2. Families/carers of participants from birth to age 14: Outcome indicators

2.1 Key findings

Box 2.1: Comparison of families or 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).
- 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 of the participant) can occur over time, for example due to phasing in the transition period.
- Compared to prior year entrants, participants from birth to age 14 who entered the Scheme in 2019-20 tend to be:

- Younger.
- More likely to have developmental delay or global developmental delay and less likely to have autism or an intellectual disability.
- More likely to have high or medium level of function and less likely to have low level of function.
- More likely to require a low level of NDIA support through the participant pathway and less likely to require a medium or high/very high level of support[7].
- Less likely to live in NSW or SA and more likely to live in QLD or WA.
- Slightly more likely to live in major cities and less likely to live in regional areas.
- Slightly more likely to be from a CALD background (9.0% compared to 7.2%).
- Much more likely to have not received services from State/Territory or Commonwealth programs prior to entering the Scheme, more likely to have entered the Scheme for early intervention (78.8% compared to 43.7%) and less likely to have entered due to disability.
- Less likely to have baseline annualised plan budget less than $10,000 or over $30,000, and more likely to fully self-manage their baseline plan (33.2% compared to 15.2%) or to use a plan manager (33.2% compared to 15.2%) rather than agency manage.
- Similar with respect to gender and Indigenous status.

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

Box 2.2: Baseline indicators for families or carers of participants entering in 2019-20 – overall

- **Employment**
  - At baseline, 46.4% of families/carers of 2019-20 entrants were working in a paid job, similar to 46.6% of prior year entrants.
  - Less than half (46.5%) of families/carers of 2019-20 entrants said that they (and/or their partner) were able to work as much as they wanted, however this was 6.3% higher than for prior years' entrants (40.2%).
  - Of the families/carers who did not work as much as they liked, 86.2% identified the situation of their child with disability as a barrier to working more, 32.2% said that insufficient flexibility of jobs was a barrier, and 17.9% said that the availability of jobs was a barrier. Similar percentages of families/carers of prior years' entrants identified these three circumstances as barriers.
- **Rights and advocacy**
  - At baseline, 61.9% of families/carers were able to identify the needs of their child and family, lower than 69.1% for prior year entrants.
  - Similar to the baseline for prior years, 72.2% of families/carers understood their rights and the rights of their child and 77.3% were able to advocate for their child. However, 56.4% had some difficulty or a great deal of difficulty in accessing available services and supports to meet the needs of their child and family, similar to 55.4% for prior year entrants.
  - Fifty-six per cent of families/carers identified at least one barrier to access or advocacy, representing a 7.5% decrease from the previous years' level. The most common barriers were limited access to information and resources (35.2%) and lack of support (26.8%), which are consistent with previous years.
- **Families feel supported**
  - At baseline, most families/carers said they lacked sufficient support and social connections, although families and carers of 2019-20 entrants tended to respond more positively than those of prior year entrants.
  - Fifty-one per cent were unable to see friends and family as often as they like (5.4% lower than for prior year entrants), 55.6% said they could not get as much practical help as they would like (4.7% lower than for prior year entrants), and 67.0% said they could not get childcare as often as they need (5.7% lower than for prior year entrants).
  - However, 63.4% of families/carers of 2019-20 entrants said they have people they can talk to for emotional support as much as they like, 5.0% higher than for prior year entrants.
- **Access to desired services, programs and activities**
  - Eighty-seven per cent (87.3%) of families/carers have good (42.6%) or very good (44.7%) relationships with their services. The percentage having a very good relationship with their services has been increasing over time, from 29.2% for families/carers of participants entering in 2016-17, to 44.7% for families/carers of 2019-20 entrants.

Box 2.2: Baseline indicators for families or carers of participants entering in 2019-20 – overall (continued)

- **Families help their children develop and learn**

– At baseline, 37.4% of families/carers knew what they could do to support their child's learning and development, with a further 55.9% saying they had some degree of knowledge.

– A similar pattern is exhibited with regards to specialist services: 37.4% of families/carers reported knowing what specialist services were needed and 55.3% had some degree of knowledge. Forty-four per cent of family and carers agreed that they received enough support to feel confident in parenting their child with disability, and a further 44.5% agreed to some extent. In addition, 86.8% felt very confident (25.8%) or somewhat confident (61.0%) in supporting their child's development.

– These baseline metrics of families/carers of 2019-20 entrants are broadly in line with those of participants entering in prior years at baseline.

- **Families understand their children's strength, abilities and special needs**

– A high proportion (79.5%) of families/carers reported being able to recognise their child's strengths and abilities and 76.7% could see how their child was progressing. Both are similar to previous years' average level.

- **Health and wellbeing**

– Only 32.2% of families/carers said that they (and/or their partner) engaged in social and community life as much as they liked (higher than those of prior years' entrants at 26.8%). Of those who did not, 88.8% identified the situation of their child with disability as a barrier to engaging more, 38.6% said time constraints was a barrier, and 28.7% said limited social networks was a barrier. This is broadly in line with the distribution among families and carers of prior years' entrants.

– Compared to the general Australian population aged 25 to 64 overall, the families and carers of NDIA participants generally rated their health as poorer. From the SF, 77.1% of families/carers rated their health as good, very good or excellent (5.1% higher than prior years), compared to 85.7% of Australians aged 25 to 69 overall.

– Compared to the general Australian population aged 25 to 64 overall, families and carers NDIA participants generally reported a more negative outlook about the future. 52.6% of families and carers of 2019-20 entrants felt delighted, pleased or mostly satisfied when thinking about the last 12 months and what they expect for the future, much lower than the 77.0% for Australians aged 25 to 64 overall. However, the percentage is higher than for families/carers of prior year entrants (43.7%).

Box 2.3 Baseline indicators for families or carers of participants entering in 2019-20 – participant characteristics

- Families/carers of participants with a hearing impairment, of participants with a higher level of function and of participants who are self-managing part or all of their plan tend to have better baseline outcomes across most indicators. Some baseline indicators are also better for families/carers of participants living in regional and remote areas, compared to those living in major cities.
- Families/carers of participants with autism or a psychosocial disability, of older children, and of those from a CALD background tended to have worse baseline outcomes across most indicators.
- Families/carers of participants with Down syndrome were more likely to be able to identify the needs of their child (66.3% compared to 61.9% overall, on a one-way basis) and to engage in social interactions and community life as much as they wanted (40.4% compared to 32.2% overall). However, they were more likely to experience barriers to access and/or advocacy and less likely to have people they can ask for childcare, as often as needed.
- Families/carers of Indigenous participants tended to have worse employment outcomes at baseline. They were less likely to be working in a paid job and more likely to find the availability of jobs a barrier to employment. However, families/carers of Indigenous participants appear to have better informal support networks at baseline.
- Families/carers of participants with a higher function level and lower baseline plan budget had better baseline outcomes for most indicators.
- Families/carers of participants receiving a higher level of NDIA support with planning had less positive results on some baseline indicators. For example, they were more likely to experience difficulties in accessing available services and supports to meet the needs of their child and family, and were less likely to have people they can ask for practical help or childcare as needed.
- Families/carers living in regional or remote areas tended to report better baseline outcomes than those living in major cities, in particular, having people to ask for help and support. However, families/carers living in regional or remote areas reported more difficulties accessing services compared to those living in major cities, consistent with those for prior year entrants.
- Families/carers of participants living in a private home that is owned by their family/carers have better baseline outcomes across almost all indicators, compared to families/carers of participants living in a private home that is rented from either a private or public landlord.
- COVID-19 had a significant impact on family/carer outcomes and results were mostly positive, apart from some employment indicators. The percentage of families and carers who were in a paid job dropped, and the percentage who perceived the availability of jobs as a barrier to employment has increased. However, more families or carers reported having friends they can see as often as they'd like, and people they can ask for help and support as much as they need.

2.2 Outcomes framework questionnaire domains

For families/carers of participants aged from birth to 14 years, the outcomes framework seeks to measure the extent to which they:

- know their rights and advocate effectively for their child with a disability (RA domain)
- feel supported (SP)
- can gain access to desired services, programs and activities in their community (AC)
- are able to help their children develop and learn (DV)
- enjoy health and wellbeing (HW).

The LF contains an extra domain, measuring the extent to which families/carers:

- understand their children's strengths, abilities and special needs (UN)

The LF also includes a number of extra questions in other domains, particularly the health and wellbeing domain.

Families and carers of participants who contributed to the age 0 to starting school participant survey and starting school to age 14 participant survey are invited to contribute to this survey. Hence the baseline cohort comprises families and carers of participants who are aged between 0 to 14 when they enter the Scheme.

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

As at 30 June 2020, the combined baseline constitutes four years of experience (families and carers of participants entering the Scheme between 1 July 2016 and 30 June 2020). The results presented in Sections 2.4 and 2.5 focus on the most recent year of baseline experience, namely families and carers of 2019-20 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. For the participants aged 0 to 14 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. Baseline results for families and carers of 2019-20 entrants are summarised in Section 2.4 (overall) and 2.5 (by participant and family/carer characteristics), including brief comparisons with results for families and carers of prior year entrants.

Figure 2.1 and Figure 2.2 summarise distributions by key characteristics for 2019-20 entrants and prior year entrants.

