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:

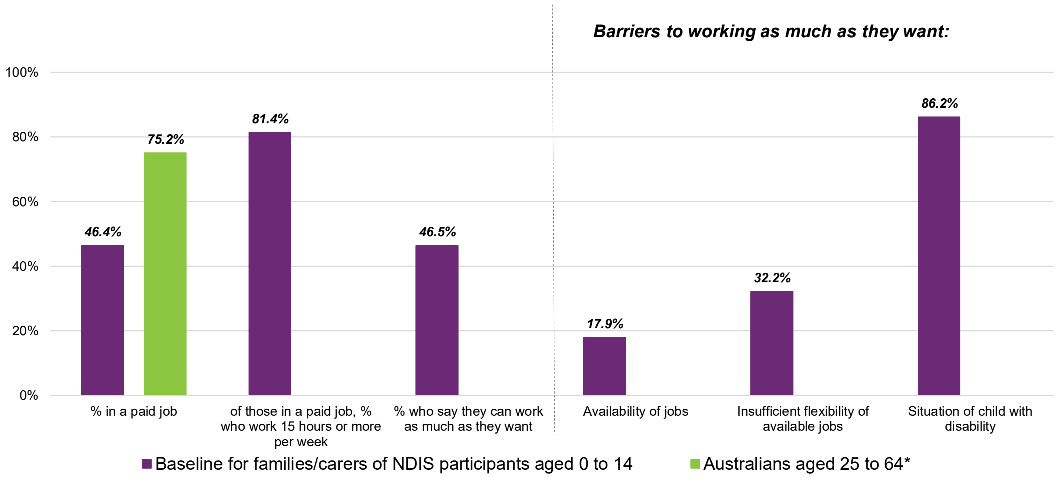
- Younger
- More likely to have developmental delay or global developmental delay and less likely to have autism
- More likely to have medium or high level of function and less likely to have low level of function.

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

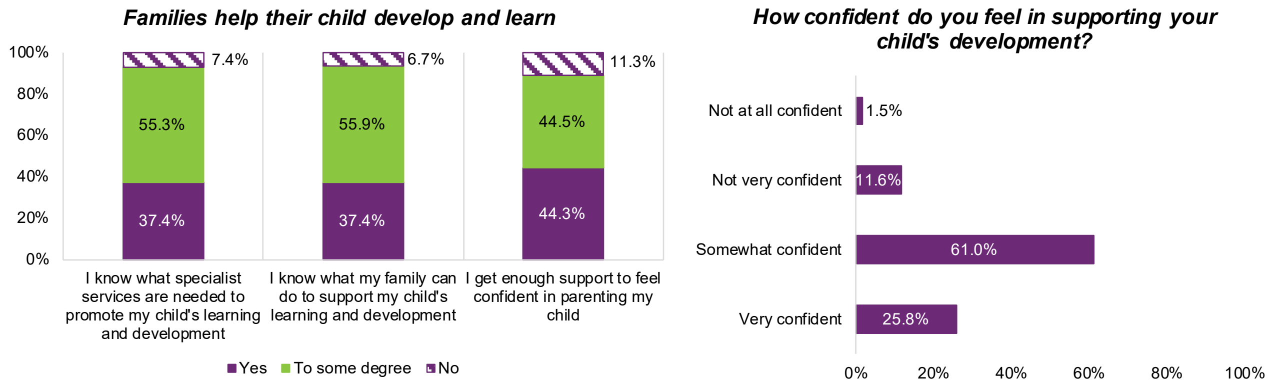
Eighty-seven per cent (87.3%) of families/carers have good (42.6%) or very good (44.7%) relationships with their services. The percentage having a very good relationship with their services has been increasing over time, from 29.2% for families/carers of participants entering in 2016-17 at baseline,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

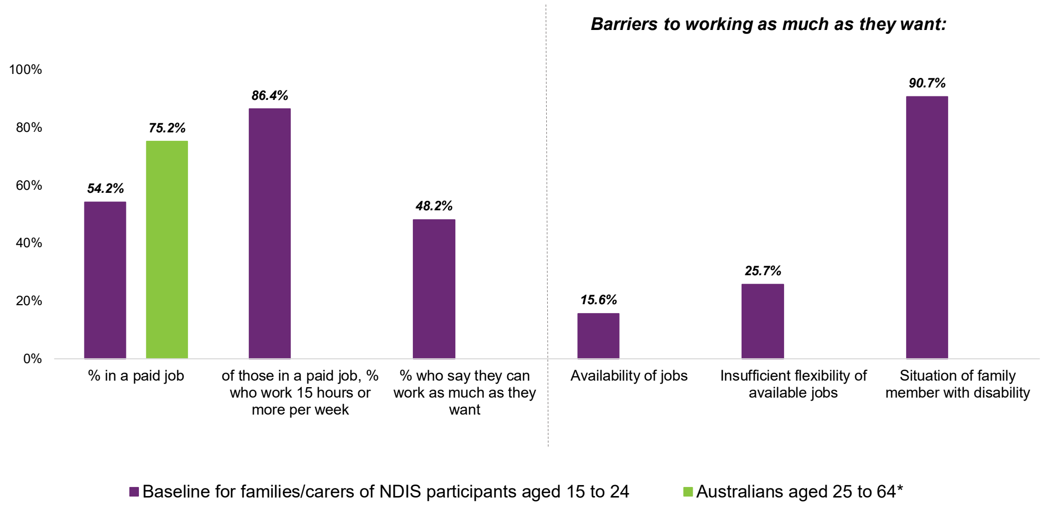
Overall results

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.

