4. Families/carers of participants aged 25 and over: Outcome indicators

4.1 Key findings

Box 4.1: Comparison of families / carers of 2019-20 entrants with prior year entrants on key characteristics

- As at 30 June 2020, the combined baseline constitutes four years of experience (participants entering the Scheme between 1 July 2016 and 30 June 2020).
- Compared to prior year entrants, participants aged 25 and over who entered the Scheme in 2019-20 tend to be:

- Older.
- More likely to have psychosocial disability (19.0% compared to 10.9% for prior year entrants) and much less likely to have intellectual disability or Down syndrome (17.3% compared to 35.1%).
- More likely to require a low level of NDIA support through the participant pathway and less likely to require a medium level of support[31].
- Less likely to live in NSW or VIC and much more likely to live in WA (20.2% compared to 5.9%).
- Slightly more likely to identify as either Indigenous (5.3% versus 3.9%) or non-Indigenous (80.7% versus 78.5%), with the percentage not stated being lower (14% compared to 17.6%).
- More likely to be from a CALD background (17.7% compared to 11.9%).
- Slightly more likely to live in major cities, slightly less likely to live in regional areas, and slightly more likely to live in remote areas.
- Much more likely to have not received services from State/Territory or Commonwealth programs prior to entering the Scheme (70.8% compared to 28.3%), slightly more likely to have entered the Scheme for early intervention (4.2% compared to 2.2%) and slightly less likely to have entered due to disability.
- More likely to have baseline annualised plan budget between $30,000 and $100,000 and less likely to have annualised plan budget less than $30,000 or over $100,000.
- More like to fully self-manage their baseline plan (10.0% compared to 7.3%) or use a plan manager (54.2% compared to 34.2%) rather than agency manage.
- Similar with respect to level of function and gender.

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[31] The level of NDIA support a participant requires as they move along the participant pathway, having regard to the complexity of their situation.

Box 4.2: Baseline indicators for participants entering in 2019-20 – overall

- **Employment**

– At baseline, 40.0% of families/carers of 2019-20 entrants are in a paid job (higher than 35.2% for families/carers of prior year entrants) and 51.7% say that the family member who provides informal care to the participant is able to work as much as they want (lower than 58.9% for families/carers of prior year entrants).

- **Rights and Advocacy**

– The majority (77.3%) of families/carers understand their rights and the rights of their family member with disability, in line with prior years. Similarly, most families/carers reported that they are able to advocate for their family member and speak up if they have issues accessing support (60.9%, lower than 67.9% among families/carers of participants entering in prior years).

- **Family support & community participation**

– Most families/carers of adult participants reported low levels of feeling supported. 65.7% could not ask for practical help, 53.0% could not ask for emotional support and 74.9% could not ask for support for their family member with a disability. These percentages are higher than for families/carers of participants entering in prior years.

– At baseline, 12.2% of families/carers said that the services the participant / family receives meets their needs, whilst 68.1% of families/carers indicated that the services they receive helped them with future planning.

- **Succession planning**

– The majority of families/carers (70.2%, compared to 60.7% for prior years' baseline) said they had not made plans for when they are no longer able to care for their family member with a disability.

– Families/carers who had started to make plans were most likely to ask assistance from siblings, extended family or service providers.

- **Health and wellbeing**

– 60.7% of families/carers rate their health as good, very good or excellent at baseline, whilst 60.5% of families/carers disagreed or strongly disagreed that their family member with disability gets the support that they need.

– In terms of expectations for the future, 46.8% of families/carers answered positively, 40.8% had mixed or uncertain feelings and 12.5% answered negatively, similar to families/carers of participants entering in prior years.

– Most families/carers felt that the services and supports they used had helped them better care for the participant, with 56.0% answering positively, 32.9% being neutral and 11.2% having a negative response. These are slightly more positive results than for families/carers of participants entering in prior years.

Box 4.3: Baseline indicators for participants entering in 2019-20 – participant and family / carer characteristics

- For the majority of indicators, baseline outcomes are better for families/carers of participants with a high level of function and lower annualised plan budgets. For example, families/carers of participants with a lower level of function were less likely to work as much as they want, have people they can ask for practical help and emotional support as often as needed.
- Disability type was highly predictive of a family/carer's baseline outcomes. For example, families/carers of participants with a psychosocial disability had generally poorer outcomes across all domains compared to those of participants with an intellectual disability. These family/carers were less likely to have people they can ask for practical help as often as they need and were less likely to rate their health as good, very good or excellent.
- Compared to families/carers of male participants, families/carers of female participants were significantly less likely to have friends they can see as often as they like, and have people they can talk to for emotional support as often as they need.
- Baseline outcomes for families/carers of participants with a CALD background were less likely to be positive. For example, families/carers of CALD participants were less likely to be in a paid job, were less likely to be able to advocate for their family member with disability, and were less likely to have friends they can see as often as they like.
- Baseline outcomes for families/carers of participants from Indigenous backgrounds were generally worse than those for families/carers of non-Indigenous participants, especially with regard to employment, health and getting the services and supports they need.
- At baseline, families/carers of participants with a hearing impairment were the least likely to cite the situation of their family member with disability as a barrier to working more. This group also exhibited the best health and wellbeing outcomes at baseline and were most likely to feel supported.
- Outcomes for families/carers of participants aged 25 or older generally become more positive as the participant gets older, especially in the access to services domains and succession planning. However, the health and wellbeing and employment outcomes of families/carers of older participants tends to deteriorate, which is likely reflecting the positive relationship between participant and family/carer age. Despite being less likely to be in a paid job, families and carers of older participants were more likely to be able to work as much as they wanted.
- COVID-19 was associated with a number of changes to family/carer outcomes, with most changes being positive, especially for outcomes related to feeling supported. For example, during the pandemic:

– For families/carers who have a paid job, the percentage working 15 hours or more per week increased. The percentage who say that those providing informal care to their family member with disability are able to work as much as they want also increased.

– Higher percentages of families/carers said: they have people they can talk to for emotional support; the services they use listen to them; their family member gets the support they need; and their health is excellent, very good or good.

4.2 Outcomes framework questionnaire domains

For families/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 (RA)
- Feel supported (SP)
- Can gain access to desired services, programs and activities in their community (AC)
- Have succession plans (SC)
- Enjoy health and wellbeing (HW).

The LF contains a number of extra questions for the adult cohorts, across all domains, but particularly in the health and wellbeing domain.

