Baseline outcomes for families and carers of NDIS participants

30 June 2020

Contents

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Executive summary

Background

The NDIS Outcomes Framework is one of only a few internationally that measures outcomes for both participants and their families and carers.

Families and carers play an important role in supporting NDIS participants. The outcomes for a participant, and for the person who supports them, are likely to be closely linked. Families and carers of participants who are well supported under the NDIS and who are achieving greater independence and social and economic participation are likely to find the caring role easier and to experience increased wellbeing and greater opportunities for social and economic participation themselves. The improved situation for families and carers should in turn translate into further improvement in outcomes for participants.

Separate reports on baseline and longitudinal outcomes for NDIS participants at 30 June 2020 have also been prepared.[1]

The NDIS Outcomes Framework questionnaires

The participant outcomes reports discuss the insurance principles on which the Scheme is based. An insurance-based approach considers the lifetime cost of participants (including early investment), and the outcomes achieved across participants' lifetimes. In view of the link with participant outcomes, monitoring family and carer outcomes contributes to an assessment of how successfully the insurance-based approach is working. Monitoring of family and carer outcomes is also important from a broader perspective, for example, increased economic participation of families and carers will have wider benefits for the Australian economy.

This report

This report summarises outcomes for families and carers of NDIS participants entering the Scheme during the four year period from 1 July 2016 to 30 June 2020, with outcomes measured at the time of entry to the Scheme (at "baseline"). The main focus is on families/carers of participants entering in the latest year (2019-20), but brief comparisons with results of prior year entrants are also provided. A separate report covers longitudinal change for families and carers of participants who have been in the Scheme for one year or more at 30 June 2020. Two previous reports have covered both baseline and longitudinal experience of families and carers, as at 30 June 2018 and 30 June 2019.[2]

Participants entering the Scheme at different times may have different characteristics (for example, due to phasing). Hence, for the participants whose families and carers are the subject of this report, a brief summary of how 2019-20 entrants compare to participants entering in the earlier three year period is also provided, on key characteristics such as disability and level of function.

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[1] Subsequently referred to as "the participant outcomes reports".

[2] Family and carer outcomes report | NDIS

The global COVID-19 pandemic that took hold from early 2020 is likely to have had an impact on at least some participant and family/carer outcomes, such as employment and social and community participation. This report investigates effects of the pandemic on outcomes via multiple regression models that allow for discontinuities in indicator levels, as well as different time trends, pre- and post-onset of the pandemic.

Baseline versus progress

As also noted in the participant outcomes reports, baseline outcomes for participants and their families and carers will differ by a range of individual and external factors, including the nature and severity of the participant's disability, the extent of support networks, local community inclusiveness, and general health.

Consequently, the success of the Scheme should be judged not on baseline outcomes, but on how far participants and their families and carers have come since they entered the Scheme, acknowledging their different starting points.

The purpose of this report is to provide a snapshot view of family and carer outcomes at the time the participants they support enter the Scheme, based on information provided by them in interviews conducted using the NDIS outcomes framework questionnaires. At this time, the NDIS has not had an opportunity to have an impact on outcomes. The separate longitudinal report considers how far families and carers have progressed since the participants they support entered the Scheme. Together, the reports provide insight into how the Scheme is making a difference, and point to any areas where improvements may be required.

A lifespan approach

Leveraging research conducted by the NDIS Independent Advisory Council (IAC), the outcomes framework takes a lifespan approach to the measurement of outcomes, recognising that different milestones are important for different participant age groups.

Many of the issues faced by families and carers are similar regardless of participant age (for example, being able to work as much as they want), however there are some differences (for example, families and carers of young children will be focussed on helping their child's early development and learning, whereas families and carers of young adults will want to help their family member to become as independent as possible).

Recognising these differences, family/carer questionnaires have been developed for three different *participant* age groups: 0 to 14, 15 to 24, and 25 and over. This report is organised with separate sections for each of these participant age groups, synthesising analyses from all data sources[3]. Since the role of the family or carer in the participant's life is most crucial during childhood, the report puts greater emphasis on the 0 to 14 participant age group, followed by the 15 to 24 age group. For the 25 and over age group, where a smaller amount of data is available, and the relationship between participants and families/carers tends to be less close, a briefer presentation of results is given.

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[3] The Short Form (SF) outcomes framework and the Long Form (LF) outcomes framework, baseline and longitudinal information.

Families/carers of participants from birth to age 14

Comparison with prior year entrants

For the participants whose families and carers are the subject of this report, compared to those entering the Scheme in prior years, 2019-20 entrants tend to be:

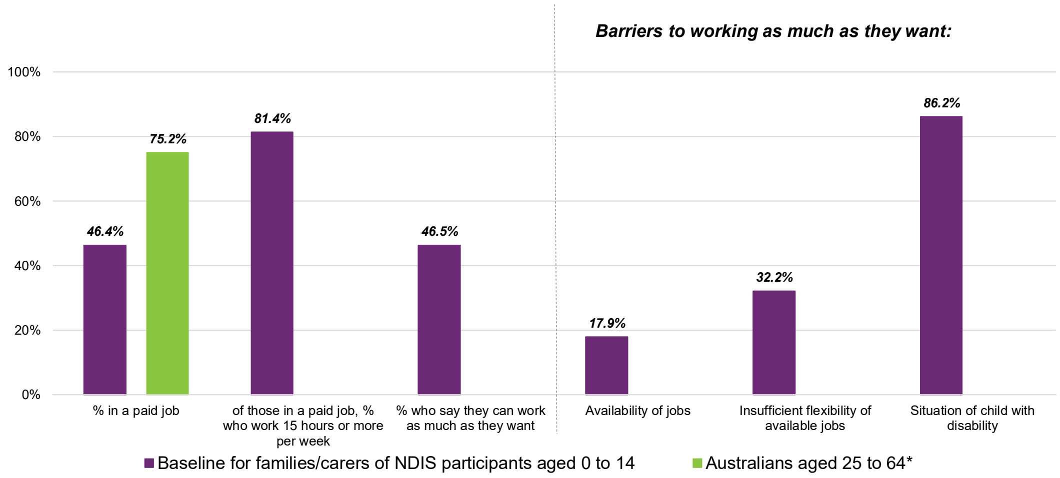
- Younger
- More likely to have developmental delay or global developmental delay and less likely to have autism
- More likely to have medium or high level of function and less likely to have low level of function.

Overall results

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.

Figure 1 Employment outcomes



*ABS Labour Force Statistics, Original Series, as at 30 June 2020. About 90% of respondents are female (mothers) and are likely to be at the younger end of the age range. For comparison, weighting by gender and restricting to age range 25 to 49 would give a benchmark of 74.2%, rather than 75.2%.

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.

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

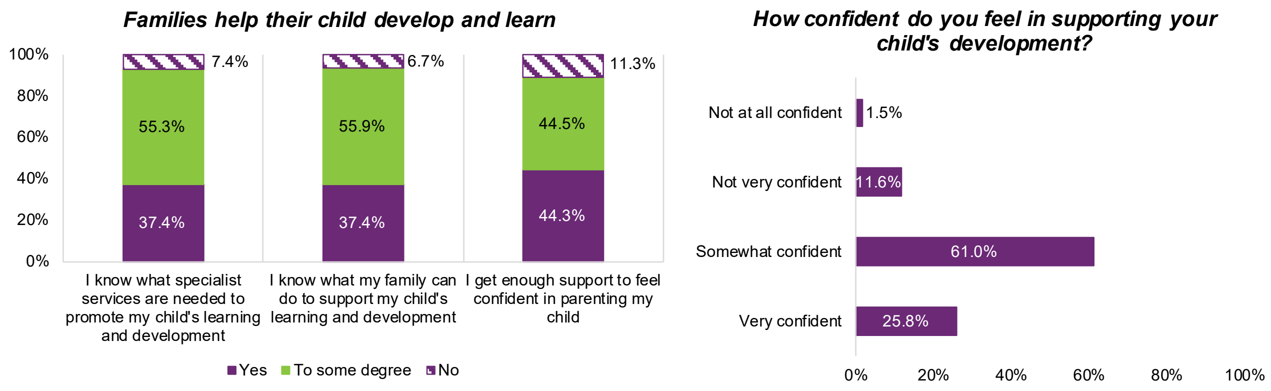
Eighty-seven per cent (87.3%) of families/carers have good (42.6%) or very good (44.7%) relationships with their services. The percentage having a very good relationship with their services has been increasing over time, from 29.2% for families/carers of participants entering in 2016-17 at baseline,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

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

Figure 2 Families help their child develop and learn



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 baseline results for families/carers of prior year entrants.

Health and wellbeing

Only 32.2% of families/carers said that they 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.

Compared to the general Australian population aged 25 to 64 overall, 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%).

Results by participant characteristics

Baseline indicators for families/carers of participants entering the Scheme in 2019-20 have been analysed by participant characteristics using one-way analyses and multiple regression modelling.

Across most domains, the participant's level of function, primary disability type, age, where they live, and the extent to which they make friends and participate in community are the characteristics most predictive of outcomes in the multiple regression models, which control for other factors.

Key results from the analysis include:

- Families/carers of participants with a hearing impairment as their primary disability, 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.
- 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 level of function and lower baseline plan budget had better baseline outcomes for most indicators. For example, families/carers of 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).
- Families/carers of participants receiving a higher level of NDIA support with planning were identified as having poorer baseline outcomes in several of the regression

models.[4] 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 often as needed.

- Families/carers living in regional or remote areas tended to report better baseline outcomes than those living in major cities. In particular, families/carers living in regional or remote areas reported more positive baseline outcomes related to having people they can ask for help and support as often as needed. However, families/carers living in regional or remote areas reported more difficulties in 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.

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[4] The level of NDIA support a participant requires as they move along the participant pathway, having regard to the complexity of their situation. This will be linked with the participant's level of function and plan budget, in general.

Families/carers of participants from age 15 to 24

Comparison with prior year entrants

For the participants whose families and carers are the subject of this report, compared to those entering the Scheme in prior years, 2019-20 entrants tend to be:

- Younger
- More likely to have autism as their primary disability and less likely to have an intellectual disability or Down syndrome
- More likely to have medium or high level of function and less likely to have low level of function.

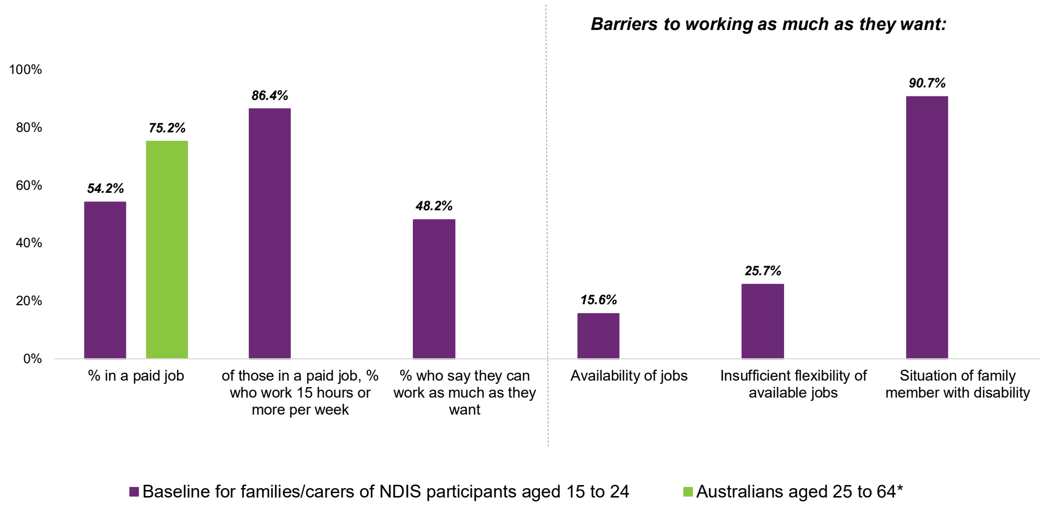
Overall results

Employment

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.

