NDIS Family and Carer Outcomes

30 June 2018

Contents

Executive summary

Background

The NDIS Outcomes Framework is one of only a few internationally that measures outcomes for both participants and their families and carers.

Families and carers play an important role in supporting NDIS participants. The outcomes for a participant, and for the person who cares for them, are likely to be closely linked. Families and carers of participants who are well supported under the NDIS and who are achieving greater independence and social and economic participation are likely to find the caring role easier and to experience increased wellbeing and greater opportunities for social and economic participation themselves. The improved situation for families and carers should in turn translate into further improvement in outcomes for participants.

A separate report on participant outcomes at 30 June 2018 has been prepared previously.[1] That report discusses the aims of the NDIS and how those aims are embedded in the legislation[2] and the NDIA Corporate Plan 2018-2022[3].

The NDIS Outcomes Framework questionnaires

The participant outcomes report discusses the insurance principles on which the Scheme is based. An insurance-based approach considers the lifetime cost of participants (including early investment), and the outcomes achieved across participants' lifetimes. In view of the link with participant outcomes, monitoring family and carer outcomes contributes to an assessment of how successfully the insurance-based approach is working. Monitoring of family and carer outcomes is also important from a broader perspective, for example, increased economic participation of families and carers will have wider benefits for the Australian economy.

This report analyses the results of the outcomes framework questionnaires for families and carers of people who entered the Scheme in 2016-17 and 2017-18 (referred to as "the baseline" as the NDIS has not influenced the outcomes of participants or their families and carers at this point), and also the one year longitudinal change in outcomes for families and carers of people who entered in 2016-17 and have been in the Scheme for one year. As pointed out in the participant outcomes report, one year is not a lot of time to measure success, however it is important to start the conversation on what factors are driving good outcomes, for families and carers of NDIS participants as well as for participants themselves.

Baseline versus progress

As also noted in the participant outcomes report, baseline outcomes for participants and their families and carers will differ by a range of factors, including the nature and severity of the participant's disability, the extent of support networks, local community inclusiveness, and general health. For example, in this report, family/carer health is found to impact their baseline outcomes.

---

[1] Subsequently referred to as "the participant outcomes report".
[2] http://www.comlaw.gov.au/Details/C2013A00020/Download
[3] https://www.ndis.gov.au/about-us/publications/corporate-plan

Consequently, the success of the Scheme should be judged not on baseline outcomes, but on how far participants and their families and carers have come since they entered the Scheme, acknowledging their different starting points.

It is also important to note that whilst some of the benefits of the Scheme should be quick to emerge (for example, assistance with daily living), others are much more long-term in nature (for example, employment), and measurable progress may take some years to emerge.

Finally, it should be recognised that some of the domains included in the outcomes framework (for example, health) are not the primary responsibility of the NDIS, but are nevertheless included in order to provide a fuller picture of the circumstances of participants and their families and carers.

A lifespan approach

Leveraging research conducted by the NDIS Independent Advisory Council (IAC), the outcomes framework takes a lifespan approach to the measurement of outcomes, recognising that different milestones are important for different participant age groups.

Many of the issues faced by families and carers are similar regardless of participant age (for example, being able to work as much as they want), however there are some differences (for example, families and carers of young children will be focussed on helping their child's early development and learning, whereas families and carers of young adults will want to help their family member to become as independent as possible).

Recognising these differences, family/carer questionnaires have been developed for three different *participant* age groups: 0 to 14, 15 to 24, and 25 and over. This report is organised with a separate subsection for each of these participant age groups, synthesising analyses from all data sources[4]. Since the role of the family or carer in the participant's life is most crucial during childhood, and since completion of the family/carer questionnaire is not compulsory where the participant is an adult, the report puts greater emphasis on the 0 to 14 participant age group, followed by the 15 to 24 age group. For the 25 and over age group, where a smaller amount of data is available (particularly longitudinally), and the relationship between participants and families/carers tends to be less close, a briefer presentation of results is given.

In-depth analysis: employment

As a result of their caring responsibilities, families and carers face a number of barriers to finding and keeping paid employment. Improving opportunities to participate in employment is expected to lead to a number of benefits for the families and carers of people with a disability, including greater financial security, reduced social isolation, and higher levels of self-esteem. More broadly, improved employment outcomes for the families and carers of people with disability is expected to contribute to long-term economic benefits for Australia through increased labour force participation and reduced costs of carer income supports.

In view of its importance, the final section of this report presents the results of in-depth analysis of employment outcomes for families and carers of NDIS participants.

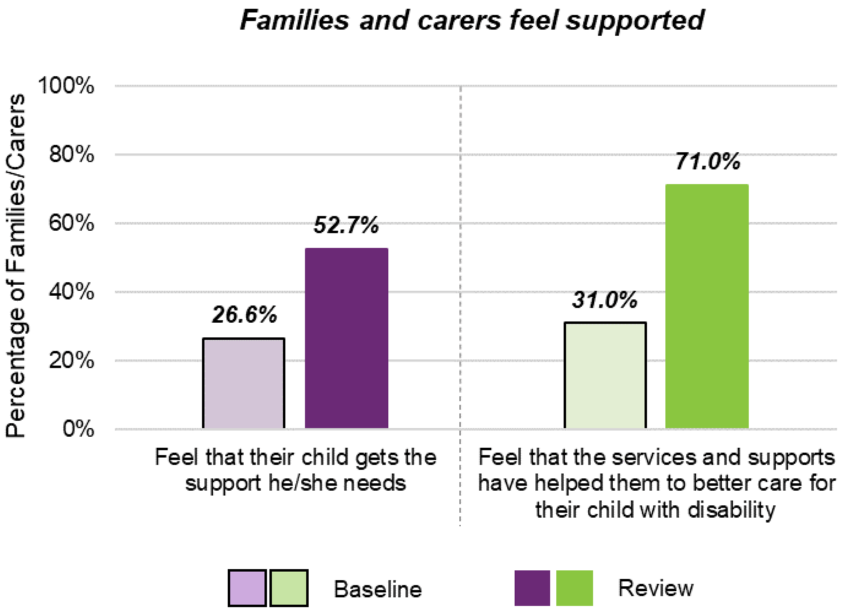
---

[4] The Short Form (SF) outcomes framework and the Long Form (LF) outcomes framework, baseline and longitudinal information.

Families and carers of participants aged 0 to 14

- In the longitudinal analysis, some large changes were observed, and the majority of these changes were positive:
    - The percentage of families/carers working in a paid job has increased from 45% at baseline to 48% at review, but is still considerably lower than for Australians without caring responsibilities (76%).[5]
    - Of those working in a paid job, the percentage of families/carers who work 15 hours or more has increased from 79% to 81%. The percentage working less than 30 hours per week has decreased from 57% to 55%, but is still much higher than the 26% of Australians working on a part-time basis as at 30 June 2018.[6]
    - Families and carers report increased levels of support to care for their child with disability. The percentage who feel that their child gets the support he/she needs increased from 27% to 53%, and the percentage who think that the services and supports have helped them to better care for their child with disability increased from 31% to 71%.

Figure 1 Families and carers of participants 0 to 14 feel better supported



- Families and carers also report increasing ability and confidence in helping their children develop and learn. The percentage of families/carers who know what they can do to support their child's learning and development has increased from 42% at baseline to 50% at review. The percentage who know what specialist services are needed to support this development has also increased (from 40% to 48%). The

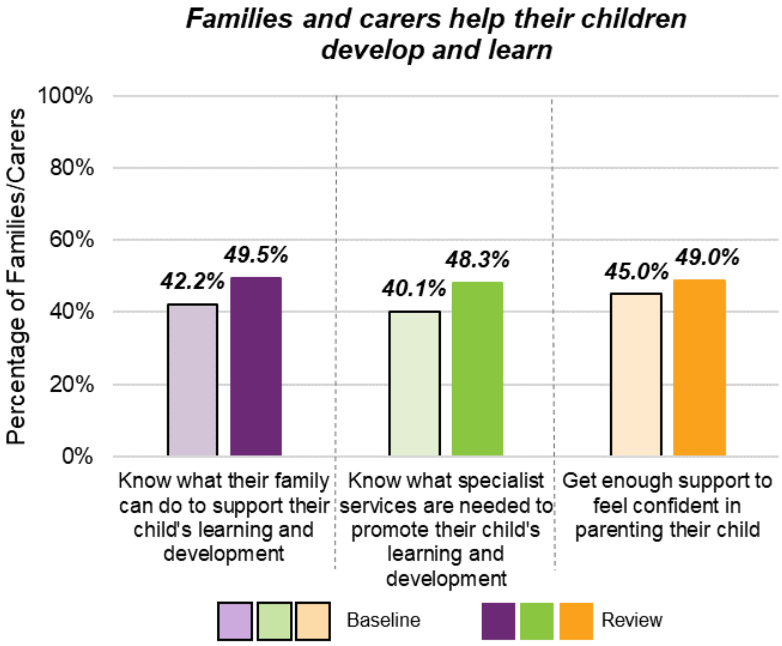
---

[5] 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

[6] Australian Bureau of Statistics. 2018. 6202.0 Labour force, Australia, Jun 2018. ABS defines part time work as less than 35 hours per week, so the percentage of the general population working less than 30 hours per week would likely be lower than 26%.

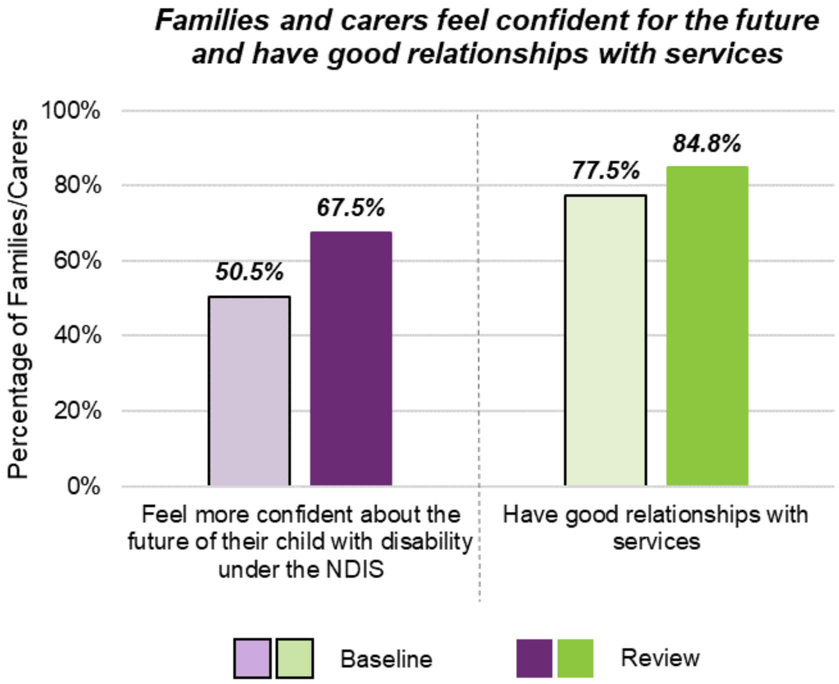
percentage who say they get enough support to feel confident in parenting their child has increased from 45% to 49%.

Figure 2 Families and carers of participants 0 to 14 help their children develop and learn



- The percentage of families/carers feeling more confident about the future of their child with disability under the NDIS has improved from 51% to 68%. The percentage describing their relationships with services as "good" or "very good" has also improved, from 78% to 85%.

Figure 3 Families and carers of participants 0 to 14: outlook for the future and relationships with services



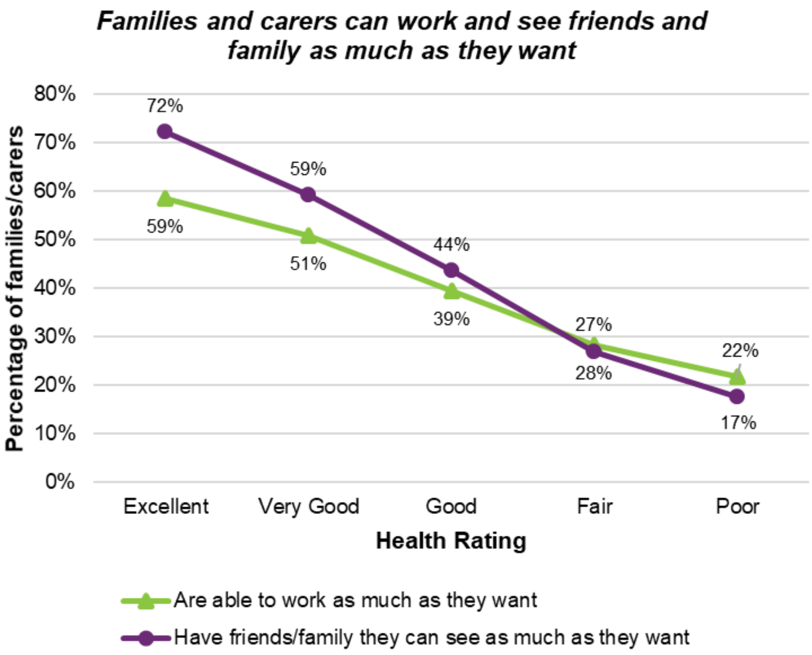
  - Some deterioration was observed in self-rated health, with the percentage rating their health as good, very good or excellent falling from 73% to 69%. For Australians aged 25 to 64, the corresponding percentage is 87%[7]. Families and carers were also more likely to perceive the situation of their child with disability as a barrier to working more (88% to 91%) and to engaging socially more (91% to 93%).

- Participant age had an impact on family/carer outcomes, with both baseline and longitudinal change tending to be better for families and carers of younger participants.

- Baseline indicators and longitudinal change for some indicators tended to be worse for families and carers of participants from CALD backgrounds. This may be due to more difficulty in accessing information and lack of support networks.

- Families and carers with poorer self-rated health tended to have worse outcomes, both baseline and longitudinal.

Figure 4 Families and carers of participants 0 to 14: impact of health on baseline outcomes



- In one-way analyses, baseline outcomes for families and carers of participants with hearing impairment tended to be better, and those for families and carers of participants with a psychosocial disability tended to be worse, than average.

- Families and carers who have sufficient information and support, know what supports their child needs and can access them, and feel confident in parenting their child, tend to have more favourable outcomes at baseline, and tend to experience greater improvement longitudinally.

---

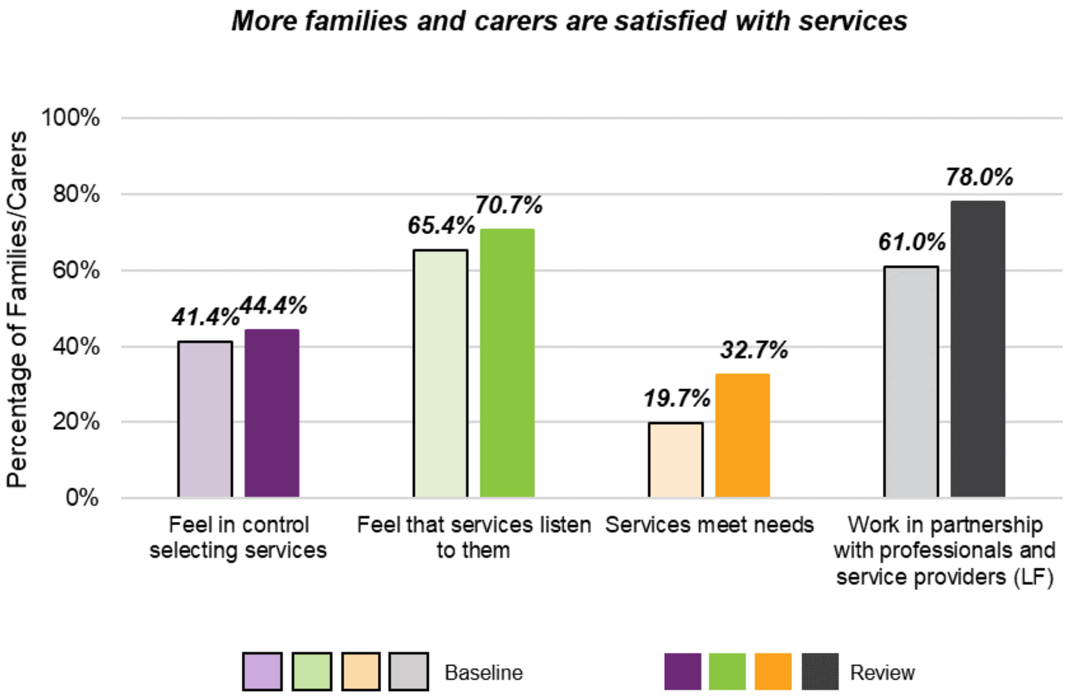
[7] ABS National Health Survey (NHS) 2014-15. Families/carers of 0 to 14 year olds are likely to be towards the younger end of the 25-64 age range.

- Opinions on whether the NDIS has helped after one year in the Scheme vary by domain, from only 38% who think that the NDIS has helped with health and wellbeing (including employment and social participation) to 69% who think that the NDIS has improved their capacity to help their child develop and learn. Results tended to be more positive for families and carers of participants who are younger, have higher baseline plan utilisation, and are from less intensive streaming categories. Families and carers with sufficient knowledge, support, access to services, and confidence in parenting their child were also more likely to respond positively.

Families and carers of participants aged 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%[8]. 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: respondents report gains in their 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.

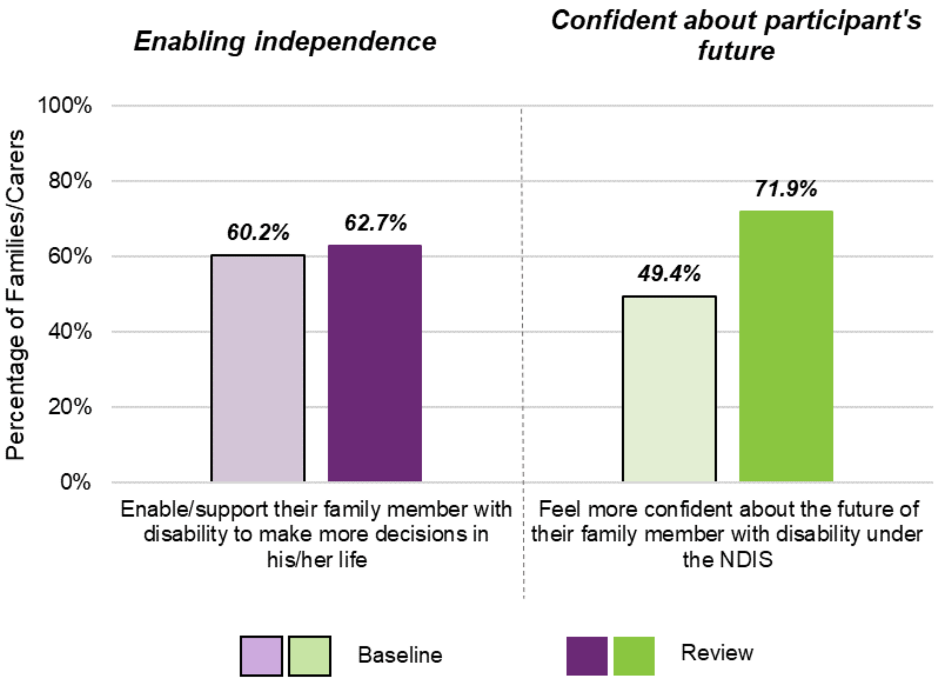
Figure 5 Families and carers of participants 15 to 24 are more satisfied with services



---

[8] Strictly speaking, 2 percentage points. This usage is adopted throughout the report.

Figure 6 Families and carers of participants 15 to 24: enabling independence and confidence for the future



- 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 families/carers of participants from CALD backgrounds tend to be worse, particularly those related to advocacy and independence.

- Results for families/carers of 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.

- Results tend to be worse 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. Possibly as a consequence, the indicators related to helping the participant become more independent are less likely to be positive compared to other types of streaming.

Figure 7 Percentage of families/carers with different types of support by region (baseline)

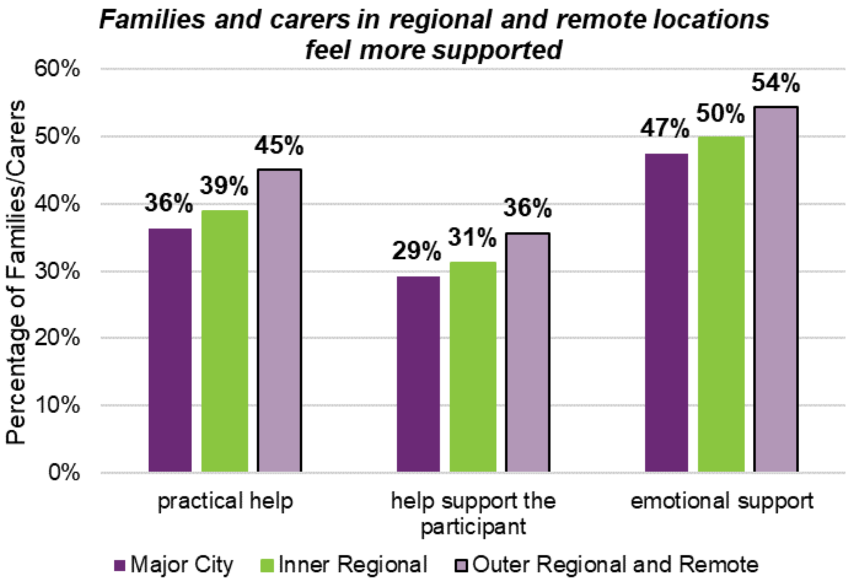
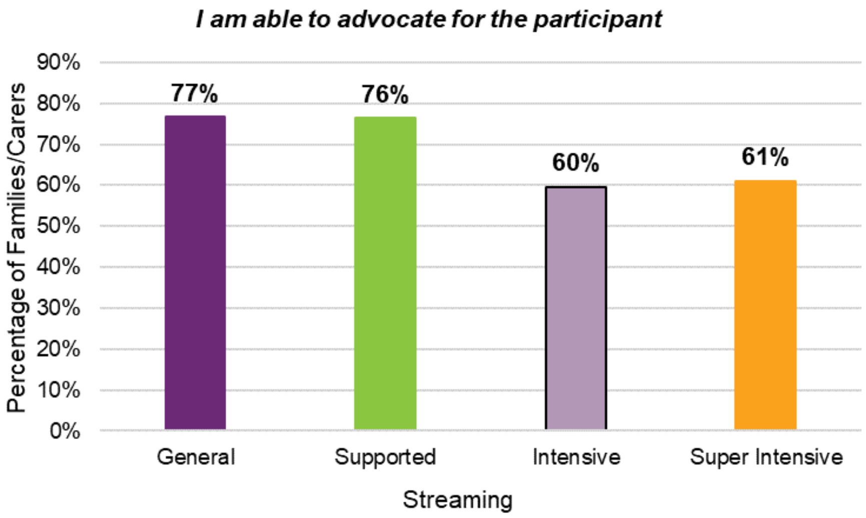


Figure 8 Percentage of families/carers who are able to advocate (stand up) for the participant in case of problems accessing supports by streaming type (baseline)



- 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 responsibilities[9]. Of those families and carers working in a paid job, 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[10]. 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.

---

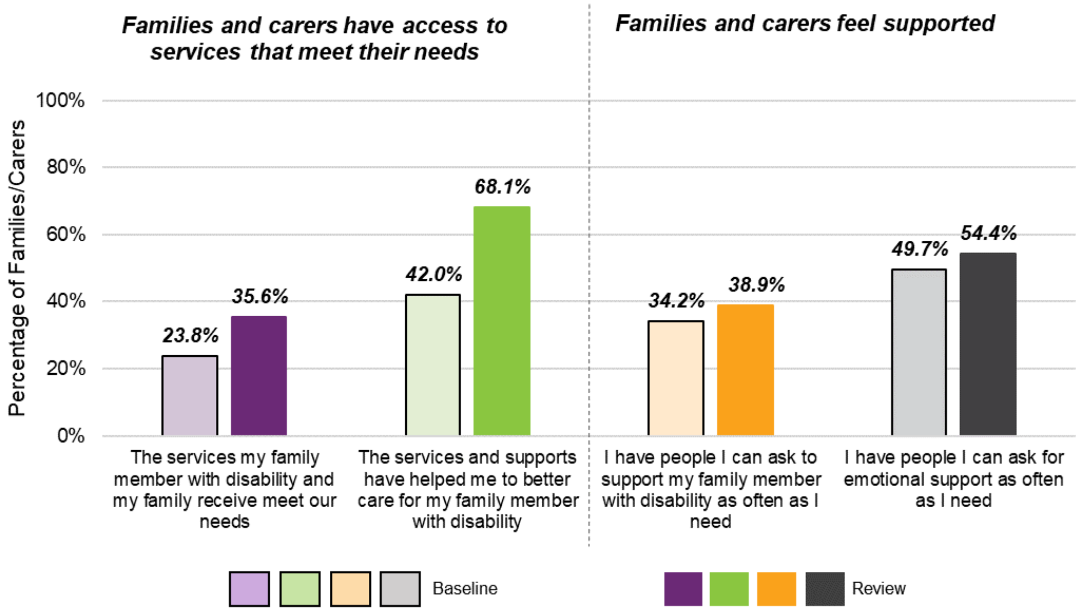
[9] ABS Survey of Disability, Ageing and Carers (SDAC) 2015, non-carers aged 15 to 64. https://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0

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

Families and carers of participants aged 25 and over

- 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%).