Families and carers of participants answer the outcomes questionnaire applicable to their family member with disability's age at the time of interview. Hence the baseline cohort comprises families and carers of participants who are aged 25 and over when they enter the Scheme.

4.3 Comparison of families or carers of 2019-20 entrants with prior years on key characteristics

As discussed in Section 2.3, differences between participants by key characteristics (such as disability type and level of function) can occur over time, for example due to phasing in the transition period. For the participants aged 25 and over whose families and carers are the subject of this report, this section compares those entering the Scheme in 2019-20 with those entering in the earlier three year period, with respect to key characteristics.[32]

Figure 4.1 and Figure 4.2 summarise distributions by key characteristics for 2019-20 entrants and those for prior year entrants.

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[32] Note that the comparison is for participants whose family members and carers chose to respond to the family/carer survey. For participants 25 and over, a lower percentage of families/carers respond compared to the younger participant age groups. While the general pattern of differences between 2019-20 entrants and prior year entrants is similar for all participants and the subset whose families/carers responded to the survey, there are some differences in the distributions by characteristics. For example, for all participants and for the subset with a family/carer survey, the percentage with a psychosocial disability is higher for 2019-20 entrants and the percentage with an intellectual disability is lower, compared to prior year entrants. However the absolute percentages are different (all participants, 2019-20 entrants: 30.3% psychosocial, 12.3% intellectual/Down syndrome; all participants, prior year entrants: 18.1% psychococial, 30.3% intellectual/Down syndrome; subset with family/carer survey, 2019-20 entrants: 19.0% psychosocial, 17.3% intellectual/Down syndrome; subset with family/carer survey, prior year entrants: 10.9% psychococial, 35.1% intellectual/Down syndrome). Full details of the distributions for all participants are available in the participant baseline outcomes report.

Figure 4.1 Distributions by key characteristics – families or carers for 2019-20 entrants compared with prior year entrants

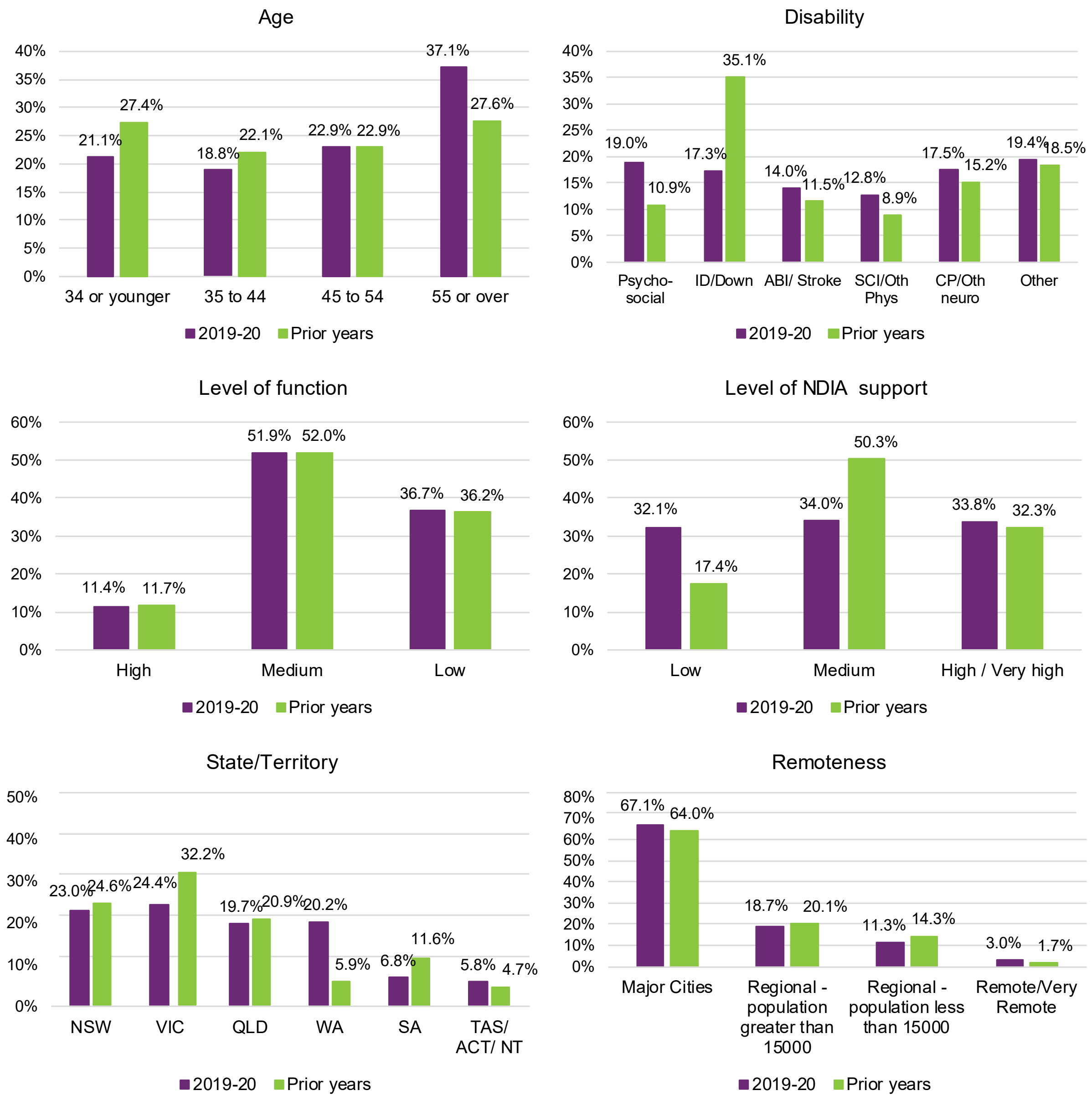
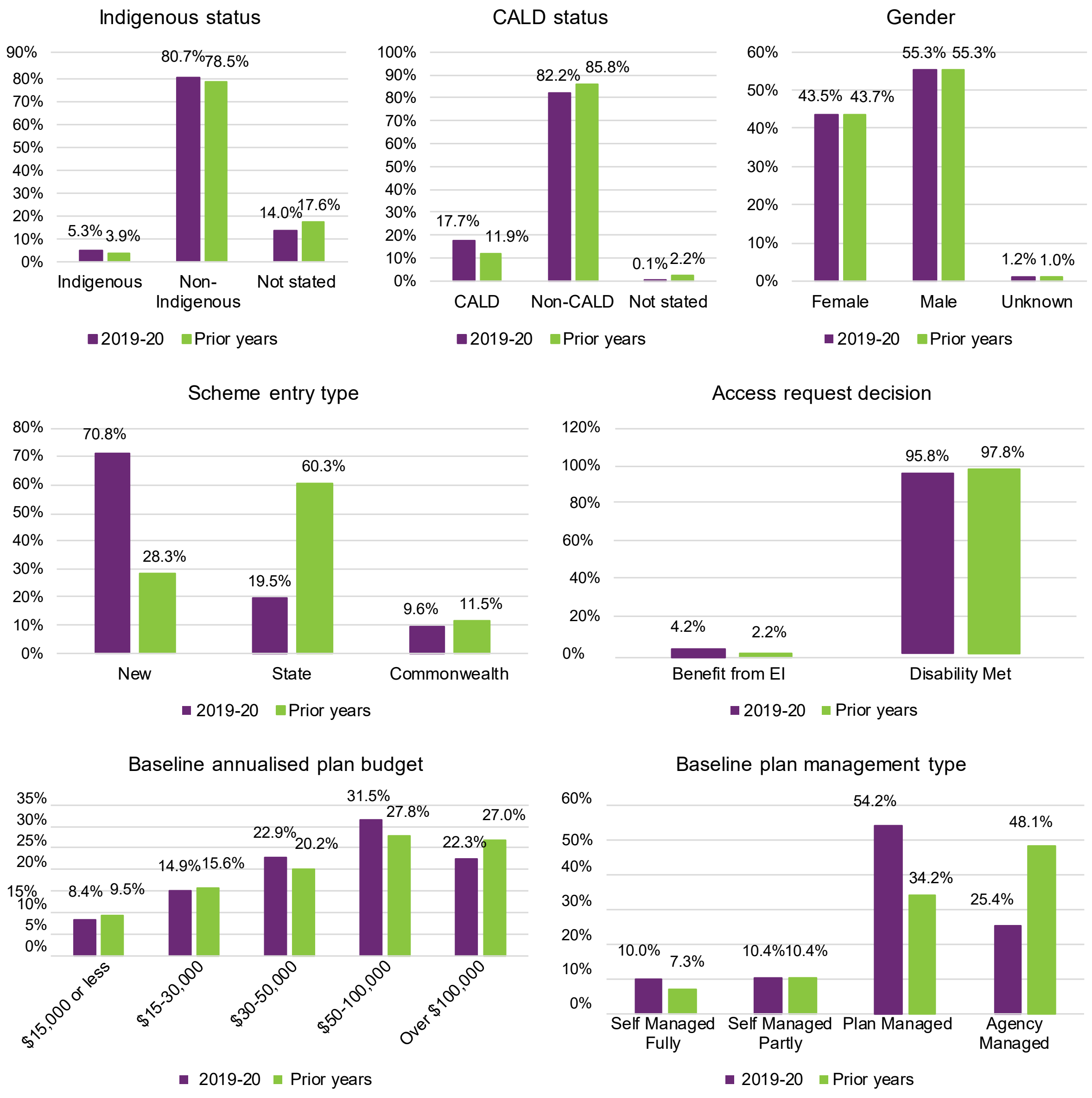


