

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 over³⁶

- 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.

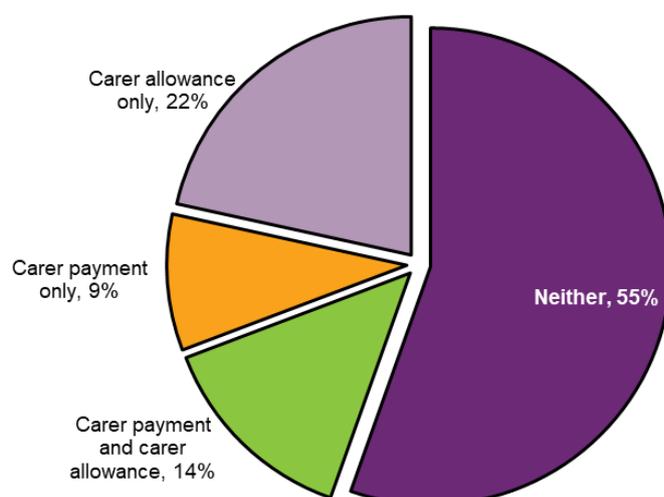
The LF survey for families and carers of participants aged 25 and over includes extra questions across each domain, with several additional questions in the health and wellbeing domain.

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

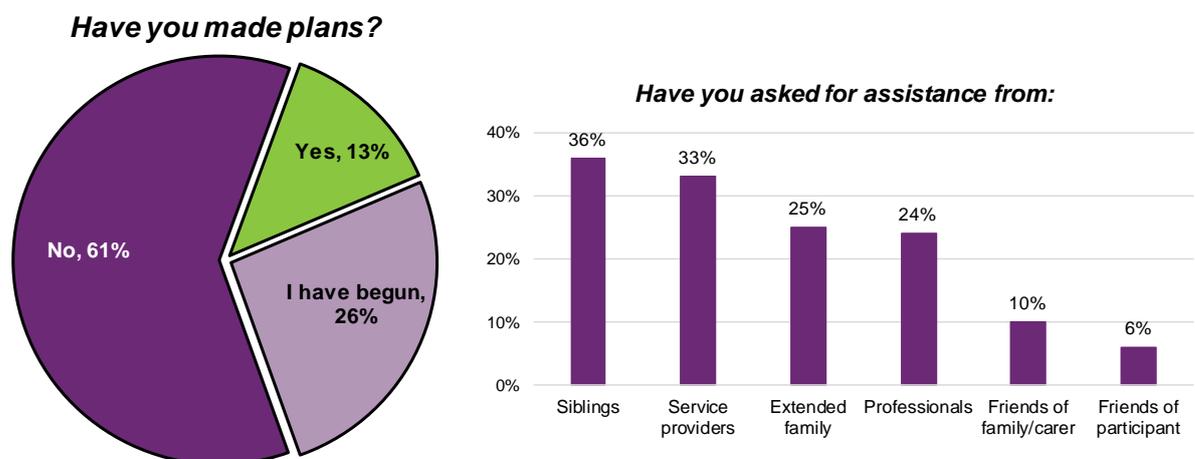
At baseline, 21% of families/carers said that the services the participant and the family receives meets their needs. Furthermore, the majority of families/carers reported that they have difficulty feeling in control when selecting services and supports that meet the needs of the family and participant, 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 (43%), service providers (40%), extended family (30%) and professionals (29%). Families and carers were the least likely to ask for assistance from their friends (13%) or friends of their family members (7%).

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 (89%), insufficient flexibility of jobs (22%), and availability of jobs (13%).

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

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

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 analyses³⁷. 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

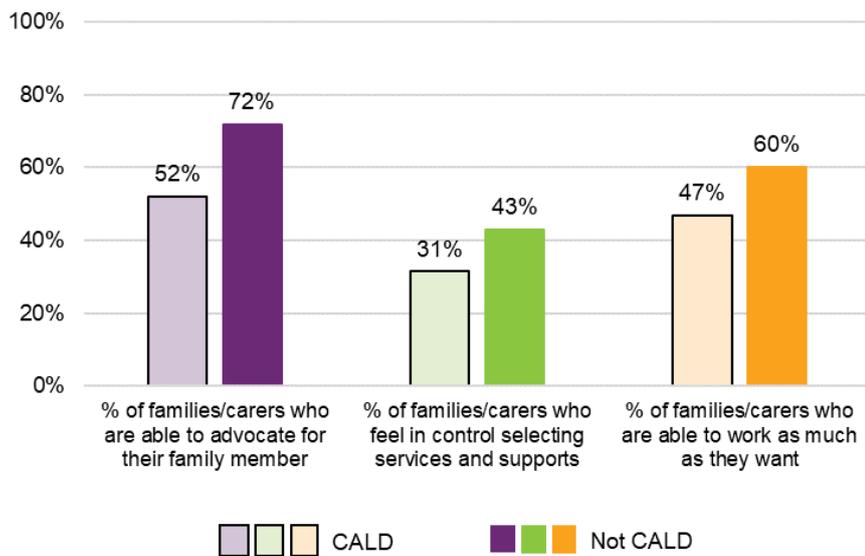
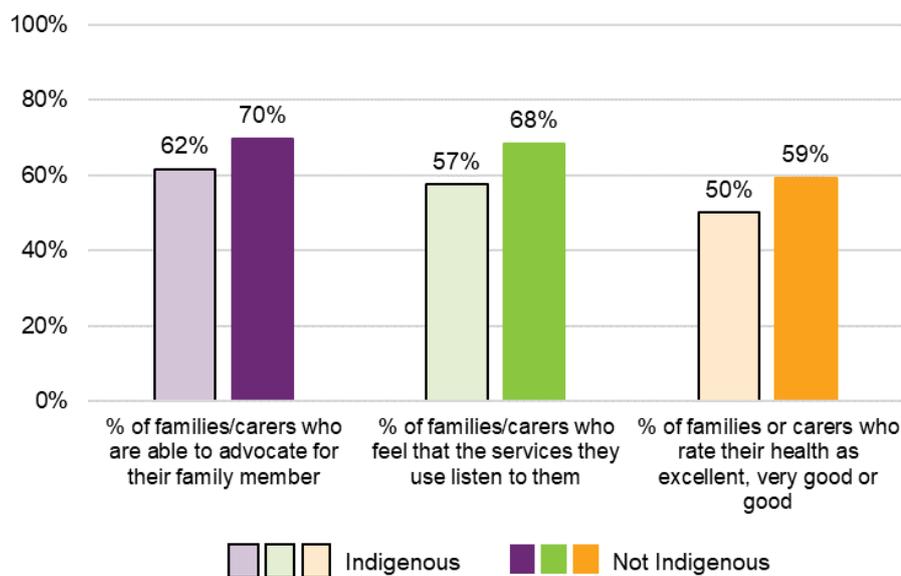


Figure 7.4 Baseline outcomes for families/carers of Indigenous and non-Indigenous participants aged 25 and over



- **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 entry³⁸.

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 characteristics has not been included for families/carers of participants aged 25 and over.