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.

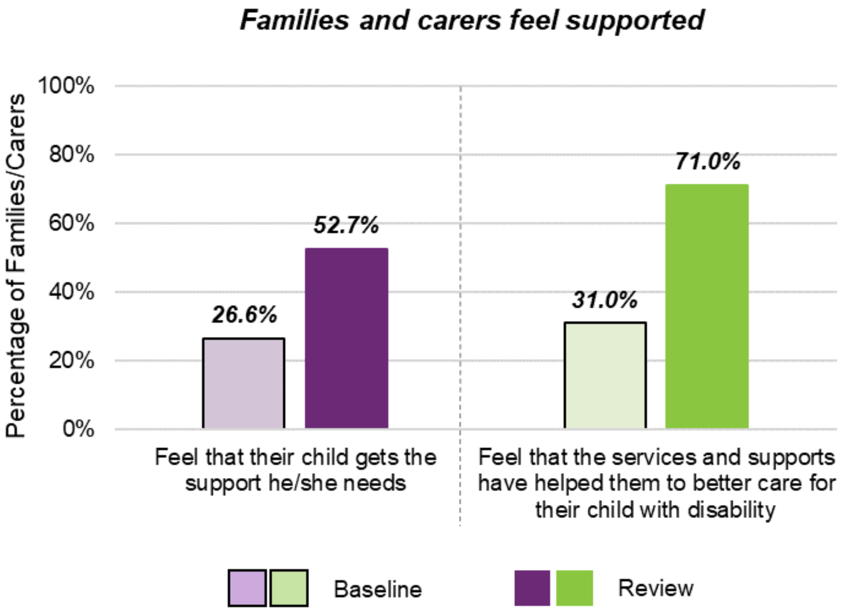
---

[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

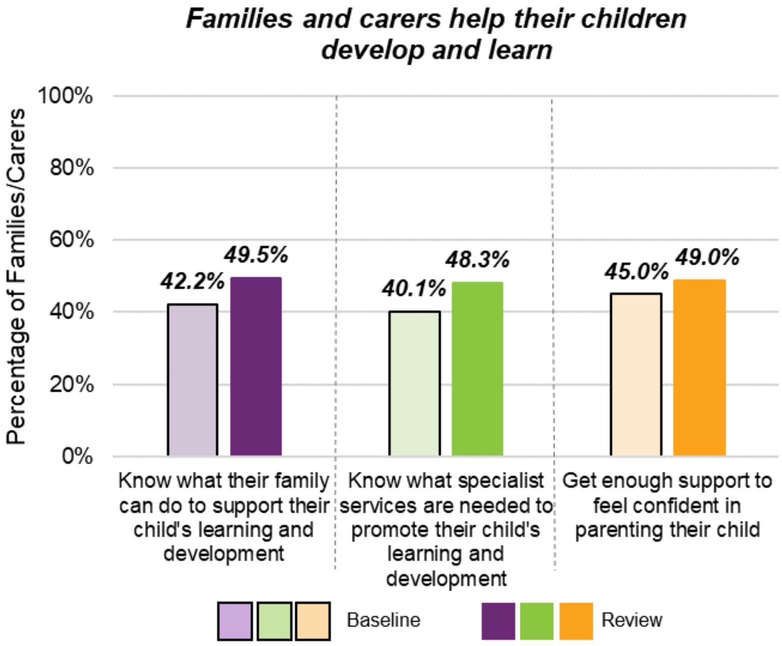
---

[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%.

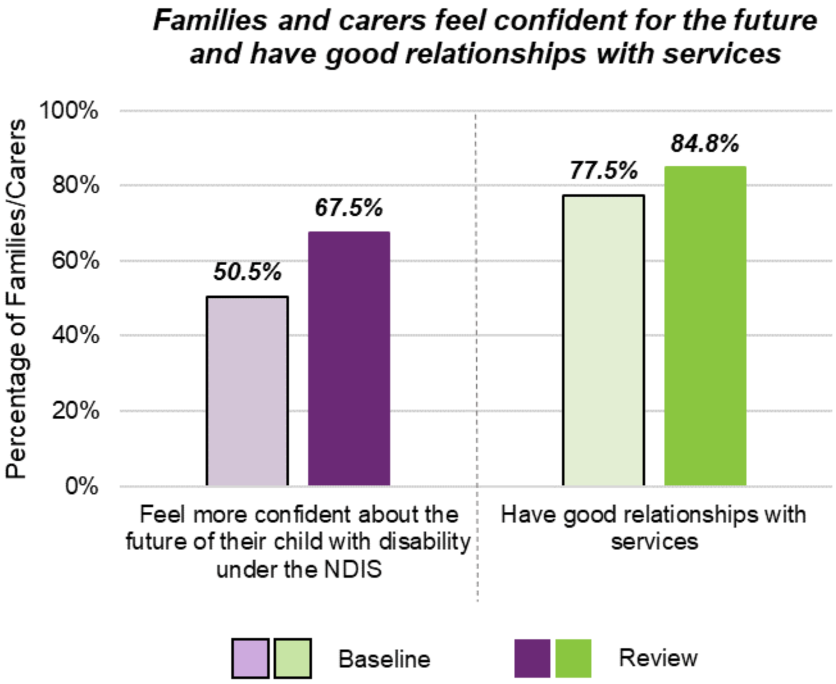
percentage who say they get enough support to feel confident in parenting their child has increased from 45% to 49%.

