# **Evaluation of the NDIS**

# **Initial Report**

**December 2015** 



National Institute of Labour Studies Flinders University, Adelaide, Australia

# **Acknowledgements**

The independent Evaluation of the Trial of the National Disability Insurance Scheme (NDIS) is led by the National Institute of Labour Studies (NILS) at Flinders University, South Australia and funded by the Australian Government Department of Social Services.

This report is the result of a team effort from those working on the Evaluation of the NDIS and has been written as part of the independent evaluation of the NDIS trial. We would like to acknowledge the support of the Department of Social Services; the National Disability Insurance Agency; the Department of Human Services; the project's Steering Committee; and the many stakeholders, whose input throughout has been invaluable. We also thank the State Experts and the International Experts for their important contribution.

Above all, we are deeply grateful to all participants of the NDIS Surveys and interviews for generously giving their time and for sharing their personal experiences to support the evaluation of the NDIS.

## **Research Team**

The following people have contributed to the research, data collection and the writing of the Initial Report.

### **Flinders University**

Kostas Mavromaras is the project's Chief Investigator. The rest of the Flinders University team is (in alphabetical order): Andreas Cebulla, Angela Crettenden, Deb Davies, Caroline Ellison, Alison Goode, Lorna Hallahan, Joshua Healy, Linda Isherwood, Genevieve Knight, Stephane Mahuteau, Megan Moskos, Deb Payne, Pammi Raghavendra, Sue Richardson, Llainey Smith, Helen Walton, Zhang Wei and Rong Zhu.

## La Trobe University

**Christine Bigby** 

## **Centre for Disability Studies**

Patricia O'Brien

#### **Social Research Centre**

Karen Kellard

#### **Data Collection**

#### **Social Research Centre**

Graham Challice, Darren Pennay and Sonia Whiteley

## **I-View**

Julia Bizdoaca

## **State and International Experts**

Christine Bigby (VIC), Di Chartres (SA), Patricia O'Brien (NSW), Margaret Reynolds (TAS) and Jacinta Cummins/Christina Ryan (ACT).

Bruce Stafford (UK), Jeff Smith (US), David Greenberg (US).

#### **Cultural Partners**

Ric Yamine and Garo Gabrielian

## **Contact for follow-up:**

Professor Kostas Mavromaras, National Institute of Labour Studies, Flinders University, GPO Box 2100. Adelaide SA 5001

Phone: +61 8 8201 3482

Email: k.mavromaras@flinders.edu.au

Website: www.NDISEvaluation.net.au Evaluation email: ndisevaluation@flinders.edu.au

# **Table of Contents**

Executive Summary	1
1. Introduction	14
1.1 The NDIS Evaluation findings reported in this Initial Report	14
1.2 Evaluation Framework	16
1.3 Key Evaluation Questions	18
2. Qualitative Impact Evaluation	21
2.1 General overview	21
2.1.1 Fieldwork and recruitment	21
2.1.2 Interviewing	22
2.1.3 Shared aims and objectives	23
2.1.4 Analysis	24
2.1.5 Structure of report	24
2.2 Interviews with people with disability, and their families and carers	25
2.2.1 Specific aims and objectives	25
2.2.2 Recruitment, sample and interview	25
2.2.3 Findings	27
2.2.3.1 The impact of disability on the lives of people with disability, and their families and carers	
2.2.3.2 Awareness and expectation of the NDIS	30
2.2.3.3 Experiences of entering the NDIS and of preparing the NDIS plan	31
2.2.3.4 Plan implementation process and receipt of NDIS-funded supports	33
2.2.3.5 Early accounts of the impact of the NDIS on people with disability, and their familie carers	
2.2.3.6 Areas for improvement	34
2.3 Interviews with disability service providers	35
2.3.1 Specific aims and objectives	35
2.3.2 Recruitment, sample and interview	36
2.3.3 Findings	38
2.3.3.1 Expectations about the NDIS	38
2.3.3.2 Initial impact of the NDIS on the disability sector	38
2.3.3.3 Initial impact of the NDIS on the organisation	40
2.3.3.4 Initial impact of the NDIS on the workforce	45
2.3.3.5 Initial impact of the NDIS on people with disability, and their families and carers	47
2.3.3.6 Experiences working with the NDIA	49
2.3.3.7 Suggestions for changes and improvements	49
2.4 Interviews with disability workforce stakeholder organisations	51

2.4.1 Specific aims and objectives	51
2.4.2 Recruitment, sample and interview	51
2.4.3 Findings	52
2.4.3.1 Initial expectations of the NDIS	52
2.4.3.2 Initial impact of the NDIS	54
2.4.3.3 Working with the NDIA	56
2.4.3.4 Areas for improvement	57
2.5 Interviews with NDIA managers and staff	59
2.5.1 Specific aims and objectives	59
2.5.2 Recruitment, sample and interview	59
2.5.3 Findings	60
2.5.3.1 NDIA employees' perceptions and experiences of NDIS implementation to da	te60
2.5.3.2 Assistance in setting and achieving goals, increasing economic participation	66
2.5.3.3 Relationship between NDIA employees and community and mainstream serv	ices68
2.5.3.4 Suggestions for improvement	70
2.6 Key Evaluation Questions addressed	71
2.6.1 Findings relating to Key Evaluation Questions	74
3. NDIS Survey of people with disability, and their families and carers	83
3.1 Introduction	83
3.2 Design and development – the sampling process	84
3.2.1 Sample design by location: trial and comparison groups	84
3.2.2 Differences within trial sites and between trial sites	85
3.2.3 Phasing in of the NDIS trial roll out and sampling timeline implications	85
3.2.4 Sampling for trial and for control samples	86
3.2.5 Sampling the Family and Carer	87
3.2.6 Initial and later sampling	87
3.2.7 Opt-out/in	88
3.2.8 Registration	89
3.2.9 Completing the first wave of interviews and commencing the second wave of inter	views91
3.3 Accessibility and design – the survey instruments	92
3.3.1 Multi-mode delivery	92
3.3.2 Accessibility of questionnaires	92
3.3.3 Designing the questionnaires and the questions	94
3.3.4 Cognitive testing	95
3.3.5 Easy English	95
3.4 Pilot study	95

3.6 Initial Findings	100
3.6.1 Part A – Socio-demographics	100
3.6.2 Part A – Disability and living arrangements	101
3.6.3 Part A – Supports before the NDIS (NDIS participants only)	106
3.6.4 Part A – Participation in the NDIS: planning and accessing supports	107
3.6.5 Part A – Participation in the NDIS: support providers	112
3.6.6 Part A – Education	114
3.6.7 Part A – Employment	119
3.6.8 Part A – Income	122
3.6.9 Part B – Overview	125
3.6.10 Part B – Social participation and wellbeing	125
3.6.10.1 Statements about yourself and how you feel	128
3.6.10.2 Statements about how happy respondents feel about things in their life	131
3.6.10.3 Statements about support respondents feel they have from other people	133
3.6.11 Education aspirations (children and adults reported separately)	136
3.6.12 Employment aspirations	138
3.6.12 Living and housing	141
3.6.13 Past disability supports	143
3.6.14 Current disability supports	144
3.7 The NDIS surveys and the Key Evaluation Questions: Preliminary thoughts	150
3.8 Summary and comments	151
4. The 2014 NDIS Disability Support Providers Surveys	154
4.1 Introduction	154
4.1.1 The purpose of the 2014 NDIS DSP surveys	154
4.1.2 2014 NDIS DSP surveys design, development and fieldwork	154
4.1.3 The achieved sample	158
4.2 Initial findings for DSP outlets	158
4.2.1 A profile of DSP outlets	158
4.2.2 Skill shortages and staff skills	161
4.2.3 Vacancies	164
4.2.4 Hiring intentions	165
4.2.5 Agency, brokered and self-employed	168
4.2.6 Volunteers	170
4.2.7 Expected changes	170
4.2.8 A brief summary of findings for DSP outlets	173

4.3 Initial findings for disability support workforce	174
4.3.1 Introduction	174
4.3.2 Main workforce characteristics	174
4.3.3 Main characteristics of the disability services work	180
4.3.4 Career paths	184
4.3.5 Experiences of working in disability support	188
4.3.6 A brief summary of the nature of the disability support workforce	190
4.4 Initial findings for self-employed DSP	191
4.4.1 Introduction	191
4.4.2 A profile of self-employed DSP	191
4.4.3 A brief summary of self-employed DSP	201

# **Tables**

Table 2.1: Fieldwork period for Qualitative Impact Evaluation (Wave 1)	22
Table 2.2: Characteristics of respondents in the qualitative study of people with disability, and their families and carers	26
Table 2.3: Characteristics of respondents in the qualitative study of disability service providers	37
Table 2.4: NDIA interviews by trial site and job role	59
Table 2.5: Key Evaluation Questions	72
Table 3.1: Estimates of NDIS eligible populations and required sample sizes	84
Table 3.2: NDIS Survey study populations and samples	88
Table 3.3: NDIS Survey sample and registrations (as at 15 July 2015)	90
Table 3.4: Types of questionnaires	94
Table 3.5: Wave 1 NDIS Survey returns, by state, and response rate (as at 15 July 2015)	98
Table 3.6: NDIS Survey responses by mode and types of questionnaire (as at end May 2015)	99
Table 3.7: NDIS Survey for Families and Carers: registrations and completions (as at 15 July 2015)	99
Table 3.8a: Demographic composition of trial and comparison samples	100
Table 3.9: Main disability	102
Table 3.10: Daily activities where assistance is needed	103
Table 3.11: Who most often provides assistance with daily activities?	104
Table 3.12: Accommodation	104
Table 3.13: Home ownership	105
Table 3.14: Who do people with disability live with?	105
Table 3.15: NDIS participants only - supports received before the NDIS	106
Table 3.16: Pre-NDIS experience with self-management of funding	107
Table 3.17: Meeting with the NDIA Planner	108
Table 3.18: Assisted in making decisions about supports	109
Table 3.19: Current types of supports received	111
Table 3.20: Respondents in receipt of an early intervention by age group	111
Table 3.21: Number of disability support providers used	112
Table 3.22: Changes in disability support providers	112
Table 3.23: Could not access supports	113
Table 3.24: Reason for not accessing support	113
Table 3.25: Currently studying or not	115
Table 3.26a: Attending school	116
Table 3.26b: Attending post-school education	116
Table 3.27: Qualification level currently studying	117
Table 3.28: What year are you currently in?	117

Table 3.29: Enrolled full time/part time	118
Table 3.30: Highest year of schooling attained	118
Table 3.31: Highest level of educational qualifications	119
Table 3.32: Work in an Australian Disability Enterprise	119
Table 3.33: Current occupation	121
Table 3.34: Work place adapted to facilitate working	121
Table 3.35: If presently not employed, have ever had a job?	121
Table 3.36: Person with disability main source of income	122
Table 3.37: Sources of additional income of a person with disability	123
Table 3.39: Total person with disability household income for the last year	124
Table 3.40: Activities that you have done recently	125
Table 3.41: Activities (top three) you would most like to do in the coming years	126
Table 3.42: Hurdles to doing things in the coming year	127
Table 3.43: Does he/she like school? (8 to 15 years)	136
Table 3.44: What would he/she like to do after finishing his/her current education? (8 to 15 years)	136
Table 3.45: Does he/she like studying? (Adults 16+)	137
Table 3.46: What would he/she like to do after finishing his/her current education? (Adults 16+)	137
Table 3.47: Do any of the following make it hard to study? (Adults 16+)	138
Table 3.48: Currently in work or not	138
Table 3.49: Does he/she like his/her job?	139
Table 3.50: Would you like to have a different job?	139
Table 3.51: Looking for a different job	139
Table 3.52: Would like to have a job	140
Table 3.53: Do any of the following make it hard to get a job?	140
Table 3.54: Is there anything stopping him/her from working or studying?	141
Table 3.55: Would like to live in a place of his/her own one day	141
Table 3.56: When would he/she like to live on his/her own	142
Table 3.57: Where currently living meets needs	142
Table 3.58: Is there anything about where he/she lives that he/she is not happy about?	143
Table 3.59: Satisfaction with quality of support before NDIS	143
Table 3.60: How much say over decisions about what support received before NDIS	144
Table 3.61: How much choice over where obtained supports before NDIS?	144
Table 3.62: Pre and post NDIS: Time to get supports, do the necessary paperwork and find out where to get the supports	145
Table 3.63: Satisfaction with quality of received supports	145
Table 3.64: How much say over decisions about what supports to receive	146
Table 3.65: How much choice over where supports are obtained	146

Table 3.66: Pre and post NDIS: changes in satisfaction, control and choice	147
Table 3.67: Pre and post NDIS comparison: Satisfaction with quality of received supports	147
Table 3.68: Pre and post NDIS comparison: How much say over decisions about what supports to receive	148
Table 3.69: Pre and post NDIS comparison: How much choice over where supports obtained	148
Table 3.70: In which areas of disability supports would you like to have more choice?	149
Table 3.71: Satisfaction that supports received are reasonable and necessary	149
Table 4.1: Distribution of outlets and all PAYG employees by State/Territory and ownership type	159
Table 4.2: Distribution of PAYG employees in outlets	159
Table 4.3: Types of disability support currently provided	160
Table 4.4: Primary disability types and ages of the current users of the outlet's supports	161
Percent of outlets recording current user age group, for each disability type listed	161
Table 4.5: Proportion of outlets reporting under-skilling	162
Table 4.6: Proportion of outlets reporting skill shortages in past 12 months	162
Table 4.7: Reasons for skill shortages	163
Table 4.8: Outlet responses to skill shortages	164
Table 4.9: Number of current vacancies by occupation	164
Table 4.10: Whether the most recent vacancy was filled	165
Table 4.11: Hiring intentions in next 12 months	166
Table 4.11a: Intentions to hire in next 12 months as a proportion of total number of new hires by occupation and outlet size	167
Table 4.11b: Hiring intentions in next 12 months by outlet size (per cent of outlets by size hiring any workers)	167
Table 4.12: Whether hiring plans change the outlet's current mix of support activities by outlet size (per cent)	168
Table 4.13: Use of non-PAYG workers by type of worker (per cent of outlets)	169
Table 4.14: Number of volunteers and voluntary hours in the outlet last week	170
Table 4.15: What outlet is already doing/planning to do in response to full NDIS rollout	171
Table 4.16: Anticipated general impact of NDIS	171
Table 4.17: Expectations about how NDIS will change outlet's operations in next 12 months	172
Table 4.18: Composition of outlets' total workforce by occupation and gender: number employed and per cent for each occupation	175
Table 4.19: Age distribution of the disability support workforce	176
Table 4.20: Country of birth of the disability support workforce	176
Table 4.21: Self-reported English language skills (per cent)	177
Table 4.22: Self-reported health of the disability support workforce	177
Table 4.23: Self-reported health problem or disability limiting day to day activities of the disability support workforce	177

Table 4.24: Level of qualifications	1/8
Table 4.25: Field of study of the highest and most relevant qualification for current role	179
Table 4.26: The highest level of qualification currently studying for	179
Table 4.27: The field of study currently studying for	180
Table 4.28: Form of employment of the PAYG disability support workforce	181
Table 4.29: Current and preferred work schedule	181
Table 4.30: Total working hours per week and preferred total work hours per week (per cent)	182
Table 4.31: Total working hours per week against preferred total work hours per week	182
Table 4.32: Weekly earnings before tax by occupation	183
Table 4.32a: Weekly earnings before tax by occupation, full-time employees	184
Table 4.32b: Weekly earnings before tax by occupation, part-time employees	184
Table 4.33: Last paid job before started working in the disability support sector	185
Table 4.34: Age at which began working in the disability support sector	185
Table 4.35: Reasons to work in the disability support sector	186
Table 4.36: The main reason for leaving one's last job in the disability support sector	186
Table 4.37: Tenure with current employer and tenure in current job	187
Table 4.38: Whether actively seeking work with another employer	187
Table 4.39: Expected activity in 12 months' time of the disability support workforce	188
Table 4.40: Job satisfaction [1-10 dissatisfied/satisfied scaling] (per cent)	188
Table 4.41: Opinions about aspects of work [1 to 7 disagree/agree scaling] (per cent)	189
Table 4.42: Time allocation in current disability support job	189
Table 4.43: Relationship between the following groups in the outlet [1 to 7 bad/good scaling] (per cent)	190
Table 4.44: Distribution of self-employed providers by state and region	191
Table 4.45: Number of employees of self-employed providers	192
Table 4.46: Self-employed DSP types of disability support provided	192
Table 4.47: Primary disability types and ages of the current users of the business's disability supports of self-employed providers (per cent)	193
Table 4.48: Age distribution of self-employed providers of disability care and supports	193
Table 4.49: Country of birth self-employed providers of disability care and supports	194
Table 4.50: Self-reported general health of self-employed providers of disability care and supports	194
Table 4.51: Level of qualifications completed of self-employed providers of disability care and supports	195
Table 4.52: Field of study of the highest and the most relevant qualification of self-employed	
providers of disability care and supports	
Table 4.53: Self-employed DSP normal weekly working hours in the business	
Table 4.54: Self-employed DSP Weekly gross income	196

cent)	197
Table 4.56: Total number of years spent working in the disability support sector by self-employed providers	
Table 4.57: The main reason for becoming a self-employed provider of disability supports	198
Table 4.58: Reasons for self-employed providers to work in the disability support sector	198
Table 4.59: Job satisfaction of self-employed providers [1 to 10 dissatisfied/satisfied scaling] (per cent)	199
Table 4.60: Opinions about aspects of work of self-employed providers	200
[1 to 7 disagree/agree scaling] (per cent)	200
Table 4.61: Time allocation at work of self-employed providers	200
Figures	
Figure 1.1: Key Evaluation Questions	19
Figure 3.1: Number of months since access request to NDIA approved	108
Figure 3.2: Working hours per week in paid job	120
Figure 3.3a: How respondent feels	128
Figure 3.3b: How respondent feels	129
Figure 3.3c: How respondent feels	129
Figure 3.3d: How respondent feels	129
Figure 3.3e: How respondent feels	130
Figure 3.3f: How respondent feels	130
Figure 3.4a: Happiness about things in life	131
Figure 3.4b: Happiness about things in life	131
Figure 3.4c: Happiness about things in life	132
Figure 3.4d: Happiness about things in life	132
Figure 3.4e: Happiness about things in life	132
Figure 3.4f: Happiness about things in life	133
Figure 3.4g: Happiness about things in life	133
Figure 3.5a: Support from others	134
Figure 3.5b: Support from others	134
Figure 3.5c: Support from others	134
Figure 3.5d: Support from others	135
Figure 3.5e: Support from others	135

# **Executive Summary**

### **Background**

In August 2011, the Australian Productivity Commission released its landmark report on disability care and support. The report was highly critical of the Australian care and support available to people with disability and their families and carers and argued for the need for deep and far reaching change. The main recommendation of the report was the setting up of a national insurance scheme in order to improve the quality and enhance the equity of disability service provisions across Australia. A series of Council of Australian Government (COAG) agreements were reached between the Australian and state and territory governments and formalised transition arrangements from the old system to the new National Disability Insurance Scheme (NDIS). The Intergovernmental Agreement (IGA) for NDIS Launch was signed by the Commonwealth and all States and Territories at the Council of Australian Governments meeting on 7 December 2012. The National Disability Insurance Scheme Act 2013 established the National Disability Insurance Agency (NDIA) and gave birth to the new Australian NDIS.

The trial of the NDIS, originally known as DisabilityCare Australia, began in July 2013 in South Australia, Tasmania, the Barwon area in Victoria and the Hunter area in New South Wales. Western Australia, the Australian Capital Territory (ACT) and the Northern Territory joined the launch in July 2014. The Nepean Blue Mountains area of New South Wales became the latest NDIS trial site to date, starting its trial in July 2015.

In May 2013 the Australian Government Department of Social Services (DSS) commissioned a consortium led by the National Institute of Labour Studies (NILS) at Flinders University to conduct the Evaluation of the trial of the NDIS.<sup>1</sup> The evaluation was originally planned to take place between 2013 and 2016 and cover South Australia, Tasmania, the Barwon area in Victoria and the Hunter area in New South Wales from 2013 and the ACT from 2014. In 2014 the NDIS Evaluation was extended to include the Northern Territory and in 2015 the end date of the whole evaluation was extended to 2017 in order to accommodate the actual timing of the NDIS trial roll-out.

In this report, generic references to "trial sites" refer specifically to the trial sites in South Australia, Tasmania, the Barwon area in Victoria, the Hunter area in New South Wales and the ACT. A separate report will document the findings of the evaluation in the Barkly NDIS trial site in the Northern Territory. The NDIS Evaluation does not include any other NDIS trial sites.

## **Reporting Framework for the NDIS Evaluation**

The NDIS Evaluation has been running for two years and this Initial Report is the first of three major reports. An Intermediate Report is scheduled for second half of 2016 and a Final Report is scheduled to be completed in 2017.

The Initial Report provides findings from all Wave 1 fieldwork that was complete by the end of June 2015. This includes the full first wave of the Qualitative Impact Evaluation, the parts of the first wave of the longitudinal survey of people with disability, and their families and carers that were completed by the end of June 2015, and the full first wave of the survey of disability support sector employers and its workforce, including data collected in Queensland. The main purpose of the Initial Report is to

<sup>&</sup>lt;sup>1</sup> The NDIS Evaluation was commissioned in May 2013 by the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA).

describe the generation of the evidence from the three major methodologies that will inform the evaluation. These are the Qualitative Impact Evaluation, the quantitative people with disability and their families and carers surveys and the quantitative disability support providers and their workforce surveys. Each of these three major evidence collections need to be well-understood in their own right before they can be synthesised and used for the purposes of the formal evaluation exercise. The ultimate purpose of the Initial Report is to present the raw evidence that will be used as the benchmark for all further development of the evidence collection and ultimately for measuring change over time. It is true for all evaluations that they can be only as good as the evidence they are based on, hence the Initial Report places a strong emphasis on the presentation of each of the three methodologies.