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%).

Figure 3 Employment outcomes



*ABS Labour Force Statistics, Original Series, as at 30 June 2020. 80% of respondents are mothers, 12% are fathers, 2% are grandmothers, 6% are others. For comparison, weighting by gender would give a benchmark of 71.4%, rather than 75.2%.

Rights and advocacy

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).

Families feel supported

As with families/carers of participants from birth to age 14, most families/carers said they lacked sufficient support and social connections. Again, families/carers of 2019-20 entrants tended to respond more positively than those of 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.

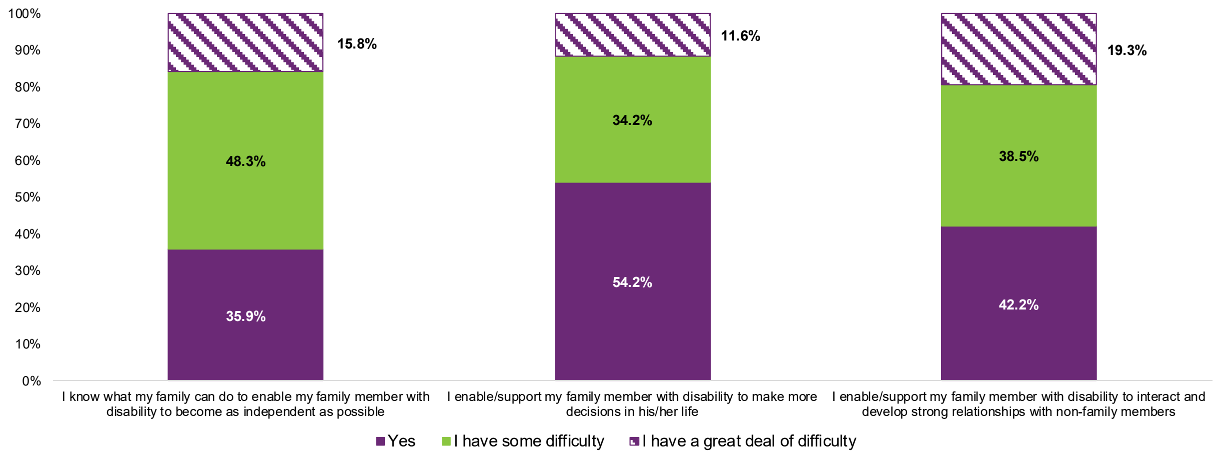
Access to desired services, programs and activities

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).

Helping their family member become more independent

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 (40.9%, 45.2% and 57.1%, respectively).

Figure 4 Families/carers help their family member become more independent



Health and wellbeing

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.

Results by participant characteristics

Baseline indicators for families/carers of participants entering the Scheme in 2019-20 have been analysed by participant characteristics using one-way analyses and multiple regression modelling.

Across most domains, the participant's level of function, primary disability type, age, and where they live are the characteristics most predictive of outcomes in the multiple regression models, which control for other factors.

Key results from the analysis include:

- 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 was being in a paid job (56.8%), when compared to families/carers of participants with intellectual disability (44.6%). Based on this modelling, compared to families/carers of participants with autism, families/carers of participants with a hearing impairment or psychosocial disability were more likely to be in a paid job, families/carers of participants with an intellectual disability were less likely, and families/carers of participants with all other disabilities were not significantly different.
- 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 those 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).
- Controlling for other factors, 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. 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 the participant to interact and 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).
- Families/carers living in regional and remote/very remote areas had better baseline outcomes in relationships and self-rated health. In addition, families and carers living in regional or remote/very remote areas who wanted 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).

Families/carers of participants aged 25 and over

Comparison with prior year entrants

For the participants whose families and carers are the subject of this report, compared to those entering the Scheme in prior years, 2019-20 entrants tend to be:

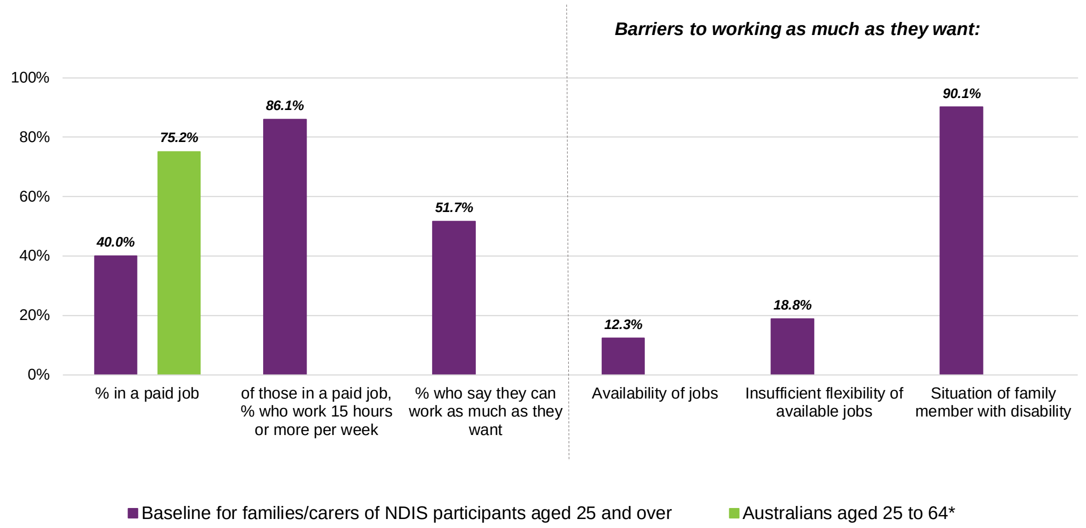
- Older
- Much more likely to have a psychosocial disability and much less likely to have an intellectual disability or Down syndrome
- Similar with respect to level of function.

Overall results

Employment

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

Figure 5 Employment outcomes



*ABS Labour Force Statistics, Original Series, as at 30 June 2020. 38% of respondents are spouses/partners, 30% are mothers, 6% are fathers, 8% are sisters, 3% are brothers, 9% are other family members and 5% are others.

Rights and advocacy

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

Families feel supported

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

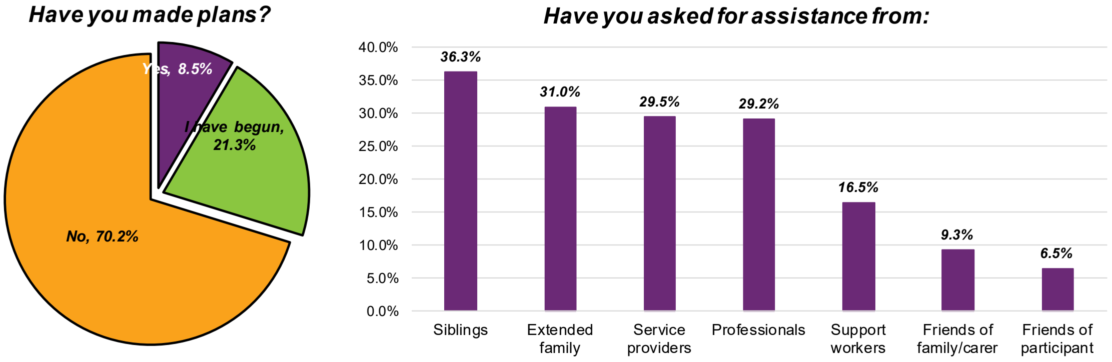
At baseline, 12.2% of families/carers said that the services the participant / family receives meets their needs, whilst 68.1% of families/carers indicated that the services they receive helped them with planning for the future.

Succession planning

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

Families/carers who had started to make plans were most likely to ask for assistance from siblings (36.3%), extended family (31.0%) or service providers (29.5%). By contrast, families/ carers of participants entering in prior years were more likely to ask for assistance from siblings (43.4%) and service providers (38.1%), with a similar percentage asking for assistance from extended family (29.5%).

Figure 6 Succession planning



Health and wellbeing

60.7% of families/carers rate their health as good, very good or excellent at baseline, whilst 60.5% of families/carers disagree or strongly disagree that their family member with disability gets the support that they need. These percentages are higher than for families/ carers of prior year participants (58.9% and 54.4%, respectively). However, the percentage rating their health as good, very good or excellent is still much lower than the general population aged 40 and over (82.3%).

When thinking about the last 12 months and what they expect for the future, 46.8% of families/carers answered positively, 40.8% had mixed or uncertain feelings and 12.5% answered negatively, a similar distribution to families/carers of prior year entrants.

Most families/carers felt that the services and supports they use had helped them better care for the participant, with 56.0% answering positively, 32.9% being neutral and 11.2% having a negative response. Families/carers of 2019-20 entrants were slightly more positive than those of prior year entrants, where 48.6% answered positively, 40.8% were neutral and 10.6% had a negative response.

Results by participant characteristics

Baseline indicators for families/carers of participants entering the Scheme in 2019-20 have been analysed by participant characteristics using one-way analyses and multiple regression modelling.

Across most domains, the participant's level of function, primary disability type, age, cultural background, where they live, plan management type and LGA unemployment rates were most predictive of outcomes in the multiple regression models, which control for other factors.

Key results from the analysis include:

- For the majority of indicators, baseline outcomes are better for families/carers of participants with a high level of function and lower annualised plan budgets. For example, families/carers of participants with a lower level of function were less likely to work as much as they want, have people they can ask for practical help and emotional support as often as needed.
- Disability type was highly predictive of a family/carer's baseline outcomes. For example, families/carers of participants with a psychosocial disability had generally poorer outcomes across all domains compared to those of participants with an intellectual disability. These family/carers were less likely to have people they can ask for practical help as often as they need and were less likely to rate their health as good, very good or excellent. On the other hand, families/carers of participants with a hearing impairment were the least likely to cite the situation of their family member with disability as a barrier to working more. This group also exhibited the best health and wellbeing outcomes at baseline and were most likely to feel supported.
- Compared to families/carers of male participants, families/carers of female participants were significantly less likely to have friends they can see as often as they like, and have people they can talk to for emotional support as often as they need.
- Controlling for other factors, baseline outcomes for families/carers of participants with a CALD background were less likely to be positive. For example, families/carers of CALD participants were less likely to be in a paid job, were less likely to be able to advocate for their family member with disability, and were less likely to have friends they can see as often as they like.
- Baseline outcomes for families/carers of participants from Indigenous backgrounds were generally worse than those for families/carers of non-Indigenous participants, especially with regard to employment, health and getting the services and supports they need.
- Baseline modelling indicates that, like the 15 to 24 cohort, outcomes for families/carers of participants aged 25 or older generally become more positive with increasing participant age, especially in the access to services domains and succession planning. However, the health and wellbeing and employment outcomes of families/carers of older participants tends to deteriorate, which is likely reflecting the positive relationship between participant and family/carer age. Despite being less likely to be in a paid job, families and carers of older participants were more likely to be able to work as much as they wanted.

COVID-19

The global COVID-19 pandemic that took hold from early 2020 is likely to have had an impact on at least some participant and family/carer outcomes, such as employment and social and community participation.

