

5. Families/carers of participants from age 15 to 24: overview of results

5.1 Key findings

Box 5.1: Key findings for families/carers of participants from age 15 to 24

- 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 CALD backgrounds tend to exhibit worse outcomes, particularly on advocacy and independence.
- Results for respondents for Indigenous participants are mixed. This group of respondents is 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.

Box 5.1: Key findings for families/carers of participants from age 15 to 24 (continued)

- 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 less intensive 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, social connections are important for balanced lifestyle, and according to one-way analysis and multiple regression, results on other outcomes tend to be better for the respondents who are socially well connected. These respondents are more likely to be able to help the participant become more independent. 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, compared to 76% for Australians without caring responsibilities²⁷. 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 SF²⁸. 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.

²⁷ ABS Survey of Disability, Ageing and Carers (SDAC) 2015, non-carers aged 15 to 64.
<https://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0>

²⁸ Rights and advocacy, Feeling supported, Access to services and supports, Supporting their young person to become independent.

5.2 Results overview

5.2.1 Outcomes framework questionnaire domains

For families and carers of participants aged from 15 to 24, the outcomes framework seeks to measure the extent to which they:

- Know their rights and advocate effectively for their family member with a disability
- Feel supported
- Can gain access to desired services, programs and activities in their community
- Are able to help their young person to become independent
- Enjoy health and wellbeing.

The LF survey for families and carers of participants aged 15 to 24 also includes 4 questions on whether families/carers understand their family members strengths, abilities and special needs, and includes several additional questions on health and wellbeing that focus on their outlook for the future and ability to meet costs of everyday living.

5.2.2 Baseline indicators – aggregate

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.

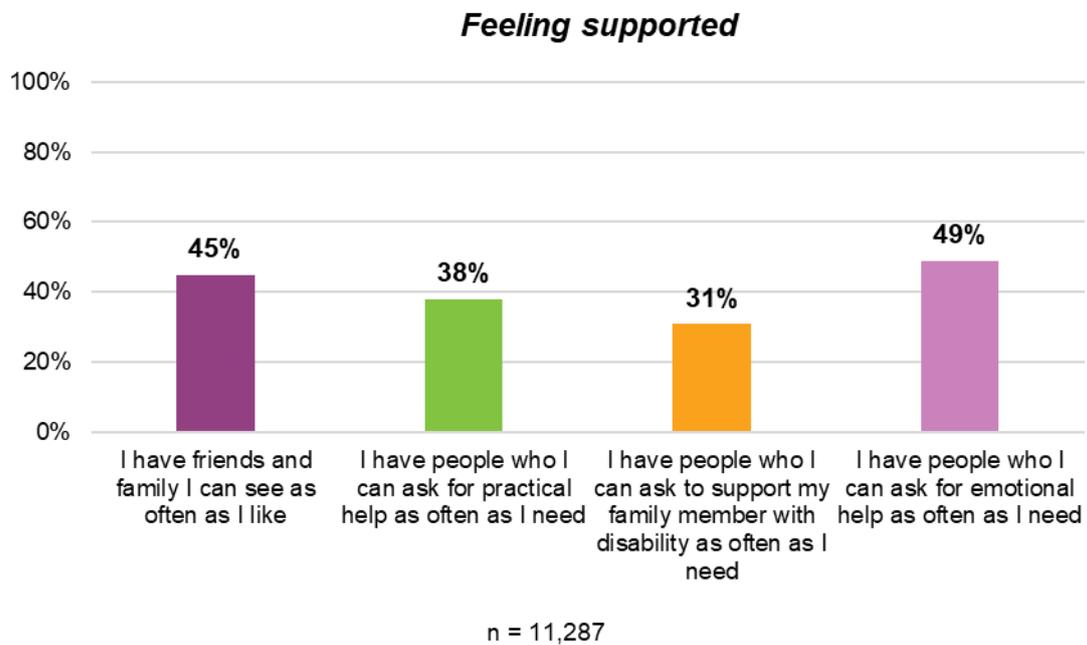
Families feel supported

As with families and carers for participants from birth to age 14, most families say they lack sufficient support or social connections. Figure 5.1 shows the percentage of respondents with support for different support types. 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. This relationship is illustrated in Figure 5.1.