Figure 4.2 Distributions by key characteristics - families or carers for 2019-20 entrants compared with prior year entrants



The graphs in Figure 4.1 and Figure 4.2 show that compared to prior year entrants, participants who entered the Scheme in 2019-20 tend to be:

- Older (37.1% aged 55 or over compared to 27.6 % for prior year entrants).
- Less likely to have an intellectual disability or Down syndrome (17.3% compared to 35.1% for prior year entrants), more likely to have a psychosocial disability (19.0% compared to 10.9%) and slightly more likely to have other disabilities.
- More likely to require a low level of NDIA support through the participant pathway (32.1% compared to 17.4%) and less likely to require a medium (34.0% compared to 50.3%) but slightly more likely to require a high/very high (33.8% compared to 32.3%) level of support.
- Less likely to live in NSW (23.0% compared to 24.6%), VIC (24.4% compared to 32.2%) or SA (6.8% compared to 11.6%) and more likely to live in WA (20.2% compared to 5.9%).

- Slightly more likely to live in major cities (67.1% compared to 64.0%) and less likely to live in regional areas, but slightly more likely to have lived in remote areas (3.0% comapred.to 1.7%).
- Slightly more likely to identify as Indigenous (5.3% compared to 3.9%, noting that the percentage not stated is lower for 2019-20 entrants).
- More likely to be from a CALD background (17.7% compared to 11.9%).
- Much more likely to have not received services from State/Territory or Commonwealth programs prior to entering the Scheme (70.8% compared to 28.3%).
- Slightly more likely to have entered the Scheme for early intervention (s24) (4.2% compared to 2.2%) and slightly less likely to have entered due to disability (s25) (95.8% compared to 97.8%).
- More likely to have baseline annualised plan budget between $30,000 and $100,000 (54.3% compared to 48.0%) and less likely to have annualised plan budget over $100,000 (22.3% versus 27.0%).
- More likely to fully self-manage their baseline plan (10.0% compared to 7.3%) or to use a plan manager (54.2% compared to 34.2%) and less likely to agency manage (25.4% compared to 48.1%).

However, distributions by level of function and by gender are similar between 2019-20 entrants and prior year entrants.[33]

4.4 Baseline indicators for participants entering in 2019-20 – overall

Government benefits (Carer Payment and Carer Allowance) [34]

In the baseline SF questionnaire, 34.7% of families/carers of adult participants report that they are receiving a government benefit for their caring responsibilities. 15.1% of families/carers receive the Carer Allowance only, 8.1% receive the Carer Payment only, and 11.4% receive both of the carer government benefits (Figure 4.3).