To investigate which outcomes may have been affected by the pandemic via quantitative modelling, additional time-related terms were included in the regression models.[5]

Families/carers of participants from birth to before age 14

There were some significant changes to family/carer outcomes during the pandemic, and results were mostly positive, apart from some employment-related 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 increased. However, the percentage working 15 hours or more per week increased, the percentage who can work as much as they want showed an increasing trend during the pandemic, and families/carers were less likely to see the situation of their child with disability as a barrier to working more.
- More families/carers reported having friends they can see as often as they'd like, and having people they can ask for practical help, emotional support, and childcare, as often as they need.
- There were improvements related to engaging in social interactions and community life, and self-rated health improved.

Families/carers of participants from age 15 to age 24

COVID-19 was associated with a number of changes to family/carer outcomes, with all changes being positive. 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.

Families/carers of participants aged 25 and over

COVID-19 was associated with a number of changes to family/carer outcomes, with most changes being positive. For example,

- For families/carers who have a paid job, the percentage working 15 hours or more per week increased. The percentage who say that those providing informal care to

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[5] The methodology and limitations of the approach are discussed in Section 2.5. In particular, the modelling is based on only about three months of experience during the pandemic, and some of the effects detected are only slight.

their family member with disability are able to work as much as they want also increased.

- A higher percentage of families/carers reported having people they can talk to for emotional support as often as they need during the pandemic.
- A higher percentage of families/carers said that the services they use listen to them.
- A higher percentage of families/carers thought that their family member with disability gets the support they need.
- The percentage of families/carers rating their health as excellent, very good or good increased.

1. Introduction

1.1 Background

Families and carers play an important role in supporting NDIS participants. Improved outcomes for participants under the NDIS can be expected to facilitate this caring role, leading to improved outcomes for families and carers also.

This report summarises outcomes for families and carers of NDIS participants entering the Scheme during the four year period from 1 July 2016 to 30 June 2020, with outcomes measured at the time of entry to the Scheme (at "baseline"). The main focus is on families/carers of participants entering in the latest year (2019-20), but brief comparisons with results of prior year entrants are also provided. A separate report covers longitudinal change for families and carers of participants who have been in the Scheme for one year or more at 30 June 2020. Two previous reports have covered both baseline and longitudinal experience of families and carers, as at 30 June 2018 and 30 June 2019.[6]

Participants entering the Scheme at different times may have different characteristics (for example, due to phasing). Hence, for the participants whose families and carers are the subject of this report, a brief summary of how 2019-20 entrants compare to participants entering in the earlier three year period is also provided, on key characteristics such as disability and level of function.

The purpose of this report is to provide a snapshot view of family/carer outcomes at the time the participants they support enter the Scheme, based on information provided by them in interviews conducted using the NDIS outcomes framework questionnaires. At this time, the NDIS has not had an opportunity to have an impact on outcomes. The separate longitudinal report considers how far families/carers have progressed since the participants they support entered the Scheme. Together, the reports provide insight into how the Scheme is making a difference, and point to any areas where improvements may be required.

The present report focusses on results. Readers requiring further background should refer to the previous reports, which contains additional information regarding the broader scope of outcomes measurement within the NDIA, and the development and implementation of the outcomes framework questionnaires.

1.2 Overview

The remainder of the report is organised as follows:

- Section 2 contains results for families/carers of participants from birth to age 14.
- Section 3 contains results for families/carers of participants aged 15 to 24.
- Section 4 contains results for families/carers of participants aged 25 and over.

More detailed results (both baseline and longitudinal) contained in the Appendices include:

- Appendix A: Variables used in the regression modelling
- Appendix B: Families/carers of participants aged 0 to 14
- Appendix C: Families/carers of participants aged 15 to 24
- Appendix D: Families/carers of participants aged 25 and over.

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[6] Family and carer outcomes report | NDIS

1.3 Questionnaires

Table 1.1 sets out the questionnaire versions and domains, including letter codes used in the report.

Table 1.1 Outcomes framework versions and domains for families/carers

Domain	Participants aged 0 to 14	Participants aged 15 to 24	Participants aged 25 and over
Families/carers know their rights and advocate effectively for their family member with disability (RA)	✓	✓	✓
Families/carers feel supported (SP)	✓	✓	✓
Families/carers are able to gain access to desired services, programs and activities in their community (AC)	✓	✓	✓
Families/carers enjoy health and wellbeing (HW)	✓	✓	✓
Families/carers help their child develop (DV)	✓		
Families/carers help their young person become independent (IN)		✓	
Families/carers have succession plans (SC)			✓
Families/carers understand their child's strengths, abilities and special needs (UN) (LF only)	✓	✓	

The report also includes information not included in any of the specific domains, on employment (WK) and receipt of government benefits (GB).

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

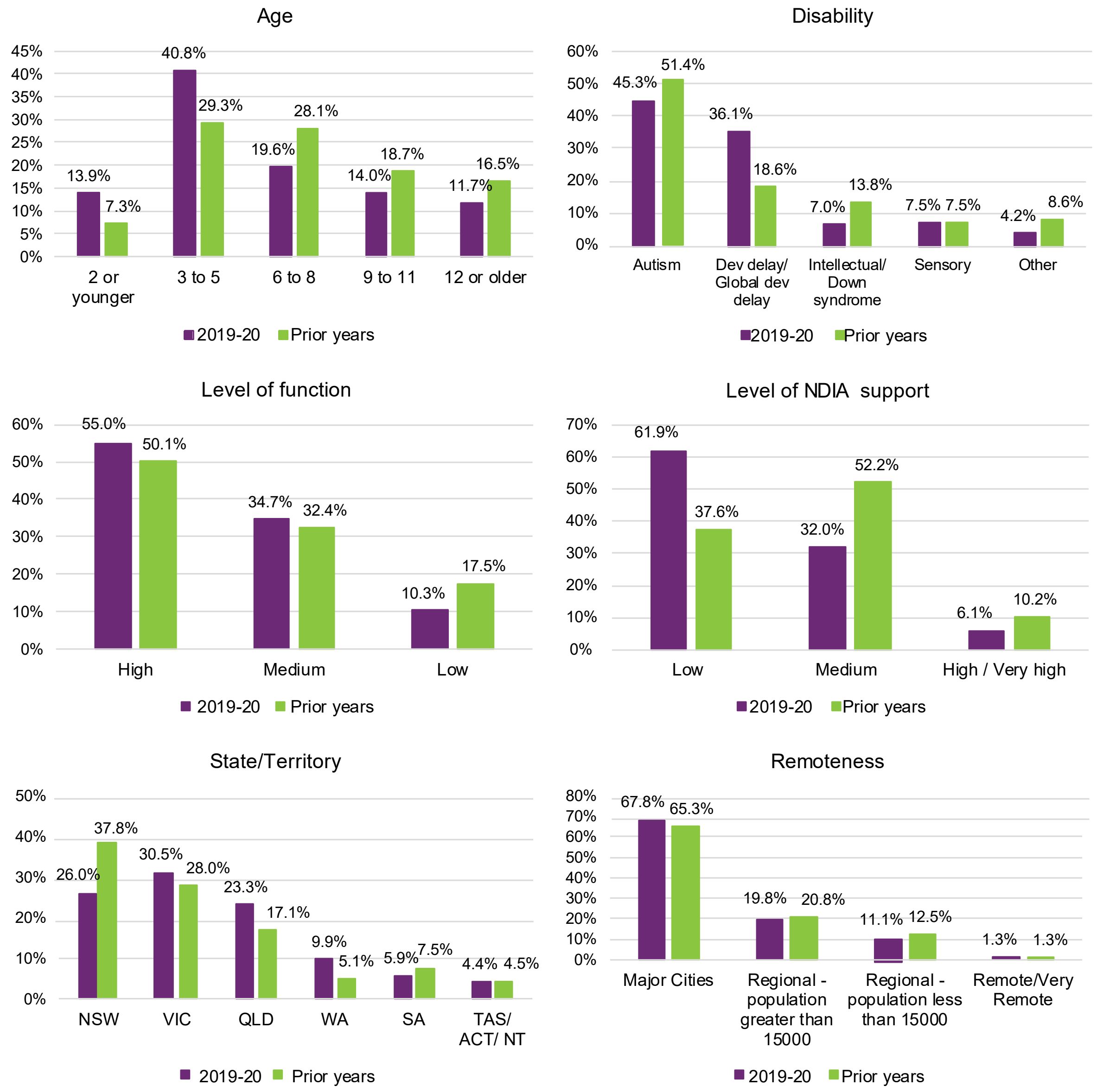
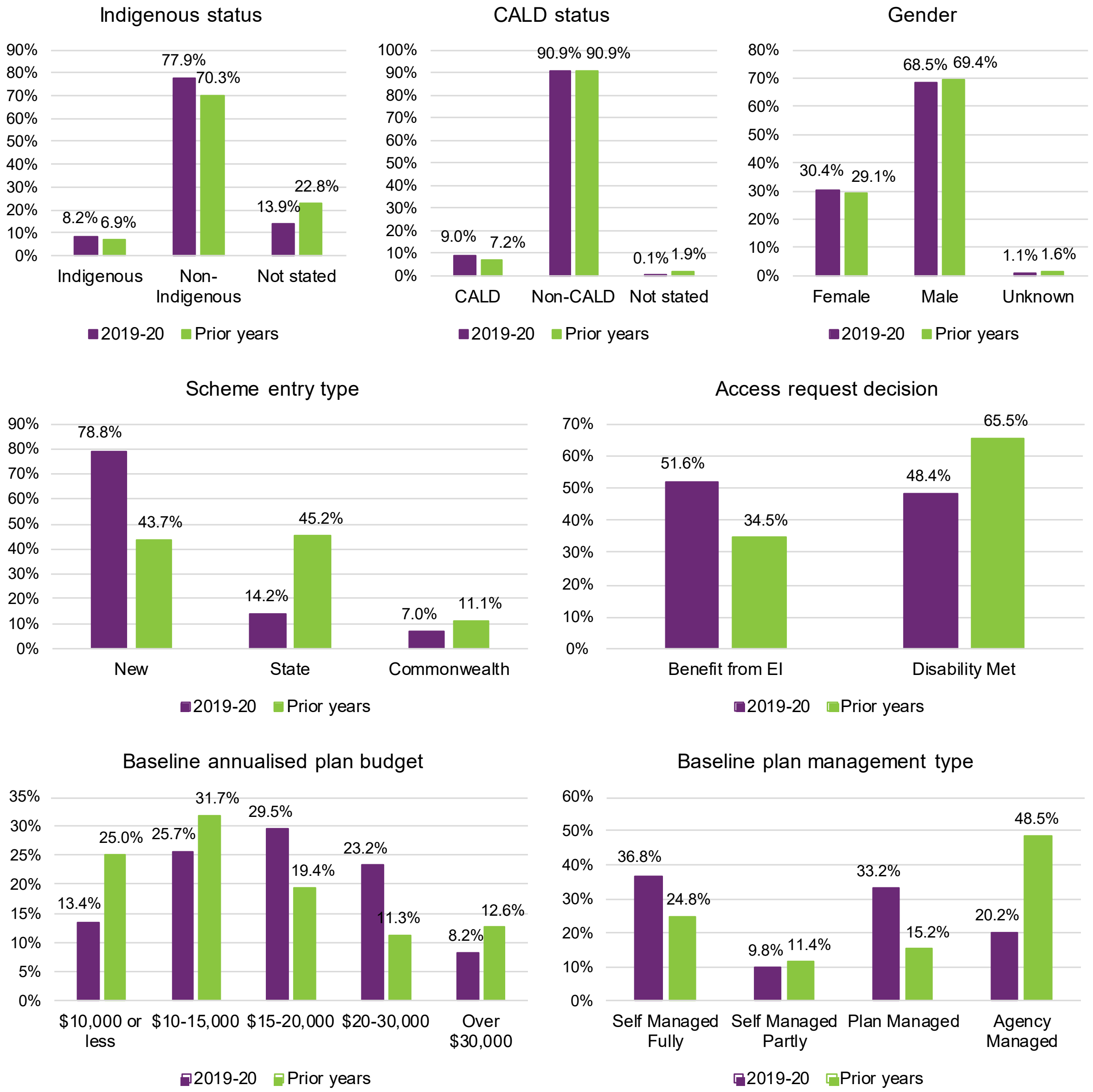


