3. Families/carers of participants from age 15 to 24: Outcome indicators

3.1 Key findings

Box 3.1: Comparison of families/carers of 2019-20 entrants with prior years 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).
- The report focusses on baseline results for families and carers of 2019-20 entrants, but also includes a brief comparison with results for families and carers of prior year entrants. 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.
- Compared to prior year entrants, participants aged 15 to 24 who entered the Scheme in 2019-20 tend to be:

– Younger.

– More likely to have high and medium level of function and less likely to have low level of function.

– More likely to have autism as their primary disability and less likely to have an intellectual disability or Down syndrome.

– More likely to be from a CALD background (9.1% compared to 6.6%) and to be female (37.2% compared to 34.6%).

– Much more likely to have not received services from State/Territory or Commonwealth programs prior to entering the Scheme (70.5% compared to 28.9%), more likely to have entered the Scheme for early intervention (s24) (17.5% compared to 9.5%) and less likely to have entered due to disability (s25) (82.5% compared to 90.5%).

– More likely to require a low level of NDIA support through the participant pathway (49.6% compared to 23.8%) and less likely to require a medium or a high/very high level of support.

– Less likely to have baseline annualised plan budget over $50,000 (22.2% versus 36.0%), and more likely to fully self-manage their baseline plan (22.2% compared to 12.0%) or to use a plan manager (44.7% compared to 29.8%) rather than agency manage.

– Similar with respect to Indigenous status.

Box 3.2: Baseline indicators for families or carers of participants entering in 2019-20 – overall

- At baseline, 54.2% of families/carers were in a paid job and 48.2% said that they were able to work as much as they wanted, higher than families/carers of entrants in prior years, of whom 49.4% were in a paid job and 46.5% were able to work as much as they wanted.
- Less than half of the families and carers of 2019-20 entrants were able to identify the needs of the participant and family and knew how to access available services and supports to meet those needs (43.6%, slightly lower than 47.0% for prior year entrants). However, most families/carers say they are able to advocate for the participant (67.6%, also slightly lower than 70.8% for prior year entrants).
- For 2019-20 entrants, 47.3% of respondents said they had friends and family they can see as often as they like, slightly higher than 43.1% for prior year entrants. 38.8% had people they can ask for practical help as often as needed, compared to 36.4% for prior year entrants.
- A generally low percentage of families/carers feel in control in selecting services and supports for their family member with disability at baseline (39.3%, similar to 40.6% for prior year entrants) and are satisfied that the services and supports they receive meet their needs (15.7%, slightly lower than 18.3% for prior year entrants). Compared to prior years, a slightly higher percentage of families and carers say that services listened to them (66.9% compared to 64.4% in prior years).
- A slightly higher percentage of families/carers of 2019-20 entrants rate their health as excellent, very good or good (65.3%) compared to families/carers of prior year entrants (60.9%). However, this is still much lower than the general population aged 40 and over, where 82.3% rate their health as excellent, very good or good.

Box 3.3: Baseline indicators for families or carers of participants entering in 2019-20 – participant and family/carer characteristics

- Families/carers of participants with autism showed poorer baseline outcomes across all domains compared to all other disability types, except that the percentage in a paid job (56.8%) is slightly higher than families/carers of participants with intellectual disability (44.6%).
- Families/carers of participants with a hearing impairment were more likely to report positive outcomes across most domains, compared to participants with other disabilities. For example, they were more likely to be working in a paid job (66.8% compared to 54.2% overall), to have people they can ask for practical help, as often as needed (69.3% compared to 38.8% overall), and to know what they can do to enable their family member with disability to be as independent as possible (63.6% compared to 35.9% overall).
- Families/carers of participants with self-managed baseline plans (fully or partly) had better baseline outcomes across all domains, than families/carers of participants with agency-managed plans. For example, they were more likely to have a paid job (67.9% and 61.2% for fully self-managed and partly self-managed participants respectively, compared to 44.4% for those agency-managed), and to be able to support their family member with disability to make more decisions in their life (63.6% and 63.3% for fully self-managed and partly self-managed participants respectively, compared to 54.3% for those agency-managed).
- Families/carers living in regional and remote/very remote areas had better baseline outcomes in relationships and self-rated health.
- Families and carers living in regional or remote/very remote areas who wanted to work more, were also more likely to identify the availability of jobs as being a barrier to working more (15.9-26.6% for regional areas; 40.5% for remote/very remote areas; compared to 14.0% for major cities).
- COVID-19 was associated with a number of changes to participant outcomes, with all changes being positive. Specifically, the baseline outcomes related to families feeling supported have generally become more positive, with increases during the pandemic in the percentages saying they: have friends they can see as often as they'd like; have people they can ask to support their family member with disability; have people they can talk to for emotional support; and feel that the services they use for their family member with disability listen to them. Additionally, a higher percentage of families/carers rated their health as excellent, very good or good compared to the pre-COVID period.

3.2 Outcomes framework questionnaire domains

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

- know their rights and advocate effectively for their family member with a disability (RA)
- feel supported (SP)
- can gain access to desired services, programs and activities in their community (AC)
- are able to help their young person to become independent (IN)
- enjoy health and wellbeing (HW).

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

Families and carers of participants answer the outcomes questionnaire applicable to the 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 between 15 and 24 when they enter the Scheme.

3.3 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 15 to 24 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.

Figure 3.1 and Figure 3.2 summarise distributions by key characteristics for 2019-20 entrants and those for prior year entrants.

Figure 3.1 Distributions by key characteristics - families or carers for 2019-20 entrants compared with prior year entrants