Figure 8 Improvements in accessing services and feeling supported, families and carers of participants aged 25 and over



- 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.

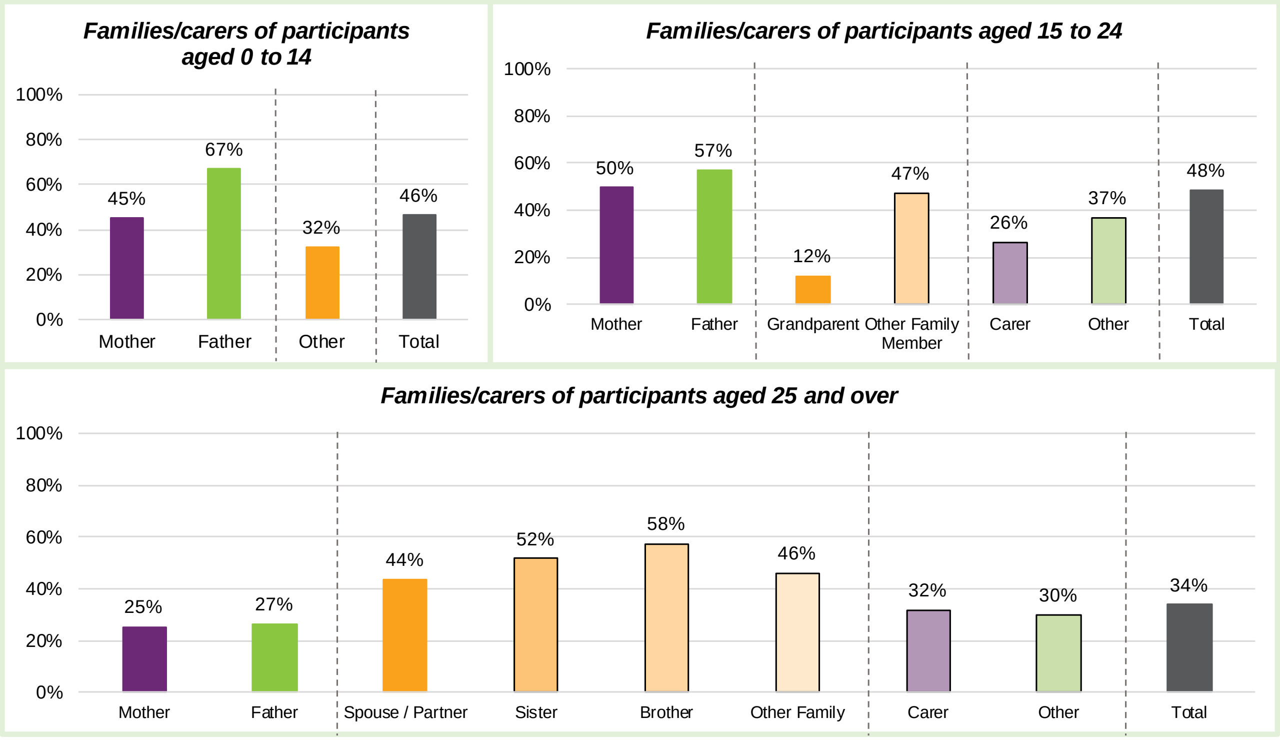
- Opinions on whether the NDIS has helped varied by domain. Most agreed that the NDIS has helped with level of support for the family (66%), access to services, programs and the community (62%), and the ability to advocate (53%). Responses were lower for succession planning (41%) and health and wellbeing (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.

Employment outcomes for families and carers of NDIS participants

- Increasing employment for families and carers of NDIS participants will result in benefits to both the individuals, as well as the wider Australian economy. In 2011, the Productivity Commission estimated that the NDIS could result in an additional 3.4% of carers entering the workforce, increased work capacity for carers already employed, and a $1.5b increase to annual real GDP.

- As at 30 June 2018, the percentage of families/carers who had a paid job upon entry into the scheme is: 46% for families/carers of participants aged 0 to 14, 48% for families/carers of participants aged 15 to 24, and 34% for families/carers of participants aged 25 and over. These percentages are considerably lower than the 76% observed for Australians without caring responsibilities.[11]

Figure 9 Percentage of families/carers in a paid job at baseline, by relationship to participant



- Mothers and fathers of participants aged 24 and under had the highest employment rates at baseline compared to other family members or carers who responded to the survey. Fathers were more likely to be in a paid job than mothers. For child participants, the percentage of mothers in paid work at baseline increases slightly as the child gets older, from 28% for mothers of children under one year of age to 46% for mothers of six year olds. However, between ages 6 and 11 no further increases are observed. For mothers in the general population, the percentage in a paid job increases from 31% for mothers of

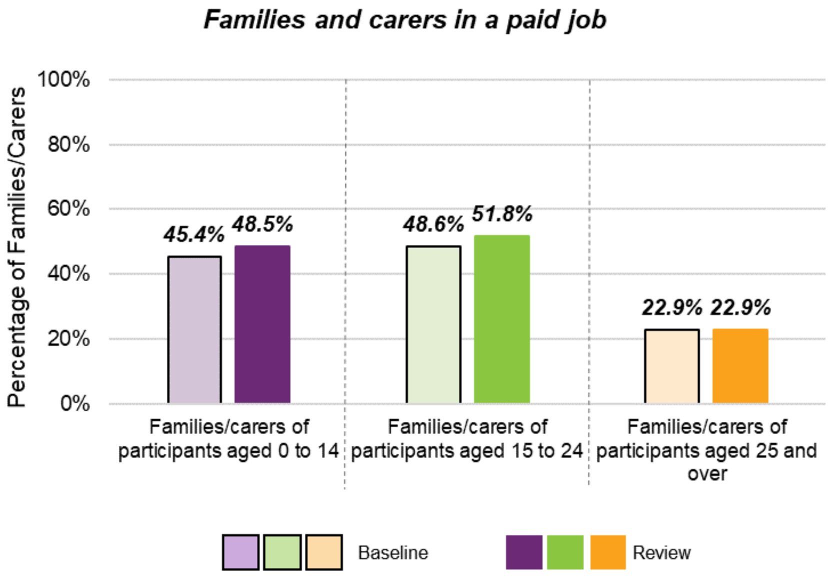
---

[11] 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

children under one year old to 67% for mothers of six year olds, and increases further to 75% for mothers of 11 year olds[12].

- For the families and carers of participants who have been in the Scheme at least one year as at 30 June 2018, the change in employment rates between baseline and review is: +3.1% for families/carers of participants aged 0 to 14, +3.3% for families/carers of participants aged 15 to 24 and no change for families/carers of participants aged 25 and over.

Figure 10 Changes in employment rates for families and carers by age of participant



- The percentage of families/carers working in casual employment (26%) has remained steady between baseline and review, and compares to 15% of Australians aged 25 to 64 overall. The proportion of families/carers working 30 or more hours per week has risen slightly from 41% at baseline to 43% at review. By contrast, 74% of Australians aged 25 to 64 work 35 or more hours per week[13].

- The most common barriers to families and carers working more were the situation with the child/family member with a disability (89%) and available jobs not having sufficient flexibility (42%). Other reported barriers included the availability of jobs, ill health of the respondent, availability and cost of childcare and after school care, and other caring responsibilities.

- For the families and carers of participants aged 0 to 14 who did not have a paid job at baseline, 12% had found paid employment at review. Multiple regression analysis suggests that families/carers have a higher likelihood of finding employment at review if

---

[12] Baxter J, 2013. *Employment characteristics and transitions of mothers in the Longitudinal Study of Australian Children*. Department of Social Services. Note that the population percentages use age of youngest child, whereas Scheme percentages use age of the participant, who may or may not be the youngest child. In addition, the LSAC percentages are based on longitudinal data across four waves of the study, whereas the SF percentages are cross-sectional (at baseline).
[13] Australian Bureau of Statistics. 2018. 6202.0 Labour force, Australia, June 2018.

they have access to services and supports, are motivated to work more, rate their health as good or better, are self-managing the participant's plan, or if the participant enters the Scheme through early intervention. Where the participant's streaming type is intensive or super intensive, the family member/carer is found to have a lower likelihood of finding paid work at review.

- For the families and carers of participants aged 0 to 14 who were already in paid employment at baseline, 93% had successfully maintained employment at review. Multiple regression analysis shows that families/carers have a higher likelihood of maintaining their employment at review when they work more hours per week and are in a permanent job. Families/carers who are very confident or somewhat confident in supporting their child's development are also more likely to keep a paid job.

1. Introduction

1.1 Purpose and scope

Families and carers play an important role in supporting NDIS participants. Improved outcomes for participants under the NDIS can be expected to facilitate this role, leading to improved outcomes for families and carers also.

The purpose of this report is to provide a picture of how the families and carers of NDIS participants are progressing, based on information provided by them in interviews conducted as part of the NDIS outcomes framework.

The results are intended to provide insight into how the Scheme is making a difference for families and carers, and point to any areas where improvements may be required.

A separate report on participant outcomes at 30 June 2018 has been prepared[14], and that report should be consulted for further information on the ways in which the NDIA is measuring outcomes more broadly, as well as general background to the development and implementation of the outcomes framework.

1.2 Questionnaires

The NDIS Outcomes Framework collects information on how participants and their families and carers are progressing in different areas (domains) of their lives. It is used to monitor individual and Scheme progress over time, to help uncover the types of supports that lead to good outcomes, and to benchmark against the experience of other populations (such as people without disability and other OECD countries).

Leveraging research conducted by the IAC, the outcomes framework takes a lifespan approach to the measurement of outcomes, recognising that different milestones are important for different age groups. Hence different versions of the questionnaires are used, for both participants and families/carers, depending on the age of the participant. The current versions and domains are summarised in Table 1.1.

---

[14] Subsequently referred to as “the participant outcomes report”.

Table 1.1 Outcomes framework versions and domains for participants and families/carers

Domain	**Participant version**				**Family version, for participant aged**		
	Children from 0 to before starting school	Children starting school to age 14	Young adults 15 to 24	Adults 25 and over	0 to 14	15 to 24	25 and over
1	Daily living	Daily living	Choice and control	Choice and control	Families know their rights and advocate effectively for their child with disability	Families know their rights and advocate effectively for their family member with disability	Families know their rights and advocate effectively for their family member with disability
2	Choice and control	Choice and control	Daily living	Daily living	Families feel supported	Families have the support they need to care	Families have the support they need to care
3	Relationships	Lifelong learning	Relationships	Relationship	Families are able to gain access to desired services, programs, and activities in their community	Families are able to gain access to desired services, programs, and activities in their community	Families are able to gain access to desired services, programs, and activities in their community
4	Social, community and civic participation	Relationships	Home	Home	Families enjoy health and wellbeing	Families enjoy health and wellbeing	Families enjoy health and wellbeing
5		Social, community and civic participation	Health and wellbeing	Health and wellbeing			
6			Lifelong learning	Lifelong learning			
7			Work	Work			
8			Social, community and civic participation	Social, community and civic participation			

Two versions of the questionnaires, a long form (LF) and a short form (SF), have been developed. The SF is completed by all participants and a family member or carer where possible, and contains questions useful for planning as well as key indicators to monitor and benchmark over time. The LF is completed for a subset of participants and their families and carers, and includes all of the SF questions plus some additional questions allowing more detailed investigation of participant and family/carer experience, and additional benchmarking.

The participant outcomes report contains further detail regarding the development and implementation of the LF and SF questionnaires.

1.3 Numbers of questionnaires

This report presents results obtained from two data sources:

- SF data collected on active transition participants with an initial plan approved during the period 1 July 2016 to 30 June 2018. These are the questionnaires included for the Q4 2017-18 COAG DRC report.
- LF data collected on the 2016 and 2017 cohorts during 2016 and 2017.

Baseline results incorporate questionnaires collected when a participant enters the Scheme. Longitudinal results are based on the subset of participants who responded at baseline and also responded to a second questionnaire approximately one year later. For the LF, this comprises participants from the 2016 cohort who responded in 2016 and 2017.

Table 1.2 provides a high-level summary of the numbers of family/carer and participant questionnaires contributing to the baseline and longitudinal analyses. Family/carer numbers as a percentage of participant numbers are also shown.

Table 1.2 Summary of numbers of questionnaires

Numbers contributing to:	SF/LF	Family/carer	Participant	Family/carer as % of participant
Baseline analysis	SF	77,746	141,638	55%
Baseline analysis	LF	2,724	3,444	79%
Longitudinal analysis	SF	17,119	40,154	43%
Longitudinal analysis	LF	712	792	90%

Full details of numbers of questionnaires collected for participants, and their families and carers, are included in Section 2.3 and Appendix A of the participant outcomes report.

2. Results overview and LF participation and representativeness analysis

2.1 Overview

The remaining sections of the report present results from analysing the family/carer outcomes framework data available as at 30 June 2018. Results are organised with a separate subsection for each questionnaire version, synthesising analyses from all data sources (SF and LF, baseline and longitudinal).

In view of the large amount of data, to keep the report manageable we have chosen to focus in depth on one area judged to be of particular importance for families and carers: employment. High level summaries of results for all questions are included in separate volumes of Appendices.

The remainder of the report is organised as follows:

- Sections 2.2 and 2.3 consider LF participation rates and representativeness by key participant characteristics.
- Sections 3 and 4 contain results for families and carers of participants aged 0 to 14.
- Sections 5 and 6 contain results for families and carers of participants aged 15 to 24.
- Sections 7 and 8 contain results for families and carers of participants aged 25 and over.
- Section 9 contains results for the in-depth analysis of family/carer employment outcomes.

More detailed results contained in the Appendices include:

- Appendix A: Families and carers of participants aged 0 to 14.
- Appendix B: Families and carers of participants aged 15 to 24.
- Appendix C: Families and carers of participants aged 25 and over.

Appendices A to C contain the following information:

1. Baseline indicators – aggregate.
2. Baseline indicators – by participant characteristics.
3. Longitudinal change in indicators – aggregate.
4. Longitudinal change in indicators – by participant characteristics.
5. Perceptions of whether the NDIS has helped – aggregate and by participant characteristics.

2.2 LF participation rates

Unlike the SF, LF participation is voluntary. Hence the degree of representativeness of the LF sample will be affected not only by phasing, but also by differential rates of participation amongst different segments of the participant population.

Full details of participation rates by participant characteristics are contained in Section 3.2 and Appendices B.1 and B.2 of the participant outcomes report. Some of the key findings included:

- Lower response rates were observed for participants with a psychosocial disability, both at baseline and re-interview.
- Lower response rates were observed for Indigenous participants, both at baseline and re-interview.
- Lower response rates were observed for CALD participants at baseline, but not at re-interview (re-interview rates were not significantly different between CALD and non-CALD participants).
- Response rates at both baseline and review tended to decrease with increasing intensity, as measured by participant streaming type.

These results relate to response rates for participant surveys, but will affect the distribution of family/carer responses by participant characteristics since only families and carers of participants who choose to respond will have the opportunity to complete a family/carer questionnaire.

For those participants who do choose to respond, the percentage supplying a family/carer questionnaire may also differ by participant characteristics. Whilst this has not been investigated in detail, age will be a key factor, since a family member or carer will almost always be available for child participants, however adult participants may live independently of families/carers and have limited contact with them.

2.3 LF representativeness

Since the LF participants form a subset of participants completing the SF (and should have their answers to the SF questions collected in CRM), it is useful to compare how similar the LF sample is to the complete SF population on demographic characteristics that might affect outcomes. As discussed in Section 2.2, representativeness is affected by phasing and by differential rates of participation amongst different segments of the participant population.

Section 3.3 and Appendices B.3 and B.4 of the participant outcomes report contain details of the representativeness analysis. Some key findings are summarised below.

Baseline

On the whole, the LF baseline was fairly representative of the SF baseline, except with respect to jurisdiction, where there are considerable differences largely driven by phasing.

For families/carers, New South Wales is considerably under-represented in the baseline for families/carers of participants under 25, but not for the 25 and over group. South Australia is over-represented across all age groups. For the young age groups this may be partly because parents of children are more likely to respond. Victoria is under-represented for the 25 and over age group, slightly under-represented for 15 to 24, but similar to benchmark for 0 to14.

Apart from jurisdiction, there are smaller differences for families and carers by:

- Primary disability: differences are fairly slight for families/carers of participants aged 0 to 14. For the 15 to 24 age group, the LF has a slightly lower proportion with autism (35% versus 40%) and a slightly higher proportion with intellectual disability/Down syndrome (44% versus 41%). The 25 and over group has a higher proportion with intellectual disability/Down syndrome (51% versus 37%), a similar proportion with autism, and lower proportions for other disabilities.
- CALD status: there is a slightly lower proportion of CALD participants in the LF baseline, particularly for the 25 and over group (4% versus 10%).

Longitudinal

For the longitudinal data, the main differences for families and carers also occurred with respect to jurisdiction: NSW is under-represented, and SA and ACT over-represented, for all age groups.

3. Families/carers of participants from birth to age 14: overview of results

3.1 Key findings

Box 3.1: Key findings for families/carers of participants from birth to age 14

- In the longitudinal analysis, some significant changes were observed, and the majority of these changes were positive:
  - The percentage of families/carers working in a paid job has increased from 45% at baseline to 48% at review, but is still considerably lower than for Australians without caring responsibilities (76%)[15].
  - The percentage of families/carers in a paid job who work 15 hours or more has increased from 79% to 81%. The percentage working less than 30 hours per week has decreased from 57% to 55%, but is still much higher than the 26% of Australians working on a part-time basis as at 30 June 2018[16].
  - Families and carers report increased levels of support to care for their child with disability. The percentage who feel that their child gets the support he/she needs increased from 27% to 53%, and the percentage who think that the services and supports have helped them to better care for their child with disability increased from 31% to 71%.
  - Families and carers report increasing ability and confidence in helping their children develop and learn. The percentage of families/carers who know what they can do to support their child's learning and development has increased from 42% at baseline to 50% at review. The percentage who know what specialist services are needed to support this development has also increased (from 40% to 48%). The percentage who say they get enough support to feel confident in parenting their child has increased from 45% to 49%.
  - The percentage feeling more confident about the future of their child with disability under the NDIS has improved (from 51% to 68%).
  - Some deterioration was observed in self-rated health, with the percentage rating their health as good, very good or excellent falling from 73% to 69%. For Australians aged 25 to 64, the corresponding percentage is 87%[17]. Families and carers were also more likely to perceive the situation of their child with disability as a barrier to working more (88% to 91%) and to engaging socially more (91% to 93%).
- Participant age had an impact on family/carer outcomes, with both baseline and longitudinal change tending to be better for families and carers of younger participants.

---

[15] 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

[16] Australian Bureau of Statistics. 2018. 6202.0 Labour force, Australia, Jun 2018. ABS defines part time work as less than 35 hours per week, so the percentage of the general population working less than 30 hours per week would likely be lower than 26%.

[17] ABS National Health Survey (NHS) 2014-15. Families/carers of 0 to 14 year olds are likely to be towards the younger end of the 25-64 age range.

Box 3.1: Key findings for families/carers of participants from birth to age 14 (continued)

- Baseline indicators and longitudinal change for some indicators tended to be worse for families and carers of participants from CALD backgrounds. This may be due to more difficulty in accessing information and lack of support networks.
- Families and carers with poorer self-rated health tended to have worse outcomes, both baseline and longitudinal.
- In one-way analyses, baseline outcomes for families and carers of participants with hearing impairment tended to be better, and those for families and carers of participants with a psychosocial disability tended to be worse, than average.
- Families and carers who have sufficient information and support, know what supports their child needs and can access them, and feel confident in parenting their child, tend to have more favourable outcomes at baseline, and tend to experience greater improvement longitudinally.
- Opinions on whether the NDIS has helped after one year in the Scheme vary by domain, from only 38% who think that the NDIS has helped with health and wellbeing (including employment and social participation) to 69% who think that the NDIS has improved their capacity to help their child develop and learn. Results tended to be more positive for families and carers of participants who are younger, have higher baseline plan utilisation, and are from less intensive streaming categories. Families and carers with sufficient knowledge, support, access to services, and confidence in parenting their child were also more likely to respond positively.

3.2 Results overview

3.2.1 Outcomes framework questionnaire domains

For families and carers of participants aged from birth to early teenage years, the outcomes framework seeks to measure the extent to which they:

- Know their rights and advocate effectively for their child with a disability
- Feel supported
- Can gain access to desired services, programs and activities in their community
- Are able to help their children develop and learn
- Enjoy health and wellbeing.

The LF for families and carers of participants aged 0 to 14 also includes four questions on whether families/carers understand their children's 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.

3.2.2 Baseline indicators – aggregate

Government benefits (Carer Payment and Carer Allowance)

The two main government benefits available to eligible carers are Carer Payment and Carer Allowance.

Carer Payment is an income replacement benefit for carers who are unable to work in substantial paid employment because they provide full-time daily care for someone with a severe long-term disability (or someone who is frail aged). Carer Payment is subject to income and assets tests and is paid at the same rate as other social security pensions.

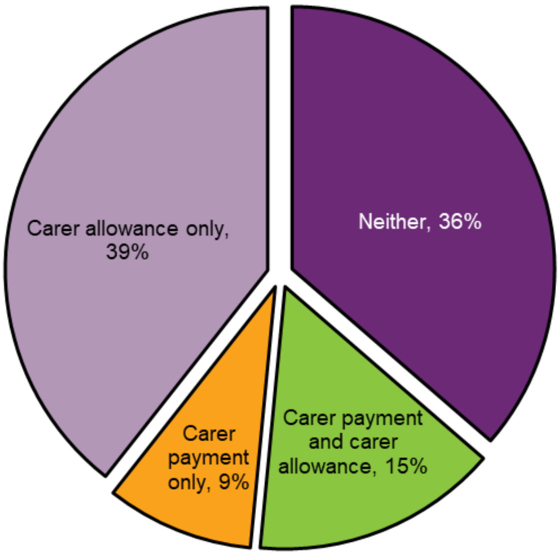
Carer Allowance is an income supplement available to carers who provide daily care in a private home for someone with a long-term disability (or someone who is frail aged). Before 20 September 2018 it was neither income nor assets tested, but from that date a $250,000 family income test threshold was introduced, affecting an estimated 1% of carers who were previously eligible.

As at 30 June 2018, 274,414 Australians were receiving Carer Payment and about 2.3 times as many, 622,423, were receiving Carer Allowance.

The outcomes framework questionnaires ask families and carers of NDIS participants whether they are currently receiving any government benefits (Carer Payment, Carer Allowance, or other benefits). At baseline, 25% of families and carers said they were receiving Carer Payment and 55% said they were receiving Carer Allowance. The ratio of Carer Allowance to Carer Payment (2.2) is similar to the 2.3 observed for the total populations in receipt of these benefits.

Figure 3.1 shows percentages of families/carers receiving Carer Payment and/or Carer Allowance.

Figure 3.1 Receipt of Carer Payment and Carer Allowance, families and carers of participants aged 0 to 14



The NDIA has also established a data linkage agreement with the Department of Human Services (DHS), with the long-term aim of measuring the wider economic impact of the NDIS. Investigation into the numbers of family members and carers of NDIS participants receiving Carer Payment and Carer Allowance from this source has commenced, and results will be reported once the analysis is completed.