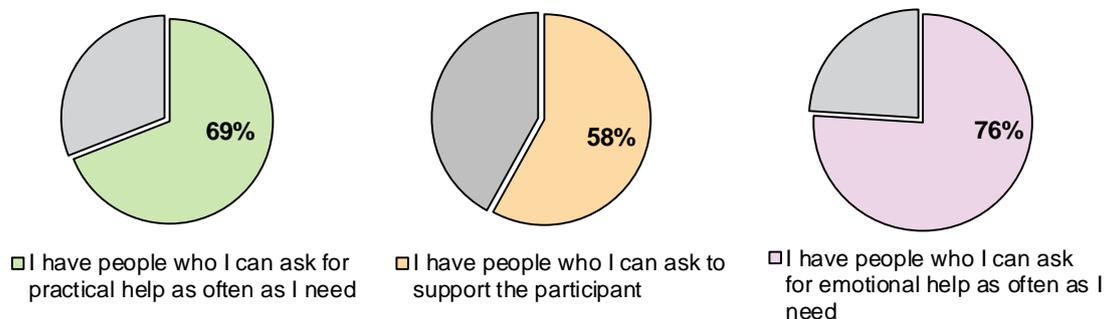
Access to Services

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.

Figure 5.1 Support and social connections



For respondents who have friends and family they can see as often as they like



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

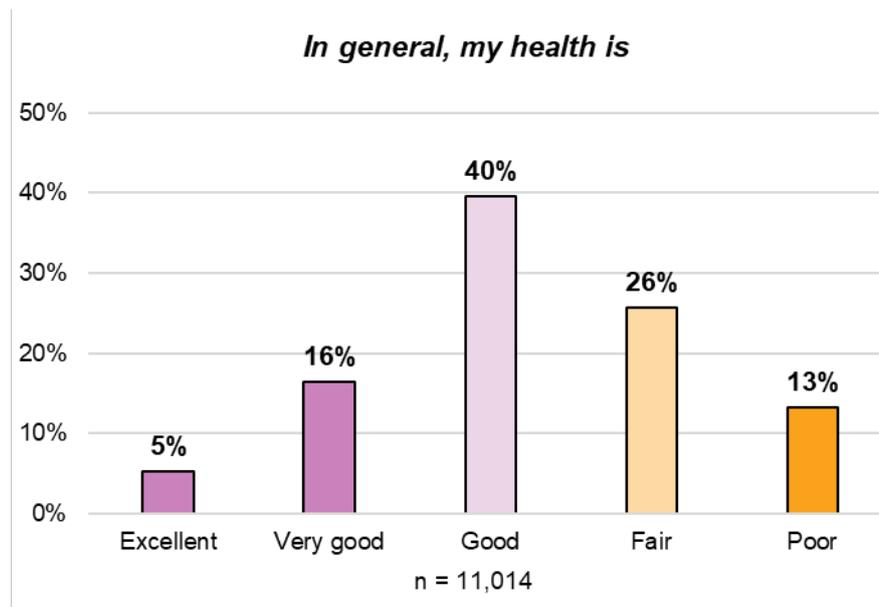
The LF includes an additional domain concerned with how families and carers perceive the strengths and abilities of their family member with disability, and how their family member is progressing. 86% of families and carers can recognise the strengths and abilities of the participant and 76% can see 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 overall²⁹. Figure 5.2 shows how the respondents rated their health at baseline.

Figure 5.2 Respondents' health rating



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 (44%), although more answered positively (43%) than negatively (13%)³⁰. The 43% responding positively is much lower than the 77% for Australians aged 25 to 64 overall³¹, 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”.

²⁹ ABS National Health Survey (NHS) 2014-15.

³⁰ Excluding “don’t know” and missing responses.

³¹ 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.

5.2.3 Baseline indicators – key characteristics

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%).

- **Indigenous 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% for family/carers of participants aged under 18, 42% for family/carers of participants aged 18 to 20, and 45% for family/carers of participants 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.

A similar pattern is shown in Figure 5.3 regarding knowing how to enable the participant to be as independent as possible.