The Intermediate Report is the second major report of the NDIS Evaluation. It is planned for second half of 2016 and is intended to present the synthesis of the evidence provided in the Initial Report and to also add to the evidence by incorporating in the report all new evidence generated after June 2015. This will include the remainder of Wave 1 longitudinal survey of people with disability, and their families and carers, and, subject to the timing and the numbers available in the ACT NDIS roll out, survey data from the ACT. The Intermediate Report will also include the continuation of the second wave of qualitative evidence collection, but not its completion. Crucially, the Intermediate Report will report on the outcomes from the beginning of the integration of the evidence collected from different sources and methodologies. The work of combining and integrating data is at the heart of the design of the evaluation and will follow all evidence collections. First, qualitative evidence will be juxtaposed and combined with quantitative evidence in a thematic way in order to inform the evaluation of potential synergies between the depth of understanding qualitative evidence offers and the overall representativeness that the quantitative survey evidence offers. Second, the Intermediate Report will present the first results from the planned data synthesis in that the data from people with disability will be matched with the data from their families and carers so that they can be analysed in the right family context. A similar synthesis will commence with the data of employers being combined with the data of their employees. In the background of this analysis will be the presence of the Policy Logic questions that the evaluation has been designed to answer. The Intermediate Report will examine the strengths and the weaknesses of the evidence we are generating in order to suggest any changes that may be feasible before wave 2 of the major data collections are finalised (especially those of people with disability and their families and carers).

The Final Report is planned for 2017 and will provide the findings from all remaining data collections and studies that were not included in the Intermediate Report. Notably, it will report on the completion of the second wave of evidence collection for the people with disabilities, their families and carers from both qualitative and quantitative methodologies. A crucial part of the evaluation is to establish what changes have happened between wave 1 and wave 2 of the data. With all evidence collection concluded, the Final Report will report on the synthesis of evidence that will inform the formal evaluation, with particular reference to the policy logic questions. It will also dwell on the methodological aspects of the evaluation design, a necessary aspect given the complexity of the design and the diversity of the evidence utilised. A major contribution of the Final Report will be the reporting of the evaluation outcomes that emerge from the formal evaluation process of comparing the change that occurred in the NDIS trial areas with the change that occurred in the comparison areas and judging the degree to which any measurable differences between these two changes can be attributed to the NDIS roll out or not.

The Final Report is planned to also report on all new evidence that will have emerged from the older people with disability study and from the mainstream providers' studies. The placing of the reporting of the Northern Territory study (within the Final Report or in a separate document) has not been decided as yet between the Department and NILS. As this study is progressing almost independently, there is no urgency for this decision.

The reporting on the NDIS Evaluation presents several difficulties that will need to be managed as the evaluation reporting progresses. First, the reports can be too segmented. Second, the reports can be too long. Third, the reports can be too technical. Finally, the three reports will have been written to be sequentially read, which can make for very long and potentially difficult reading. It is recognised that these difficulties will need to be addressed as the evaluation progresses, especially when the evaluation comes to the stage when it will be reporting for the full NDIS trial impact.

Although the evaluation has been agreed to report in just three steps, segmentation is unavoidable as each reporting step must contain the outcomes of several simultaneous but inter-related studies that need to be presented almost independently, as their methodologies are different and their uses are diverse. Segmented reporting will be most prominent in the Initial Report, but will continue to be very visible in the Intermediate Report and will still be present in the Final Report, despite the fact that by the time the Final Report is written most of the evidence from different methodologies will have been synthesised.

Apart from the segmentation of the reported studies, the nature of the content at each of the three reporting points accounts for both the length and the technical complexity of each of the three planned reports. Finally, the end product of the evaluation will need to be both technically detailed (long) and accessible (easy to read/short). This conflict of attributes will need to be addressed ideally before the preparation of further reports commences and definitely before the preparation of the Final Report commences.

The remainder of this Executive Summary deals with the contents of the Initial Report which can be divided into three main parts:

- the Qualitative Impact Evaluation
- the NDIS Survey of People with Disability, and their Families and Carers
- the 2014 NDIS Disability Support Providers Surveys

## **Qualitative Impact Evaluation**

The Qualitative Impact Evaluation consisted of a number of in-depth interviews with:

- people with disability, their families and carers
- disability service providers
- disability workforce stakeholder organisations
- NDIA managers and staff.

These interviews collected impressions and assessments of the progress and achievements of the early implementation of the NDIS.

#### Interviews with People with Disability, and their Families and Carers

Interviews were conducted with 62 NDIS participants, and family members and carers in the five trial sites. The interviews targeted people who had already moved into the scheme and commenced or completed the NDIS plan preparation and implementation. Recruitment for the interviews targeted people with a range of disabilities, including about a third who were living with a developmental condition, a quarter experiencing a neurological or brain condition, and a fifth living with an intellectual disability.

## Key findings were:

- Respondents explained that their disability had an adverse impact on their health, and social and
  economic participation. The NDIS was seen as an opportunity for improving their lives and
  increasing social activities, but there had also been uncertainty as to how eligibility for the
  Scheme was going to be assessed.
- Experiences of transitioning into the NDIS were varied. Communications with the NDIA and the latter's responsiveness to public enquiries were described as problematic, in particular in the early stages of the trial.
- NDIS participants often found the new experience of plan development overwhelming.
   Participants valued the support given by the NDIS planners but also occasionally found planners lacked specialist disability expertise. NDIS participants would have liked the opportunity to involve advocates in developing their plan.
- Many participants typically limited their plan to retaining existing services and service providers.
   NDIS participants would have welcomed better information about plan and provider options from the NDIA to strengthen their choice and control.
- For some family members and carers, the NDIS was reported to have reduced the financial stress
  and strain often associated with supporting a person living with disability. Some participants felt
  that the NDIS was beginning to provide them with more opportunities for developing
  independence and personal skills, and engaging in new activities.

## **Interviews with Disability Service Providers**

Interviews were conducted with five NDIA-registered disability service providers in each of the trial sites between September and November 2014. Interviews were undertaken with employers of 'Pay as you go' (PAYG) workers, brokered workers and self-employed sole providers. Selective sampling ensured that the types of disability service providers broadly reflected the characteristics of the types of disability services provided in each trial site. Providers varied in size and were operating primarily in the trial state.

## Key findings:

- In common with people with disability, disability service providers shared many positive expectations of the NDIS, but also expressed concern about the impact it would have on their businesses and activities. Some of these concerns appeared to be confirmed during the early implementation of the NDIS—for example, when relationships between providers were reported as becoming less collaborative. However, feedback about later stages of the roll-out suggested a cautious return to a more collaborative environment, and that disability services providers were more commonly exchanging experiences and shared learning of the NDIS.
- Providers were worried that the NDIA's payment-in-arrears system would threaten the financial
  viability of smaller providers. Providers reported undertaking increasing amounts of unfunded
  work, including administrative tasks to comply with NDIA regulations, and having less funding
  available for fixed costs (e.g. property maintenance) or staff training and development. The NDIS
  pricing structure was also criticised for not allowing full cost recovery.
- In order to keep up with the structural changes brought about by the NDIS, providers had begun to change their administrative systems, including finance, pay, rostering and data systems.
- According to providers, NDIS clients were increasingly seeking individualised rather than group-based services, in particular requesting supports for independent living in the home. Some providers felt that delivering fewer group-based services may risk reducing social participation opportunities for NDIS participants.
- Providers reported more competition for staff since the implementation of the NDIS
  trial, in particular from the NDIA, which was able to offer better terms and conditions.
  While some providers responded by improving training and staffing flexibility within the
  organisation, they still felt staff might leave because of a change in the values and ethos
  of disability service provision under the NDIS.
- Disability service providers appreciated recent opportunities to participate in the
  planning process with individual clients and to advocate on their clients' behalf.
   Providers questioned whether bureaucracy in the NDIS was making it more difficult for
  people with disability to navigate the disability supports environment.

#### **Interviews with Disability Workforce Stakeholder Organisations**

Senior personnel of 15 disability workforce stakeholder organisations were interviewed between September and December 2014. The organisations represented a mix of occupations and workforces supporting people with disability.

#### Key findings were:

- The disability workforce shared many of the high expectations of the NDIS already reported by people with disability and disability support providers. Extra funding under the NDIS was anticipated to benefit support users and the sector, generating more diverse service options, greater service flexibility and enhanced person-centred care.
- Expectations were more muted as to the impact of the scheme on working conditions.
   Stakeholders were concerned that competition between providers might force disability service providers to reduce their operating costs, lower wages, use more temporary and casual staff, or weaken career structures. Stakeholders were also concerned that staff training and professional development might be cut back.
- To date few significant changes since the introduction of the NDIS were reported. Some accounts
  pointed to disability providers proactively engaging with the new systems of service delivery,
  combining specialist disability services with other provisions, brokered in collaboration with
  mainstream and third sector organisations.
- Stakeholders were concerned about state and territory governments withdrawing from the provision of disability services before other providers were ready to meet increasing demand.
- Workforce stakeholders observed that providers were finding it difficult to transition from the
  old block funding system to the new individualised funding model of the NDIS. The viability of
  smaller providers was perceived to be at risk as NDIA determined prices were not matching the
  costs of service delivery.
- In particular trade unions and those aligned to allied health felt distant from the NDIA. Few had been in direct contact with the NDIA, at the federal or state office level. Many were disappointed not to have been consulted prior to the start of the NDIS trial.
- The workforce organisations felt they could offer a valuable interface between the disability and the mainstream sector, because they were engaged in health, mental health, education and aged care, as well as disability services.

## Interviews with NDIA managers and staff

Forty-six NDIA staff across the original five trial sites were interviewed between October 2014 and April 2015, including managerial and operational staff, and practitioners.

## Key findings were:

- NDIA staff who participated in the evaluation reflected positively on the achievements of the NDIS and the NDIA to-date, although the initial set up had been difficult and, some felt, rushed.
- The rapid launch of the trial meant that policies and procedures had not been in place to guide staff and to assist NDIS participants, and their families and carers. Considerable resources were invested to develop and improve policies and procedures over time, making them more consistent.
- The absence of process guidelines within the NDIA at the start of the trial was said to have adversely affected NDIS eligibility determinations and plan development processes. Both were felt to have improved over time.

- Transitioning into the NDIS proved problematic in the early stages because of a lack of quality information about potentially NDIS-eligible people with disability. Information technology essential for the effective operation of such a complex project was also found inadequate, resulting in increased administrative burden placed on planners, Plan Support Coordinators and Local Area Coordinators. Pressure on staff, due to this and other workload commitments, was described as very high, often at stress level.
- These pressures affected efforts to engage with specific populations, including people with psychosocial disabilities, and those from culturally and linguistically diverse or Indigenous backgrounds. Specialist training that could have helped NDIA staff to connect with these target populations was described as inadequate and too generic.
- NDIA staff felt that NDIS participants were having difficulties adapting to the NDIS, particularly in regards to thinking about goals and aspirations. Some argued that the capacity of NDIS participants and their families and carers to negotiate access and to undertake planning and plan implementation might have been over-estimated. Progress towards articulating or realising more ambitious objectives was not expected until future plan review meeting.
- Despite these concerns, NDIS participants were now seen to have the right support plans. There
  was also agreement that the then emerging pre-planning sessions with new NDIS participants
  were of considerable value to the plan development process.
- The take up of fully self-managed funding options was reported to be low. NDIA staff felt that the time pressure that they were operating under prevented them from dedicating more resources towards assisting people with learning about and understanding self-managed funding.
- Disability service providers, it was felt, were finding it hard to adapt to the changing policy environment, although progress was said to be evident. Many NDIA staff described the sector as still being slow to move from block to individualised funding. More recently, disputes about pricing structures were described to be complicating NDIS plan development and plan implementation.

## The NDIS Survey of People with Disability, and their Families and Carers

The NDIS survey of people with disability, and their families and carers has been designed to help us understand how the lives of people with disability, and their families and carers, have been affected by the roll-out of the NDIS. The survey follows a two-wave longitudinal design and focuses on information that will help the evaluation answer its core policy logic questions.

## **Design and development**

The objective of the survey design is: first, to collect information on the changes that happened to NDIS participants in the trial sites; second, to collect information on the changes that happened to NDIS non-participants in areas that are not affected by the NDIS yet; and finally, to help measure the difference in the change that happened to NDIS participants with that of NDIS non-participants. This method is called difference-in-difference. By using this methodology we can measure the impact of the NDIS in the trial sites.

- The survey is being conducted in all trial sites and also includes a comparison group which
  comprises people with disability, and their families and carers who would have been NDIS
  participants if they were living within the trial sites. Following the NDIS trial design, the sample
  composition of the survey participants differs by site.
- The survey follows a mix of opt-out and opt-in consent rules designed to comply with the
  project's ethics requirements. These rules have worked well in terms of protecting the ethical
  integrity of the project's design, but they have come at the cost of reducing the final number of
  survey respondents. With the hindsight provided by the first wave collection, it is conceivable
  that this process could be simplified without loss of integrity for future data collections.
- The survey uses a specially designed registration process to allow respondents to be approached
  in their preferred way. They are offered the possibility of a Computer Assisted Telephone
  Interview (CATI), an online response, a hard copy mail response, and a Face to Face interview.
  The registration process also allows respondents to provide further information on their
  disability and to nominate their preferred family member or carer to be interviewed in the
  families and carers part of the survey.
- The timelines of the survey have been following the timing of the NDIS trial rollout. The slow initial rollout numbers have been mirrored in the initial sample sizes of the survey. Due to the small initial numbers of NDIS participants, the survey's first wave was divided chronologically into three separate samplings: the first one happened at the end of 2014, the second in the middle of 2015 with the third sample scheduled to begin in the second half of 2015. The third sampling is timed to happen when the NDIS participation numbers are sufficient to enable the evaluation to reach its original targeted sample size and get as close as possible to the original composition by state and territory.
- The survey is divided into two major components; the first one addresses people with disability and the second addresses their families and carers. The views of both are obtained through different questionnaires.

## Accessibility and design of the survey instruments

Accessibility is one of the core objectives of the NDIS Survey. Extensive use was made of accessibility, disability and inclusion experts in order to design questionnaires that are as accessible as possible to complete.

- In order to facilitate completion, the questionnaires were divided into two parts: Part A and Part B. Part A deals mainly with factual, less subjective information. Where it is necessary to use a proxy, this proxy can provide accurate information on behalf of a respondent. Part A includes information on disability, supports, activities undertaken, supports before and during the NDIS, and socio-demographic indicators.
- In contrast, Part B asks mainly subjective questions which have to do with opinions, assessments and perceptions. Here the survey design prefers to encourage the person with disability to answer. Part B questions include social participation, well-being, aspirations, opinions and needs.
- Part B is also offered in a pictorial easy English format and both versions can be completed either with or without the support of someone else. Whether such support was necessary is recorded and will inform the analysis.
- Questionnaires that are age-appropriate are designed and distributed accordingly. Children below the age of 8 years are not asked to provide any direct information, their surveys typically being completed by their parents.
- The diversity of the respondents' categorisations is reflected in the fact that there are in total 18 different questionnaires used in the survey, all targeted at and designed for specific sub-groups.

## Pilot and fieldwork

A pilot study has already been conducted and the fieldwork for the first wave is underway.

- A pilot study, including extensive cognitive testing, was conducted in the first half of 2014. The
  results of the pilot confirmed the need for a more extensive registration process than was
  initially anticipated. Although the registration process adds length to the overall duration of the
  fieldwork, it empowers respondents by allowing them to choose their preferred mode of
  response.
- Fieldwork for Wave 1 commenced in August 2014 in the form of screening registrations and in December 2014 in the form of answering the full survey. The first part of Wave 1 (referred to as Wave 1a) consisted of about one-third of the target sample size for the whole of the NDIS survey. The second part of Wave 1 was sampled in March 2015 (referred to as Wave 1b) and covered less than an additional one-third of the full NDIS target sample size. Both Waves 1a and 1b have been in essence a census of all NDIS participants who had consented to take part in research at the time of sampling.
- Fieldwork for families and carers has been lagging behind the collection of information from people with disability. The families and carers sample size was too small for reporting in 15 July 2015 when the last data for this report was received by NILS. This shortcoming will be fully addressed in the Intermediate Report.
- Fieldwork for the remainder of Wave 1 is planned to be completed during the second half of 2015.

- The re-sampling of Waves 1a and 1b (that is, for the second wave of the longitudinal collection) is to commence at the end of 2015 about 10–12 months after the first interviews took place. The second wave is planned to have a shorter fieldwork duration.
- Despite the major delays experienced with establishing fieldwork for the first wave (primarily due to the need to wait for the sample size of those who consent to taking part in research to grow in numbers), the quality of the data obtained has been high.

# Initial findings of the NDIS Survey of People with Disability, and their Families and Carers

Several findings have become apparent from the data collections. For now, these findings have to be read as preliminary and interpreted with several important caveats in mind. First, by design, this data will only be of full use when we have both Waves 1 and 2 at hand. It is only then that we will be able to observe actual change and appropriately apportion its impact on those concerned. The differencein-difference methodology requires this. Second, to the degree in which the phasing-in of the NDIS in the trial sites has been non-random, we can expect that the data collected may also be non-random and possibly not as precise a representation of the expected total NDIS participants population as we would wish. This type of statistical bias can be corrected (or at least alleviated) through appropriate statistical methods at a later stage of the analysis when both waves are at hand. Until then we must treat our conclusions as preliminary and with caution. We need to bear this point in mind, especially when we are looking at Wave 1 data alone. Third, an additional reason for being cautious when talking about Wave 1 is that the sample size is still well below what we expect will give our sample the desired statistical power. This becomes a more prominent caveat when we refer to cases that are less prevalent in the data, where the relevant cell sample sizes may be too low. This is the case in several of the tables we present, but we still include them to illustrate the forthcoming full data potential. Fourth, we should be wary of making comparisons between the trial and the comparison sample statistics without having performed the appropriate probabilistic matching in advance, in order to make the trial and comparison sub-samples comparable.

Bearing these caveats in mind, some findings are worth noting. The richness of the data collection is especially worth noting as it shows the potential for answering the Key Evaluation Questions that the full data set will have once both waves have been collected.

- The proportion of children is much larger in the trial group. We expect this to be temporary as
  the age structure of the growing sample will grow to resemble more the age structure of the
  population.
- The composition of the already surveyed people with disability shows a majority of people with intellectual or developmental conditions. The majority also report they have not just one type of disability but several.
- The role of families shows prominently in results concerning support and activities.
- We trace problems with access to supports, which could be an early indication of bottlenecks in the relevant supply chains.
- We already see complex support relationships between people with disability and the providers of the supports they need, especially in less populated areas.

- A large proportion of people with disability in the trial sites have changed support providers after they joined the NDIS. This suggests that the data collection captures adequately the change that is happening with the NDIS rollout.
- Data relating to household incomes suggests households of people with disability are slightly below the national average; however, data for individuals shows the majority of persons with disability are recipients of very low incomes. Results suggest that people with disability are strongly supported financially by their families and that many people with disability would be living in poverty if it were not for that support, reflected in their total household income. This further confirms the value of performing both surveys of people with disability, and their families and carers.
- The reporting of wellbeing has been done through three suites of questions that can be analysed as a whole to derive validated indicators of well-being, or independently to study each component in more depth.
- The number of people with disability in employment was too small for reliable conclusions. The same applied to education. We expect the full Wave 1 data to become more informative in the reporting of actual employment and education as well as employment and education aspirations.
- There are early indications of the NDIS delivering on its promises. A much larger proportion of NDIS participants report that things got better after joining the NDIS than those reporting that things had got worse. Three aspects have been asked explicitly: satisfaction with quality of support, input over decisions about what supports to receive, and choice of where to get the supports. In all three aspects there is a clear pattern of things having got better after joining the NDIS.

We should reiterate that these results are preliminary and should be treated with caution. Utilising the full Wave 1 data, they will be analysed and presented as part of the Intermediate Report in second half of 2016. The full strength of the data will only become apparent after the completion of the second wave, which will allow the necessary longitudinal analysis to commence.

## **Towards Wave 2 and beyond**

The quality of the information will become more apparent and more precise as we look at what we already have through a multivariate analysis statistical lens. We will report first results in the Intermediate Report.

A requirement of the project is that the design of the core longitudinal data collection on people with disability, and their families and carers is conducted on a template that would allow the continued collection of more waves beyond the present timeframe and beyond Wave 2 to enable future investigation and monitoring.

## The 2014 NDIS Disability Support Providers Surveys

The survey of disability support providers (DSP) sought to help understand whether there will be sufficient workforce capacity to meet the growing and changing demands of a full NDIS roll-out. The 2014 surveys provided a baseline for this understanding from the perspective of both DSP outlets and the DSP workforce. Separate questionnaires were administered for DSP outlet managers, a random sample of DSP workers, and self-employed disability service providers.

The surveys found a rich mixture of providers—large and small, mainly not-for-profit, with some smaller for-profit providers and a modest number of large public providers. About 28 per cent employed 50 or more people, while 34 per cent employed fewer than 10. There was clear evidence of specialisation in the types of disabilities that were supported, and the types of services that were offered. The diversity in size, ownership and services suggested that the sector had the capacity for resilience and adaptability.

The key findings from the survey of outlets were:

- Two-thirds of the workforce of DSP outlets was disability/residential support or personal/home care workers. These occupations dominated the concerns about workforce competence, skill shortages, vacancies and intentions to hire more staff.
- Most outlets thought that their staff had the skills they needed to do their jobs.
- Less than one in ten outlets reported that they faced a continuous (as distinct from occasional or no) skill shortage.
- Over two-thirds of outlets said they had no current vacancies for most occupations.
- Most outlets intended to hire staff in the coming year. One-quarter said that their hiring plans would increase their capacity to provide disability services.
- The requirement for specialist knowledge and geographic location were the most common reasons cited for a skills shortage. More training and longer hours for their existing workforce were the main responses.