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



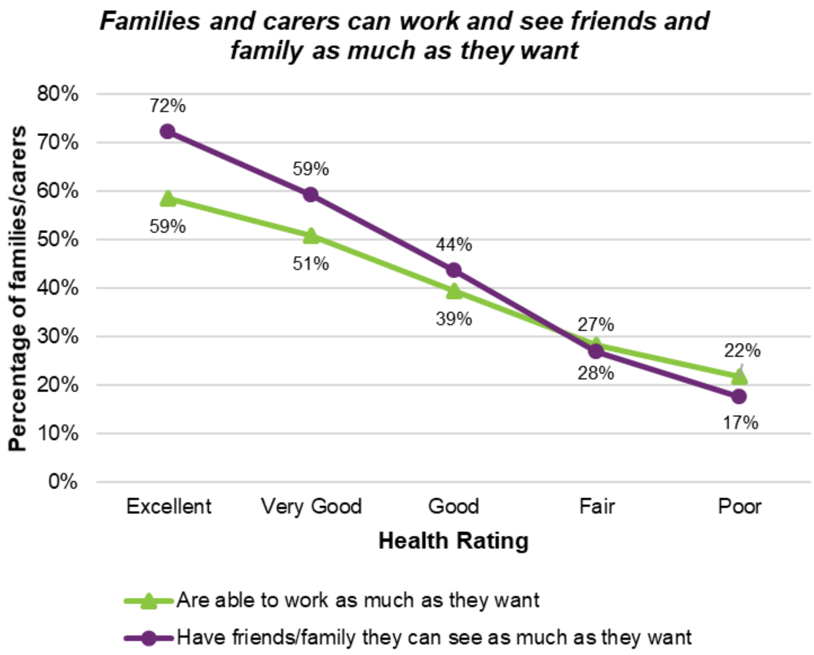
  - Some deterioration was observed in self-rated health, with the percentage rating their health as good, very good or excellent falling from 73% to 69%. For Australians aged 25 to 64, the corresponding percentage is 87%[7]. Families and carers were also more likely to perceive the situation of their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

---

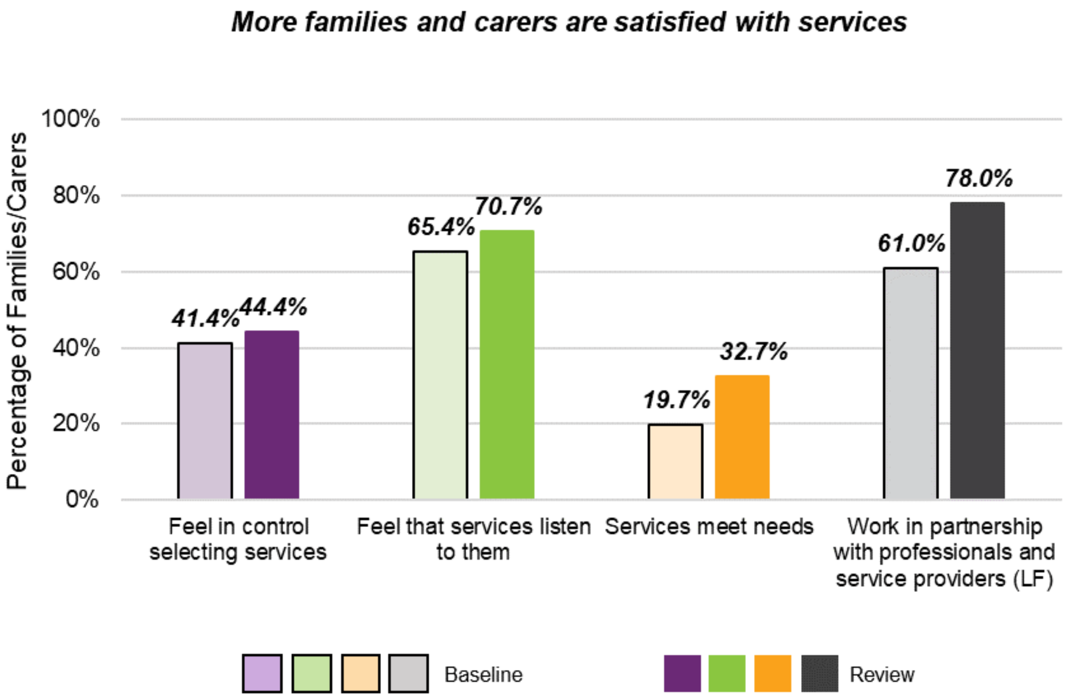
[7] ABS National Health Survey (NHS) 2014-15. Families/carers of 0 to 14 year olds are likely to be towards the younger end of the 25-64 age range.