Figure 2.1 Distributions by key characteristics - families or carers for 2019-20 entrants compared with prior year entrants

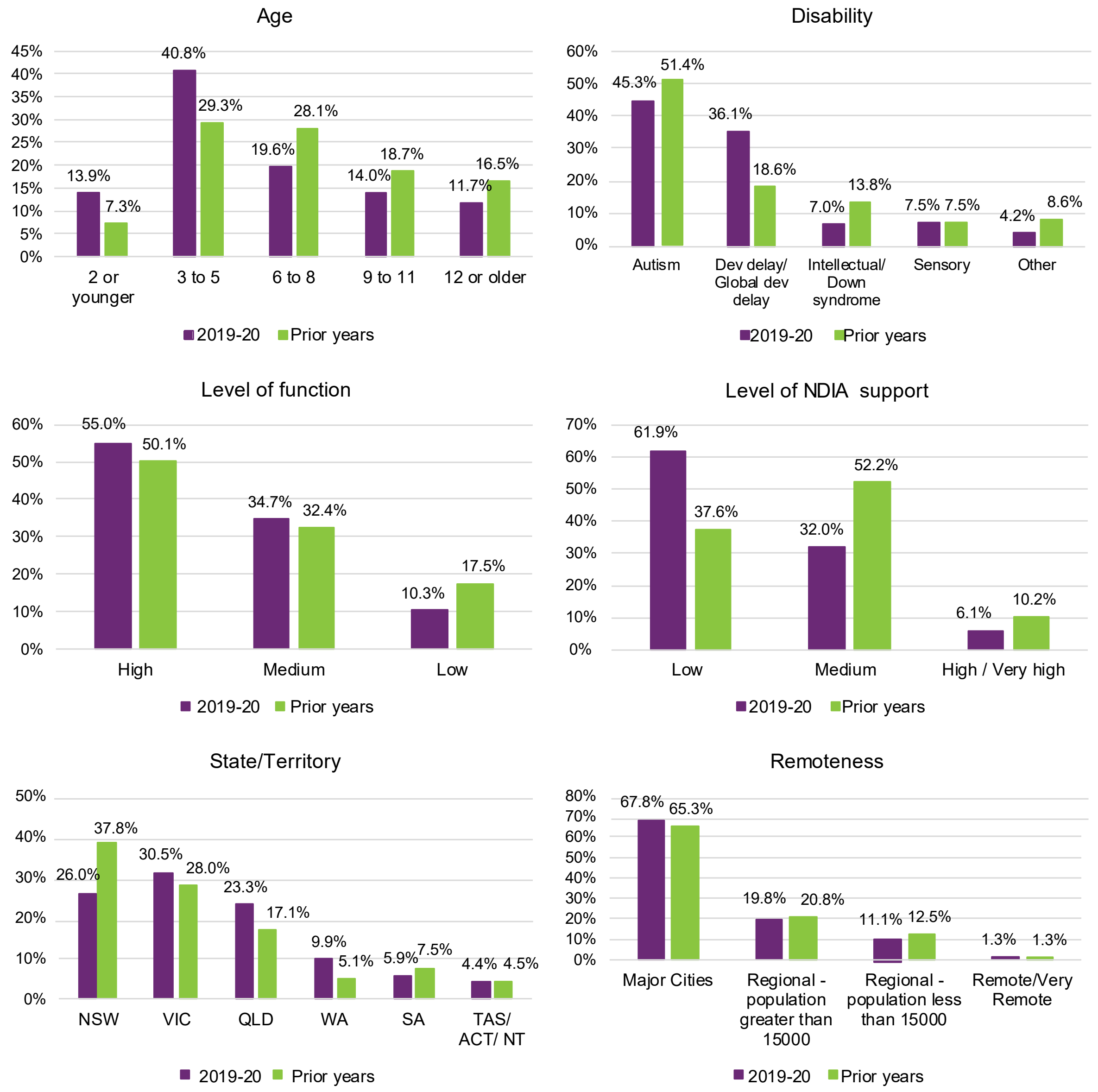
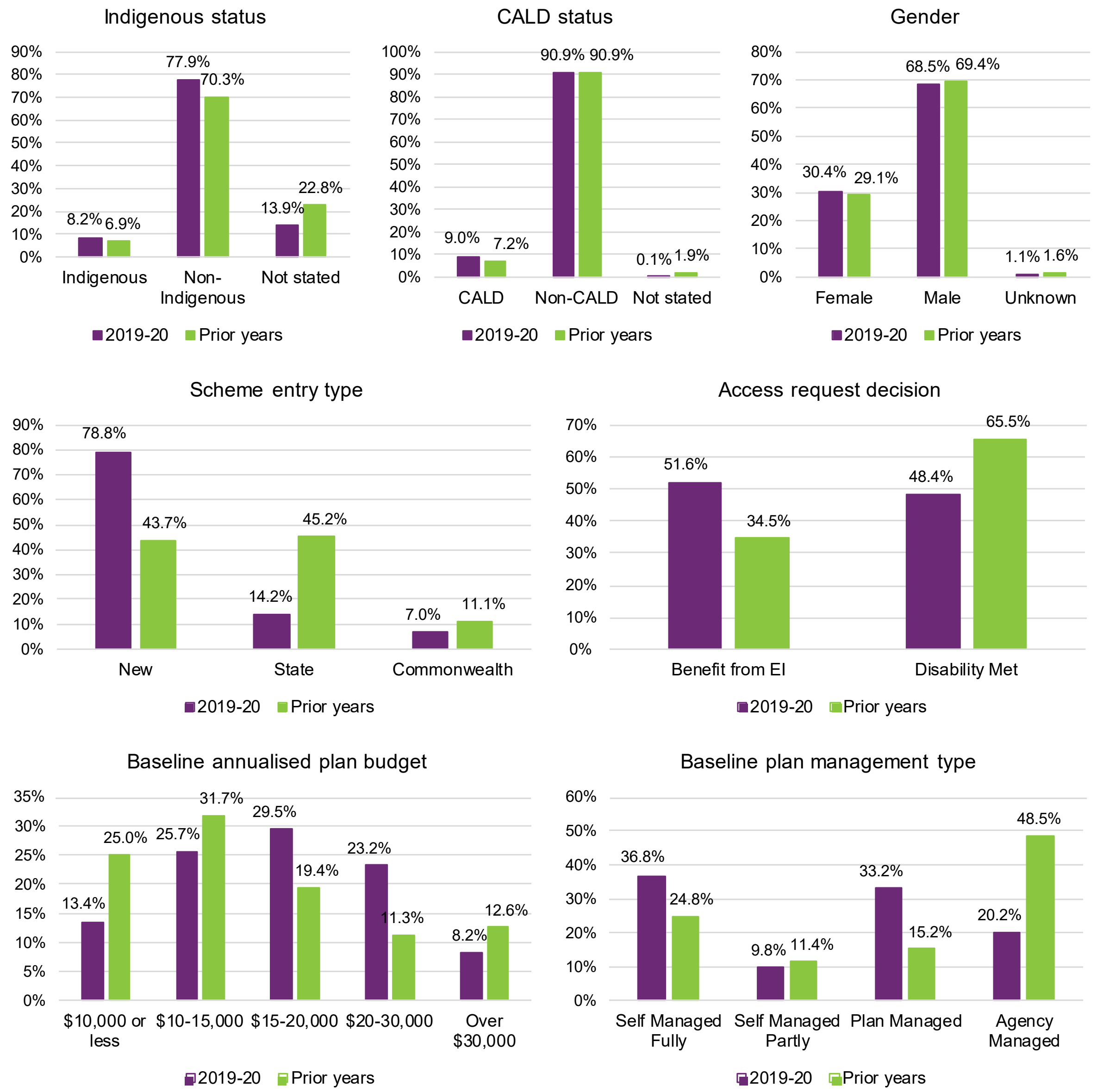


Figure 2.2 Distributions by key characteristics - families or carers for 2019-20 entrants compared with prior year entrants



The graphs in Figure 2.1 and Figure 2.2 show that compared to prior year entrants, participants who entered the Scheme in 2019-20 tend to be:

- Younger (54.7% aged 5 or younger, compared to 36.6% for prior year entrants).
- More likely to have developmental delay or global developmental delay (36.1% compared to 18.6% for prior year entrants) and less likely to have autism (45.3% compared to 51.4%), intellectual disability or Down syndrome (7.0% compared to 13.8%) or other disabilities (4.2% compared to 8.6%). The proportion having a sensory disability (hearing or visual impairment or another sensory/speech disability) is similar to prior years at 7.5%.
- More likely to have high or medium level of function (55.0% and 34.7% compared to 50.1% and 32.4%) and less likely to have low level of function.

- More likely to require a low level of NDIA support through the participant pathway (61.9% compared to 37.6%) and less likely to require a medium or a high/very high level of support.[8]
- Less likely to live in NSW (26.0% compared to 37.8%) or SA (5.9% compared to 7.5%), more likely to live in QLD (23.3% compared to 17.1%) and WA (9.9% compared to 5.1%), and slightly more likely to live in other States/Territories.
- Slightly more likely to live in major cities (67.8% compared to 65.3%) and less likely to live in regional areas.
- Slightly more likely to be from a CALD background (9.0% compared to 7.2%).
- Much more likely to have not received services from State/Territory or Commonwealth programs prior to entering the Scheme (78.8% compared to 43.7%).
- Much more likely to have entered the Scheme for early intervention (s24) (51.6% compared to 34.5%) than due to disability (s25) (48.4% compared to 65.5%).
- Less likely to have baseline annualised plan budget less than $10,000 (13.4% compared to 25.0%) or over $30,000 (8.2% compared to 12.6%), and more likely to have annualised plan budget between $15,000 and $30,000 (52.7% compared to 30.7%).
- More likely to fully self-manage their baseline plan (36.8% compared to 24.8%) or to use a plan manager (33.2% compared to 15.2%) and less likely to agency manage (20.2% compared to 48.5%).