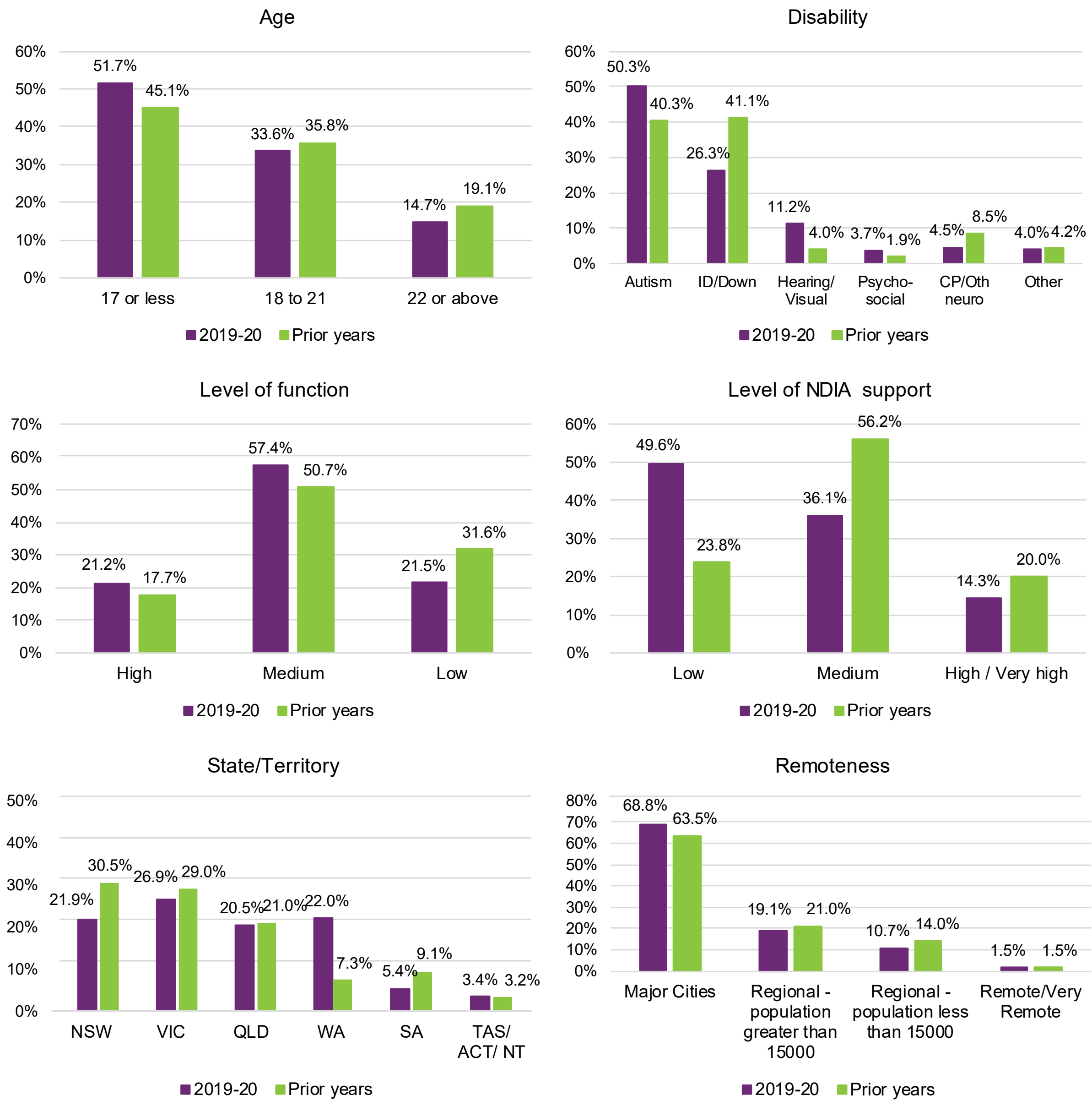
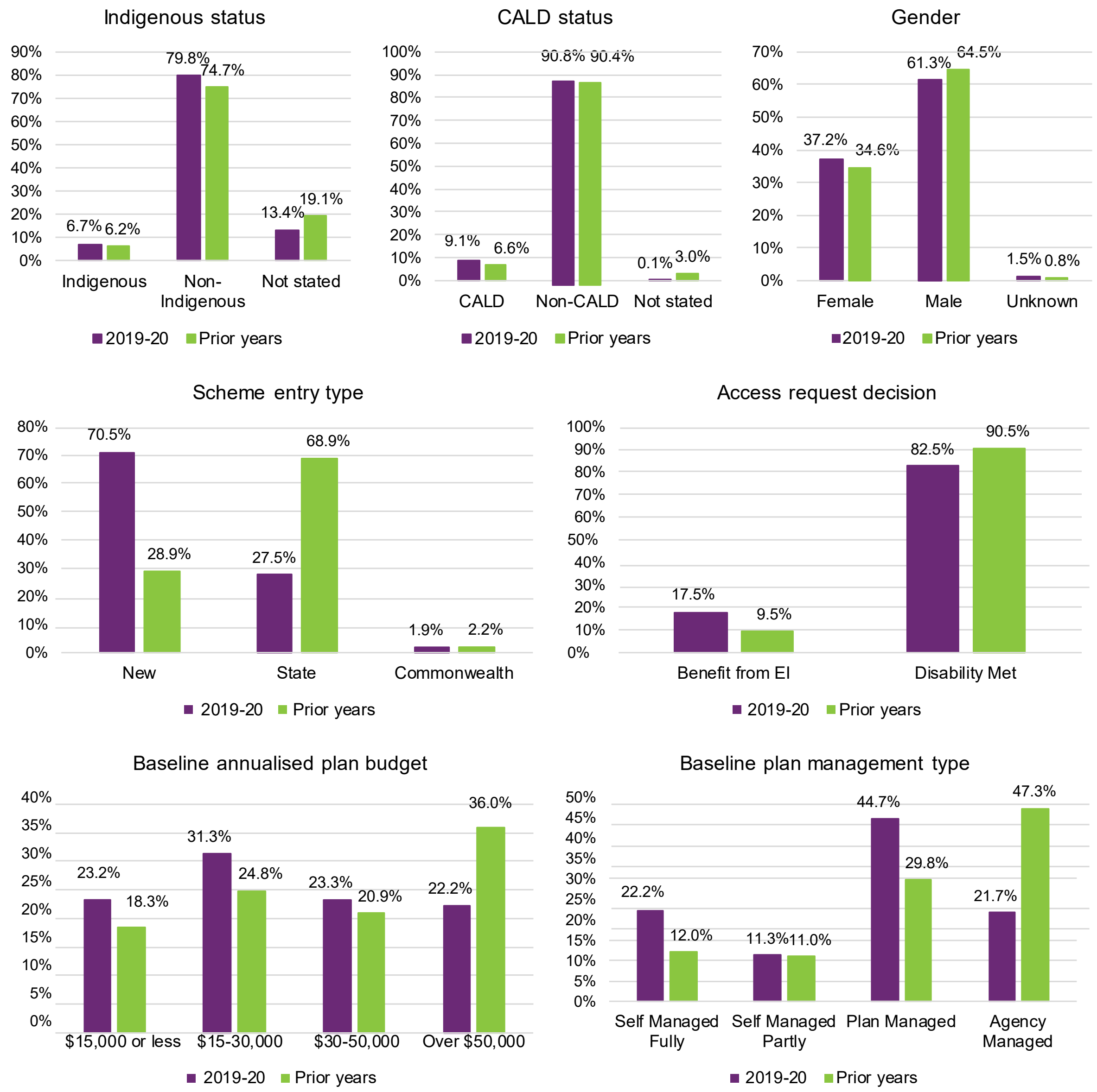


Figure 3.2 Distributions by key characteristics - families or carers for 2019-20 entrants compared with prior year entrants



The graphs in Figure 3.1 and Figure 3.2 show that compared to prior year entrants, participants who entered the Scheme in 2019-20 tend to be:

- Younger (51.7% aged 17 or younger, compared to 45.1% for prior year entrants).
- More likely to have autism (50.3% compared to 40.3% for prior year entrants), a hearing/visual impairment (11.2% compared to 4.0%) or a psychosocial disability (3.7% compared to 1.9%), and less likely to have an intellectual disability or Down syndrome (26.3% compared to 41.1%) or cerebral palsy/another neurological disability (4.5% compared to 8.5%).
- More likely to have high or medium level of function (21.2% and 57.4% compared to 17.7% and 50.7%) and less likely to have low level of function (21.5% compared to 31.6%).
- More likely to require a low level of NDIA support through the participant pathway (49.6% compared to 23.8%) and less likely to require a medium or a high/very high level of support.