Rights and advocacy

At baseline, 72% of families and carers were able to identify the needs of their child and family, 70% understood their rights and the rights of their child (LF question), and 78% were able to advocate for their child. However, 55% had some difficulty or a great deal of difficulty in accessing available services and supports to meet the needs of their child and family. 64% of families and carers identified at least one barrier to access or advocacy, the most common being limited access to information and resources (40%) and lack of support (33%).

Families feel supported

At baseline, most families and carers said they lacked sufficient support and social connections. 55% were unable to see friends and family as often as they like, 59% said they could not get as much practical help as they would like, and 72% said they could not get childcare as often as they need. However, 60% of families and carers said they have people they can talk to for emotional support as much as they like.

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

The LF survey reveals that 78% of families and carers have good (43%) or very good (35%) relationships with their services.

Families help their children develop and learn

At baseline, the SF reveals that 41% of families and carers know what they can do to support their child's learning and development, with a further 51% saying they have some degree of knowledge. A similar pattern is exhibited with regards to specialist services: 40%

of families and carers know what specialist services are needed and 52% have some degree of knowledge. 44% of family and carers agree that they get enough support to feel confident in parenting their child with disability, and a further 41% agree to some extent. 86% feel very confident (28%) or somewhat confident (58%) in supporting their child's development.

Families understand their children's strengths, abilities and special needs

The LF includes an additional domain concerned with how families and carers perceive the strengths and abilities of their child with disability, and how their child is progressing. 84% of families and carers can recognise their child's strengths and abilities and 78% can see how their child is progressing.

Health and wellbeing

At baseline, only 41% of families and carers say that they (and their partner) are able to work as much as they want. 45% say that they themselves would like to work more and 9% say that both they and their partner would like to work more. Of the families and carers who do not work as much as they like, 87% identified the situation of their child with disability as a barrier to working more, and 39% said that insufficient flexibility of jobs was a barrier.

Only 28% of families and carers say that they (and their partner) engage in social and community life as much as they like. Of those who do not, 90% identified the situation of their child with disability as a barrier to engaging more, and 46% said time constraints were a barrier.

From the SF, 72% of families/carers rate their health as good, very good or excellent, compared to 87% of Australians aged 25 to 64 overall.[18] Figure 3.2 compares the distribution of responses for families and carers to the population benchmark.

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 child in particular. Families and carers most commonly had "mixed" feelings about the future generally (47%), although more answered positively (45%) than negatively (8%)[19]. The 45% responding positively is much lower than the 77% for Australians aged 25 to 64 overall[20], and is lower than for participants aged 25 and over (52%). Response distributions for families/carers and the general population are compared in Figure 3.3.

---

[18] ABS National Health Survey (NHS) 2014-15. Families/carers of 0 to 14 year olds are likely to be towards the younger end of the 25-64 age range.

[19] Excluding "don't know" and missing.

[20] 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.

Figure 3.2 Self-rated health, families/carers of participants aged 0 to 14

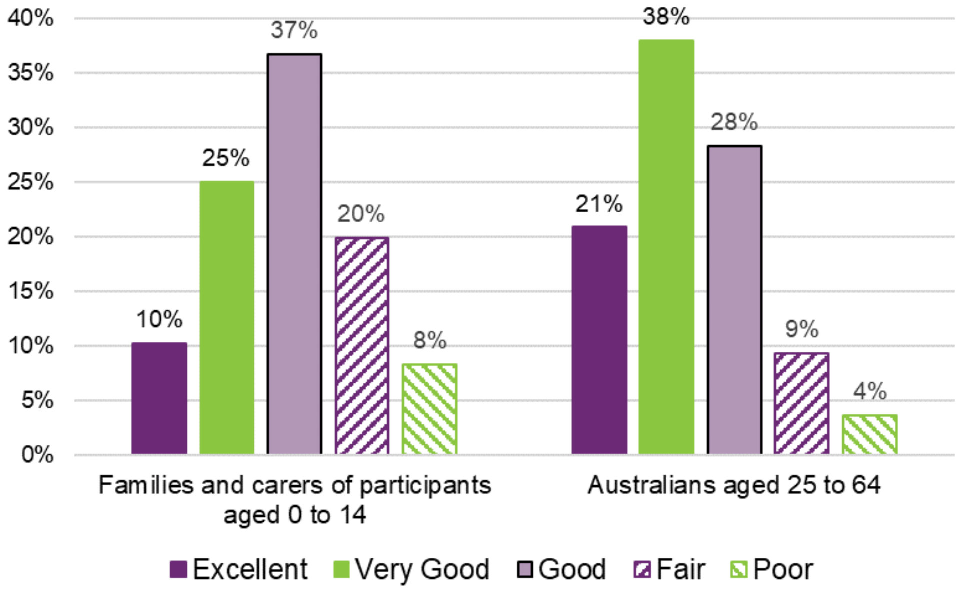
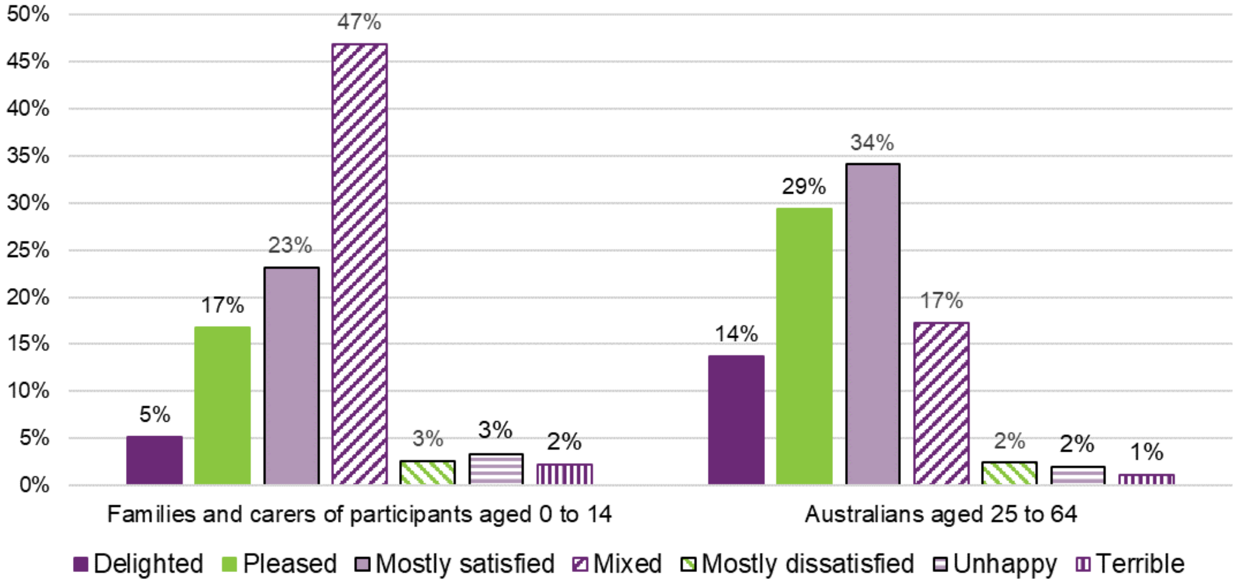


Figure 3.3 Outlook for the future, families/carers of participants aged 0 to 14



With regard to their child with disability, 73% agreed or strongly agreed that having a child with disability has made it more difficult to meet everyday costs of living. 51% agreed or strongly agreed that they feel more confident about the future of their child with disability under the NDIS, with 45% feeling neutral about this statement and only 4% expressing a negative opinion. The percentages agreeing or strongly agreeing that their child gets the support they need, or that the services and supports help them to better care for their child, are lower (34% for both statements). For these last two statements, the most common response was again “neutral” (40% and 42%, respectively).

3.2.3 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 age**
  In many cases, baseline outcomes for families and carers tend to deteriorate as their child gets older.[21] This is apparent from the one-way analyses and is generally confirmed by the multiple regression modelling. For example, the percentage of families and carers who say they are able to access available services and supports to meet the needs of their child and family decreases significantly with participant age: from 54-58% where the child is aged 6 or younger to 33% where the child is aged 14 (the overall percentage is 45%). Families and carers of older participants are also significantly more likely to cite limited access to information and resources as a barrier to access or advocacy: increasing from 27% where their child is aged 0 to 1, to 46% where they are aged 14 (the overall percentage is 37%). Support networks also appear to deteriorate as the child gets older, for example the percentage of families and carers with enough emotional support decreases from 75% where their child is 0-1 to 51% where their child is 14 (60% overall). Family and carer's self-rated health, and the ability to participate socially, also tend to deteriorate with participant age. Receipt of Carer Payment and Carer Allowance tends to increase with participant age.

- **Culturally and linguistically diverse backgrounds**
  Baseline outcomes for families and carers from CALD backgrounds tend to be worse in many cases than those from non-CALD backgrounds. Controlling for other factors, those from CALD backgrounds were less likely to feel able to advocate for their child (60% compared to 79% for non-CALD on a one-way basis) and more likely to cite limited access to information and resources as a barrier to access or advocacy (47% compared to 36%). They were also less likely to have people to ask for practical help (32% versus 42%) and emotional support (48% versus 60%), and less likely to be able to work as much as they want (35% versus 41%).

- **Indigenous participants**
  Respondents for Indigenous participants are less likely to be the parents of the participant (82% versus 95%). Families and carers of Indigenous participants are less likely to be working in a paid job (29% versus 48%) and consequently more likely to be receiving Carer Payment (34% versus 24%).

- **Participant level of function and plan cost**
  Baseline outcomes tended to be better for families and carers of participants with higher level of function, and for lower baseline plan costs. For example, the percentage experiencing difficulties in accessing available services and supports to meet the needs of their child and family was higher for children with lower level of function. Families and carers of participants with lower level of function also tended to be less likely to have adequate support networks, such as family and friends they see as often as they like, and people to ask for practical and emotional support. Receipt of government benefits increases with decreasing level of function/increasing plan cost.

---

[21] The age of the family member/carer is expected to be correlated with participant age, and may be driving some of the trends (for example, health).

- **Participant streaming intensity**
  Families and carers of participants requiring a higher level of support with planning (as measured by streaming intensity) were identified as having poorer baseline outcomes in several of the regression models. For example, families and carers of participants in the intensive and super intensive streams were more likely to experience difficulties in accessing available services and supports to meet the needs of their child and family, and were less likely to have people they can talk to for emotional support.

- **Family/carer self-rated health**
  In some instances, families and carers with better self-rated health tended to have better baseline outcomes. Controlling for other factors, this trend was observed for the percentage with family and friends they see as often as they like and the percentage with someone to ask for practical help as often as they need. Those with better health were also more likely to say they were able to work as much as they want.

- **Geography**
  Some mixed results were observed by State/Territory and by geographical remoteness. One-way analyses suggest that families and carers of participants from NT, and those in more remote locations, tended to experience worse outcomes in relation to advocacy and accessing services and supports. However, in multiple regression models, families and carers living in more remote locations were more likely to have people to ask for practical help as often as they needed, and more likely to be able to work as much as they want. On a one-way basis, receipt of government benefits was particularly high in Tasmania, where 44% received Carer Payment (compared to 25% overall) and 68% received Carer Allowance (compared to 55% overall).

- **Participant disability**
  The child's disability appears to have an impact on outcomes for families and carers. From the one-way analyses,[22] families and carers of participants with hearing impairment tend to have the best outcomes at baseline, and families and carers of participants with a psychosocial disability tend to have the worst.[23] Families and carers of participants with other sensory disabilities also tend to fare better than average, and families and carers of participants with intellectual disability tend to fare worse. For the health and wellbeing domain, families and carers of participants with autism tend to have poorer outcomes, being less likely to work and engage in social interactions as much as they want, and more likely to cite the situation of their child with disability as a barrier to working or engaging socially more. Families and carers of participants with Down syndrome were much more likely to be in receipt of Carer Allowance (72% compared to 55% overall), whereas families and carers of participants with another sensory/speech disability or developmental delay were less likely to be receiving both Carer Payment and Carer Allowance.

  In multiple regression analyses controlling for other factors, families and carers of participants with hearing impairment were significantly more likely to have people they

---

[22] The one-way analyses should be interpreted with caution since age distributions will differ between disabilities. For example, participants with a psychosocial disability in the 0-14 age range would be older than average.

[23] Based on a relatively low number of participants (188) with a psychosocial disability in this age group.

could ask for practical help as often as they need (64% versus 41% overall on a one-way basis).

- **Self-management**

  Families and carers who self-manage their child's plan have better baseline outcomes on some indicators. Those who fully self-manage or partly self-manage are more likely to be working in a paid job (60% and 52% respectively, compared with 46% overall). Participants who fully self-manage are more likely to be able to meet the needs of their child and family (80% versus 72% overall), to be able to advocate for their child (85% versus 78%), and to be able to access available services and supports (55% versus 45%). They also tend to respond more positively to indicators around helping their child develop and learn.

- **Family/carer knowledge and support**

  Favourable outcomes at baseline were generally observed for families and carers who:

  - Are able to identify their child's needs and to advocate for their child;
  - Know what services are required to support their child and are able to access those services;
  - Have adequate support networks; and
  - Feel confident in parenting and supporting their child.

  These factors come up as important predictors in multiple regression models. For example, overall 55% of families/carers experience difficulties in accessing available services and supports to meet the needs of their child and family, but this percentage is much higher for those who also had difficulties advocating for their child (90%), and those who cited limited access to information and resources as a barrier to access/advocacy. Conversely, those able to identify the needs of their child and family were much less likely to experience difficulties (14%).

  The importance of strong social networks is highlighted by Table 3.1, which shows how the percentage responding positively to three questions about levels of support depends strongly on whether the family/carer has friends and family they see as often as they like.

Table 3.1 Inter-relationships between questions about support networks

Question	Percentage responding "Yes" to question where answer to "I have friends and family that I see as often as I like" is:	
	Yes (45%)	No (55%)
I have people who I can ask for practical help as often as I need	74%	15%
I have people who I can ask for childcare as often as I need	53%	8%
I have people who I can talk to for emotional support as often as I need	85%	39%

3.2.4 Longitudinal indicators – aggregate

Longitudinal analysis describes how outcomes have changed for families and carers of participants during the time the participant has been in the Scheme. Included here are families and carers of 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 entry.[24]

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.[25]

Table 3.2 summarises changes for the 16 selected indicators.

Table 3.2 Selected longitudinal indicators for families/carers of participants aged 0 to 14

SF/LF	Domain description	Indicator	Baseline	Review	Change	Improvement/ Deterioration
SF	Work	% working in a paid job	45.2%	48.2%	3.0%	**Improvement**
SF	Work	Of those in a paid job, % working 15 hours or more	79.0%	81.3%	2.3%	**Improvement**
SF	Families feel supported	% who have people who they can talk to for emotional support as often as they need	60.3%	62.6%	2.2%	**Improvement**
LF	Families feel supported	% who have as much contact with other parents of children with disability as they would like	37.8%	56.7%	18.9%	**Improvement**
LF	Access to services	% who describe their relationship with services as Very Good or Good	77.5%	84.8%	7.2%	**Improvement**
SF	Families help their children develop and learn	% who know what specialist services are needed to promote their child's learning and development	40.1%	48.3%	8.2%	**Improvement**
SF	Families help their children develop and learn	% who know what their family can do to support their child's learning and development	42.2%	49.5%	7.3%	**Improvement**
SF	Families help their children develop and learn	% who get enough support to feel confident in parenting their child	45.0%	49.0%	4.0%	**Improvement**
LF	Health and wellbeing	% who feel more confident about the future of their child with disability under the NDIS	50.5%	67.5%	17.1%	**Improvement**
LF	Health and wellbeing	% who feel that their child gets the support he/she needs	26.6%	52.7%	26.1%	**Improvement**
LF	Health and wellbeing	% who feel that the services and supports have helped them to better care for their child with disability	31.0%	71.0%	40.0%	**Improvement**
SF	Government benefits	% receiving Carer Allowance	56.2%	63.9%	7.7%	**Context dependent**

---

[24] 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.

[25] Since there is much more data available for the SF, 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, selection is based on statistical significance.

SF/LF	Domain description	Indicator	Baseline	Review	Change	Improvement/ Deterioration
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	88.2%	90.8%	2.6%	**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	39.5%	45.4%	5.9%	**Deterioration**
SF	Health	% who rate their health as good, very good or excellent	73.4%	68.9%	-4.5%	**Deterioration**
SF	Social and community participation	Of those unable to engage as much as they want, % who say the situation of their child/family member with disability is a barrier to engaging more	90.5%	92.9%	2.4%	**Deterioration**

Some large changes, the majority of them positive, appear in the above table. Significant changes have been observed for:

- Work: the percentage working in a paid job has increased from 45% at baseline to 48% at review, and the percentage working 15 hours or more has also increased. However, parents/carers who are not able to work as much as they want are more likely to perceive the situation of their child as a barrier to working more, and are also more likely to cite insufficient flexibility of jobs as a barrier.
- Families/carers feeling supported: families and carers report increased levels of emotional support and interactions with other families of children with disabilities. The percentages of parents/carers who feel that their child gets the support he/she needs, and that the services and supports have helped them to better care for their child with disability, have increased considerably.
- Support for families/carers in helping their child to develop and learn: families and carers report improved knowledge of what they can do, and the specialist services that are needed, to support their child’s learning and development. Family and carers are also more likely to get enough support to feel confident in parenting their child.
- Outlook for their child’s future: the percentage feeling more confident about the future of their child with disability under the NDIS has improved from 51% to 68%.
- Health: the percentage rating their health as good, very good or excellent has decreased.
- Social and community participation: as for work, parents/carers who are not able to engage in social interactions and community life as much as they want are more likely to perceive the situation of their child as a barrier to engaging more.

3.2.5 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 these two analyses can produce different results, particularly where there is a large difference in the indicator at baseline between subgroups.

Some key features of the analyses by domain, and for selected indicators, are summarised below.

Government benefits - Carer Allowance

An 8 percentage point increase in the percentage receiving Carer Allowance has been observed over the year. From the one-way analyses, increases were greater for families and carers of younger participants (13 percentage points for participants aged two or younger decreasing to 6 percentage points for participants aged 14).

Of those who did not receive Carer Allowance at baseline, 24% received it at review. Based on the logistic regression model for receiving the allowance at review, for this cohort:

- Respondents in VIC (17%) were less likely to receive the allowance and those in SA (29%) were more likely to receive it.
- Families and carers of participants with autism (31%) and Down syndrome (41%) were more likely to receive the allowance.

In contrast to the one-way analyses, participant age was not a significant predictor in the model for receiving the allowance at review amongst those who did not receive it at baseline. This difference in results may reflect the fact that families/carers of older participants were more likely to be receiving Carer Allowance at baseline.

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

Whilst aggregate changes in this domain tended to be relatively small, the one-way analyses show a consistent trend towards greater improvement at younger participant ages.

Domain 2: Families feel supported

Families/carers reported improved levels of emotional support, and having as much contact as they want with other parents of children with disability. Improvements appear slightly higher in regional and remote areas compared to major cities.

Domain 3: Families are able to gain access to desired services, programs, and activities in their community

Indicators in this domain relate to satisfaction with the development and implementation of the child’s plan. These questions are similar in nature to the questions about whether the NDIS has helped, and are discussed in Section 4.

Domain 4: Families help their children develop and learn

There were significant improvements of more than two percentage points overall across a number of indicators for this domain. The one-way analyses again suggest that results are more positive for families/carers of younger participants.

I know what specialist services are needed to promote my child's learning and development (overall improvement of .082)

Of those who said they did not know what services were needed at baseline, 22% said they did know at review. Based on the logistic regression model for improvement:

- Improvement was less likely for families/carers of CALD participants (14%).
- Improvement was considerably higher for respondents who knew what their family could do to support their child's learning and development (56%).
- Improvement was positively correlated with family members/carers level of confidence in supporting their child's development (increasing from 6% for those who are not at all confident to 43% for those who are very confident).

I know what my family can do to support my child's learning and development (overall improvement of .073)

Of those who said they did not know what their family could do at baseline, 21% said they did know at review. Based on the logistic regression model for improvement:

- Families/carers who were able to identify the needs of their child and family were more likely to improve (29%), as were those able to advocate for their child (27%).
- Respondents who had friends and family they saw as often as they liked were more likely to improve (28% compared to 17% for those who did not have friends and family they saw as often as they liked).
- Respondents who knew what specialist services were needed to promote their child's learning and development were more likely to improve (57%).

I get enough support to feel confident in parenting my child (overall improvement of .040)

Of those who said they did not get enough support at baseline, 18% said they did get enough support at review. Based on the logistic regression model for improvement:

- Families/carers who had people they could ask for practical help as often as they needed were more likely to improve (32%).
- Respondents who knew what specialist services were needed to promote their child's learning and development were more likely to improve (35%).
- Families and carers who had better levels of self-rated health were more likely to improve.

4. Families/carers of participants from birth to age 14: Has the NDIS helped?

4.1 Aggregate results

For participants entering the Scheme in the first year of transition, and who have been in the Scheme for at least one year as at 30 June 2018, Figure 4.1 shows results after one year in the Scheme for:

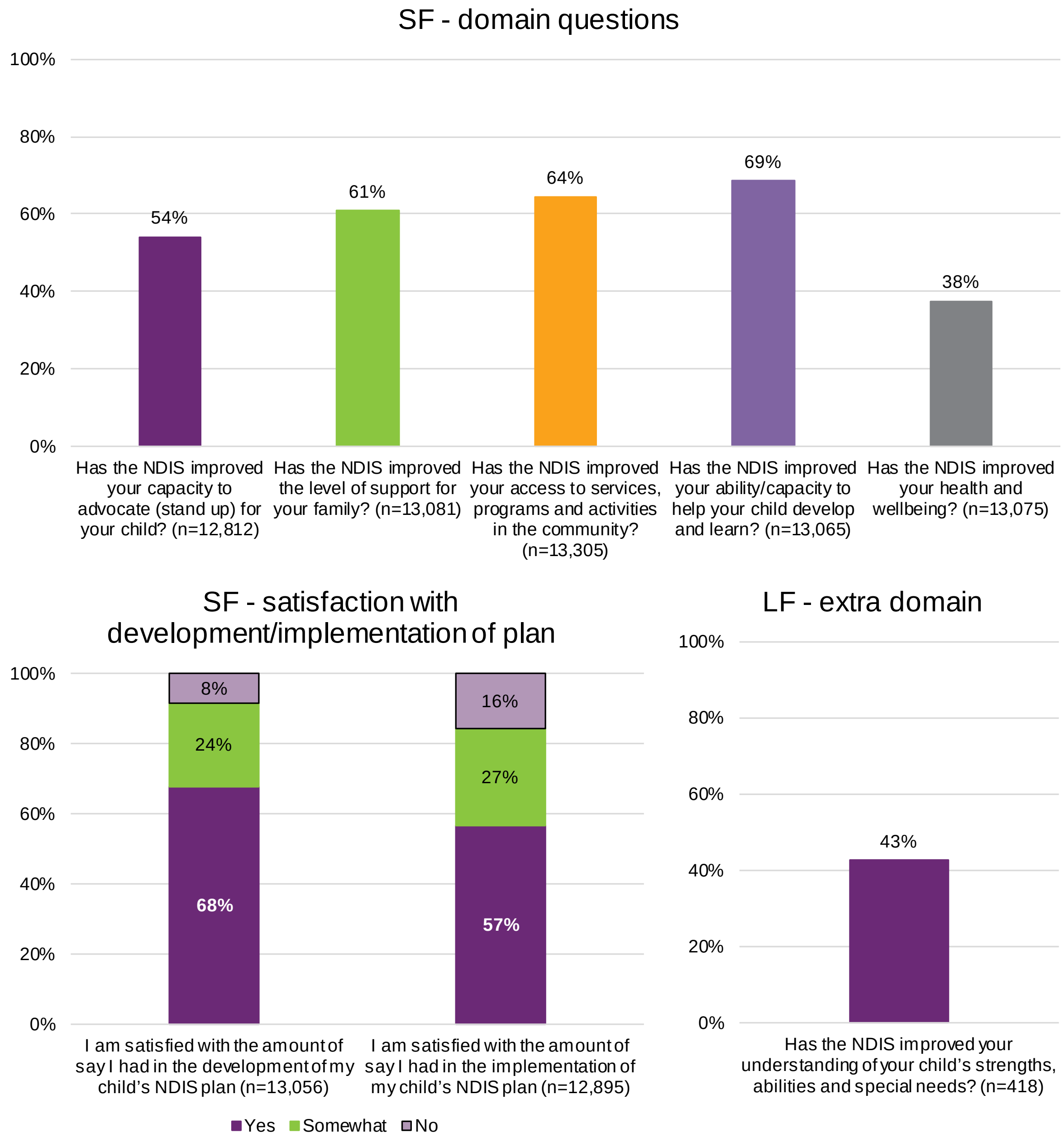
- The percentage of families/carers who think that the NDIS has helped with outcomes related to each of the five SF domains (top plot).
- The percentage of families/carers who think that the NDIS has improved their understanding of their children’s strengths, abilities and special needs (bottom right plot). This is an extra domain included in the LF.
- The distribution of responses to the questions asking whether families/carers are satisfied with the amount of say they had in (1) the development and (2) the implementation of their child’s plan. These questions are included in this Section because they also measure satisfaction with the NDIS, and require the accumulation of sufficient Scheme experience in order to provide meaningful insights.