However, distributions by gender and Indigenous status are similar between 2019-20 entrants and prior year entrants.[9]

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

Government benefits (Carer Payment and Carer Allowance)

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

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

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

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

[9] 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 from birth to age 14, the p-value for indigenous status was 0.0002 but all other p-values were less than 0.0001.

family income test threshold was introduced, affecting an estimated 1% of carers who were previously eligible.[10]

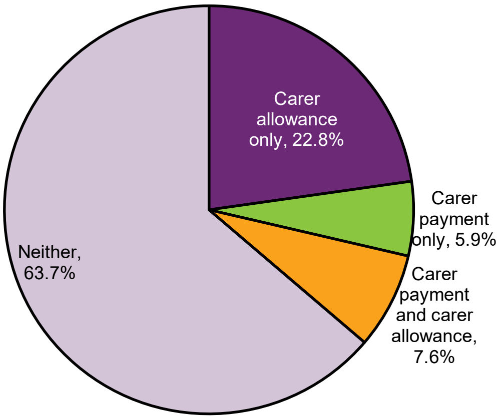
As at June 2020, 294,272 Australians were receiving Carer Payment and about 2.1 times as many, 619,038 Australians, were receiving Carer Allowance.[11]

The outcomes framework questionnaires ask families/carers of NDIS participants whether they are currently receiving any government benefits (Carer Payment, Carer Allowance, or other benefits). At baseline, 13.5% of families/carers of 2019-20 entrants said they were receiving Carer Payment and 30.4% said they were receiving Carer Allowance. These self-reported percentages are lower than for families/carers of participants entering the Scheme in prior years (22.9% for Carer Payment and 51.9% for Carer Allowance), and have been decreasing since 2017-18.

The ratio of Carer Allowance to Carer Payment (2.25) is similar to the 2.1 observed for the total populations in receipt of these benefits.

Figure 2.3 shows the percentages of family/carer respondents of participants aged 0 to 14 who reported receiving Carer Payment and/or Carer Allowance at baseline.

Figure 2.3 Receipt of Carer Payment and Carer Allowance, families/carers of participants aged 0 to 14[12]



Rights and advocacy

Figure 2.4 shows selected outcomes in the Rights and Advocacy domain for families/carers of participants aged 0 to 14 who entered the Scheme in 2019-20. At baseline, 61.9% of families/carers were able to identify the needs of their child and family, lower than 69.1% for prior year entrants. This proportion was 73.3% for 2016-17 entrants and has been decreasing for each entry year cohort since then. Similar to the baseline for prior years,

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[10] Fact Sheet – New services for carers, Commonwealth of Australia (Department of Social Services) 2018 https://www.dss.gov.au/sites/default/files/documents/04_2018/fact_sheet_-_new_services_for_carers.pdf

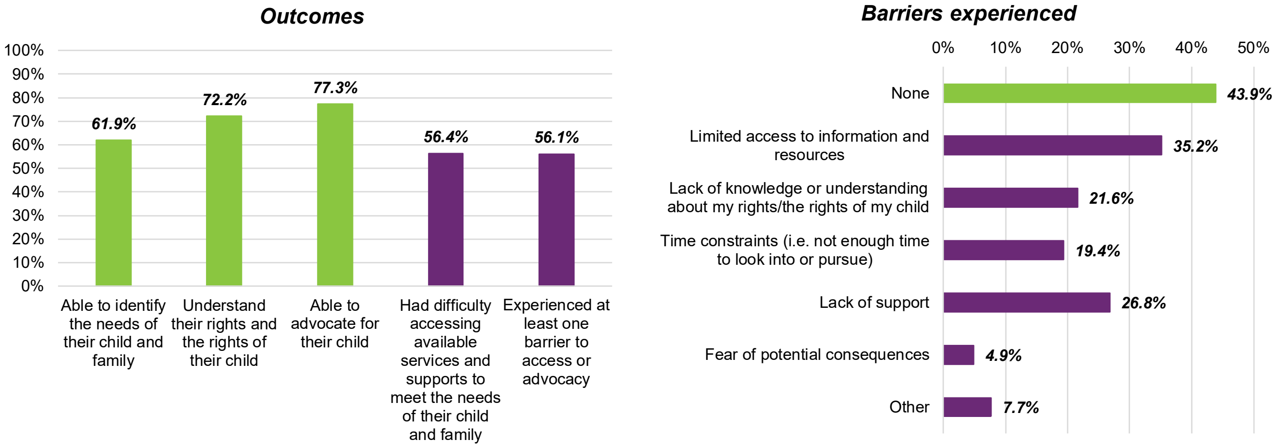
[11] Annual report 2019-20, Commonwealth of Australia (Department of Social Services) 2020, https://www.dss.gov.au/sites/default/files/documents/10_2020/01720_dss_ar_2020.pdf

[12] Note that this is self-report data.

72.2% of families/carers understood their rights and the rights of their child and 77.3% were able to advocate for their child. However, 56.4% had some difficulty or a great deal of difficulty in accessing available services and supports to meet the needs of their child and family, similar to 55.4% for prior year entrants.

Fifty-six per cent (56.1%) of families/carers identified at least one barrier to access or advocacy, representing a 7.5% decrease from the previous years' level. The most common barriers were limited access to information and resources (35.2%) and lack of support (26.8%), which are consistent with previous years.

Figure 2.4 Rights and advocacy for families/carers of participants aged 0 to 14



Families feel supported

At baseline, most families/carers said they lacked sufficient support and social connections, although families and carers of 2019-20 entrants tended to respond more positively than those of prior year entrants. Fifty-one per cent were unable to see friends and family as often as they like (5.4% lower than for prior year entrants), 55.6% said they could not get as much practical help as they would like (4.7% lower than for prior year entrants), and 67.0% said they could not get childcare as often as they need (5.7% lower than for prior year entrants). However, 63.4% of families/carers of 2019-20 entrants said they have people they can talk to for emotional support as much as they like, 5.0% higher than for prior year entrants.

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

The LF survey revealed that 87.3% of families/carers have good (42.6%) or very good (44.7%) relationships with their services. The percentage having a very good relationship with their services has been increasing over time, from 29.2% for families/carers of participants entering in 2016-17 at baseline, to 44.7% for families/carers of 2019-20 entrants.

Families help their children develop and learn

At baseline, the SF showed that 37.4% of families/carers knew what they could do to support their child's learning and development, with a further 55.9% saying they had some degree of knowledge. A similar pattern is exhibited with regards to specialist services: 37.4% of families/carers reported knowing what specialist services were needed and 55.3% had some degree of knowledge. Forty-four per cent of family and carers agreed that they received enough support to feel confident in parenting their child with disability, and a further 44.5% agreed to some extent. In addition, 86.8% felt very confident (25.8%) or somewhat confident (61.0%) in supporting their child's development.

These baseline metrics of families/carers of 2019-20 entrants are broadly in line with those of participants entering in prior years.

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

The LF includes an additional domain dealing with how families/carers perceive the strengths and abilities of their child with disability, and how their child is progressing. A high proportion (79.5%) of families/carers reported being able to recognise their child's strengths and abilities and 76.7% could see how their child was progressing. Both are similar to baseline results for families/carers of prior year entrants.

Employment

At baseline, 46.4% of families/carers of 2019-20 entrants were working in a paid job, similar to 46.6% of prior year entrants. Less than half (46.5%) of families/carers of 2019-20 entrants said that they (and/or their partner) were able to work as much as they wanted, however this was 6.3% higher than for prior years' entrants (40.2%). Forty-one per cent (41.4%) said that they themselves would like to work more and 7.3% said that both they and their partner would like to work more (lower than 45.6% and 8.7% for families and carers of prior years' entrants). Of the families/carers who did not work as much as they liked, 86.2% identified the situation of their child with disability as a barrier to working more, 32.2% said that insufficient flexibility of jobs was a barrier, and 17.9% said that the availability of jobs was a barrier. This distribution of barriers identified is similar to that among families and carers of prior years' entrants.

Health and wellbeing

Only 32.2% of families/carers said that they (and/or their partner) engaged in social and community life as much as they liked (higher than for prior years' entrants at 26.8%). Of those who did not, 88.8% identified the situation of their child with disability as a barrier to engaging more, 38.6% said time constraints was a barrier, and 28.7% said limited social networks was a barrier. This is broadly in line with the distribution among families and carers of prior years' entrants.

From the SF, 77.1% of families/carers rated their health as good, very good or excellent (5.1% higher than prior years), compared to 85.7% of Australians aged 25 to 69 overall[13]. Figure 2.5 compares the distribution of responses for families/carers to the population benchmark.

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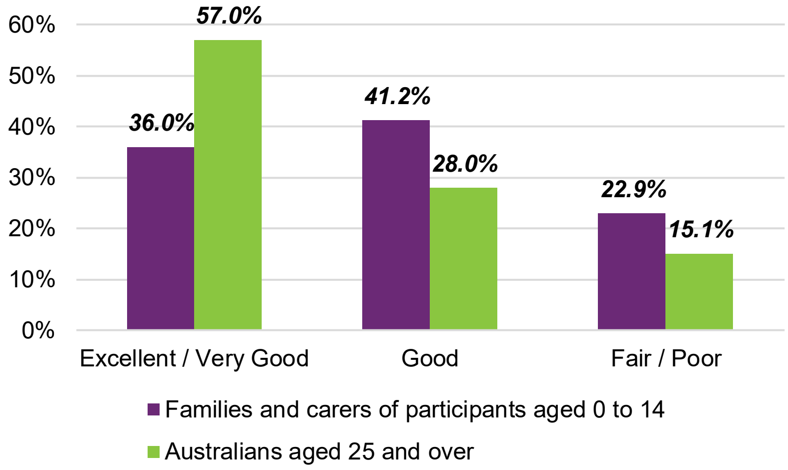
[13] ABS General Social Survey (GSS) 2019. Families/carers of 0 to 14 year olds are likely to be towards the younger end of the 25-69 age range.