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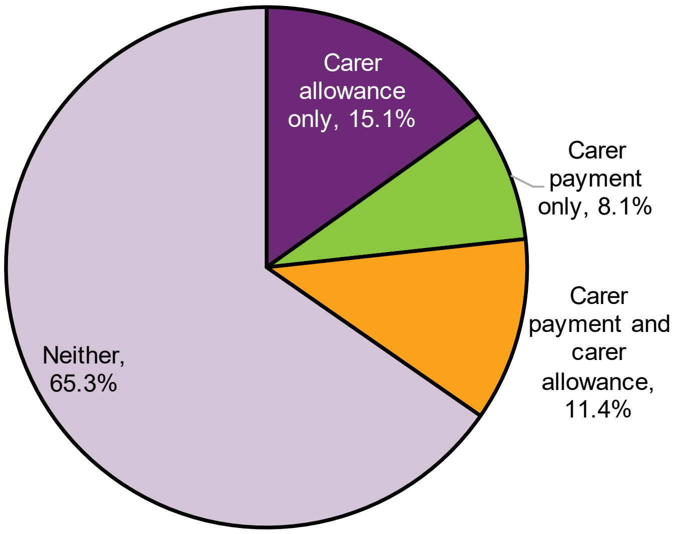
[33] Chi-squared tests for differences in the distributions were performed, but due to the large volume of baseline data, they are powered to detect very small differences. For families or carers of participants aged 25 and above, there was no significant difference for level of function (p=0.531) or gender (p=0.880), but all other p-values were less than 0.0001.

[34] Families/carers self-report whether they receive carer payment or carer allowance.

Figure 4.3 Percentage of families/carers of participants aged 25 and over receiving government carer benefits at baseline



Rights and advocacy

The LF asks families/carers if they understand their rights and the rights of their family member with disability, to which the majority (77.3%) answered in the affirmative at baseline, in line with prior years. Similarly, in the SF most families/carers reported that they are able to advocate for their family member and speak up if they have issues accessing support (60.9%, lower than 67.9% among families/carers of participants entering in prior years).

On the other hand, only 38.4% of families/carers reported in the baseline SF that they are able to identify the needs of their family member with disability and know how to access the services and support that the family member needs. For this question, 40.2% of families/carers reported that they had some difficulty, and 21.5% had great difficulty, higher than the baseline for prior years, where 36.8% of families/carers reported that they had some difficulty, and 15.9% 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 (45.6%) said they have family and friends that they see as often as they like, lower than 48.5% for prior years' baseline. In terms of being able to ask for support as often as needed, 65.7% could not ask for practical help, 53.0% could not ask for emotional support and 74.9% could not ask for support for their family member with disability. These percentages are higher than the average baseline response of families/carers of participants entering in prior years where 61.3% could not ask for practical help, 50.7% could not ask for emotional support and 70.1% could not ask for support for their family member with a disability.

In the LF, 52.5% of families/carers reported that they had as much contact with other families of people with a disability as they would like, slightly lower than the average baseline response from families/carers of participants entering in prior years, where 55.1% reported having 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, 12.2% of families/carers said that the services the participant and their family receives meets their needs, lower than 20.3% among families/carers of participants entering in prior years at baseline. 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 44.4% having some difficulty and 22.4% facing a great deal of difficulty.

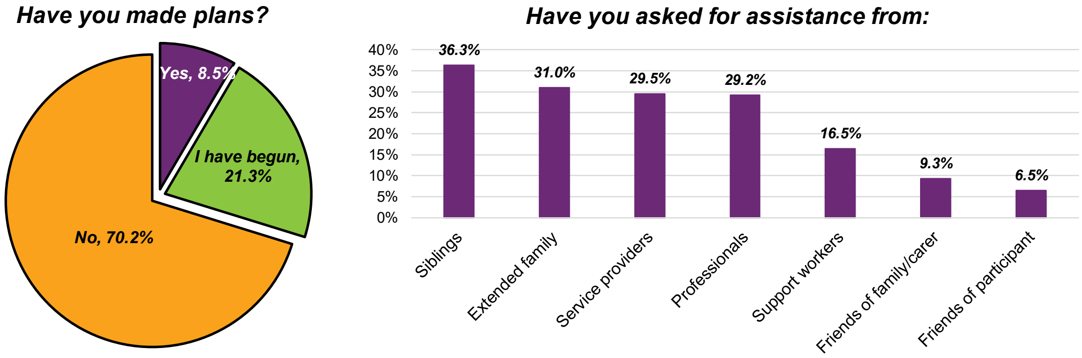
On the other hand, at baseline 66.0% of families/carers reported that the services they and their family member with a disability use listen to them (68.5% among families/carers of participants entering in prior years at baseline), and 68.1% said that the services they received helped them plan for the future (63.7% among families/carers of participants entering in prior years at baseline).

Succession planning

At baseline, the majority of families/carers (70.2%, compared to 60.7% for prior years' baseline) said they had not made plans for when they are no longer able to care for their family member with a disability, and 21.3% said they had begun making preparations, compared to 27.1% for prior years' baseline.

For the families/carers who reported that they had asked for assistance, the most common sources of assistance were the participant's siblings (36.3%), extended family (31.0%), service providers (29.5%) and professionals (29.2%). Families/carers were least likely to ask for assistance from their friends (9.3%) or friends of their family members (6.5%). By contrast, families/ carers of participants entering in prior years were more likely to ask for assistance from siblings (43.4%) and service providers (38.1%), with a similar percentage asking for assistance from extended family (29.5%).

Figure 4.4 Succession planning for families/carers of participants aged 25 and over



Employment

At baseline, 40.0% of families/carers of 2019-20 entrants are in a paid job (higher than 35.2% for families/carers of prior year entrants) and 51.7% say that the family member who provides informal care to the participant is able to work as much as they want (lower than 58.9% for families/carers of prior year entrants). The main barriers to working more were the situation of the family member with a disability (90.1%, compared to 89.4% for prior year entrants), insufficient flexibility of jobs (18.8% compared to 21.0%), and availability of jobs (12.3% compared to 12.5%).

It is important to note that a higher proportion of families/carers of participants aged 25 and over have reached retirement age, compared to the families/carers of younger participants, which has an impact on the percentage of families/carers in a paid job. However, the percentage who are able to work as much as they want is higher than for other participant age cohorts.

Health and wellbeing

60.7% of families/carers rate their health as good, very good or excellent at baseline, higher than 58.9% among families/carers of participants entering in prior years at baseline. This is lower than the results for the other participant age groups, likely reflecting the older age of this cohort. 60.5% of families/carers disagreed or strongly disagreed that their family member with disability gets the support that they need at baseline, higher than 54.4% among families/carers of participants entering in prior years at baseline.

Several additional questions are included in the LF regarding the wellbeing of families/carers and their outlook on life generally. For the question on their own expectations for the future, 46.8% of families/carers answered positively, 40.8% had mixed or uncertain feelings and 12.5% answered negatively, similar to prior years' baseline. With respect to their family member with a disability, 61.6% of families/carers agreed or strongly agreed that they feel more confident about the future of their family member with disability under the NDIS, while 28.3% responded neutrally. Families/carers of prior year entrants tended to be less positive on this indicator: 47.8% agreed or strongly agreed that they feel more confident about the future of their family member with disability under the NDIS and 45.5% responded neutrally.

