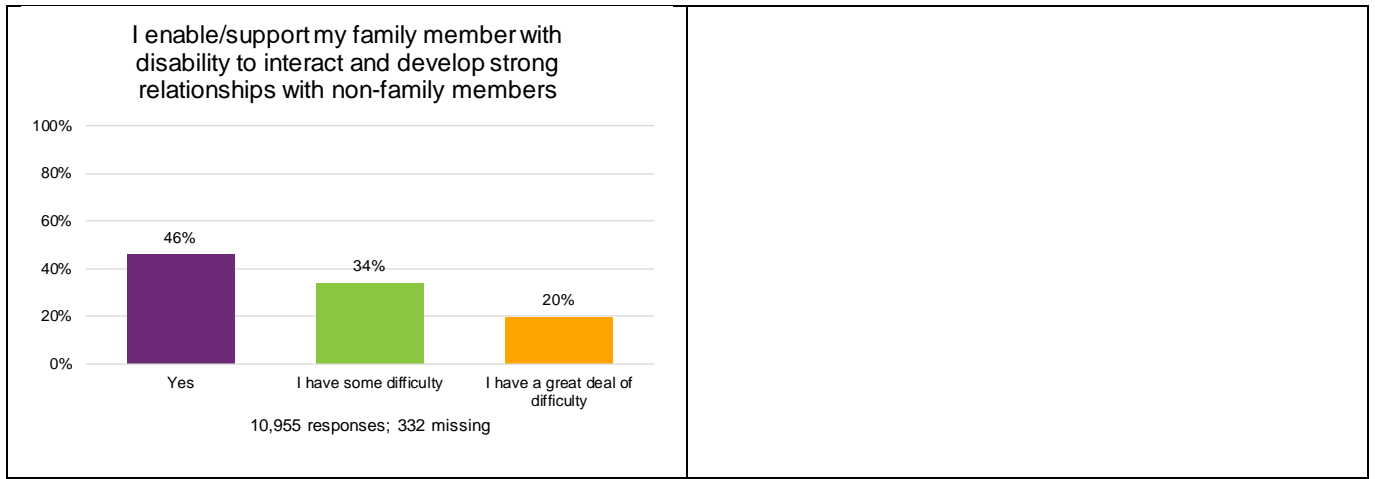
Appendix B.1.4 – Access to Services



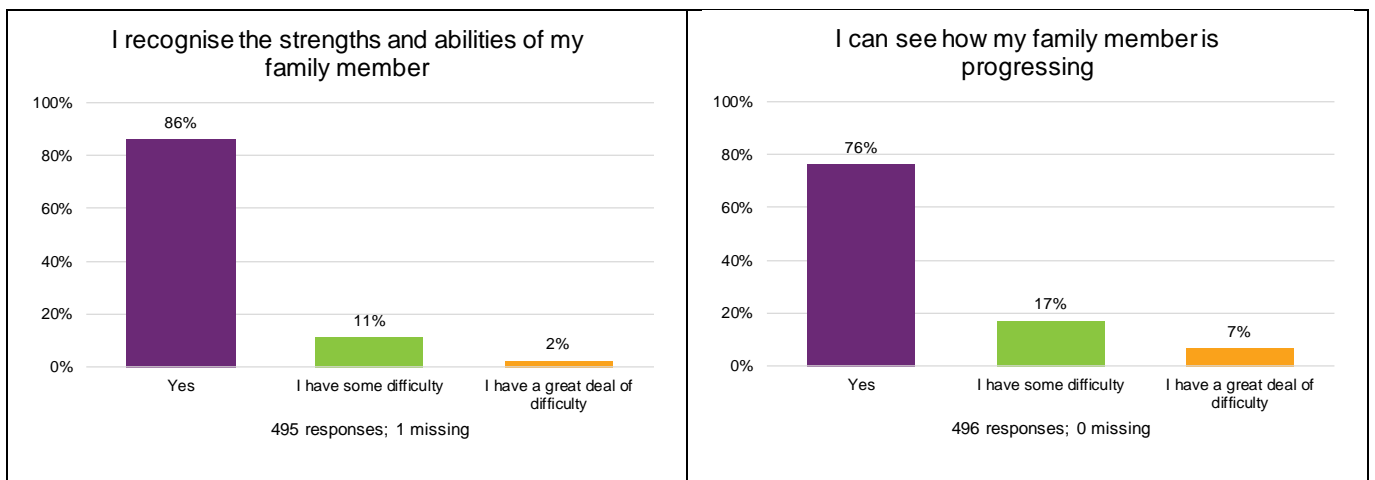


Appendix B.1.5 – Independence

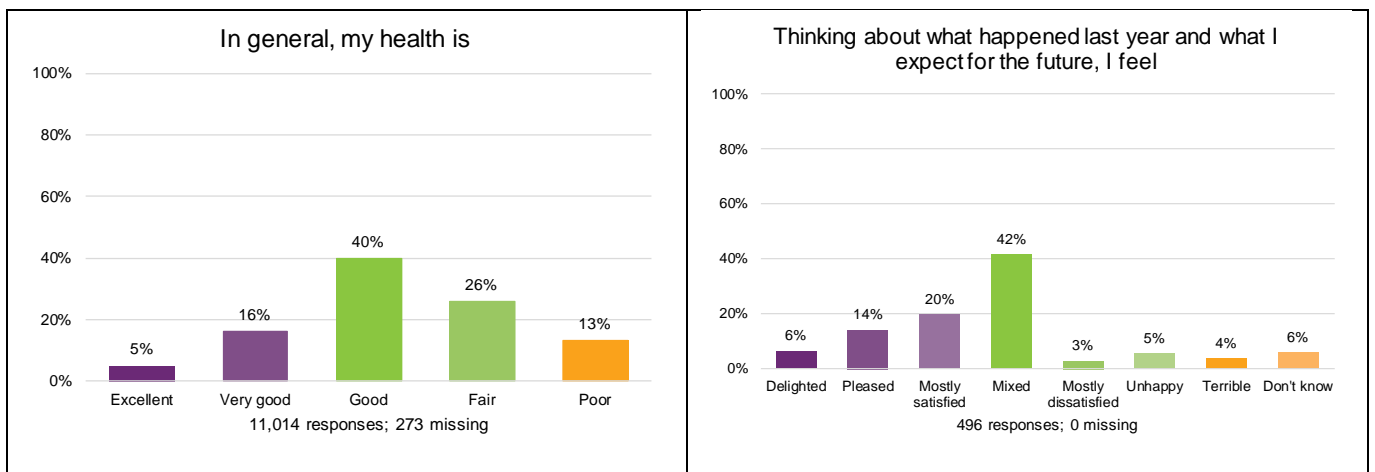


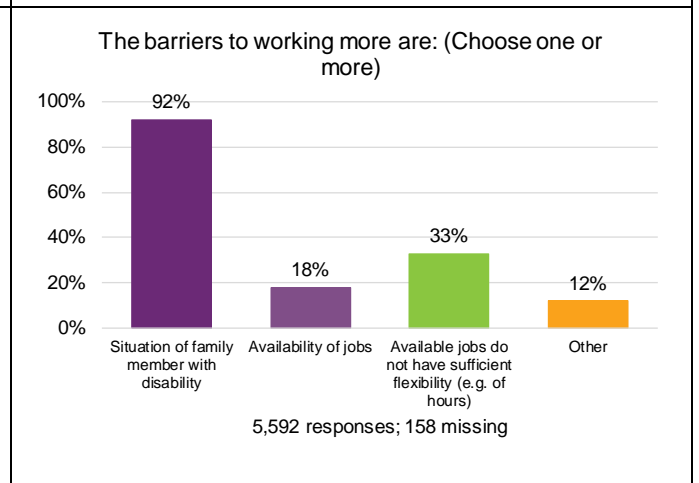
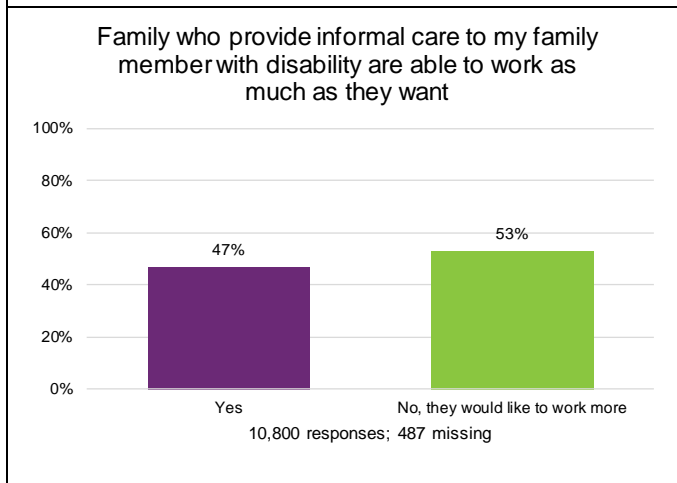
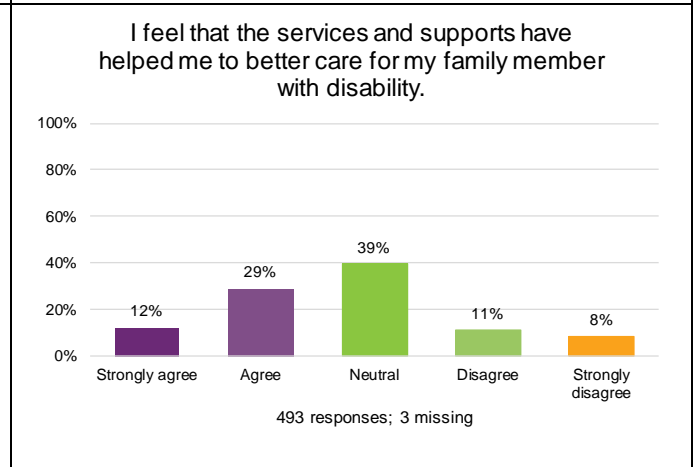
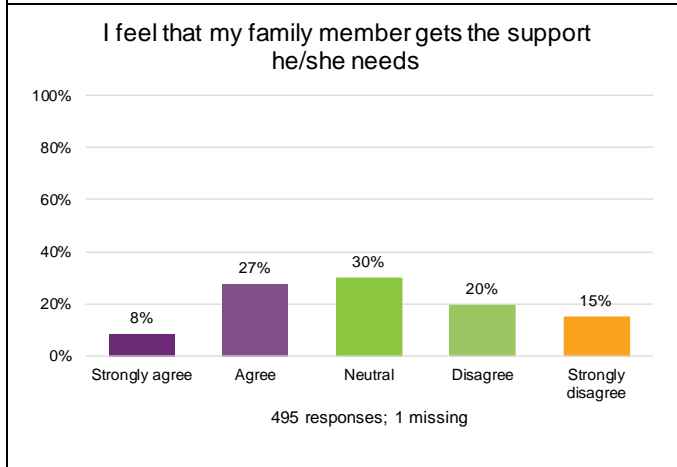
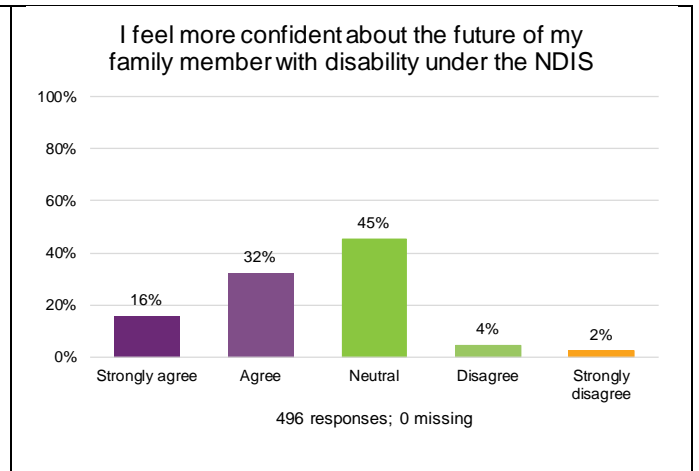
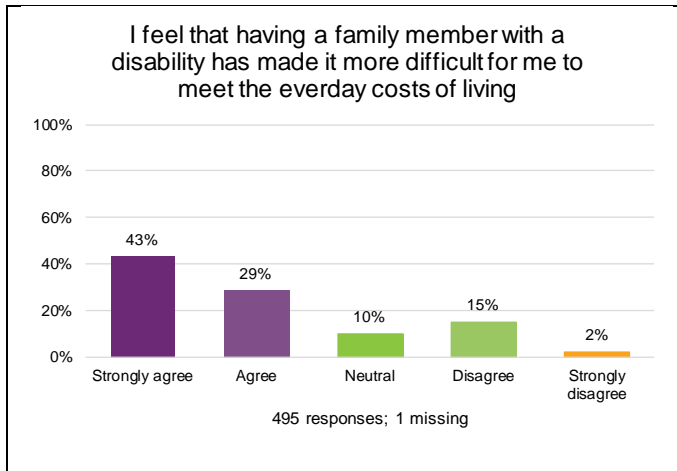


Appendix B.1.6 – Family Member’s Strengths and Abilities



Appendix B.1.7 – Health and wellbeing





Appendix B.2 – Baseline indicators for SF and LF – participant characteristics

Summary

Baseline indicators have been analysed by key characteristics of the participant and the family member/carer using one-way analyses and multiple logistic regression modelling. Key findings from these analyses include:

- **Participant level of function**

For the majority of indicators, outcomes improve with increasing participant level of function. Family members/carers are more likely to be able to work as much as they want, from 36% having no barriers to working more for respondents for participants with low level of function, to 53% for medium level of function, and 60% for high level of function. Additionally, social connection and support that respondents have tend to vary considerably with level of function. For example, the percentage who have family and friends that they see as often as they like increases from 33% for low level of function, to 52% for medium level of function, and 59% for high level of function. Furthermore, the percentage of family members/carers who have people they can ask for emotional support, practical help and to support the participant increases with participant level of function.

The indicators related to helping the participant become more independent also differ by level of function. The respondents are more likely to know what their family can do to enable the participant to become as independent as possible for participants with higher level of function.

- **Culturally and linguistically diverse backgrounds**

Family/carers of participants from CALD backgrounds are less likely to work (41% versus 49%), however they are more likely to study (9% versus 7%). Moreover, this group of respondents exhibits worse outcomes on advocacy and independence. In particular, the percentage who are able to advocate (stand up) for the participant if they have issue or problems accessing supports is 50%, compared to 74% for non-CALD respondents. Also, the percentage who enable the participant to make more decisions in their life is considerably lower (41% versus 60%).

- **Aboriginal and Torres Strait Islander participants**

Respondents for Indigenous participants are less likely to be the parents of the participant (78% versus 92%). For employment related indicators, this group of respondents is less likely to be working in a paid job (32% versus 49%). Of those who want to work more, they are more likely to see jobs availability as a barrier (24% versus 17%), and note that available jobs do not have sufficient flexibility (38% versus 32%).