- More likely to live in WA (22.0% compared to 7.3%), less likely to live in NSW (21.9% compared to 30.5%) or SA (5.4% compared to 9.1%), and slightly less likely to live in other States/Territories.
- Slightly more likely to live in major cities (68.8% compared to 63.5%) and less likely to live in regional areas.
- Slightly more likely to be from a CALD background (9.1% compared to 6.6%) and slightly more likely to be a female (37.2% compared to 34.6%).
- Much more likely to have not received services from State/Territory or Commonwealth programs prior to entering the Scheme (70.5% compared to 28.9%).
- More likely to have entered the Scheme for early intervention (s24) (17.5% compared to 9.5%) and less likely to have entered due to disability (s25) (82.5% compared to 90.5%).
- More likely to have baseline annualised plan budget $30,000 or less (54.5% compared to 43.1%) and less likely to have annualised plan budget over $50,000 (22.2% versus 36.0%).
- More likely to fully self-manage their baseline plan (22.2% compared to 12.0%) or to use a plan manager (44.7% compared to 29.8%) and less likely to agency manage (21.7% compared to 47.3%).

However, distributions by Indigenous status are similar between families and carers for 2019-20 entrants and prior year entrants.[23]

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

Government benefits (Carer Payment and Carer Allowance)

For families/carers of participants aged 15 to 24 who entered the Scheme in 2019-20, 18.8% were receiving Carer Payment and 33.8% were receiving Carer Allowance at baseline. These self-reported percentages are lower than for families/carers of participants entering the Scheme in prior years (27.8% for Carer Payment and 51.1% for Carer Allowance), and have been decreasing since 2016-17.

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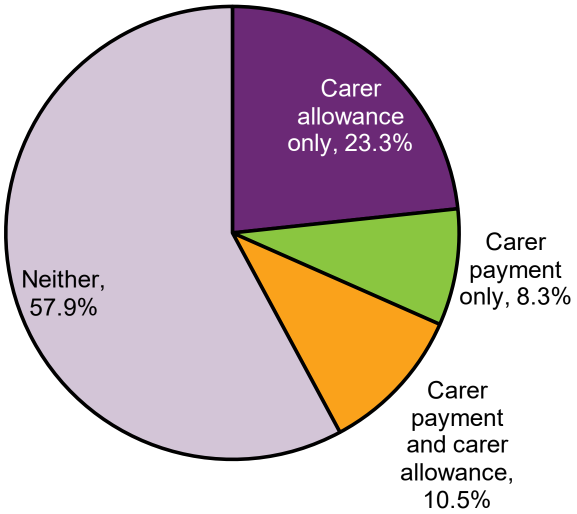
[23] Chi-squared tests for differences in the distributions were performed, but due to the large volume of baseline data, they are powered to detect very small differences. For families or carers for participants aged 15 to 24, there was no significant difference for indigenous status (p = 0.745) but all other p-values were less than 0.0001.

Figure 3.3 Receipt of Carer Payment and Carer Allowance for families/carers of participants aged 15 to 24



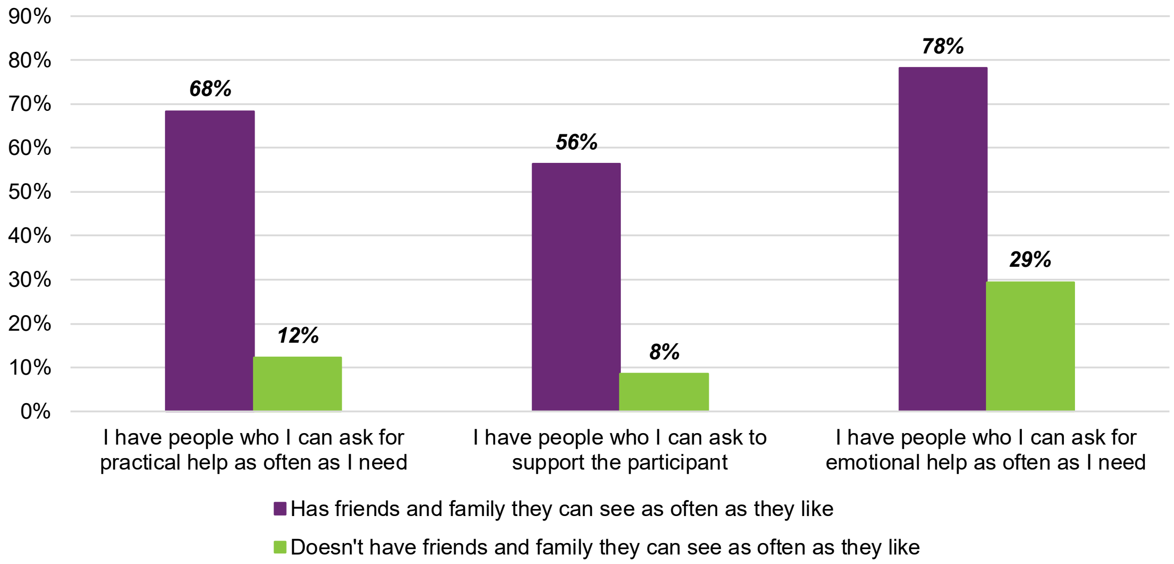
Rights and advocacy

Forty-four per cent of families/carers were able to identify the needs of the participant and family and knew how to access available services and supports to meet those needs. Furthermore, the majority (67.6%) reported being able to advocate (stand up) for the participant, where there may be issues or problems with accessing supports. These two percentages are slightly lower than the baseline for families/carers of participants entering in prior years, of whom 47.0% said they were able to identify the needs of the participant and family and knew how to access available services and supports to meet those needs, and 70.8% said they were able to advocate (stand up) for the participant.

Families feel supported

As with families/carers of participants from birth to age 14, most families/carers of participants aged 15 to 24 say they lack sufficient support or social connections. Forty-seven per cent of respondents had friends and family that they saw as often as they liked, higher than among families/carers of prior years' entrants at 43.1%. A slightly higher percentage of families/carers (52.5%) had someone who they could ask for emotional support as often as they needed, which is also higher than 47.9% among families/carers of prior years' entrants at baseline. However, fewer (38.8%, and 36.4% for prior years) families/carers had people they could ask for practical help as often as they needed. Similarly, 31.1% (and 29.1% for prior years) had people they could ask to support the participant as often as they needed. Nevertheless, having family and friends that the respondent could see as often as they liked increased the likelihood of receiving emotional and practical support. This relationship is illustrated in Figure 3.4.

Figure 3.4 Relationship between feeling supported outcomes and having friends and family they can see as often as they like for families/carers of participants aged 15 to 24



Access to services

Thirty-nine per cent of families/carers felt in control when selecting services and supports for their family member with disability, lower than 40.6% of families/carers of entrants in prior years at baseline. A higher proportion of families/carers felt heard, with 66.9% reporting that services listened to them, which is also higher than 64.4% of prior years. When services were considered on the whole, at baseline, only 15.7% stated that the services met their needs, slightly lower than 18.3% among families/carers of entrants in prior years at baseline.

Independence of family member with disability

In terms of independence, 35.9% of families/carers knew what their family could do to enable the participant to become as independent as possible. Forty-two per cent of families/carers enabled the participant to interact and develop strong relationships with non-family members, while 54.2% enabled their family member with disability to make more decisions in their life. These percentages are slightly lower compared to families/carers of participants entering in prior years, of whom 40.9% knew what their family could do to enable the participant to become as independent as possible, 45.2% enabled the participant to interact and develop strong relationships with non-family members and 57.1% enabled their family member with disability to make more decisions in their life.