- 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.

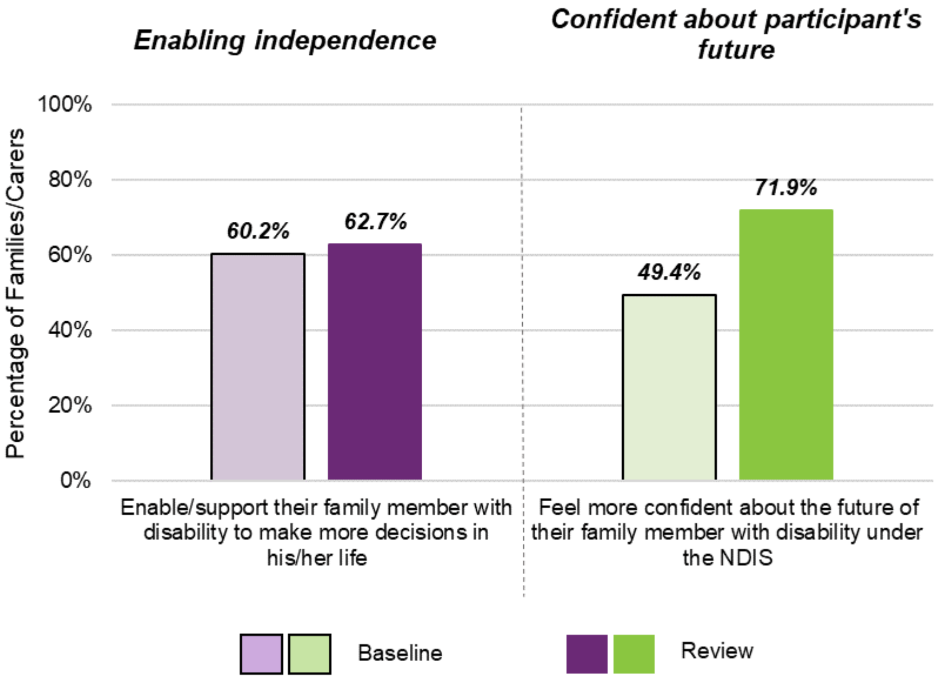
Figure 5 Families and carers of participants 15 to 24 are more satisfied with services



---

[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)