Outcomes on the indicators of having necessary support are slightly better for family/carers of Indigenous participants. In particular, the percentage who have people they can ask for practical help is 36%, compared with 27% for respondents for non-Indigenous participants. On the other hand, less respondents for Indigenous participants feel that the services they use listen to them (57% versus 64%).

- **Participant age**

The indicators related to education and employment tend to vary with participant age. The percentage who are able to work as much as they want increases from 43% for respondents for participants aged under 18, to 50% for respondents for participants aged 18 to 20, and 52% for respondents for participants aged 21 to 24. For those who are facing barriers to working more, the percentage who see job flexibility as a barrier declines from 35% for respondents for participants aged under 18 to 27% for respondents for participants aged 21 to 24. On the other

hand, the percentage who study declines from 8% for family/carers of participants aged under 18 to 5% for family/carers of participants aged 21 to 24.

As the ability to be independent becomes more important with age, the support of family/carers to help the participant develop necessary skills increases. In particular, respondents for older participants are more likely to know what their family can do to enable the participant to become as independent as possible (41% where the participant is aged under 18, 42% where they are aged 18 to 20, and 45% where they are aged 21 to 24).

- **Participant disability**

Respondents for participants with a hearing or visual impairment are more likely to report positive outcomes across all domains. For example, 60% of respondents for participants with a hearing impairment and 69% of respondents for participants with a visual impairment support the participant to interact and develop strong relationships with non-family members. By contrast, the percentages are 40% and 39% where the participant has autism or a psychosocial disability.

Similarly, only 31% of families and carers of participants with a psychosocial disability know how to enable their family member to become as independent as possible, compared to 55% where the participant has a hearing impairment, 60% where the participant has a visual impairment, and 42% overall. There is a general trend towards poorer baseline outcomes for families and carers of participants with a psychosocial disability, but particularly for outcomes related to fostering independence. In addition to the two indicators highlighted above, the percentage who support the participant to make more decisions in his/her life is lower than average (50% compared with 58% overall).