Families understand the strengths, abilities and special needs of their family member

The LF includes an additional domain concerned with how families/carers perceive the strengths and abilities of their family member with disability, and how their family member is progressing. A large majority (85.9%, similar to 86.2% for prior years' baseline) of families/carers reported being able to recognise the strengths and abilities of the participant, and 71.3% (lower than 76.3% for prior years' baseline) could see how the participant was progressing.

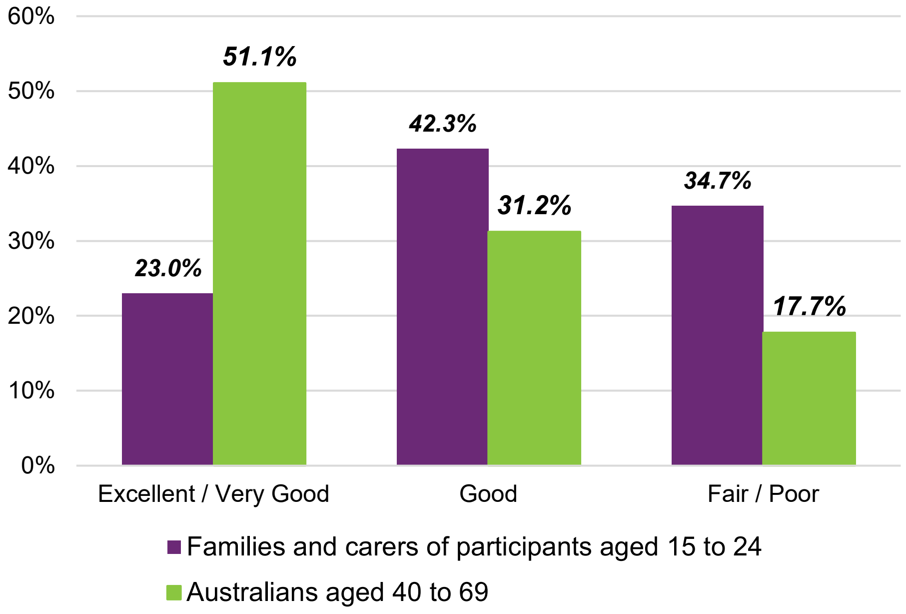
Employment

At baseline, 54.2% of families/carers were in a paid job and 48.2% of families/carers said that they were able to work as much as they wanted, higher than families/carers of entrants in prior years, of whom 49.4% were in a paid job and 46.5% were able to work as much as they wanted. Of the families/carers who did not work as much as they wanted, the following barriers to working were identified: the situation of their family member with disability (90.7%), insufficient flexibility of jobs (25.7%), and the availability of jobs (15.6%). Prior year entrants were slightly more likely to identify insufficient flexibility of jobs as a barrier (29.8%) and less likely to choose “Other” as response (13.8% compared to 16.5%).

Health and wellbeing

At baseline, 65.3% of families/carers rate their health as good, very good or excellent. While this percentage is higher than the baseline for families/carers of entrants in prior years (60.9%), it is considerably lower compared to the 82.3% of Australians aged 40 to 69 overall[24]. Figure 3.5 shows how the respondents rated their health at baseline.

Figure 3.5 Distribution of family/carer self-rated health ratings at baseline



The LF includes a number of extra questions asking about the wellbeing of families/carers and their outlook on life generally, and for their family member with disability in particular. The outcomes appear to be slightly poorer, when compared to the families/carers of participants from birth to age 14. Respondents most commonly had “mixed” or uncertain feelings about the future (44.8%, lower than 47.8% for prior years at baseline), although more answered positively (46.1%, higher than 42.6% for prior years at baseline) than negatively (9.1%, similar to 9.6% for prior years at baseline). The 46.1% responding positively is much lower than the 77% for Australians aged 25 to 64 overall[25] , and is similar

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[24] ABS General Social Survey (GSS) 2019

[25] ABS General Social Survey (GSS) 2010. For GSS 2014 the question changed from using seven descriptive categories to a rating on a 0 to 10 scale.

to families/carers of participants aged 25 and over (46.8%), as reported in later sections of this report.

A high proportion of families/carers (73.8%) agreed or strongly agreed that having a child with disability made it more difficult to meet everyday costs of living. When considering family/ carers' level of confidence about the future of their family member with disability under the NDIS, 58.8% agreed or strongly agreed that they felt more confident, with 32.3% feeling neutral about this statement and 8.8% expressing a negative opinion. These reflect a more positive view compared to that of families/carers of participants entering in prior years (for example, 53.8% of families/carers of participants entering in prior years agreed or strongly agreed that they felt more confident about the future of their family member under the NDIS). Thirty-seven per cent of families/carers agreed or strongly agreed that the family member with disability gets the support he/she needs, higher than 30.0% for prior years at baseline, and 40.9% responded neutrally. A slightly higher percentage of respondents agreed or strongly agreed that the services help them to better care for their family member with disability (42.0%, higher than 38.5% for prior years at baseline), and 45.0% responded as "neutral".

3.5 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, geography and who manages their plan are the characteristics most predictive of family/carer outcomes in the multiple regression models (controlling for other factors).

Key findings for each characteristic are summarised below, including the direction of the effect for selected characteristics. 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

Generally and controlling for other factors, families/carers of participants with autism showed poorer baseline outcomes across all domains compared to all other disability types. Based on the regression modelling, the only indicator for which families/carers of participants with autism had a better outcome related to being in a paid job (56.8%), when compared to families/carers of participants with intellectual disability (44.6%).

Families/carers of participants with hearing impairment were more likely to report positive outcomes across most domains, compared to participants with other disabilities. For example, they were more likely to:

- be working in a paid job (66.8% compared to 54.2% overall)
- identify the needs of their family member with disability and know how to access available services and supports to meet their needs (63.2% compared to 43.6% overall)
- have people they can ask for practical help, as often as needed (69.3% compared to 38.8% overall)

- know what they can do to enable their family member with disability to be as independent as possible (63.6% compared to 35.9% overall).

Families/carers of participants with visual impairment were also more likely to report positive outcomes across most domains, but not to the same extent as those with hearing impairment.

Compared to families/carers of participants with autism, families/carers of participants with psychosocial disability showed statistically significant positive effects across two indicators,[26] based on the regression modelling. However, on a one-way basis, they tended to show poorer outcomes across most indicators, when compared to all participants. For example, families/carers of participants with psychosocial disability were less likely to:

- be able to identify the needs of their family member with disability and know how to access available services and supports to meet their needs (32.7% compared to 43.6% overall)
- have people they could ask for practical help, as often as they needed (27.9% compared to 38.8% overall)
- know what they could do to enable their family member with disability to be as independent as possible (17.9% compared to 35.9% overall)
- enable their family member with disability to interact and develop strong relationships with non-family members (28.0% compared to 42.2% overall).