Figure 4.1 shows that most families/carers think that the NDIS has helped with the first four SF domains. The most positive results are: 69% agree that the NDIS has improved their capacity to help their child develop and learn; and 64% agree that the NDIS has improved their access to services, programs and activities in the community. However, only 38% felt that the NDIS had improved their health and wellbeing, noting that this is partly the responsibility of the Health system (although this domain also includes questions on employment and social participation).

For the extra LF domain, only 43% thought that the NDIS had improved their understanding of their children’s strengths, abilities and special needs.

Families and carers tended to be more satisfied with the development of their child’s plan (92% satisfied or somewhat satisfied) than with its implementation (84% satisfied or somewhat satisfied).

Figure 4.1 Percentage of families/carers who think that the NDIS has helped with outcomes related to each domain



4.2 Results by key characteristics

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

- Participant age:[26] Families and carers of younger participants tended to be more likely to think that the NDIS had helped. A decreasing trend with increasing

---

[26] Note that these are cross-sectional, not longitudinal, results.

participant age is apparent in the percentage of positive responses from the one-way analyses, and this is generally confirmed by multiple regression results. For example:

  - Satisfaction with the amount of say in the implementation of their child's plan is significantly higher for families/carers of younger participants (73% for families/carers of participants aged 3-4 decreasing to 46% for families/carers of participants aged 13 or older);
  - The percentage agreeing that the NDIS had improved their capacity to help their child develop and learn decreased significantly with participant age (from 87% for families/carers of participants aged 2 or younger to 54% for families/carers of participants aged 13 or older); and
  - The percentage agreeing that the NDIS had improved their health and wellbeing was significantly higher for families/carers of participants aged 0-5 (50%) than for families/carers of older participants (35%).

- Participant disability: In one-way analyses, families/carers of participants with developmental delay were consistently the most positive across all domains, and families/carers of participants with visual impairment were consistently the least positive. Regression modelling confirms this finding for domain 2 (families feel supported). Disability was not a significant predictor for domain 3 (access to services, programs and activities in the community), but was for the other domains, although no very clear patterns across domains emerged.
- Baseline plan utilisation: As noted in the participant outcomes report, the level of satisfaction tends to increase with baseline plan utilisation. The one-way analyses show a lower satisfaction rate for low utilisation (below 20%). In multiple regression analyses, an increasing trend with baseline plan utilisation was observed for the percentage saying that the NDIS had helped with:
  - The level of support for their family
  - Their access to services, programs and activities in their community
  - Their ability/capacity to help their child develop and learn.

  In addition, higher baseline plan utilisation was associated with greater satisfaction with the implementation of their child's plan.
- Streaming type: Families/carers of participants who required planning assistance at the Intensive and Super Intensive levels were less likely to agree that the NDIS had improved their ability/capacity to develop and learn (55% and 50%, respectively, compared to 69% overall). They were also less likely to be satisfied with the amount of say they had in the implementation of their child's plan (45% and 40%, respectively, compared to 57% overall).
- Access to information and supports: In multiple regression models, satisfaction rates were significantly associated with a number of outcomes framework questions aimed at assessing whether families and carers have sufficient information and support, whether they can identify their child's needs and feel confident in parenting their child, and whether they are able to access supports and services. These results are summarised in Table 4.1, which highlights the importance of access to supports and information for families and carers.

Table 4.1 "Has the NDIS helped?" for domains 3-5 and satisfaction with development and implementation of child's plan: impact of other outcomes framework questions

Question	D3 Access to services, programs and activities (64%)	D4 Helping children develop and learn (69%)	D5 Health and wellbeing (38%)	Development of plan (68%)	Implementation of plan (57%)
D1.1 I am able to identify the needs of my child and family				Lower for those who had a great deal of difficulty (45%)	
D1.2 I am able to access available services and supports to meet the needs of my child and family		Higher for those who said "Yes" (79%)	Higher for those who said "Yes" (46%)		
D1.4 What barrier to access and/or advocacy have you experienced?		Lower for those who said "Lack of knowledge or understanding about my rights/ the rights of my child" (62%)			
D4.1 I know what specialist services are needed to promote my child's learning and development	Lower for those who said "No" (38%)	Higher for those who said "Yes" (78%)			Lower for those who said "No" (34%)
D4.4 How confident do you feel in supporting your child's development?				Higher for those who felt more confident (increasing from 41% for those not at all confident to 77% for those very confident)	
D5.1 In general, my health is…			Higher for those who rated their health as excellent or very good (45%)		

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 responsibilities[27]. 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[28]. 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.

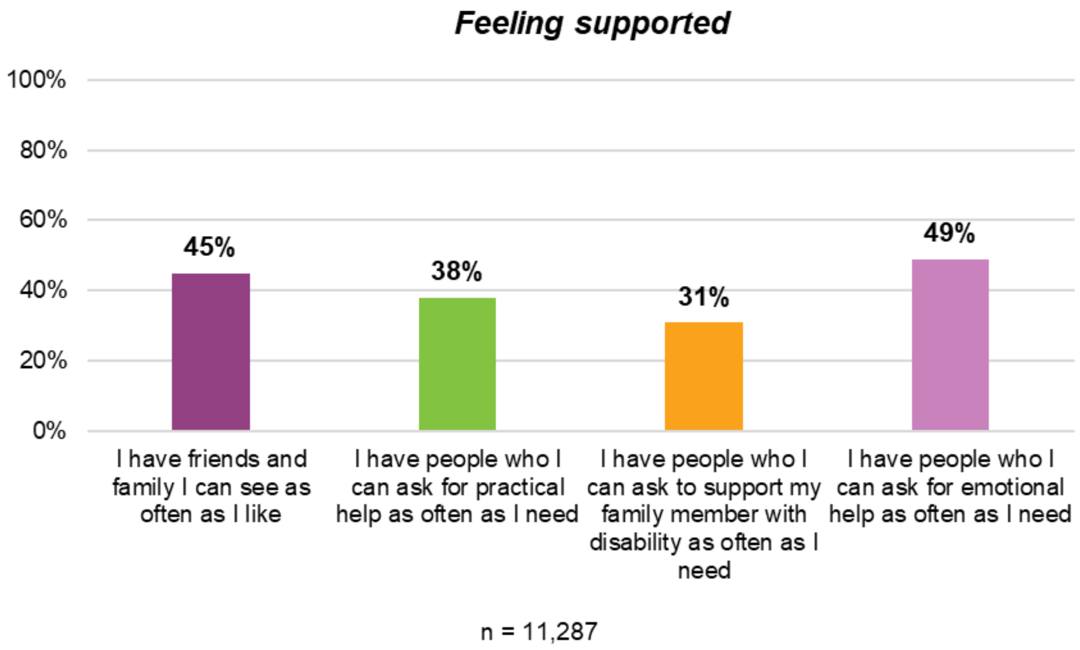
Families feel supported

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.

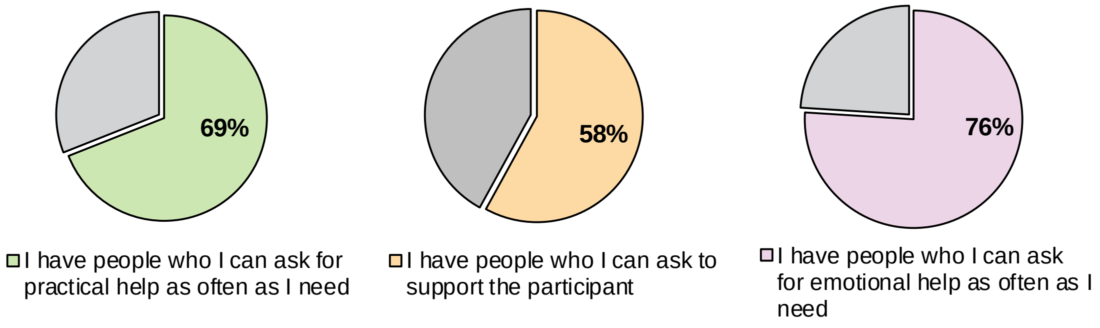
Access to Services

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

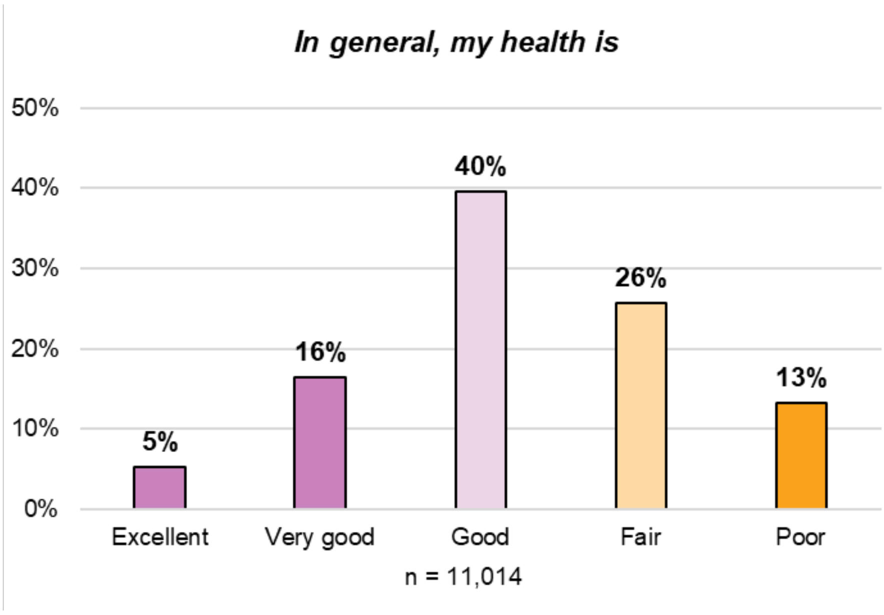
The LF includes an additional domain concerned with how families and carers perceive the strengths and abilities of their family member with disability, and how their family member is progressing. 86% of families and carers can recognise the strengths and abilities of the participant and 76% can see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

Health and wellbeing

At baseline, 50% of families and carers say that they (and their partner) are able to work as much as they want. Of the families and carers who do not work as much as they like, 89% identified the situation of their family member with disability as a barrier to working more, and 26% 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 overall[29]. 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 overall[31], 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

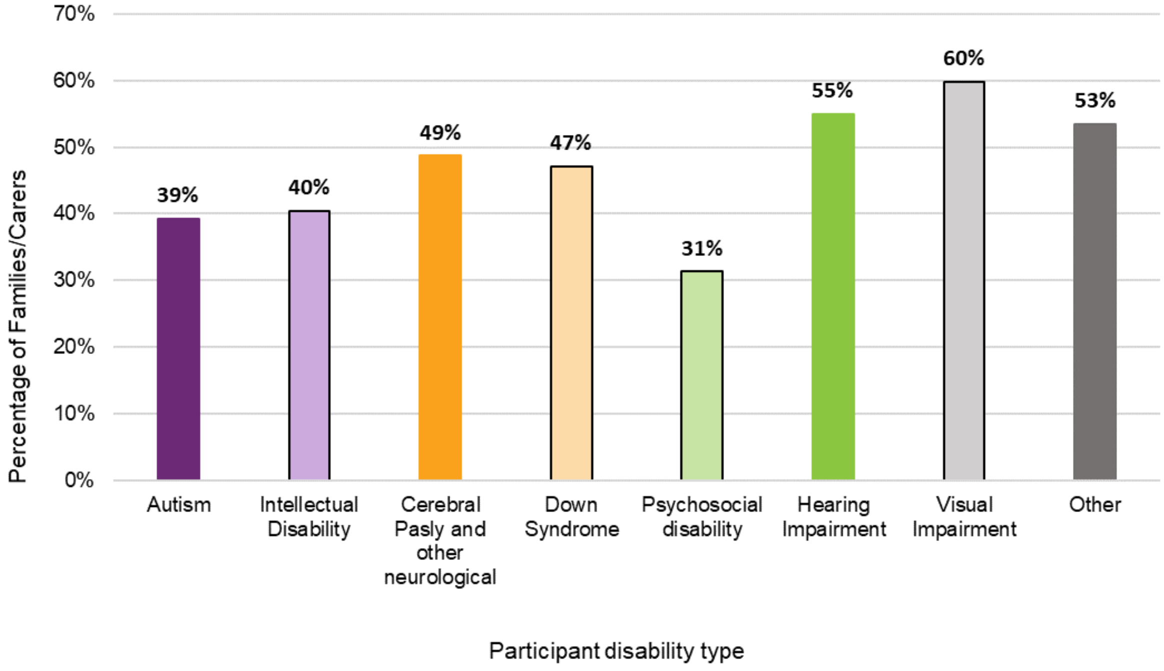


Figure 5.3 shows that only 31% of families and carers of participants with a psychosocial disability know how to enable their family member to become as independent as possible (compared to 42% overall). There is a general trend towards poorer baseline outcomes for these respondents, but particularly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

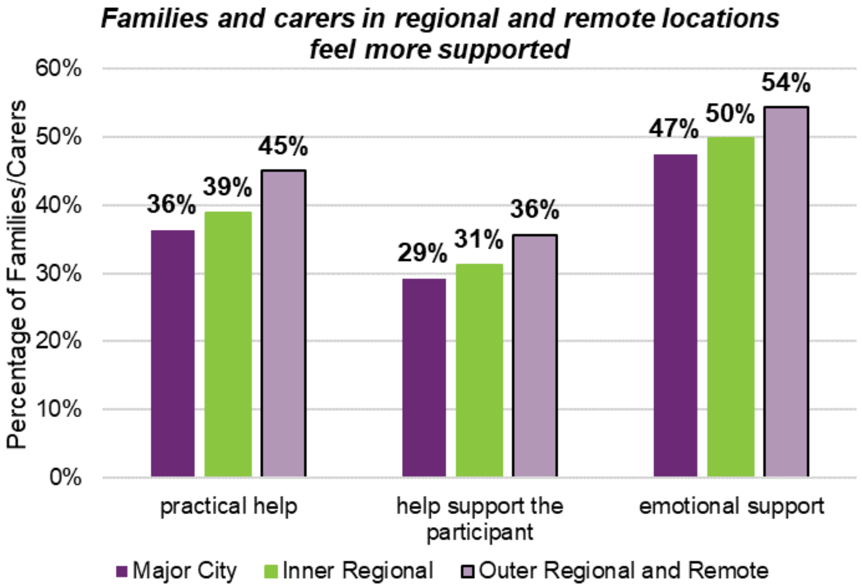
(39% and 32% compared with 18% overall). By contrast, only 10% of family/carers of participants with psychosocial disability are satisfied with the services they received.

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

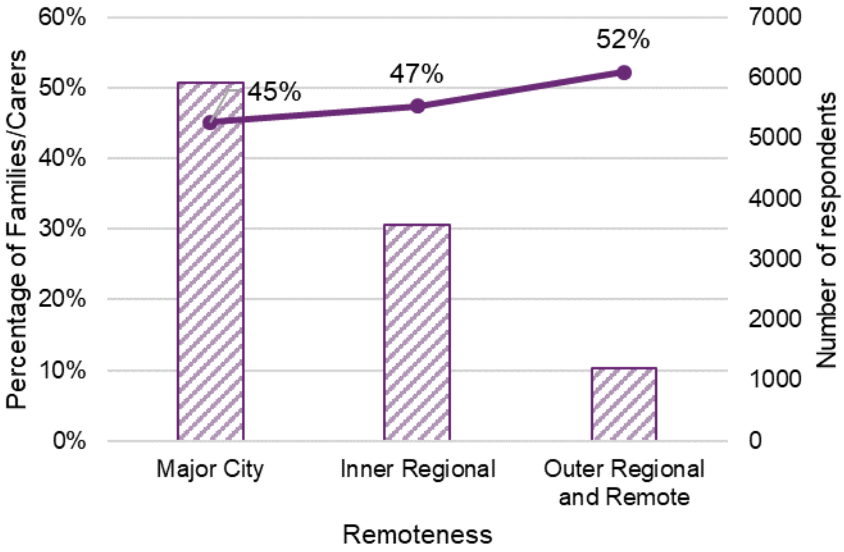
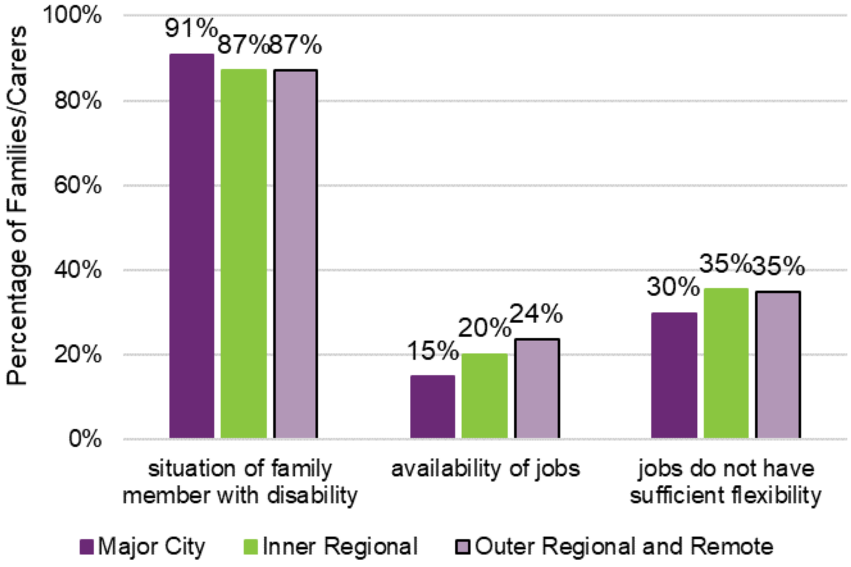


Figure 5.7 For those who are unable to work as much as they want, percentage of families/carers with different barriers to working more by region



- **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

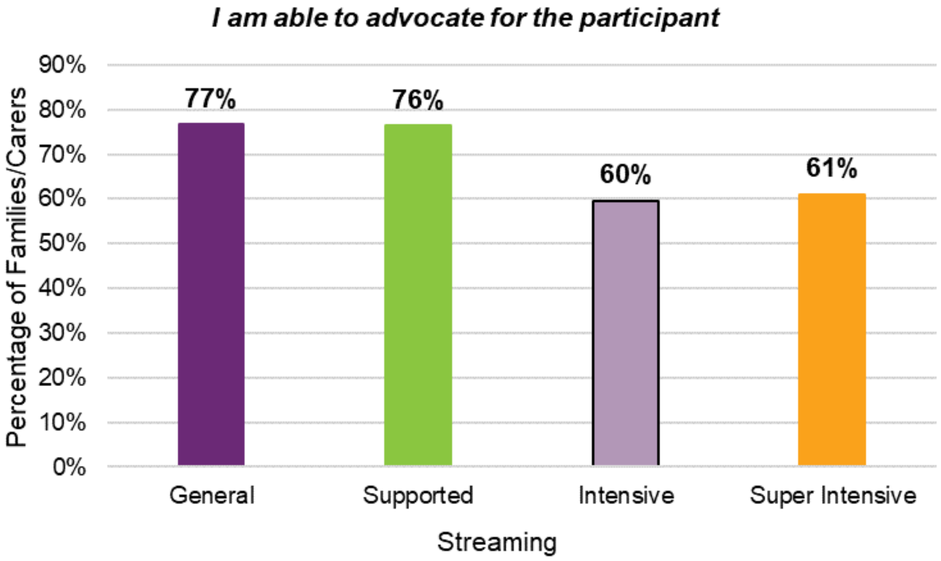
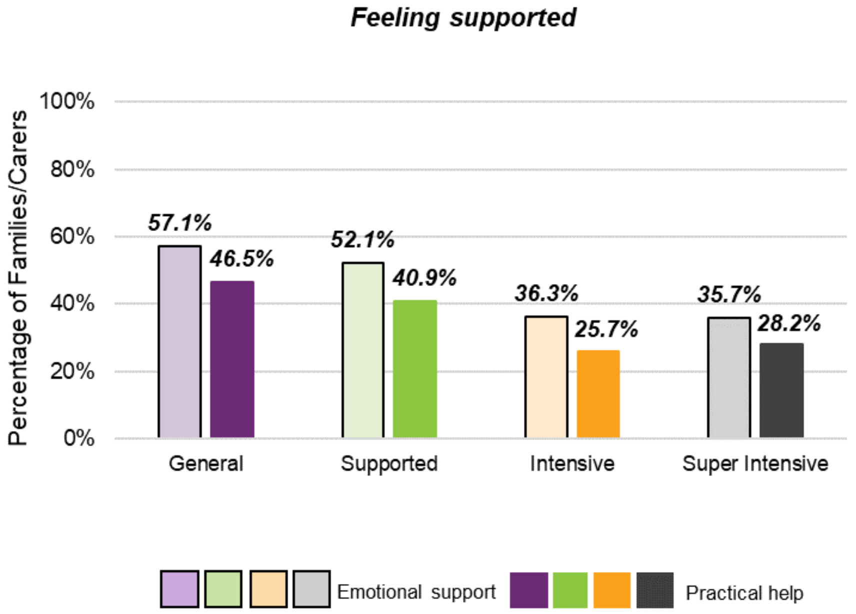


Figure 5.9: Percentage of families/carers with sufficient levels of emotional support and practical help by streaming type



- **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 entry[32].

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 HILDA[35] 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

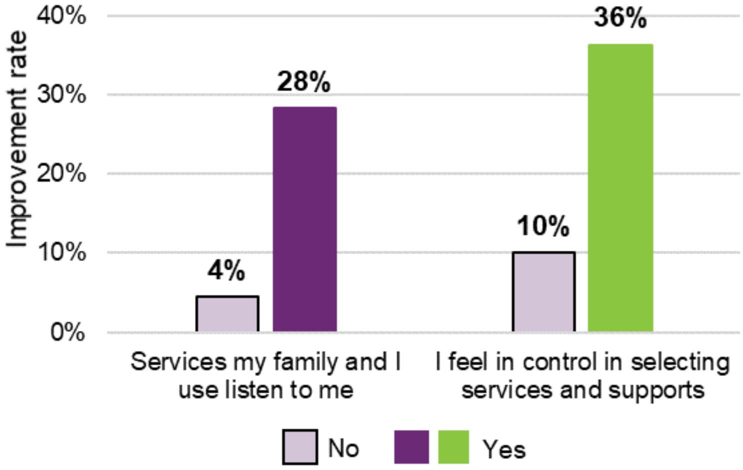
Significant improvements were observed for most indicators for this domain. Notably, overall satisfaction with services has increased by 13%, from 20% at baseline to 33% at review.

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 familes/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.

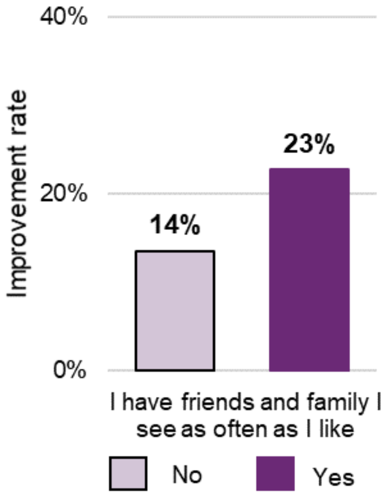
I enable/support my family member with disability to make more decisions in their life (overall improvement of 0.025)

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%).