Satisfaction with the services the participant and their family received also varies by disability group. The percentage who said the services met their needs for family/carers of participants with a hearing or visual impairment is higher than average (39% and 32% compared with 18% overall). By contrast, only 10% of family/carers of participants with psychosocial disability are satisfied with the services they received.

Satisfaction with the services the participant and their family received also varies by disability group. The percentage who said the services met their needs for family/carers of participants with a hearing or visual impairment is higher than average (39% and 32% compared with 18% overall). By contrast, only 10% of family/carers of participants with psychosocial disability are satisfied with the services they received.

- **Geography**

Results for respondents from regional and remote locations are more positive on some indicators. The percentage who are able to advocate for the participant if they have issues or problems with accessing supports is higher – 76% for inner regional areas and 77% for outer regional and remote areas, compared with 69% in major cities. Also of note are results on the indicators related to having necessary supports to care for the participant. Compared with major cities, family/carers in regional and remote locations are more likely to have people they can ask for practical help (39-45% in regional/remote compared with 36% in major cities), emotional support (50-54% in regional/remote compared with 47% in major cities) or to support the participants as often as they need (31-36% in regional/remote compared with 29% in major cities).

The indicators related to supporting the participant to become more independent also show more positive results for respondents from regional and remote locations. For example, the percentage who know what their family can do to enable the participant to become as independent as possible is higher for those in regional and remote locations (45-46% compared with 39% for major cities).

The results on employment in regional and remote locations are mixed. The percentage in paid employment is the highest in major cities (50%), followed by inner regional locations (47%) and

outer regional and remote locations (45%). On the other hand, the percentage of respondents who are able to work as much as they want increases with remoteness: from 45% for major cities, to 47% for inner regional locations, and 52% for outer regional and remote location. Of those who not able to work as much as they want, the percentage of respondents who see the situation with the participant as a barrier to working more also decreases with remoteness: 91% for major cities and 87% for regional/remote locations. However, other barriers such as availability of jobs (20-24% in regional/remote locations compared with 15% in major cities) and insufficient flexibility of jobs (35% in regional/remote locations compared with 30% in major cities) seem to be more of a problem in regional and remote locations.

- **Self-management**

Respondents with self-managed plans (fully or partly) exhibit better outcomes on some indicators. The results on the advocacy questions are significantly more positive. In particular, respondents with self-managed plans are more likely to be able to identify the needs of the participant and know how to access available services and supports to meet those needs (55-61% for partly/fully-managed plans compared with 46% for agency-managed plans). Likewise, they are more likely to be able to advocate (stand up) for the participant if they have problems with accessing supports (79-84% for partly/ fully-managed plans compared with 71% for agency-managed plans).

In addition, the percentage who feel in control in selecting services that meet the needs of the participant and their family is higher for respondents with self-managed plans (47-52% for partly/fully self-managed plans compared with 39% for agency-managed plans).

In contrast, the respondents with plan-managed items in their plans are slightly less likely to report positive results. In particular, the percentages are lower for the indicators related to having necessary supports to care for participant. For example, respondents with plan-managed plans are less likely to have friends and family they can see as often as they like (36% compared with 48% for agency-managed plans), have people the respondent can ask for practical help (29% compared with 41% for agency-managed plans), emotional support (41% compared with 50% for agency-managed plans) and to support the participant (22% compared with 33% for agency-managed plans) as often as they need.

- **Streaming**

Results tend to be worse for families and carers of participants streamed as intensive or super intensive. These respondents are less likely to have necessary social supports, including being able to see family and friends as often as they like and having people who they can ask for practical help or emotional support. They are also less likely to feel in control in selecting services and supports that meet the needs of the participants. Perhaps as a consequence of insufficient levels of support, the respondents from intensive and super intensive streams are less likely to be able to enable the participant to become more independent. For example, the percentage of respondents from intensive and super intensive streams who enable their family member with disability to make more decisions in his/her life is lower, 50% and 45%, respectively, compared to 61% overall.

- **Feeling supported**

Results tend to be better for the respondents who are socially well connected. For example, those who have friends and family that they see as often as they like are more likely to enable/support the participant to be more independent, including making more decisions in his/her life (55% versus 32%) and developing strong relationships with non-family members (58% versus 35%). Additionally, these respondents are more likely to be in better health and work as much as they want – both factors could be either a consequence of better social support or be driving it.

Appendix B.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	11,287	63%	40%	18%
Relationship To Participant				
Mother	8,887	63%	41%	18%
Father	1,352	63%	38%	18%
Grandparent	297	68%	38%	25%
Other Family Member	193	63%	32%	20%
Carer	201	66%	47%	29%
Other	264	67%	41%	17%
Age Group				
15 or younger	1,375	61%	38%	15%
16	2,198	63%	38%	17%
17	2,435	63%	41%	19%
18	1,312	63%	39%	18%
19	868	62%	42%	19%
20	697	63%	40%	20%
21	597	63%	41%	21%
22	551	66%	42%	22%
23	527	66%	43%	21%
24 or older	727	68%	43%	20%
Disability Type				
Autism	4,465	61%	38%	16%
Cerebral Palsy	683	64%	43%	20%
Intellectual Disability & Down Syndrome	4,686	64%	40%	19%
Other	1,453	67%	43%	23%
Level of function				
High	2,303	65%	45%	25%
Medium	5,447	63%	41%	19%
Low	3,537	62%	36%	14%
State				
ACT	84	65%	55%	25%
NSW	5,470	61%	38%	17%
NT	40	49%	22%	13%
QLD	1,219	63%	47%	17%
SA	1,262	65%	46%	25%
TAS	293	63%	38%	16%
VIC	2,831	66%	40%	18%
WA	88	59%	38%	27%
Remoteness				
Major City	6,189	64%	39%	19%
Inner Regional	3,728	63%	42%	18%
Outer Regional / Remote / Very Remote	1,290	63%	42%	19%
Annualised cost of baseline plan				
\$10,000 or less	1,278	68%	52%	28%
\$10-15,000	1,078	62%	43%	22%
\$15-20,000	1,097	61%	43%	19%
\$20-30,000	1,840	62%	39%	18%
Over \$30,000	5,994	63%	37%	16%
Aboriginal and Torres Strait Islander Status				
Indigenous	704	57%	39%	17%
Non-Indigenous	10,143	64%	40%	19%
CALD Status				
CALD	672	60%	26%	16%
Non-CALD	10,599	63%	41%	19%
Gender				
Female	3,886	63%	40%	19%
Male	7,295	63%	40%	18%
Plan management type				
Agency-managed	6,462	63%	39%	20%
Self-managed	941	65%	52%	19%
Plan-managed	2,448	61%	34%	14%
Combination	1,095	66%	47%	17%
Access Type				
Benefit from EI	1,103	64%	42%	18%
Disability Met	10,123	63%	40%	19%
Scheme access				
New	3,003	61%	38%	17%
State	8,012	64%	41%	19%
Commonwealth	272	65%	48%	26%
Plan cost allocation				
Capital 5-100%	1,194	66%	41%	20%
Capacity Building 0-75%	8,616	63%	39%	18%
Capacity Building 75-95%	833	66%	43%	23%
Capacity Building 95-100%	636	63%	43%	22%

Baseline indicators for LF

	N	% who work in partnership with professionals and services to meet the needs of my family member with disability	% who say the service their family member with disability and family receive help them to plan for the future
Overall	496	66%	54%
Age Group			
16 or younger	133	60%	52%
17 to 18	85	71%	57%
19 to 21	137	70%	53%
22 to 24	96	64%	58%
25 or older	31	74%	55%
Disability type			
Autism	171	59%	44%
Cerebral Palsy & Other Neurological	57	75%	61%
Intellectual Disability & Down Syndrome	220	65%	56%
Other	48	81%	70%
Level of Function			
High	84	57%	54%
Medium	211	69%	54%
Low	146	67%	54%
State			
ACT & NT	<20	na	na
NSW	140	68%	58%
QLD	74	77%	58%
SA	173	57%	47%
VIC	92	74%	59%
Remoteness			
Inner Regional	150	73%	62%
Major City	285	61%	49%
Outer Regional / Remote / Very Remote	55	68%	64%
Annualised cost of baseline plan			
\$10,000 or less	44	67%	49%
\$10-15,000	42	57%	57%
\$15-20,000	49	51%	53%
Over \$20,000	332	69%	54%
Aboriginal and Torres Strait Islander Status			
Indigenous	25	57%	52%
Non-Indigenous	456	67%	54%
CALD Status			
CALD	<20	na	na
Non-CALD	475	66%	55%
Gender			
Female	156	64%	56%
Male	320	68%	55%
Plan Management Type			
Agency-managed	238	66%	58%
Combination	43	72%	49%
Plan-managed	59	76%	51%
Self-managed	<20	na	na
Access Type			
Benefit from EI	35	63%	52%
Disability Met	458	66%	54%
Reporting Access Entry Type			
Commonwealth	45	67%	40%
New	68	58%	57%
State	381	67%	55%
Plan cost allocation			
Capital 5-100%	52	75%	65%
Capacity Building 0-75%	357	66%	54%
Capacity Building 75-100%	57	56%	45%