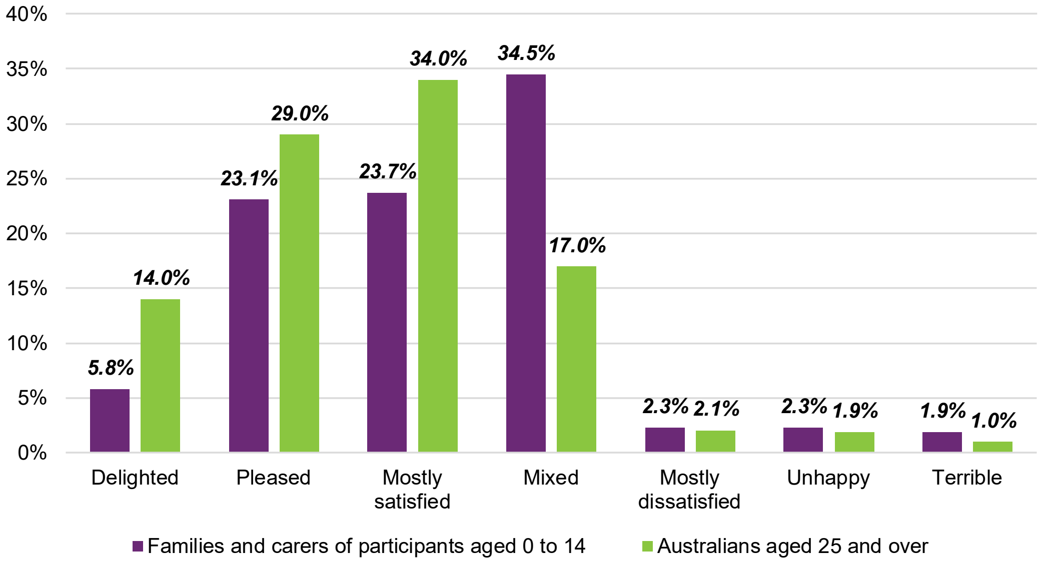
Figure 2.5 Self-rated health, families/carers of participants aged 0 to 14



The LF includes a number of extra questions asking about the wellbeing of families/carers and their outlook on life generally, and for their child in particular. Families/carers most commonly had “mixed” or unknown feelings about the future (40.9%, decreased from previous years’ baseline average at 49.6 %), although more answered positively (52.6%, higher than previous years’ baseline average at 43.7%) than negatively (6.4%, lower than previous years’ baseline average at 6.6 %).

The 52.6% responding positively is much lower than the 77.0% for Australians aged 25 to 64 overall[14], but is higher than for families/carers of participants aged 25 and over (46.8%). Response distributions for families/carers and the general population are compared in Figure 2.6.

Figure 2.6 Outlook for the future, families/carers of participants aged 0 to 14



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[14] 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.

With regard to their child with disability, 71.3% agreed or strongly agreed that having a child with disability has made it more difficult to meet everyday costs of living, lower than 73.9% for prior year entrants. Sixty-nine per cent of respondents agreed or strongly agreed that they felt confident about the future of their child with disability under the NDIS, with 24.6% feeling neutral about this statement and only 6.1% expressing a negative opinion. Prospects for the future of their child showed an overall improvement from prior years' baseline. A lower proportion of family/ carers agreed or strongly agreed that their child gets the support they need (53.4%, higher than prior years' baseline average at 38.6%), or that the services and supports help them to better care for their child (61.9%, higher than prior years' baseline average at 45.2%).

2.5 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, their living situation, age, 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. Table 2.1 provides a key to aid interpretation of the arrow symbols used in these tables, including some examples.

Table 2.1 Definition of symbols used in baseline key driver tables

Symbol	Meaning	Impact	Example
⬆	**More likely to respond "Yes" to the question**	**Positive**	Families/carers of participants with a hearing impairment being their primary disability are more likely to be in a paid job
⬇	**Less likely to respond "Yes" to the question**	**Negative**	Families/carers of participants with a lower level of function are less likely to be able to engage in social interactions and community life as much as they want
⬆	**More likely to respond "Yes" to the question**	**Negative**	Families/carers of older participants who are also unable to work as much as they want are more likely to say the situation of their child/family member with disability is a barrier to working more
⬇	**Less likely to respond "Yes" to the question**	**Positive**	Families/carers of CALD[15] participants who are also unable to work as much as they want are less likely to say insufficient flexibility of jobs is a barrier to working more

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[15] Culturally and Linguistically Diverse.

Symbol	Meaning	Impact	Example
⬆	**More likely to respond "Yes" to the question**	**Depends on context**	Families/carers of Indigenous participants are more likely to be receiving carer payment
⇩	**Less likely to respond "Yes" to the question**	**Depends on context**	Families/carers of participants living in a remote or very remote area are less likely to be receiving carer allowance

Participant primary disability type

There is a significant relationship between participant primary disability type and family/carer outcomes. Typically, for a given disability type, the direction (positive or negative) of the relationship with outcomes is consistent for all domains. Compared to the reference level (developmental delay), outcomes are worse across most domains for families/carers of participants with autism and psychosocial disability, while almost all outcomes are better for families/carers of participants with a hearing impairment, a visual impairment and cerebral palsy.

Outcomes for families/carers of participants with Down syndrome and intellectual disability were mostly not significantly different to those for participants with developmental delay. Apart from being more likely to receive Carer Payment and Carer Allowance, significant differences occurred in only five out of 24 models. Interestingly, apart from one indicator (families/carers of participants with either Down syndrome or intellectual disability being less likely to say the availability of jobs was a barrier to working more), they were different models for the two disabilities.

Families/carers of participants with Down syndrome were more likely to be able to identify the needs of their child (66.3% compared to 61.9% overall, on a one-way basis) and to engage in social interactions and community life as much as they wanted (40.4% compared to 32.2% overall). However, they were more likely to experience barriers to access and/or advocacy and less likely to have people they can ask for childcare, as often as needed.

Families/carers of participants with intellectual disability were more likely to have friends they see as often as they'd like and to get enough support to feel confident in parenting their child. However, their child's disability was more likely to be a barrier to both: working more (90.1% compared to 86.2% overall), and engaging more in the community (91.3% compared to 88.8% overall).

Families/carers of participants with Down syndrome and autism were much more likely to be in receipt of Carer Allowance (45.2% and 43.9% respectively, compared to 30.4% overall, on a one-way basis), whereas families/carers of participants with hearing impairment, another sensory/speech disability or developmental delay were less likely to be receiving both Carer Payment and Carer Allowance.

Controlling for other factors, families/carers of participants with hearing impairment were significantly more likely to have people they could ask for practical help, as often as they need (68.2% versus 44.4% overall, on a one-way basis).

Table 2.2 shows baseline family/carer outcomes for which participant primary disability type is a significant ($p<0.05$) predictor in the multiple regression model.[16]

Table 2.2 Relationship of disability type with the likelihood of selected outcomes

Outcome	Participant primary disability Compared to participants with primary disability of developmental delays						
	Down Syndrome	Autism	Hearing impairment	Cerebral Palsy	Intellectual disability	Psychosocial disability	Visual Impairment
Being in a paid job		⬆	⬆	⬆			⬆
For family/carers with a paid job, the paid job being a permanent position		⬆	⬆				⬆
For family/carers with a paid job, working 15 or more hours per week			⬆			⬆	
Receiving carer payment	⬆	⬆	⇩	⬆	⬆		⬆
Receiving carer allowance	⬆	⬆	⬆	⬆	⬆	⬆	⬆
Currently studying							⇩
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			⬆	⬆		⬇	⬆
Being able to advocate for their child if they have issues or problems		⬆	⬆	⬆			⬆

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[16] The reference level is developmental delay.

Outcome	Participant primary disability Compared to participants with primary disability of developmental delays						
	Down Syndrome	Autism	Hearing impairment	Cerebral Palsy	Intellectual disability	Psychosocial disability	Visual Impairment
Having experienced no barriers to access and/or advocacy	↓	↓	↑			↓	↑
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 for childcare as often as needed	↓	↓	↑	↑		↓	↑
Having people they can talk to for emotional support as often as needed		↓	↑			↓	↑
Get the services and supports they need to care for their child		↓	↑	↑			↑
Knowing what specialist services are needed to promote their child's learning and development		↑	↑	↑			↓
Knowing what their family can do to support their child's learning and development			↑	↑		↓	↑
Getting enough support to feel confident in parenting their child		↓	↑	↑	↑		↑
Feeling confident in supporting their child's development		↓	↑	↑		↓	↑
Rating their health as excellent, very good or good		↓	↑			↓	↑

Outcome	Participant primary disability Compared to participants with primary disability of developmental delays						
	Down Syndrome	Autism	Hearing impairment	Cerebral Palsy	Intellectual disability	Psychosocial disability	Visual Impairment
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	⬇	⬇		⬇	⬇		⬇
For those unable to work as much as they want, the insufficient flexibility of jobs being a barrier to working more		⬇		⬇			⬇
Being able to engage in social interactions and community life as much as they want	⬆	⬇	⬆	⬆			⬆
For those unable to engage in the community as much as they want, the situation of their child/family member with disability being a barrier to engaging 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 have better baseline outcomes, and participants with autism tended to have worse baseline outcomes.

However, there were a few minor differences on specific indicators. For example, for prior year entrants, parents/carers of participants with visual impairment were less likely to be in recept of Carer Payment or Carer Allowance. For 2019-20 entrants, parents/carers of participants with visual impairment are more likely to be in receipt of Carer Payment or Carer Allowance.

Participant age

In many cases, baseline outcomes for families/carers tended to be worse for those with older children[17]. This is apparent from the one-way analyses and is confirmed by the multiple regression modelling.

Across most domains, there are significant differences in outcomes indicators by participant age. Families/carers of older participants were significantly less likely to:

- be able to access available services and supports to meet the needs of their child and family (decreases from 52.3% where the child is aged 2 or younger, to 31.7% where the child is aged 14 or older).
- have friends they see as often as they'd like (decreases from 60.3% where the child is aged 2 or younger, to 37.8% where the child is aged 14 or older)
- have people they can ask for practical help, as often as they need (decreases from 55.2% where the child is aged 2 or younger, to 32.2% where the child is aged 14 or older)
- have people they can ask for childcare (decreases from 42.1% where the child is aged 2 or younger, to 23.4% where the child is aged 14 or older)
- have people they can talk to for emotional support (decreases from 73.0% where the child is aged 2 or younger, to 49.3% where the child is aged 14 or older).
- get enough support in parenting their child (decreases from 52.9% where the child is aged 2 or younger, to 34.3% where the child is aged 14 or older)
- rate their health as excellent, very good or good (decreases from 83.3% where the child is aged 2 or younger, to 65.0% where the child is aged 14 or older)
- engage in social interactions and community life as much as they want (decreases from 43.4% where the child is aged 2 or younger, to 24.9% where the child is aged 14 or older).