In the LF, at baseline, 54.5% 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 26.4% disagreed or strongly disagreed (19.1% were neutral). This view is similar to that of families/carers of participants entering in prior years at baseline. For the question on whether families/carers felt that services and supports had helped them better care for the participant, 56.0% answered positively, 32.9% were neutral and 11.2% had a negative response. The response for this question from families/carers of 2019-20 entrants is slightly more positive than that for prior year at baseline, where 48.6% answered positively, 40.8% were neutral and 10.6% had a negative response.

4.5 Baseline indicators for families/carers of participants entering in 2019-20 – participant and family/ carer characteristics

Baseline indicators have been analysed by participant and family/carer characteristics using one-way analyses and multiple regression modelling.

Across most domains, the participant's primary disability type, age, CALD status, annualised plan budget and who manages their plan are the characteristics most predictive of family/carer outcomes in the multiple regression models, which control for other factors.

Key findings for each characteristic are summarised below. Tables summarising the direction of the effect for selected characteristics, in the regression models for selected outcomes, are also included. The arrow symbols in the tables indicate whether participants from a group are more likely (up arrow) or less likely (down arrow) to respond "Yes" to a question. Table 2.1 (in the family/carers of participants from birth to age 14 chapter) provides a key to aid interpretation of the arrow symbols, including some examples.

Participant primary disability type

Controlling for other factors, families/carers of participants with psychosocial disability had generally poorer outcomes across all domains compared to the reference level (i.e. families/carers of participants with intellectual disability). They were less likely to be able to advocate for their family member (50.9% compared to 60.9% overall), have people they can ask for practical help as often as they needed (25.8% compared to 34.3% overall), get the services and supports that they need to care for their family member with disability (4.2% compared to 7.9% overall), have made plans for when they are no longer able to care for their family member with disability (6.2% compared to 8.5% overall), rate their health as excellent, very good or good (50.8% compared to 60.7% overall) and to be able to work as much as they want (48.0% compared to 51.7% overall).

Families/carers of participants with autism also had generally poorer outcomes across multiple domains compared to those with intellectual disability. In particular, they were less likely to have friends they can see as often as they'd like, have people they can ask for practical help as often as they need, get the services and supports they need to care for their family member with disability, rate their health as excellent, very good or good and to be able to work as much as they want.

Families/carers of participants with other neurological disabilities had mixed, but mostly positive baseline outcomes relative to those with intellectual disability. For example, they were more likely to be in a paid job (46.8% compared to 40.0% overall), to advocate for their family member with disability (65.7% compared to 60.9% overall) and to feel that the services they use listen to them (70.2% compared to 66.0% overall). However, they were less likely to say that the services for them and their family member with disability meet their needs (9.9% compared to 12.2% overall), and to be able to work as much as they want (47.3% compared to 51.7% overall).

Families/carers of participants with multiple sclerosis exhibited mixed baseline outcomes. They were more likely to be in a paid job, to be able to advocate for their family member, and to have someone to talk to for emotional support. However, they were less likely to have made plans for when they are no longer able to care for their family member with disability (5.0% compared to 8.5% overall) and to feel that their family member gets the support they need (15.1% compared to 18.6% overall).

Families/carers of participants with ABI or Down syndrome had few significant effects relative to those with Intellectual disability, however, for the few results which were significant, they were positive and had better outcomes. For example, families/carers of participants with ABI were more likely to rate their health as excellent, very good or good (62.1% compared to 60.7% overall), and families/carers of participants with Down syndrome were more likely to feel that their family member gets the support they need (35.0% compared to 18.6% overall) and more likely be able to advocate for their family member with disability (73.0% compared to 60.9% overall).

Families/carers of participants with other physical disabilities were mixed. For example, they were more likely to be able to identify the needs of their family member with disability (51.5% compared to 38.4% overall), however, they were also less likely to feel that the services they use listen to them (65.5% compared to 66.0% overall).

Table 4.1 shows baseline family/carer outcomes of which participant's primary disability type is a significant ($p<0.05$) predictor in the multiple regression model[35].

Table 4.1 Relationship of disability type with the likelihood of selected outcomes:

	Participant primary disability Compared to participants with primary disability of intellectual disability						
Outcome	Psychosocial disability	Other Neurological	Other Physical	Autism	ABI	Down Syndrome	Multiple Sclerosis
Being in a paid job		⬆	⬆		⬆		⬆
Receiving carer payments		⇩			⇩	⇩	⬆
Receiving carer allowance	⇩	⇩	⇩				
Being able to identify the needs of their family member with disability		⬆	⬆		⬆		
Being able to advocate for their family member with disability	⬇	⬆				⬆	⬆
Having friends they can see as often as they'd like	⬇			⬇			
Having people they can ask for practical help as often as needed	⬇	⬆		⬇			
Having people they can ask to support their family member with disability as often as needed	⬇			⬇			
Having people they can talk to for emotional support as often as needed	⬇	⬆	⬆	⬇			⬆

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[35] The reference level is Intellectual disability.

Outcome	Participant primary disability Compared to participants with primary disability of intellectual disability						
	Psychosocial disability	Other Neurological	Other Physical	Autism	ABI	Down Syndrome	Multiple Sclerosis
Getting the services and supports they need to care for their family member with disability	↓			↓			
Feeling the services they and their family member with disability use listen to them	↓	↑	↓				
Feeling in control of selecting the services and supports that meet the needs of their family member with disability	↓	↑	↓				
Saying the services for them and their family member with disability meet their needs	↓	↓		↓			↓
Having made plans for when they are no longer able to care for their family member with disability	↓						↓
Rating their health as excellent, very good or good	↓	↑		↓	↑		↑
Feeling their family member gets the support they need	↓			↓		↑	↓
Being able to work as much as they want	↓	↓		↓			

Comparing families/carers of 2019-20 entrants with families/carers of prior year entrants, baseline results by disability are generally similar. As for 2019-20 entrants, families/carers of participants with psychological disability or autism tended to report more negative baseline outcomes, and participants with Down syndrome tended to have better baseline outcomes.