The key findings from the survey of the DSP workforce were:

- The workforce was older than average and predominantly female; although 30 per cent of disability/residential support workers were male.
- The workforce included relatively few migrants, and especially, recent migrants.
- It was highly educated: 90 per cent had post-school qualifications, including 36 per cent who had a bachelor's degree, and these qualifications were mostly relevant to the jobs.
- Twenty nine per cent of workers were employed on casual terms and only 38 per cent were happy with the hours they work. Forty per cent wanted to work fewer hours, whereas 21 per cent wanted to work more hours.
- Professional and managerial workers had much higher earnings than care or support workers.

- People came to disability work through very diverse pathways; nearly all had worked in a different field first (e.g. sales, teacher, clerical, hospitality). Only 7 per cent came from aged care.
- A desire to help others and to do something worthwhile was the dominant reason for working in the disability support sector. Job security and pay were not attractors.
- Overall, workers were highly satisfied with their job. They were particularly satisfied with the
  work itself and the sense of achievement they got from it. They were least satisfied with their
  pay and job security and some felt excessive pressure and stress.
- Workers were confident that they had the necessary skills and freedom to do a good job and felt that they received respect for doing it well. They also expressed high levels of loyalty and pride in their workplace.
- Over 90 per cent thought that there were very good relationships between workers and their clients.
- There was substantial stability of the workforce within the sector, with some mobility between employers and jobs. Six per cent of workers expected to leave the sector in the next 12 months. Sixteen per cent expected to change employer or job.
- The employee workforce was supplemented by self-employed providers, who were mostly graduates in allied health, psychology or counselling. They particularly worked with children and in early intervention and therapeutic services.
- Over half had been working in the disability sector for 15 or more years and 97 per cent expected
  to still be doing so in 12 months' time. Even more than the employees, 'desire to help others'
  and 'desire to do something worthwhile' were their dominant reasons for working in disability
  care.

From a workforce planning perspective, it is a positive that it appeared to be drawing on a wide demographic. The diverse pathways into disability care also implied that there was quite a wide scope for expanding employment in the field: it did not rely on a narrow pipeline of potential workers. Both these factors suggested that there was a substantial pool of people currently working in other areas of the economy who could potentially be attracted into disability care. One qualification to this view was that the workforce was unusual in the emphasis that it placed on job satisfaction as a motivation, in contrast to the material perquisites of work (such as pay, job security and opportunities for promotion). The pool of people in the wider workforce that has a high motivation to care and to improve the daily lives of others is likely to be much smaller than the pool of people that has the potential to otherwise become a carer. The distinctive caring character of the job might be one reason why intention to leave, for both the job and the occupation, was quite low. Of note, only seven per cent of employees came to disability care from aged care: they seemed to be quite distinct work forces.

## 1. Introduction

## 1.1 The NDIS Evaluation findings reported in this Initial Report

This Initial Report is the first of three reports on the Evaluation of the trial of the National Disability Insurance Scheme (NDIS), conducted by Flinders University in 2013-2017. One preliminary document, the Evaluation Framework<sup>2</sup>, has already been published explaining the nature of the evaluation. A second supporting document detailing the relationship between the Key Evaluation Questions and the methodologies developed by the evaluation is planned to become public at a future date.

The Initial Report describes the first stage of the evaluation work, namely how the evaluation was put together and how the large data collection that underpins it has commenced. The Initial Report covers the period of May 2013 to July 2015 and presents the initial findings from Wave 1 fieldwork into the background and context of the development of the trial of the NDIS trial in the four initial sites: South Australia; Tasmania; the Barwon area in Victoria; and the Hunter area in New South Wales. Because of its later launch, material from the ACT trial site is presented in less detail. We report on both the quantitative and the qualitative evidence collections. On the quantitative side, we report the most up to date version of the first wave of the longitudinal survey of people with disability, and their families and carers and the complete first wave of the survey of disability support providers, including employers, specialist workers and the self-employed for all trial sites (with the addition of the Queensland study). On the qualitative side, we report the analysis undertaken in the four initial trial sites, New South Wales, Victoria, Tasmania and South Australia, and subsequently the ACT. This includes the early qualitative analysis results from the first of two waves of surveys and interviews with people with disability, and their families and carers, including NDIS participants and others not (yet) participating in the NDIS; disability service providers; disability workforce stakeholder organisations; and the NDIA.

The Evaluation of the trial of the NDIS also extends to the Northern Territory. As the Evaluation of the trial of the NDIS in the Northern Territory is still in its early stages, it will not be included in this Initial Report. The unique character of the NDIS trials in the Northern Territory requires additional design elements. Discussions with the Department of Social Services concluded that inclusion in this report would not be the most appropriate format for reporting findings from the NT. The format to be used must guard the confidentiality of the information and ensure anonymity of the respondents.

As the roll out of the NDIS in the ACT commenced in July 2014, that is, one full year later than in the other four trial sites, information collection in the ACT is not as well developed. This has required that we adapt data collections and subsequent reporting to accommodate this difference. The evaluation design includes a single data collection on providers of disability supports in Queensland, which is reported along with the rest of disability support providers.

In agreement with the Department of Social Services, the evaluation of the impact of the NDIS on mainstream providers and services has been delayed to allow for more time to develop and design this study. An initially intended community study was not commissioned so that impacts on the wider community would need to be collected indirectly, using the agreed and commissioned evaluation instruments. The Evaluation of the trial of the NDIS is also intended to evaluate high-level processes, focusing on elements of the NDIS which contributed to or impeded the intended positive outcomes. Reporting on this part of the evaluation will be one of the objectives of the Intermediate Report to be delivered in second half of 2016.

<sup>&</sup>lt;sup>2</sup> The Evaluation Framework contains a lot of the necessary preliminary information on the NDIS Evaluation. We recommend consulting the Framework as a reference point on the overall design of the evaluation.

The evaluation design includes an extensive data collection of potentially eligible people with disability, and their families and carers in areas where the NDIS is not available as yet. This collection is designed to provide the evaluation with a comparison group of respondents. The aim of this type of sampling is that the comparison group is as similar as possible to the NDIS participants group, in order to enable us to analyse what happens to people with similar needs, some within and some outside of the NDIS at the time we collect their information. However, before the full data sets have been collected and before we have established the degree to which these two groups contain similar people, comparisons cannot be reliable. For instance, the distinction between a disability support provider who is operating within or outside an NDIS trial area is not always clear as several providers operate in more than one area and through more than one outlet. Furthermore, several providers are also operating in more than just the disability supports product market. Their products or services may be accessed by clients that may or may not become NDIS participants once the NDIS reaches their area. A comparison group is therefore not easily defined in the context of support providers and their workforces. Similarly, we cannot know with certainty the composition of the future population of NDIS participants and, hence, the appropriate composition of the comparison group.

It is critical to clarify from the outset that this report does not contain definitive information and that should not be utilised as a source of a definitive understanding of Wave 1 data. For this the reader must wait for the Intermediate Report which will present the full complement of Wave 1 data sets, after these have been examined thoroughly and undergone the necessary extensive testing through statistical analyses. It is critical for the reader to bear in mind that most of the evaluation questions will only be answered after the full complement of the two waves of evaluation data has been collected and appropriately analysed. Reaching definitive conclusions on incomplete data must be avoided. Finally, it is also critical for the reader to bear in mind that the subject of the study of this evaluation, the trial of the Australian NDIS, has already undergone substantial development in its first two years and in continually developing and changing, as indeed a trial ought to. As a direct consequence, for the evaluation to be true to its objectives, it has to follow these changes and incorporate them in its evidence collection and subsequent analyses.

The precise objective of the Evaluation of the trial of the NDIS is to assess the impacts of the NDIS in South Australia, Tasmania, New South Wales, Victoria and the Australian Capital Territory on:

- people with disability, and their families and carers
- the disability sector and its workforce
- selected mainstream providers and services
- the wider community.

This Initial Report provides us with an initial assessment of the performance of the data collection processes, our focus being on understanding the adequacy and potential of the present data collections. To this purpose it also describes the initial findings that can already be seen in all evidence collections to date. Much of the information it presents will be superseded by the more thorough and complete Intermediate Report which is planned for second half of 2016 and will contain the analysis of all Wave 1 evidence collections.

#### 1.2 Evaluation Framework

The Evaluation Framework presented a reasoned assessment of the scope, scale and potential challenges of the evaluation, discussing the data, design and methodological options. Much of what was presented in that framework has since been applied and is reported in this Initial Report.

The Evaluation Framework took into account several specific features of the NDIS, notably:

- The differences in the implementation of the NDIS in the five initial trial sites, in particular variations in eligible populations, phasing-in processes, and start dates, notably the delayed trial start in the ACT
- The risk to the evaluation that the NDIS may get rolled out in comparison sites, as indeed happened with the extension of the NDIS into the Blue Mountain region in New South Wales
- Practical challenges of collecting data in remote areas, especially in South Australia, which
  resulted in the introduction of a flexible design allowing for different data collection modes to be
  used
- The diversity of the population of people with disability, including people with diverse
  communication needs, children and young people, Aboriginal and Torres Strait Islander people,
  and people from culturally and linguistically diverse backgrounds. The evaluation addressed
  these challenges by engaging specialist, and multi-lingual and multi-cultural researchers and
  consultants at different levels and during different phases of the research
- The need to consider the relevant experiences and changes in the disability and mainstream sectors, including the workforce of disability support providers and their service users. This informed the choice and thematic focus of different evaluation instruments
- The ethical issues associated with the research. These have been considered during research
  design and are monitored in close collaboration with Flinders University's Social and Human
  Behaviour Research Ethics Committee.

The phased beginning of the NDIS trial and the associated phased transitioning of participants into the Scheme have been the main challenge to this evaluation, alongside the absence of a genuine baseline for the proposed before-after evaluation design. The evaluation has sought to respond to these specific challenges through a flexible design that is responsive to continued variations of the implementation of the NDIS within and across launch sites. Examples of such flexible design can be found in the repeated top-up sampling during survey fieldwork (in the context of the NDIS survey of people with disability, and their families and carers), and in sampling of comparison and (in the qualitative fieldwork) trial groups that seeks to reflect the anticipated future profile of NDIS participants as well as their current characteristics. Additional flexible design measures presently considered for implementation in the second waves of fieldwork, include further top-up sampling in order to yield information on the more recent NDIS participants and on the newly established or arriving disability service providers and their workforces. This flexibility will enhance substantially the scope, scale and statistical robustness of the evaluation's analyses.

The Evaluation Framework had assumed a design that combined existing administrative data with the new survey data collections by the evaluation research team. The combination of administrative and survey data sets would have facilitated a more comprehensive impact assessment; however this has not been feasible to date. The flexible design measure introduced to alleviate this problem has been the introduction of a registration process that allows survey respondents to provide this information as part of their survey responses.

The Evaluation Framework explained that the evaluation will be implemented in three phases with the Phase 1 including the preparation of the Framework itself. In addition it had been anticipated that this Phase would also include the conduct, completion and start of analysis of the first waves of survey data from people with disability, and their families and carers, and the disability service sector. The slowness of the rollout of the NDIS has not allowed for this objective to be achieved in its entirety, with the two NDIS Surveys of people with disability, and their families and carers remaining in field at the time of the writing of this Initial Report.

The Initial Report, which was formerly known as the Baseline Report, forms an essential part of Phase 2 of the evaluation, which, besides reporting twice in the Initial and then the Intermediate Report, continues the quantitative and the qualitative fieldwork.

## 1.3 Key Evaluation Questions

A central focus of the Evaluation Framework has been the Key Evaluation Questions originally identified by the Department of Social Services to guide the NDIS Evaluation.

The Evaluation Framework grouped and presented the 32 principal evaluation questions into those that concern impact assessments with respect to:

- people with disability, and their families and carers
- the disability sector
- the mainstream services sector
- neighbourhoods, social networks and voluntary organisations and
- high-level policy processes.

A total of 56 questions is reached after including 24 additional sub-questions. Part of this set of 56 questions is reproduced in Figure 1 below. We note that the mainstream study has not yet commenced and that a community study has not been commissioned. We also note that the discussion of high level policy processes will only become feasible once the full evaluation material has been collected and will be delivered within the Final Report. Figure 1 is, therefore, limited to those Key Evaluation Questions which relate to the data collection tools presented and discussed in this report. These include the data collections pertaining to people with disability, and their families and carers and to the disability sector, and omit the data collections pertaining to the mainstream services sector and the neighbourhoods, social networks and voluntary organisations.

Key Evaluation Questions that pertain to outcomes for people with disability, and their families and carers have been grouped according to whether they relate to the evaluation of (a) impacts, (b) processes or (c) the realisation of the NDIS. As was explained in the Evaluation Framework, differentiating between 'processes' and 'realisation' allows the analysis to distinguish between matters that are designed or directed by the NDIA (processes) and others that may be shaped by, but are not directed by the Agency's activities (realisation).

The differentiation between impacts, processes and realisation also implies a timeline for the evaluation's reporting on NDIS outcomes. Impacts can only be reported at the end of the evaluation, that is, after the full completion and analysis of at least two waves of data collection. In contrast, it is possible that we could report some early findings about processes and realisation, noting however, that such reporting will need to be subject to review and possible revision upon the arrival and analysis of the second wave data. In this Initial Report, we focus our discussion of how initial evaluation findings may relate to the Key Evaluation Questions primarily in the context of the Qualitative Impact Evaluation and to a much lesser degree in the context of the two major quantitative data collections on people and providers. This is because the qualitative fieldwork generated sufficiently detailed insights into the experiences of NDIS participants, the disability sector and the NDIA that allowed such early assessments. The quantitative evaluation components, in contrast, will require complete Wave 1 and Wave 2 data for the in-depth comparative analyses of trial and comparison groups they are designed to produce.

Figure 1.1: Key Evaluation Questions

## Outcomes for people with disability, and their families and carers

#### **Impacts**

- To what extent has the NDIS contributed to changes in wellbeing and quality of life for people with disability, and their families and carers?
- To what extent has the NDIS contributed to changes in social and economic participation (including employment, education and the ability to express wishes and have them respected) for people with disability, and their families and carers?
- To what extent has the NDIS enabled people with disability to set and achieve their goals?
- For whom has the NDIS worked well or less well?
- Have there been any significant differences in the experiences of people with disability, and their families and carers, in the different launch sites?
- Have there been any other changes, including unintended changes (anticipated and unanticipated, positive and negative), in the experiences of people with disability, and their families and carers as a result of the scheme?

#### **Process**

- To what extent has the NDIS enabled people with disability to have increased choice and control over their supports?
- What sort of assistance do people with disability (or their families and carers, if they are managing the care) require to gain more control and navigate the system?
- To what extent has there been an appropriate balance between choice and control and safeguards for vulnerable people?
- To what extent has the NDIS enabled people with disability to gain confidence that their 'reasonable and necessary' needs will be addressed?
- To what extent have people with disability, and their families and carers seen the NDIS review and dispute resolution processes as effective and fair?
- How effective are Local Area Coordinators and other supports (e.g. website) in helping people with disability to gain control and access to necessary community and mainstream supports?

## Realisation

- To what extent have people with disability been able to manage their funding on their own, customise creative sets of options for themselves, or find suitable brokers, depending on their preferences?
- For people with disability who previously received supports, to what extent has the NDIS contributed to changes in their patterns and use of supports?
- To what extent has the NDIS contributed to equity and fairness?
- To what extent has the NDIS helped people with disability, and their families and carers during major life transitions such as starting preschool or school, leaving school, starting tertiary education, starting work, leaving home, leaving state care, leaving the workforce, and entering the aged care system?

 How effective has the NDIS been in using early interventions to minimise the impact of a disability on functional capacity over time?

## Outcomes for the disability sector

- What has been the impact of the NDIS on the overall provision and quality of disability supports?
- What has been the impact of the NDIS on the disability sector, including the relevant government agency in each jurisdiction and advocacy organisations?
- To what extent has the supply of disability supports responded to demand?
- To what extent has the NDIS contributed to an increase in the provision of early interventions from disability services?

The remainder of the Initial Report is structured as follows. Chapter 2, summarises the findings from the four elements of qualitative research conducted with (a) people with disability, and their families and carers, (b) disability service providers, (c) disability workforce stakeholder organisations, and (d) NDIA employees.

Chapter 3 reports the early findings from the analysis of the NDIS Survey of people with disability and the NDIS Survey for Families and Carers. Both surveys continue to remain in the field so that the analysis was based on a partial subset of data received by 15 July 2015. A report using the final first wave data is expected to be included in the Intermediate Report.

Chapter 4 presents the findings from the analysis of the completed first wave of the survey of the specialist providers and their workforces.

All three chapters follow a similar format, reporting first on approaches to sampling and data collection, response rates and the characteristics of respondents. This is followed by the presentation of initial findings, their discussion and summary.

# 2. Qualitative Impact Evaluation

## 2.1 General overview

This part of the Initial Report of the Evaluation of the trial of the NDIS presents the main findings of the evaluation's qualitative components. These included in-depth interviews with:

- people with disability, and their families and carers
- representatives of disability service providers
- representatives of stakeholder organisations with responsibility for disability workforce representation or development
- representatives and employees of the National Disability Insurance Agency (NDIA).

In this first section, we present a general overview of the qualitative fieldwork that was conducted with these four groups of people and organisations affected by the trial of the NDIS, before the findings from these interviews are presented separately for each population in the subsequent chapters.

#### 2.1.1 Fieldwork and recruitment

Interviews with the four parties of interest were conducted in all five initial trial sites and states, that is, New South Wales, South Australia, Tasmania, Victoria and the Australian Capital Territory (ACT). Interviews with people with disability, and their families and carers were limited to NDIS participants and, hence, took place in the actual trial sites. Disability service providers were located in the trial states or expected to have active links to the sites. Workforce stakeholder organisations, in contrast, were typically national bodies operating Australia-wide. NDIA representatives and employees were, of course, located in the trial sites. Further detail about the primary characteristics of participants in the qualitative studies will be presented in the relevant chapters below.

Whilst the evaluation has been extended to include the trial of the NDIS in the Northern Territory, the Northern Territory is excluded from this Initial Report. The late addition of the evaluation component in the Northern Territory, which did not commence until July 2014, and the special character of the NDIS trial there require that the findings for that trial site are reported separately.

The fieldwork for all four components of the Qualitative Impact Evaluation took place between September 2014 and April 2015, varying with trial site and component (Table 2.1). Notably, interviews with NDIS participants and NDIA staff started and completed later in the ACT, where the NDIS trial had only commenced in July 2014. The delay was necessary in order to identify NDIS participants and relevant NDIA staff. The intention was to interview all parties in the other trial sites at approximately similar points in time to ensure that the accounts that respondents gave of their experiences and anticipations related to comparable development stages in the roll out of the trial of the NDIS.

Table 2.1: Fieldwork period for Qualitative Impact Evaluation (Wave 1)

Fieldwork component	Fieldwork start	Fieldwork end
People with disability, and their families and carers		
in NSW (Hunter), Tasmania and Victoria (Barwon)	September 2014	October 2014
People with disability, and their families and carers in SA	August 2014	November 2014
People with disability, and their families and carers in the ACT	December 2014	February 2015
Disability service providers	September 2014	November 2014
Workforce stakeholder organisations	September 2014	December 2014
National Disability Insurance Agency	November 2014	April 2015

Recruitment for interviews had often commenced two to three months prior to the time when the interviews actually took place. Respondents were recruited via a diversity of means, which typically included advertising the research by distributing information leaflets with, for instance, disability service providers, or through notification in the newsletters of support and advocacy groups.<sup>3</sup> This was the typical approach for recruiting people with disability, and their families and carers, whilst in the case of recruiting employees of the NDIA, senior management assisted by informing staff about the study and way in which employees could register their interest in participating. Both people with disability, and their families and carers, and NDIA employees could express their interest by contacting the evaluation team using a toll free phone number or via email.

In addition to these indirect recruitment strategies, direct approaches were made to disability service providers and stakeholder organisations. Disability service providers were purposively selected from a list of organisations that indicated their interest to participate in these in-depth interviews via the NDIS Disability Support Providers Survey.

In all trial sites, recruitment took great care that the profile of respondents represented, as far as was possible to determine at the time, that of NDIS participants, service providers, and known or anticipated prominent service needs in the trial site. The samples were thus, purposely selected. It is important to note that the interviews with people with disability, and their families and carers were intended to capture then current NDIS participants. As a result, the characteristics of this sample of respondents may not reflect the future profile of NDIS participants. Profiles of all samples will be presented in the relevant subsequent chapters.

#### 2.1.2 Interviewing

Participation in interviews was voluntary. In accordance with established principles of research ethics, all respondents were informed about the aims and objectives of the study, the likely duration of interviews, and their rights to withdraw from the interview or not answer specific questions prior to the interview taking place. Respondents were also informed that participation would not affect services they may receive from the NDIA. In accordance with the respondents' preferences, interviews were conducted face-to-face or by telephone. Face-to-face interviews were conducted in a location of the respondents' choice and an environment ensuring that privacy and confidentiality were maintained. In the case of interviews with people with disability, and their families and carers, face-to-face interviews were mostly undertaken in the respondents' homes or public places of their choice. Interviews with disability service providers, stakeholder organisations and NDIA staff were all done by telephone, with one exception that was conducted face-to-face.

<sup>&</sup>lt;sup>3</sup> We would like to take the opportunity to thank the numerous organisations and individuals who assisted the researcher with recruitment, as well as, of course, the many respondents.

With the consent of respondents, interviews were audio-recorded, transcribed and de-identified prior to analysis. Analysis was conducted using NVivo and an analysis framework agreed and tested by the researchers. Interview topic guides were tested by the researchers and both the DSS and the NDIS Evaluation Steering Committee were given an opportunity to comment. All research components had previously been given ethics approval by the Social and Behavioural Sciences Research Ethics Committee (SBREC) at Flinders University.

