1. Introduction

1.1 Purpose and scope

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

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.

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.

A separate report on participant outcomes at 30 June 2018 has been prepared[14], and that report 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 Questionnaires

The NDIS Outcomes Framework collects information on how participants and their families and carers are progressing in different areas (domains) of their lives. It is used to monitor individual and Scheme progress over time, to help uncover the types of supports that lead to good outcomes, and to benchmark against the experience of other populations (such as people without disability and other OECD countries).

Leveraging research conducted by the IAC, the outcomes framework takes a lifespan approach to the measurement of outcomes, recognising that different milestones are important for different age groups. Hence different versions of the questionnaires are used, for both participants and families/carers, depending on the age of the participant. The current versions and domains are summarised in Table 1.1.

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[14] Subsequently referred to as “the participant outcomes report”.

Table 1.1 Outcomes framework versions and domains for participants and families/carers

Domain	**Participant version**				**Family version, for participant aged**		
	Children from 0 to before starting school	Children starting school to age 14	Young adults 15 to 24	Adults 25 and over	0 to 14	15 to 24	25 and over
1	Daily living	Daily living	Choice and control	Choice and control	Families know their rights and advocate effectively for their child with disability	Families know their rights and advocate effectively for their family member with disability	Families know their rights and advocate effectively for their family member with disability
2	Choice and control	Choice and control	Daily living	Daily living	Families feel supported	Families have the support they need to care	Families have the support they need to care
3	Relationships	Lifelong learning	Relationships	Relationship	Families are able to gain access to desired services, programs, and activities in their community	Families are able to gain access to desired services, programs, and activities in their community	Families are able to gain access to desired services, programs, and activities in their community
4	Social, community and civic participation	Relationships	Home	Home	Families enjoy health and wellbeing	Families enjoy health and wellbeing	Families enjoy health and wellbeing
5		Social, community and civic participation	Health and wellbeing	Health and wellbeing			
6			Lifelong learning	Lifelong learning			
7			Work	Work			
8			Social, community and civic participation	Social, community and civic participation			

Two versions of the questionnaires, a long form (LF) and a short form (SF), have been developed. The SF is completed by all participants and a family member or carer where possible, and contains questions useful for planning as well as key indicators to monitor and benchmark over time. The LF is completed for a subset of participants and their families and carers, and includes all of the SF questions plus some additional questions allowing more detailed investigation of participant and family/carer experience, and additional benchmarking.

The participant outcomes report contains further detail regarding the development and implementation of the LF and SF questionnaires.

1.3 Numbers of questionnaires

This report presents results obtained from two data sources:

- SF data collected on active transition participants with an initial plan approved during the period 1 July 2016 to 30 June 2018. These are the questionnaires included for the Q4 2017-18 COAG DRC report.
- LF data collected on the 2016 and 2017 cohorts during 2016 and 2017.

Baseline results incorporate questionnaires collected when a participant enters the Scheme. Longitudinal results are based on the subset of participants who responded at baseline and also responded to a second questionnaire approximately one year later. For the LF, this comprises participants from the 2016 cohort who responded in 2016 and 2017.

Table 1.2 provides a high-level summary of the numbers of family/carer and participant questionnaires contributing to the baseline and longitudinal analyses. Family/carer numbers as a percentage of participant numbers are also shown.

Table 1.2 Summary of numbers of questionnaires

Numbers contributing to:	SF/LF	Family/carer	Participant	Family/carer as % of participant
Baseline analysis	SF	77,746	141,638	55%
Baseline analysis	LF	2,724	3,444	79%
Longitudinal analysis	SF	17,119	40,154	43%
Longitudinal analysis	LF	712	792	90%

Full details of numbers of questionnaires collected for participants, and their families and carers, are included in Section 2.3 and Appendix A of the participant outcomes report.