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

6.1 Aggregate results

For participants entering the Scheme in the first year of transition, and who have been in the Scheme for at least one year as at 30 June 2018, Figure 6.1 shows results after one year in the Scheme for:

- The percentage of families/carers who think that the NDIS has helped with outcomes related to each of the five SF domains.
- The percentage of families/carers who think that the NDIS has improved their understanding of their children's strengths, abilities and special needs. This is an extra domain included in the LF.

Figure 6.1 Percentage who think that the NDIS has helped with outcomes related to each domain

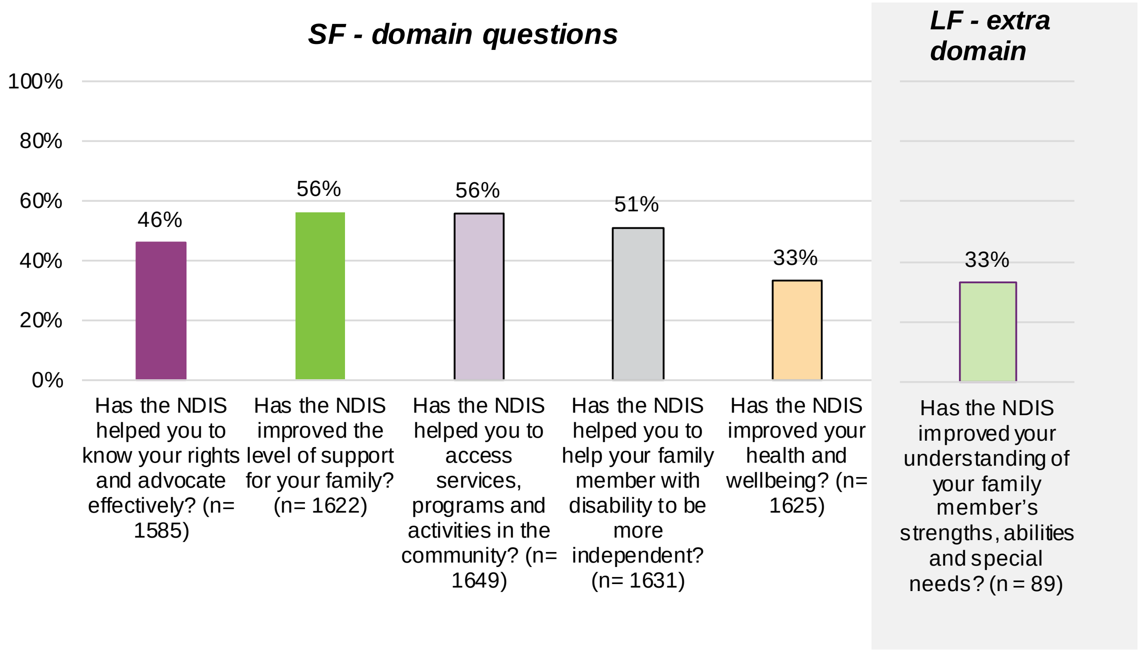


Figure 6.1 shows the percentages responding positively to the "Has the NDIS helped?" questions. The opinions are slightly less positive compared to families and carers of participants from birth to age 14. Nevertheless, the majority agrees that the NDIS improved the level of support for their family (55%), as well as helped access services, programs and activities in the community (55%). Slightly smaller percentages of respondents think the NDIS helped them to help their family member with disability to be more independent (51%), and to know their rights and advocate effectively (46%). One third of respondents agree that the NDIS improved their health and wellbeing.

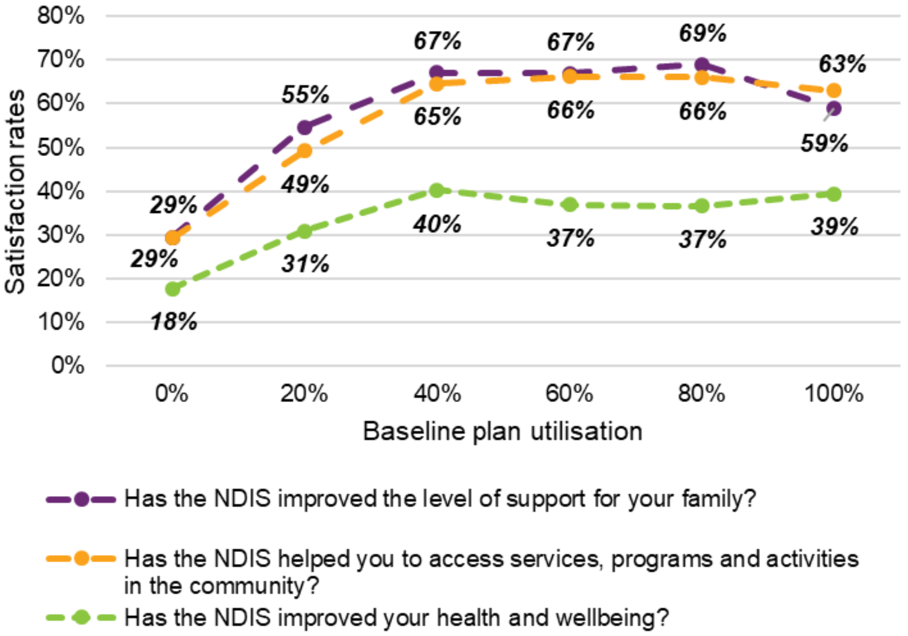
For the extra LF domain, 33% agree that the NDIS improved their understanding of their family member's strengths, abilities and special needs (although the number of respondents is small – only 89 persons).

6.2 Results by participant characteristics

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). Figure 6.2 shows the relationship between the satisfaction rates and baseline plan utilisation for some of the domains.

Figure 6.2 Percentage of families/carers who think the NDIS has helped by baseline plan utilisation rate



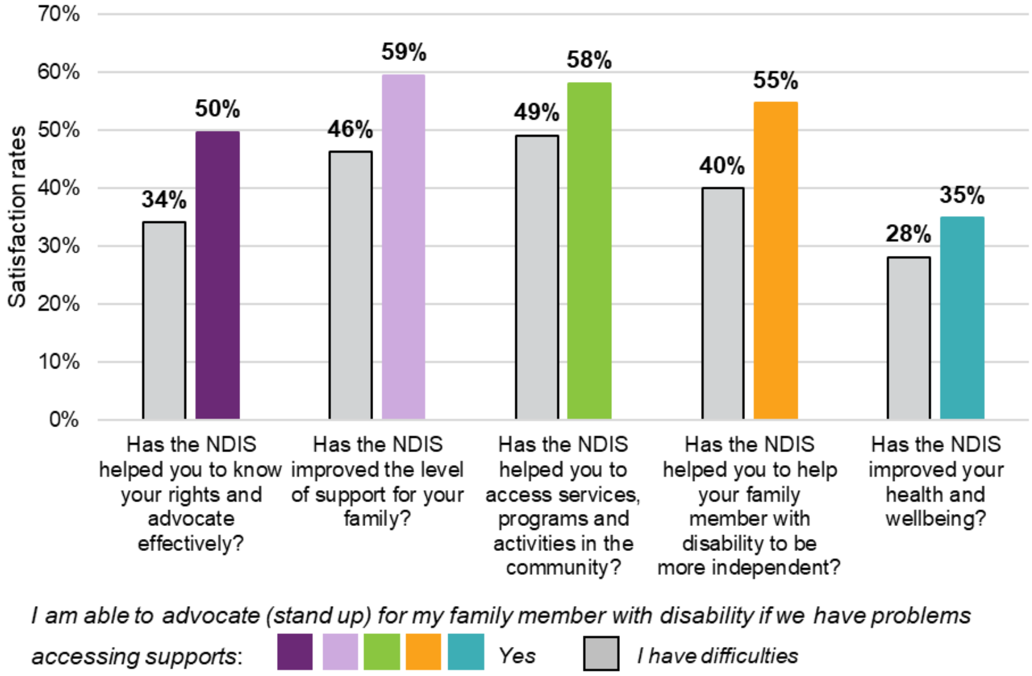
- Review plan cost: The percentages who think the NDIS helped increase with increasing plan cost. The relationship is particularly strong for the domain 2 question “Has the NDIS improved the level of support for your family?”, with the percentage of respondents answering “Yes” increasing from 47% for 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 a 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%). Figure 6.3 shows higher positive response rates for the respondents who are able to advocate for their family member in case of problems accessing supports.

Figure 6.3 Percentage of families/carers who think the NDIS has helped by the respondent's ability to advocate in case of problems accessing supports



7. Families/carers of participants aged 25 and over: overview of results

7.1 Key findings

Box 7.1: Key findings for participants aged 25 and over[36]

- 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.

---

[36] Since the numbers of families/carers contributing to the analysis is considerably lower than for the younger participant age groups, less in-depth analysis was done for this group.

7.2 Results overview – participants aged 25 and over

7.2.1 Outcomes framework questionnaire domains

For families and carers of participants aged 25 and over, 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
- Have succession plans
- Enjoy health and wellbeing.

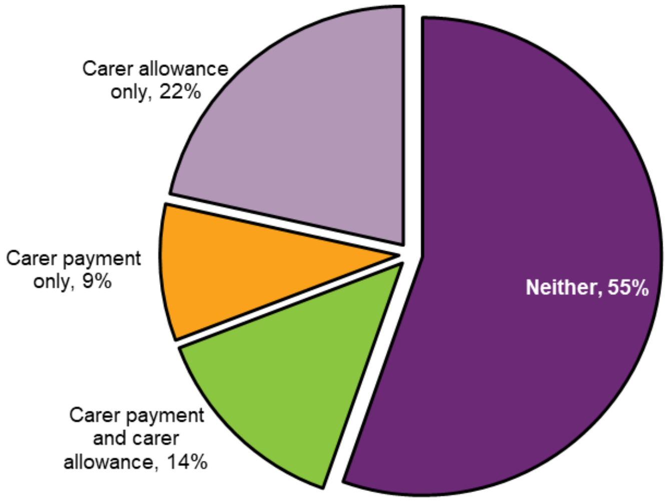
The LF survey for families and carers of participants aged 25 and over includes extra questions across each domain, with several additional questions in the health and wellbeing domain.

7.2.2 Baseline indicators – aggregate

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 (Figure 7.1).

Figure 7.1 Percentage of families/carers of participants aged 25 and over receiving government carer benefits at baseline



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

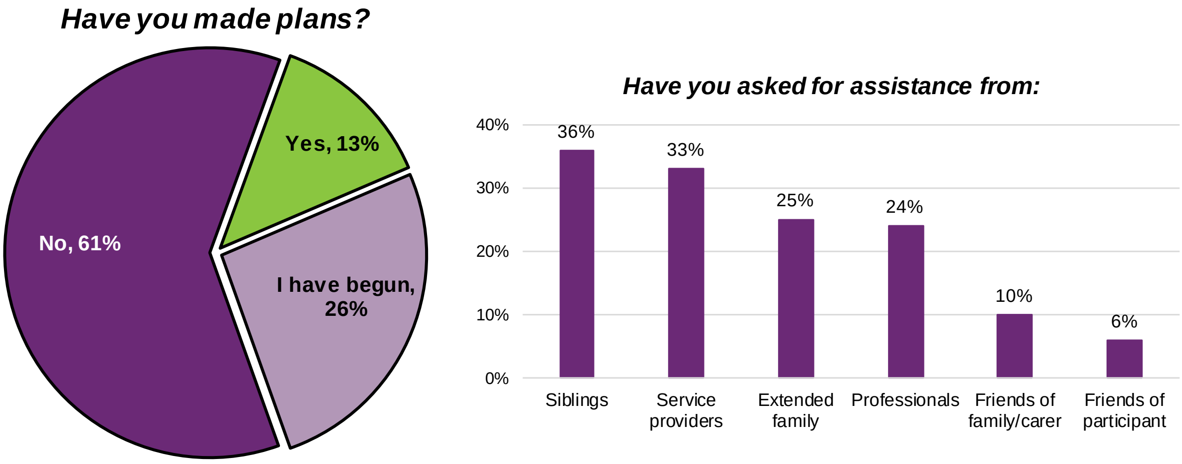
At baseline, 21% of families/carers said that the services the participant and the family receives meets their needs. Furthermore, the majority of families/carers reported that they have difficulty feeling in control when selecting services and supports that meet the needs of the family and participant, 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 (36%), service providers (33%), extended family (25%) and professionals (24%). Families and carers were the least likely to ask for assistance from their friends (10%) or friends of their family members (6%).

Figure 7.2 Succession planning for families/carers of participants aged 25 and over



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 (87%), insufficient flexibility of jobs (21%), 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.

7.2.3 Baseline indicators – key characteristics

Baseline indicators have been analysed by key characteristics of the participant and the family member/carer using one-way analyses[37]. Key findings include:

- **Participant level of function and plan cost**
  Families and carers of participants with higher levels of function or lower annualised baseline plan costs tended to have better outcomes at baseline. For example, 70% of families/carers were able to work as much as they wanted to if the participant had a high level of function, compared to 49% if the participant had a low level of function. Furthermore, the difference in positive response rates for families/carers of participants with high level of function versus low level of function was at least 10% for all questions related to whether the family feels supported. Receipt of government benefits also increases with decreasing level of function/increasing plan cost.

- **Culturally and linguistically diverse background**
  Baseline outcomes for the families and carers of participants from a CALD background were worse across all domains compared to the families/carers of participants from a non-CALD background. In particular, families/carers of CALD participants were less likely to be able to advocate for their family member (52% vs 72% for non-CALD participants), felt less in control selecting services and supports (31% vs 43%), and were less able to work as much as they wanted to (47% vs 60%). These results are illustrated in Figure 7.3.

---

[37] Multiple logistic regression modelling was not used for the families and carers of participants 25 and over due to the small sample size of this cohort

- **Indigenous status**
  Families and carers of Indigenous participants generally had poorer baseline outcomes compared to families/carers of non-Indigenous participants. As shown in Figure 7.4, the largest differences were for the percentage who feel that the services they use for the family member with a disability listen to them (57% for Indigenous vs 68% for non-Indigenous), those who rate their health as excellent, very good or good (50% vs 59%), and those who are able to advocate for their family member (62% vs 70%).

Figure 7.3 Baseline outcomes for families/carers of CALD and non-CALD participants aged 25 and over

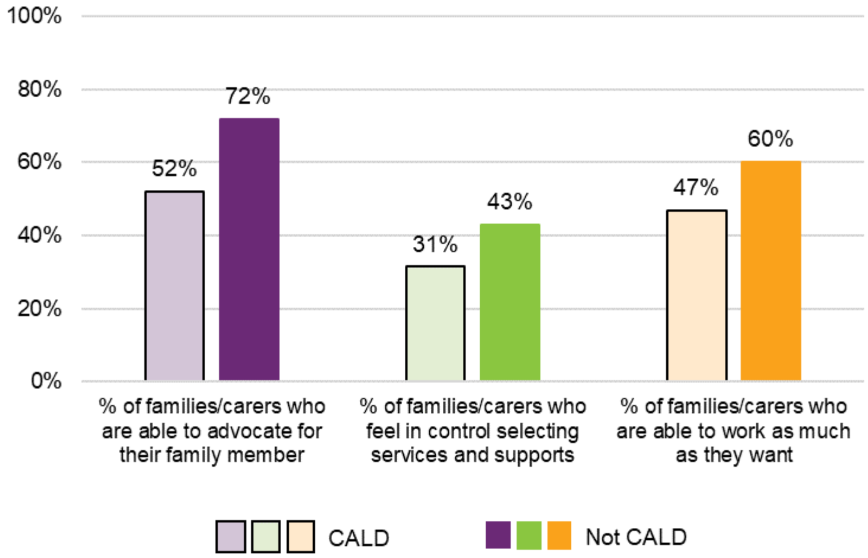
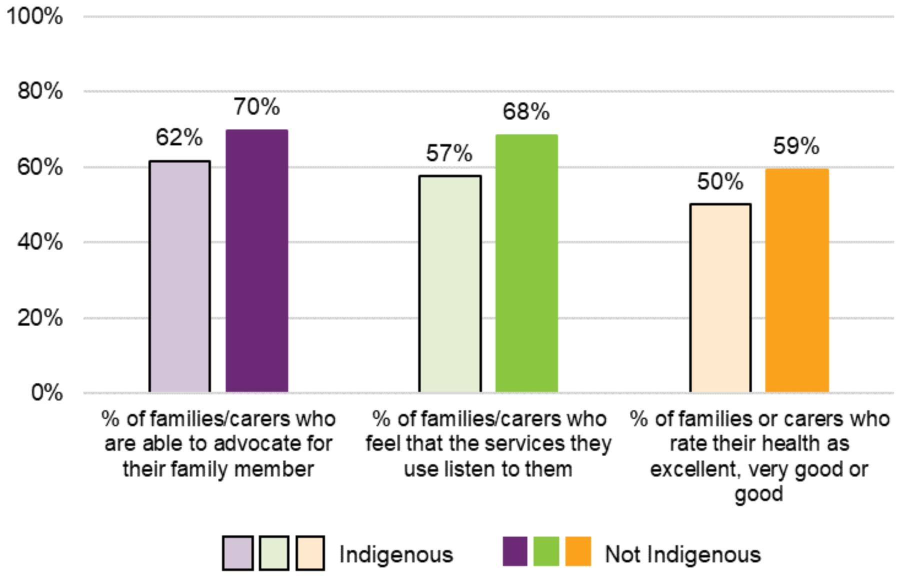


Figure 7.4 Baseline outcomes for families/carers of Indigenous and non-Indigenous participants aged 25 and over



- **Disability type**
  Families and carers of participants with hearing impairments were the least likely to say that the situation of their family member with a disability was a barrier to working more, and the most likely to rate their health as good, very good or excellent compared to families/carers of participants of all other disability types. They also generally had the highest positive response rate for questions related to whether they feel supported, and had the lowest rate of receipt of government benefits (8% for Carer Payment, and 13% for Carer Allowance).

7.2.4 Longitudinal indicators – aggregate

Longitudinal analysis describes how outcomes have changed for families and carers of participants during the time the participant has been in the Scheme. Included here are families and carers of 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 entry[38].

As expected during this relatively short period, many indicators have not changed a great deal. For this summary, indicators have been selected based on whether the change is statistically significant at the 5% level.

The table below summarises changes for the 7 selected indicators.

Table 7.1 Selected longitudinal indicators for families/carers of participants aged 25 and over

SF/LF	Domain description	Indicator	Baseline	Review	Change	Improvement/ Deterioration
SF	Families feel supported	% who have people they can ask to support their family member with disability as often as they need	34.2%	38.9%	4.7%	**Improvement**
SF	Families feel supported	% who have people they can ask for emotional support as often as they need	49.7%	54.4%	4.7%	**Improvement**
SF	Access to services	% who say the services their family member with a disability/family receive meet their needs	23.8%	35.6%	11.7%	**Improvement**
SF	Succession plans	% who have made plans (or begun to make plans) for when they are no longer able to care for their family member with disability	32.1%	37.5%	5.4%	**Improvement**
SF	Health and wellbeing	% who feel that their family member with disability gets the support he/she needs	32.1%	38.6%	6.4%	**Improvement**
LF	Health and wellbeing	% who feel that the services and supports have helped them to better care for their family member with disability	42.0%	68.1%	26.1%	**Improvement**
SF	Government benefits	% receiving Carer Allowance	34.6%	44.6%	10.1%	**Context dependent**

In general, the changes for this cohort have been positive with significant improvements observed in the following domains:

---

[38] 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.

- Families/carers feeling supported: More families and carers reported that they had people they could ask for support, whether it was for the family member with a disability or emotional support. In both cases, the improvement at review was an increase of 5% for positive responses.
- Access to and quality of services: There was a large improvement in families/carers who say that the services the family member with a disability and the family receives meets their needs (from 24% to 36%). Furthermore, considerably more families and carers report that the services and supports have helped them to better care for their family member (from 42% to 68%).
- Succession planning: The percentage of families/carers who have made or started making succession plans has increased from 32% at baseline to 38% at review.
- Health and wellbeing: The percentage of respondents who felt that their family member with a disability gets the support that they need increased from 32% to 39%.

7.2.5 Longitudinal indicators – key characteristics

Due to a small sample size of less than 300 respondents, an analysis of longitudinal indicators by key charateristics has not been included for families/carers of participants aged 25 and over.

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

8.1 Aggregate results

Figure 8.1 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).

Figure 8.1 Percentage of families/carers who think that the NDIS has helped with outcomes related to each domain

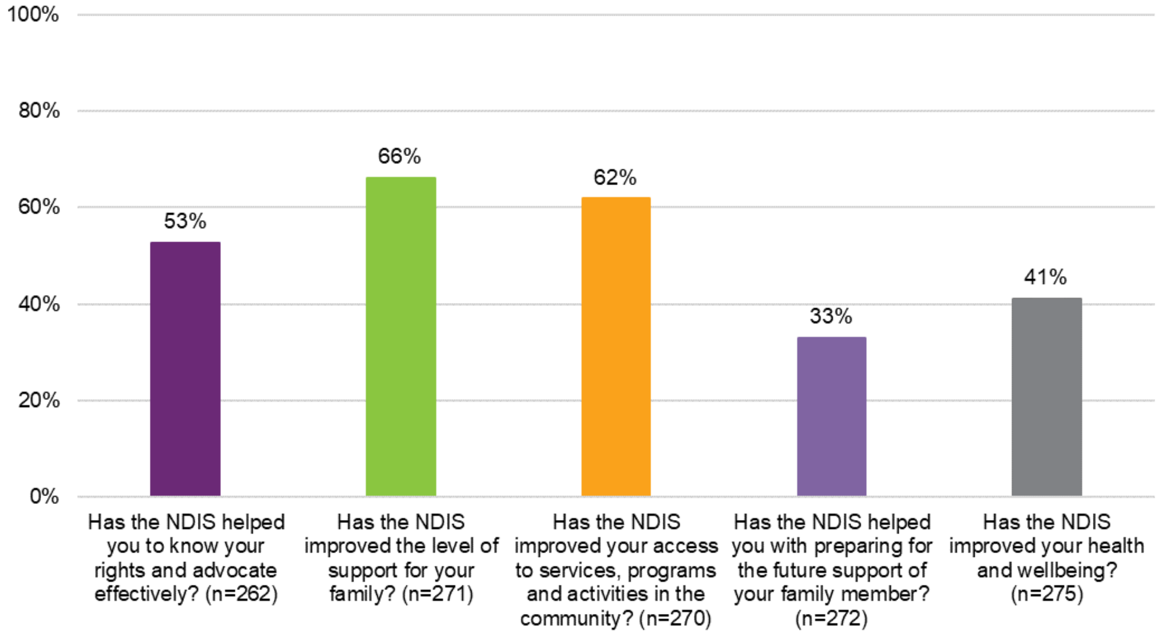


Figure 8.1 highlights that most families/carers think that the NDIS has helped with three out of the five SF domains. The most positive responses are for improving the level of support for the family (66%), and improving access to services, programs and activities in the community (62%). However, only 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.

8.2 Results by participant characteristics

One-way analysis[39] 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:

---

[39] Multiple logistic regression modelling was not used for the families and carers of participants 25 and over due to the small sample size of this cohort.

    - 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[40]: 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).

---

[40] Note the small sample sizes for CALD background (n=32) and Indigenous status (n=15) reduces the reliability of these results

9. Employment outcomes for families and carers of NDIS participants

9.1 Key findings

Box 9.1: Key findings for employment outcomes for families and carers of NDIS participants

- Increasing employment for families and carers of NDIS participants will result in benefits to both the individuals, as well as the wider Australian economy. In 2011, the Productivity Commission estimated that the NDIS could result in an additional 3.4% of carers entering the workforce, increased work capacity for carers already employed, and a $1.5b increase to annual real GDP.
- As at 30 June 2018, the percentage of families/carers who had a paid job upon entry into the scheme is: 46% for families/carers of participants aged 0 to 14, 48% for families/carers of participants aged 15 to 24, and 34% for families/carers of participants aged 25 and over. These percentages are considerably lower than the 76% observed for Australians without caring responsibilities[41].
- Mothers and fathers of participants aged 24 and under had the highest employment rates at baseline compared to other family members or carers who responded to the survey. Fathers were more likely to be in a paid job than mothers. For child participants, the percentage of mothers in paid work at baseline increases slightly as the child gets older, from 28% for mothers of children under one year of age to 46% for mothers of six year olds. However, between ages 6 and 11 no further increases are observed. For mothers in the general population, the percentage in a paid job increases from 31% for mothers of children under one year old to 67% for mothers of six year olds, and increases further to 75% for mothers of 11 year olds[42].
- For the families and carers of participants who have been in the Scheme at least one year as at 30 June 2018, the change in employment rates between baseline and review is: +3.1% for families/carers of participants aged 0 to 14, +3.3% for families/carers of participants aged 15 to 24 and no change for families/carers of participants aged 25 and over.
- The percentage of families/carers working in casual employment (26%) has remained steady between baseline and review, and compares to 15% of Australians aged 25 to 64 overall. The proportion working 30 or more hours per week has risen slightly from 41% at baseline to 43% at review. By contrast, 74% of Australians aged 25 to 64 work 35 or more hours per week[43].
- The most common barriers to families and carers working more were the situation with the child/family member with a disability (89%) and available jobs not having sufficient flexibility (42%). Other reported barriers included the availability of jobs, ill health of the respondent, availability and cost of childcare and after school care, and other caring responsibilities.