Self-rated health and work outcomes tended to be better for families/carers with hearing and visual impairment, and poorer for those with psychosocial disability and autism (compared to the overall one-way percentage). Positive self-rated health outcomes also generally tended to be correlated to positive work outcomes by disability type, as seen in Figure 3.6 below.

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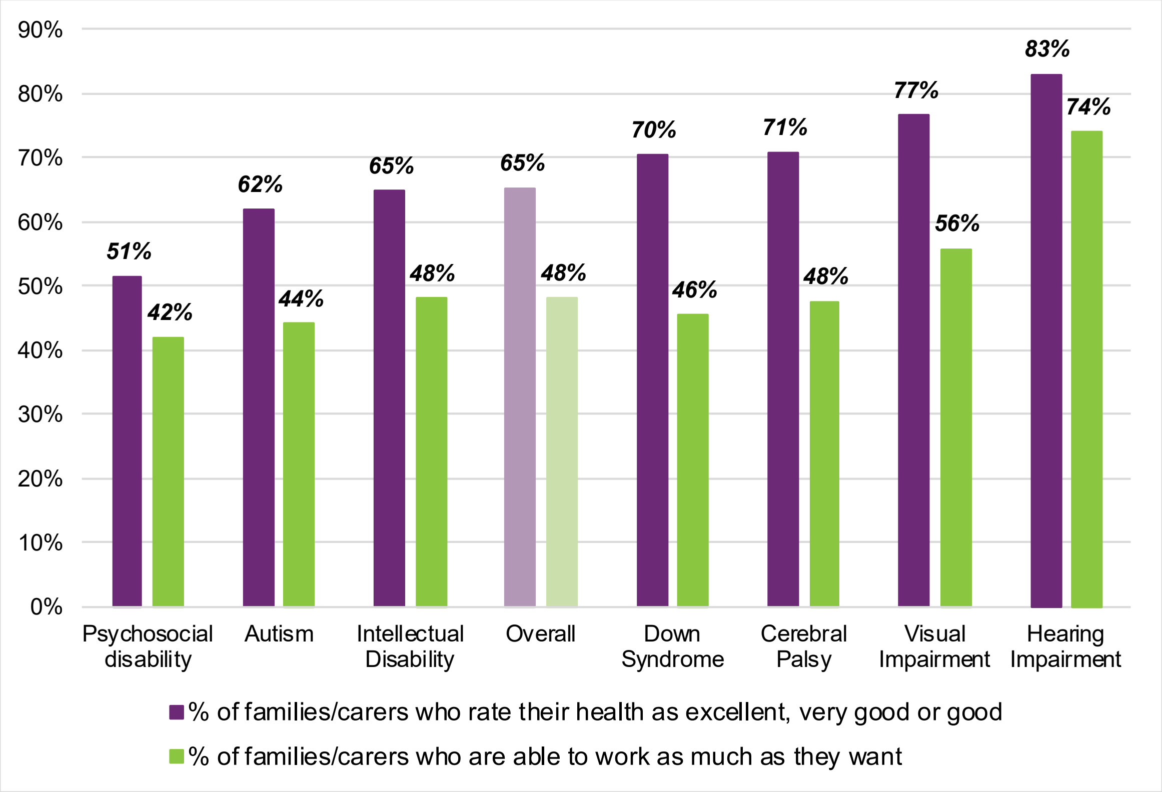
[26] Controlling for other factors, families/carers of participants with psychosocial disability were more likely to be in a paid job and to feel that the services that they and their family members with disability use listen to them. However, these effects were no apparent in the one-way analyses, due to the presence of confounders (for example, participant age).

Figure 3.6 Self-rated health and work outcomes by participant disability type



Additionally, families/carers of participants with Down syndrome were more likely to receive Carer Payment and Carer Allowance (30.4% and 58.3% respectively compared to 18.8% and 33.8% overall), and those with hearing impairment were less likely to be receiving these government payments (7.0% and 15.1% respectively).

Table 3.1 shows baseline family/carer outcomes for which participant primary disability type is a significant (p<0.05) predictor in the multiple regression model.[27]

Table 3.1 Relationship of disability type with the likelihood of selected outcomes

	Participant primary disability Compared to participants with primary disability of autism					
Outcome	**Cerebral Palsy**	**Down Syndrome**	**Hearing Impairment**	**Intellectual disability**	**Psychosocial disability**	**Visual Impairment**
Being in a paid job			⬆	⬇	⬆	
Receiving carer payment		⬆	⇩			
Receiving carer allowance		⬆	⇩	⇩	⇩	

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[27] The reference level is participants with autism.

	Participant primary disability Compared to participants with primary disability of autism					
Outcome	**Cerebral Palsy**	**Down Syndrome**	**Hearing Impairment**	**Intellectual disability**	**Psychosocial disability**	**Visual Impairment**
Being able to identify the needs of their family member with disability and know how to access available services and supports to meet these needs	↑	↑	↑	↑		
Being able to advocate (stand up) for their family members 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			↑	↑		

Outcome	Participant primary disability Compared to participants with primary disability of autism					
	Cerebral Palsy	Down Syndrome	Hearing Impairment	Intellectual disability	Psychosocial disability	Visual Impairment
Saying the services for them and their family member with disability meet their needs			↑	↑		
Knowing what they can do to enable their family member with disability to become more independent	↑		↑	↑		
Enabling and supporting their family member with disability to make more decisions in their life			↑	↑		
Enabling and supporting their family member with disability to develop strong relationships with non-family members	↑	↑	↑	↑		↑
Rating their health as excellent, very good or good	↑	↑	↑	↑		↑
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			↓	↓		

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 hearing impairment or visual impairment tended to report more positive baseline outcomes, and families/carers of participants with autism tended to have worse baseline outcomes.

Participant age

Generally, controlling for other factors, outcomes were better for families/carers of older participants as seen in Table 3.2 below.

The findings suggest that families/carers appear to feel more capable and/or confident in supporting their family member with disability, as the participant gets older. In particular, families/carers of older participants are more likely to know what their family can do to enable the participant to become as independent as possible (36.1% for families/carers of participants aged 17 or less, decreasing to 34.8% for families/carers of those aged 22 or above, on a one-way basis).

As the ability to become independent increases with age, work outcomes are generally more positive for families/carers of older participants. The percentage of families/carers of participants aged 17 or less, who are able to work as much as they want, is 46.6%, which increases to 51.0% for families/carers of participants aged 22 or above. For those who are unable to work, identifying insufficient job flexibility as a barrier to working more decreases from 27.9% for families/carers of participants aged 17 or younger, to 21.1% for families/carers of participants aged 22 or above.

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

Gender

Gender was a significant predictor in only one of 25 regression models.

Families/carers of female participants were less likely to have friends they can see as often as they like (46.6% compared to 47.7% for male participants, on a one-way basis).