Participant age

Controlling for other factors, families/carers of older participant exhibited better outcomes in the domains of feeling supported, access to services, and succession planning. However, they had poorer outcomes in the domains of employment and health/wellbeing, which is expected as they approach retirement. From the regression modelling, families/carers of older participants were:

- Less likely to be in a paid job;
    - However, they were more likely to be able to work as much as they wanted.
- More likely to have friends they can see as often as they'd like;
- More likely to get the services and supports they need to care for their family member with disability and to feel that the services they use listen to them;
- More likely to have made plans for when they are no longer able to care for their family member with disability; and
- Less likely to rate their health as excellent, very good or good.

Table 4.2 shows baseline family/carer outcomes of which participant age is a significant ($p<0.05$) predictor in the multiple regression model[36].

Gender

Families/carers of female participants were significantly less likely to:

- have friends they can see as often as they like (42.6% compared to 48.1% for male participants)
- have people they can talk to for emotional support as often as they need (44.1% compared to 49.3% for male participants).

On the other hand, of those in paid work, families/carers of female participants were more likely to work 15 hours or more per week (87.7% compared to 84.7% for male participants).

CALD status

Controlling for other factors, families/carers of participants with a CALD background exhibited poorer outcomes across all the domains surveyed. For example, they were less likely to:

- be in a paid job (36.6% compared to 40.7% for non-CALD) and to be able to work as much as they wanted (38.6% compared to 54.5%)
    - For those unable to work as much as they wanted, more likely to identify the situation of their child with disability (91.0% compared to 89.9%) and the availability of jobs (16.8% compared to 11.0%) as a barrier to working more
- be able to identify the needs of their family member with disability (26.3% compared to 41.0% for non-CALD) and to be able to advocate for them (40.6% compared to 65.4%)

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[36] The reference level is NSW.

- have friends they can see as often as they'd like (40.5% compared to 46.7% for non-CALD), have people they can ask for practical help (28.0% compared to 35.7%), support for their family member (20.3% compared to 26.2%) and emotional support (40.1% compared to 48.5%) whenever they need.
- get the services and supports they need to care for their family member with disability (5.5% compared to 8.4%), feel that the services they use listen to them (60.1% compared to 67.2%), and feel in control of selecting those services (22.8% compared to 35.5%)
- ask for help from service providers, professionals or support workers for those who have made plans for when they are no longer able to care for their family member with disability (51.3% compared to 56.7% for non-CALD).

Table 4.2 shows baseline family/carer outcomes of which CALD status is a significant (p<0.05) predictor in the multiple regression model.

Indigenous status

Controlling for other factors, families/carers of Indigenous participants had generally poorer outcomes across all domains. In particular, they were less likely to:

- be in a paid job (22.0% compared to 40.7% for non-indigenous)
    - For those not working as much as they want, they were significantly more likely to identify the availability of jobs (39.3% compared to 10.8%) and the insufficient flexibility of available jobs (30.7% compared to 18.2%) as a barrier to working more.
- get the services and supports they need to care for their family member with disability (4.9% compared to 8.2% for non-indigenous)
- rate their health as excellent, very good or good (57.2% compared to 60.8% for non-indigenous)

However, they were more likely to have friends they can see as often as they'd like (55.1% compared to 45.2% for non-indigenous).

Table 4.2 shows baseline family/carer outcomes of which Indigenous status is a significant (p<0.05) predictor in the multiple regression model.

Table 4.2 Relationship of participant age, CALD status and Indigenous status with the likelihood of selected outcomes

Outcome	Variable			
	Participant is older	Participant is female	Participant is CALD	Participant is Indigenous
Being in a paid job	⬇		⬇	⬇
For family/carers with a paid job, working 15 or more hours per week	⬇	⬆		
Receiving carer payment			⬆	⬆
Receiving carer allowance				⬆

Outcome	Variable			
	Participant is older	Participant is female	Participant is CALD	Participant is Indigenous
Currently studying	⇩			
Being able to identify the needs of their family member with disability			⬇	
Being able to advocate for their family member with disability			⬇	
Having friends they can see as often as they'd like	⬆	⬇	⬇	⬆
Having people they can ask for practical help as often as needed			⬇	
Having people they can ask to support their family member with disability as often as needed			⬇	
Having people they can talk to for emotional support as often as needed		⬇	⬇	
Getting the services and supports they need to care for their family member with disability	⬆		⬇	⬇
Feeling the services they and their family member with disability use listen to them	⬆		⬇	
Feeling in control of selecting the services and supports that meet the needs of their family member with disability			⬇	
Saying the services for them and their family member with disability meet their needs			⬇	
Having made plans for when they are no longer able to care for their family member with disability	⬆			
of those who made or have begun making plans, families or carers who have asked for help from service providers, professionals or support workers			⬇	
Rating their health as excellent, very good or good	⬇			⬇
Feeling their family member gets the support they need			⬇	⬇
Being able to work as much as they want	⬆		⬇	
For those unable to work as much as they want, the situation of their child/family member with disability being a barrier to working more	⬇		⬆	

	Variable			
Outcome	**Participant is older**	**Participant is female**	**Participant is CALD**	**Participant is Indigenous**
For those unable to work as much as they want, the availability of jobs being a barrier to working more	⬇		⬆	⬆
For those unable to work as much as they want, the insufficient flexibility of jobs being a barrier to working more	⬇			⬆

Comparing baseline outcomes by age, gender, Indigenous and CALD status for families/carers of 2019-20 entrants with those of prior year entrants:

- Trends by age are largely similar: baseline outcomes tend to be better for families/carers of older participants, with the exception of self-reported health status.
- Some of the same differences by gender were identified, with families/carers of female participants being more likely to work 15 or more hours per week and less likely to have people they can talk to for emotional support than families/carers of male participants. However, for prior year entrants, a few more indicators were more positive for families/carers of female participants.
- Consistent with prior years' baseline, outcomes for families/carers of participants from Indigenous backgrounds were generally worse than those for families/carers of non-Indigenous participants, especially with regard to employment and health and wellbeing.
- Differences between CALD and non-CALD participants are largely consistent. Baseline outcomes for families/carers of participants from CALD backgrounds tend to be worse than those from non-CALD backgrounds in almost all domains.