---

[41] 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

[42] Baxter J, 2013. *Employment characteristics and transitions of mothers in the Longitudinal Study of Australian Children*. Department of Social Services. Note that the population percentages use age of youngest child, whereas Scheme percentages use age of the participant, who may or may not be the youngest child. In addition, the LSAC percentages are based on longitudinal data across four waves of the study, whereas the SF percentages are cross-sectional (at baseline).

[43] Australian Bureau of Statistics. 2018. 6202.0 Labour force, Australia, Jun 2018.

- For the families and carers of participants aged 0 to 14 who did not have a paid job at baseline, 12% had found paid employment at review. Multiple regression analysis suggests that families/carers have a higher likelihood of finding employment at review if they have access to services and supports, are motivated to work more, rate their health as good or better, are self-managing the participant's plan, or if the participant enters the Scheme through early intervention. Where the participant's streaming type is intensive or super intensive, the family member/carer is found to have a lower likelihood of finding paid work at review.
- For the families and carers of participants aged 0 to 14 who were already in paid employment at baseline, 93% had successfully maintained employment at review. Multiple regression analysis shows that families/carers have a higher likelihood of maintaining their employment at review when they work more hours per week and are in a permanent job. Families/carers who are very confident or somewhat confident in supporting their child's development are also more likely to keep a paid job.

9.2 Employment experience of Australian carers

The families and carers of people with a disability play an invaluable role in providing help and support to the people in their care. As a result of these responsibilities, they also face a number of barriers to finding and keeping paid employment. Primary carers[44] in Australia experience considerably poorer employment outcomes, with a 52.2% employment to population ratio compared to 75.9% for people without caring responsibilities. Non-primary carers also have slightly worse employment experience, but to a lesser extent compared to primary carers. The statistics shown in Table 9.1 are from the 2015 ABS Survey of Disability, Ageing and Carers (SDAC) for persons aged 15 to 64.

Table 9.1 Australian employment statistics for persons aged 15 to 64, by carer status

Employment statistics	Primary carers	Non-primary carers	Not a carer
Employment to population ratio[45] (%)	52.2	72.2	75.9
Labour force participation rate[46] (%)	56.3	77.2	80.3
Unemployment rate[47] (%)	7.5	6.5	5.5

9.3 Benefits of increased employment for the family members and carers of people with a disability

Improving opportunities to participate in employment is expected to lead to a number of benefits for the families and carers of people with a disability, including greater financial security, reduced social isolation, and higher levels of self-esteem. Additionally, employment can serve as a form of respite, allowing families and carers to take a break from their responsibilities and develop a sense of identity outside of their caring role.[48]

More broadly, improved employment outcomes for the families and carers of people with a disability is expected to contribute to long-term economic benefits for Australia through increased labour force participation and reduced costs of carer income supports. In 2011 the Productivity Commission[49] estimated that increased employment opportunities for carers as a result of the NDIS could, over time, result in:

- Approximately 7,500 more carers finding paid employment (an increase of 3.4%)
- An increase in working hours and a reduction in time off for carers already employed
- An increase to real GDP of $1.5 billion annually

However, this estimate does not allow for the offsetting impact of a reduction in unmeasured informal care as a result of families and carers entering the workforce.

---

[44] From ABS Survey of Disability, Ageing and Carers: a primary carer is the person who provides the most informal assistance with mobility, self-care and/or communication to a person with a disability

[45] Number of persons employed as a percentage of the relevant age population

[46] The labour force (employed plus looking for work) as a percentage of the relevant age population

[47] Number of persons unemployed as a percentage of the labour force

[48] Carers Australia. 2014. *Combining Work and Care: The Benefits to Carers and the Economy*

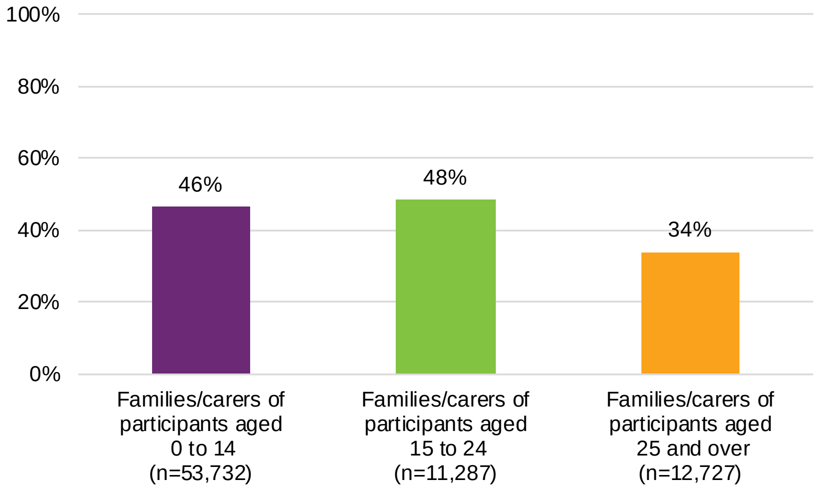
[49] Productivity Commission Inquiry Report. 2011. *Disability Care and Support* pp. 966-969

9.4 Employment experience of families/carers: baseline

9.4.1 Employment participation

To measure the employment status of the families and carers of NDIS participants, the SF questionnaire includes the question ‘Are you currently working in a paid job?’. The response to this question at baseline is summarised in Figure 9.1.

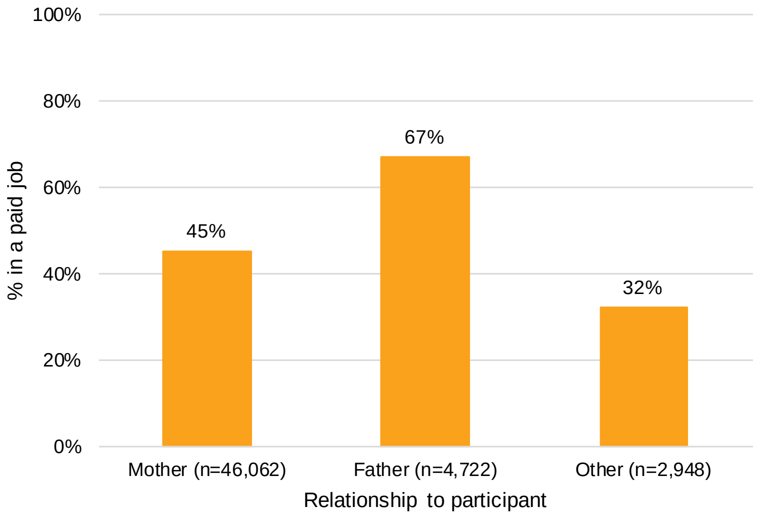
Figure 9.1 Percentage of families and carers in a paid job at baseline



The families and carers of participants aged 15 to 24 are the most likely to be in paid employment at baseline (48%), followed by the families and carers of participants aged 0 to 14 (46%). Only 34% of families and carers of participants aged 25 and over reported that they were in paid work at baseline, which may reflect a higher proportion of respondents who have never been able to consider employment and who are close to or past retirement age.

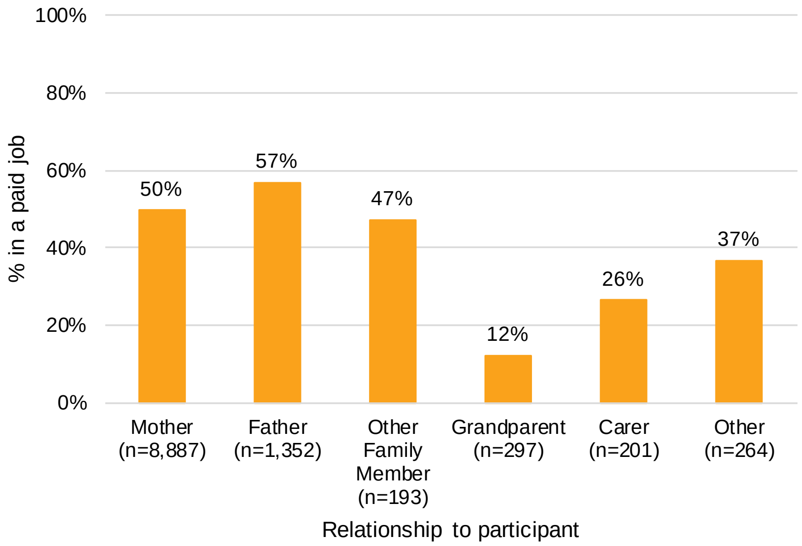
The SF questionnaire also asks respondents ‘What is your relationship to the participant?’, with different response options for each version of the questionnaire. The following three figures show the percentage of families and carers in paid work at baseline, by their answer to this question.

Figure 9.2 Percentage of families/carers of participants aged 0 to 14 in a paid job at baseline, by relationship to participant



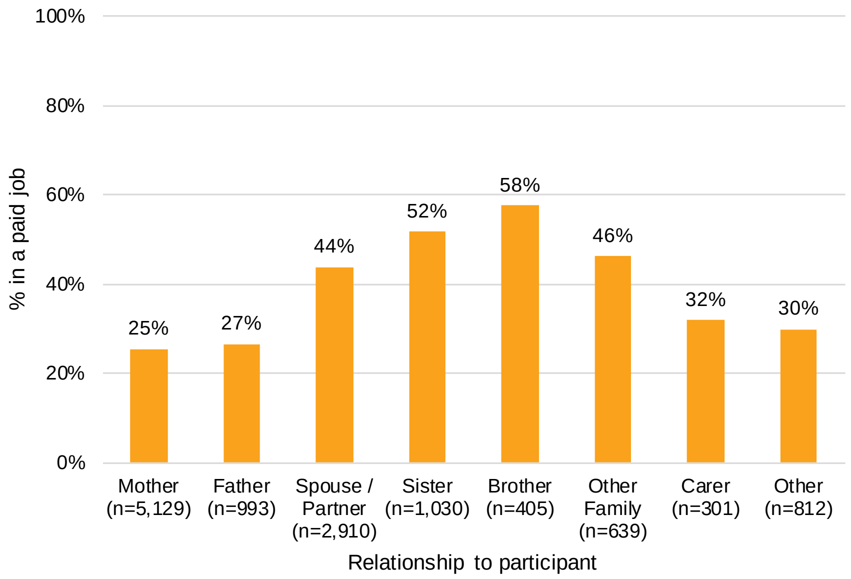
For the families and carers of participants aged 0 to 14, the large majority of respondents (86%) are the participant's mother. Mothers report lower rates of paid employment at baseline compared to fathers (45% vs 67%), but are more likely to be employed than respondents in the 'other' category (32%). There is a free text field in the SF questionnaire for those who respond 'other' to specify their relationship to the participants, with common responses being grandparents and foster carers.

Figure 9.3 Percentage of families/carers of participants aged 15 to 24 in a paid job at baseline, by relationship to participant



For families/carers of participants aged 15 to 24, mother is again the most commonly reported relationship (79% of respondents). However, the differential in baseline employment rates between mothers and fathers is less pronounced compared to the younger participant cohort (50% for mothers and 57% for fathers). As expected based on their older age, grandparents have the lowest rates of paid employment at baseline (12%).

Figure 9.4 Percentage of families/carers of participants aged 25 and over in a paid job at baseline, by relationship to participant



The mother and spouse/partner are the main relationships reported for families/carers of participants aged 25 and over (40% and 23% of respondents, respectively). Overall, parents have the lowest baseline employment rates for this cohort, likely as a result of them nearing or reaching retirement age. The highest reported baseline employment rates are for siblings (58% for brothers, 52% for sisters), other family members (46%), and then the spouse/partner (44%).

Figure 9.5 investigates the impact of participant age[50] on baseline employment rates for parents of participants aged 0 to 14. For mothers, there is a large increase in employment after the participant reaches one year of age, which likely reflects return to work after maternity leave. This is followed by a small increasing trend in the baseline employment rates as participants get older. For fathers, the reverse relationship holds with a generally decreasing trend in baseline employment as participant age increases.

Figure 9.5 Percentage of families/carers of participants aged 0 to 14 in a paid job at baseline, by relationship to participant and age of participant

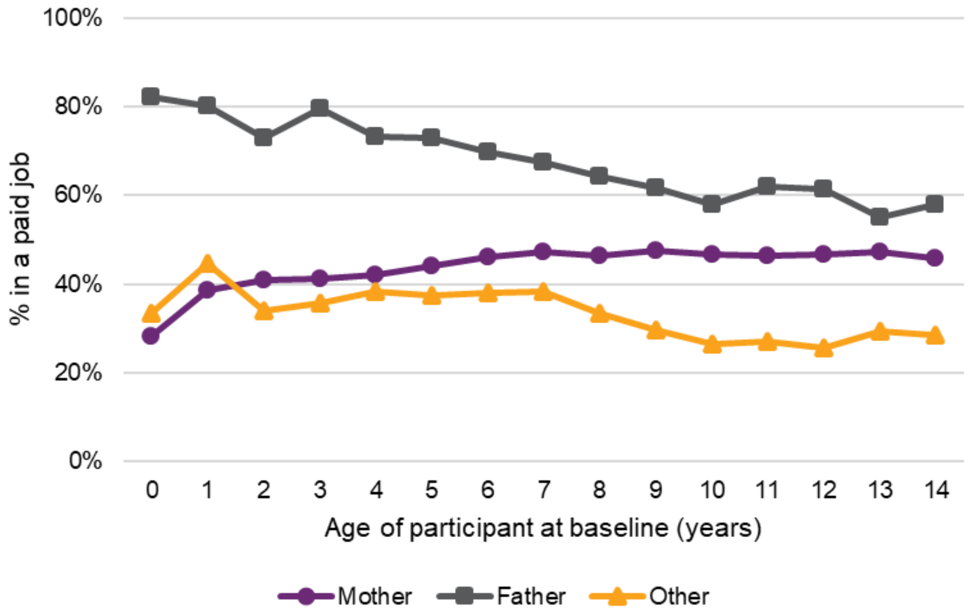
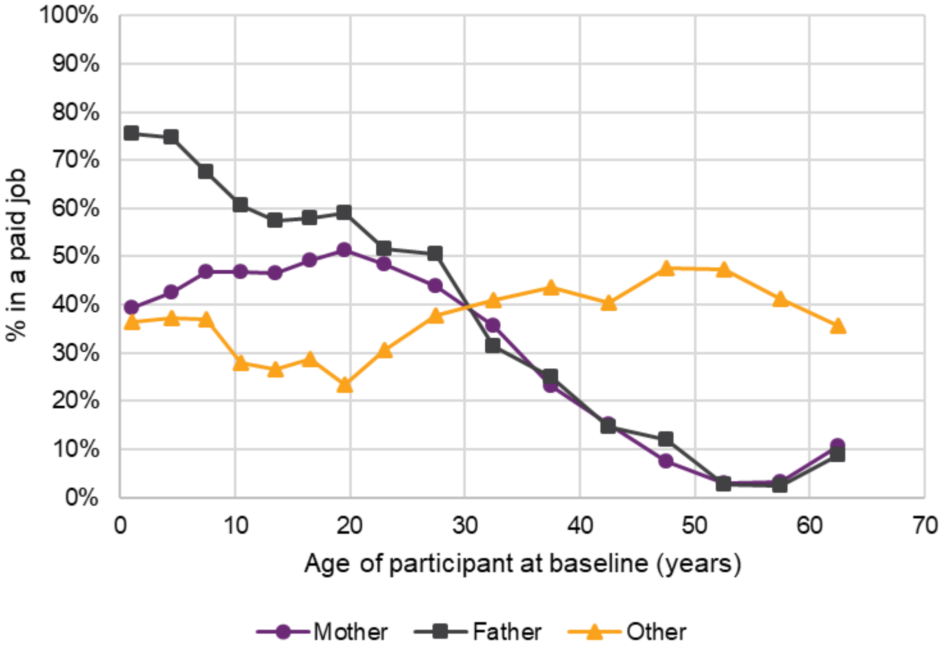


Figure 9.6 is similar to Figure 9.5 but extends the age range for participants by combining questionnaires from all three versions. Beyond age 30, percentages are similar for mothers and fathers, and decrease as they approach retirement. The increase beyond age 20 for the “Other” group reflects the increasing component of spouses and partners in this group.

---

[50] Note that the trends referred to are cross-sectional, not longitudinal.

Figure 9.6 Percentage of families/carers of participants (all ages) in a paid job at baseline, by relationship to participant and age of participant



The employment experience of mothers of NDIS participants aged 0 to 11 can be compared to the employment rates of mothers in the general population by the age of their *youngest* child, using results from the Longitudinal Study of Australian Children (LSAC)[51,52]. This comparison is given in Figure 9.7, noting that the two employment measures are not like-for-like as it is not possible to determine whether or not the participant is the mother's youngest child in the SF questionnaire[53].

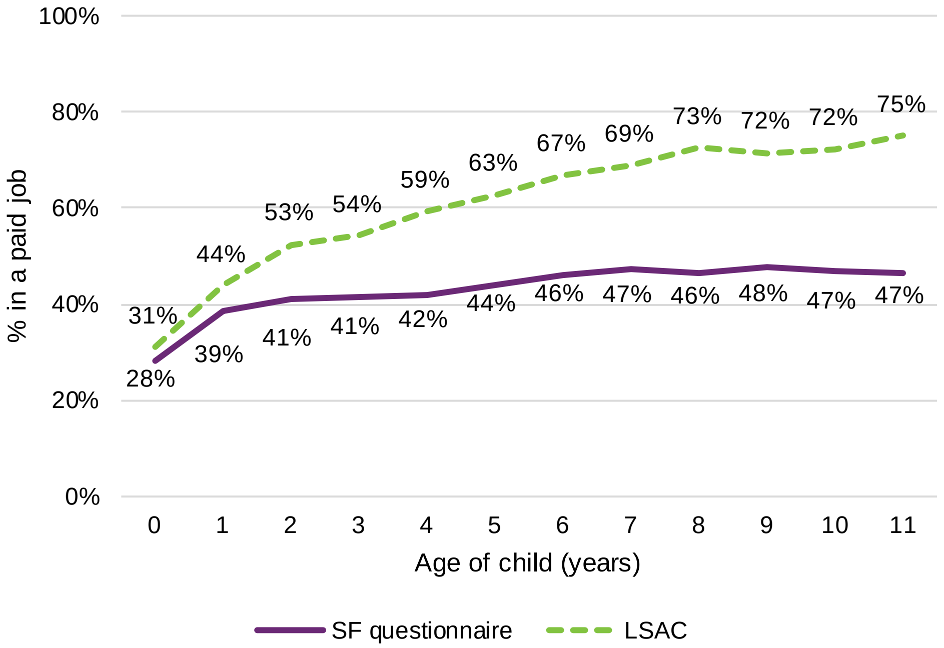
---

[51] Baxter J, 2013. *Employment characteristics and transitions of mothers in the Longitudinal Study of Australian Children*. Department of Social Services.

[52] Employment rates are for mothers who are employed and at work. It excludes mothers who are employed and away from work i.e. employed but currently on leave or otherwise absent.

[53] In addition, the LSAC percentages are based on longitudinal data across four waves of the study, whereas the SF percentages are cross-sectional (at baseline).

Figure 9.7 Percentage of mothers of participants aged 0 to 11 in a paid job at baseline, compared to population benchmark, by age of participant



As expected, the overall employment rates for mothers of NDIS participants are lower at baseline compared to mothers in the general population. Furthermore, the differential increases significantly as children get older with 75% of mothers in the general population being at work when their youngest child is 11, compared to an employment rate of 47% for mothers of NDIS participants aged 11. This difference may reflect that mothers of children with a disability have more difficulty returning to work as their children get older compared to mothers in the general population. Alternatively it may be a result of the difference in the benchmark measure, as the mothers of NDIS participants may have other children that are younger than the participant which delays their return/entry into paid work.

9.4.2 Families and carers working as much as they want

The SF also asks whether families and carers are able to work as much as they want. For families and carers of participants aged 0 to 14, 41% of respondents said that they (and/or their partner) were able to work as much as they wanted to at baseline. A logistic regression model for the probability of being able to work as much as desired identified the following factors as important:

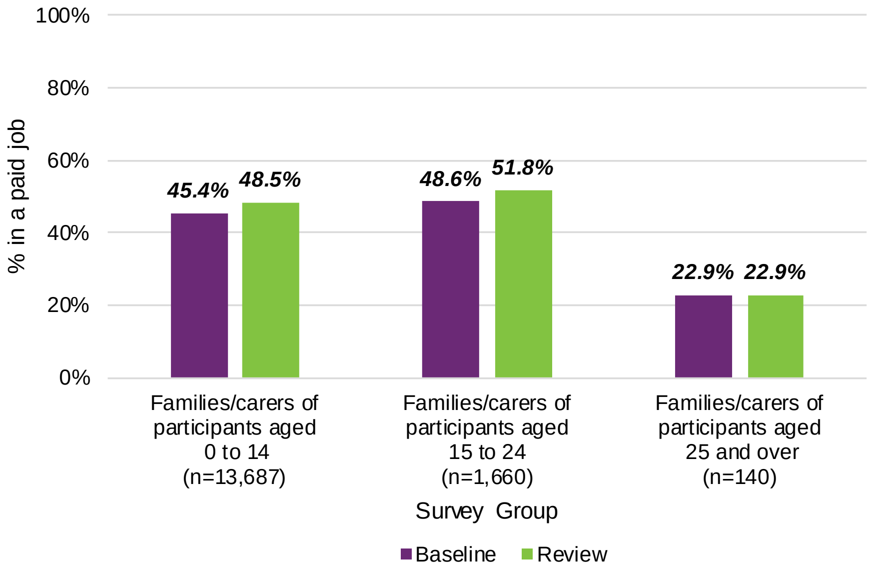
- CALD status: families and carers for participants from CALD backgrounds were less likely to say they were able to work as much as they want at baseline (33%).
- Family/carer health: families and carers with better self-rated health were more likely to say they were able to work as much as they want.
- Remoteness: families and carers of participants residing in remote areas were more likely to be able to work as much as they want (48%).
- Casual employment: families and carers in casual employment were less likely to be able to work as much as they want (35%).
- Family circumstances: the percentage working as much as they want was higher for those able to access available services and supports to meet the needs of their child and family (49%), those with people to ask for childcare as much as they need (61%), and those with higher levels of confidence in supporting their child (53% for

those who felt very confident decreasing to 14% for those who were not at all confident).

9.5 Employment experience of families/carers: trend

The trend analysis considers the employment experience of families and carers of participants who have been in the Scheme for at least one year and have received a review plan.[54] For this cohort, Figure 9.8 shows the percentage of families/carers who answer yes to the SF question ‘Are you currently working in a paid job?’ at baseline and at review.

Figure 9.8 Percentage of families and carers in a paid job, at baseline and review



The overall change in employment rates for families/carers between baseline and review as at 30 June 2018 is:

- A **+3.1%** improvement for families and carers of participants aged 0-14 years old
- A **+3.3%** improvement for families and carers of participants aged 15-24 years old
- No change for families and carers of participants aged 25 years and older.

Part of this increase in reported employment rates for families and carers of participants aged 0 to 24 may be due to improved Australian labour market conditions. Over the last two years, the employed to population ratio for 25 to 64 year olds[55] has steadily increased from 75.9% in July 2016 to 77.0% in June 2018[56]. However, the significant improvement[57] in employment for families/carers does not appear to be due to a strengthening job market alone, and may be a result of the impact of the NDIS. The drivers of employment outcomes for families and carers of NDIS participants are explored further in Section 9.7.