Appendix B.2.5 – Independence

Baseline indicators for SF

	N	% of families or carers who know what their family can do to enable their family member with disability to be as independent as possible	% of families or carers who enable and support their family member with disability to make more decisions in their life	% of families or carers who enable and support their family member with disability to interact and develop strong relationships with non-family members
Overall	11,287	42%	58%	46%
Relationship To Participant				
Mother	8,887	42%	58%	46%
Father	1,352	39%	58%	47%
Grandparent	297	41%	56%	43%
Other Family Member	193	37%	53%	48%
Carer	201	55%	66%	55%
Other	264	47%	60%	45%
Age Group				
15 or younger	1,375	37%	54%	40%
16	2,198	41%	57%	44%
17	2,435	43%	59%	48%
18	1,312	42%	58%	45%
19	868	43%	62%	50%
20	697	39%	56%	45%
21	597	44%	59%	49%
22	551	44%	61%	50%
23	527	45%	58%	49%
24 or older	727	47%	64%	51%
Disability Type				
Autism	4,465	39%	57%	40%
Cerebral Palsy	683	48%	64%	55%
Intellectual Disability & Down Syndrome	4,686	41%	57%	47%
Other	1,453	50%	68%	58%
Level of function				
High	2,303	49%	67%	57%
Medium	5,447	42%	60%	47%
Low	3,537	37%	50%	39%
State				
ACT	84	60%	74%	55%
NSW	5,470	40%	55%	44%
NT	40	17%	34%	17%
QLD	1,219	49%	67%	52%
SA	1,262	49%	66%	53%
TAS	293	44%	63%	49%
VIC	2,831	40%	56%	45%
WA	88	37%	59%	51%
Remoteness				
Major City	6,189	39%	55%	43%
Inner Regional	3,728	45%	62%	50%
Outer Regional / Remote / Very Remote	1,290	46%	65%	53%
Annualised cost of baseline plan				
\$10,000 or less	1,278	53%	70%	59%
\$10-15,000	1,078	47%	66%	52%
\$15-20,000	1,097	44%	62%	49%
\$20-30,000	1,840	41%	60%	46%
Over \$30,000	5,994	39%	53%	42%
Aboriginal and Torres Strait Islander Status				
Indigenous	704	42%	56%	45%
Non-Indigenous	10,143	42%	59%	46%
CALD Status				
CALD	672	28%	41%	34%
Non-CALD	10,599	43%	60%	47%
Gender				
Female	3,886	43%	58%	47%
Male	7,295	42%	59%	46%
Plan management type				
Agency-managed	6,462	42%	58%	46%
Self-managed	941	51%	67%	51%
Plan-managed	2,448	36%	53%	42%
Combination	1,095	47%	62%	51%
Access Type				
Benefit from EI	1,103	41%	61%	46%
Disability Met	10,123	42%	58%	46%
Scheme access				
New	3,003	39%	59%	43%
State	8,012	43%	58%	47%
Commonwealth	272	49%	67%	50%
Plan cost allocation				
Capital 5-100%	1,194	47%	63%	55%
Capacity Building 0-75%	8,616	41%	57%	44%
Capacity Building 75-95%	833	46%	64%	51%
Capacity Building 95-100%	636	47%	65%	56%

Appendix B.2.6 – Family Member’s Strengths and Abilities

Baseline indicators for LF

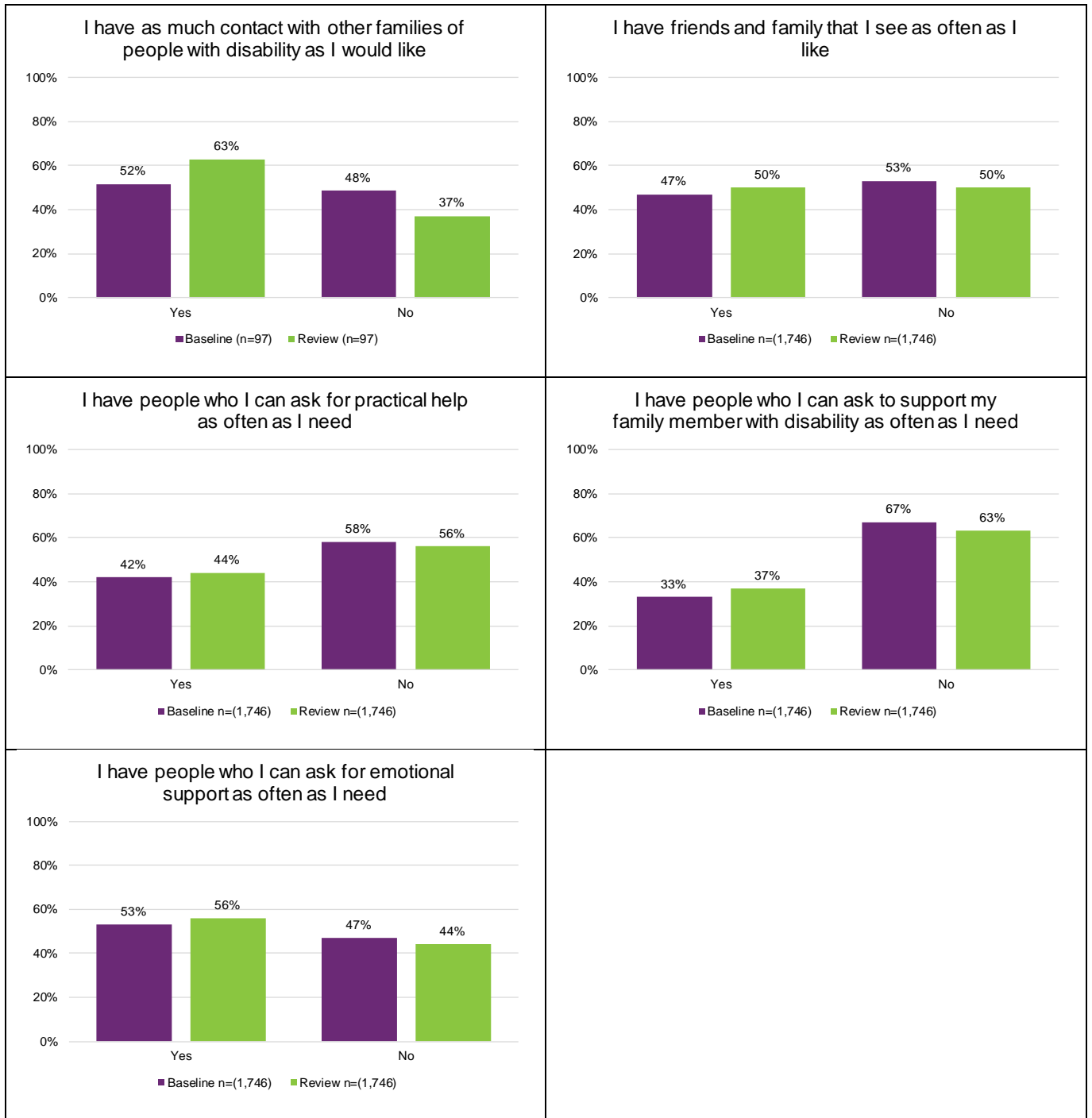
	N	% who have no difficulties in recognising their family member's strength and abilities	% who have no difficulties in seeing their family member is progressing
Overall	496	86%	76%
Age Group			
16 or younger	133	86%	80%
17 to 18	85	84%	74%
19 to 21	137	85%	74%
22 to 24	96	90%	78%
25 or older	31	90%	74%
Disability type			
Autism	171	87%	72%
Cerebral Palsy & Other Neurological	57	86%	75%
Intellectual Disability & Down Syndrome	220	86%	77%
Other	48	85%	90%
Level of Function			
High	84	88%	79%
Medium	211	88%	78%
Low	146	83%	70%
State			
ACT & NT	<20	na	na
NSW	140	87%	81%
QLD	74	89%	86%
SA	173	85%	73%
VIC	92	84%	68%
Remoteness			
Inner Regional	150	90%	81%
Major City	285	84%	72%
Outer Regional / Remote / Very Remote	55	87%	82%
Annualised cost of baseline plan			
\$10,000 or less	44	91%	82%
\$10-15,000	42	93%	95%
\$15-20,000	49	78%	78%
Over \$20,000	332	86%	73%
Aboriginal and Torres Strait Islander Status			
Indigenous	25	84%	84%
Non-Indigenous	456	87%	76%
CALD Status			
CALD	<20	na	na
Non-CALD	475	87%	77%
Gender			
Female	156	89%	80%
Male	320	86%	76%
Plan Management Type			
Agency-managed	238	82%	74%
Combination	43	88%	81%
Plan-managed	59	93%	68%
Self-managed	<20	na	na
Access Type			
Benefit from EI	35	79%	74%
Disability Met	458	87%	76%
Reporting Access Entry Type			
Commonwealth	45	84%	73%
New	68	94%	82%
State	381	85%	76%
Plan cost allocation			
Capital 5-100%	52	98%	81%
Capacity Building 0-75%	357	85%	75%
Capacity Building 75-100%	57	84%	79%