Figure 5.3 Percentage of families/carers who know what their family can do to enable the participant to be as independent as possible by participant disability type

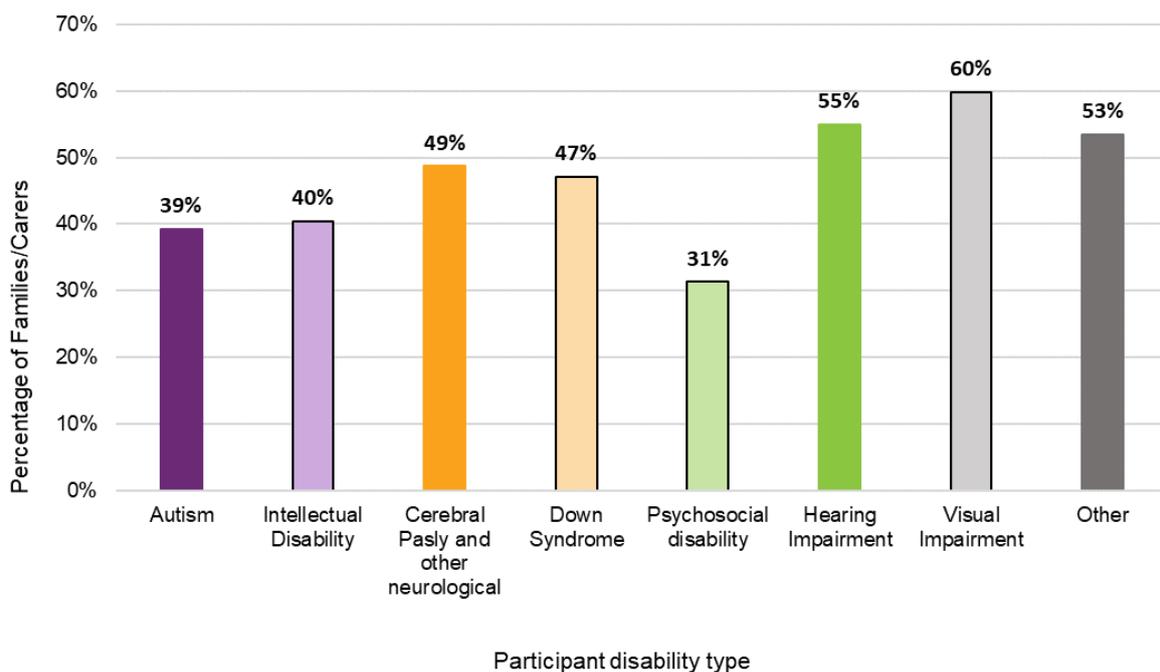


Figure 5.3 shows that only 31% of families and carers of participants with a psychosocial disability know how to enable their family member to become as independent as possible (compared to 42% overall). There is a general trend towards poorer baseline outcomes for these respondents, but particularly 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

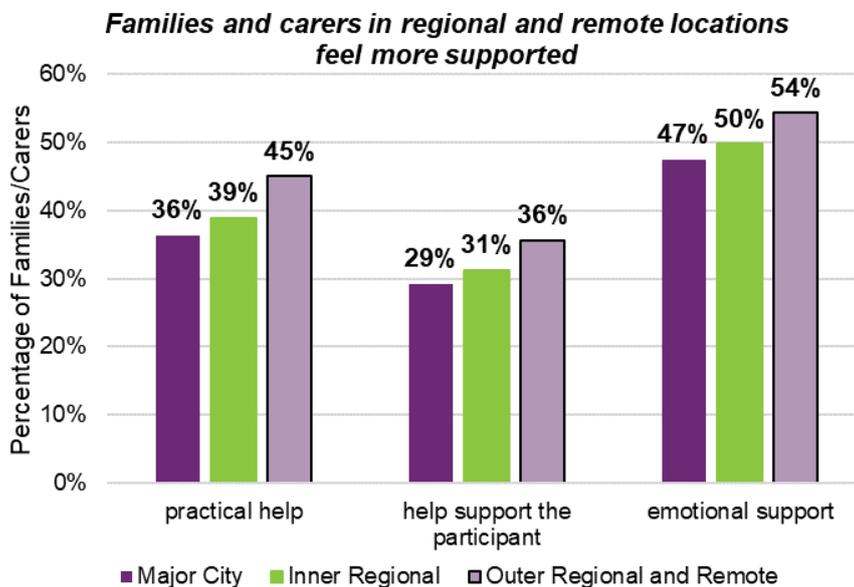
(39% and 32% compared with 18% overall). By contrast, only 10% of family/carers of participants with psychosocial disability are satisfied with the services they received.

