

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 is the second annual report on outcomes for families and carers of NDIS participants, including baseline and longitudinal change up to 30 June 2019 for families and carers of participants entering the Scheme since 1 July 2016. The previous report summarised experience to 30 June 2018⁷.

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 2018 and at 30 June 2019 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 2019. Results are organised with separate sections for each questionnaire version, synthesising analyses from all data sources (SF and LF, baseline and longitudinal). 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 appendices⁸ include:

- Appendix A: Families/carers of participants aged 0 to 14
- Appendix B: Families/carers of participants aged 15 to 24
- Appendix C: Families/carers of participants aged 25 and over

Appendices A to C contain the following information:

1. Baseline indicators – aggregate
2. Baseline indicators – by participant characteristics

⁷ NDIS Family and Carer Outcomes Report 2018, National Disability Insurance Scheme 2020, <https://data.ndis.gov.au/reports-and-analyses/family-and-carer-outcomes-report>

⁸ Appendix B of the participant outcomes report also contains information on response rates and representativeness for the LF family/carer survey.

3. Longitudinal change in indicators over one year for families/carers of participants entering the Scheme in 2017-18 – aggregate
4. Longitudinal change in indicators over one year for families/carers of participants entering the Scheme in 2017-18 – by participant characteristics
5. Longitudinal change in indicators over one and two years for families/carers of participants entering the Scheme in 2016-17 – aggregate
6. Longitudinal change in indicators over two years for families/carers of participants entering the Scheme in 2016-17 – by participant characteristics
7. Perceptions of whether the NDIS has helped after one year in the Scheme – aggregate
8. Perceptions of whether the NDIS has helped after one year in the Scheme – by participant characteristics
9. Perceptions of whether the NDIS has helped after two years in the Scheme – aggregate
10. Perceptions of whether the NDIS has helped after two years in the Scheme – by participant characteristics.

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 two cohorts of families/carers:

- Families/carers of participants entering the Scheme in the first year of transition (1 July 2016 to 30 June 2017), for whom a record of outcomes is available at Scheme entry (baseline), and approximately two years after Scheme entry (second review). The large majority of these families/carers also responded at one year after Scheme entry (first review). This cohort is referred to as the “B,R1,R2” cohort.
- Families/carers of participants entering the Scheme in the second year of transition (1 July 2017 to 30 June 2018), for whom a record of outcomes is available at Scheme entry (baseline), and approximately one year after Scheme entry (first review). This cohort is referred to as the “B,R1” cohort.

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

It should also be noted that the longitudinal analysis is restricted to cases where the same person responded at each of the time points being considered.⁹

⁹ As far as can be ascertained from their relationship to the participant.