Participant level of function and annualised plan budget

Controlling for other factors, families/carers of participants with a lower level of function / higher annualised plan budget had generally poorer baseline outcomes across all the domains. For example, families/carers of participants with a lower level of function were less likely to:

- be in a paid job, and work as much as they want (44.2% for those with a low level of function, increasing to 62.4% for those with a high level of function)
    - Of those unable to work as much as they want, they were more likely to identify the situation of their child with disability as a barrier to working more (93.5% for those with a low level of function, increasing to 83.8% for those with a high level of function)
- be able to identify the needs of their family members with disability (33.4% for those with a low level of function, increasing to 47.8% for those with a high level of function) and to advocate for them (55.2% for those with a low level of function, increasing to 67.5% for those with a high level of function)
- have people they can ask for practical help (25.9% for those with a low level of function, increasing to 47.9% for those with a high level of function) and emotional support (38.6% for those with a low level of function, increasing to 57.2% for those with a high level of function) as often as needed

- get the services they need to care for their family member with disability (6.0% for those with a low level of function, increasing to 15.9% for those with a high level of function) and feel that the services they use listen to them (62.7% for those with a low level of function, increasing to 69.7% for those with a high level of function)
- rate their health as excellent, very good or good (54.9% for those with a low level of function, increasing to 69.2% for those with a high level of function)
- feel their family member gets the support they need (16.5% for those with a low level of function, increasing to 26.4% for those with a high level of function).

The direction of the effect of a higher annualised plan budget on baseline outcomes was similar to the effect of a lower level of function, except that employment outcomes tended to be more positive for higher annualised plan budget (controlling for other factors).

Table 4.3 also shows baseline family/carer outcomes of which level of function and annualised plan budget amount is a significant ($p<0.05$) predictor in the multiple regression model.

Table 4.3 Relationship of participant level of function and annualised plan budget with the likelihood of selected outcomes:

Outcome	Variable	
	Lower level of function	Higher annualised plan budget
Working in a paid job	⬇	⬆
For family/carers with a paid job, working in a permanent job		⬆
For family/carers with a paid job, working 15 or more hours per week		⬆
Receiving carer payment	⬆	⇩
Receiving carer allowance	⬆	⇩
Being able to identify the needs of their family member with disability	⬇	⬇
Being able to advocate for their family member with disability	⬇	⬇
Having friends they can see as often as they'd like	⬇	⬇
Having people they can ask for practical help as often as needed	⬇	⬇
Having people they can ask to support their family member with disability as often as needed	⬇	⬇
Having people they can talk to for emotional support as often as needed	⬇	⬇

Outcome	Variable	
	Lower level of function	Higher annualised plan budget
Getting the services and supports they need to care for their family member with disability	⬇	
Feeling the services they and their family member with disability use listen to them	⬇	
Feeling in control of selecting the services and supports that meet the needs of their family member with disability	⬇	
Saying the services for them and their family member with disability meet their needs	⬇	
Having made plans for when they are no longer able to care for their family member with disability	⬇	
of those who made or have begun making plans, % of families or carers who have asked for help from service providers, professionals or support workers		⬆
Rating their health as excellent, very good or good	⬇	⬇
Feeling their family member gets the support they need	⬇	
Being able to work as much as they want	⬇	⬇
For those unable to work as much as they want, the situation of their child/family member with disability being a barrier to working more	⬆	⬆
For those unable to work as much as they want, the availability of jobs being a barrier to working more		⬇

Comparing 2019-20 entrants with participants entering in earlier years, baseline trends by level of function and annualised plan budget are very similar. Baseline indicators are generally better for families/carers of participants with higher level of function / lower annualised plan budget.

However, there were a few minor differences on specific indicators. For example, for prior year entrants, parents/carers of participants with higher annualised budget did not report significantly different outcomes in the rights and advocacy domain. However, the families/carers of participants with a higher annualised budget tended to have worse baseline outcomes in the rights and advocacy domain for entrants in 2019-20.

Plan Management Type

Baseline outcomes are generally better for families/carers of participants with self-managed plans (either partly or fully). For example, they are more likely to be working in a paid job, and more likely to have informal support networks.

Remoteness

Families/carers of participants living in regional areas were less likely to have a paid job, but more likely to have people they can ask for practical help and to support their family member with disability. Families/carers of participants living in remote/very remote areas were also more likely to have people they can ask for practical help and to support their family member with disability, but less likely to feel that the services they use listen to them.

Impact of COVID-19

The methodology for investigating the impact of COVID-19 has been outlined in Section 2.5.

For families/carers of participants aged 25 and over who entered the Scheme in 2019-20, there were seven indicators for which one or both of the COVID-related terms was significantly different from zero.

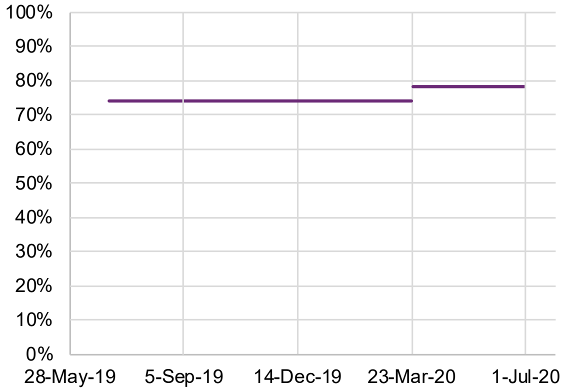
For all seven indicators, there was a significant step change at the assumed date of onset of the pandemic, but no significant time trend either before or after this date. Most of the changes were positive during the pandemic. Specifically, during the pandemic:

- For families/carers who have a paid job, the percentage working 15 hours or more per week increased.
- The percentage who say that those providing informal care to their family member with disability are able to work as much as they want also increased.
- A higher percentage of families/carers reported having people they can talk to for emotional support as often as they need during the pandemic.
- A higher percentage of families/carers said that the services they use listen to them.
- A higher percentage of families/carers thought that their family member with disability gets the support they need.
- The percentage of families/carers rating their health as excellent, very good or good increased.
- For families/carers who have begun to make plans for the future support of their family member, the percentage who have asked for help from service providers, professionals or support workers decreased.

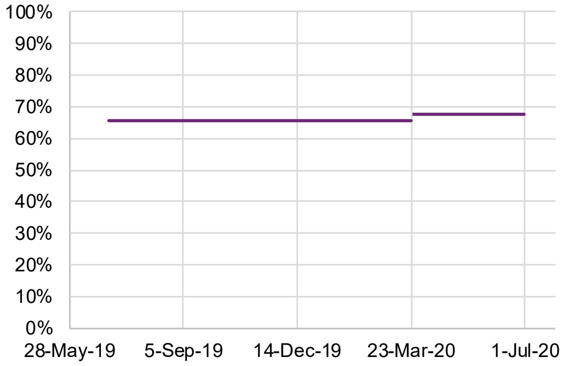
These trends are illustrated in Figure 4.5 and Figure 4.6.