They were also more likely to receive Carer Payment (increases from 8.4% where the child is aged 2 or younger, to 21.8% where the child is aged 14 or older) and Carer Allowance (increases from 17.9% where the child is aged 2 or younger, to 44.5% where the child is aged 14 or older).

On the other hand, families/carers of older participants were more likely to be working in a paid job (increases from 38.6% where the child is aged 2 or younger, to 52.2% where the child is aged 14 or older), and more likely to work 15 or more hours per week.

Table 2.3 below shows baseline family/carer outcomes for which participant age is a significant ($p<0.05$) predictor in the multiple regression model.

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

Gender

Baseline outcomes for families/carers of female participants tended to be slightly worse than those of male participants. Controlling for other factors, families/carers of female participants were significantly less likely to:

- be in a paid job (45.4% compared to 46.8% for male participants)
- rate their health as excellent, very good or good (75.8% compared to 77.8% for male participants)
- have people they can talk to for emotional support as often as they need (63.2% compared to 63.4% for male participants), have friends they can see as often as they like, and have people they can ask for practical help/childcare as often as needed.
- be able to work as much as they want (46.3% compared to 46.6% for male participants).

Families/carers of female participants were more likely to receive Carer Allowance (31.1% compared to 30.0% for male participants).

CALD status

Baseline outcomes for families/carers of participants from Culturally and Linguistically Diverse (CALD) backgrounds tended to be worse than those from non-CALD backgrounds, across all domains. Controlling for other factors, those from CALD backgrounds were less likely to:

- have a paid job (42.7% compared to 46.8% for non-CALD participants, on a one-way basis), and for those with a paid job, less likely to be in a permanent position
- be receiving Carer Payment (11.5% compared to 13.7% for non-CALD participants) and Carer Allowance (23.5% compared to 31.0% for non-CALD participants)
- be able to identify the needs of their child and family (48.5% compared to 63.2% for non-CALD participants)
- be able to access available services and supports to meet the needs of their child and family (33.6% compared to 44.5% for non-CALD participants)
- be able to advocate for their child (58.6% compared to 79.2% for non-CALD participants)
- have people they can ask for:
  - practical help, as often as they need (34.6% compared to 45.4% for non-CALD participants)
  - childcare, as often as they need (24.5% compared to 33.8%)
  - emotional support (53.5% compared to 64.3% for non-CALD participants)
- know what specialist services are needed to promote their child's learning and development (27.2% compared to 38.3% for non-CALD participants)
- know what they can do to support their child's learning and development (27.8% compared to 38.3% for non-CALD participants)
- get enough support in parenting their child (36.2% compared to 45.0% for non-CALD participants)
- feel very confident or somewhat confident in supporting their child's development (78.3% compared to 87.7% for non-CALD participants).

However, families/carers of CALD participants were more likely to rate their health as excellent, very good or good, and less likely to see their child's disability as a barrier to engaging more in social interactions and community life.

Indigenous status

Some baseline outcomes are better and some are worse for families/carers of Indigenous participants, compared to families/carers of non-Indigenous participants. Controlling for other factors in multiple regression models, respondents for Indigenous participants were less likely to:

- be working in a paid job (28.6% compared to 48.2% for non-Indigenous participants)
- know what specialist services are needed to promote their child's learning and development (31.0% compared to 38.1% for non-Indigenous participants).

For those unable to work as much as they wanted, respondents were more likely to identify that the:

- availability of jobs was a barrier to working more (26.0% compared to 17.4% for non-Indigenous participants)
- insufficient flexibility of jobs was a barrier (37.9% compared to 31.9%).

However, families/carers of Indigenous participants were more likely to:

- have friends that they can see as often as they'd like (52.2% compared to 48.5% for non-Indigenous participants)
- have people they can ask for practical help (48.4% compared to 44.0% for non-Indigenous participants), childcare (34.4% compared to 32.8%) and emotional support (65.3% compared to 32.1%)
- be able to engage in social interactions and community life, as much as they want (34.7% compared to 32.1% for non-Indigenous participants).

Table 2.3 shows baseline family/carer outcomes for which participant Indigenous status is a significant ($p<0.05$) predictor in the multiple regression model.

Table 2.3 Relationship of participant age, CALD status and Indigenous status with the likelihood of selected outcomes:

	Variable			
Outcome	**Participant is older**	**Participant is female**	**Participant is CALD**	**Participant is Indigenous**
Being in a paid job	⬆	⬇	⬇	⬇
For family/carers with a paid job, the paid job being a permanent position	⬇		⬇	
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 access available services and supports to meet the needs of their child and family	↓		↓	
Being able to advocate for their child if they have issues or problems	↓		↓	
Having experienced no barriers to access and/or advocacy	↓		↓	
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 for childcare as often as needed	↓	↓	↓	↑
Having people they can talk to for emotional support as often as needed	↓	↓	↓	↑
Get the services and supports they need to care for their child	↓		↓	
Knowing what specialist services are needed to promote their child's learning and development	↓		↓	↓
Knowing what their family can do to support their child's learning and development	↓		↓	
Getting enough support to feel confident in parenting their child	↓		↓	↑
Feeling confident in supporting their child's development	↓		↓	
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				↓

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 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	⬆		⬇	⬆
Being able to engage in social interactions and community life as much as they want	⬇			⬆
For those unable to engage in the community as much as they want, the situation of their child/family member with disability being a barrier to engaging 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, with baseline outcomes for families/carers generally worse for those with older children.
- Differences by gender are also similar, with baseline outcomes for families/carers of female participants tending to be worse for both 2019-20 and prior year entrants. However, for prior year entrants families/carers of female participants were more likely to feel confident in supporting their child's development whereas for 2019-20 entrants there was no significant difference compared to families/carers of male participants on this indicator.
- Differences by Indigenous status are generally consistent. Families/carers of Indigenous participants are less likely to be working in a paid job and more likely to identify the availability of jobs as a barrier to working as much as they want. However, for both 2019-20 and prior year entrants, families/carers of Indigenous participants consistently appear to have better informal support networks at baseline.
- 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.

Participant level of function and annualised plan budget

Baseline outcomes tended to be better for families/carers of participants with higher level of function, and with lower annualised plan budgets[18]. For example, families/carers of

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[18] Note that variations in baseline outcomes by annualised plan budget reflect characteristics associated with having a higher or lower plan budget, rather than the amount of the plan budget itself, since participants are at the start of their first plan at baseline.

participants with a higher level of function (or lower annualised plan budget) were more likely to:

- be able to access available services and supports to meet the needs of their child and family (50.0% for families/carers of participants with a high level of function, decreasing to 32.3% for those with a low level of function)
- have friends they can see as often as they'd like (58.7% for families/carers of participants with a high level of function, decreasing to 31.7% for those with a low level of function)
- have people they can ask for practical help (53.6% decreasing to 27.1%), for childcare (41.0% decreasing to 18.1%) and for emotional support (71.0% decreasing to 48.6%) as often as they need
- be able to engage in social interactions and community life, as much as they want (41.7% for families/carers of participants with a high level of function, decreasing to 17.3% for those with a low level of function).

Furthermore, families/carers of participants with a higher level of function (or lower annualised plan budget) who were unable to work as much as they wanted, were less likely to identify the situation of their child/family member with disability as a barrier to working more (79.9% for families/carers of participants with a high level of function, increasing to 94.6% for those with a low level of function). A similar result holds for families/carers being unable to engage in social interactions and community life as much as they want.

Receipt of government benefits also increased with decreasing level of function/increasing plan budget. In particular, 10.1% and 21.1% of families/carers of participants with a high level of function were receiving Carer Payment and Carer Allowance, respectively, compared to 22.2% and 43.8% for families/carers of participants with low level of function.

Table 2.4 shows baseline family/carer outcomes for which participant level of function and/or annualised plan budget are significant ($p<0.05$) predictors in the multiple regression model.

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.

Level of NDIA support

Families/carers of participants receiving a higher level of NDIA support[19] with planning were identified as having poorer baseline outcomes in several of the regression models. For example, families/carers of participants receiving a higher level of NDIA support were more likely to experience difficulties in accessing available services and supports to meet the needs of their child and family, and were less likely to have people they can ask for practical help or childcare as needed.

Table 2.4 below shows baseline family/carer outcomes for which the participant's level of NDIA support are significant ($p<0.05$) predictors in the multiple regression model.

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

Comparing 2019-20 entrants with participants entering in earlier years, baseline differences by level of level of NDIA support are very similar. For both 2019-20 entrants and prior year entrants, baseline indicators are generally worse for families/carers of participants receiving a higher level of NDIA support.

Plan Management Type

Families/carers who self-managed their child's plan tended to have better baseline outcomes than those who were agency-managed. For example, those who fully self-managed were more likely to:

- work in a paid job (58.0% compared to 35.6% for agency-managed participants and 46.4% overall)
- be able to:
    - identify the needs of their child and family (69.5% compared to 56.8% for agency-managed participants and 61.9% overall)
    - advocate for their child (85.1% compared to 70.9% for agency-managed participants and 77.3% overall)
    - access available services and supports to meet the needs of their child and family (51.6% compared to 41.2% for agency-managed participants and 43.6% overall)
- know what specialist services were needed to promote their child's learning and development (45.7% compared to 32.2% for agency-managed participants and 37.4% overall).

For those families/carers who self-managed their child's plan, more negative baseline outcomes were mostly related to the degree of work and social interactions. As an example, self-managed families/carers were less likely to be able to work as much as they liked (47.2% compared to 49.8% for agency-managed participants), more likely to identify the situation of their child with disability to be a barrier from them to work more (88.5% compared to 80.7% for agency-managed participants), and less likely to be able to engage in social interactions and community life as much as they want (30.7% compared to 38.7% for agency-managed participants).