CALD Status

Families/carers of participants from CALD backgrounds had significantly poorer outcomes across all domains compared to those from a non-CALD background (controlling for other factors). For example, respondents were less likely to:

- be in a paid job (40.6% compared to 55.6% for non-CALD participants) and to be able to work as much as they wanted (41.3% compared to 48.9%). For those unable to work as much as they wanted, they were more likely to identify the availability of jobs as a barrier (24.3% compared to 14.7%)
- be able to identify the needs of their family member with disability (27.3% compared to 45.2% for non-CALD participants)
- have people they could ask (as often as they needed) for:
    - practical help (30.2% compared to 39.7% for non-CALD participants)
    - help to support their family member with disability (22.4% compared to 31.9%)
    - emotional support (44.0% compared to 53.3%)
- feel in control of selecting services and supports that meet the needs of their family member with disability (22.5% compared to 41.0% for non-CALD participants)
- know what they could do to enable their family member with disability to become more independent (22.2% compared to 37.2% for non-CALD participants).

Families/carers of CALD participants were also less likely to be receiving Carer Payment and Carer Allowance (16.1% and 24.0% respectively compared to 19.1% and 34.8% for non-CALD participants).

Table 3.2 shows baseline family/carer outcomes of which CALD status is a significant (p<0.05) predictor in the multiple regression model.

Indigenous status

After controlling for other factors, participant Indigenous status was a significant factor in only two of 24 regression models of family/carer baseline outcomes. This may be partly due to small numbers in the analyses. In these two models, families/carers of Indigenous participants had more positive baseline outcomes, and results were consistent with the one-way analyses, with families/carers of Indigenous participants being:

- more likely to have people they can ask to support their family member with disability as often as needed (34.0% compared to 30.2% for families/carers of non-Indigenous participants, on a one-way basis)
- less likely, for those unable to work as much as they want, to identify the situation of their child/family member with disability as being a barrier to working more (80.7% compared to 91.8%).

On a one way basis, families/carers of Indigenous participants were less likely to be the parents of the participant (75.5% for Indigenous compared to 93.5% for non-Indigenous). In employment related indicators, families/carers of Indigenous participants were less likely to be working in a paid job (33.4% compared to 55.5%), and of those who wanted to work more, they were more likely to report the availability of jobs (22.6% compared to 14.5%) and the insufficient flexibility of available jobs (30.0% compared to 25.2%) as barriers to working more.

Outcomes in the support domain, on a one way basis, were slightly more positive for families/carers of Indigenous participants. In particular, they were slightly more likely to have friends they could see as often as they would like (49.9% compared to 46.7% for non-indigenous), have people to ask for practical help (39.0% compared to 37.9%), support for their family member with disability (34.0% compared to 30.2%, as discussed above) and emotional support (52.5% compared to 51.8%).

On the other hand, fewer families/carers of Indigenous participants felt that the services they used listened to them (58.9% compared to 67.5% for families/carers of non-Indigenous participants). Families/carers of Indigenous participants were also more likely to be receiving Carer Payment and Carer Allowance (25.6% and 37.0% respectively compared to 18.8% and 33.6% for non-Indigenous).

Table 3.2 below shows baseline family/carer outcomes of which Indigenous status is a significant ($p<0.05$) predictor in the multiple regression model.

Table 3.2 Relationship of participant age, gender, CALD status and Indigenous status with the likelihood of selected baseline outcomes

	Variable			
Outcome	**Participant is older**	**Participant is female**	**Participant is CALD**	**Participant is Indigenous**
Being in a paid job			⬇	
Receiving Carer Payments			⇩	
Receiving Carer Allowance	⇩		⇩	
Currently studying	⇩		⬆	

Outcome	Variable			
	Participant is older	Participant is female	Participant is CALD	Participant is Indigenous
Being able to identify the needs of their family member with disability	↑		↓	
Being able to advocate (stand up) 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			↓	
Knowing what they can do to enable their family member with disability to become more independent	↑		↓	
Enabling and supporting their family member with disability to make more decisions in their life	↑		↓	
Enabling and supporting their family member with disability to develop strong relationships with non-family members			↓	
Being able to work as much as they want	↑		↓	

Outcome	Variable			
	Participant is older	Participant is female	Participant is CALD	Participant is Indigenous
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, availability of job is a barrier			⬆	
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 and Indigenous and CALD status for families/carers of 2019-20 entrants with those of prior year entrants:

- Trends by age are largely similar, with baseline outcomes for families/carers tending to be better for families/carers of older participants. However, for entrants in prior years, the families/carers of older participants reported significantly better baseline outcomes in terms of better access and being listened to by the services needed to support the participant, whereas the differences were not significant for entrants in 2019-20.
- Participant gender was significant in three models last year, with families/carers of female participants having more positive outcomes for these three indicators (being able to access services, having someone to ask for practical help, and enabling and supporting their family member to develop relationships). By contrast, gender was significant in only one model for 2019-20 entrants, and families/carers of female participants were less likely to have friends they can see as often as they'd like.
- Indigenous status was only a significant factor for very few regression models, partly due to small sample size.
- 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 (46.0% increasing to 61.7% for those with a high level of function) and to be able to work as much as they want (33.8% increasing to 64.1%). For those unable to work as much as they want, more likely to identify their situation of their child with disability as a barrier to working more (96.6% increasing to 80.6%)
- be able to identify the needs of their family member with disability and to access available services and supports to meet their family member's needs (37.8% increasing to 55.7% for those with a high level of function)

- have friends they could see as often as they would like (31.4% increasing to 64.8% for those with a high level of function) and have people they can ask for practical help (25.9% increasing to 58.4%) and emotional support (42.6% increasing to 65.7%)
- know what they could do to enable their family member with disability to become as independent as possible (28.2% increasing to 51.5% for those with a high level of function) and to make more decisions in their life (44.0% increasing to 66.5%)
- rate their health as excellent, very good or good (56.7% increasing to 76.3% for those with a high level of function).

Those with higher annualised plan budgets also observed poorer outcomes relating to the domains of feeling supported, and health and work. For example, they were less likely to:

- have people they could ask for practical help, as often as they need (25.4% for those with an annualised plan budget of over $50,000, increasing to 56.1% for those with annualised plan budget of $15,000 or less)
- rate their health as excellent, very good or good (54.9% for those with an annualised plan budget of over $50,000, increasing to 76.5% for those with annualised plan budget of $15,000 or less)
- be able to work as much as they wanted (35.5% for those with an annualised plan budget of over $50,000, increasing to 62.6% for those with annualised plan budget of $15,000 or less).

Table 3.3 also shows baseline family/carer outcomes for which level of function and annualised plan budget amount is a significant (p<0.05) predictor in the multiple regression model.

Table 3.3 Relationship of participant level of function and annualised plan budget with the likelihood of selected baseline outcomes

Outcome	Variable	
	Lower level of function	Higher annualised plan budget
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 access available services and supports to meet the needs of their child and family	⬇	
Having friends they can see as often as they'd like	⬇	⬇
Having people they can ask for practical help as often as needed	⬇	⬇

Outcome	Variable	
	Lower level of function	Higher annualised plan budget
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	⬇	⬇
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	⬇	
Knowing what they can do to enable their family member with disability to become as independent as possible	⬇	
Enabling/supporting their family member with disability to make more decisions in their life	⬇	⬇
Enabling/supporting their family member with disability to develop strong relationships with non-family members	⬇	
Rating their health as excellent, very good or good	⬇	⬇
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 is a barrier to working more		↓
For those unable to work as much as they want, insufficient flexibility of job is 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. For both 2019-20 entrants and prior year entrants, baseline indicators are generally better for families/carers of participants with higher level of function / lower annualised plan budget. An exception is that for 2019-20 entrants, families/carers of participants with higher annualised budget reported to be less likely to perceive the availability of jobs as a barrier to working more, however, in prior years, the families/carers of participants with lower annualised budget tended to be less likely to report perceive the availability of jobs as a barrier.