For indicators related to family/carers having necessary supports to care for the participant, 60% of respondents for participants with a hearing impairment and 47% of respondents for participants with a visual impairment have people who they can ask to support the participant as often as they need. This is considerably higher compared to respondents for participants with autism or psychosocial disability (both 27%).

- **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).

Figure 5.5 Percentage of families/carers with different types of support by region



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.

Figure 5.6 Percentage of families/carers who are able to work as much as they want by region

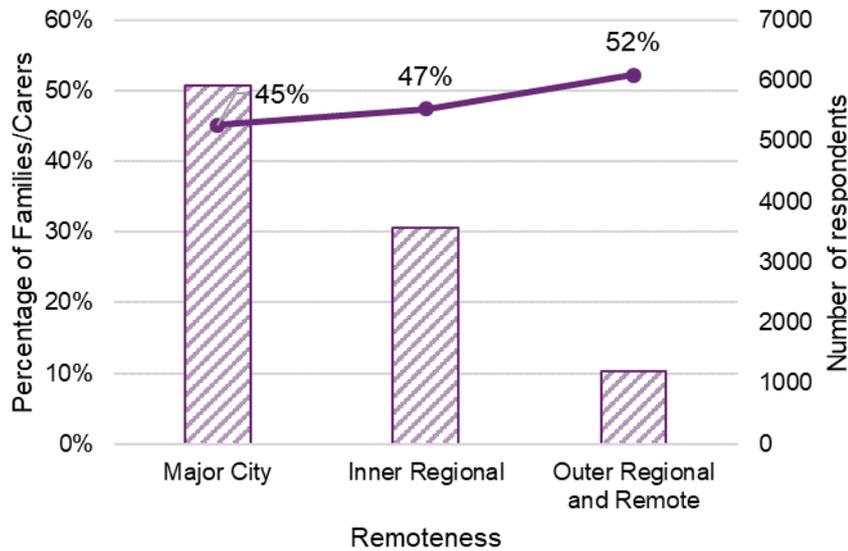
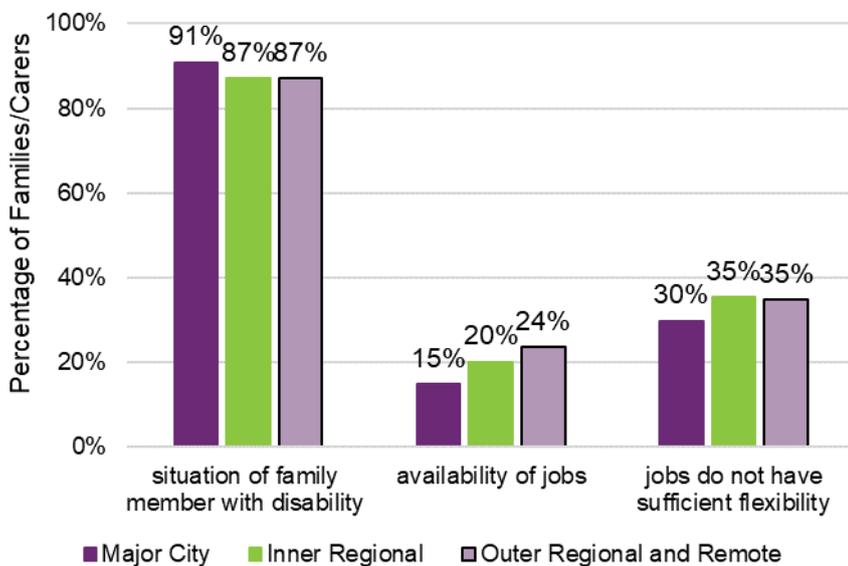


Figure 5.7 For those who are unable to work as much as they want, percentage of families/carers with different barriers to working more by region



• **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.

Figure 5.8 Percentage of families/carers who are able to advocate (stand up) for the participant if they have problems accessing supports by streaming type