Table 2.4 shows baseline family/carer outcomes for which participants who have a plan management type of self-managed are significant ($p<0.05$) predictors in the multiple regression model.[20]

Comparing 2019-20 entrants with participants entering in earlier years, baseline trends by plan management type are very similar. Families/carers who self-managed their child's plan tended to have better baseline outcomes than those who were agency-managed.

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[20] The reference level is Agency-managed.

Table 2.4 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	High level of support from the NDIS	Self managed
Being in a paid job	⬇	⬇	⬇	⬆
Receiving carer payment	⬆			⇩
Receiving carer allowance	⬆	⬆		⇩
Currently studying	⇩		⇩	
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	⬇	⬇	⬇	⬆
Being able to advocate for their child if they have issues or problems	⬇	⬇	⬇	⬆
Having experienced no barriers to access and/or advocacy	⬇	⬇		⬆
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 for childcare as often as needed	⬇	⬇	⬇	
Having people they can talk to for emotional support as often as needed	⬇	⬇		⬆
Knowing what specialist services are needed to promote their child's learning and development	⬇			⬆
Knowing what their family can do to support their child's learning and development	⬇	⬇	⬇	⬆
Getting enough support to feel confident in parenting their child	⬇	⬇	⬇	⬆
Feeling confident in supporting their child's development	⬇	⬇	⬇	⬆
Rating their health as excellent, very good or good	⬇	⬇	⬇	

Outcome	Variable			
	Lower level of function	Higher annualised plan budget	High level of support from the NDIS	Self managed
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		⬇		⬇
For those unable to work as much as they want, the insufficient flexibility of jobs being a barrier to working more		⬇		⬇
Being able to engage in social interactions and community life as much as they want	⬇	⬇	⬆	⬇
For those unable to engage in the community as much as they want, the situation of their child/family member with disability being a barrier to engaging more	⬆	⬆		

State/Territory

Results by State/Territory were mixed. Controlling for other factors, baseline outcomes were generally worse for families/carers of participants living in Victoria (VIC), Queensland (QLD), Western Australia (WA) and the Australian Capital Territory (ACT), when compared to the reference level (i.e. New South Wales (NSW)). However, families/carers living in Tasmania (TAS) had generally better outcomes than NSW across all domains (although on a one-way basis, differences were generally slight). For example, families/carers living in TAS were more likely to be able to advocate for their child (80.9% compared to 79.9% for NSW), experience no boundaries to access or advocacy (48.6% compared to 48.3% for NSW), and to feel confident in supporting their child's development (90.9% compared to 88.7% for NSW).

Families/carers living in the Northern Territory (NT) also had better outcomes specifically in the domains of 'families feeling supported' and 'health and wellbeing'. For example, they were more likely to have friends they could see as often as they'd like (62.2% compared to 56.6% for NSW), have people they can ask for practical help (53.1% compared to 51.6% for NSW) and for childcare (39.9% compared to 38.0% for NSW) as often as they need. They were also more likely to rate their health as excellent, very good or good (88.7% compared to 80.8% for NSW – whilst participant age was controlled for, family/carer age may still be a confounding factor in this comparison) and be able to work as much as they wanted (64.3% compared to 49.3% for NSW).

Table 2.5 shows baseline family/carer outcomes for which State/Territory of residence is a significant ($p<0.05$) predictor in the multiple regression model.[21]

Table 2.5 Relationship of State/Territory of residence with the likelihood of selected outcomes:

	State						
Outcome	**VIC**	**QLD**	**SA**	**WA**	**TAS**	**ACT**	**NT**
Being in a paid job	⬇	⬇		⬇			⬆
For family/carers with a paid job, the paid job being a permanent position	⬆					⬆	⬆
For family/carers with a paid job, working 15 or more hours per week	⬇			⬇		⬆	⬆
Receiving carer payment		⬆			⬆		⇩
Receiving carer allowance	⬆	⬆	⬆		⬆	⇩	⇩
Currently studying	⇩			⇩	⇩		⇩
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	⬇					⬇	⬇
Being able to advocate for their child if they have issues or problems	⬇			⬇	⬆		⬇
Having experienced no barriers to access and/or advocacy	⬇	⬇		⬇	⬆	⬇	⬇
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 for childcare as often as needed	⬇	⬇		⬇	⬆	⬇	⬆
Having people they can talk to for emotional support as often as needed	⬇	⬇		⬇			

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[21] The reference level is NSW.

Outcome	State						
	VIC	QLD	SA	WA	TAS	ACT	NT
Get the services and supports they need to care for their child	⬇	⬇	⬇	⇧	⬇	⬇	
Knowing what specialist services are needed to promote their child's learning and development	⬇			⬇		⬇	⬇
Knowing what their family can do to support their child's learning and development	⬇		⬇	⬇		⬇	⬇
Getting enough support to feel confident in parenting their child	⬇	⬇	⬇	⬇		⬇	⬇
Feeling confident in supporting their child's development	⬇			⬇	⇧		
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 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	⇩	⬆	⇩	⇩		⇩	
Being able to engage in social interactions and community life as much as they want	⬇			⬇			⇧

Comparing 2019-20 entrants with participants entering in earlier years, baseline trends by State or Territory seem to have slightly shifted. Controlling for other factors, NSW tended to have the worst baseline outcomes among families/carers of participants entering in prior years, and ACT had the best outcomes. However among families/carers of 2019-20 entrants, NSW exhibited better baseline outcomes than ACT, and TAS had generally better outcomes than NSW across all domains.

Remoteness

Controlling for other factors, families/carers living in regional or remote areas tended to have better baseline outcomes than those living in major cities, particularly in the domains of ‘feeling supported’ and ‘health and wellbeing’. For example, when compared to families/carers living in major cities, families/carers living in regional and remote areas were more likely to:

- have people they can ask for:
    - practical help (47.5-49.4% and 45.8% for regional and remote areas respectively, compared to 42.6% for major cities)
    - childcare (35.6-36.7% and 32.4% for regional and remote areas respectively, compared to 31.6% for major cities)
    - emotional support (65.0-67.1% and 66.2% for regional and remote areas respectively, compared to 62.1% for major cities)
- rate their health as excellent, very good or good (77.2-78.7% and 83.1% for regional and remote areas respectively, compared to 76.7% for major cities)
- be able to work as much as they want (50.6-52.4% and 54.9% for regional and remote areas respectively, compared to 44.2% for major cities)
- be able to engage in social interactions and community life as much as they want (34.2-38.9% and 38.4% for regional and remote areas respectively, compared to 30.1% for major cities).

However, families/carers living in regional and remote areas were less likely to be able to access available services and supports to meet the needs of their child and family (36.8-44.0% and 28.7% for regional and remote areas respectively, compared to 44.8% for major cities). Furthermore, families/ carers living in regional and remote areas who were not working as much as they would like were more likely to identify the following barriers to working more:

- Availability of jobs (19.8-24.3% and 35.8% for regional and remote areas respectively, compared to 16.2% for major cities)
- Insufficient flexibility of jobs (34.8-36.5% and 38.2% for regional and remote areas respectively, compared to 30.8% for major cities).

Table 2.6 shows baseline family/carer outcomes for which remoteness is a significant (p<0.05) predictor in the multiple regression model.

Table 2.6 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**[22]
Being in a paid job	⬇	⬆
For family/carers with a paid job, the paid job being a permanent position	⬇	
For family/carers with a paid job, working 15 or more hours per week	⬇	⬇

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[22] Modelling results for Remote and Very Remote areas reflects more of the experience of families living in the Remote areas, due to small numbers in the Very Remote areas.

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[22]
Receiving carer payment	⬆	⇩
Receiving carer allowance		⇩
Currently studying	⬆	⇩
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	⬇	⬇
Being able to advocate for their child if they have issues or problems	⬆	⬆
Having experienced no barriers to access and/or advocacy		⬇
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 for childcare as often as needed	⬆	⬆
Having people they can talk to for emotional support as often as needed	⬆	⬆
Getting enough support to feel confident in parenting their child	⬆	⬆
Feeling confident in supporting their child's development	⬆	⬆
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 being a barrier to working more	⬆	⬆

	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**[22]
For those unable to work as much as they want, the insufficient flexibility of jobs being a barrier to working more	⬆	⬆
Being able to engage in social interactions and community life as much as they want	⬆	⬆
For those unable to engage in the community as much as they want, the situation of their child/family member with disability being a barrier to engaging 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 less access to services compared to those living in major cities, consistently with those for prior year entrants.

For both 2019-20 entrants and prior year entrants, controlling for other factors in the multiple regression modelling, families/ carers living in a remote area were more likely to be in a paid job, and those in a regional area were less likely to be in a paid job, compared to families/carers living in a major city.

Family/carer knowledge and support

On a one-way basis, favourable outcomes at baseline were observed for families/carers who:

- are able to advocate for their child
- have adequate support networks
- know what they can do to support their child and are able to access available services and supports.

The importance of strong social networks is highlighted by Table 2.7, which shows how the percentage responding positively to four questions about levels of support and engagement depend strongly on whether the family/carer has friends and family they see as often as they would like.

Table 2.7 Inter-relationships between questions about support networks

Question	Percentage responding "Yes" to question where answer to "I have friends and family that I see as often as I like" is:	
	Yes (48.8%)	No (51.2%)
I have people who I can ask for practical help as often as I need	75.1%	15.2%
I have people who I can ask for childcare as often as I need	57.1%	10.0%
I have people who I can talk to for emotional support as often as I need	87.6%	40.3%
I/(my partner and I) am/are able to engage in social interactions and community life as much as I/we want	53.3%	11.8%

Table 2.8 shows the inter-relationships between key outcomes questions related to understanding and supporting their child with disability. The results indicate that the percentage responding positively to three questions about knowledge and support are linked to whether the family/carer knows what their family can do to support their child's learning and development.