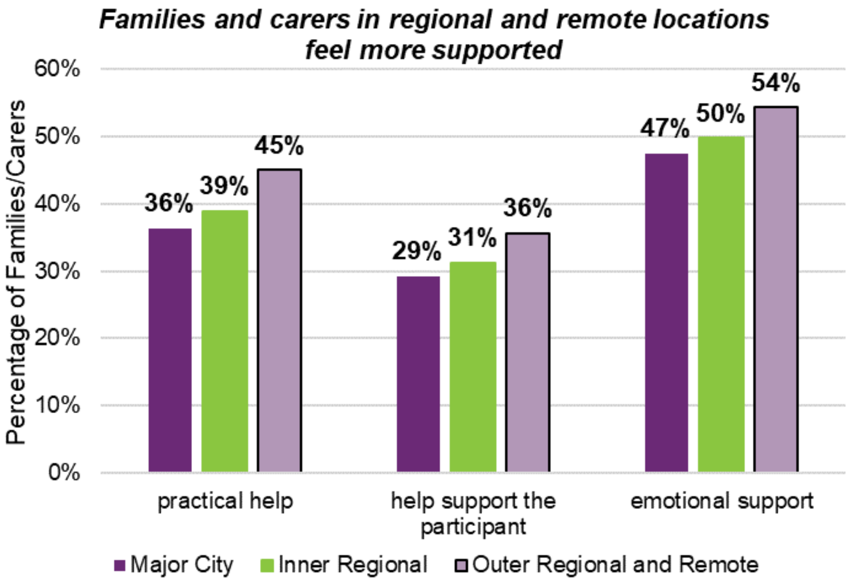
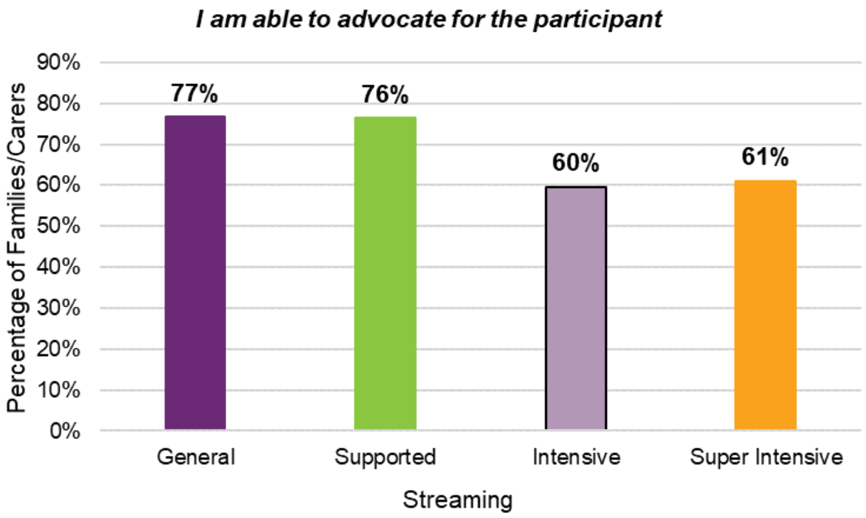


Figure 8 Percentage of families/carers who are able to advocate (stand up) for the participant in case of problems accessing supports by streaming type (baseline)



- 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.

---

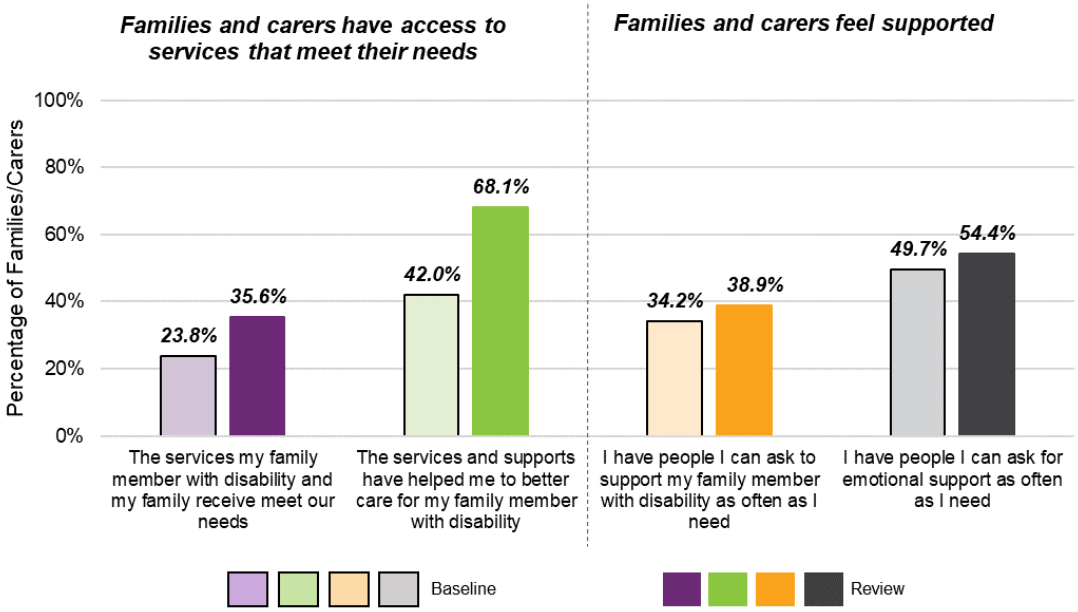
[9] ABS Survey of Disability, Ageing and Carers (SDAC) 2015, non-carers aged 15 to 64. https://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0

[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.