Figure 2.2 Distributions by key characteristics - families or carers for 2019-20 entrants compared with prior year entrants



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]

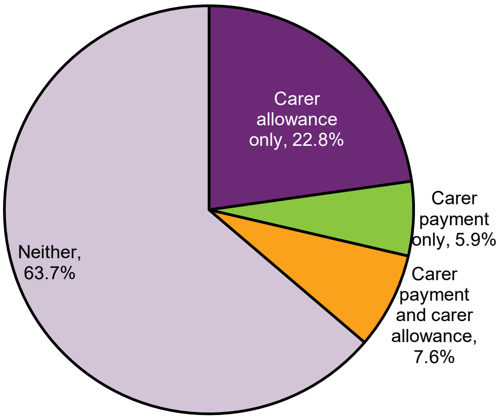
As at June 2020, 294,272 Australians were receiving Carer Payment and about 2.1 times as many, 619,038 Australians, were receiving Carer Allowance.[11]

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

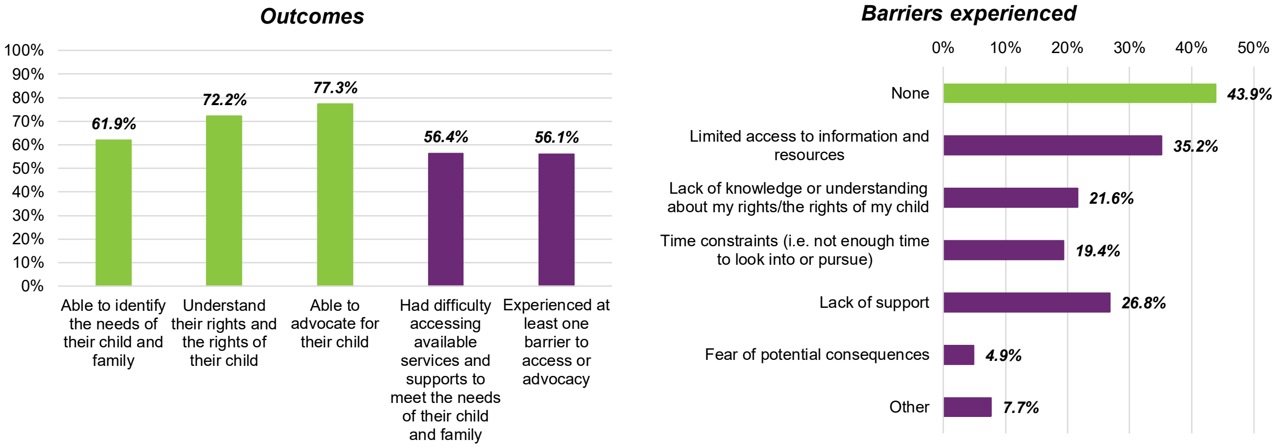
[11] Annual report 2019-20, Commonwealth of Australia (Department of Social Services) 2020, https://www.dss.gov.au/sites/default/files/documents/10_2020/01720_dss_ar_2020.pdf

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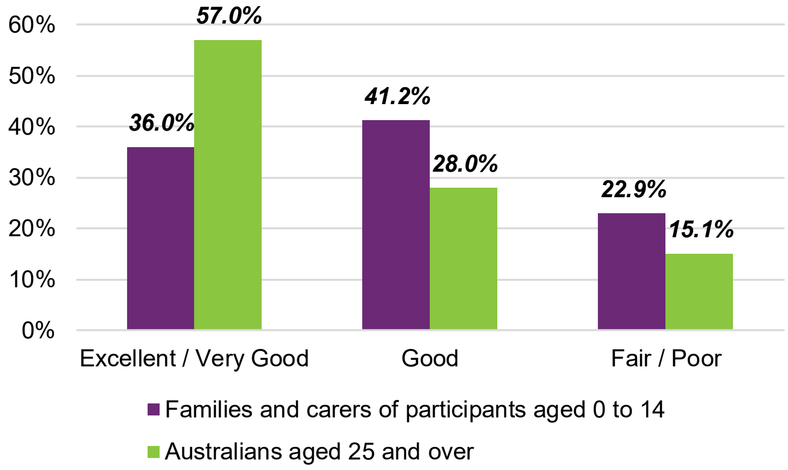
[13] ABS General Social Survey (GSS) 2019. Families/carers of 0 to 14 year olds are likely to be towards the younger end of the 25-69 age range.

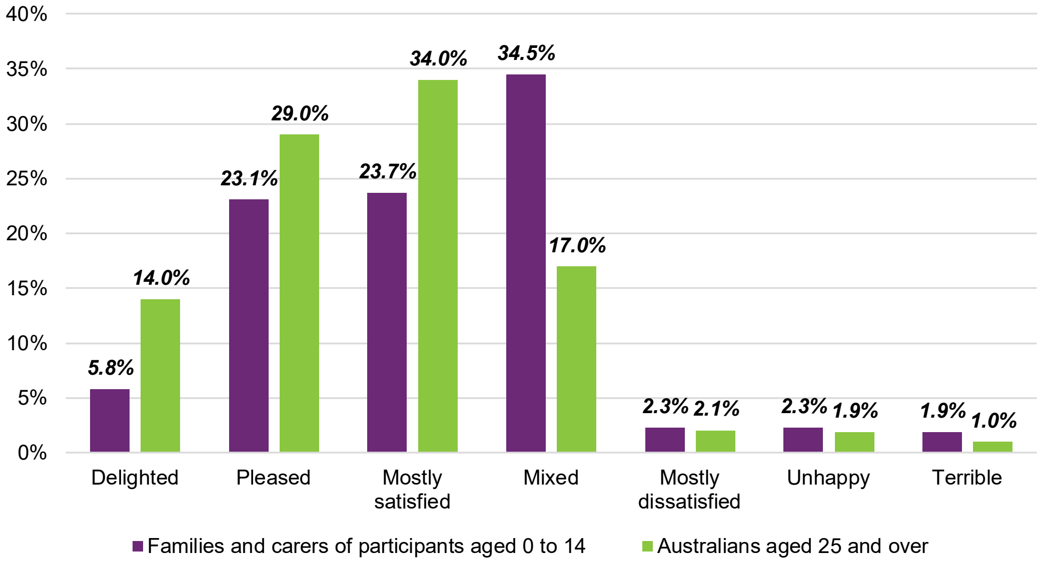
Figure 2.5 Self-rated health, families/carers of participants aged 0 to 14



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:

Outcome	Variable			
	Participant is older	Participant is female	Participant is CALD	Participant is Indigenous
Being in a paid job	⬆	⬇	⬇	⬇
For family/carers with a paid job, 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:

Outcome	State						
	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.

	State						
Outcome	**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:

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]
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	⬆	⬆

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]
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:

	Variable		
Relationship of the variable with the likelihood of:	**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

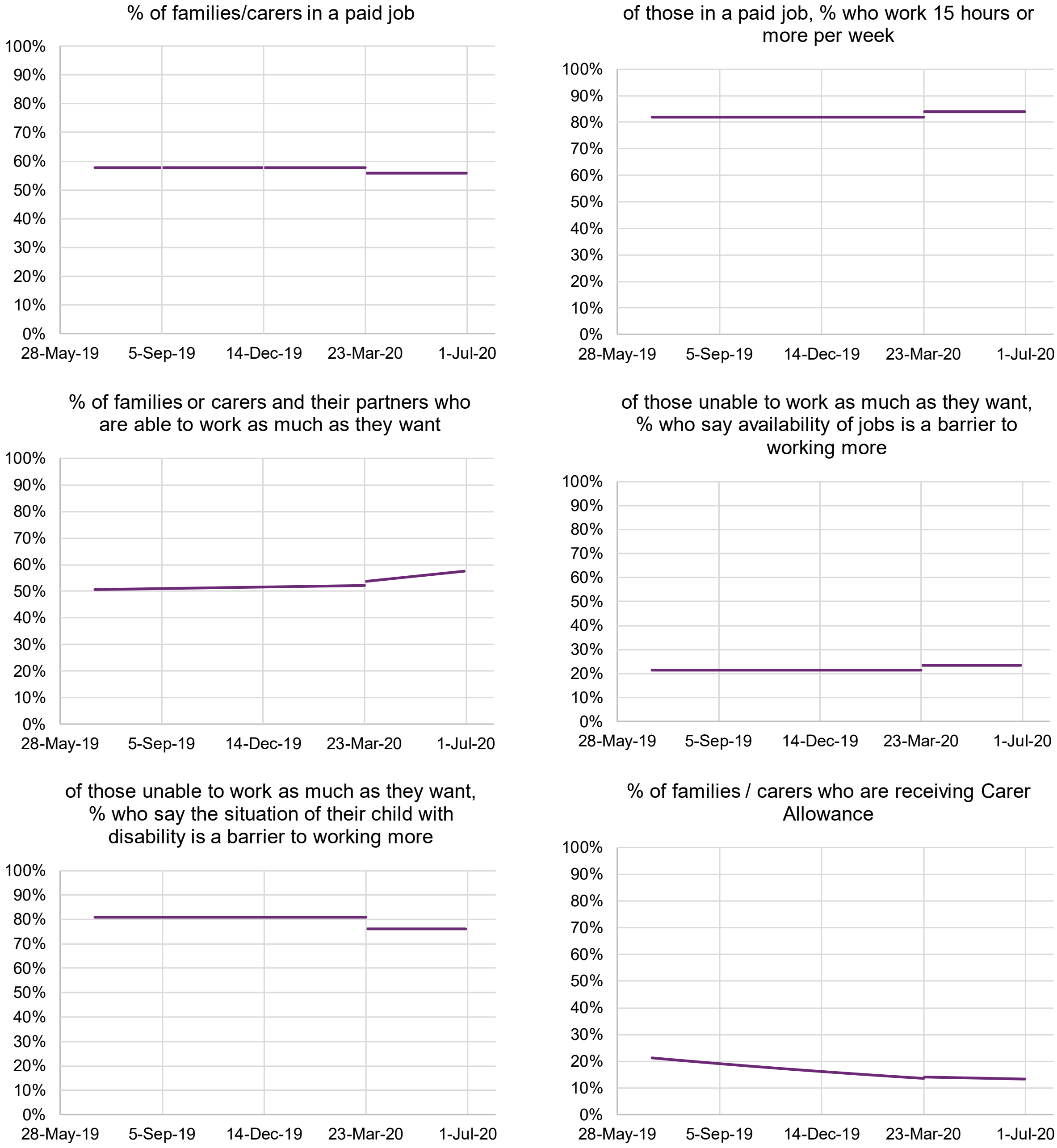


Figure 2.7 shows that:

- 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

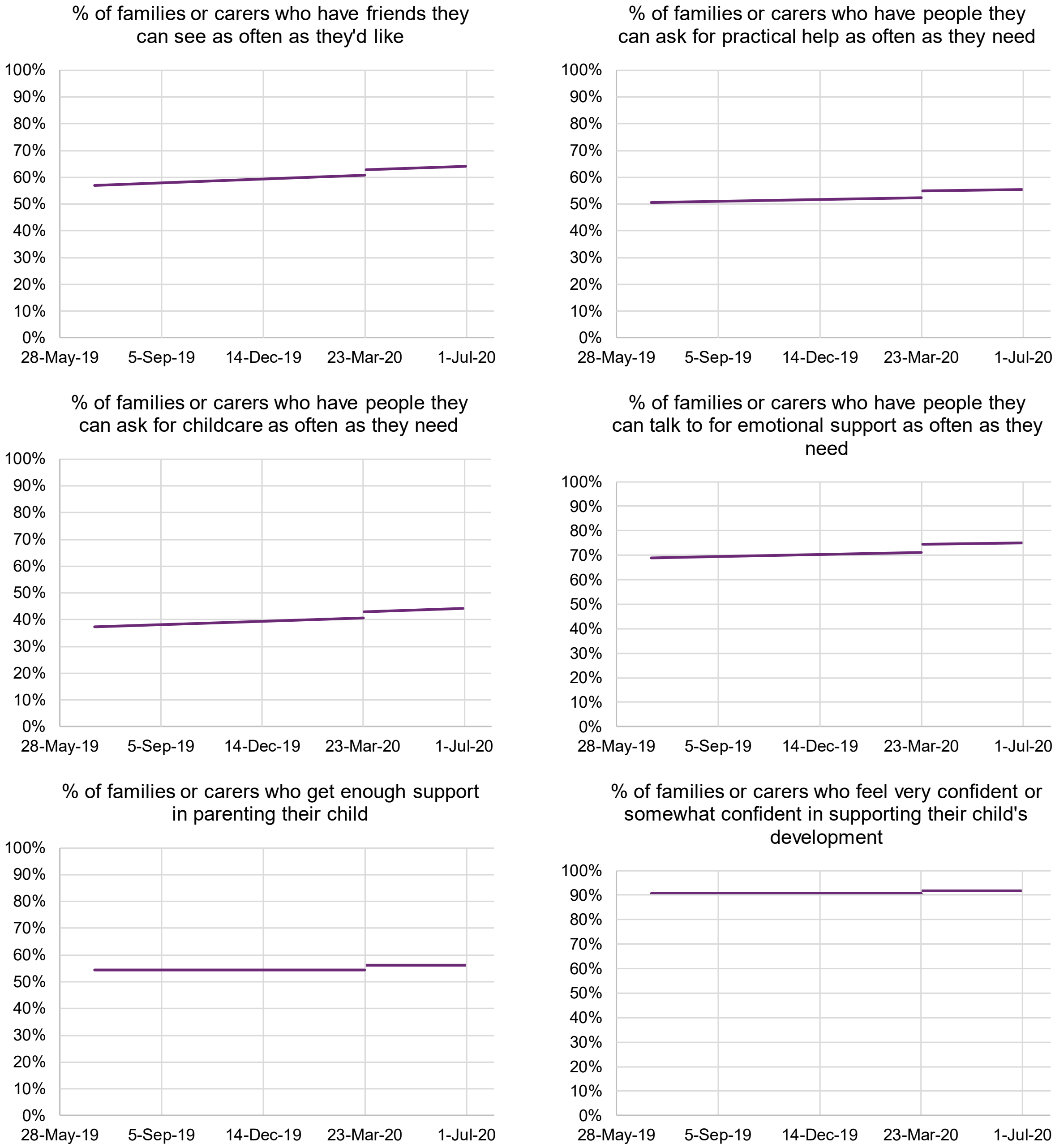


Figure 2.8 shows that:

- 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

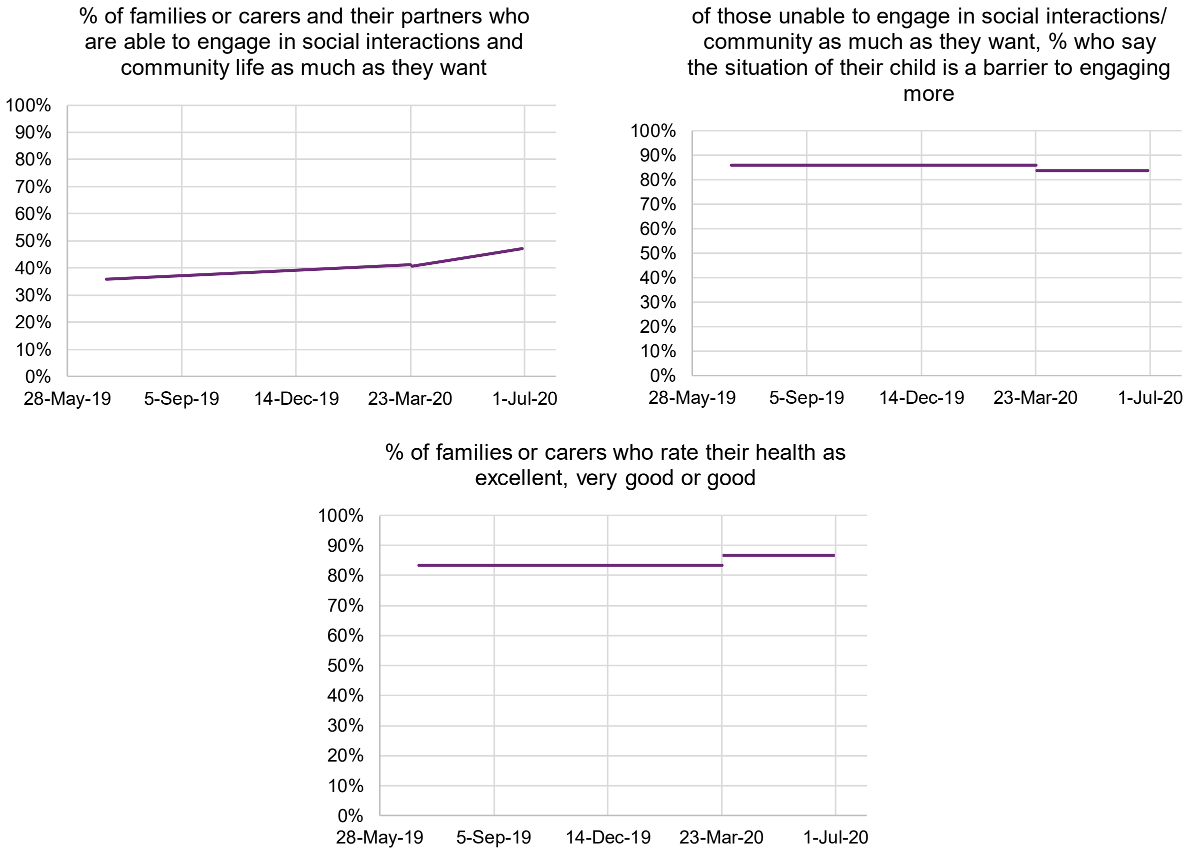


Figure 2.9 shows that:

- 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.

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

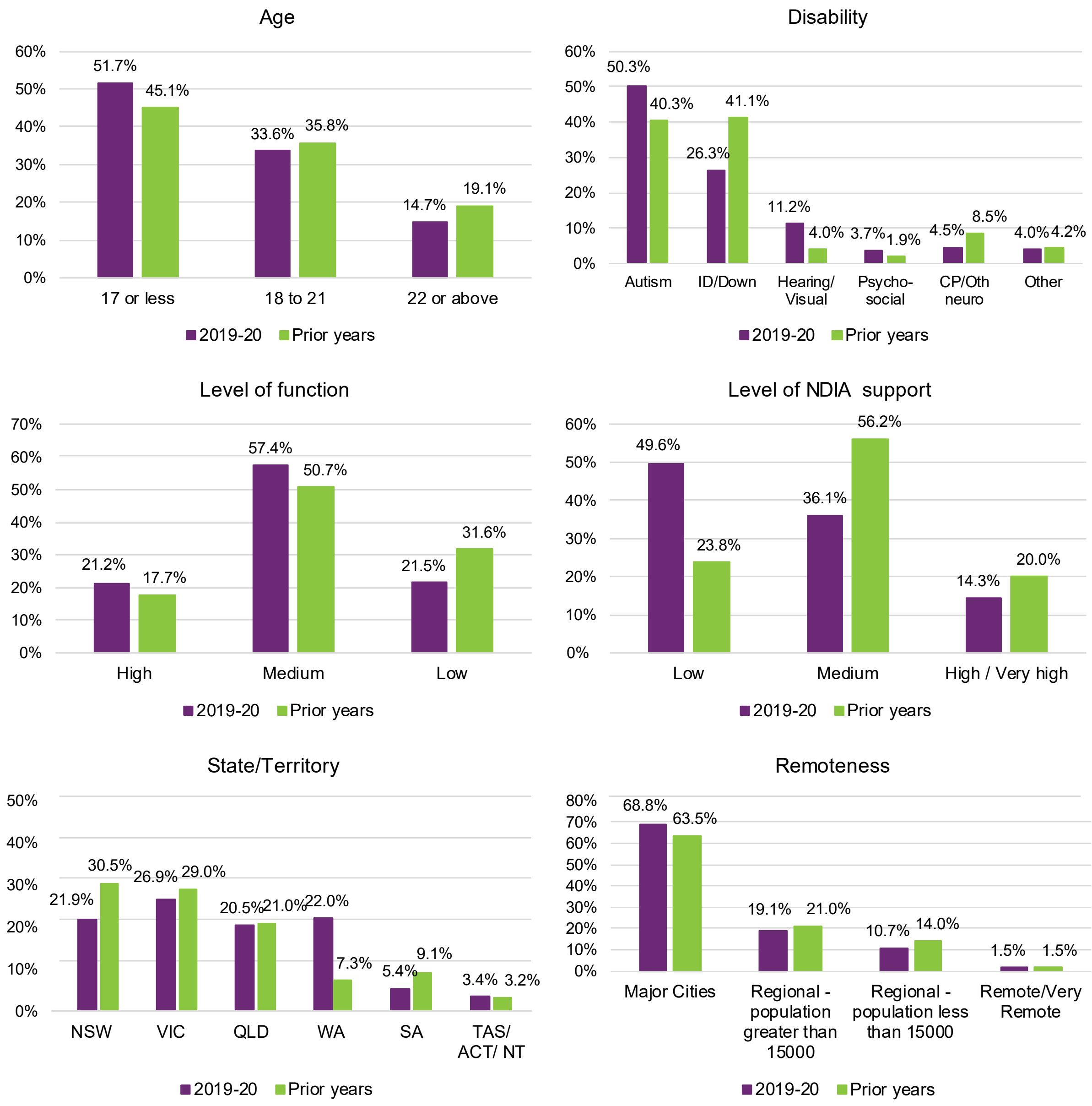
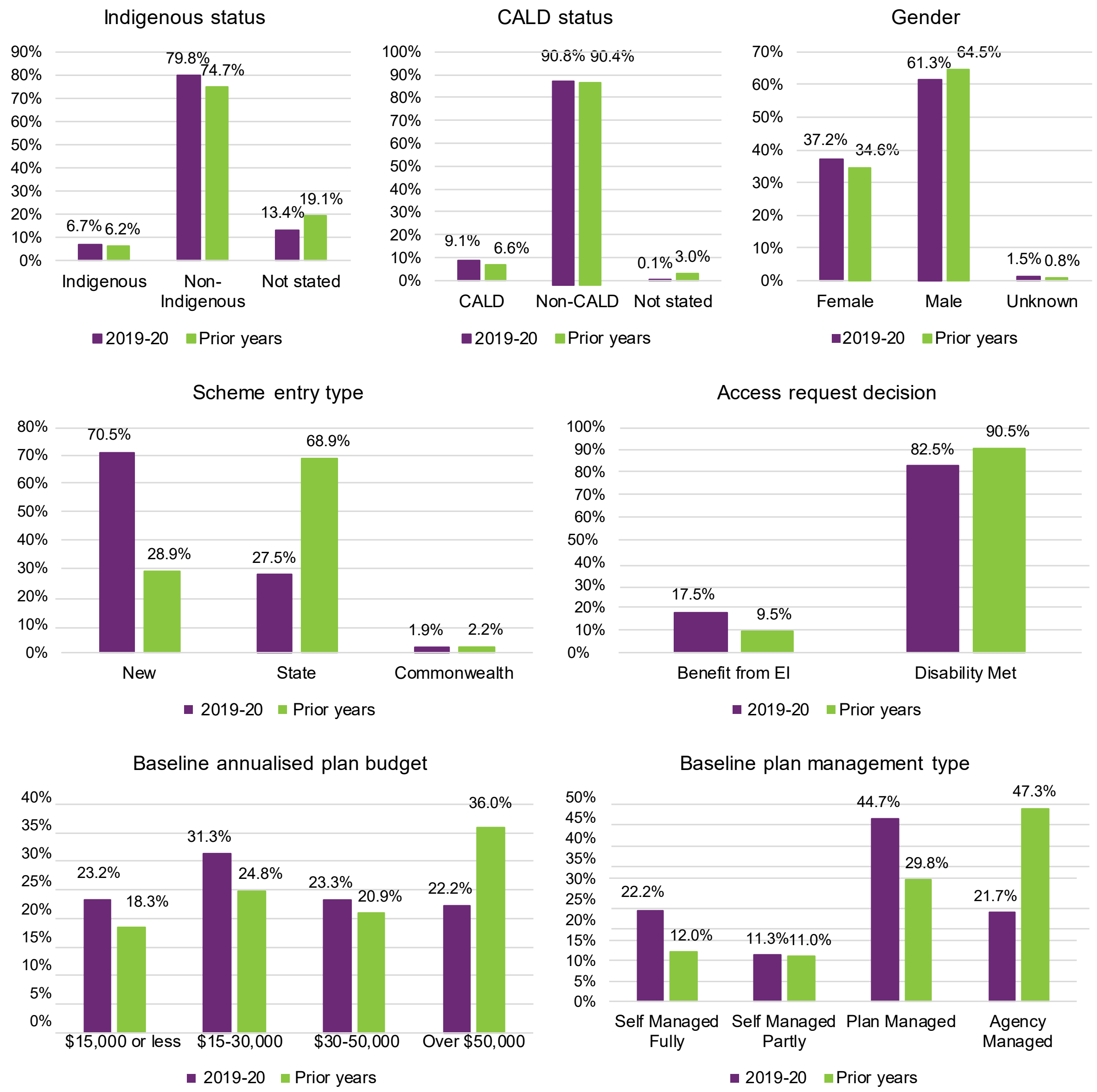