Table 2.8 Inter-relationships between questions about access to services and supporting the needs of the participant

Question	Percentage responding "Yes" to question where answer to "I know what my family can do to support my child's learning and development" is:	
	Yes (37.4%)	No (62.6%)
I am able to access available services and supports to meet the needs of my family and child	70.2%	27.7%
I know what specialist services are needed to promote my child's learning and development	76.7%	13.9%
I feel very confident or somewhat confident in supporting my child's development	97.2%	80.7%

Comparing 2019-20 entrants with participants entering in earlier years, inter-relationships between questions about support networks, and between questions about access to services and supporting the needs of the participant, are very similar.

Living arrangements and LGA unemployment rate

Controlling for other factors, families/carers living in a private rented home (from a private landlord, or more significantly from a public authority), have poorer baseline outcomes across all domains, when compared to families/carers living in a private home that they or their family member owns. This likely reflects factors related to income and socio-economic status. For example, respondents who were renting and unable to work as much as they wanted reported the availability and/ or inflexibility of jobs as key barriers to working more, and the situation of their child or family member with disability as less of a barrier.

Additionally, families/carers who were renting were more likely to receive Carer Payment and Carer Allowance.

As for families/carers who were renting, those living in LGAs with a higher unemployment rate tended to have poorer outcomes across multiple domains, controlling for other factors. They were also more likely to receive Carer Payment and Carer Allowance. However, the regression modelling shows that families/carers living in LGAs with a high unemployment rate had better outcomes in the domain ‘families feel supported’. In particular, they were more likely to have friends they can see as often as they would like, and have people they can ask for practical help and childcare. They were also more likely to be able to engage in social interactions and community life as much as they wanted.

Table 2.9 shows baseline family/carer outcomes for which participant living arrangements and/or LGA unemployment rate are significant ($p<0.05$) predictors in the multiple regression model.

Table 2.9 Relationship of participant’s living situation with the likelihood of selected outcomes for families/carers:

Relationship of the variable with the likelihood of:	Variable		
	Private home rented from a private landlord	Private home rented from a public authority	Living in LGA with high unemployment rate
Being in a paid job	↓	↓	↓
For family/carers with a paid job, the paid job being a permanent position	↓	↓	↓
For family/carers with a paid job, working 15 or more hours per week	↓	↓	
Currently studying	↑	↑	
Receiving carer payment	↑	↑	↑
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	↓	↓	↓
Being able to advocate for their child if they have issues or problems	↓	↓	↓
Having experienced no barriers to access and/or advocacy	↓	↓	

Relationship of the variable with the likelihood of:	Variable		
	Private home rented from a private landlord	Private home rented from a public authority	Living in LGA with high unemployment rate
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 for childcare as often as needed	⬇	⬇	⬆
Having people they can talk to for emotional support as often as needed	⬇	⬇	
Getting the services and support they needed to care for their child	⬇	⬇	⬇
Knowing what specialist services are needed to promote their child's learning and development	⬇	⬇	⬇
Knowing what their family can do to support their child's learning and development	⬇	⬇	⬇
Getting enough support to feel confident in parenting their child	⬇	⬇	
Feeling confident in supporting their child's development	⬇	⬇	
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, % who say availability of jobs is a barrier to working more	⬆	⬆	⬆
For those unable to work as much as they want, % who say insufficient flexibility of jobs is a barrier to working more	⬆	⬆	
Being able to engage in social interactions and community life as much as they want	⬇	⬇	⬆

Comparing 2019-20 entrants with participants entering in earlier years, the difference in baseline outcomes by living arrangement are very similar. For both cohorts, families/carers living in a private rented home have poorer baseline outcomes compared to families/carers living in a private home that they or their family member owns.

Impact of COVID-19

The global pandemic that took hold from early 2020 is likely to have had an impact on at least some family/carer outcomes, such as having a job and feeling supported.

Methodology

To investigate which outcomes may have been affected by the pandemic via quantitative modelling, the following terms were added to the models:

1. An indicator taking the value 0 for dates up to 23 March 2020 (the announcement of stronger restrictions by the Prime Minister, such as closure of restaurants and gyms), and 1 for later dates.
2. A general time trend.
3. The interaction between 1. and 2.

The first term allows for a step change in the indicator from 23 March 2020. The second term allows for temporal changes in the indicator not related to COVID-19, whereas the third term allows for different time trends before and after 23 March 2020.

Results of this analysis should be interpreted with care due to the following limitations:

1. The modelling is based on only about three months of experience during the pandemic, and some of the effects detected are only slight.
2. Some of the indicators where the pandemic might be thought to have an effect have a time frame specified. For example, for social and community participation, adult participants are asked “Have you been actively involved in a community, cultural or religious group *in the last 12 months?*”. At least nine months of this period will be prior to the start of the pandemic.
3. Significance of the COVID indicator and/or the interaction term does not imply causality: it is not possible to say that changes in the indicator were caused by the COVID-19 pandemic.
4. The full impact of the pandemic cannot be evaluated using quantitative methods alone: qualitative research (such as focus groups and interviews with participants) would also be needed. Some qualitative research into economic and social participation outcomes, including the effect of the pandemic, is being undertaken.

Results

For families/carers of participants from birth to age 14 who entered the Scheme in 2019-20, there were 15 indicators for which one or both of the COVID-related terms was significantly different from zero.

Figure 2.7 illustrates employment-related indicators where one or both COVID-related terms was significant.

Figure 2.7 Estimated trend for employment-related indicators pre- and post-onset of the COVID-19 pandemic

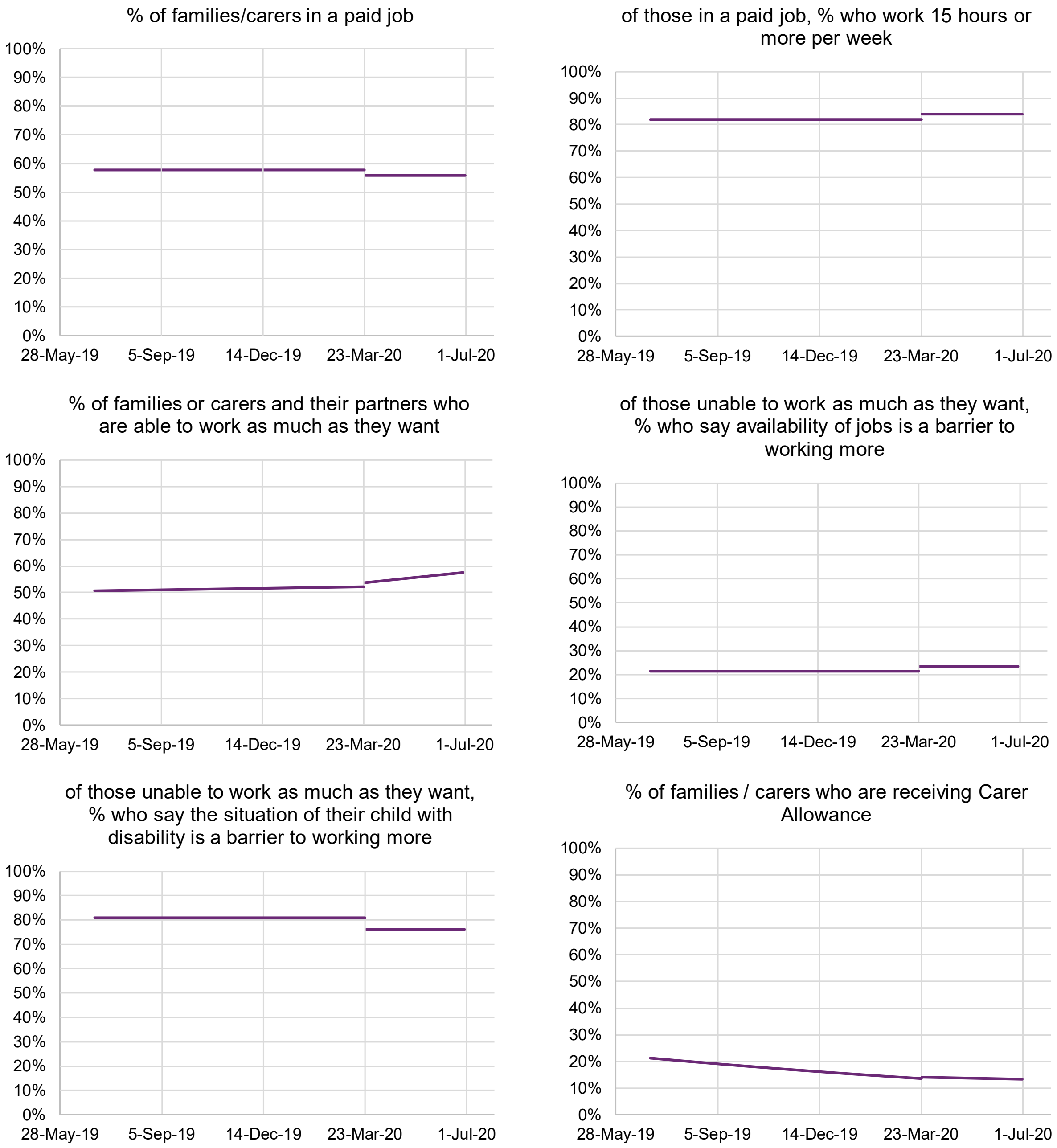


Figure 2.7 shows that:

- There was a significant drop in the percentage of families/carers who have a paid job at the COVID-19 date, however there was a significant step increase in the percentage working 15 hours or more per week.
- The percentage who say that they (and/or their partner) are able to work as much as they want increased more strongly over time during the pandemic. Of those unable to work as much as they want, the percentage who say that availability of jobs is a barrier to working more rose to a higher constant level during the pandemic, but the percentage saying the situation of their child with disability was a barrier dropped to a lower constant level.

- The percentage receiving Carer Allowance had been declining over time prior to the pandemic, but this decreasing trend levelled off during the pandemic.

Figure 2.8 illustrates estimated effects for indicators related to support for the family, and support for helping their child develop and learn. All of these effects were positive.