Figure 4.5 Estimated trend over time for indicators where the COVID indicator term was significant

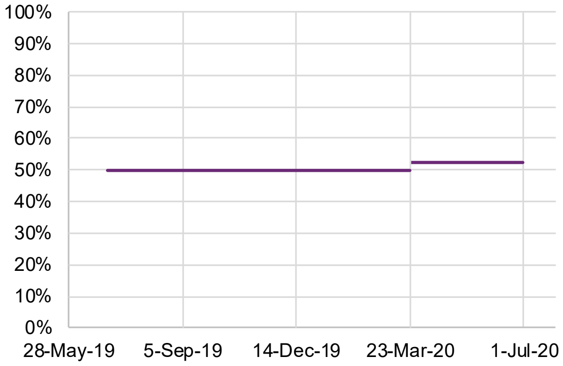
of those in a paid job, % who work 15 hours or more per week



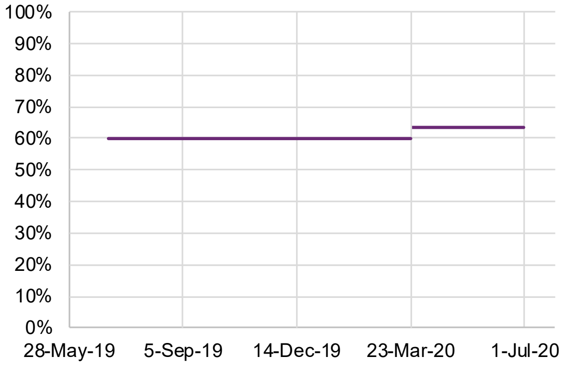
% of families or carers who provide informal care to their family member with disability and are able to work as much as they want



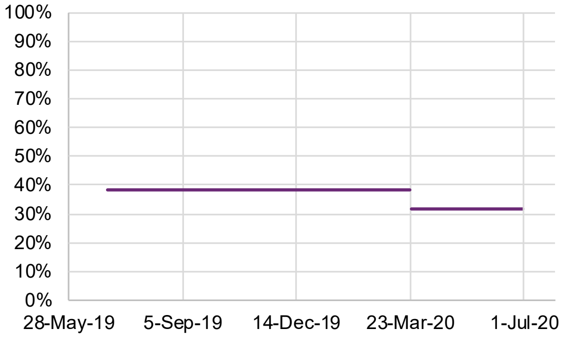
% of families or carers who have people they can talk to for emotional support as often as they need



% of families or carers who feel that the services they use for their family member with disability listen to them



of those who made or have begun making plans, % of families or carers who have asked for help from service providers, professionals or support workers



% of families or carers who rate their health as excellent, very good or good

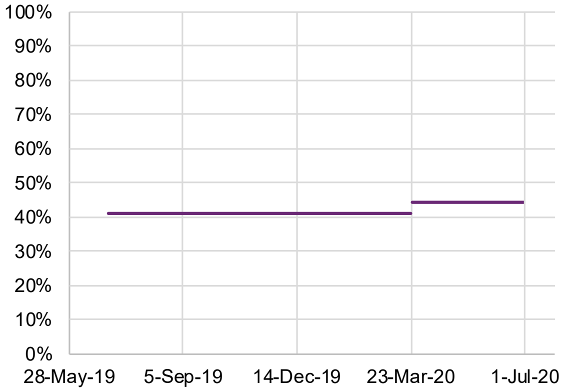
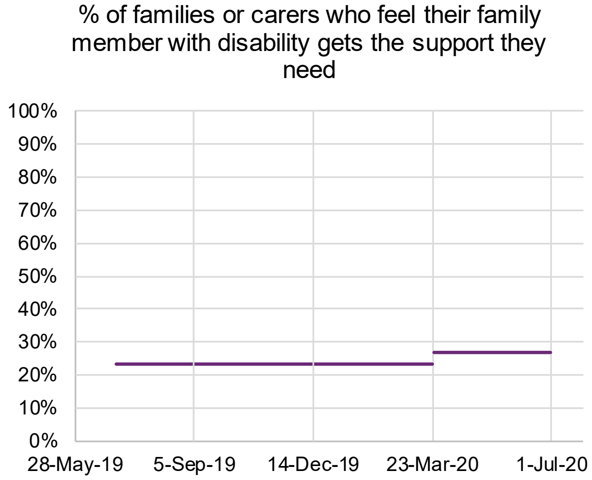


Figure 4.6 Estimated trend over time for indicators where the COVID indicator term was significant



Box 4.4 summarises the key findings from this section.

Box 4.4: Summary of findings – results by participant and family/carer characteristics

- For the majority of indicators, baseline outcomes are better for families/carers of participants with a high level of function and lower annualised plan budgets. For example, families/carers of participants with a lower level of function were less likely to work as much as they want, have people they can ask for practical help and emotional support as often as needed.
- Family/carer baseline outcomes vary by participant disability type. For example, families/carers of participants with a psychosocial disability had generally poorer outcomes compared to those of participants with an intellectual disability. Families/carers of participants with a hearing impairment exhibited the best health and wellbeing outcomes at baseline and were most likely to feel supported.
- Compared to families/carers of male participants, families/carers of female participants were significantly less likely to have friends they can see as often as they like, and have people they can talk to for emotional support as often as they need.
- Baseline outcomes for families/carers of participants with a CALD background were less likely to be positive. For example, families/carers of CALD participants were less likely to be in a paid job, were less likely to be able to advocate for their family member with disability, and were less likely to have friends they can see as often as they like.
- Baseline outcomes for families/carers of participants from Indigenous backgrounds were generally worse than those for families/carers of non-Indigenous participants, especially with regard to employment, health and getting the services and supports they need.
- Outcomes for families/carers of participants aged 25 or older generally become more positive as the participant gets older, especially in the access to services domains and succession planning. However, the health and wellbeing and employment outcomes of families/carers of older participants tends to deteriorate.
- COVID-19 was associated with a number of changes to family/carer outcomes, with most changes being positive, especially for outcomes related to feeling supported. For example, during the pandemic:

– For families/carers who have a paid job, the percentage working 15 hours or more per week increased. The percentage who say that those providing informal care to their family member with disability are able to work as much as they want also increased.

– Higher percentages of families/carers said: they have people they can talk to for emotional support; the services they use listen to them; their family member gets the support they need; and their health is excellent, very good or good.