Figure 3.2 Distributions by key characteristics - families or carers for 2019-20 entrants compared with prior year entrants



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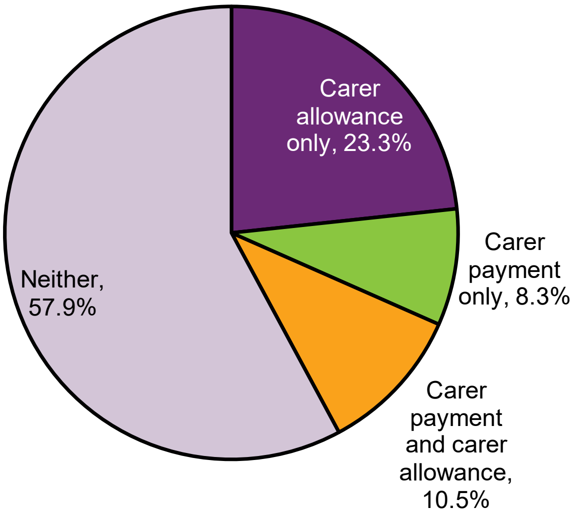
[23] Chi-squared tests for differences in the distributions were performed, but due to the large volume of baseline data, they are powered to detect very small differences. For families or carers for participants aged 15 to 24, there was no significant difference for indigenous status (p = 0.745) but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



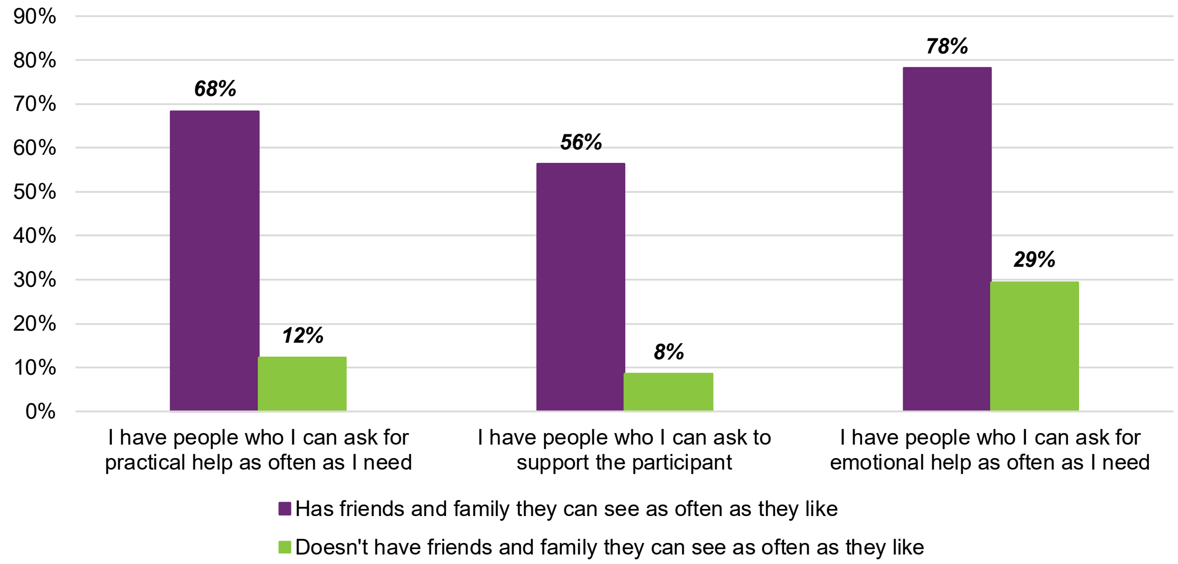
Rights and advocacy

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.

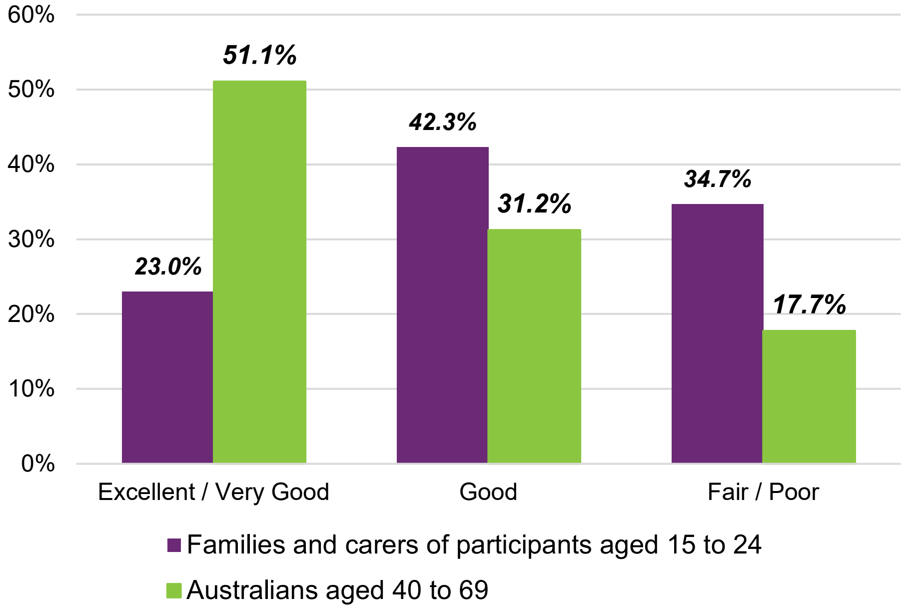
Employment

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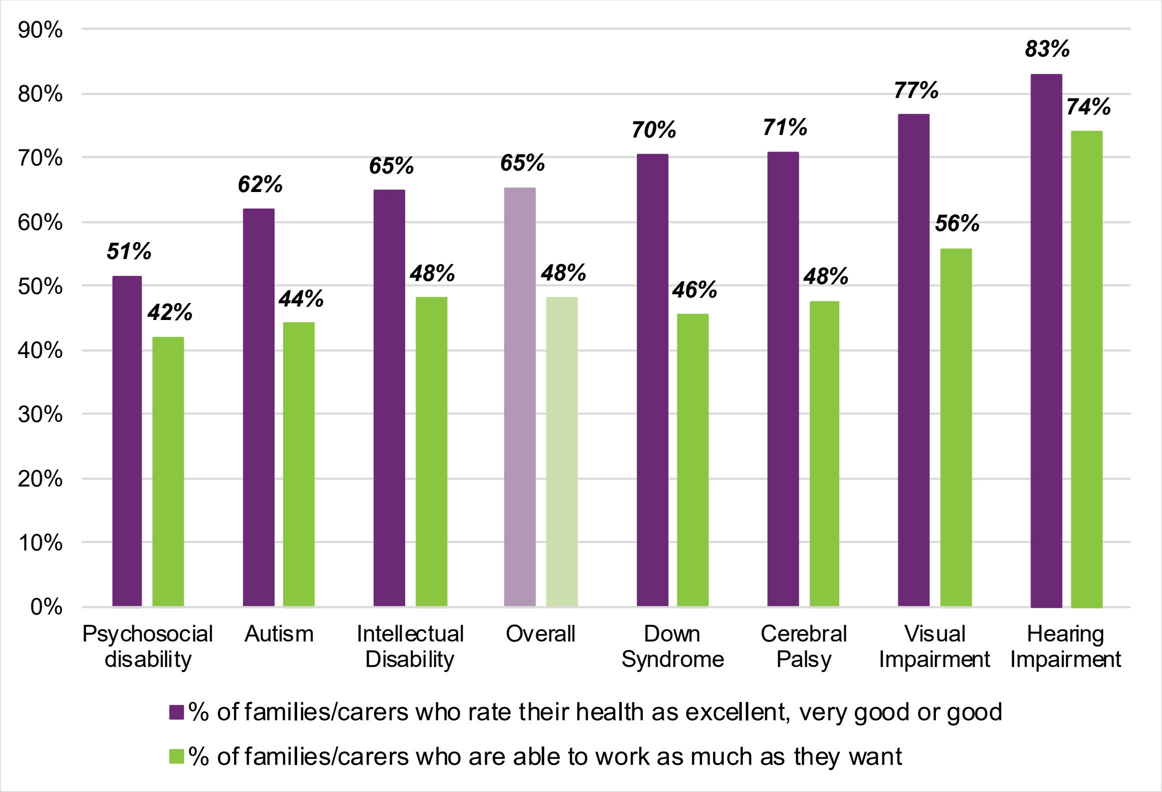
[26] Controlling for other factors, families/carers of participants with psychosocial disability were more likely to be in a paid job and to feel that the services that they and their family members with disability use listen to them. However, these effects were no apparent in the one-way analyses, due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

Outcome	Participant primary disability Compared to participants with primary disability of autism					
	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	⇩		⬆	

	Variable			
Outcome	**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:

	State/ Territory						
Outcome	**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.

	State/ Territory						
Outcome	**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:

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
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.

	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**
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.