In each instance, participants in these interviews will be invited to participate in a second interview about 12 months after the first. This will help to update information about the experiences of the NDIS amongst respondents and to develop the analysis of impact and change over time. Respondents at Wave 1 who decline to participate in a second interview or for some other reasons cannot be re-interviewed may be replaced with new respondents in the second wave sample.

## 2.1.3 Shared aims and objectives

The Qualitative Impact Evaluation is closely connected to the quantitative element of the evaluation, as both seek to inform and complement each other's focus of enquiry. Similar to the quantitative studies, the development of the Qualitative Impact Evaluation has been structured so to provide insights that will enable the evaluation to provide answers to the Key Evaluation Questions.

The topic guides used in the qualitative interviews were designed to assist the researchers in addressing Key Evaluation Questions that were relevant and most appropriate in the context of the conversations with people with disability, disability service providers, workforce stakeholders, and the NDIA. Naturally, not all Key Evaluation Questions were immediately relevant or indeed appropriate to explore with all respondents and respondent groups; nor could all be addressed in the first wave of interviews. Some would require longer periods of observation and, for this reason, will be suited for inclusion in the second wave of interviews. Others seek to measure or otherwise capture change over time and, hence, also require two waves of data.

In order to focus the qualitative research on the most appropriate Key Evaluation Questions, a set of rules were applied to guide the design and application of topic guides. These were:

- parsimony. Given that interview time was limited, it was necessary to direct questions to
  essential topics, that is, information that (i) could only be gathered by this particular mode and
  from this population and/or (ii) was required to be collected in the first interview in order to
  serve as a baseline for the second
- relevance. The focus of the interview and, thus, the Key Evaluation Questions that were covered
  had to reflect the level of experience and exposure that respondents had to the relevant theme.
  In other words, it was important to ask questions to those who could answer them because the
  issue in hand affected them personally; reliance on secondary observers, on the other hand, was
  to be kept to a minimum
- realism. Not all questions may have answers because the time for change to occur and become
  observable may be too short, or because no-one was able to comment and provide relevant
  insight on an issue
- reflection. Whilst some Key Evaluation Questions seek assessments of change or impact (e.g. KEQ29 "How effective has the NDIS been in helping people to look ahead?"), the purpose of qualitative research is not to 'measure' responses by asking for assessments or opinion, but to contextualise reported or observed behaviours. Doing so will only be feasible at the point of integration of findings in later stages of the research when the evaluation will draw on all sources of information.

The final section of this chapter will summarise the findings from the Qualitative Impact Evaluation with respect to those Key Evaluation Questions it was able to address in this initial round of interviews.

## 2.1.4 Analysis

With the consent of participants, interviews were recorded using a digital recorder and transcribed verbatim using a professional transcription service. All identifying information was removed from the resulting transcripts and throughout the reports participants are referred to using pseudonyms. The analysis of all interview data was conducted according to the framework approach (Ritchie and Spencer 1994) which is particularly suited to applied social research, including evaluations. The analysis proceeded through a number of steps.

First, the research team began familiarisation with the data through reading transcripts and listening to audio recordings. At the same time, the process of identifying a thematic framework began. After the initial familiarisation, the research team met to identify a number of a priori and emergent themes. Members of the research team then independently coded a small number of the transcripts against the identified themes to test the thematic framework. The level of agreement between coders was then assessed and, if appropriate, the framework was altered to address any disagreement or inconsistencies that were found. Coding of the whole data set proceeded according to the thematic framework. Patterns within the data were found and key themes and sub-themes established. NVivo was used to assist in the analysis, storage and retrieval of the interview data.

## 2.1.5 Structure of report

The following sections will present and summarise the findings of the qualitative research with people with disability, and their families and carers; disability service providers; workforce stakeholder organisations; and representatives of the NDIA. The final section will relate the evidence to a significant subset of relevant and, if preliminarily, answerable Key Evaluation Questions.

## 2.2 Interviews with people with disability, and their families and carers

## 2.2.1 Specific aims and objectives

The aim of conducting interviews with people with disability, and their families and carers was to provide a better understanding of:

- the expectation and experience thus far of participating in the NDIS or of being a family member/caring for someone who is participating in the NDIS
- the experience of living with disability or being a family member/caring for a person with disability, and how this may have changed (or not) through the NDIS.

As with all qualitative components of this evaluation, qualitative interviews with people with disability, and their families and carers provided a vehicle for deepening our understanding of findings from the corresponding quantitative survey-based work, both now and later on, after the second wave of interviews. Great care was therefore taken to balance information needs and information gathered from these two principal sources, with a view to informing the interpretation of findings over the course of the evaluation.

In order to record impressions and experiences of people with disability in the early phases of the trial of the NDIS, and to map the circumstances and conditions under which NDIS participants were living with disability, the qualitative interviews focused on a range of topics, each representing a subset of the Key Evaluation Questions. In broad categories, these topics covered:

- the impact of disability on the lives of people with disability as well as the lives of family members and carers, including on social and economic participation
- awareness and expectation of the NDIS
- experiences of entering the NDIS and of preparing the NDIS plan
- plan implementation process and receipt of NDIS-funded supports
- early accounts of the impact of the NDIS on people with disability, and their families and carers
- areas of improvement identified by respondents.

In all instances, the focus of the interviews was to get the respondents' perspective, and to isolate activities and effect associated with the NDIS from other influences.

## 2.2.2 Recruitment, sample and interview

Interviews were conducted with 62 NDIS participants, and family members and carers across the four initial trial sites and the ACT. The interviews targeted people who had already moved into the scheme and commenced, or indeed completed, the NDIS plan preparation and implementation.

Recruitment for the interview was conducted by way of advertisement through stakeholder organisations and disability support providers, using and encouraging the dissemination of information flyers, which had been distributed electronically or in the form of paper copies. People with disability interested in participating in the study were asked to contact the evaluation team and register for the study. Selective sampling was then used to ensure that the characteristics of the NDIS participants registering to be interviewed broadly reflected the characteristics of the NDIS participant population within each of the trial sites at the time. In addition, the researchers selected people who

had been living with disability for different lengths of time, including both people who had been living with disability since birth and people who had more recently acquired a disability.

In the end, almost two thirds (64 per cent) of NDIS participants who took part in the qualitative study were male; one third (36 per cent) were female (Table 2.2). Respondents were fairly evenly distributed across different age categories. However those aged 0-12 years (29 per cent) and 18-24 years (27 per cent) were overrepresented because the two trial sites in South Australia and Tasmania targeted younger age groups.

Table 2.2: Characteristics of respondents in the qualitative study of people with disability, and their families and carers

		Respondent
		S
	Characteristic	%
Gender	Female	36
	Male	64
Age	0 to 12 years	29
	13 to 17 years	10
	18 to 24 years	27
	25 to 34 years	8
	35 to 44 years	7
	45 to 54 years	7
	55+ years	13
Primary Disability Type	Congenital or inherited condition <sup>1</sup>	11
	Developmental condition <sup>2</sup>	31
	Mental health condition/psychosocial disability <sup>3</sup>	7
	Neurological condition <sup>4</sup>	24
	Intellectual disability <sup>5</sup>	21
	Physical condition <sup>6</sup>	5
	Speech condition	2
Joined NDIS	1 July to 31 Dec 2013	51
	1 Jan to 30 June 2014	23
	1 July 2014 onwards	27
Residence	Lives alone	8
	Lives with family	86
	Supported accommodation	7

Note: <sup>1</sup> incl. spina bifida, muscular dystrophy, cystic fibrosis; <sup>2</sup> incl. autism, Asperger syndrome, or other pervasive, mixed or specific developmental disorder not otherwise specified; <sup>3</sup> incl. anxiety, depression, post-traumatic stress disorder, schizophrenia, Tourette syndrome, psychosis; <sup>4</sup> incl. acquired brain injury, cerebral palsy, epilepsy, multiple sclerosis; <sup>5</sup> including learning disability, cognitive impairment, Down Syndrome; <sup>6</sup> incl. amputation, arthritis, crush injuries, musculoskeletal, spinal and other physical disorders.

Close to a third (31 per cent) of respondents reported to be living with a developmental condition (e.g. autism, Asperger syndrome). Around a quarter of NDIS participants (24 per cent) described their primary disability as a neurological or brain condition (e.g. acquired brain injury, cerebral palsy, epilepsy, multiple sclerosis), whilst a fifth (21 per cent) were living with an intellectual disability (e.g. learning disability, cognitive impairment, Down Syndrome). Others indicated congenital or inherited conditions, a mental health condition/psychosocial disability or a physical condition.

Half of all NDIS participants who participated in an interview joined the NDIS in the initial 6 months of the trial (from 1<sup>st</sup> July 2013 to 31<sup>st</sup> December 2013). The remaining participants were fairly evenly distributed between those that joined in the first and second half of 2014. The majority of those who entered the NDIS from the 1st of July 2014 were located in the ACT; reflecting the delayed rollout of the trial in this site.

The majority of respondents in this study were living with a family, be it a partner or parents. However, a small proportion was living independently or in supported accommodation.

People with disability, and their families or carers were given the choice to be interviewed individually or jointly. In the majority of cases, respondents chose to be interviewed jointly, although in one fifth of cases (21 per cent) only the person with disability was interviewed. This was typically the case for individuals living independently and without (permanent) access to a carer. Overall, 92 per cent of interviews also included a family member or carer, either separately or jointly with the person with disability. Almost three quarters of the latter were the mother of the person with disability, partially reflecting the high proportion of under 18 year olds in the sample; in the remaining instances, they were spouses or children of the NDIS participant.

A small group of people with disability (19 per cent) were unable to participate in the interview themselves, because the person had a severe and profound intellectual disability. In these instances an extended interview of the family member or carer was conducted asking questions pertaining to both the person with disability and the family member or carer. NDIS participants aged 12 years or below were not interviewed. In these instances we also conducted an extended interview with the family member or carer.

As noted in the previous introductory chapter, the interviews were conducted between August 2014 and February 2015, preceded by a pilot conducted in August 2014. Each interview typically lasted between 1 and 1.5 hours, although extended interviews typically lasted longer. Most interviews were undertaken face-to-face and at the respondent's home.

# 2.2.3 Findings

## 2.2.3.1 The impact of disability on the lives of people with disability, and their families and carers

In our interviews, respondents described a number of ways in which disability impacted on their lives, in particular their general health and wellbeing, but also social activities inside and outside the home, and their employment. These accounts stretched across the range of respondents' disabilities, whether acquired at birth or later in life.

**Health** and the sometimes unpredictable nature of a disability were repeated themes in our discussions. People with disability often reported multiple health issues that were associated with their disability, in particular when the disability was linked to a degenerative condition. Thus, for example, cerebral palsy was described to have secondary effects, such as arthritis or chronic fatigue; whilst psychosocial disability was also reported to have physical side effects. These additional effects of disability were not always present, but fluctuated, in particular for people with mental health

<sup>&</sup>lt;sup>4</sup> This age range differs from the survey of people with disability conducted as part of the NDIS Evaluation. This is because the qualitative interviews were designed to explore, in depth, NDIS participants' experiences of NDIS processes and procedures (i.e. joining the NDIS, developing plans, implementing plans, satisfactions with supports etc.). Advice from state experts, capacity builders and stakeholders indicated that the age at which a person would have only very limited understanding of these processes would be 12 years or below as it would be the parent who would be interacting with the NDIA the most. The exclusion of 12 year olds and below did not rule out a child having input into the interview where they were able to do so. However, we sought to not unduly burden NDIS participants of this age with questions which they might have had limited ability to answer.

issues. These fluctuations had the potential to severely limit a person's capacity to pursue their everyday activities whilst supports needs could suddenly change.

In general, people with a lifelong or acquired severe disability reported a high level of support needs, often involving assistance for most day to day activities, such as cooking, cleaning and personal care. People with less severe, yet nonetheless permanent conditions felt their support needs were relatively lower with the boundaries clear and predictable, involving perhaps just twice weekly visits from an attendant care worker or weekly therapy sessions.

For young and very young NDIS participants family members reported support needs as being of a very high level as their children required help and support to participate in almost any activities of daily living:

'What's common sense for us, easy for us, is a challenge for him, like opening a padlock gate, whether it's doing the buttons and lining them all up, whether it's putting your jumper on inside out, back to front, whether it's hanging something up on a coat hanger and half and half is on each side. Now that might sound like a really simple thing to do, but it's not a simple thing to do for Jacob.' (PWD&C42)

Providing support with daily care needs impacted markedly on the family member or carer. Caregiving family members and carers reported adverse effects on their personal physical and psychological wellbeing, experiencing, amongst other things, stress, tiredness and physical exhaustion; and also impacts for family and marital relationships more broadly. These experiences were yet more marked where the caregivers were themselves living with disability. For some parents, concern about an uncertain future of their child coupled physical with emotional exhaustion.

**Social, educational and economic participation** were all affected by a person's disability. Choices and the feasibility of activities were reported to be limited, and more so than for people without disability. This was most apparent with respect to employment, as both people with disability and their families or (informal) carers reported facing limited opportunities for labour market participation, albeit for different reasons.

A small number of NDIS participants in this qualitative study had paid employment, either a full-time or part-time job, or casual work. Others were receiving assistance from providers in their job search or, failing that, had family members or carers assume the responsibility of finding employment for them. Even those not already taking active steps to gaining employment typically expressed a desire for employment or opportunities to undertake voluntary work, as did some family members and carers. Employment was seen as a means to feeling "useful" and having something "meaningful" to do, and offering positive effects for self-esteem, but also physical health (through activity and mobility).

The scope for participating in the labour market, however, was often curtailed by the nature of a person's disability or care commitments, and associated difficulties encountered in finding a job. People with disability, and their families and carers reported a number of obstacles to paid or unpaid work including but not limited to personal physical and psychological barriers to accessing public places; lack of appropriate volunteer/employment opportunities, including disability-confident workplaces ready to accommodate people with disability; lack of appropriate and reliable transport; lack of employment service providers assisting in job search; and fluctuating symptoms of disability that made NDIS participants reluctant to commit to ongoing arrangements.

The families and carers of people with disability, on the other hand, lacked the time for active labour market participation as long as they remained the sole or even just the primary caregiver. In fact, several family members and carers had given up their careers as a result of care responsibilities, which, in turn, had adverse effects for their well-being and self-worth. Caregivers were also aware that time out of work might reduce their chances of a return to work in the future:

'Yeah, it does make it very difficult. So of course in the process I've allowed my registration (as a personal trainer) to lapse... so I'd have to reregister, I'd have to restudy, I'd have to do my first aid certificates and things like that, to even consider going back to work even part-time.' (PWD&C38)

The few family members and carers in paid employment had been forced to choose flexible work arrangements in to order combine work with their care responsibilities. Such arrangements included working part-time, out of hours or on weekends, and working from home.

'I only work two days. I was working three days and then Travis and I were just getting sick; he was getting sick and then I was getting run down and I was sick, and in the end I spoke to work and they were going to talk to me apparently anyway, and they just said "maybe work less days because you're just not able to do it". I said "yep, that'd be great", so I went to two days, and that's enough.' (PWD&C19)

Not everyone, however, was able to switch so easily to a shorter working week as the costs associated with disability forced some family members to work long hours; but this was typically only an option in households with two (or more) family members sharing the tasks of caring for a child or parent:

'My husband works seven days a week to keep us afloat.' (PWD&C36)

Unsurprisingly, given the various access barriers encountered by people with disability and the high costs involved, especially when earnings were often low, engaging in **social activities** was more often an aspiration than a regular reality. As with employment, the absence of <u>safe</u> and <u>accessible</u> transport made social participation a challenge at times. Being cognitively, emotionally and financially in a position to use taxis or other means of private transport independently greatly facilitated social participation. Limited interaction or communication skills, personal anxiety and a reluctance to mix and connect with other people, and the risk of being excluded or rejected by others, posed real and, for some, ever-present limits to social participation. Feeling personally safe was a high priority for people with disability, and for their families and carers.

'Just even getting him to go out because he doesn't interact with anyone, doesn't have any friends. To him, I'm his best friend so that's the complete interaction he has with a lot of people....He mainly has that support person when they're with him as the person he talks to.' (PWD&C15)

NDIS participants in this study, especially when living with intellectual or psychosocial disability, often found navigating public services, including community transport facilities, restricted their ability to be mobile and access public and private spaces:

'It's certainly hard to say, like once he's been shown where to get on and where to get off; he can probably do that but to just kind of get on a bus and, you know, pick the right bus and things like that, no. That's something he probably wouldn't be able to master.' (PWD&C50)

People with disability often needed additional supports when outside the home, regardless of the means of transport chosen. The trouble with public transport that study participants noted was its unreliability, particularly in areas outside of major metropolitan centres. Route changes, (connecting) service cancellations and long-distance journeys could cause anxiety in both the person with disability, and their family member and carer. One participant with spina bifida described the barriers to her social participation as follows:

'So it has affected me in the fact that with my lack of independence I can't go out obviously. I can't just run down the street or catch a taxi and catch up with friends. Then with my blue spells [periods of being unable to breathe linked to spina bifida]) I'm not allowed to go out by myself without someone with me. So it can be kind of awkward just because I have to go out when it's convenient with someone else too not just when it's convenient for me.' (PWD&C16)

Carers also found their social activities heavily curtailed by their caring responsibilities, regardless of the age or disability type of the person they cared for. Families and carers typically reported limited time and energy and spoke of the need to be flexible, to be able to "drop everything at a moment's notice" if and when their support was needed. Some also pointed out the effect of the NDIS on their time management:

'...between dealing with the NDIS and coordinating Rory's [care]...there's probably two to three days gone a week.' (PWD&C57)

Carers rarely remarked on their own personal barriers to **education**, but were concerned about the impact that disability had on the educational participation of the person with disability. This concern was most articulate in South Australia and Tasmania where the trial of the NDIS focused on children and young people. Parents and carers were most concerned about determining the 'right' type of education for the child, be it in mainstream or special schools. The risk of being bullied or otherwise 'picked on' was foremost on the mind of many parents.

The stigma that disability continues to bear in society was repeatedly referred to in our conversations as people with disability, and their families and carers sought to manage their daily lives. Whilst frustrated by the everyday manifestations of this stigma, families and carers expressed a personal determination to face this challenge as they sought to live their lives, as this parent explained:

'Like, it was my birthday the other day, we went down to a café and people were all staring at him, and everything, and it made my husband feel uncomfortable. Like, I didn't mind, but afterwards I said to him, "You know, you have to stop worrying about what other people think. Jordan is who he is, so you just need to get over it. Like, you just make everyone miserable when you are worried about what he's doing." You see, that's the whole problem, this is what our whole lives are like.' (PWD&C25)

In summary, people with disability, and their families and carers faced a number of personal and societal challenges that affected their social and economic lives, their health, emotional and material wellbeing. These challenges were not borne by one person, but shared, and as a result, affected family or spousal relationships. Thus, individual impacts of disability were not independent from one another but interrelated, sometimes compounding individual effects.

## 2.2.3.2 Awareness and expectation of the NDIS

Against the background of these everyday challenges that many of the participants in our interviews had been experiencing, often for many years, respondents were optimistic that the NDIS would improve their lives. Much weight was placed on expectations that the NDIS would help to improve

access to services and supports that people with disability, but also families and carers needed. Some family members and carers were also explicit in their hope that the NDIS would help them return to paid work.

Initially however, there was considerable uncertainty as to what the NDIS was going to yield and who would be eligible to join the scheme.

'I was never certain whether I'd be eligible, because they are still very vague about severity... I would accept that somebody who had this permanently in a wheelchair with quadriplegia or whatever is clearly severely (disabled). But with other things, it's a matter of degree and I kept waiting to hear some sort of definition of cut-off points. Well even after I had applied, I still couldn't get a straight answer to that.' (PWD&CO2)

This view was particularly prevalent among people with a psychosocial disability or mental health problem who were confused by the lack of a clear direction on eligibility in the early months of the trials. Where people with disability were very young children, such as was predominately the case in South Australia, concerns about eligibility were compounded by the emotional consequences of the process of establishing a diagnosis and finding out their child has a potentially life-long disability.

There also was a strongly felt belief amongst participants in our study that, as they were transitioning into the NDIS, people with disability would be able to retain their existing services, with the NDIS merely taking over their funding. Although some expressed concern that the trial of the NDIS could herald a change in supports, which would have unsettling consequences for the user, by and large the hope and expectation was that the range of supports available to people with disability would increase, as would their funding levels. From before the time of the trial of the NDIS, "choice and control" had been heavily marketed. For participants in this study, "choice and control" was interpreted to mean more funding and greater access to higher quality supports.

The precise content of supports that people with disability anticipated to be receiving under the NDIS varied with disability and age. Most notable, whereas participants with mental illness expressed a desire for more support in initiating and facilitating social leisure and group activities, participants with physical disabilities were more inclined to expect more and better self-care supports and a greater number of hours of support provided in and outside their homes. This was in particular to reduce reliance on family members.

Carers of participants with intellectual disabilities expected services to assist participants to link better with broader community in such arenas as school, accommodation, and non-disability specific social activities. Carers' expectations typically concerned the needs of the persons for whom they cared, rather than their own needs, although a few carers had hoped that the extra support that the NDIS would provide to the person with disability would also allow them to undertake other activities, including paid work. These expectations of improved supports were balanced by an awareness of the likely cost implications, raising questions among some about the sustainability of a fully-grown NDIS.

'Well if everyone's claiming, you know, the government's going to come back to you and say look, we just can't afford to -- because it is highly expensive to have all these plans and stuff for our children.' (PWD&C44)

# 2.2.3.3 Experiences of entering the NDIS and of preparing the NDIS plan

The accounts of people's experiences of entering the NDIS varied greatly, ranging from most positive and administratively simple to highly problematic and personally disconcerting.