Plan Management Type

Controlling for other factors, families/carers of participants who self-manage their baseline plan (fully or partly) had better baseline outcomes across all domains, than families/carers of participants who were agency-managed. In particular, they were more likely to:

- work in a paid job (67.9% and 61.2% for fully self-managed and partly self-managed participants respectively, compared to 44.4% for those agency-managed)
- be able to identify the needs of their family member with disability and access available services and supports to meet those needs (54.7% and 52.0% for fully self-managed and partly self-managed participants respectively, compared to 42.2% for those agency-managed),
- be able to support their family member with disability to make more decisions in their life (63.6% and 63.3% for fully self-managed and partly self-managed participants respectively, compared to 54.3% for those agency-managed)
- enable/support their family member with disability to develop strong relationships with non-family members (49.6% and 51.9% for fully self-managed and partly self-managed participants respectively, compared to 43.1% for those agency-managed).

Those families/carers of participants who self-managed fully were particularly more likely to enable their family member with disability to become as independent as possible (44.0% compared to 38.0% for those agency-managed) and to rate their health as excellent, very good or good (74.2% compared to 65.3% for those agency-managed).

Families/carers of plan-managed participants showed poorer outcomes compared to agency-managed participants, particularly in the support and independence domains. For example, these families/ carers were less likely to have people they could ask to support their family member with disability, as often as needed (27.0% compared to 36.1% for those agency-managed). Families/carers of plan-managed participants were also less likely to enable their family member with disability to become as independent as possible (29.1% compared to 38.0% for those agency-managed).

Table 3.4 also shows baseline family/carer outcomes of which plan management type is a significant (p<0.05) predictor in the multiple regression model[28].

Table 3.4 Relationship of plan management type with the likelihood of selected baseline outcomes

Outcome	Plan Management Type		
	Plan Managed	Self Managed Fully	Self Managed Partly
Being in a paid job	⬆	⬆	⬆
Being able to identify the needs of their family member with disability		⬆	⬆

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[28] The reference level is Agency-managed.

Outcome	Plan Management Type		
	Plan Managed	Self Managed Fully	Self Managed Partly
Being able to access available services and supports to meet the needs of their child and family		↑	↑
Having friends they can see as often as they'd like	↓		
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	↓		
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	↓		
Knowing what they can do to enable their family member with disability to become as independent as possible	↓	↑	
Enabling/supporting their family member with disability to make more decisions in their life	↓	↑	↑
Enabling/supporting their family member with disability to develop strong relationships with non-family members	↓	↑	↑
Rating their health as excellent, very good or good		↑	
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 plan management type are generally similar. Families/carers of participants who self-managed their plan tended to have better baseline outcomes than those who were agency-managed.

State/Territory

Controlling for other factors, families/carers in Victoria had poorer baseline outcomes compared to the reference level State (i.e. NSW) across most domains. On the other hand, families/carers living in QLD, SA and WA had better baseline outcomes compared to NSW across most domains. NT had poorer outcomes across a few indicators when compared to NSW; for example, they were less likely to be able to identify the needs of their family member with disability and less likely to enable them to become as independent as possible.

Table 3.5 shows baseline family/carer outcomes of which the State/Territory they live in is a significant ($p<0.05$) predictor in the multiple regression model[29].

Table 3.5 Relationship of remoteness with the likelihood of selected outcomes:

Outcome	State/ Territory						
	VIC	QLD	SA	WA	TAS	ACT	NT
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 access available services and supports to meet the needs of their child and family	⬇	⬆	⬆	⬆			⬇
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	⬇		⬆			⬆	
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	⬇						
Knowing what they can do to enable their family member with disability to become as independent as possible	⬇	⬆	⬆	⬆			⬇
Enabling/supporting their family member with disability to make more decisions in their life		⬆	⬆	⬆			

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[29] The reference level is NSW.

Outcome	State/ Territory						
	VIC	QLD	SA	WA	TAS	ACT	NT
Enabling/supporting their family member with disability to develop strong relationships with non-family members	↓	↑		↑			↓
Rating their health as excellent, very good or good			↓	↑			
Being able to work as much as they want	↓		↑	↑			

In general, results by State/Territory were consistent between families/carers of 2019-20 entrants and familes/carers of prior year entrants.

Remoteness

Controlling for other factors, families/carers living in regional and remote/very remote areas had better baseline outcomes generally than those living in major cities. For example, they were more likely to:

- have friends they could see as often as they would like (44.3-54.1% for regional areas; 64.9% for remote/very remote areas; compared to 46.3% for major cities)
- have people they could ask for practical help (40.8-46.4% for regional areas; 50.5% for remote/very remote areas; compared to 36.9% for major cities) and emotional support (52.2-57.1% for regional areas; 64.0% for remote/very remote areas; compared to 51.4% for major cities), as often as they needed
- enable their family member with disability to develop relationships with non-family members (41.4-47.8% for regional areas; 45.3% for remote/very remote areas; compared to 40.9% for major cities)
- rate their health as excellent, very good or good (62.4-68.3% for regional areas; 74.8% for remote/very remote areas; compared to 64.5% for major cities)
- be able to work as much as they wanted (48.9-53.5% for regional areas; 58.7% for remote/very remote areas; compared to 46.7% for major cities).

However, those respondents with a participant living in regional or remote/very remote areas that desired to work more, were more likely to identify the availability of jobs as being a barrier to working more (15.9-26.6% for regional areas; 40.5% for remote/very remote areas; compared to 14.0% for major cities).

Those living in regional areas particularly, were more likely to be receiving Carer Payment and Carer Allowance (20.6-22.4% and 33.3-39.4% respectively for regional areas compared to 17.8% and 33.0% for major cities), and those living in remote/very remote areas were less likely to be receiving those benefits (11.7% and 16.2% respectively compared to 17.8% and 33.0% for major cities).

Table 3.6 shows baseline family/carer outcomes for which remoteness is a significant ($p<0.05$) predictor in the multiple regression model[30].

Table 3.6 Relationship of remoteness with the likelihood of selected outcomes:

	Variable	
Outcome	**Lives in a regional area compared to living in a major city**	**Lives in a remote or very remote area compared to living in a major city**
Receiving carer payments	⬆	⇩
Receiving carer allowance	⬆	⇩
Being able to identify the needs of their family member with disability	⬆	
Being able to access available services and supports to meet the needs of their child and family	⬆	
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	⬆	⬆
Knowing what they can do to enable their family member with disability to become as independent as possible	⬆	
Enabling/supporting their family member with disability to make more decisions in their life	⬆	
Enabling/supporting their family member with disability to develop strong relationships with non-family members	⬆	⬆
Rating their health as excellent, very good or good	⬆	⬆
Being able to work as much as they want	⬆	⬆

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[30] The reference level is NSW.