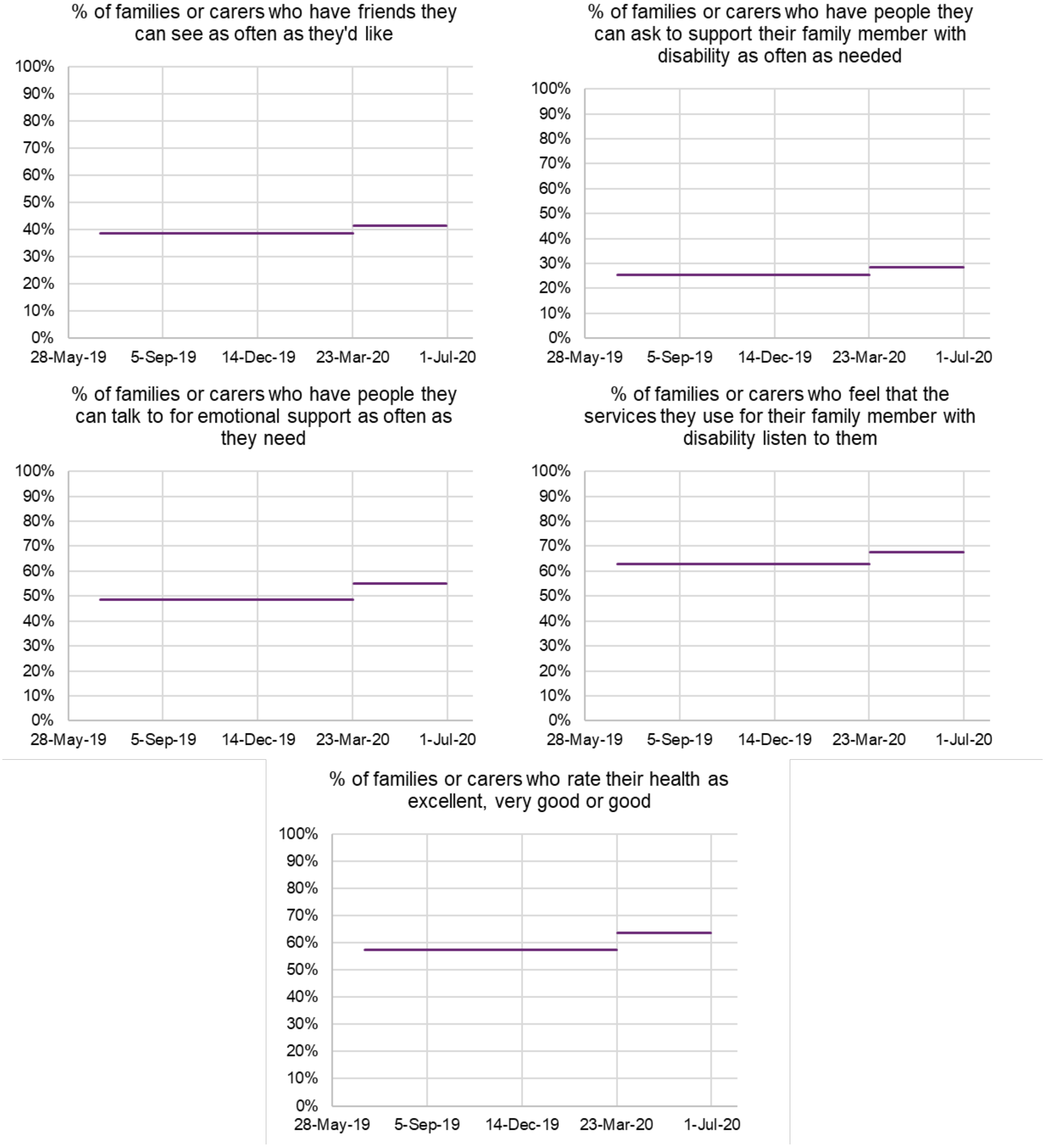
For families/carers of participants aged 15 to 24 who entered the Scheme in 2019-20, there were five indicators for which one or both of the COVID-related terms was significantly different from zero.

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



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.

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

4.1 Key findings

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

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

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

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

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

- **Employment**

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

- **Rights and Advocacy**

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

- **Family support & community participation**

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

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

- **Succession planning**

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

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

- **Health and wellbeing**

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

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

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

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

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

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

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

4.2 Outcomes framework questionnaire domains

For families/carers of participants aged 25 and over, the outcomes framework seeks to measure the extent to which they:

- Know their rights and advocate effectively for their family member with a disability (RA)
- Feel supported (SP)
- Can gain access to desired services, programs and activities in their community (AC)
- Have succession plans (SC)
- Enjoy health and wellbeing (HW).

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

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

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

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

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

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

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

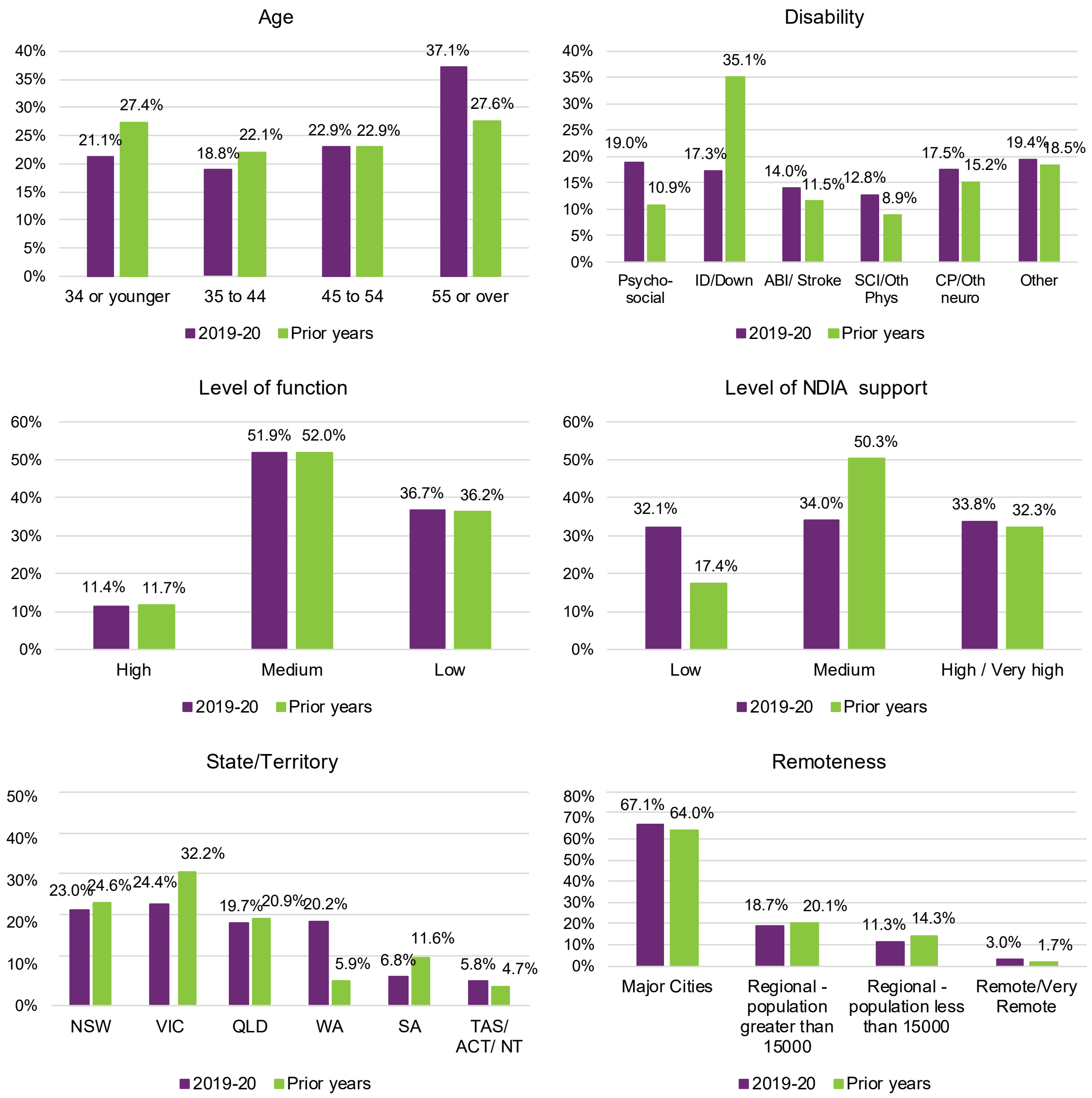
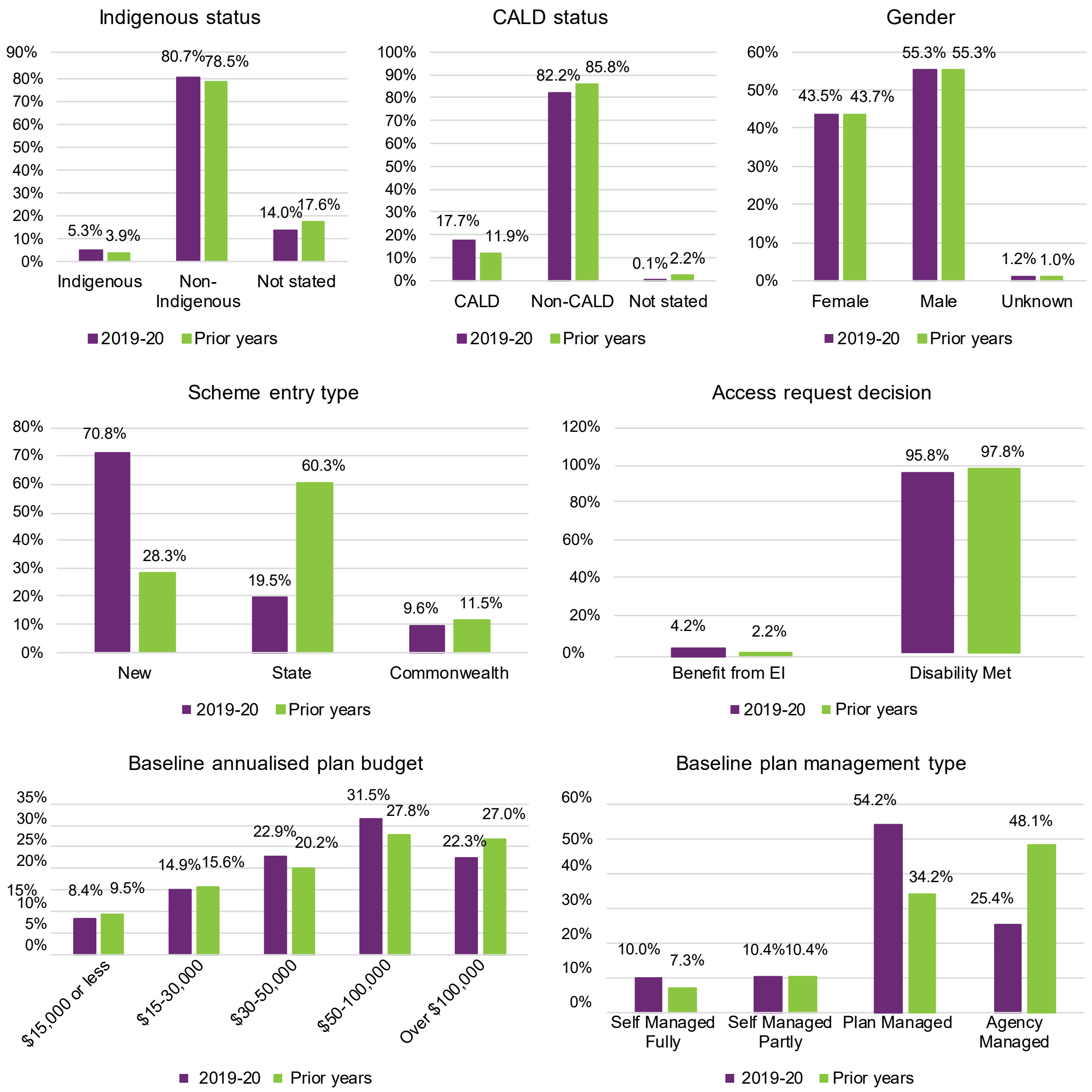