Respondents who had an easy transition into the NDIS were generally those who had a service provider who assisted them with enrolling in the scheme (often also retaining their services), had other family members already in the scheme, or were seeking services for the very first time. Yet even then, the experience of transitioning into the NDIS was not always easy:

'I have to tell you it was a really confronting experience because it was in the early stages of the disease, and I was still finding it difficult to actually think ahead of things that I might require.... We just felt as though the system was there to help us, not to try and prevent us from being involved in the system.' (PWD&C24)

The most common concerns about the transitioning processes that participants in this study noted were:

- a lack of responsiveness by the NDIA, with many having to follow-up first contact from the NDIA with a phone call or email due to problems with receiving paperwork, having paperwork mislaid, and needing to complete multiple applications
- frustrations with the amount of paperwork required, with additional concerns being raised about the accessibility of the scheme given the complexity and amount of requisite paperwork
- additional assessment being needed to establish eligibility for the NDIS, costing respondents time and money
- dissatisfaction with some NDIA staff members' disability-specific knowledge, which resulted in
  the need to have multiple meetings with different NDIA staff, in speculation over the person's
  eligibility, and the accessing individuals becoming concerned about the extent to which the NDIS
  would be able to meet their support needs.

Once accepted into the NDIS, respondents worked with an NDIA planner on **developing their NDIS plan**. The success of the planning process was found to depend on three factors; namely (a) the extent to which people with disability and their family members or carers felt they themselves were prepared for the planning process, (b) the planner's experience and understanding of the disability, and (c) the presence of an advocate in the planning process.

Overall, most NDIS participants and their families were content with the plan outcome and were satisfied that the plan adequately addressed the support needs of the person with disability. Some family members and carers of NDIS participants also felt that their own needs and the needs of the family more broadly had been taken into consideration during the planning process.

Remaining dissatisfaction with plans was triggered by perceptions that plans did not reflect the participants' recollection of conversations and agreements reached with the NDIA planner during the planning meeting or meetings.

Some participants who had previously received disability supports found that those subsequently agreed with the NDIA differed substantially, in particular where the support was for children. This caused confusion and upset where supports were perceived to have been scaled back, leaving gaps in provision and funding. Several family members and carers reported that their child had been denied funding for services because their effectiveness was judged to be lacking firm evidence. Yet these services had previously been supported under federally funded programmes.

Others reported difficulties in understanding the language and terminology used by the plan. Finally, social networks, hearsay and the use of social media had enabled NDIS participants in our study to make comparisons between their own agreed support plans and those of others that they had heard of or indeed seen. In particular in the early phases of the trial (in 2013 and into mid- to late 2014), these comparisons brought to light (what was seen as) inconsistencies in plans between NDIS

participants with the similar or indeed identical diagnoses or conditions; as well as variations within and between trial sites (and planners in those sites) in the types of supports that were being funded in participants plan.

The planning process also appeared not to discuss in sufficient detail, if at all, the opportunity for people with disability or family members and carers, to manage their own funding. The option of **self-managed funding** was not always well understood. Most respondents in this study had chosen not to self-manage, as they perceived it as complex, time consuming and incurring a large administrative burden. This said, the few that had decided to self-manage funding were typically positive about its benefits, principally in relation to greater choice and flexibility in accessing non-NDIS service providers.

## 2.2.3.4 Plan implementation process and receipt of NDIS-funded supports

Many respondents in this study continued to access the same supports and support providers under the NDIS as they had previously done, seeing no need to change them. In some instances, this included supports not funded under the NDIS, such as home help provided by the local council or specialist supports the participants had been funding privately.

NDIS participants were generally satisfied with the implementation of their NDIS plan. There was evidence that participation in the NDIS had increased choice and control of supports. In particular, self-management of funding was thought to have provided markedly greater access to service providers, which also included those not registered with the NDIA. Some NDIS participants who were not self-managing their funding, however, felt aggrieved by having to very specifically detail their supports for approval under the NDIS. It was argued that this prevented NDIS participants from adapting their support uses spontaneously to changing circumstances which, in turn, limited the extent to which NDIS participants could fully enjoy their new freedoms of choice and control.

In regional and some outer metropolitan areas, respondents often felt their choice and control over supports were impeded by the small number or low capacity of service providers in their area. This particularly affected the provision of therapy, respite and employment services. Limitation of choice was also attributed to inflexibility of support hours by service providers, rigid structures in the NDIS claiming system and fixed prices for certain types of support. Many respondents felt that the NDIA had been slow to respond to their queries before and after joining the scheme.

Whereas some respondents reported that the NDIS had helped them to increase their hours of supports, increase the frequency of service provision, access better equipment and a wider range of therapeutic or social activities (typically socialising with other people with disability), others were surprised to see items and activities they had hoped to access not funded under their NDIS plan. Plans were thus described as not always meeting expectations; in part, these differences were the result of continued uncertainty as to whether supports should be sourced from the NDIS or from mainstream services, notably in health and education.

# 2.2.3.5 Early accounts of the impact of the NDIS on people with disability, and their families and carers

Many NDIS participants and their family members and carers felt that the well-being and quality of life of the NDIS participant had been enhanced through the support they were receiving as part of their NDIS plan, in particular as a result of increased choice of funded provisions, choice in hours of support, and a choice of activities – and how positive that felt for participants. Participation in social and every day activities had generally increased and participants were learning new skills and enhancing their existing capabilities. Whilst NDIS participants did not report many incidents of

greater economic participation at this stage, they spoke about how the NDIS had increased the independence they had over life, including living arrangements and transport. This said, we encountered notable geographical variations in that NDIS participants living in regional areas felt the effect of the NDIS had to date been far less apparent and, at times, negligible, often because service infrastructure, already comparatively underdeveloped, had remained unchanged.

Many family members and carers felt that being in the NDIS had helped to reduce the financial strain that living with disability and caring for a person with disability entailed. Increased access to supports including respite, support to assist with personal care and independent living and life skills, and supports around the house eased the burden for some family members and carers, and allowed them to be involved in other valued activities such as employment, social activities and quality time with other family members.

The administrative burden associated with working with the NDIS nonetheless remained an issue, to the extent that some parents felt the added paperwork was both stressful and consumed time usually spent as a family.

# 2.2.3.6 Areas for improvement

This research with NDIS participants, and their families and carers highlighted some difficulties that participants encountered when working with the NDIS, which in turn resulted in some suggestions for improvements that respondents felt may inform the development of the NDIS into the future. The most prominent suggestions are summarised next.

## Communication between the NDIA, providers and participants

Respondents called for improved administrative processes within the NDIA, which would allow more timely responses to queries and enquiries, and promote greater clarity and understanding of participation and planning processes. Participants would welcome a system, perhaps automated, for confirming the receipt of documents, appointments and processing update.

## Increased support and preparation for the planning stage

Respondents would like more support and preparation during the NDIS plan development stage, including help with identifying and unpacking goals and aspirations, and planning for the future. For many these were novel tasks and concepts, and required opportunities for learning.

To assist with making choices, respondents also called for more and better information about disability support providers and their services, including examples of activities and services that had been shown to help others with similar needs or goals.

# Improved access to advocacy

It was also suggested that access to advocacy be improved as this would help people with disability develop and implement their plan, and to support them in meetings with the NDIA.

## **Planning processes**

Respondents felt the planning processes needed to be made more open and transparent, and greater consistency be achieved across funding packages for NDIS participants with similar disability and support needs. Participants would have also liked planners to more readily accept existing statements of need, including therapists' assessments of a person's support needs. Specific recommendations included (i) training to help NDIA planners better understand different disability

types or diagnoses, and (ii) matching NDIS participants to NDIA planners with appropriate specialist expertise in disability.

## Plan implementation flexibility

Plan implementation was often still perceived to be rigid because the plan required a close detailing of supports approved under the NDIS. Participants would have welcomed more discretion and flexibility in the implementation of NDIA plan. This would allow changes at short as well as long notice (via the review process) and allow supports to be assembled, packaged, combined and divided at different points in time and as required.

## Improvements to processes for participants going through a transition

Where respondents were transitioning to school; from school aged services to adult services; or from living at home to moving into supported accommodation, there appeared to be complexities in moving from different support services coupled with transitioning to NDIS. Further support in navigating these transitions was suggested, to ensure that services and support were not lost or delayed.

Related to transition planning, the evidence also suggested a need for enhanced support for participants during major life transitions. For example, among those who were not in any paid employment at the time of the interview was an expressed desire to be able to find an activity, ideally paid work. Gaining work experience and work placements were paramount. Respondents wanted to be in a work place environment, learning new skills, interacting with others and perhaps earning some of their own money. However, according to some there was limited support in this area with providers struggling to find inclusive employment opportunities, and not actively supporting NDIS participants in taking the next steps once a work activity/experience had ended. In addition, several parents/carers of young NDIS participants wanted more help (and potentially funding) to assist their children to access community services, and for the NDIA to advocate and support inclusive community-based programmes for children with disabilities.

The evidence from these interviews also suggests that, over time, NDIS participants experienced improvements in NDIS plan development and implementation, greater clarity of eligibility and greater availability of pre-planning supports. This was the case for both early entrants to the NDIS, who felt processes were improving during their participation, and for later entrants who tended to report more positive experiences from the start.

# 2.3 Interviews with disability service providers

# 2.3.1 Specific aims and objectives

The aim of conducting interviews with disability service providers was to provide a better understanding of:

- how the NDIS has impacted specialist disability service providers
- how the NDIS has impacted the specialist disability workforce
- disability service providers' responses to NDIS (innovative practices, changes in skills or training requirements, leadership issues)
- how specialist disability supports assist NDIS participants.

In order to record the experiences of disability service providers in the early phases of the trial of the NDIS, the qualitative interviews focused on a range of topics, each representing a sub-set of the Key Evaluation Questions. In broad categories, these topics covered:

- expectations about the NDIS
- initial impact of the NDIS on the disability sector
- initial impact of the NDIS on the organisation
- initial impact of the NDIS on the disability workforce
- initial impact of the NDIS on people with disability, and their families and carers
- experiences working with the NDIA
- suggestions for changes and improvements.

These broad topics incorporated the impact of the NDIS on the disability service provider market, the supply of disability supports and services, service delivery, and financial viability and sustainability. The focus was to seek from respondents both organisational and disability sector perspectives, and to isolate activities and effect associated with the NDIS from other influences.

## 2.3.2 Recruitment, sample and interview

Interviews were conducted with five disability support providers/employers in each of the five initial trial sites. The total of 25 in-depth interviews included employers of PAYG workers, brokered workers and self-employed sole providers. All those interviewed were registered NDIA providers.

Respondents were selected from among organisations that had previously been approached for the quantitative provider survey (Survey of Disability Support Providers and their Workforce) and, at the time, indicated their interest in participating in an in-depth interview. Selective sampling was used to ensure that the types of disability service providers that were interviewed as part of the NDIS Evaluation broadly reflected the characteristics of the types of disability services provided in each trial site (as informed by Australian Institute of Health and Welfare data). Variation was also sought on the size of the organisation.

Of the 25 disability service providers interviewed, five were self-employed sole providers of disability services, one from each of the trial sites. Eleven disability service providers were small businesses with fewer than 50 employees; five were medium sized businesses employing between 50 and 200 employees; and eight were large businesses employing more than 200 employees (Table 2.3). The majority of disability service providers (84 per cent) were state based, while the remaining 16 percent were national organisations providing disability services Australia wide.

Table 2.3: Characteristics of respondents in the qualitative study of disability service providers

	Characteristic	Number
Туре	Organisation	20
	Self-employed	5
Staffing Numbers	< 50	11
	50 to 200	5
	201+	8
	Unknown	1
National/State based	National	4
	State	21
Percentage of disability service in total services (approx.)	< 20%	2
	21 to 50%	3
	51 to 75%	6
	>75 %	13
	Unknown	1
Service Type	Early intervention	7
	Personal support	9
	Respite	7
	Therapeutic services	15
	Accommodation support	11
	Employment support	6
	Community access	10
	Aids and equipment	6
	Development of daily living and life skills	10
	Managing life transitions	4

The large majority of disability service providers (76 percent) reported that disability services made up 50 percent or more of their total service provision. The most common types of disability services provided were therapeutic services, accommodation support, development of daily living and life skills, community access and personal support. Comparatively few provided support to assist with managing life transitions, employment support, or aids and equipment.

Of those disability service providers that participated in the in-depth interviews, two large organisations specialised in the provision of mental health services, whilst others provided mental health services as a component of overall service provision.

As noted in the introductory chapter, the interviews were conducted between September and November 2014. The interviews lasted between 1 and 1.5 hours and were conducted by telephone, using a common set of questions. Participants were free to decide the day and time that best suited them for the interview. While most interviews were conducted with one respondent, two providers elected for two staff members to be interviewed together.

## 2.3.3 Findings

## 2.3.3.1 Expectations about the NDIS

Expectations of the NDIS varied amongst disability service providers, but overall providers expressed agreement with the fundamental principles and philosophy underpinning the NDIS and the expected benefits the NDIS would have for people with disability:

'We all knew that the scheme was going to mean a lot to clients with disability in terms of being able to have more choice and control, more access to services, quicker access to services and ... a broader range of people would benefit from that.' (D01S)

Providers expected the NDIS to improve access to services, reduce waiting lists, increase the range and volume of services, offer access to services catering to individual needs, offer more choice and reduce costs borne by people with disability.

Disability service providers, particularly larger providers, also had clear expectations about how the NDIS would impact on their organisation and the disability sector more broadly:

'It was going to impact on everything that we do. So, you know, in terms of IT, in terms of finances, in terms of the workforce, in terms of governance.' (A01S)

Disability service providers expected the NDIS to impact on their organisation and the disability sector more broadly with a shift to more individualised service provision. Providers believed the NDIS would provide opportunities for disability providers to review and improve service delivery, to have greater freedom around service delivery including increased flexibility around the types of services they provided, the frequency with which services were offered as well as inspiring them to be innovative in the way they provided services. They also expected the NDIS to make provider organisations working in the disability sector more accountable, which would ensure the best quality and value for money services.

# 2.3.3.2 Initial impact of the NDIS on the disability sector

Disability service providers reported a number of impacts from the NDIS trial on the disability sector. These included reports of some limited change in the provider market to date, changing relationships between existing providers, substantial concerns about the financial viability and sustainability of the sector under the new funding system and potential service gaps for people with disability.

While an anticipated influx of new providers to the sector had not eventuated, disability service providers did indicate that providers new to the local market were registering with the NDIA, although few were actively providing services in the trial sites. Respondents attributed this to new providers playing a 'wait and see' game.

'My suspicion is they'll sit back and let us go through the transition period and the changes ...lron out the problems and then once the dust settles, they may very well offer services.' (CO4S)

Existing providers, particularly large ones, speculated that after the trial phase for-profit organisations would enter the disability sector, target the profitable supports or "pick the easy clients" (C01S). This would leave existing disability service providers to manage the more difficult and challenging clients.

Disability service providers also suggested that the NDIA pricing for services was acting as a barrier to new providers:

'Well, I suppose we were told there would be national players and international players...But there's probably not as many providers as I thought there would be and I think that's constrained by the pricing.' (B02S)

There were also concerns about the impact on service quality if (more) for-profit organisations were to enter the sector:

'NDIA may think that the health providers will come in but they actually have to make a profit too and so, you know, that may, well it may or may not work but if it did it would be very low cost, low quality, services and that's a concern.' (B01S)

While there was little evidence of new disability service provider organisations entering local provider markets, disability service providers reported an increase in allied health professionals establishing their own private practices. This was attributed to both the expectation that the NDIS would create increased demand for services and the reduction in public sector service provision that resulted from the restructuring of disability services in some trial sites due to the implementation of the NDIS.

Disability service providers suggested that the move to a competitive market had resulted in changes to the relationship between existing providers, with organisations now being guarded in their interaction with other, competing providers operating in the disability sector. This said, as the trial progressed, there was also evidence of some disability service providers increasing collaborations in efforts to "share learnings" and experiences about operating under the NDIS.

Notably, there were no reports of disability service providers exiting the market in the trial sites. However, concerns were raised about the financial viability of the sector although it was too early for most providers to ascertain the full financial impact of the NDIS on their own organisation. For a number of providers this was because the funding sources that they relied on prior to the NDIS trial continued to be in place. Most disability service providers however, were concerned about the impact in the future:

"...we don't sort of see how we survive into the future because the money that comes in through us supporting people with NDIS funding does not cover all of our operational costs and replacement costs." (D02S)

Provider concerns about financial viability and sustainability were directed at the payment-in-arrears system and in particular, reports of substantial amounts of unfunded work that was being undertaken as a result of the NDIS. This unfunded work included work carried out to assist clients with plan development and implementation, support coordination, case management, and providing information for potential new clients. While some of this work simply could not be claimed under the NDIS, other work, such as case management, was acknowledged to be potentially fundable but not always included in plans.

Disability service providers viewed much of this unfunded work as important and necessary and, while block funding was still in place, attempted to absorb the extra costs. However, they anticipated that their capacity to do so in the future would diminish or cease entirely, creating potential service gaps for people with disability:

'All organisations are doing an awful lot off the side of the desk unfunded. If organisations stopped doing that there would be real problems in the system. But I think the nature of organisations and providers is that we want to make it work and at the moment while you've got block funding at least you can do stuff knowing that you've got some funds to operate with but if you had to bill in arrears to assist the organisation, I don't think there'd be anyone assisting them.' (C01S)

Providers also expressed particular concerns about the sustainability of small disability providers under the NDIS. Small providers with fewer financial resources, smaller staff numbers and less capacity to absorb extra work were thought to face more difficulty managing the work required to transition to the NDIS:

'I really feel for some of the smaller organisations. In some of the working groups that I've been in it just highlights when you listen to some of the very small disability services how they just don't have the finance resource[s] to be able to even look at what the unit cost might be. And the understanding of the staff in those teams. We've been very lucky that we've got a fairly robust finance team that can help us with that so if you don't have that understanding yourself you're going to have to buy it in.' (A03S)

After transition to the NDIS small providers were still considered vulnerable as they were less able to cross subsidise and more likely to experience cash flow problems. Some questioned whether small providers could remain sustainable, if they had a place in the future under the NDIS and if not, what that meant for the services being offered and choice available for people with disability.

Disability service providers also expressed concern about the interface between disability and mainstream services. In their view, "blurred lines" about who was responsible for funding particular services was creating the potential for service gaps for people with disability:

'Are people going to fall between the cracks of the different service systems...who's responsible and the argy-bargy of, "No. We're not responsible. You're responsible." Some of those things are being played out. So I think there's danger that vulnerable people may not get a service at all.' (B02S)

Changes in state government funding in response to the rollout of the NDIS exacerbated concerns about service provision and potential service gaps across the sector, particularly amongst mental health service providers.

## 2.3.3.3 Initial impact of the NDIS on the organisation

Disability service providers explained how the NDIS had affected their organisation. This included accounts of the amount of work undertaken to prepare for the NDIS, the organisation's ability to plan for the future, changes to organisational structures, systems, supports and services.

## **Preparation for the NDIS**

The amount of time and effort invested in preparing for the NDIS varied between service providers. For a number of large providers, planning and restructuring began three or more years before the NDIS trial commenced; there was less evidence of preparation for the NDIS amongst the smaller disability service providers.

Disability service providers reported that the work undertaken to prepare for the transition to the NDIS had generated substantial costs both in real financial terms and in staff time. For some large

providers that were part of Australia-wide organisations, there was an acknowledgment that their involvement in the NDIS trial would benefit the whole of the organisation once the scheme rolled out nationally. However, several providers weighed this up against the amount of work required of providers in the trial sites to prepare for the new scheme.

## Strategic plans

Disability service providers had undertaken, or were in the process of undertaking, strategic reviews to better understand their operational costs, and how their financial planning and budgeting might be impacted by the NDIS trial.

Several disability service providers reported that they were considering strategic alliances and partnerships, and the possibility of mergers and acquisitions in the future to alleviate the administrative burden of working within the NDIS as well as to expand the breadth of service provision. A number of providers also remarked that they either had or would need to redesign their services and their models of service provision to reflect the new system.

A small number of disability service providers reported that strategic planning within the organisation had been deferred or delayed as a result of the NDIS trial. This was either because implementing the changes required to operate under the NDIS was consuming all of the organisation's resources or because they lacked the information that they needed to implement any future planning. Uncertainty prevailed in the disability services environment as the NDIS was being trialled, yet information about its likely future shape and operations was still largely lacking, which meant that some providers only planned for the short term.

## **Structures and systems**

The NDIS trial and the change to a fee-for-service model of service delivery meant that disability service providers had undertaken or would need to undertake changes to organisational structures and systems. This included changes to administrative systems, IT systems, and marketing systems. In some organisations these changes had been initiated some time ago and were now well advanced in their implementation. Other organisations were more cautious, reluctant to execute changes because of the lack of information about the scheme and its future shape. Among those who had already begun implementing changes to structures and systems, some expressed confidence in their future direction. Others felt that having operated with minimal information about the emerging NDIS they could only hope to remain flexible and that their changes would fit the eventual model:

'I guess that's one of the big sort of overall sense about the NDIA; we just had to move in this kind of evolutionary time and we don't have any control over that; we just have to hope that we're flexible enough to be able to respond as things, you know, kind of unfold and reveal themselves.' (E04S)

Disability service providers had undertaken changes to administrative systems including revisions of finance, pay, rostering and data systems in order to satisfy the service data required to be collected by the NDIS and to accommodate a fee-for-service model of service delivery. Some disability service providers noted that purchasing and implementing new administration systems and software packages was costly for the organisation:

"...we're in the process of implementing a very expensive—in excess of a million dollars—integrated data system, both a client management system, a customer relationship system, finance and human resource system, in order to cater to the transactional model that the NDIS is based on and the data that the NDIS requires as well as data that we're wanting and needing in terms of understanding our business performance." (A01S)

A considerable number of providers across the trial sites also noted that the NDIS had created an "administrative burden" (D04S) for providers including extra paperwork and processing and time

spent managing problems with the NDIS portal. This extra administrative work was borne by a range of staff in provider organisations including managers, therapists and disability support staff as well as administrative staff. Providers observed that the workload for staff had increased as a result of the NDIS, in particular in administration and finances.