Appendix B.2.7 – Health and Wellbeing

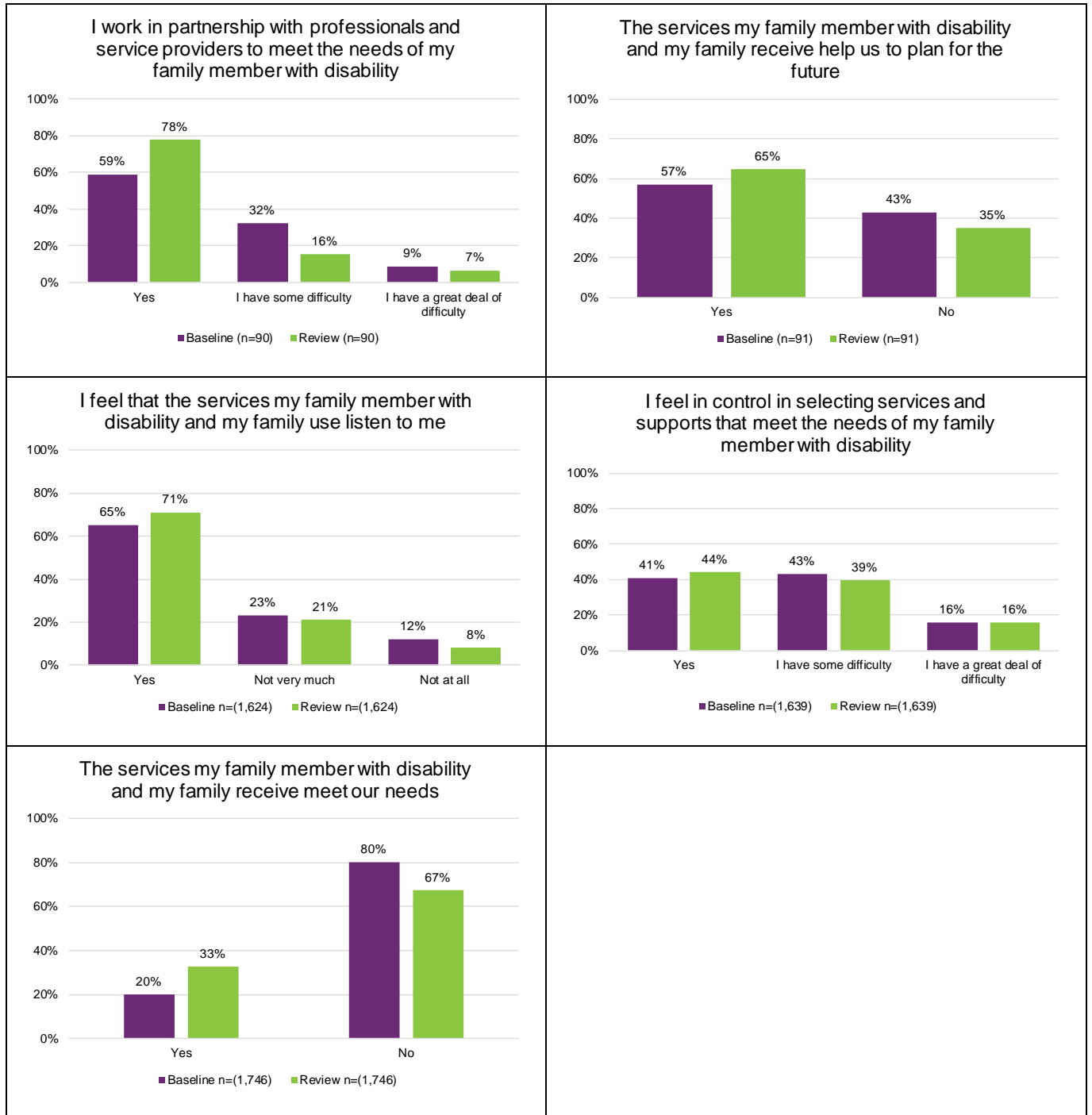
Baseline indicators for SF

	N	% of families or carers who rate their health as excellent, very good or good	% of families or carers who provide informal care to the family member with disability that are able to work as much as they want	of those unable to work as much as they want, % who say the situation of their child/family member with disability is a barrier to working more	of those unable to work as much as they want, % who say insufficient flexibility of jobs is a barrier to working more
Overall	11,287	61%	47%	92%	33%
Relationship To Participant					
Mother	8,887	61%	45%	92%	34%
Father	1,352	64%	48%	91%	29%
Grandparent	297	47%	67%	86%	24%
Other Family Member	193	72%	57%	85%	19%
Carer	201	75%	64%	87%	32%
Other	264	65%	55%	92%	22%
Age Group					
15 or younger	1,375	63%	39%	92%	39%
16	2,198	62%	44%	93%	36%
17	2,435	62%	46%	92%	34%
18	1,312	64%	50%	91%	32%
19	868	62%	52%	90%	31%
20	697	56%	48%	90%	31%
21	597	60%	49%	91%	29%
22	551	58%	52%	93%	31%
23	527	60%	52%	90%	22%
24 or older	727	57%	53%	92%	28%
Disability Type					
Autism	4,465	58%	45%	93%	34%
Cerebral Palsy	683	60%	45%	95%	32%
Intellectual Disability & Down Syndrome	4,686	63%	48%	91%	33%
Other	1,453	65%	50%	90%	32%
Level of function					
High	2,303	69%	58%	86%	37%
Medium	5,447	62%	51%	90%	33%
Low	3,537	54%	33%	96%	32%
State					
ACT	84	68%	63%	96%	36%
NSW	5,470	61%	48%	92%	35%
NT	40	60%	60%	100%	58%
QLD	1,219	62%	49%	89%	40%
SA	1,262	62%	53%	91%	30%
TAS	293	64%	43%	88%	34%
VIC	2,831	60%	40%	93%	29%
WA	88	66%	59%	97%	13%
Remoteness					
Major City	6,189	61%	45%	93%	31%
Inner Regional	3,728	59%	47%	89%	36%
Outer Regional / Remote / Very Remote	1,290	66%	52%	89%	36%
Annualised cost of baseline plan					
\$10,000 or less	1,278	69%	61%	86%	36%
\$10-15,000	1,078	69%	57%	87%	38%
\$15-20,000	1,097	63%	49%	89%	35%
\$20-30,000	1,840	63%	50%	90%	35%
Over \$30,000	5,994	57%	40%	94%	31%
Aboriginal and Torres Strait Islander Status					
Indigenous	704	57%	49%	92%	33%
Non-Indigenous	10,143	61%	47%	88%	39%
CALD Status					
CALD	672	59%	41%	93%	25%
Non-CALD	10,599	61%	47%	92%	34%
Gender					
Female	3,886	62%	46%	92%	32%
Male	7,295	61%	47%	91%	34%
Plan management type					
Agency-managed	6,462	62%	49%	91%	34%
Self-managed	941	68%	49%	94%	34%
Plan-managed	2,448	54%	41%	92%	30%
Combination	1,095	63%	42%	94%	35%
Access Type					
Benefit from EI	1,103	68%	51%	90%	34%
Disability Met	10,123	60%	46%	92%	33%
Scheme access					
New	3,003	66%	50%	90%	32%
State	8,012	59%	45%	92%	33%
Commonwealth	272	59%	65%	94%	37%
Plan cost allocation					
Capital 5-100%	1,194	64%	44%	94%	33%
Capacity Building 0-75%	8,616	59%	45%	92%	33%
Capacity Building 75-95%	833	68%	60%	84%	37%
Capacity Building 95-100%	636	71%	60%	86%	32%