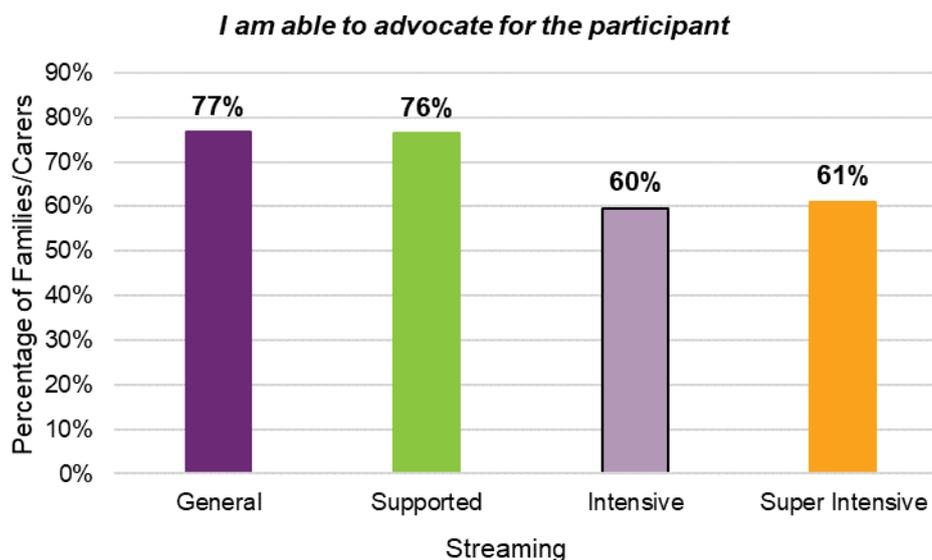
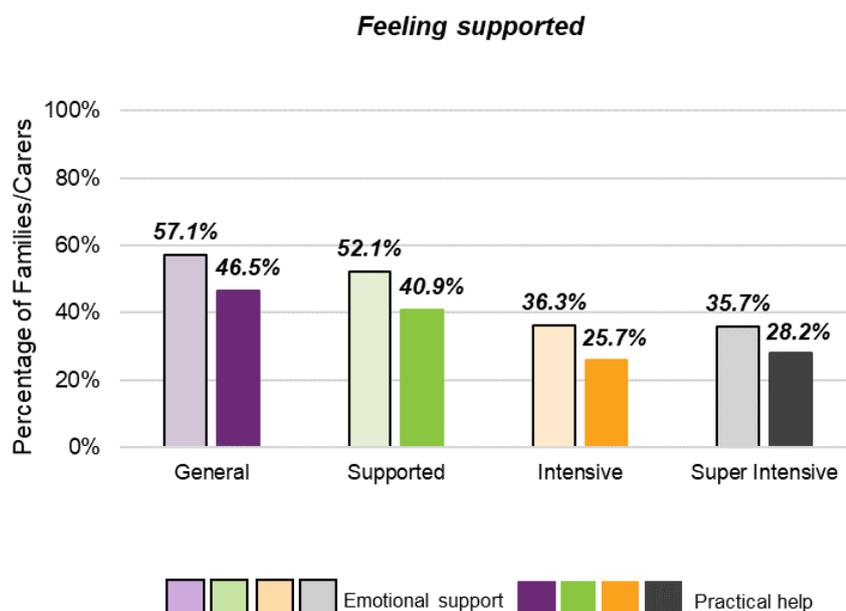


Figure 5.9: Percentage of families/carers with sufficient levels of emotional support and practical help by streaming type



- **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.

5.2.4 Longitudinal indicators – aggregate

Longitudinal analysis describes how outcomes have changed for families/carers during the time the participant has been in the Scheme. Included here are participants entering the Scheme in the first year of transition (from 1 July 2016 to 30 June 2017) for whom a record of outcomes is available at two time points: at scheme entry and at approximately one year following scheme entry³².

As expected during this relatively short period, many indicators have not changed a great deal. For this summary we select indicators based on a combination of statistical significance and magnitude of change^{33,34}.

³² Only pairs of responses where the person had the same relationship to the participant are included. For example, if the participant’s mother responded at baseline and the participant’s father responded at review, then the pair of responses would be excluded.

³³ Since there is much more data available for the SF, with more than 1700 participants contributing to the analysis, statistical testing would identify indicators where the magnitude of change is unimportantly small, so we only consider SF indicators where the absolute magnitude of change in the indicator is greater than 0.02 (all of these changes are statistically significant). For the LF, where the quantity of data is much smaller (less than 100 participants), selection is based on statistical significance.

³⁴ Note that at least some of the observed change may be attributable to normal age-related development, since the family member will be one year older at the second time point.

Table 5.1 summarises changes for the 19 selected indicators.