## **Supports and services**

Disability service providers reported on the impact of the NDIS on disability supports and services including referral pathways, demand for services, individualised services replacing some group-based services, the financial viability of service provision, quality of services and relationships with clients. It should be noted that these impacts remained somewhat uncertain at the time of the first round of interviews as providers were still only servicing a small number of NDIS clients or were not yet delivering all of the services that they had registered with the NDIS.

Most disability service providers reported that referral pathways had remained largely unaffected by the NDIS trial. Those that had observed change reported more self-referrals (rather than referrals via other providers) or a greater reluctance on the part of mainstream and community organisations to share clients as a result of competition within the market.

One of the most obvious changes to service provision resulting from the NDIS trial and reported by disability service providers was a need to provide clients with information about, and support with, transitioning into the scheme. This included providing clients with information about the transition process, assisting NDIS participants and their families to identify their goals and aspirations in preparation for their planning meeting, and advocating for participants if plans did not meet the participants' needs or expectations.

Disability service providers reported that there had been an increase in demand for services around participants gaining more independence in the home and in the community as a result of the NDIS trial. These services included independent living assessments, skills-based programs and assistive technology.

Similarly, respite was a service considered by many disability service providers to be in demand from clients and desirable for disability service providers to deliver. One disability service provider speculated that the demand for respite services had not changed on aggregate but participants were using individual, in-home supports in lieu of facility-based respite.

Disability service providers reported that the NDIS resulted in a general move away from group-based services to individual services. The move was necessary so that providers offered services that were in demand and available at the times and locations that suited participants.

In response to the increased demand for flexible service delivery, some disability service providers had extended their operating hours and some also expanded the range of clients that they were able to service. The change to individualised service provision also resulted in disability service providers having more conversations with their clients around what services they wanted.

Disability service providers did not see the move to individualised services as unproblematic. Group-based services were viewed as providing social opportunities both for the participants and their families:

'I think the biggest loss that families talk about, and it came out in the marketing research as well, that we just did is that the families missing... well social interaction with one another, which is what they were able to get when they came

and used... participated in the groups as well. So families would build up very, very good strong relationships with one another, which were typically lifelong.' (D04S)

Group-based services also facilitated transdisciplinary collaboration between service providers. In addition, delivering more services in people's homes created challenges for disability service providers around risk assessment and ensuring the safety of staff. Further, the flexibility required to deliver individualised services and supports also challenged industrial relations (IR):

'Individualised support is all about choice and control and giving people the option to have their support when they want it and with whom they want it but that has its own complications particularly from an IR perspective on how we contract with people and the flexibility of our employees around particularly when we're under Awards and MEA's and things like that that may not be as flexible as the requests we're getting.' (CO2S)

NDIS pricing for services and the viability of service provision based on the costs covered by the NDIA influenced provider decisions about what services they would offer. To a large extent, any changes in service provision occurred in response to demand and provider assessments of the financial viability of delivering particular services under the NDIS.

Employment services, supports for people with high needs and supported holidays and camps were examples of services that were identified as in demand but not cost-effective to run under the NDIS pricing at the time of interview. Other services that were viewed as being non-viable under that NDIS pricing included group therapy, out of school hours care programs, and night shifts for residential rehabilitation.

A number of disability service providers noted that they were in the process of assessing whether they would continue to offer particular services where the NDIA price did not cover the cost of service delivery. Some large providers were absorbing losses from services by cross subsiding but advised this was not sustainable long term.

In addition, NDIA pricing was reported to not cover travel. This was seen to impact directly on the types of services that could be provided and on participants' access to these services:

'At the moment we've got a vehicle that we go out and pick children up and bring them in... But under the NDIA that type of transport for the majority of children isn't an option, they won't fund it.' (A02S)

NDIS pricing was also reported to impact on an organisation's ability to maintain and repair facilities, which unlike under block funding, were not deemed to be eligible costs claimable under the NDIS and which could impact on future service provision:

"...so there's nothing to allow us to buy new equipment. So we have people here with challenging behaviours who put holes in walls, who jump on chairs and break them, there's no way of replacing any of that equipment or doing any repairs to buildings that the clients might come in and cause." (D02S)

Providers were concerned about the impact of NDIS pricing on their ability to deliver quality services. In considerations about future service provision, both within provider organisations and across the disability sector, providers stressed the importance of maintaining service quality:

'We need to be able to have a healthy discussion about what's working well, what are the problems, to actually get the very best outcome, and I suppose for us we want to be a quality service provider and that's the issue for us is do we have a future, is there a role for quality services.' (B02S)

In addition to seeking the best outcomes for people with disability, providers also recognised the importance of service quality to attract clients and ensure their place in the market:

'I think [organisation] is very embracing of the fact that we need to ensure our services are the best quality and most value for money so that parents do select us.' (A01S)

## **Relationships with clients**

Disability service providers observed changes to their relationship with clients. The main impact of the NDIS trial on the relationship between providers and their clients was the greater role that disability service providers took in advocating for clients and helping them to navigate the transition to the NDIS. Providers were also more open with clients about the types and costs of the services they offered and this openness had not had an adverse impact on relationships with existing clients. Providers reported that most clients had opted to remain with existing providers and they attributed the retention of clients who had transitioned to the NDIS to satisfaction with services and the organisation overall. However there was some concern that the focus on financial aspects of service provision may interfere with the ability of disability service providers to establish a caring relationship with potential new clients and their families:

'I don't think before we've had to say to them upfront 'how are you going to pay for this?'... It's like yeah...okay that's what you want, but how are you going to pay for it. Because already if I've spoken to you for an hour, how have I paid for that hour?...And yet you're in a situation where you're trying to create this I suppose caring relationship or some sense that you give a damn about the person beyond the buck that they can give you...' (E01S)

# 2.3.3.4 Initial impact of the NDIS on the workforce

In addition to impacts on their organisation and disability sector more generally, disability service providers also reported a number of impacts the NDIS had had on the workforce. These included the skills and training required by their workforce, recruitment and retention of staff, staff workloads and on industrial relations.

Disability service providers described maintaining staff skills as integral to delivering quality services:

'Training's really important in the quality of your service, so the quality of your staff, the quality of your service, and if you're going to work with people with complex needs safely and try and achieve great outcomes for them.' (B02S)

To maintain or develop these skills providers typically provided staff with in-house job training. The introduction of the NDIS model and its emphasis on transdisciplinary working and individualised service provision had resulted in changes to the provision of training for staff and the skills sought by organisations. Disability service providers sought to develop a skills base around in-home support provision, person-centred care, transdisciplinary working, and, for some of the more innovative supports, recruiting staff with specialist recreation skills. Concerns were raised about the NDIS

funding model and the availability of time and money that disability service providers had to engage in training staff.

Recruiting good quality staff had been challenging for disability service providers prior to the introduction of the NDIS and remained so since the trials had commenced. One disability service provider linked problems with recruiting good quality staff not just to lower rates of pay in the disability sector, but to how people with disability and the disability sector more generally were valued across the community:

'Yes, support worker staff we've always struggled with getting people to see the value of working in the field but because the pay has been so low it's not been attractive to anyone other than people who will take any job... people with disabilities are devalued and people who work with people with disabilities are devalued as well. Until that nexus is overcome it's going to be very difficult I think to attract well educated, good quality people.' (C01S)

Providers reported more competition for staff since the implementation of the NDIS:

'So the demand of staff is so much higher and the competition of course is that you work across so many other agencies and people are starting picking with wages, conditions, all sorts of things.' (A03S)

Strategies to attract support workers included hiring staff based on their values and attitudes rather than their qualifications and then providing on-the-job training, and increasing the number of permanent roles.

However, some providers reported that offering permanent roles was problematic, at least in the short term:

'I suppose there's a growing number of casual staff as well...To cater to the flexibility required with NDIS...It's really a temporary thing till we get our head around how things are going because our preference is actually to have part time staff...Because we really, what we're finding we need is more staff so we actually need to look at how we can give job security to staff... but really we're still, because NDIA has been, it's been such a rush and it's changing all the time we're still working on our workforce strategy.' (B01S)

Comparatively lower wages in the sector were also a challenge to recruitment at the professional level. For many disability service providers the main competitors for allied health staff were private practice and the public sector, including the NDIA itself, which were able to offer more attractive salaries. There was some concern among disability service providers that NDIS pricing would affect wages within the disability sector and had the potential to exacerbate existing difficulties in attracting staff to the sector.

In order to retain staff, disability service providers attempted to offer other benefits to staff including providing on-going training and opportunities to move around within the organisation. However, some providers argued that the move to a more commercial, business-like model of service provision had led to staff attrition as a result of change to the values and ethos of service provision and increasing job insecurity.

Disability service providers were concerned that NDIS pricing arrangements conflicted with their industrial relations responsibilities. Providers identified a lack of capacity within NDIA pricing to pay staff the wages outlined by award rates and Enterprise Bargaining Agreements, particularly with

respect to penalty rates for weekends and night shifts. Similarly, disability service providers reported that the NDIS pricing did not account for staff to be provided with the necessary breaks, or for their shifts to conform to the requirements outlined in relevant awards.

## 2.3.3.5 Initial impact of the NDIS on people with disability, and their families and carers

Disability support providers commented on a number of strengths and weaknesses of the emerging NDIS that were affecting people with disability. Those specifically addressed concerned support services and NDIS plans, self-managed funding, impacts on social and economic participation, particular issues affecting people with psycho-social disability and supporting people from different backgrounds.

Disability service providers reported mixed outcomes in service provision for people with disability under the NDIS. Providers observed positive changes for many clients, and, on the whole, disability support plans provided NDIS participants with the supports and services that they needed. Providers were impressed that access to allied health supports and services had increased due to better funding arrangements. However, some NDIS participants were reported to have fewer support services included in their support plans compared to what they had been receiving prior to joining the NDIS.

Providers observed considerable variation in NDIS plans, which created different levels of satisfaction among NDIS participants, and their families and carers:

'A huge degree of variability; some parents expressing satisfaction with the process of engaging with the NDIA and satisfaction with the outcome of their plan for their child, so that's at one end of the spectrum, all the way through to the other end of the spectrum of complete dissatisfaction, confusion, anger...' (A01S)

Some attributed this apparent inconsistency to planners' variable levels of skills and experience in the disability sector, with some planners viewed as lacking knowledge of the range of supports that were potentially available. Other disability service providers attributed this variability to the pace of change brought about by the fast introduction of the NDIS and the much slower development of expertise amongst planners.

It was argued that people with disability who were more able to navigate the system and interact with NDIA planners experienced better outcomes in terms of the supports included in their plans:

'I still think that it's a system for the savvy. In the sense that if you've got really good advocacy or a family who understands the system or an advocate that does, or you do as a participant, then you still seem to come out with a better result through the planning process.' (B01S)

Providers believed those people with disability who did not fully understand the approach to disability services or could not fully articulate their needs were considered at risk of being left behind or underserviced under the new system. Providers saw the need for more support coordination for the most complex cases and stronger protections for their most vulnerable clients.

Disability service providers felt that people with disability and their families were not always aware of the types of support services that were available or appropriate. Consequently, they did not know what supports to ask for when attending planning meetings. Some providers argued that without knowledge of services relevant to their circumstances, the ability of people with disability to exercise choice was limited and "people are just going to stick to what they know" (E02S). Several providers

cited the importance of NDIA staff in providing information about services to participants and their families, including workshops or pre-planning meetings.

Providers saw little evidence of an uptake of self-managed funding among NDIS participants. Although they felt that self-managing funding had the potential to increase choice for NDIS participants, they were also concerned about NDIS participants' capacity to self-manage their funding effectively. In particular, providers pointed to the risk of NDIS participants using unregistered providers whose skills and quality of service were questioned. Providers called for greater safeguards including a clear quality assurance process to ensure people with disability were not financially exploited by their family, service providers or others in the community.

Service providers were more likely to report increased social participation amongst NDIS participants than increased economic participation. One provider attributed increased social participation among NDIS participants to the greater flexibility in the delivery of support services. For example, flexibility in service delivery hours gave people with disability the opportunity to become involved in social activities in the evenings and weekends.

However, other providers argued that only very limited supports were being provided in NDIS plans to facilitate social participation. As noted earlier, some also felt that the shift from group-based to individualised supports could, in fact, be counteracting efforts to increase social participation. Service providers urged for more information about supports available to assist NDIS participants and their family members and carers to increase social participation as, "you've got to know it's there to ask for it" (C04S).

While few in numbers, disability service providers did provide examples of how NDIS supports facilitated the economic participation of the NDIS participant and/or their family member or carer. One disability service provider cited the example of an NDIS client that they were providing services to who had undertaken a TAFE course in Business Administration, and had subsequently started working two days a week. Another provider advised that a mother of a NDIS participant had been able to return to full time work because NDIS support helped her arrange care for her daughter for the period after the day support ended and the mother arrived home from work.

Others however, thought that the NDIS may actually reduce economic participation. One disability service provider reported that families were worse off under the NDIS due to a "lack of overt support for parents' respite" (A01S), concerns about the ongoing viability of out of school hours care (OSHC) and the potential adverse effect on parents' employment if these services for children with disability were to close.

Particular concerns were raised about the capacity of the NDIS to meet the needs of people with psychosocial disability. Providers delivering mental health services identified several barriers to people with psychosocial disability engaging with the NDIS. Firstly, the language of permanent disability used in the NDIS was felt to be in contradiction to the recovery model used in the mental health sector. Secondly, amongst people with psychosocial disability "there's a lot of clients who don't even recognise they've got a mental illness. They're not going to go to the NDIA" (B04S). Thirdly, mental health service providers were concerned about the capacity of people with psychosocial disability to navigate the various NDIA processes effectively, particularly the plan development process and that "those that most need it will find the process extremely difficult" (E01S).

Most of the disability service providers worked with at least some clients who identified as Aboriginal or Torres Strait Islander people or were of culturally and linguistically diverse community background. In general providers described the introduction of the NDIS as having no notable impact

upon the number of clients that they supported from different backgrounds. A number of disability service providers specifically stated that whilst they had clients from different backgrounds, they did not provide any specific products or services for these clients.

## 2.3.3.6 Experiences working with the NDIA

Disability service providers, particularly large providers, expressed their desire to be more closely involved in the design and implementation of the NDIS, and regretted that, in their view, this collaboration had not been facilitated from the scheme's inception. Many continued to seek opportunities to build relationships with the NDIA and those that had made the connection described their relationships with the NDIA in positive terms:

'I think we've had a really good relationship with them. I think that we've been on their journey with them. We've certainly been a helper where required.' (D01S)

Several disability service providers reported attending quarterly meetings organised by the NDIA as well as monthly forums facilitated by the National Disability Services (NDS). Providers valued the opportunity to have their staff attend information and training sessions conducted by the NDIA. These sessions were viewed as an effective way for the NDIA to communicate information about changes to the scheme and NDIA processes.

Disability service providers appreciated opportunities to be involved in the planning process with individual clients, which allowed providers to offer their knowledge about services and the clients' support needs. By being involved in the planning process, providers felt they were also able to advocate for their clients, particularly for those with less capacity to articulate their needs.

Disability service providers questioned the level of bureaucracy apparent within the NDIS system and NDIA processes. Concerns were raised about the responsiveness of the new system and whether it in fact added to the burden that people living with disability were already experiencing when navigating the disability supports environment. There was also concern that NDIA processes created barriers to accessing the NDIS which could result in some people with disability being excluded from service provision. However, providers reported that the NDIA was open to provider feedback about the adverse impacts of bureaucracy and complexity, which gave them confidence that these matters would be addressed.

Disability service providers indicated that the NDIA provider portal was a particular source of frustration. The system was described as difficult to use and plagued with operational difficulties. This said, the same providers also stressed that, on the whole, NDIA helpdesk staff were responsive and in most cases quick to resolve problems.

## 2.3.3.7 Suggestions for changes and improvements

Disability service providers suggested several areas where, in their view, changes and improvements might improve the operations of the NDIS.

#### **Communication and collaboration**

Communication and collaboration between the NDIA and disability service providers were, in particular in the early months of the trial, problematic or indeed non-existent. While both had improved with time, providers sought more opportunities for discussions and regular interaction between the NDIA and themselves. Providers felt their insights could be helpful to informing the future design of the NDIS, whilst feedback from the NDIA could help providers improve supports for their clients.

Monthly NDIA forums were favoured over obtaining information from the NDIS website. Disability service providers considered the information included on the NDIS website to be too generic and reported that monitoring the NDIA website for updates was unnecessarily time consuming. Sole providers suggested that the NDIA should improve access to training and information sharing opportunities for them.

## Less bureaucratic processes

Providers would have welcomed simpler and less bureaucratic processes. Improvements to the IT system, especially the provider portal, were seen as essential in order to alleviate the administrative burden the NDIS imposed on providers.

## **NDIS Funding**

Disability service providers would like the NDIS pricing system to reflect better the actual costs of staffing and service provision. They also recommended greater effort to increase understanding and better manage interactions between the NDIA, and different sectors and state-based systems. Such policies could address disability service providers' concerns about which bodies assumed responsibility for funding particular supports and potential service gaps for people with disability.

# Support for people with disability

A number of improvements to assistance for people with disability, and their families and carers were suggested. These included more support for people with disability during the transition into the NDIS, and more support coordination and stronger protections for the most vulnerable clients.

## Specific improvements for psycho-social supports

Providers also suggested improvements to support services for people with psychosocial disability, including developing specialist support clusters, establishing processes to accommodate participants who did not recognise that they had a psychosocial disability, and offering dedicated support services for the families of people with psychosocial disability.

# 2.4 Interviews with disability workforce stakeholder organisations

## 2.4.1 Specific aims and objectives

This Chapter summarises the discussion points that arose from in-depth interviews with chief executives, senior managers and other employees of stakeholder organisations representing the interests and concerns of those working in the disability sector in Australia.

The aim of these interviews was to add a sector and workforce perspective to the Evaluation of the trial of the NDIS. The specific objectives were to provide an understanding of the disability workforce perspective of:

- the impact of the NDIS on the disability sector in general
- the impact of the NDIS on those working in the sector
- the disability sector's responses to the NDIS, including any innovative practices adopted, changes
  in skills or training requirements, and leadership issues.

In the first wave of interviews, respondents were invited to describe:

- their initial expectation of the NDIS with respect to their working environment, organisational matters and the wider disability sector
- the impact of the NDIS to date, in particular with respect to intra- and inter-organisational matters, and how it related to expectations
- their experience of working with the NDIA.

The second wave of interviews is expected to explore in more detail how the disability sector has been changing from the view point of the workforce and its stakeholder organisations. Wave 2 will provide opportunities specifically to explore structural and operational changes in the sector.

## 2.4.2 Recruitment, sample and interview

Respondents to the disability workforce stakeholder sample were purposively sampled. The sampling sought to ensure an appropriate representation of organisations affected by the NDIS and representing people or organisations working in the disability sector. The recruitment also targeted occupations and workforces supporting people with disability already represented in the NDIS or expected to be so in the future.

In total, interviews were conducted with 15 disability workforce stakeholder groups, including two separate interviews with senior national and regional personnel of one organisation. In some instances, more than one representative from the stakeholder organisation participated in the interview. The interviews lasted between 1 and 1.5 hours, and were conducted between September and December 2014 using a common set of questions. Interviews were conducted by telephone at a date and time chosen by the respondents. With the consent of participants, interviews were recorded using an electronic recording device and transcribed verbatim using a professional transcription service.

## 2.4.3 Findings

The interviews with stakeholder organisations were designed to focus on expectations and current outcomes of the NDIS for the sector and its workforce. Although inadvertently covered in the conversations, stakeholders' perceptions of the effects of the NDIS on people with disability were not at the core of the interviews and hence addressed only briefly. Initial impressions of the trial of the NDIS were that the scheme was having the expected positive effect on NDIS participants' ability to enhance their choice and control over disability supports.

'There is an overriding sense of optimism that the NDIS creates a situation where people can be more aspirational about their goals and are not constrained in terms of choosing to participate in certain programs which have been designed by bureaucrats, but can be more open in their thinking about their goals and aspirations and how they want to lead a normal life.' (05R, Peak body)

Stakeholders noted that NDIS participants appeared to be seeking new and different types of services, in particular to facilitate social and community participation, communication, as well as personal care. But some stakeholders also felt that not all NDIS participants, in particular those with complex and high support needs, appeared to be receiving all necessary supports, and in some instances previous levels of service provision were not being matched under NDIS funding. Service provision and funding across plans were observed as being variable and, at times, inconsistent. This was attributed to differences in the skills and expertise of NDIA planners within and between NDIA offices, but also the capacity of participants to advocate for services.

## 2.4.3.1 Initial expectations of the NDIS

It is perhaps not surprising that, according to the stakeholder organisations interviewed for this evaluation, the disability workforce shared many of the high expectations of the NDIS that have been reported in previous chapters for people with disability and disability support providers. A recurrent theme among participating organisations was the expectation that a federally coordinated disability insurance scheme would bring with it not only more equitable and, ultimately, reliable provisions of supports, but also enhanced and more appropriately distributed funding.

This extra funding was not only seen directly to benefit support users, but the overall sector, which was expected to increase as demand for supports grew and got more diverse. It was anticipated that the NDIS would encourage and even require the development of new forms of service delivery, typically through more diverse service options, the promotion of service flexibility and enhanced person-centred care.