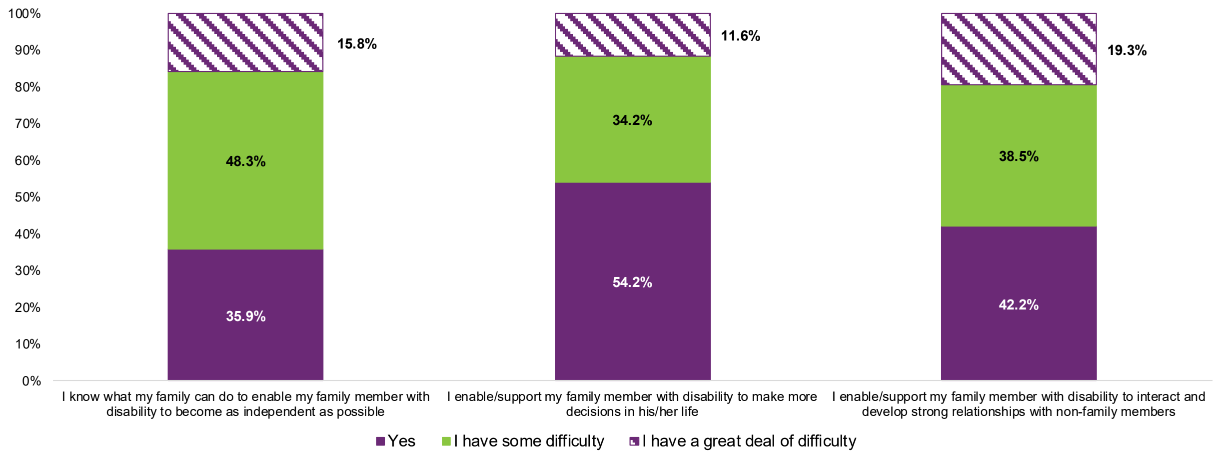
Access to desired services, programs and activities

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:

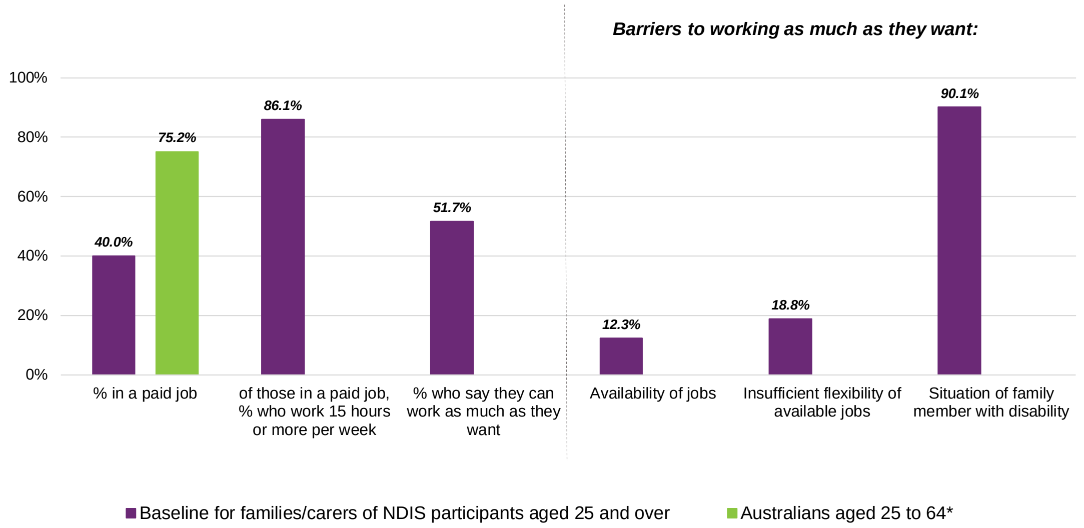
- Older
- Much more likely to have a psychosocial disability and much less likely to have an intellectual disability or Down syndrome
- Similar with respect to level of function.

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.

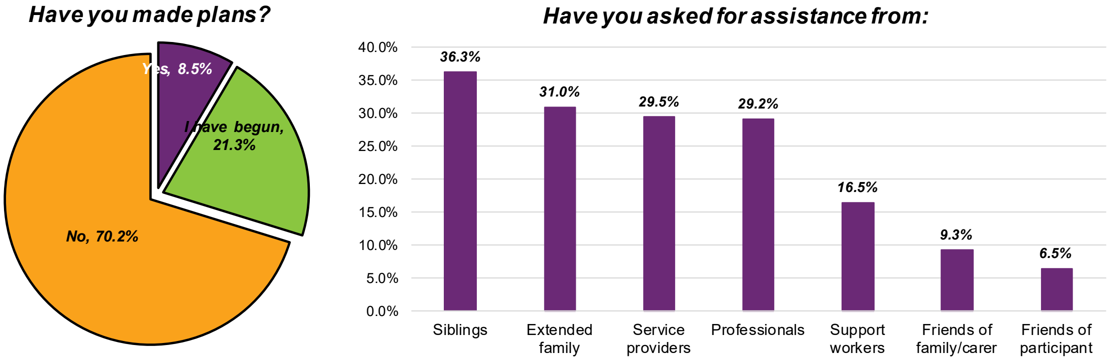
At baseline, 12.2% of families/carers said that the services the participant / family receives meets their needs, whilst 68.1% of families/carers indicated that the services they receive helped them with planning for the future.

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.