Outcome	Variable	
	Lives in a regional area compared to living in a major city	Lives in a remote or very remote area compared to living in a major city
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, insufficient flexibility of job is a barrier to working more	⬆	

Comparing 2019-20 entrants with participants entering in earlier years, baseline trends by remoteness are very similar. Families/carers living in regional or remote areas tended to report generally better baseline outcomes than those living in major cities. For example families/carers living in regional or remote areas reported particularly positive baseline outcomes relating to having a support network to ask for help. However, families/carers living in regional or remote areas reported mixed outcomes in the employment domain, consistently with those for prior year entrants.

Impact of COVID-19

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

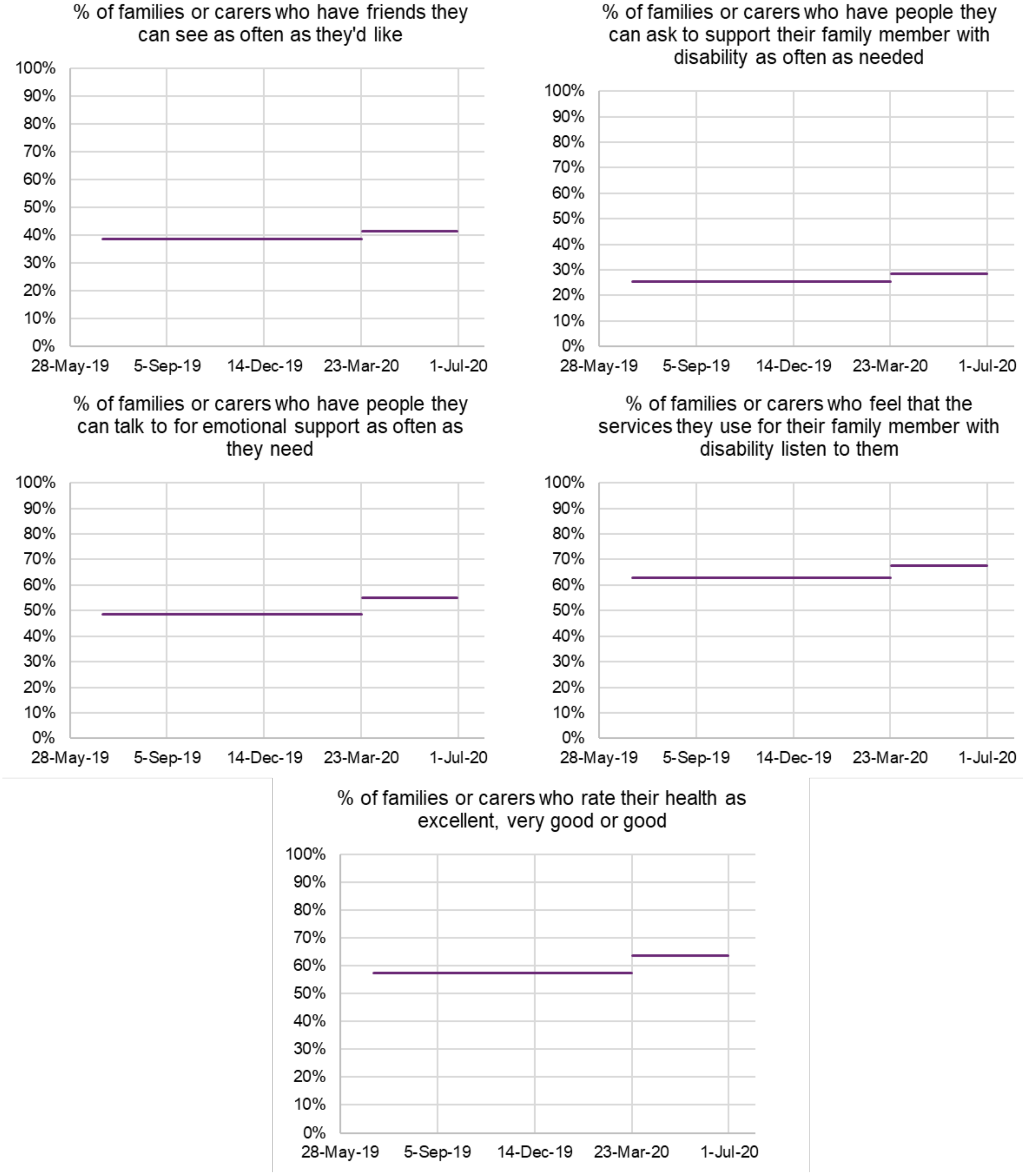
For families/carers of participants aged 15 to 24 who entered the Scheme in 2019-20, there were five indicators for which one or both of the COVID-related terms was significantly different from zero.

For all five 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. In all five cases, the change was positive during the pandemic. Specifically,

- The baseline outcomes related to families feeling supported have become more positive, with increases during the pandemic being observed for the percentage of families/carers who:
    - have friends they can see as often as they'd like
    - have people they can ask to support their family member with disability as often as they needed
    - have people they can talk to for emotional support as often as they needed
    - feel that the services they use for their family member with disability listen to them.
- Additionally, a higher percentage of families/carers rated their health as excellent, very good or good compared to the pre-COVID period.

Figure 3.7 illustrates the fitted trends for these five indicators.

Figure 3.7 Estimated trend over time for the indicators where the COVID indicator term was significant



% of families or carers who have friends they can see as often as they'd like

% of families or carers who have people they can ask to support their family member with disability as often as needed

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

Box 3.4 summarises the key findings from this section.

Box 3.4: Summary of findings – results by participant and family/carer characteristics

- Families/carers of participants with autism showed poorer baseline outcomes across all domains compared to all other disability types, except that the percentage in a paid job (56.8%) is slightly higher than families/carers of participants with intellectual disability (44.6%).
- Families/carers of participants with a hearing impairment were more likely to report positive outcomes across most domains, compared to participants with other disabilities. For example, they were more likely to be working in a paid job (66.8% compared to 54.2% overall), to have people they can ask for practical help, as often as needed (69.3% compared to 38.8% overall), and to know what they can do to enable their family member with disability to be as independent as possible (63.6% compared to 35.9% overall).
- Families/carers of participants with self-managed baseline plans (fully or partly) had better baseline outcomes across all domains, than families/carers of participants with agency-managed plans. For example, they were more likely to have a paid job (67.9% and 61.2% for fully self-managed and partly self-managed participants respectively, compared to 44.4% for those agency-managed), and to be able to support their family member with disability to make more decisions in their life (63.6% and 63.3% for fully self-managed and partly self-managed participants respectively, compared to 54.3% for those agency-managed).
- Families/carers living in regional and remote/very remote areas had better baseline outcomes in relationships and self-rated health.
- Families and carers living in regional or remote/very remote areas who wanted to work more, were also more likely to identify the availability of jobs as being a barrier to working more (15.9-26.6% for regional areas; 40.5% for remote/very remote areas; compared to 14.0% for major cities).
- COVID-19 was associated with a number of changes to participant outcomes, with all changes being positive. Specifically, the baseline outcomes related to families feeling supported have generally become more positive, with increases during the pandemic in the percentages saying they: have friends they can see as often as they'd like; have people they can ask to support their family member with disability; have people they can talk to for emotional support; and feel that the services they use for their family member with disability listen to them. Additionally, a higher percentage of families/carers rated their health as excellent, very good or good compared to the pre-COVID period.