'I think it's just an enormous opportunity to really think about some, to be innovative around service delivery. I just hope that that opportunity is actually met....So it takes away that, you know, moving from being a state based service provision model to being a national service provision model really does kind of change, really completely change the profile of how services can or could be, may or could be provided. So that's really exciting and I think that, you know, so just the general idea of helping people, providing people choice and control, really changing that paradigm is really exciting, and know that people have found that really refreshing and exciting really.' (13R, Allied health peak body)

A recurrent theme of our conversations with workforce stakeholders was their sustained worry that the NDIS might lack a pricing structure that offered to comprehensively cover the costs of service provision. Without this, it was argued, the sustainability of some service providers, in particular smaller ones, could be at risk.

'It's going to create great uncertainty for service providers, particularly where they are put in a position where they have to compete for participants with such low dollar value packages. It'll very much impact in the in-home support area. And it will impact where people are able to move around and to take their funding with them...And it's the problem with a market-driven philosophy that it creates this incredible pressure for services to do a lot more with a lot less.' (10R, Trade union)

Funding was not only seen to affect the range of supports that would be provided under the new scheme, but also their quality, in particular as delivered through a qualified and well trained workforce. Only with adequate funding in place, which would allow providers to cover their costs, did stakeholders see opportunities for developing and expanding the disability workforce.

Meeting any anticipated demand for a larger disability workforce was rarely seen as problematic. Labour supply was expected to increase as a result of the visibility of the disability sector and of "employers...making the sector an attractive place to work" (05R, Peak body), which would be accentuated by the trial and any subsequent roll out of the NDIS. This in turn was expected to encourage new workers to seek employment in the disability sector.

However, this optimism was somewhat tempered by more muted expectations as to the impact of the scheme on working conditions. Stakeholders were concerned that the competition between providers brought about by a new market-orientated disability support model might force disability service providers to reduce their operating costs. This would especially be the case if the individualised funding under the NDIS did not enable service providers to cover their fixed costs. It was repeatedly argued that providers might seek to achieve cost savings by lowering wages, increasingly use of temporary and casual workers and employees, or weakening career structures. Stakeholders were also concerned that the disability sector may cut back on staff training and professional development.

'We are deeply concerned about employment standards and workforce qualification, skills and knowledge...Things like training and development, professional development and support for staff, the HR management functions and the like...I think that the funding model needed to be better balanced between some of the real costs of employment, which are fixed costs and the fixed costs around accommodation, support and the like, as well as individualised funding support to ensure that people are able to participate in the community and have social inclusion, and have lifelong development based on their individual needs.' (10R, Trade union)

But there also were competing views that urged the disability sector in Australia to become more flexible so that it can provide its services in a manner that is more closely aligned with the needs of NDIS participants.

'At the moment we have a situation where the industrial relations settings, particularly the industrial relations instruments which are primarily used in the sector—in other words, the modern award—doesn't provide sufficient flexibility, or doesn't properly align to the social policy objectives and goals of the NDIS, and our view is that one should fall into line with the other and that the social policy goals should come first and that the industrial relations settings then should assist or support the achievement of those social policy goals.' (05R, Peak body)

## 2.4.3.2 Initial impact of the NDIS

Stakeholders were observing changes in how the **disability sector** was operating as a result of the trial of the NDIS, although most of these observations appeared anecdotal rather than based on any type of systematic monitoring. The reporting also suggested that the changes were varied, affecting different locations and initiated by different service providers. Some accounts pointed to disability providers proactively engaging with the new systems of service delivery, combining specialist disability services with other provisions, brokered in collaboration with mainstream and third sector organisations.

Whereas stakeholders welcomed these changes, they also reported what in their eyes were less positive developments. In particular, stakeholders were concerned about state governments withdrawing from the provision of disability services before other providers had positioned themselves successfully to meet the increasing demand for their services.

'Western Australia, New South Wales and Queensland already made the decision to outsource all of their public sector disability services to the not-for-profit sector, and there's a clear differentiation between the level of pay and terms and conditions between the two sectors. So clearly those governments have made a decision that in order to not have to pay more under the NDIS they have to outsource the services. And Victoria is heading down the same path....And effectively they are outsourcing the same job, the same hours, the same residents and clients, to simply a lower pay sector.' (10R, Trade union)<sup>5</sup>

Commercial and third sector providers were still seen some time off from being able to step in and provide full service coverage. Workforce stakeholders observed that providers were finding it difficult to transition from the old block funding system to the new individualised funding model of the NDIS. They thus felt their initial concerns about the financial viability of smaller providers confirmed, since, in their view, the NDIA's pricing structure was not matching the costs of service delivery. In particular, the NDIA pricing was said not to cover the fixed costs of employment and the costs of administrative work not involving direct client contact. Allied health workers and their organisations also noted that the rates paid by the NDIA were lower than under other schemes, such as Medicare. For these reasons, some stakeholders expressed concern about the long-term sustainability of disability service providers, expecting larger disability organisations eventually to dominate the provider market. This, in turn, would lead to reduced choice of supports that people with disability were just beginning to gain.

'We're in transition from essentially block funded arrangements to individualised funding arrangements, and that the very process of transitioning and unwinding your services and unbundling those services and then responding to individual plans imposes a cost on service providers, which we feel that hasn't adequately been taken account of, and then the pricing which was set a week before the trial sites started in July of last year, as soon as those prices came out we realised—or we took a view—that those prices were inadequate based on the feedback from our members and our own analysis, and that of subsequent reviews of those

https://www.communities.qld.gov.au/gateway/reform-renewal/disability-services/national-disability-insurance-scheme-queensland/getting-ready-ndis-queensland/accommodation-support-respite-services-rs

<sup>&</sup>lt;sup>5</sup> In Queensland, this decision was amended in 2015 when the Queensland Government committed to continue to provide Accommodation Support and Respite Services.

prices. We have maintained that they don't accurately reflect the true cost of delivering quality supports to people with disabilities.' (05R, Peak body)

Some of the stakeholder organisations contributing to this component of the evaluation got themselves more actively involved with matters concerning the NDIS as a result of increasing demand from their membership, but also in recognition of opportunities to inform the future shape of the NDIS. These organisations dedicated extra resources to respond to submissions, monitor developments, liaise with members, and lead workforce initiatives. Many had not felt part of earlier discussions and consultation that had taken place under the auspices of the NDIA and its predecessor body prior to the commencement of the trial of the NDIS; these organisations were now taking steps to becoming more engaged for their members, but also to improve linkages with the NDIA.

'There hadn't been a lot of engagement either at the policy or a membership level and so I guess I set about really finding out where members were up to in terms of their knowledge and experience with the scheme. I did a survey for them, and then I've run education sessions....So I've done four sessions including some representatives from the NDIA in those sessions....I set up a community of practice for those people interested in talking about their engagement and ongoing concerns and, you know, the experience of the issues that were unfolding as people became more involved through the launch sites....There are regular bulletins both at the state and national level and so particular articles of relevance [on the NDIS] are included in those.' (04R, Allied health peak body)

Some organisations ran training sessions for their members (and others), exploring practical approaches to implementing the NDIS principles of 'choice and control' and person-centred capacity building, and promoting "an understanding of the tools and resources within the NDIS that support the insurance model framework, so the reasonable/necessary decision-making, evidence-based practice, tools for measuring progress, key performance indicators that they need to work with" (16R, Allied health peak body). At the same time, trade unions reported becoming more focused on members in the disability sector and their concerns about working conditions and job security.

The feelings of anxiety and uncertainty that characterised several workforce stakeholders' assessments of the current and longer term impact of the NDIS on the disability sector extended to their perceptions of the future shape of the **workforce** and its working conditions. We were told that, in particular the employees of state-operated disability services felt vulnerable and their job prospects uncertain, a feeling that was accentuated by the early – and for some, premature – withdrawal of disability services provided by state governments, and associated job changes and losses. But the workforce stakeholders also acknowledged that there was at least anecdotal evidence of compensating increases in employment opportunities as a result of increasing service demand, which caused some providers to expand and others to enter the market.

Our interviews highlighted growing recognition of the potential for a professionalisation of disability support worker roles as a result of the NDIS and at the expense of a model that was previously built very much on allied health staff providing disability services. Although no robust evidence of this happening as yet was presented, the prospect of professionalisation repeatedly led the workforce organisations to return the conversation to the importance of a coordinated approach to staff training and career development that was still largely absent.

'There is a shift towards...a higher expectation of qualification, particularly, but also, I mean most of that is happening in an ad hoc way. There's not really any clear process about how this is developing, and it's happening all across the sector...So there's much more expectation now of things like case coordination and case management requiring tertiary education....There are no discussions around professionalisation; things are just happening.

So we're kind of trying to intervene in those where we can and to form a coherent narrative around that direction that the industry's moving in.' (07R, Trade union)

The perceived need for formal training provisions to be set into place was frequently accompanied by urgent pleas to ensure that the NDIS funding system was structured so to allow specialist providers to invest in staff training and development.

'Initially there didn't seem to be a recognition of the skill set involved in complex case management. Again the pricing around that was pretty low and again the sense that well maybe you don't really need skilled people doing that whereas I think [our] profession would say frankly you need highly skilled people doing that.' (04R, Allied health peak body)

## 2.4.3.3 Working with the NDIA

Amongst all organisations contacted and interviewed as part of this evaluation, several workforce stakeholder organisations, in particular the trade unions and those aligned to allied health, felt most distant from the NDIA. Few had been in direct contact with the NDIA, be it at a federal or state office level. Moreover, the organisations typically reported contact with the NDIA only occurring after the start of the trial, and expressed disappointment about a lack of consultation and collaboration at the planning and early implementation stages of the NDIS trial. Some felt very much excluded.

'It's also a communication problem in the sense that all sorts of discussions happen inside the NDIA, inside the Department of Social Services, inside COAG, but us non-government folk on the outside aren't privy to that, and so we don't know where we're at in the process of resolving these things. And meantime we're at the frontline of having to answer questions about them.' (08R, Peak body)

A few, however, reported having being more closely involved in the original set up and planning of the NDIS:

'Well we work closely with the NDIA and so both in our formal role as an advisor to government at all levels of government - at the federal government and state governments - we you know, we respond to policy submissions and we advise them on matters relating to the NDIS.' (05R, Peak body)

The workforce organisations felt they would be a valuable source of information about, and important interface between, the disability and the mainstream sector, as their workforces were engaged in health, mental health, education and aged care, as well as disability services. Respondents spoke about the need for greater clarity about divisions of labour and responsibility between the mainstream and the disability sectors, in particular with respect to the inclusion or otherwise of psychosocial disability under the auspices of the NDIS. Respondents were aware of the risk of costs being shifted between the NDIS and mainstream sectors.

'How the interface occurs is really what's going to be the impact. And I guess the largest area of concern...at the moment is how will that interface between health and disability and care and that transition because as I said, what we do is a lot of rehabilitation work in the hospital and at what point does it become NDIS or disabilities responsibility to take on those services and will there be attempts at cost shifting between the two areas are a concern to us.' (12R, Allied health peak body)

# 2.4.3.4 Areas for improvement

Workforce stakeholder organisations strongly identified with the principles of the NDIS and its fundamental values of 'choice and control'. The aim of the NDIS to centralise funding for disability services was perceived to bring equity to people with disability across the different states and territories in Australia. Overall, respondents were positive about the trial of the NDIS so far. The trial was deemed to be working well, especially in light of the obvious challenges involved in rolling out such a large scheme at such speed.

Nonetheless, our informants highlighted some areas in which they would like to see changes, which could improve relationships between the various parties engaged in or affected by the NDIS trial, and ultimately the operations of the NDIS itself. Key recommendations to support or engage (i) workforce organisations, (ii) the workforce itself and (iii) people with disability included:

## **Workforce organisations**

- more consultation and more frequent communication opportunities for workforce
  organisations. The key stakeholders expressed a strong desire to contribute actively to the
  development of the NDIS, and would have liked more opportunities to do so. Better
  communication between them and the NDIA was recommended to facilitate enhanced sharing
  of information
- a national strategy to provide support to disability providers and to assist in the development of the supply of services. Specifically, this included the suggestion to help smaller not-for-profit organisations to develop new business models in accordance with NDIS processes
- a review of the NDIS pricing structure to cover the true costs of service provision. This was seen
  to be critical for ensuring high quality disability supports and the financial viability of service
  providers. Related to this, the NDIA was urged to clarify the intersection with the mainstream
  sectors to address current confusion over support eligibility and the risk of cost shifting

## The workforce

- providing or supporting a (funded) disability workforce training infrastructure. This was
  proposed alongside recommendations to review and nationally co-ordinate disability workforce
  training courses and their content in order to ensure their relevance to the principles and
  processes of the NDIS. It was also suggested that an accreditation process be set up under the
  NDIS to promote a skilled workforce and ensure quality services for participants
- workforce planning at a national level and by individual disability service providers. This was suggested as a means to attract and retain a skilled workforce and to promote good working conditions within the sector. Full cost recovery under the NDIS pricing structure was seen as a pre-condition that would allow investment in training and a good workplace

## People with disability

- more consistency in funding arrangements across trial sites. Current arrangements were not seen to fully achieve the objective of greater equity of service provision for people with disability
- improved NDIA planning processes supported by training needs assessments for NDIA planners.
   This was hoped to assist with overcoming variability in participant plans
- improving the ability of people with disability to engage actively in the planning process. It was
  proposed that this be achieved by increasing the time permitted for planning meetings,
  improving resources available to NDIS participants and their families, and funding advocacy
  services to support participants and assist in building their capacity as consumers of services
- pathways for people with disability not eligible for the NDIS. Stakeholders were concerned about ensuring that provisions and funding remained in place and were clearly sign posted for all people with disability.

# 2.5 Interviews with NDIA managers and staff

## 2.5.1 Specific aims and objectives

In this chapter, we report the principal findings from interviews held with 46 NDIA staff across the initial four trial sites of the NDIS, and in the ACT. These interviews were conducted between October 2014 and April 2015. The objectives were to help the researchers to better understand:

- NDIA employees' perceptions and experiences of implementing the NDIS to date
- assistance provided at the point of personal plan development to people with disability in setting and achieving goals, and in increasing social and economic participation
- relationships between NDIA employees and community and mainstream services.

Our presentation of findings from the first wave of interviews that follows below will address these three objectives in turn.

## 2.5.2 Recruitment, sample and interview

The interviews included managerial and operational staff, and practitioners at each of the NDIS trial sites. Practitioners included Local Area Coordinators, NDIA planners, Business or Regional Support Officers, and Plan Support Officers. A breakdown of the number of participants by their job roles is shown in Table 2.4.

Table 2.4: NDIA interviews by trial site and job role

Trial Site	Manager*	LAC	Planner <sup>#</sup>	PSC⁺	BSO/RSO <sup>++</sup>	Total
New South Wales	1	3	4			8
South Australia	1	4	2		1	8
Tasmania	2	6	2			10
Victoria	3	6	2		1	12
Australian Capital Territory	3			5		8
TOTAL	10	19	10	5	2	46

Note: \*Inclusive: Trial Site Managers, Directors and/or Assistant Directors

Managers interviewed in this study included Trial Site Managers and a number of Directors/Assistant Directors managing specialist teams. Some of the Trial Site Managers reported dual responsibilities at the operational level in the trial site and at a strategic level at the NDIA Operations Branch in Geelong, Victoria. At the operational level their responsibilities included staff management, supporting the leadership team, advising senior staff, leading recruitment processes, working with some participants and families and approving plans over \$150,000. At the Agency level they were part of the executive team involved in strategic planning and interactions with stakeholders, including state governments and disability support providers.

The roles of **Planners** included interviewing participants, establishing goals, aspirations and support needs, following up information needed to create plans from families, medical staff and providers, collating this information and generating a plan. They met with participants to discuss and handover the plan and conducted plan reviews including review meetings with participants.

<sup>#</sup> Inclusive: Planners and Senior Planners

<sup>+</sup>PSC=Plan Support Coordinator

<sup>++</sup>BSO=Business Support Officer, RSO=Regional Support Officer

**Local Area Coordinators** were charged with undertaking community engagement activities, promoting inclusiveness amongst community organisations and facilitating opportunities for NDIS participants to access unfunded community based services (with the aim of increasing social and economic participation). Many were also involved in plan implementation, including assisting participants and their families in finding disability service providers.

**Plan Support Coordinators** are a new position the NDIA introduced in the ACT (and WA and NT). This role blends the functions of the Planner with that of the Local Area Coordinator. Finally, **Business Support Officers/Regional Support Officers** undertook primarily administrative work, including answering participant and provider queries, booking appointments and sending out correspondence. Some were also involved in supporting plan implementation and gathering information for eligibility decisions.

Many NDIA staff interviewed had some type of professional/allied health or education background, or experience of working in the disability sector, and had previously worked in state or federal government or the not-for-profit sector. To protect the identity of respondents, we do not specify their roles or NDIA branch locations other than in a general and generic form.

In the following sections, quotes taken from interviews with NDIA Managers will be identified as such in recognition of the Managers' strategic roles and responsibilities in the trial of the NDIA. Where a respondent is not identified as a Manager, he or she may be a Planner, Local Area Coordinator, Plan Support Coordinator, or Business Support Officers/Regional Support Officer.

# 2.5.3 Findings

## 2.5.3.1 NDIA employees' perceptions and experiences of NDIS implementation to date

NDIA staff who participated in the evaluation reflected positively on the achievements of the NDIS and the NDIA to date, in particular with respect to delivering on establishing the trial sites and facilitating the timely access of people with disability to additional funding and supports. The initial set up, however, had proved difficult as outreach appeared insufficient or ineffective, attracting few early access requests.

'Initially, probably our biggest problem was getting people in. We weren't getting a lot of Access Request forms back... we were waiting around for participants to come to us. So we really had to refine a lot of things and do a lot more engagement than we thought we'd have to.' (E07N-Manager)

'...for the first three months...I think we probably had 30 to 40 per cent of the consent forms in that we needed. And of those consent forms, we probably only got 10 per cent return on the access request forms.' (B13-Manager)

Repeatedly, our respondents remarked that people with disability attempting to access the NDIS appeared to be assuming that completing the online Access Checker was sufficient not only to determine eligibility but also to be formally admitted to the scheme.

'(The) My Access Checker confused people because they thought they were registering with the Agency... they presumed the Agency would be contacting them.' (E05N-Manager)

'We'll get them ringing us a month or two later going, 'Look, I completed (the My Access Checker)... online and I've not heard anything. Yeah, so that bit doesn't work at all.' (B12N).

As these and other early organisational challenges and 'teething problems' were being addressed (some of which will be described below), there was a general feeling among NDIA staff that NDIS participants were now in a better place than they were before the scheme was implemented. Most were having more funding available to meet needs, had improved choice and control over services and support, and there was also evidence of improved social and economic participation.

'If you talk to the participants the vast majority, the vast, vast majority of participants will say their life is better. And that's what all of this is all about.' (B01N-Manager)

## Staffing and workloads

The NDIA staff spoke highly about their colleagues and the fact that, in their view, the NDIA had managed to attract a high calibre of Managers, Planners, Local Area Coordinators and other staff.

'It's just unprecedented to work in an environment where you have that level of skill and experience amongst the people that you're working with, I think, and the diversity that we had to draw on with each other.' (B14N)

Whilst the skills, goodwill and indeed enthusiasm of NDIA colleagues was perceived to have greatly facilitated the launching of the NDIS trial sites, several NDIA staff also felt that the NDIS had been rolled out ahead of time. This continued to pose challenges even for the most skilled and dedicated individuals and teams.

'We've been generally under resourced in terms of being able to do a really good job... I think when the original modelling was done it was all best guess stuff so the scheme's still working out how long does it take to write a plan or a review plan and how many should people be doing a week and all those types of things are areas that need ongoing work.' (D07N)

Acknowledging the need to start small, i.e. as a <u>trial</u>, ahead of any roll out of the NDIS across the country, the rushed launch meant that policies and procedures had not been in place to guide staff and to assist NDIS participants, and their families and carers in understanding the operations of the scheme. These circumstances were thought in some cases to have adversely impacted on the quality and consistency of the planning process for participants. High workloads were also said to have contributed to elevated stress levels among NDIA staff and, indeed, staff resignations.

'I'm taking work home, I'm doing it on the weekends, my flex is up to a week,' I had 38 hours, other people had more. And people were encouraged to come in on the weekend and they were tired during the week.' (E04N)

'A lot of the original cohort are now looking for jobs, and also people who've recently come are looking for jobs elsewhere, because they just can't sustain the hours that they're working and the pressure that's on them...' (D02N)

Considerable work and time was invested into developing policies and procedures, which improved and became clearer over time, leading to greater consistency within and between trial sites.

In particular in the very early phases of the trial, NDIA staff were said to have been under pressure to achieve the participant numbers that had been specified in collaborative agreements between the state and federal governments, and were identified as Key Performance Indicators (KPI) to be met by NDIA staff. This resulted in resources in the first year being directed towards the rolling-in of participants, even if a support plan could not be prepared immediately. While it appeared that, over time, the NDIA was able to progress increasingly more NDIS participants to the plan development

and implementation stages, and provide more pre-planning support, this was a steady, sometimes slow process. Some tasks involved intricate, yet critical improvements to processes and procedures, such as making documents and tools more accessible to participants.

'... it's clear that they [NDIA forms] haven't been designed with people with disability. They're unintuitive, hard to read, you know, they're probably a bit long... I would struggle to complete, to be honest. They're really government forms.' (B11N)

# **Operational challenges**

Recruitment of participants into the NDIS in the early stages heavily relied on data relating to clients in existing state-based disability services (accessed under the Section 55 clause in the NDIS legislation). Respondents suggested this data was often of poor quality and unreliable. The additional effort then required to identify people with disability who might be eligible for joining the NDIS and resultant underestimates of their numbers were found to be "a very significant challenge in putting extra workload on the Agency and extra strain on the Agency." (A06N)

A contributing factor that was said to have added to, rather than alleviated the workload was the Information Technology (IT) systems used for documenting planning and plan implementation. It was repeatedly described as "unyielding, cumbersome and not fit for purpose" (E01N-Manager). Many staff raised concerns about the Siebel database, of which Managers were very aware. There were reports of improvements over time, but NDIA staff did not expect a new system to be available until full rollout.