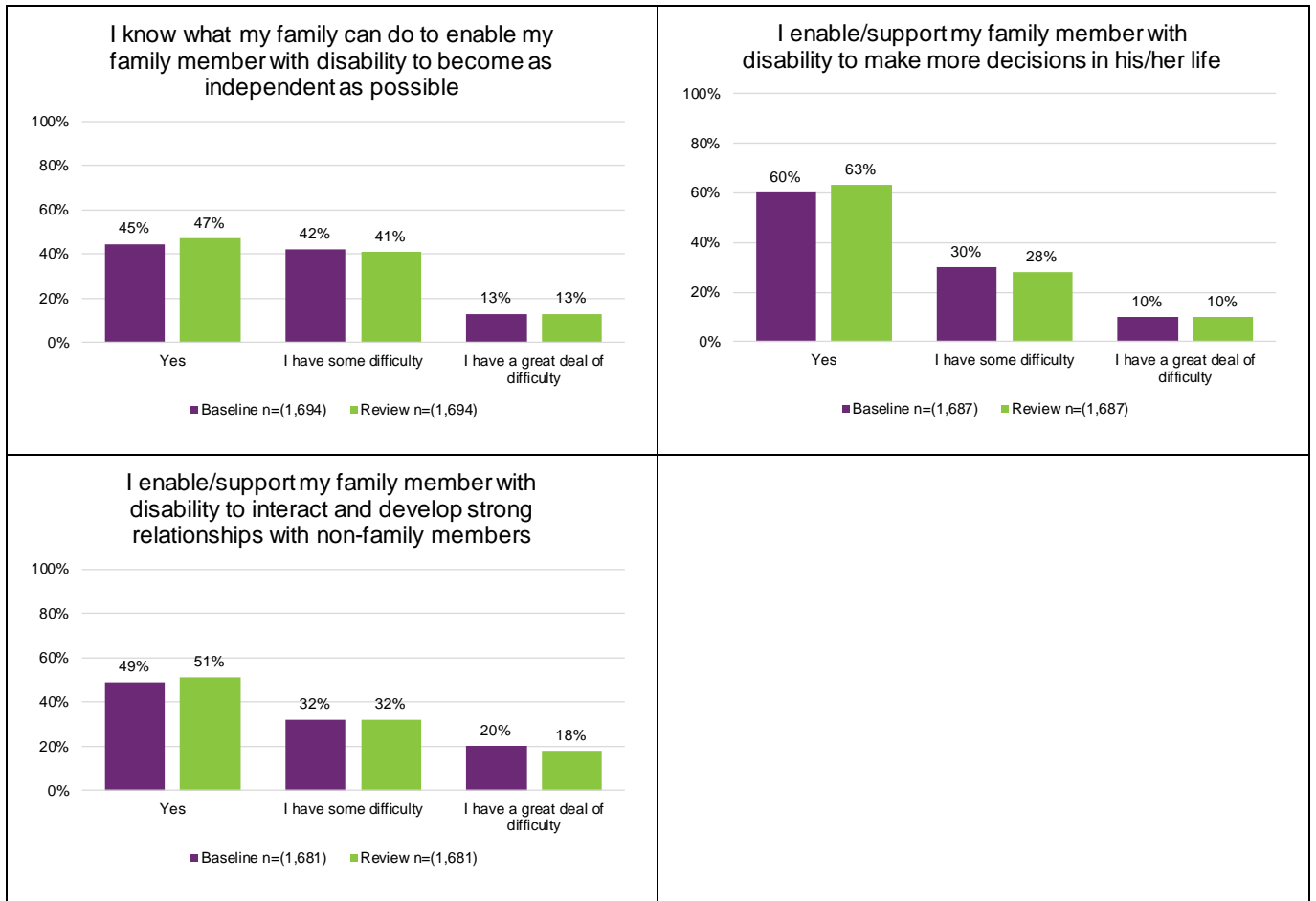
Appendix B.3.3 – Families feel Supported



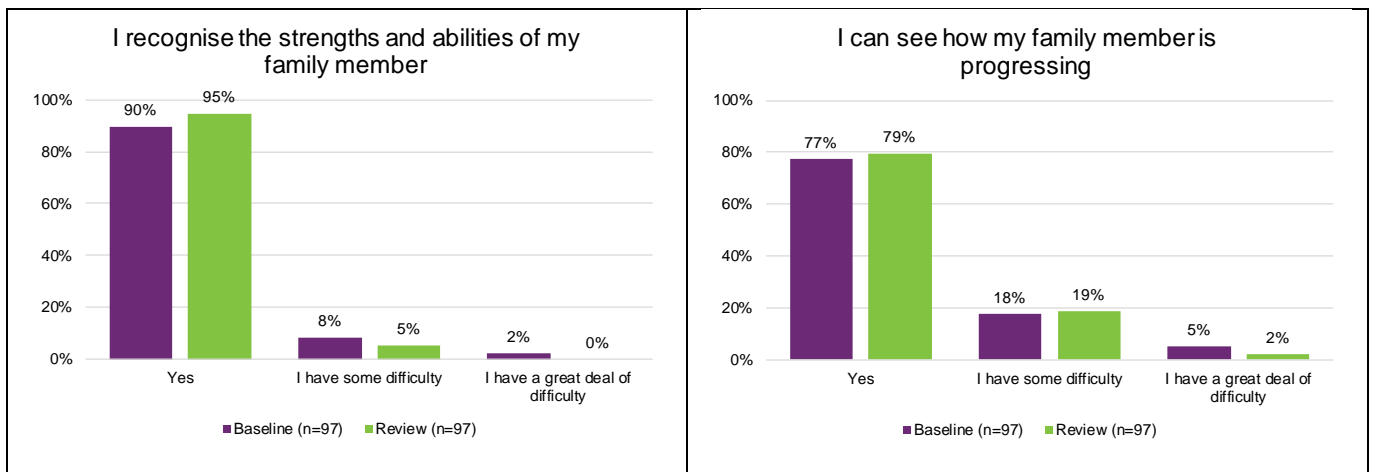
Appendix B.3.4 – Access to Services



Appendix B.3.5 – Independence



Appendix B.3.6 – Family Member’s Strengths and Abilities



Appendix B.3.7 – Health and wellbeing



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

Analysis of changes in outcomes by key characteristics has been examined in two ways:

1. A simple comparison of the percentage meeting the indicator at review with the percentage meeting the indicator at baseline. The difference (review-baseline) is compared for different subgroups.
2. Multiple regression analyses modelling improvement (or sometimes deterioration) in the indicator. That is, for the subset without the indicator at baseline, the probability of meeting the indicator at review is modelled as a function of participant and family member/carer characteristics.
3. If no significant changes were observed, multiple regression analysis was used to examine the relationships between the indicator at review and participant and family member/carer characteristics.

It should be noted that the first two types of analysis can produce different results, particularly where there is a large difference in the indicator at baseline between subgroups.

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

Carer allowance

A 4 percentage point increase in the percentage receiving Carer Allowance has been observed over the year. Of those who did not receive Carer Allowance at baseline, 20% received it at review. Based on the logistic regression model for receiving the allowance at review, for this cohort:

- The percentage receiving the allowance at review decreased with participant level of function: from 28% for low level of function, to 18% for medium level of function, and 14% for high level of function.
- The respondents who agreed that the NDIS improved the level of support for their family were more likely to receive the carer's allowance at review (22% versus 14%).

Domain 1: Families know their rights and advocate effectively for their child with disability

Changes in indicators have been relatively minor, with no significant changes observed.

Domain 2: Families feel supported

There were significant improvements of more than two percentage points overall across a number of indicators for this domain.