---

[54] Only where the family member/carer is the same at baseline and review, based on the response to the SF question ‘What is your relationship to the participant?’. If the family/carer chooses ‘Other (please specify)’ as a response, they must specify the same relationship at baseline and review.

[55] The majority of respondents to the family and carers survey for participants aged 0 to 24 were the mother or father (95% and 91% for families/carers of participants aged 0 to 14 and 15 to 24, respectively), thus it is assumed that most family/carers will fall broadly in the 25 to 64 age range.

[56] Australian Bureau of Statistics. 2018. 6202.0 Labour force, Australia, Jun 2018.

[57] McNemar’s test, $p<0.0001$.

The detailed transition rates between employment status at baseline and review are given in the tables below.

Table 9.2 Employment transition rates, families/carers of participants aged 0 to 14

Baseline Employment Status	Review Employment Status	
	In paid work (n=6639)	Not in paid work (n=7048)
In paid work (n=6219)	93% (n=5780)	7% (n=439)
Not in paid work (n=7468)	12% (n=859)	88% (n=6609)

Table 9.3 Employment transition rates, families/carers of participants aged 15 to 24

Baseline Employment Status	Review Employment Status	
	In paid work (n=860)	Not in paid work (n=800)
In paid work (n=806)	96% (n=775)	4% (n=31)
Not in paid work (n=854)	10% (n=85)	90% (n=769)

Table 9.4 Employment transition rates, families/carers of participants 25 and over

Baseline Employment Status	Review Employment Status	
	In paid work (n=32)	Not in paid work (n=108)
In paid work (n=32)	88% (n=28)	13% (n=4)
Not in paid work (n=108)	4% (n=4)	96% (n=104)

Families and carers who report that they are in a paid job in the SF questionnaire are also asked about their type of employment and the number of hours worked per week. The responses at baseline and review are illustrated in Figure 9.9 and Figure 9.10 for families and carers of participants, all ages combined.

Figure 9.9 Type of employment for families and carers in a paid job

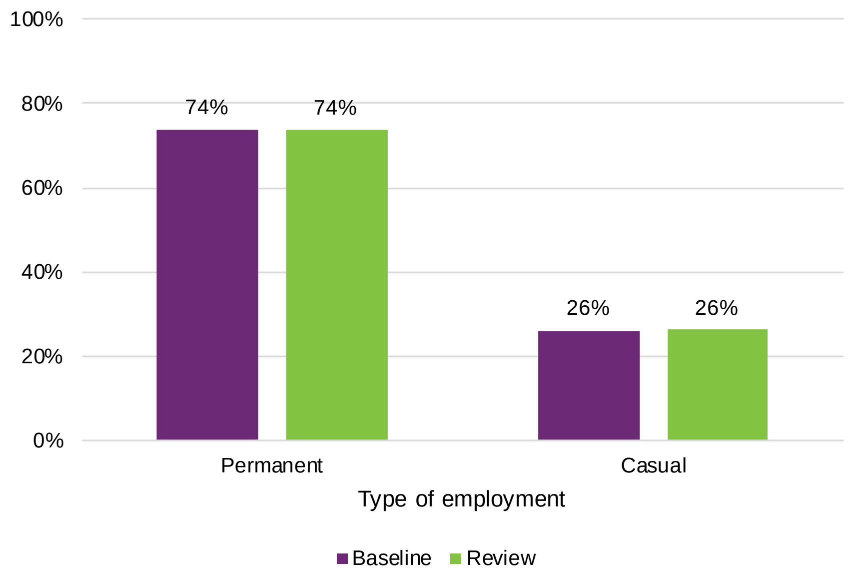
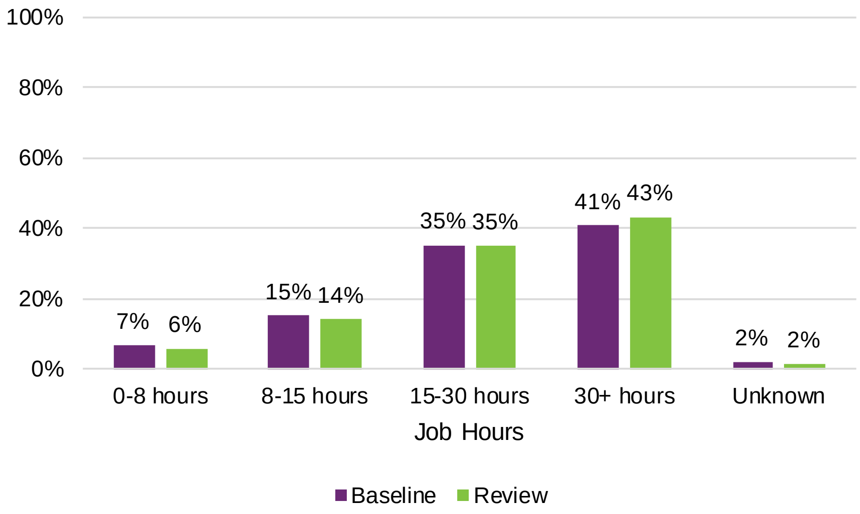


Figure 9.10 Typical hours worked per week for families and carers in a paid job



For families and carers in a paid job, 26% are reported to be working in casual rather than permanent employment and this result has remained steady over time. In comparison, 15% of employees aged 25 to 64 in the general population were casually employed in 2016[58]. Furthermore, Figure 9.10 shows that 57% of families and carers of NDIS participants work less than 30 hours per week at baseline, decreasing slightly to 55% at review. For the general population, only 26% of employees aged 25 to 64 were working on a part-time basis as at June 2018[59].

These results show that families/carers who are in a paid job work less hours on average than employees in the general population, and are more likely to be in casual employment.

---

[58] HILDA Survey 2016, Wave 16

[59] Australian Bureau of Statistics. 2018. 6202.0 Labour force, Australia, Jun 2018. ABS defines part time work as less than 35 hours per week, so the percentage of the general population working less than 30 hours per week would likely be lower than 26%

The need to balance both work and caring commitments is expected to make part-time work more appealing to families and carers of people with a disability, and part-time work is more likely to be associated with casual employment than full-time work.[60]

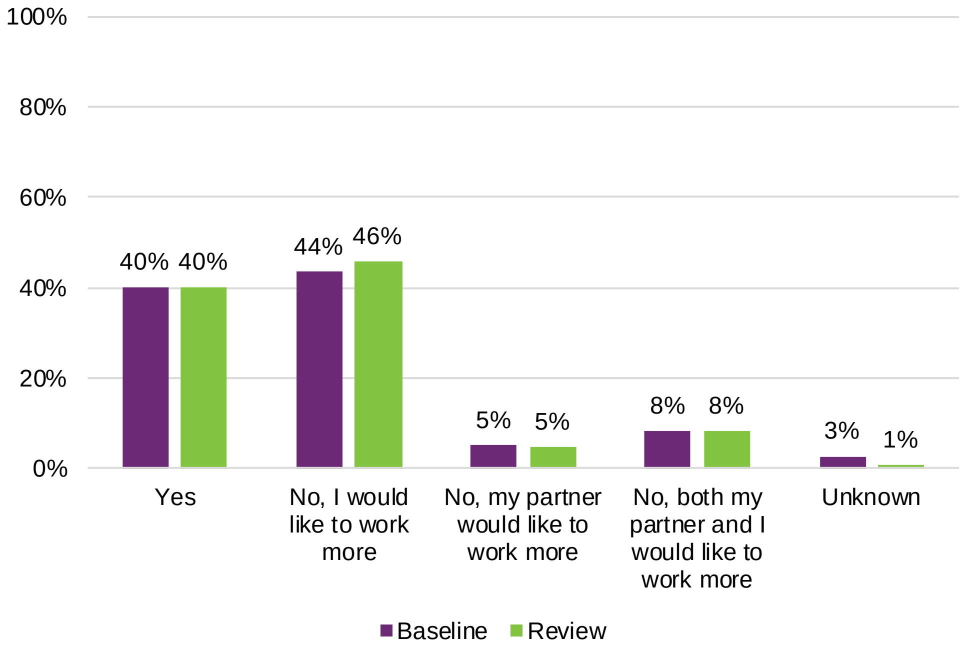
9.6 Barriers to employment for families/carers

While overall employment rates are improving for the families and carers of NDIS participants, it is also important to understand whether barriers remain that prevent families and carers working as much as they would like to. In the SF questionnaire, families/carers are asked the following questions (regardless of whether or not they are in a paid job):

- 'I/(my partner and I) am/are able to work as much as I/we want" for families/carers of participants aged 0 to 14
- "Family who provide informal care to my family member with a disability are able to work as much as they want" for families/carers of participants aged 15 to 24, and 25 and over

The answers to these questions at baseline and review are illustrated in Figure 9.11 and Figure 9.12 for each age group.

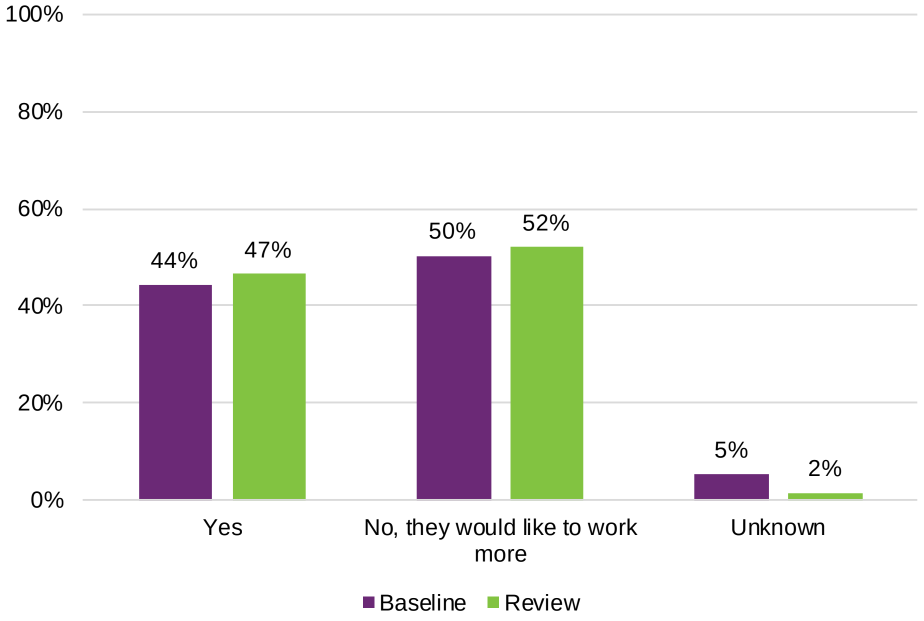
Figure 9.11 Ability of families/carers and their partners to work as much as they want - for families and carers of participants aged 0 to 14



---

[60] HILDA Survey 2018: Selected Findings from Waves 1 to 16 pp. 66.

Figure 9.12 Ability of families/carers and their family members to work as much as they want - for families and carers of participants aged 15 and over

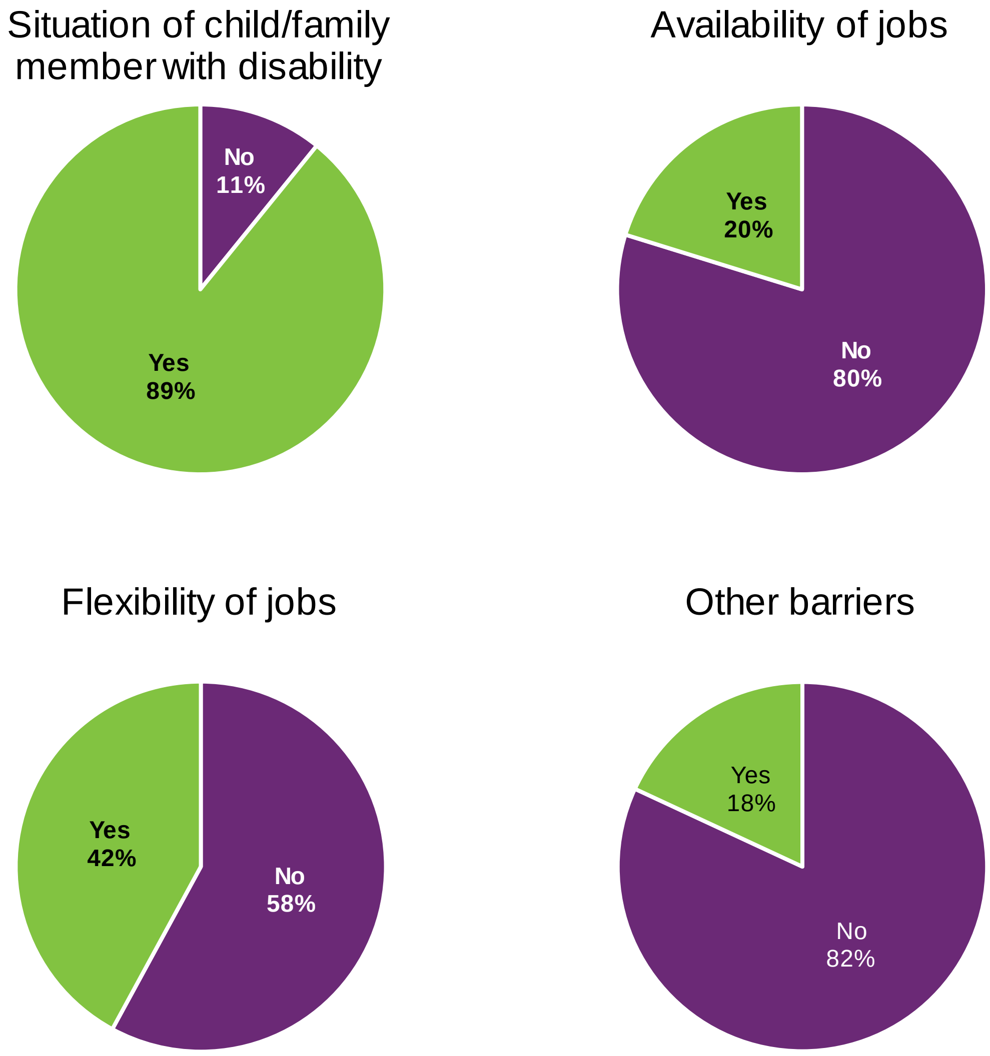


Families and carers of participants aged 0 to 14 have not reported any increase in their (and their partner's) ability to work as much as they want between baseline and review, despite a significant increase in the reported employment rate. For families and carers of participants aged 15 and over, both the positive and negative response options regarding the ability of family members to work as much as they wanted increased as a result of a decrease in missing responses at review. Therefore, there is no evidence to suggest that the percentage of families/carers (and their partners/family) who are able to work as much as they want to has increased as a result of participants being involved with the NDIS.

On the other hand, the overall increase in the typical working hours for families/carers in a paid job (see Figure 9.10) suggests that some families/carers may be *progressing* towards working as much as they would like to, but are not yet achieving their optimal employment hours. A single year may not be a long enough period for families and carers of NDIS participants to adapt to the support provisions and requirements under the Scheme, and to then adjust their own employment accordingly. Furthermore, it may take additional time for families and carers who are already in paid work to negotiate new working hours and conditions with their employers.

To understand why families and carers are limited in their ability to work as much as they want to, the SF questionnaire asks families/carers what barriers they face to working more. Respondents can choose more than one option, and the results at review are illustrated below for all age groups combined.

Figure 9.13 Barriers to families/carers working more, for those who can't work as much as they would like to at review



The majority (89%) of families and carers who reported that they were not able to work as much as they would like to found the situation with their child or family member with a disability to be a barrier to working more. A large proportion (42%) also reported a lack of job flexibility as a barrier to meeting their employment goals. This could include both families/carers who cannot find jobs with sufficient flexibility to accommodate their responsibilities, as well as those whose current jobs are not suitably flexible. The general availability of jobs was also reported to be a barrier to employment for 20% of families and carers.

For the 18% of families and carers who reported that other barriers prevented them from working more, they were asked in the SF questionnaire to specify what those barriers were. The key themes that emerged from the responses are given in Table 9.5 below with examples.

Table 9.5 Other barriers to families/carers working more, for those who can't work as much as they would like to at review

Other barriers to work	Examples
Ill health	'We cannot work due to ill health - my husband has a disability and I have chronic pain.' 'My own mental health issues and my other children have mental health issues as well.'
Cost and availability of childcare and after school care	'Cost of child care and vacancy rates' 'No appropriate childcare with experience in ASD'
Additional caring responsibilities	'3 of the 5 children in the family have a disability. Father is also the guardian of his brother with a significant ABI' 'I've had a new baby.' 'Currently in caring role for ageing parent'
Study	'Studying Aged care diploma' 'Studying towards qualifications that will increase employment opportunities.'
Language barriers	'Language and skill barrier. Has limited English.'

9.7 Key drivers of employment outcomes

The key drivers of employment success for families and carers of NDIS participants have been identified using multiple logistic regression analysis, where the binary response (dependent) variable is one if the family member or carer has a paid job at review and zero otherwise. A stepwise regression approach is used to determine the statistically significant predictors of employment success from a number of different variables related to both the family/carer and participant that are expected to influence the ability of family members and carers to find or maintain a job.

For the SF questionnaire variables, responses were measured at baseline only (i.e. changes to responses at review were not included in the regression analysis).

The regression modelling has only been applied to the families and carers of participants aged 0 to 14 to ensure sufficient data is available for analysis. The results of this analysis are given below for two different cohorts of families/carers:

- Families and carers of participants aged 0 to 14 who are not in paid work at baseline
- Families and carers of participants aged 0 to 14 who are in paid work at baseline.

9.7.1 Families and carers of participants aged 0 to 14, who are not in paid work at baseline

Of the 7,468 families and carers of participants aged 0 to 14 who reported that they were not in paid work at baseline, 859 had found a paid job at review. This corresponds to 12% of families/carers who were not employed at baseline successfully finding a paid job over the review period. The key drivers of this employment success, as determined by multiple regression analysis, are outlined in Table 9.6 below. The key drivers relate to either the participant, or to the family member/carer using answers from the SF questionnaire at baseline. The direction of the relationship between each key driver and the likelihood of finding paid work at review is also shown.

Table 9.6 Key drivers of employment success for families and carers of participants aged 0 to 14, who are not in paid work at baseline

Type	Key driver	Relationship to employment success
Participant characteristics	Streaming type is intensive or super intensive	↓
	Scheme access reason is 'benefit from early intervention'	↑
	Plan is fully or partly self-managed	↑
	Identifies as Indigenous	↓
	Index of Relative Socio-Economic Disadvantage (IRSD) decile score for the participant's local government area (LGA)[61]	↑ with lower relative disadvantage
	Participant lives in NSW, QLD or SA	↑
Family/carer baseline SF questionnaire responses[62]	Is able to access available services and supports to meet the needs of the participant and their family	↑
	Would like to receive services and supports needed to care for the participant at different times	↑
	Family/carer would like to work more and participant is of school age	↑
	Self-assessed health status is fair or poor	↓
	Has friends and family they see as often as they like	↑
	Relationship to participant is "other" (rather than mother or father)	↓
	Currently studying part-time or full-time	↑

---

[61] The IRSD is an index published by the ABS which ranks areas in Australia according to their relative socio-economic disadvantage based on a range of information about the economic and social conditions of people and households within an area. A low score indicates relatively greater disadvantage in general and a high score indicates a relative lack of disadvantage in general.

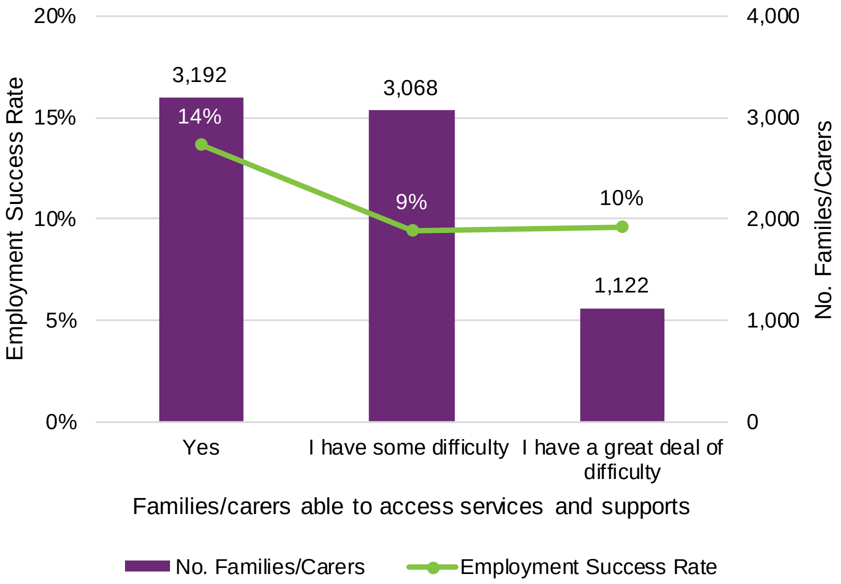
[62] The modelling also suggested a positive relationship between missing answers to some SF questions and employment success. This is likely to be a consequence of the way data are collected in the ICT system, rather than indicating a genuine impact on employment success.

Selected key drivers from Table 9.6 are now examined in more detail. All supporting figures show the impact of the key drivers on the likelihood of families/carers finding paid work at review on a one-way basis (i.e. not allowing for the other explanatory factors from the multiple regression analysis).

Access to services and supports

In the SF questionnaire, families and carers of participants aged 0 to 14 are asked whether 'I am able to access available services and supports to meet the needs of my child and family'. The employment success rate by the response to this question at baseline is illustrated in Figure 9.14 below.

Figure 9.14 Employment success rates by whether families/carers are able to access services and supports – for families/carers of participants aged 0 to 14, not in paid work at baseline*

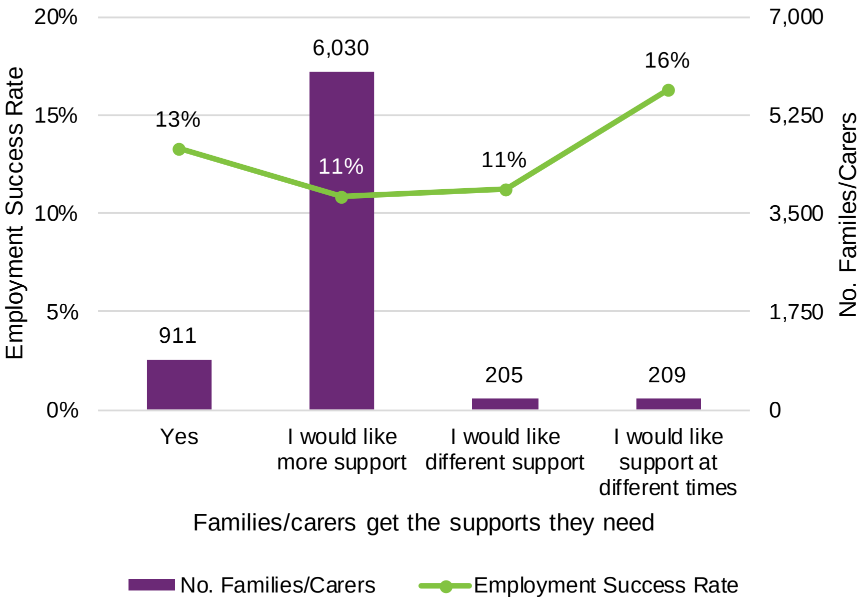


* Excludes missing responses

The likelihood of finding paid employment at review is highest for the families/carers who are able to access available services and supports for their child and family without difficulty. This finding highlights the importance of families and carers having access to reasonable and necessary supports for their child through the NDIS and other informal and mainstream services that will enable them to have the time and confidence to pursue paid employment.

Families and carers are also asked in the SF questionnaire whether 'I get the services and supports I need to care for my child with a disability'. This question addresses the quality and the amount of support that families/carers receive, rather than accessibility. Figure 9.15 shows the family/carer employment success rate by the baseline response to this question.

Figure 9.15 Employment success rates by whether families/carers get the supports they need – for families/carers of participants aged 0 to 14, not in paid work at baseline*



* Excludes missing responses

Families and carers who respond that they would like support at different times are found to have a significantly higher likelihood of finding employment at review compared to the other response options. A possible reason for this result is that these families and carers may have already been interested in paid employment prior to the child entering the Scheme but were not able to find supports that were flexible enough to accommodate a work schedule. Under the NDIS, there is greater flexibility in the way participants access supports compared to the old State-based disability system, and this may have resulted in an increase in paid employment for families and carers.