Figure 4.2 Distributions by key characteristics - families or carers for 2019-20 entrants compared with prior year entrants



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

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

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

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

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

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

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

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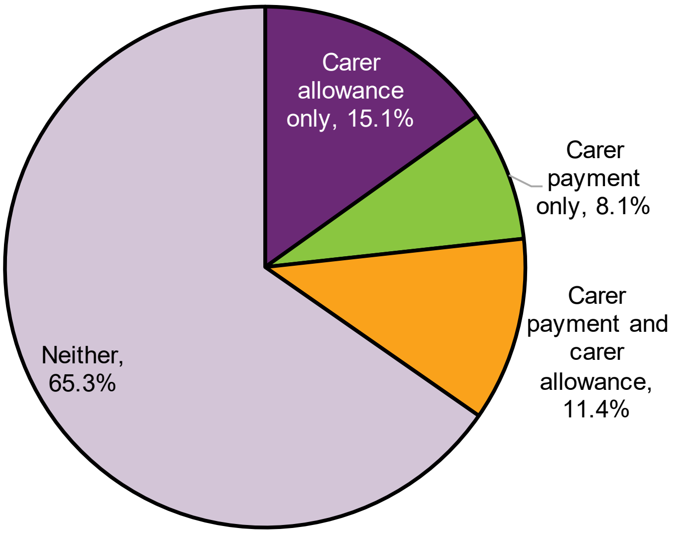
[33] Chi-squared tests for differences in the distributions were performed, but due to the large volume of baseline data, they are powered to detect very small differences. For families or carers of participants aged 25 and above, there was no significant difference for level of function (p=0.531) or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

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

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



Rights and advocacy

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

On the other hand, only 38.4% of families/carers reported in the baseline SF that they are able to identify the needs of their family member with disability and know how to access the services and support that the family member needs. For this question, 40.2% of families/carers reported that they had some difficulty, and 21.5% had great difficulty, higher than the baseline for prior years, where 36.8% of families/carers reported that they had some difficulty, and 15.9% had great difficulty.

Families feel supported

At baseline, most families/carers of adult participants reported that they did not feel supported across all relevant questions in the SF. Less than half (45.6%) said they have family and friends that they see as often as they like, lower than 48.5% for prior years' baseline. In terms of being able to ask for support as often as needed, 65.7% could not ask for practical help, 53.0% could not ask for emotional support and 74.9% could not ask for support for their family member with disability. These percentages are higher than the average baseline response of families/carers of participants entering in prior years where 61.3% could not ask for practical help, 50.7% could not ask for emotional support and 70.1% could not ask for support for their family member with a disability.

In the LF, 52.5% of families/carers reported that they had as much contact with other families of people with a disability as they would like, slightly lower than the average baseline response from families/carers of participants entering in prior years, where 55.1% reported having as much contact with other families of people with a disability as they would like.

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

At baseline, 12.2% of families/carers said that the services the participant and their family receives meets their needs, lower than 20.3% among families/carers of participants entering in prior years at baseline. Furthermore, the majority of families/carers reported that they have difficulty feeling in control when selecting services and supports that meet the needs of the family and participant, with 44.4% having some difficulty and 22.4% facing a great deal of difficulty.

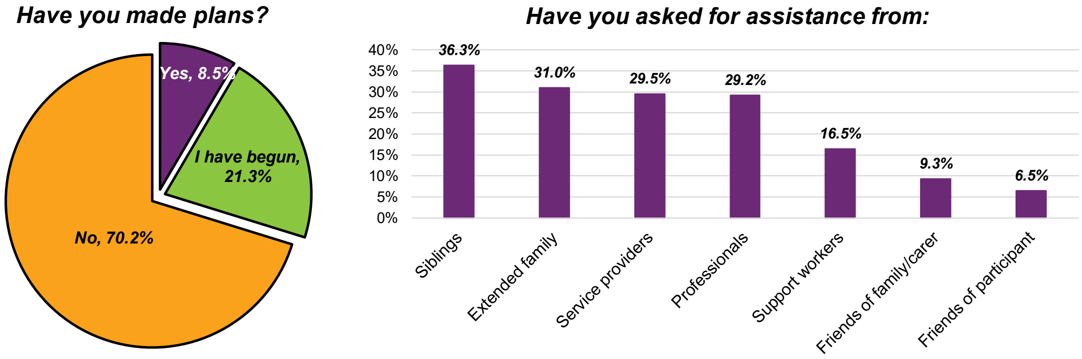
On the other hand, at baseline 66.0% of families/carers reported that the services they and their family member with a disability use listen to them (68.5% among families/carers of participants entering in prior years at baseline), and 68.1% said that the services they received helped them plan for the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

Succession planning

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

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

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



Employment

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

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

Health and wellbeing

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

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

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

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

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

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

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

Participant primary disability type

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

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

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

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

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

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

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

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

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

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[35] The reference level is Intellectual disability.

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

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

Participant age

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

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

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

Gender

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

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

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

CALD status

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

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

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[36] The reference level is NSW.

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

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

Indigenous status

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

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

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

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

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

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

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

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	⬇			⬆

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

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

Participant level of function and annualised plan budget

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

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

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

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

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

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

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

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

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

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

Plan Management Type

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

Remoteness

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

Impact of COVID-19

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

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

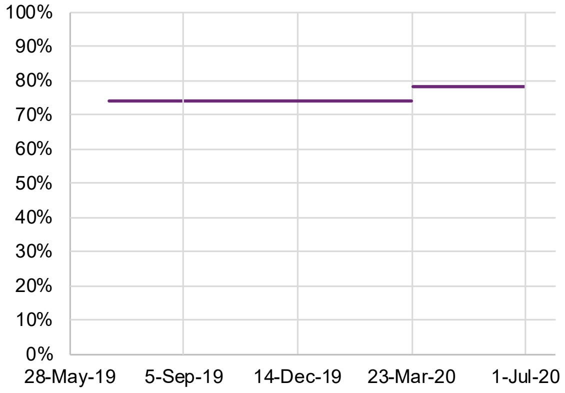
For all seven indicators, there was a significant step change at the assumed date of onset of the pandemic, but no significant time trend either before or after this date. Most of the changes were positive during the pandemic. Specifically, during the pandemic:

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

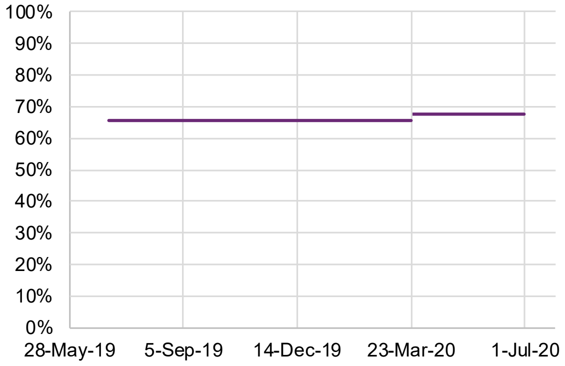
These trends are illustrated in Figure 4.5 and Figure 4.6.

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

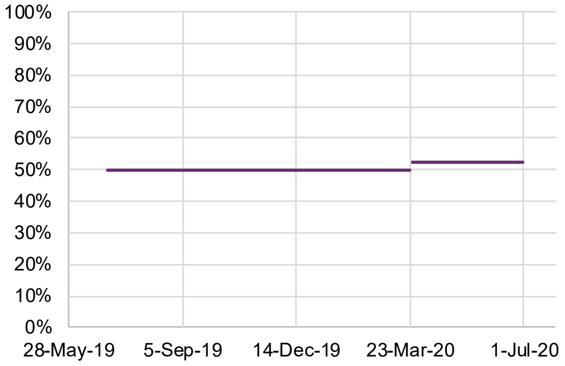
of those in a paid job, % who work 15 hours or more per week



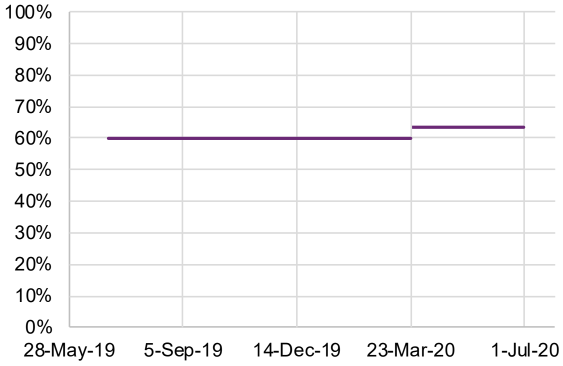
% of families or carers who provide informal care to their family member with disability and are able to work as much as they want



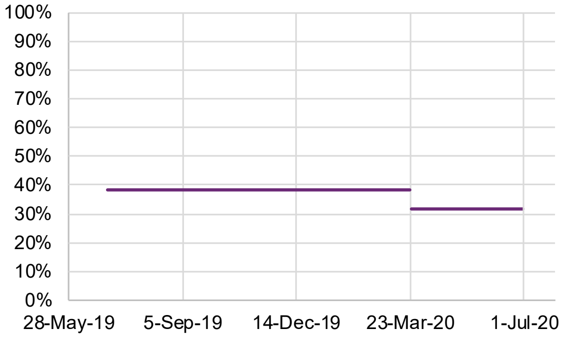
% of families or carers who have people they can talk to for emotional support as often as they need



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



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



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

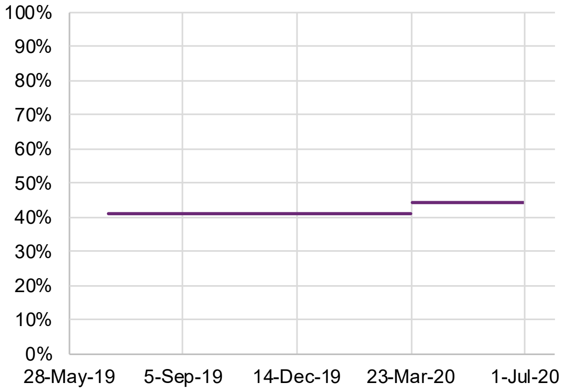
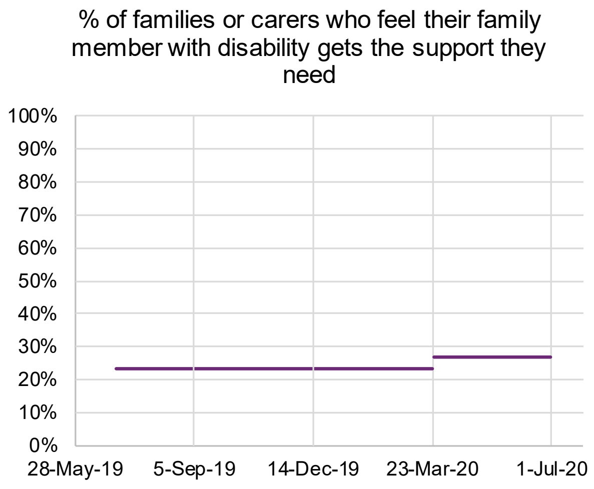


Figure 4.6 Estimated trend over time for indicators where the COVID indicator term was significant



Box 4.4 summarises the key findings from this section.

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

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

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

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