

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 longitudinal outcomes for families and carers of participants who have been in the Scheme for one year or more at 30 June 2020. A separate report covers baseline results for families and carers of NDIS participants entering the Scheme during the four year period from 1 July 2016 to 30 June 2020. Two previous reports have covered both baseline and longitudinal experience, as at 30 June 2018 and 30 June 2019.⁸

The purpose of this report is to provide a picture of how the families and carers of NDIS participants are progressing, based on information provided by them in interviews conducted as part of the NDIS outcomes framework questionnaires. The results are intended to provide insight into how the Scheme is making a difference for families and carers, and point to any areas where improvements may be required.

Separate reports on participant outcomes at 30 June 2020 and for the preceding two years have been prepared, and those reports should be consulted for further information on the ways in which the NDIA is measuring outcomes more broadly, as well as general background to the development and implementation of the outcomes framework.

1.2 Overview

The remaining sections of the report present results from analysing the outcomes framework data available as at 30 June 2020. Results are organised with separate sections for each questionnaire version, including analysis of data from both the short-form (SF) and long-form (LF). Specifically:

- Sections 2 and 3 contain results for families/carers of participants from birth to age 14.
- Sections 4 and 5 contain results for families/carers of participants aged 15 to 24.
- Sections 6 and 7 contain results for families/carers of participants aged 25 and over.

More detailed results contained in the appendices⁹ 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.

⁸ [Family and carer outcomes report | NDIS](#)

⁹ Appendix B of the participant outcomes report also contains information on response rates and representativeness for the LF family/carer survey.

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).

1.4 Cohorts used in the longitudinal analysis

Longitudinal results for outcome indicators are considered separately for three cohorts of families/carers:

- Cohort C3: Families/carers of participants entering the Scheme between 1 July 2016 and 30 June 2017, for whom a record of outcomes is available at Scheme entry (baseline), and approximately three years after Scheme entry (third review). The large majority of these families/carers also responded at one year and/or two years after Scheme entry (first and/or second review).

- Cohort C2: Families/carers of participants entering the Scheme between 1 July 2016 and 30 June 2018, for whom a record of outcomes is available at Scheme entry (baseline), and approximately two years after Scheme entry (second review)¹⁰. The large majority of these participants also responded at one year after Scheme entry (first review). For this cohort, the 2019-20 experience represents changes over their second year in the Scheme.
- Cohort C1: Families/carers of participants entering the Scheme between 1 July 2016 and 30 June 2019, for whom a record of outcomes is available at Scheme entry (baseline), and approximately one year after Scheme entry (first review¹¹). For this cohort, the 2019-20 experience represents changes over their first year in the Scheme.

These three cohorts are distinct (that is, a family member/carer contributing to the longitudinal analysis belongs to one cohort only).

It should also be noted that the longitudinal analysis is restricted to instances where the same person responded at each of the time points being considered.¹²

1.5 Modelling the 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 employment and community participation.

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

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.

The regression models in this report look at changes between two timepoints, either from baseline to first, second or third review, or from an earlier review to a later review. In all cases only the later review can have occurred after the assumed COVID-19 date of 23 March 2020, and the time variables are measured with reference to that later review (for example, the COVID-19 indicator is 1 where the later review occurs during the COVID period).

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

¹⁰ Most of these participants entered the Scheme between 1 July 2017 and 30 June 2018, however a small number of participants entering between 1 July 2016 and 30 June 2017 who had a response at year 2 but not at year 3 are included in the C2 cohort.

¹¹ Most of these participants entered the Scheme between 1 July 2018 and 30 June 2019, however a small number of participants entering between 1 July 2016 and 30 June 2018 who had a response at year 1 but not at year 2 or 3 are included in the C1 cohort.

¹² As far as can be ascertained from their relationship to the participant.

1. The modelling is based on only about three months of experience during the pandemic (23 March 2020 to 30 June 2020), 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.