Streaming type and access decision

A participant's streaming type reflects the level of support they need to manage the NDIS Pathway, and child participants are often streamed intensive or super intensive when one or more of the following circumstances apply:

- Participant exhibits behaviours of concern
- Participant has minimal/no informal or community supports
- Parent/carer/other family members have a disability
- History of abuse/neglect or current involvement with Child Protection

A participant being streamed as intensive or super intensive may therefore indicate that the family member or carer has additional caring responsibilities with regards to the child and/or the rest of the family that makes finding paid employment more difficult. On the other hand, child participants who access the scheme through early intervention generally have a higher level of function compared to other participants, and with the supports provided by the NDIS may be able to reduce the impact of their disability over time. As a result, the families and carers of these participants may experience fewer barriers to finding employment compared to the families and carers of participants with higher needs. Figure 9.16 and Figure 9.17 illustrate the employment success rate by streaming type and access decision, respectively.

Figure 9.16 Employment success rates by participant's streaming type – for families/carers of participants aged 0 to 14, not in paid work at baseline

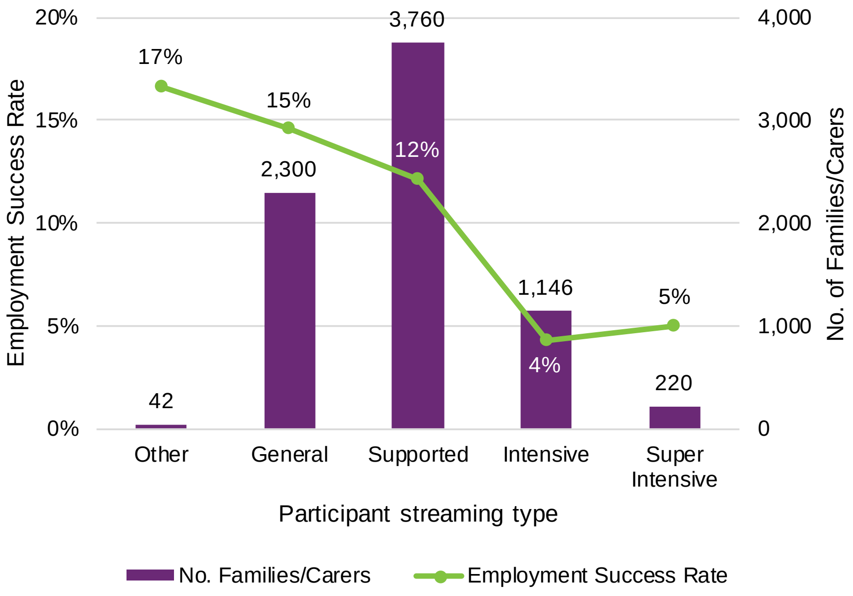
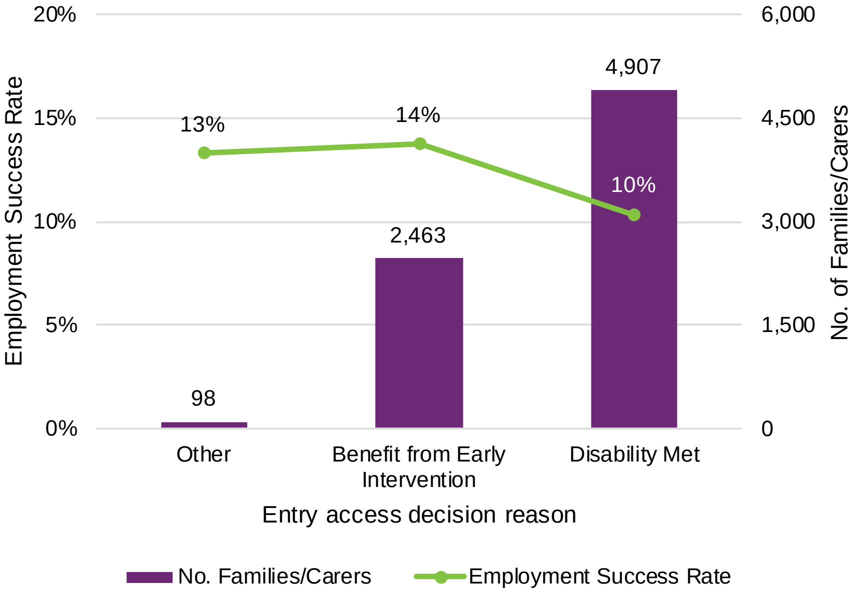


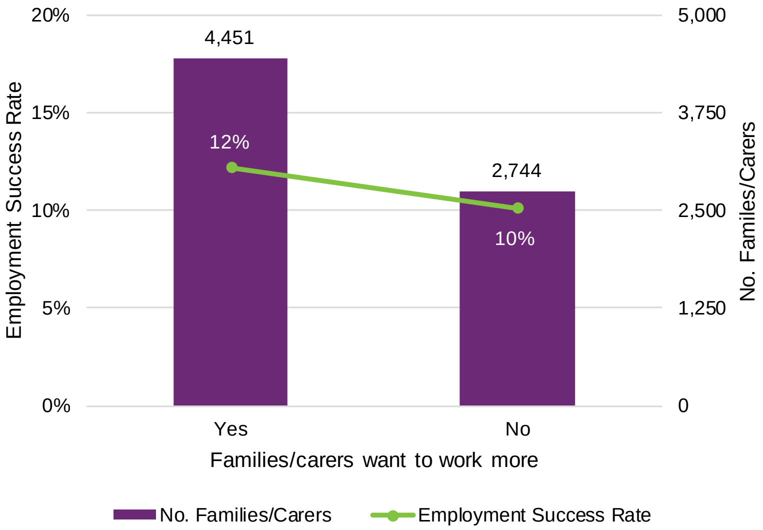
Figure 9.17 Employment success rates by participant's entry access decision reason – for families/carers of participants aged 0 to 14, not in paid work at baseline



Families/carers want to work more

For families and carers who do not have paid work at baseline, their motivation to find work is expected to have a significant impact on their employment success. For example, a parent with a newborn baby may not have the capacity or interest in finding employment until the child is older. The family and carers SF questionnaire asks respondents the question 'I/(my partner and I) am/are able to work as much as I/we want". Families/carers who are not in paid work at baseline and answer this question with 'No, I would like to work more' or 'No, both my partner and I would like to work more' are assumed to be motivated to find paid employment. The relationship between motivation and employment success is illustrated in Figure 9.18 below.

Figure 9.18 Employment success rates by whether families/carers want to work more – for families/carers of participants aged 0 to 14, not in paid work at baseline*

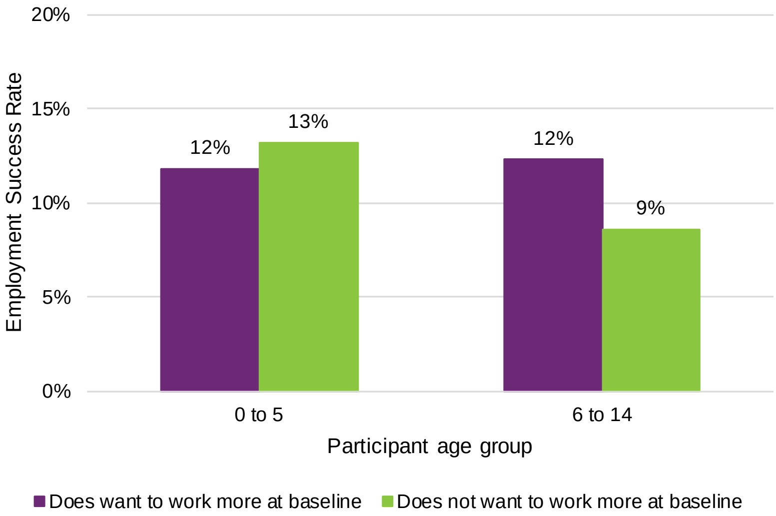


* Excludes missing responses

As expected, the likelihood of finding a job at review is higher for families/carers who are motivated to find employment compared to families/carers who don't want to work more, although not by a large margin. Since motivation for work is measured at baseline, this result may actually reflect that some families/carers changed their minds regarding employment over the review period. This is likely to occur if there has been a change of circumstances within the family, such as the child beginning school or childcare.

In Figure 9.19, the employment success rate is shown by both the family member/carer's motivation to work more at baseline as well as the participant's age group. A positive relationship between motivation and employment success is only observed when participants are aged 6 to 14, at which age most children are enrolled in school and the circumstances of the family may have become more stable.

Figure 9.19 Employment success rates by whether families/carers want to work more and participant age – families/carers of participants aged 0 to 14, not in paid work at baseline*

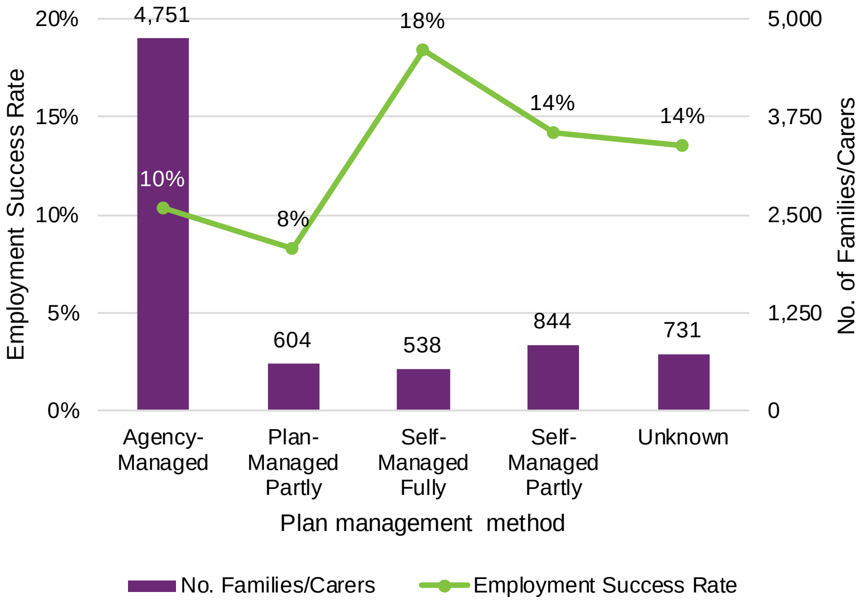


* Excludes missing responses

Participant's plan is self-managed

Figure 9.20 shows the employment success rate for families and carers by the participant's plan management method. For child participants with self-managed plans, it is generally expected that the family member/carer who answers the SF questionnaire during the planning process will also be the primary plan manager.

Figure 9.20 Employment success rates by participant's plan management method – for families/carers of participants aged 0 to 14, not in paid work at baseline



Families and carers who fully or partly self-manage a child participant's plan are found to have a significantly higher likelihood of finding paid work at review compared to families/carers who use other plan management methods.[63] Although self-managing a plan can often be more time consuming than agency- or plan-management, it also gives the family member or carer more flexibility and control in choosing the appropriate supports for the child. As a result, families and carers who self-manage may have an increased level of confidence in the supports provided to the participant, and will feel more comfortable leaving the child in alternative care in order to participate in the workforce.

In addition, choosing to self-manage the child's plan may indicate that the family member or carer has a greater level of work-readiness than those who choose other plan management methods. The responsibilities of self-managers include purchasing supports, negotiating provider agreements, managing funding, recording invoices and receipts, and more. These are skills that are desirable in many workplaces, and hence families/carers who are able to self-manage may be more attractive to potential employers.

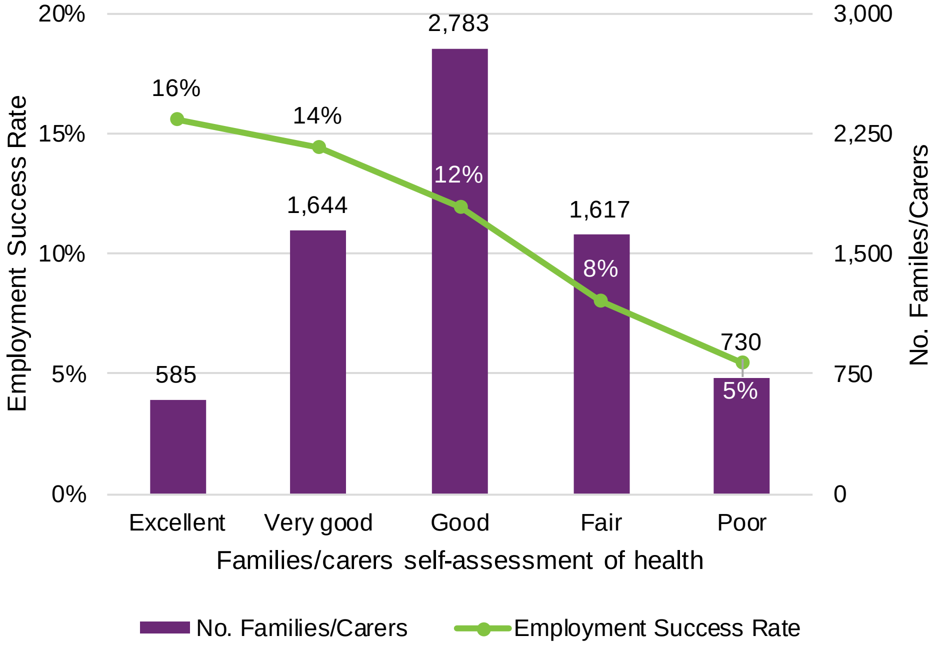
---

[63] Unknown plan management also has a high likelihood of employment success on a two-way basis. However, because a large proportion of this group (60%) entered the scheme under early intervention, it was not found to be a significant driver of employment success in the regression analysis after allowing for access reason.

Health status of family and carers

In the SF questionnaire, families and carers are asked to rate their overall health on a 5-point scale between Excellent and Poor. Figure 9.21 illustrates the employment success rate by the family member or carer's response at baseline.

Figure 9.21 Employment success rates by families/carers self-assessment of health – for families/carers of participants aged 0 to 14, who are not in paid work at baseline*



There is a clear downward trend in the likelihood of a family member or carer finding work as the assessment of their health deteriorates. This result is not surprising as families and carers identified their own ill health, whether physical or mental, as a barrier to working more in the SF questionnaire (see Table 9.5).

9.7.2 Families and carers of participants aged 0 to 14, who are in paid work at baseline

For families and carers of participants aged 0 to 14, 6,219 respondents reported that they were in paid work at baseline. Of this group, 5,780 also reported that they were in paid work at review. The employment success rate is the proportion of families/carers that have successfully maintained paid work at review, which is 93% for this cohort. It is important to note that this does not necessarily say anything about the *consistency* of employment status over the plan period, only whether the family/carer is in paid employment at the start and end of the period.

The key drivers of employment success for families/carers who are in paid work at baseline are determined by multiple regression analysis, and are outlined in Table 9.7 below. The direction of the relationship between each key driver and the likelihood of maintaining employment at review is also shown.

Table 9.7 Key drivers of employment success for families and carers of participants aged 0 to 14, who are in paid work at baseline

Type	Key driver	Relationship to employment success
Participant characteristics	Scheme entry age	↑ with increasing age
	Streaming type is intensive or super intensive	↓
	Scheme access reason is 'benefit from early intervention'	↑
	Plan is partly self-managed	↑
	Participant relocated during plan period	↓
	Participant lives in VIC	↑
Family/carer baseline SF questionnaire responses	Type of employment is casual	↓
	Number of hours typically worked per week	↑ with increasing hours (approx.[64])
	Is very confident or somewhat confident in supporting the child's development	↑
	Is able to access available services and supports to meet the needs of the participant and their family	↑
	Would like to receive services and supports needed to care for the participant at different times	↑
	Relationship to participant is father (rather than mother or other)	↑

Selected key drivers from Table 9.7 are now examined in more detail. All supporting figures show the impact of the key drivers on the likelihood of families/carers maintaining employment at review on a one-way basis (i.e. not allowing for the other explanatory factors from the multiple regression analysis).

Employment type and number of hours typically worked per week

The likelihood of a person keeping their job is expected to be strongly influenced by the characteristics of the job itself e.g. industry, benefits, how well suited it is to the person etc. For families and carers who are working in a paid job at baseline, the SF questionnaire asks about two features of their employment: 1) is the job permanent or casual, and 2) what are the typical hours worked per week. Figure 9.22 and Figure 9.23 illustrate the employment success rate for families and carers at review, by their response to these questions at baseline.

---

[64] Hours reported in broad ranges i.e. categorical variable.

Figure 9.22 Employment success rates by families/carers employment type – for families/carers of participants aged 0 to 14, who are in paid work at baseline

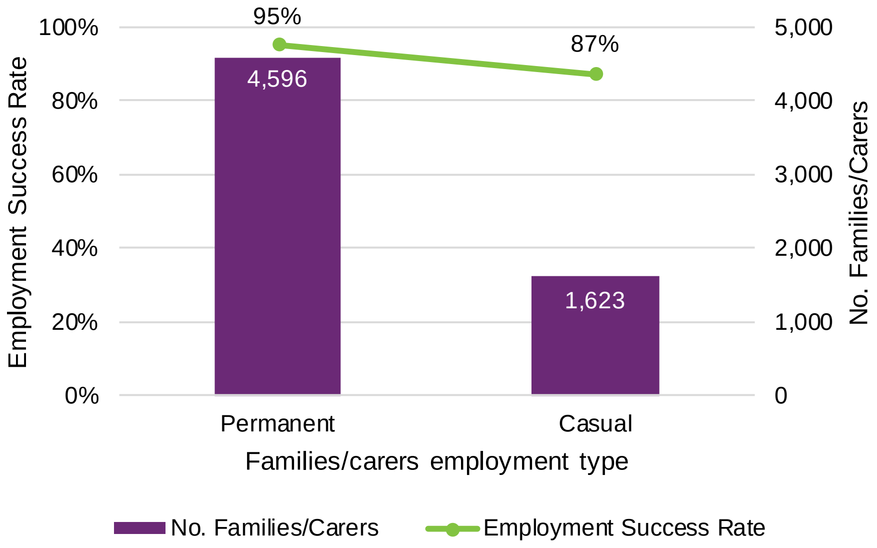
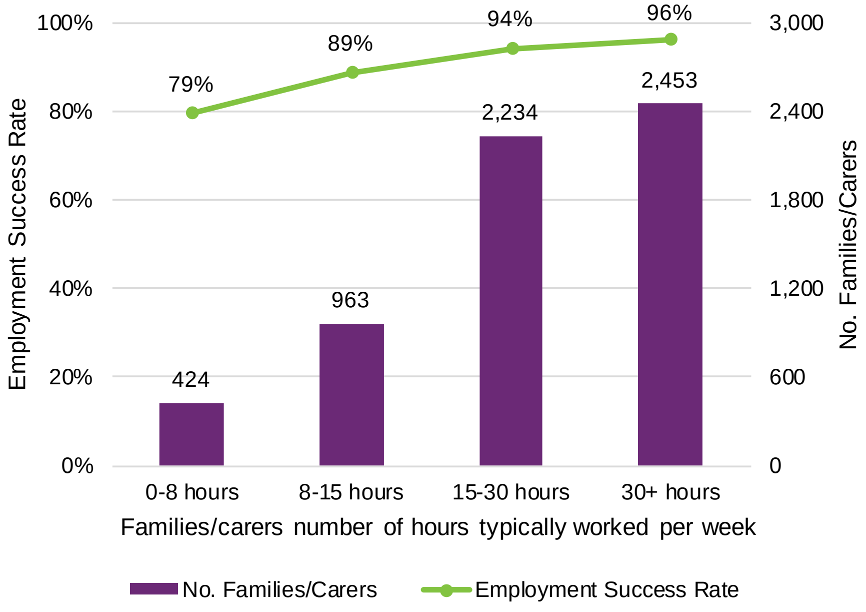


Figure 9.22 shows that families and carers who are employed in a casual job at baseline are less likely to have paid work at review compared to those who are permanently employed. This result could reflect that casual employment is generally less secure than permanent employment, as employers do not need to provide notice of termination or redundancy benefits to casual employees. Alternatively, some families and carers may find it difficult or unappealing to maintain casual work because the irregular hours and lack of paid leave entitlements can make it challenging to balance work and caring responsibilities.

Figure 9.23 Employment success rates by families/carers number of hours typically worked per week – for families/carers of participants aged 0 to 14, who are in paid work at baseline*



* Excludes missing responses

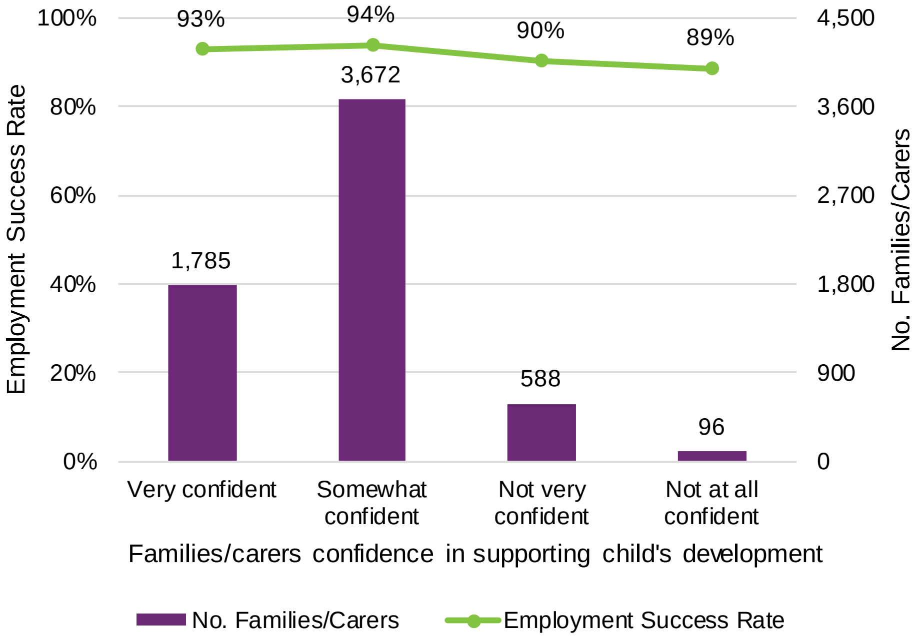
In Figure 9.23 the likelihood of maintaining paid work at review is shown to increase with the number of hours the family/carer works per week at baseline. While lower employment success rates for part-time workers may be partly due to higher rates of casual employment, the regression analysis suggests an additional impact that may be related to capacity to work. Families/carers who are only working a few hours per week may have chosen to do so because of the situation with the child participant or their own circumstances e.g. ill health, which could reduce the likelihood of maintaining employment. Similarly, those families/carers who are working full-time at baseline may have chosen to do so because the situation with the child and the rest of the family is relatively stable, and thus they are more likely to have the capacity to retain their job at review.

Between baseline and review, the overall percentage of families/carers who are working 30+ hours per week has increased by approximately 2% whereas casual employment rates have remained steady (see Section 9.5). If the observed relationship between number of work hours and employment success continues into the future, it is expected that this increase in hours worked will result in more families and carers of NDIS participants successfully maintaining their paid employment (holding all other factors constant).

Confidence in supporting child's development

In the SF questionnaire, families and carers of participants aged 0 to 14 are asked 'How confident do you feel in supporting your child's development'. The employment success rate by the response to this question at baseline is illustrated in Figure 9.24 below.

Figure 9.24 Employment success rates by families/carers level of confidence in supporting the child's development – for families/carers of participants aged 0 to 14, who are in paid work at baseline*



* Excludes missing responses

A high proportion (88%) of families/carers feel somewhat or very confident in supporting their child's development at baseline, and this is associated with a higher likelihood of maintaining paid employment at review. If the NDIA is able to further increase the confidence of families and carers to support their children with a disability by providing reasonable and necessary supports for their development, it is possible that the percentage of families and carers who are able to maintain their employment will increase over time.

Access to services and supports, plan management, streaming type and access decision

These factors were also found to be key drivers of employment success for families and carers who are not in paid work at baseline i.e. they influence both the likelihood of finding and keeping a job. For further commentary on the relationship of these drivers to employment success, see Section 9.7.1.