Table 5.1 Selected longitudinal indicators for families/carers of participants from age 15 to 24

SF/LF	Domain description	Indicator	Baseline	Review	Change	Improvement/Deterioration
SF	Work	% working in a paid job	48.0%	51.1%	3.2%	Improvement
SF	Work	Of those in a paid job, % working 15 hours or more	83.4%	85.6%	2.2%	Improvement
SF	Families feel supported	% who have friends and family they see as often as they like	46.6%	49.6%	3.0%	Improvement
SF	Families feel supported	% who have people they can ask for practical help as often as they need	41.7%	44.2%	2.5%	Improvement
SF	Families feel supported	% who have people they can to support their family member with disability as often as they need	33.4%	36.5%	3.2%	Improvement
SF	Families feel supported	% who have people they can ask for emotional support as often as they need	52.7%	56.1%	3.4%	Improvement
SF	Access to services	% who feel in control selecting services	41.4%	44.4%	2.9%	Improvement
SF	Access to services	% who feel that the services their family member with disability/family use listen to them	65.4%	70.7%	5.3%	Improvement
SF	Access to services	% who say the services their family member with disability/family receive meet their needs	19.7%	32.7%	13.0%	Improvement
LF	Access to services	% who work in partnership with professionals and service providers to meet the needs of their family member with disability	61.0%	78.0%	17.1%	Improvement
SF	Families help their young person become independent	% who enable/support their family member with disability to make more decisions in his/her life	60.2%	62.7%	2.5%	Improvement
SF	Families help their young person become independent	% who enable/support their family member with disability to interact and develop strong relationships with non-family members	48.7%	50.7%	2.0%	Improvement
LF	Health and wellbeing	% who feel more confident about the future of their family member with disability under the NDIS	49.4%	71.9%	22.5%	Improvement
LF	Health and wellbeing	% who feel that their family member gets the support he/she needs	28.1%	49.4%	21.3%	Improvement
LF	Health and wellbeing	% who feel that the services and supports have helped them to better care for their family member with disability	33.3%	74.7%	41.4%	Improvement
SF	Government benefits	% receiving Carer Allowance	54.0%	58.0%	4.0%	Context dependent
SF	Work	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	89.1%	92.6%	3.5%	Deterioration

SF/LF	Domain description	Indicator	Baseline	Review	Change	Improvement/Deterioration
SF	Work	Of those unable to work as much as they want, % who say insufficient flexibility of jobs is a barrier to working more	37.3%	40.4%	3.1%	Deterioration
SF	Health and wellbeing	% who rate their health as good, very good or excellent	65.0%	61.6%	-3.4%	Deterioration

As with families and carers for participants aged from birth to 14, the majority of significant changes are positive. Large changes have been observed for the following domains:

- **Work:** the results are mixed. On the positive side, 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. 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. Data from HILDA³⁵ wave 16 (2016) shows employment rates averaging around 79% for respondents from households with children aged 15-24. Whilst the rates fluctuate between about 75% and 83% for single years of age within this range, there is no clear trend apart from a possible slight decline after the child's age reaches 20, possibly due to parents/carers approaching retirement. On the negative side, parents/carers who are not able to work as much as they want are more likely to perceive the situation of their family member with disability as a barrier to working more, and are also more likely to cite insufficient flexibility of jobs as a barrier.
- **Families/carers feeling supported:** all SF indicators have increased. In particular, the percentage of families and carers who have friends and family they see as often as they like has increased from 47% at baseline to 50% as review. Likewise, the percentages who have people they can ask for practical help, emotional help, and to support the participant as often as they need have increased.
- **Access to services:** the majority of the indicators have increased. Families and carers are more likely to feel in control in selecting services, and the services listen to them more often. Overall, the services the participant and their family receive are more likely to meet their needs. From the LF, the percentage who work in partnership with professionals and service providers to meet the needs of the participant has increased from 61% at baseline to 78% at review.
- **Families help their young person become independent:** families and carers are more likely to enable/support their family member with disability to make more decisions in his/her life. Likewise, the percentage of those who enable/support their family member with disability to interact and develop strong relationships with non-family members has increased.
- **Health and wellbeing:** the results are mixed. Large increases have been observed for some LF indicators. For example, the percentage who feel that their family member with disability gets the support he/she needs has increased from 28% at baseline to

³⁵ <https://melbourneinstitute.unimelb.edu.au/hilda>

49% at review. However, the percentage rating their health as good, very good or excellent has decreased.