I have friends and family that I see as often as I like (overall improvement of 0.03)

Of those who disagreed with this statement at baseline, 17% agreed at review. Based on the logistic regression model for improvement:

- Families and carers who received services that met their needs were more likely to improve (30% versus 12%). Perhaps, receiving necessary services allows additional time to spend with family and friends.
- Respondents for participants streamed as intensive and super intensive were less likely to improve (10% and 2%, respectively).
- The rate of improvement was inversely related to cost of plan at review, possibly reflecting the relationship between cost of plan and participant level of function.

Domain 3: Access to services

Significant improvements were observed for most indicators for this domain. Notably, overall satisfaction with services has increased by 13%, from 20% at baseline to 33% at review.

Appendix B.4.6 – Family Member’s Strengths and Abilities

Longitudinal change in indicators for LF – participant characteristics

	N	% who have no difficulties in recognising their family member's strength and abilities	% who have no difficulties in seeing their family member is progressing
Overall	89	5%	2%
Age group			
14 or younger	<20	na	na
15	38	8%	-3%
16	22	5%	-5%
17 or older	<20	na	na
Disability type			
Autism	33	6%	3%
Cerebral Palsy & Other Neurological	<20	na	na
Intellectual Disability & Down Syndrome	31	3%	-3%
Other	<20	na	na
Level of function			
High	21	0%	10%
Medium	<20	na	na
Low	26	8%	27%
State			
ACT	<20	na	na
NSW	20	0%	-5%
QLD	<20	na	na
SA	49	2%	0%
Remoteness			
Major City	64	5%	3%
Inner Regional	<20	na	na
Outer Regional / Remote / Very Remote	21	14%	-5%
Annualised cost of baseline plan			
\$10,000 or less	<20	na	na
\$10-15,000	<20	na	na
\$15-20,000	<20	na	na
\$20-30,000	20	5%	-5%
Over \$30,000	29	14%	28%
Aboriginal and Torres Strait Islander Status			
Indigenous	<20	na	na
Non-Indigenous	76	7%	1%
CALD Status			
CALD	<20	na	na
Non-CALD	87	6%	1%
Gender			
Female	29	0%	0%
Male	60	8%	5%
Access Type			
Benefit from EI	20	20%	5%
Disability Met	69	1%	3%
Reporting Access Entry Type			
New	40	5%	5%
State	49	6%	2%
Plan cost allocation			
Capital 5-100%	<20	na	na
Capacity Building 0-25%	22	5%	32%
Capacity Building 25-50%	<20	na	na
Capacity Building 50-75%	<20	na	na
Capacity Building 75-100%	22	5%	0%

Appendix B.4.7 – 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 provide informal care to the family member with disability that are able to work as much as they want	% of families or carers as much as they want, of those unable to work as much as they want, % who say the situation of their child/family member with disability is a barrier to working more	% of those unable to work as much as they want, % who say insufficient flexibility of jobs is a barrier to working more
	1,746	-3%	0%	3%	3%
Relationship to Participant					
Mother	1,470	-4%	-1%	4%	4%
Father	173	-1%	6%	2%	-1%
Other	103	-2%	-3%	0%	6%
Age Group					
15 or younger	432	-4%	0%	4%	1%
16	603	-3%	0%	2%	4%
17	579	-4%	-3%	4%	4%
18	63	-8%	5%	7%	-3%
19 to 21	38	6%	3%	0%	-7%
22 or older	31	7%	4%	10%	20%
Disability Type					
Autism	741	-4%	-2%	4%	2%
Cerebral Palsy	133	-4%	-1%	7%	5%
Down Syndrome	94	2%	1%	6%	0%
Intellectual Disability	568	-3%	1%	1%	4%
Other	109	-3%	-4%	6%	4%
Psychosocial Disability	28	-7%	0%	10%	20%
Sensory	73	-6%	6%	0%	0%
Level of function					
High	491	-4%	-1%	7%	2%
Medium	679	-2%	0%	4%	2%
Low	576	-5%	0%	1%	4%
State					
ACT	27	-4%	-9%	0%	0%
NSW	961	-3%	-1%	5%	5%
QLD	155	1%	1%	1%	3%
SA	269	-4%	3%	1%	-1%
TAS	111	-5%	-2%	6%	6%
VIC	200	-9%	2%	2%	1%
WA	23	0%	-9%	0%	0%
Remoteness					
Major City	1,145	-3%	0%	3%	4%
Inner Regional	419	-6%	-2%	6%	1%
Outer Regional / Remote / Very Remote	173	-1%	2%	0%	4%
Annualised cost of baseline plan					
\$10,000 or less	247	-2%	0%	10%	-1%
\$10-15,000	207	-4%	0%	-3%	4%
\$15-20,000	210	-3%	2%	8%	0%
\$20-30,000	275	-3%	-1%	4%	6%
Over \$30,000	807	-4%	-1%	2%	4%
Aboriginal and Torres Strait Islander Status					
Indigenous	80	-8%	-5%	5%	5%
Non-Indigenous	1,612	-3%	0%	3%	3%
CALDSts					
CALD	124	-3%	3%	6%	2%
Non-CALD	1,622	-3%	-1%	3%	3%
Gender					
Female	580	-2%	-1%	4%	3%
Male	1,158	-4%	0%	3%	3%
Plan management type					
Agency-managed	893	-3%	-2%	5%	5%
Self-managed	91	0%	-3%	3%	-8%
Plan-managed	135	-1%	4%	5%	-2%
Combination	407	-4%	2%	3%	5%
Access Type					
Benefit from EI	174	-2%	-2%	0%	-5%
Disability Met	1,551	-4%	0%	4%	4%
Scheme access					
New	483	-3%	-1%	6%	3%
State	1,255	-3%	0%	3%	3%
Commonwealth	<20	na	na	na	na
Plan cost allocation					
Capital 5-100%	155	-7%	-1%	4%	7%
Capacity Building 0-75%	1,411	-3%	0%	3%	3%
Capacity Building 75-95%	85	-1%	0%	6%	3%
Capacity Building 95-100%	94	-2%	-1%	19%	10%

Longitudinal change in indicators for LF – participant characteristics

	N	Thinking about what happened last year, and what they expect for the future, % who feel delighted, pleased or mostly satisfied.	% who disagree or strongly disagree that having a family member with disability has made it more difficult to meet the everyday cost of living	% who strongly agree and agree that they feel confident about the future of their family member under the NDIS	% who strongly agree or agree that their family member gets the support he/she needs	% who strongly agree or agree that the services and supports have helped them to better care for their family member with disability
Overall	89	-4%	9%	22%	24%	43%
Age group						
14 or younger	<20	na	na	na	na	na
15	38	0%	8%	26%	11%	42%
16	22	-18%	9%	32%	36%	55%
17 or older	<20	na	na	na	na	na
Disability type						
Autism	33	3%	9%	30%	24%	56%
Cerebral Palsy & Other Neurological	<20	na	na	na	na	na
Intellectual Disability & Down Syndrome	31	-19%	10%	16%	19%	35%
Other	<20	na	na	na	na	na
Level of function						
High	21	-19%	10%	14%	29%	38%
Medium	<20	na	na	na	na	na
Low	26	0%	4%	38%	19%	40%
State						
ACT	<20	na	na	na	na	na
NSW	20	-15%	10%	-5%	20%	32%
QLD	<20	na	na	na	na	na
SA	49	0%	10%	37%	18%	43%
Remoteness						
Major City	64	-5%	6%	23%	22%	41%
Inner Regional	<20	na	na	na	na	na
Outer Regional / Remote / Very Remote	21	-5%	14%	19%	24%	45%
Annualised cost of baseline plan						
\$10,000 or less	<20	na	na	na	na	na
\$10-15,000	<20	na	na	na	na	na
\$15-20,000	<20	na	na	na	na	na
\$20-30,000	20	5%	10%	30%	25%	61%
Over \$30,000	29	-7%	3%	38%	10%	38%
Aboriginal and Torres Strait Islander Status						
Indigenous	<20	na	na	na	na	na
Non-Indigenous	76	-5%	8%	21%	24%	36%
CALD Status						
CALD	<20	na	na	na	na	na
Non-CALD	87	-5%	8%	23%	22%	41%
Gender						
Female	29	-7%	-3%	21%	21%	36%
Male	60	-3%	13%	23%	22%	44%
Access Type						
Benefit from EI	20	10%	10%	15%	40%	60%
Disability Met	69	-9%	7%	25%	16%	36%
Reporting Access Entry Type						
New	40	0%	5%	15%	40%	54%
State	49	-8%	10%	29%	6%	31%
Plan cost allocation						
Capital 5-100%	<20	na	na	na	na	na
Capacity Building 0-25%	22	5%	5%	36%	14%	41%
Capacity Building 25-50%	<20	na	na	na	na	na
Capacity Building 50-75%	<20	na	na	na	na	na
Capacity Building 75-100%	22	0%	-5%	0%	27%	36%

Appendix B.5 – Has the NDIS helped?