Figure 2.8 Estimated trend for indicators related to support for families/carers and their child, pre- and post-onset of the COVID-19 pandemic

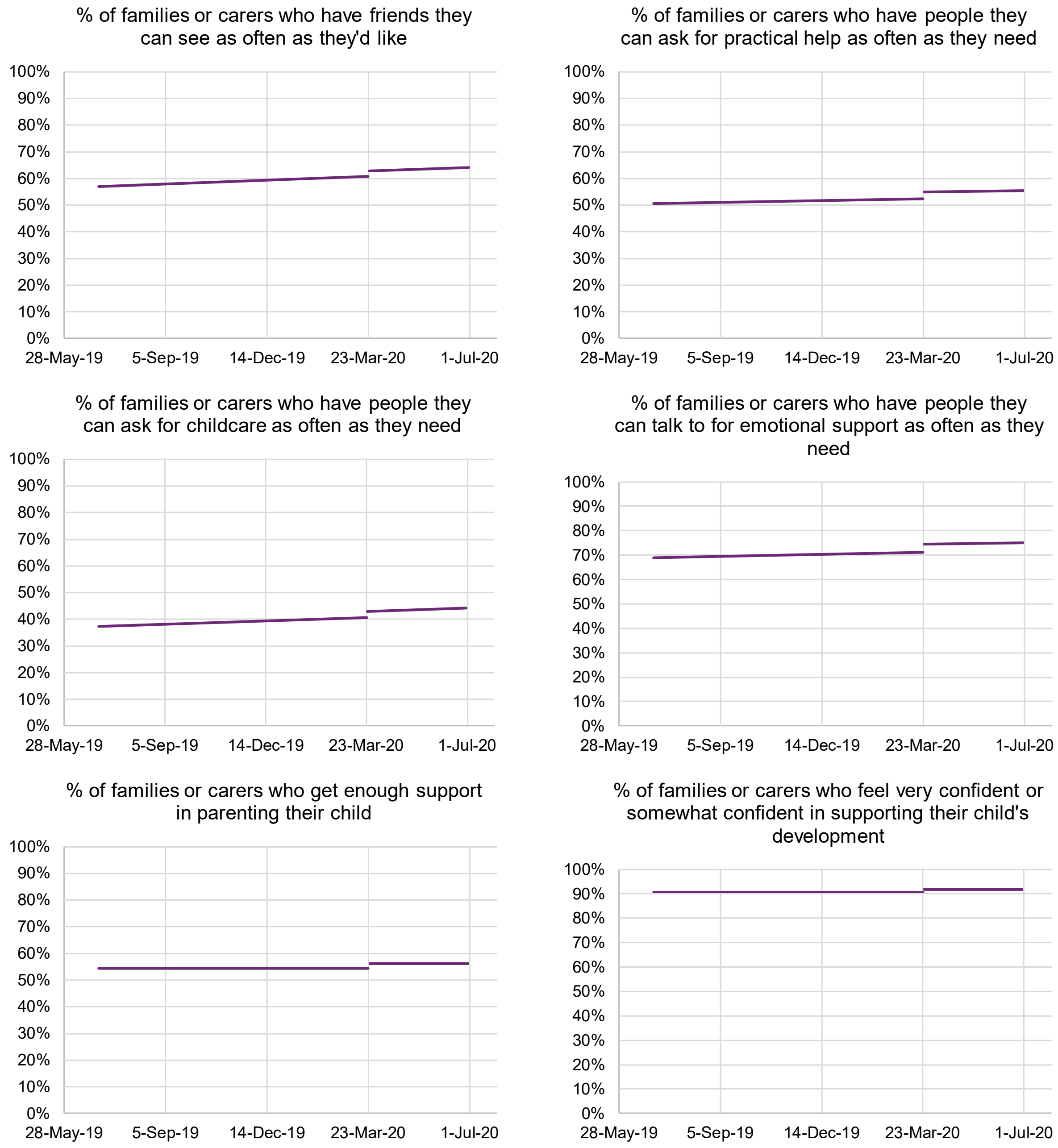


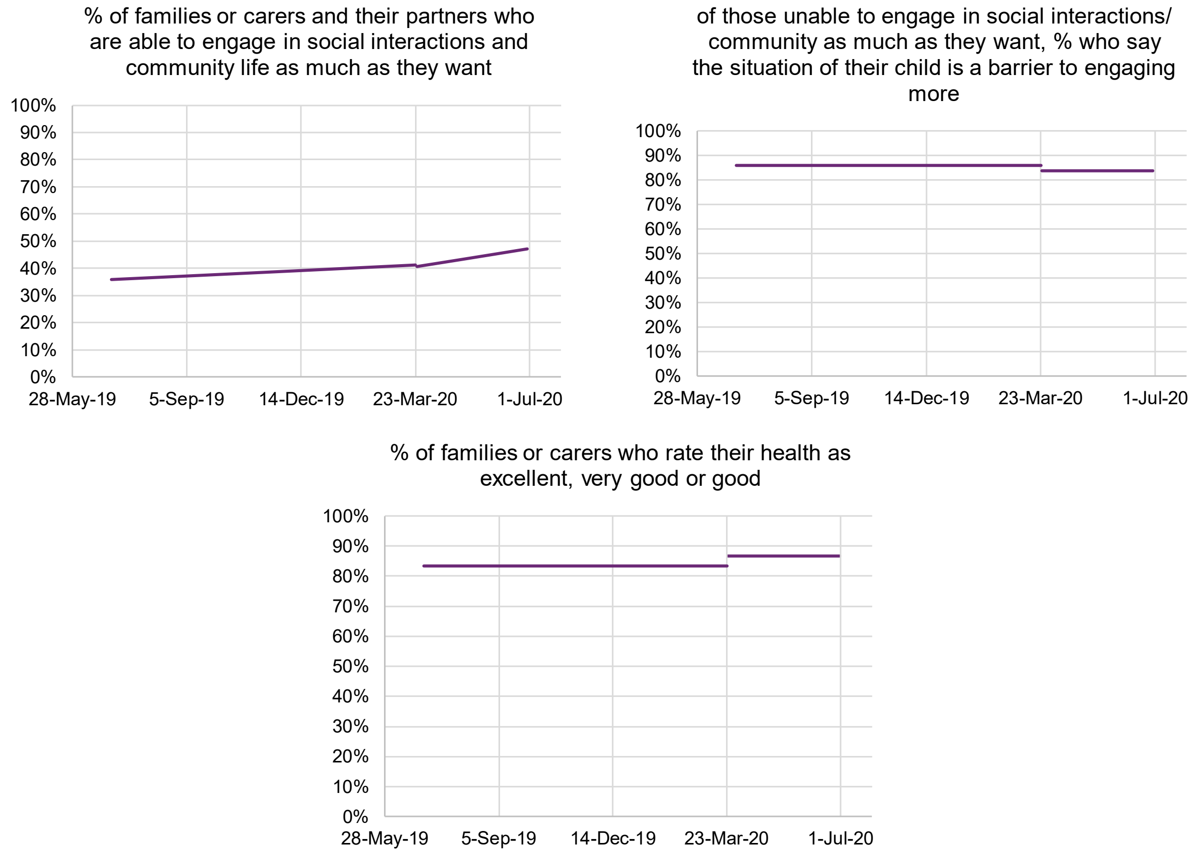
Figure 2.8 shows that:

- For the four indicators related to families feeling supported (having friends they can see as often as they like; having people they can ask for practical help, childcare, and emotional support as often as they need): there was a general increasing trend in these indicators prior to the start of the pandemic, a significant step increase at the start date, and a continuation of the same increasing trend post-onset of the pandemic.

- For the two indicators related to families/carers being supported in helping their child develop and learn (getting enough support in parenting their child, and feeling confident in supporting their child's development): there was a significant improvement in these indicators to a new constant level post-onset of the pandemic.

Figure 2.9 shows estimated trends for indicators related to social and community engagement, and self-rated health. All of these effects were positive.

Figure 2.9 Estimated trend for indicators related to social and community engagement, and self-rated health, pre- and post-onset of the COVID-19 pandemic



% of families or carers and their partners who are able to engage in social interactions and community life as much as they want

of those unable to engage in social interactions/ community as much as they want, % who say the situation of their child is a barrier to engaging more

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

Figure 2.9 shows that:

- The percentage of families/carers who are able to engage in social interactions and community life as much as they want showed an increasing trend prior to the pandemic. The increasing trend persisted, but at a higher rate, after the start of the pandemic.
- For those unable to engage as much as they want, the percentage who see the situation of their child with disability as a barrier to engaging more dropped to a lower constant level during the pandemic.
- The percentage of families/carers rating their health as excellent, very good or good rose to a new constant level during the pandemic.

Box 2.4 summarises the key findings from this section.

Box 2.4 Summary of findings – results by participants and family/carer characteristics

- Families/carers of participants with a hearing impairment, of participants with a higher level of function and of participants who are self-managing part or all of their plan tend to have better baseline outcomes across most indicators. Some baseline indicators are also better for families/carers of participants living in regional and remote areas, compared to those living in major cities.
- Families/carers of participants with autism or a psychosocial disability, of older children, and of those from a CALD background tended to have worse baseline outcomes across most indicators.
- Families/carers of Indigenous participants tended to have worse employment outcomes at baseline. They were less likely to be working in a paid job and more likely to find the availability of jobs a barrier to employment. However, families/carers of Indigenous participants appear to have better informal support networks at baseline.
- Families/carers of participants living in a private home that is owned by their family/carers have better baseline outcomes across almost all indicators, compared to families/carers of participants living in a private home that is rented from either a private or public landlord.
- COVID-19 had a significant impact on family/carer outcomes and results were mostly positive, apart from some employment indicators. The percentage of families and carers who were in a paid job dropped, and the percentage who perceived the availability of jobs as a barrier to employment has increased. However, more families or carers reported having friends they can see as often as they'd like, and people they can ask for practical help, emotional support, and childcare as often as they need.