5.2.5 Longitudinal indicators – key 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.

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 think 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 the two 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

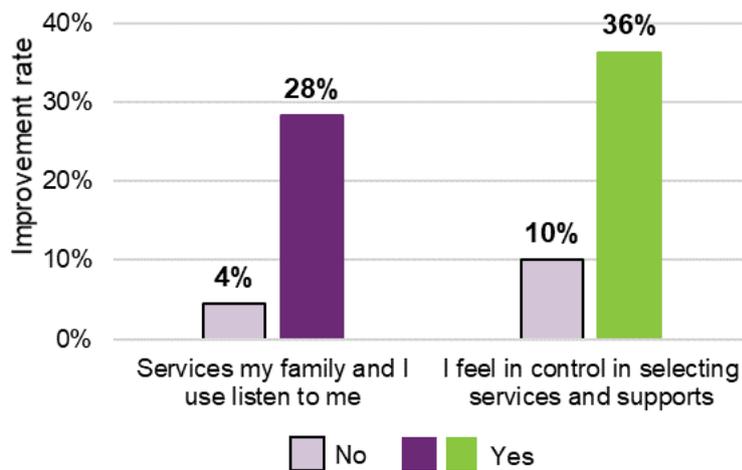
Significant improvements were observed for most indicators for this domain. Notably, overall satisfaction with services has increased by 13%, from 20% at baseline to 33% at review.

The services my family member with disability and my family receive meet our needs (overall improvement of 0.13)

Of those who said services did not meet their needs at baseline, 20% said they did at review. Based on the logistic regression model for improvement:

- Quality of services was found to be a significant predictor of improvement. Feeling in control in selecting services and supports, as well as dealing with services that listen increased the likelihood of a positive response at review. Figure 5.10 illustrates this relationship on a one-way basis.
- Improvement was more likely for families and carers who had people they could ask to support the participant as often as needed (33% versus 14%).
- Baseline plan utilisation was found to be positively correlated with improvement.

Figure 5.10: Rate of improvement in the number of families/carers who say the services meet the needs of their family member with disability by SF indicators related to quality of the services



Domain 4: Families help their young person become independent

As the participant becomes one year older, families and carers are building confidence to help him or her be as independent as possible. All indicators for this domain have increased, and two of three have changed by 2% or more.

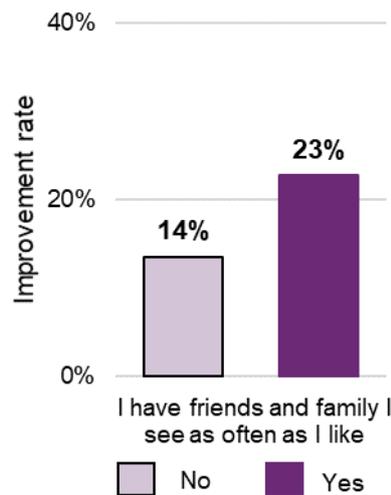
I enable/support my family member with disability to make more decisions in their life (overall improvement of 0.025)

Of those answering negatively at baseline, 17% answered positively at review. Based on the logistic regression model for improvement:

- Families and carers who were able to identify the needs of their family member with disability and their family and knew how to access available services and supports to meet those needs were more likely to report improvement at review (32%).
- The percentage of those who improved at review was higher for respondents who were able to advocate (stand up) for the participant if they had issues or problems with accessing support (25%).

- The rate of improvement was higher for those who said the NDIS helped them to help the participant to be more independent (25%).
- Although the number of observations is small, respondents from a CALD background were significantly less likely to report improvement (5%).
- The rate of improvement was higher for those with friends and family they see as often as they like.

Figure 5.11 Rate of improvement in the number of families/carers who support their family member with disability to make more decisions in his/her life by level of social connectedness



Domain 5: Health and wellbeing

Health in general is an age-dependent factor. As time goes by, some deterioration in health of respondents is expected.

In general, my health is excellent, very good or good (overall deterioration of -0.034)

Of those whose health was excellent, very good or good at baseline, 12% said it was fair or poor at review. Based on the logistic regression model for deterioration:

- Families and carers who did not have people who they could ask for emotional support as often as they needed were more likely to experience deterioration in health (19%).
- Having difficulties in supporting the participant to become as independent as possible was found to be associated with deterioration in health of the parent/carer.
- Respondents for Indigenous participants were twice as likely to experience deterioration in health (24%).