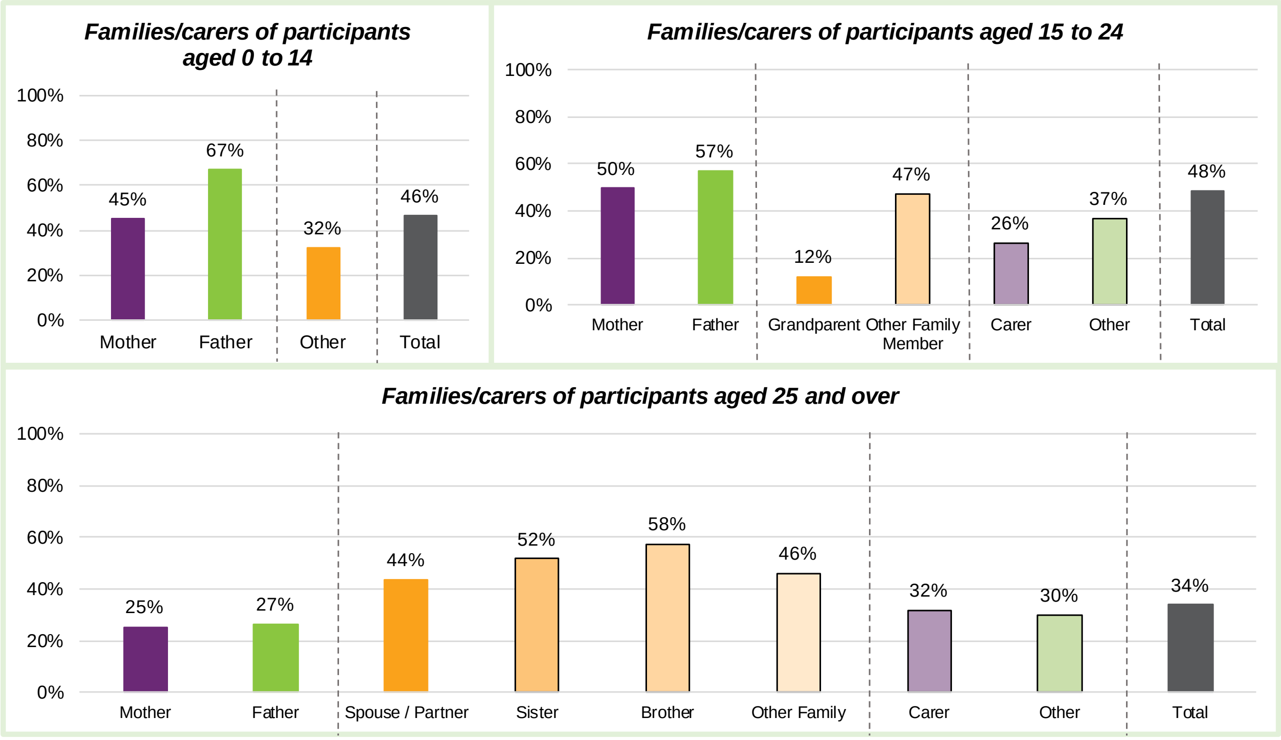
- Opinions on whether the NDIS has helped varied by domain. Most agreed that the NDIS has helped with level of support for the family (66%), access to services, programs and the community (62%), and the ability to advocate (53%). Responses were lower for succession planning (41%) and health and wellbeing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

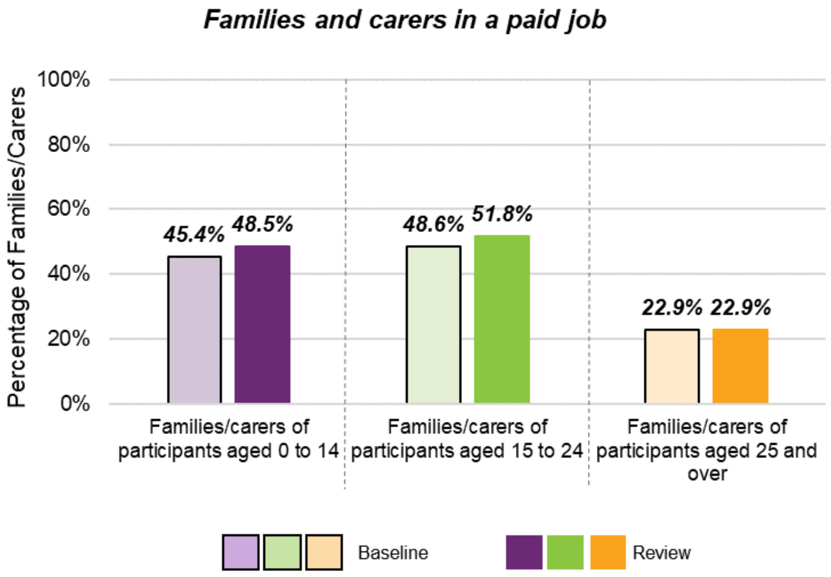
---

[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.