Summary

Overall results (Appendix B.5.1)

The opinions on whether the NDIS has helped are slightly less positive compared to families and carers of participants from birth to age 14. Nevertheless, the majority agrees that the NDIS improved the level of support for their family (55%), as well as helped access services, programs and activities in the community (55%). A slightly smaller percentages of respondents think the NDIS helped them to help their family member with disability to be more independent (51%), as well as to know their rights and advocate effectively (46%). A third of respondents agrees that the NDIS improved their health and wellbeing.

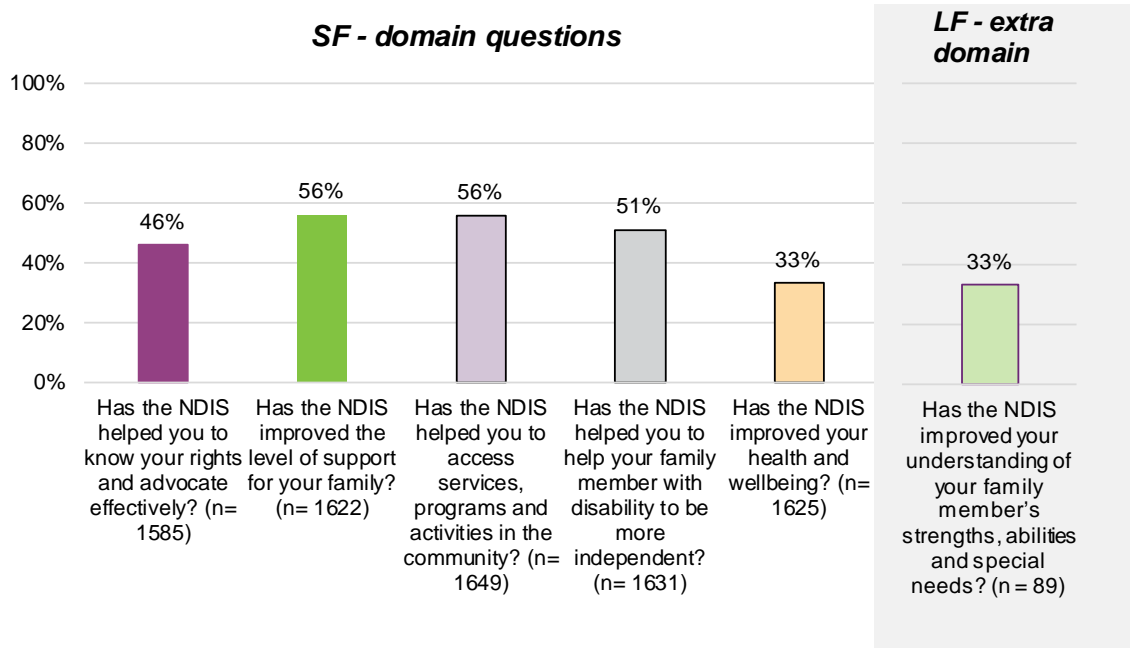
For the extra LF domain, 33% agree that the NDIS improved their understanding of their family member's strengths, abilities and special needs (although the number of respondents is small – only 89 persons).

Results by participant characteristics (Appendix B.5.2)

Analysis by key participant and family/carer characteristics, using one-way analysis and multiple regression, reveals the following key findings:

- **Baseline plan utilisation:** The level of satisfaction increases with baseline plan utilisation across all SF domains. In one-way analyses, the percentages of respondents who agree that the NDIS helped are significantly higher for those with plan utilisation of 50% and above. For example, respondents with plan utilisation of 50% and above are more likely to agree that the NDIS improved the level of support they have (64% compared with 46% for respondents with lower utilisation).
- **Review plan cost:** The percentages who think the NDIS helped increase with increasing plan cost. The relationship is particularly strong for the domain 2 question “Has the NDIS improved the level of support for your family?”, with the percentage of respondents answering “Yes” increasing from 47% for plan cost below \$20,000 to 56% for plan cost of \$20,000-50,000, and 65% for plan cost of \$50,000 and above.
- **Satisfaction with services:** Multiple regression analysis confirms a relationship between the level of satisfaction with the NDIS, and the level of satisfaction with services the participant and their family have in place. In particular, respondents who feel that the services their family member with disability receive meet their needs, and those who feel that the services listen to them, are more likely to agree that the NDIS has helped in all domains.
- **Rights and advocacy:** Being able to identify the needs of the family member with disability and advocate for them in case of problems with accessing services is an important step towards setting the right goals and ensuring the participant's progress. Having both these skills is associated with the higher level of satisfaction with the NDIS. For example, the percentage of respondents who think the NDIS helped them help their family member with disability to be more independent is higher for those who are able to identify the needs of their family member and know how to access available services and supports to meet those needs (60% versus 42%).

Appendix B.5.1 – Summary by domain



Appendix B.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 helped you to access services, programs and activities in the community?	Has the NDIS helped you to help your family member with disability to be more independent?	Has the NDIS improved your health and wellbeing?
	1,746	46%	56%	56%	51%	33%
Relationship to participant						
Mother	1,470	46%	57%	56%	52%	33%
Father	173	45%	51%	53%	48%	30%
Other	103	42%	55%	52%	47%	36%
Age Group						
15 or younger	432	44%	56%	53%	46%	34%
16	603	46%	55%	57%	52%	34%
17	579	47%	57%	57%	53%	32%
18	63	41%	58%	55%	49%	24%
19 to 21	38	54%	49%	55%	63%	31%
22 or older	31	52%	75%	61%	66%	43%
Disability Type						
Autism	741	45%	57%	57%	51%	34%
Cerebral Palsy	133	49%	61%	58%	48%	34%
Down Syndrome	94	58%	65%	66%	62%	36%
Intellectual Disability	568	46%	56%	55%	51%	35%
Other	109	40%	55%	50%	55%	30%
Psychosocial Disability	28	25%	42%	35%	32%	8%
Sensory	73	48%	41%	44%	46%	20%
Level of Function						
High	491	41%	49%	52%	46%	29%
Medium	679	44%	55%	54%	51%	33%
Low	576	53%	63%	61%	55%	38%
State/Territory						
ACT	27	24%	43%	38%	40%	48%
NSW	961	43%	55%	53%	48%	32%
QLD	155	51%	62%	61%	61%	39%
SA	269	48%	60%	61%	54%	40%
TAS	111	52%	49%	59%	55%	27%
VIC	200	53%	57%	56%	52%	28%
WA	23	59%	73%	64%	55%	45%
Remoteness						
Major City	1,145	44%	56%	56%	50%	33%
Inner Regional	419	51%	57%	57%	53%	32%
Outer Regional / Remote / Very Remote	173	47%	54%	54%	52%	36%
Annualised cost of baseline plan						
\$10,000 or less	247	42%	41%	48%	44%	26%
\$10-15,000	207	43%	47%	48%	40%	27%
\$15-20,000	210	44%	57%	53%	48%	35%
\$20-30,000	275	42%	56%	56%	54%	35%
Over \$30,000	807	50%	63%	61%	56%	36%
Aboriginal and Torres Strait Islander Status						
Indigenous	80	48%	62%	45%	49%	25%
Non-Indigenous	1,612	46%	56%	56%	51%	34%
CALD Status						
CALD	124	52%	56%	59%	52%	40%
Non-CALD	1,622	45%	56%	56%	51%	33%
Gender						
Female	580	43%	54%	55%	49%	31%
Male	1,158	47%	58%	56%	52%	34%
Plan management type						
Agency-managed	893	42%	52%	52%	47%	31%
Self-managed	91	53%	63%	58%	55%	44%
Plan-managed	135	52%	65%	69%	60%	31%
Combination	407	49%	61%	60%	57%	36%
Access Type						
Benefit from EI	174	44%	54%	56%	50%	31%
Disability Met	1,551	46%	56%	56%	51%	34%
Scheme access						
New	483	47%	56%	57%	51%	35%
State	1,255	46%	57%	56%	51%	33%
Commonwealth	<20	na	na	na	na	na