'So, while we're bearing with the interim solution, it's very, very heavy on data entry, it's not user-friendly; it's the best they could cobble together at the time and, but as such, yeah, that really has a significant impact on the day-to-day administrative duties that we do at the Agency.' (B11N)

The result of inadequate IT in combination with the challenging task of needing to identify and then support NDIS participants meant that early projections of NDIA staff workloads and activity patterns had to be revised. This was especially the case for Planners:

'We hired people on the basis that the modelling was that 60 per cent... of Planner time would be working with families... That's never been true from the beginning and hasn't got a lot better, so that, it's probably more 20, 30 per cent forward facing participant time; the rest is heavily stuck at a computer doing administration.' (CO3N)

The increased administrative burden that the Planners and Plan Support Coordinators experienced also affected Local Area Coordinators, who were increasingly drawn into supporting the former in the early stages of roll out. Consequently, several Local Area Coordinators felt they were spending more time in the office rather than in the community identifying and building opportunities for inclusion.

'The LAC role... became very attached to the Planner role, and became all about plan implementation. And I got very quickly bored and frustrated with that and felt that my skills weren't really being used and I wasn't being stimulated or really building my expertise very much in that space.' (D02N)

Some respondents described being asked to undertake planning activities and expressed concern that this would lead to the further "watering down" or potentially the removal of the Local Area Coordinator role, in favour of the Plan Support Coordinator model.

'The Local Area Coordinator position could be lost then and I think that would be a real tragedy. I think these positions are extremely important in the country, they're just as important as the planning process because really what you're doing is you're essentially building a foundation for people, you're finding out what they can tap into, what they can't, you're working out whether things are working for them and you're being proactive in whatever you do. If you're doing pure planning you don't do any of that. It's a completely different model.' (A02N)

Early feedback was critical of the evolving Plan Support Coordinator model. It was seen to attempt to combine two very different sets of activities and responsibilities that were too complex and demanding to be fulfilled by one person.

In Tasmania, where the Local Area Coordination role had been outsourced to two large non-government agencies, views differed as to the merits of this approach. Local Area Coordinators saw advantages to being based in community settings, but acknowledged the challenge of "having two masters" (C11N) and keeping in touch with the NDIA, complicated by NDIA offices being spread across three different locations. This made it "difficult to access your management, difficult to get quick speedy replies, difficult to establish rapport and relationships with your colleagues"(C05N). Others felt that out-sourcing Local Area Coordinators had deprived the NDIA of some of its flexibility and effectiveness, in particular, with respect to connecting and integrating plan support development with implementation.

## **Community outreach and communication**

Concurrently, NDIA staff felt there was a general lack of knowledge in the community about the NDIS, which, in turn, resulted in the NDIS encountering problems in engaging specific population groups, notably people with mental health disabilities; and those from culturally and linguistically diverse backgrounds or Aboriginal or Torres Strait Islander people. Tying up Local Area Coordinators with operational matters reduced opportunities to engage in more proactive linkage activities in the early stages of the NDIS.

Although more resources were subsequently being directed towards exploring ways of improving recruitment of these groups, the interviews suggested that, even in late 2014, this process still seemed to be in its very early stage. For instance, only once did a respondent note that their NDIA team included a staff member who was an Aboriginal or Torres Strait Islander, despite potential NDIS participants including significant proportions of Aboriginal or Torres Strait Islander people and despite an awareness within the organisation of the culturally specific needs and expectations of that population. When working with NDIA participants with disability from culturally and linguistically diverse backgrounds and in the absence of a set of diverse language skills available within a branch office, Planners reverted to using interpreting services. This enabled them to make sure that "participants and their families are given a proper opportunity to tell their story and get their needs across" (A08N). However, not all respondents were aware that using translation services could be part of the planning process.

Specialist training that might have helped NDIA staff to connect with specific target populations was described as not yet adequate, too generic and too short, and hence lacking profundity. Staff typically relied on their own personal skill sets in order to master communications with NDIS participants.

'I guess when you walk in to a family you're sort of figuring out, when you're talking to them, what stage they're at, what their understanding is. You know, can they read, can they understand what they're reading? You know, what sort of language do you use to help them to understand what they're doing and what we're trying to talk about. So you just adapt as you go, I think. And that's a skill in itself as well.' (A05N)

## **Eligibility and planning**

After some early problems with determining eligibility in the absence of clear guidelines, processes around determining eligibility for the NDIS and designing the planning process were felt to have improved over time and to be now working reasonably well. Although we were told that it had been comparatively straight forward to determine the eligibility for the NDIS of people with severe disability, this was not necessarily the case for people with less severe impairments. In their cases, the need to collect evidence of the permanency of the disability often proved complex and time consuming, was frustrating to some people with disability, and diverted NDIA Planners from their planning tasks. Several NDIA offices subsequently set up teams dedicated to determining eligibility, which appeared to streamline the process, making it speedier and more resource efficient. Respondents felt that the feedback they had received from NDIS participants showed that processes had indeed improved over time.

'The eligibility side of things has grown leaps and bounds and it's a lot more clearer and concise... I think as an organisation that's really improved.' (D03N)

Respondents felt NDIS participants for the most part had plans that supported them appropriately, and that Planners had greater confidence in explaining and applying "reasonable and necessary" guidelines when making decisions about funding. There was agreement as to the value of preplanning sessions with new participants, and community workshops or forums with potential participants. There was also consensus that plan implementation had not been as well resourced or carried out in the early days of the NDIS when the focus was on plan completion.

# Staff roles and their definition

Several respondents highlighted a tension between the concurrent yet potentially conflicting roles as facilitators of service provision and their funding. This led some Planners feeling uncomfortable about their interactions with parents, unsure as to how far their support and guidance should go, and whether they should promote take up of supports or monitor spending.

'Am I an advocate for the parents or am I the funding approver?' (A04N).

Others suggested this confusion also led to inconsistency of practice - especially for those who had come from welfare backgrounds (for example, having worked as a social worker or in a child protection environment). In this latter instance there was a feeling that some staff struggled with a "them or us" mentality.

'We haven't worked out what we are yet. Are we an insurance scheme? Are we a part of government? Are we a business? Are we a not-for-profit organisation? Are we a social support organisation... There's not clarity on what is our clear priority. Most insurance Schemes, they have a philosophy they don't want to meet the person that is insured with them.' (B02N)

NDIA staff often felt challenged by the varying expectations of NDIS participants as to what the scheme might provide them with. Where expectations were deemed high or indeed excessive, perhaps turning into demands, NDIA Planners and Plan Support Coordinators referred back to

general principles, notably, that supports (and their funding) needed to be "reasonable and necessary". This was especially the case in the early days as internal guidelines for needs assessment and plan development were still being devised.

'So many people come in and think that they can have choice of whatever they want and control whatever they want... the reality is that it has to be reasonable and necessary and... then you will have choice and control about how you implement it.' (B06-Manager)

Responses to such challenges were described as often strongly informed by staff members' personal background and previous employment. With that, they brought with them certain practices that, on reflection and with hindsight, were much more 'conventional' and less guided by principles of goal setting and the pursuit of aspiration than the philosophy of the NDIA had anticipated. As illustrated in these instances:

'(Staff) who've come across in to the scheme... from the Commonwealth Rehabilitation Service (CRS) or Centrelink... culturally they're so different in terms of how they work... kind of like "these are the rules" and they're not really flexible... thinkers. So what they go for is funded supports. So what you see in plans is a real emphasis on the funded supports, the disability specific supports. So they look at the person's disability without looking at the whole person or their context.' (D02N)

'My main background is... autism and mental health so if I was working with a teenager with autism I would have a very different idea about what would be reasonable and necessary than one of my co-workers who, you know, is a physiotherapist and works predominantly with people with cerebral palsy and spina bifida.' (C04N-Manager)

## **Promoting self-managed funding**

The take up of the fully self-managed funding option among NDIS participants was reported to be low in all trial sites, as people tended to opt primarily for letting the Agency manage their funds.

'Given that (participants have been)... told for decades "you get no choice, these are the supports that you have, shut up and don't complain, otherwise you get nothing" pretty much...they're basically shopping in a free market now. And that's just such a big cultural leap, even for highly educated middle class carers who can navigate and shop in any other context in their life. It's just conceptually it's difficult, it's really hard.' (D02N)

Some trial sites reported high numbers of participants who were self-managing a single line item in the plan – in most cases this was funding for transport and equipment. NDIA staff typically believed that self-managed funding had the greatest potential for providing participants with choice and control over services and supports. However, they also observed that some NDIS participants or their carers appeared to lack the confidence or emotional capacity to take on the challenging task of self-management, cognisant of the likely burden it would place on a person's time and negotiation skills when working with (new) service providers. Moreover, some staff acknowledged their concerns for NDIS participants' financial abilities to self-manage and potential exposure to risks, such as the use of unregistered providers may entail. Critically, NDIA staff felt that the time pressure under which they were operating prevented them from dedicating more of their time and resources towards assisting people with (learning about and understanding) self-managed funding.

'I do think the (NDIA) has a responsibility to be a little bit more assistive to make sure that people who are self-managing that type of funding are not being set up to fail, not being tempted to purchase things. It's not a welfare payment. It's a support payment.' (C08N)

'I can see that we'll have some real issues, and in fact I believe we already have, of ... misuse of funds. I think that we... have a duty of care to make sure that this person can actually do this, or at least have a case manager... who can actually help them with managing those funds, because a lot of them can't do it.' (B12N)

## **Engagement with support providers**

Disability service providers, it was felt, were also finding it hard to adapt to the changing policy environment, although progress was said to be evident. Many NDIA staff described the sector as still in places unprepared and slow to move from block to individualised funding, sometimes resistant to changing business and practice models.

'It's a challenge to reform the sector and to educate providers that... they no longer have a direct relationship with government. It's been frustrating and a long learning curve, and sending lots of emails and conversations back and forth telling providers, 'No, you can't come to us asking for more money. You need to talk to the participant about what's in their plan and how you can deliver on that. And if you can't you need to tell that to the participant and they will decide whether they come back and ask for a review of their plan or not'.' (CO3N)

Some providers were said to lack some of the know-how and general capability that would be required to successfully adapt to and co-operate with new service and payment management systems of the NDIA.

'... you know (a service provider) has never had a funding agreement but they've just been approved... You know they are struggling to even answer an email... we want them to then come on and do their on-line claiming and work on service agreements and things...' (E05-Manager)

Providers were thought to have been slow to register with the NDIA. Despite many publicity campaigns since and indeed before the start of the trial of the NDIS, NDIA staff continued to encounter a lack of knowledge and awareness of the NDIS and the NDIA itself in many local communities.

'A lot of people still don't have a lot of knowledge about the NDIA...Recently one of my colleagues and I went to a bowls club and they thought that we were trying to sell them insurance.' (C10N)

More recently, disputes about pricing structures were described to be complicating NDIS plan development and plan implementation, whilst in some trial sites, respondents suggested services were reaching capacity or remained limited, especially in regional and rural areas.

## 2.5.3.2 Assistance in setting and achieving goals, increasing economic participation

NDIA staff were universally cognisant of the objective of the NDIS to support the independence, and social and economic participation, of people with disability, and the importance to be striving towards achieving this objective. However there were warnings not to expect too much too soon during the setting up of the NDIS, as participants and the NDIA were still learning to adjust to new ways of supporting living with disability.

In the first instance NDIS participants were facing very practical hurdles as they were asked to think about new and perhaps innovative ways to support and structure their lives. In the eyes of many NDIA staff, this revealed that the capacity of NDIS participants, and their families and carers to negotiate access and to undertake planning and plan implementation might have been overestimated.

'Most people we've found have come in and they haven't really filled out their participant statement and haven't thought about it yet and you do have to actually take that extra time to just go back and talk to them and just try to find out basic things about them.' (E02N)

'(These) are really hard discussions to have with people, and particularly in a way that couches it in a really kind of empowering and supportive way. And that's quite skilled work.... sometimes it might be around things like us talking about a childcare or a playgroup option as opposed to a respite option. Now, that's really quite a sensitive conversation to have with... (a) parent who's coming in saying, "I need respite."' (A01N-Manager)

Some NDIA staff found that NDIS participants had difficulty adjusting their mind sets to the new concept of 'choice and control', in particular around individualised funding. In some instances, NDIS participants were described to be attending planning meetings with "a shopping list", rather than readiness to explore needs, or expected the Planner to make decisions on their behalf.

'That's the challenge, working with participants who aren't, who want you to do it for them. That's a real challenge. It's like, 'Well, actually I'm not here to do it for you. I'm here to do it with you. And they are very, very different practices.' (C08N)

A dominant theme though was the considerable level of anxiety and fear about the scheme on the part of participants and their families and carers, and resistance to change that had consequences for the outcomes of planning and plan content. For many this reflected and was occasionally exacerbated by anxieties held by their existing service providers.

The role of the NDIA in supporting social and community participation was seen to commence with the planning process. NDIA staff stressed the importance of individualising goals for participation, and not having pre-conceptions as to what participants wanted or ought to want:

'Sometimes people don't like being around other people so we have to be careful not to think everyone wants to go out to social things in groups...A lot of people just are so used to not being able to go anywhere they might say 'I just want to go down the shops and get the newspaper'' (E03N)

NDIS Planners typically described support plans as vehicles for providing opportunities and funding for skills assessment and training, designed to build capacity for independent living, and social and economic activity. Respondents were particularly concerned that plans clearly and realistically formulated expectations and objectives so to inform and tailor service provision.

'Really the funding provides a scaffold and a platform for a participant that's been unable to explore community and participate economically, and all the things that the NDIS aspire to achieve for its participants. It provides that opportunity.' (C08N)

'So what we're actually doing at the moment is we're really articulating in our plans... "We're funding you, one on one, to work with this person to enable them to join the Scout Group. Or enable them to go to Guides. Or enable them to go bowling or join the basketball team".' (B13-Manager)

Whilst encouraging NDIS participants to articulate such goals and aspiration, in the experience of NDIS staff, many NDIS participants found this challenging. Rather than assuming greatly ambitious projects, NDIS Planners conceived, with the NDIS participants, strategies consisting of small steps that were hoped to prepare the person for higher level goal setting in the future. This included breaking down goals and aspirations into prerequisite learning tasks, such as the need and opportunity to develop money handling skills, to develop or improve self-presentation and communication skills, or to connect to the wider social environment via volunteering.

'We identified volunteering as a really valuable role for people, and a skill building role. So... we just signed off on a project funding where we're going to have a number of participants working through [name of local scheme] to get them into volunteering roles within the community with volunteer mentors.' (B13-Manager)

Some respondents also felt that employment in a disability specific work place, i.e. an Australian Disability Enterprise (ADE) should be considered a stepping stone to seeking mainstream employment, and that the role of the NDIA was to "work with those ADEs in getting them to recognise that their service is a... skill building transition service to open employment" (B13-Manager).

Whilst all these considerations and reflections were taking place, the impression gained was that everyone still considered themselves and the NDIS in a learning phase, and that genuine progress towards enhancing the social and economic participation of NDIS participants was not expected to be made until after the first plan review meeting. It was then that NDIA staff could hear about the change that NDIS participants had or had not experienced and, based on these learnings, determine better informed plans for next steps.

'It's only really in now, heading forward as we're doing the plan reviews, that we have the opportunity to see those that have run with things we've put in like independent living skills assessments.... and have really embraced that, and are now looking out and beyond their world to see what else is out there, we see that.' (B13-Manager)

## **Assisting families and carers**

At present, planning meetings still focused almost exclusively on the needs and aspirations of people with disability, whereas those of family members and carers had yet to be more explicitly addressed. In the view of some NDIA staff, this lesser focus on family members' and carers' needs could be seen in the fact that few family members or carers had reported positive social or economic outcomes. This said, NDIA staff were conscious of the impact their decisions on the acceptability of certain supports for NDIS participants may have on the life opportunities of their families and carers. This was most apparent with respect to funding for in-home support to assist with the care of young children, which was described as

'to allow parents to study to think about their careers, think about job prospects, and that has worked in some cases' (B02N).

# 2.5.3.3 Relationship between NDIA employees and community and mainstream services

Our interviews highlighted desire and effort inside the NDIA to work with mainstream service providers, but also awareness of the need to clarify budgetary responsibilities and to determine the disability-specific and, hence, NDIS-eligible activities and cost items. NDIA staff at all levels were acutely aware that boundaries defining the financial and task-specific divisions between the NDIS and

other state or federal services had yet to be agreed upon. In the meantime, interaction with the health, education, child welfare, housing and also justice sectors were described as often fraught with difficulty.

'The interface with other mainstream services (Health Department, Justice, Child Protection, other service systems) still needs a lot of work.... (the) service systems are saying yeah "No that's not up to us, you have a disability so that's up to the NDIS" whereas that's not the case.' (C05N)

'There's still so much confusion of who's doing what, why, when and how... there's no living document to say "Well here's the agreement between how health interfaces with the NDIS and here's a document about justice". We're developing them on the run.' (B06-Manager)

Higher level policy matters were the principal domain of NDIA Managers, and subject to on-going negotiation. The daily practice of NDIA Planners, Plan Support Coordinators and Local Area Coordinators, however, brought them into regular contact with mainstream providers, both in state and federal government services, and community services. Planners often encouraged NDIS participants to use mainstream instead of disability specific programmes where possible, and involved Local Area Coordinators to help participants to access community services during plan implementation. In part, the role of the Local Area Coordinator was thought to include mapping opportunities for inclusion in mainstream and community within the trial sites. Collaboration between the NDIA and mainstream providers appeared mostly case-specific. In part, this seemed to reflect the strong initial focus of NDIA regional office activities on phasing in participants and (then) developing support plans, which was reducing opportunities for developing linkages with the community and the mainstream sector in a more systematic manner.

NDIA staff found some community organisations and facilities prepared and sometimes keen to provide services to NDIS participants. Existing and sometimes long established organisations were called upon to assist the NDIA with providing supports. Perhaps unknowingly, they also helped the NDIA to develop a better understanding of what works best in helping NDIS participants achieve their goals and aspirations, and better wellbeing.

'We have got young people into Men's Sheds, we've got them doing cooking classes in community houses who hadn't thought about offering that to a young person who wanted to learn to cook. So we've got those individual stories. It's building that up to give us evidence based...There are a growing number of stories that tell me that they're not the small exception.' (C01N-Manager)

However, the interactions between the NDIA and community services also brought to light some of the challenges that both partners may be facing if greater inclusion of people with disability in society is to be achieved. The most obvious challenge was for those offering or asked to provide services to NDIS participants being appropriately equipped.

'I think community centres are really wanting to be inclusive, for example, but often they're a little bit stuck because what they need is infrastructure... Same with a lot of the sports organisations. In community organisations they have little buses, so there's oodles of fantastic holiday programs that go on in the community, oodles of them. What do the buses not have? Accessible lifts. A lot of it is around big money stuff.' (C05N)

Moreover, NDIA Planners and coordinators also felt that many community organisations and General Practitioners did not have the personal resources and capabilities to work and communicate with NDIS participants, understanding how disability was affecting the latter's lives and what needed

doing to facilitate inclusion. The greatest challenge for effective community inclusion however was perceived to be not social, but economic integration. Although, as noted earlier, some NDIA staff felt employment at Australian Disability Enterprises could serve NDIS participants as a stepping stone into the mainstream economy, many doubted this was realistic and, if so, then only for people with less severe disability. Moreover, a few NDIA staff felt that Australian Disability Enterprises themselves did not always share this view or aspiration. Even if they did, given the sheer number of people with disability outside the labour market, the challenge, for many, was to convince the mainstream employer to employ people with disability.

'So we've got a hell of a lot of work to do with mainstream employment providers and businesses around looking at the benefits of employing someone with a disability, and how you might support someone with a disability in work place and make reasonable adjustments, and all those sorts of things.' (D02N)

## 2.5.3.4 Suggestions for improvement

In sum, NDIA staff reported considerable and often fast-paced change in the early implementation phase of the scheme. As policies and procedures evolved, so did staff roles, sometimes resulting in high levels of reported staff stress and fears that the organisational culture was changing and becoming more bureaucratic. The rate of change was subsequently thought to have slowed, and workloads lessened in some trial sites over time. This allowed some NDIA staff to spend more time with NDIS participants or in the communities, and contributed to markedly improved working conditions. Changes to organisational structures, for example the setting up of specialist teams in some of the trial sites, were also thought beneficial.

Nonetheless, respondents made a number of additional recommendations that they saw could further improve the operations of the NDIA and, ultimately, benefit NDIS participants.

In order to assist their own work as NDIA employees, respondents wanted to see further improvements to the organisation's IT systems, and revisions to the workforce and resource model that reflected recent experiences, in particular with respect to time spent doing administrative tasks as opposed to working with NDIS participants. Respondents also would like to see more investment in training, including specialist training working with specific disabilities, and professional development opportunities.

In order to provide better guidance and assistance to NDIS participants, staff suggested more resources be set aside to prepare participants for planning meetings as well as for the planning meetings themselves. It was also felt that further work was required to improve the transparency and consistency of NDIA procedures across the trial sites.

In relation to working with participants, NDIA staff thought more consideration should be given to the involvement of advocacy support during the support plan development. Several of our respondents also remarked that the information and documents prepared by the NDIA for NDIS participants were not always adequate and should be made more accessible to different audiences.

Finally, respondents stressed the importance of increasing community awareness and understanding of the NDIS in the community, and amongst people with disability and service providers more specifically. It was suggested the NDIA offered more support and capacity building with disability service providers, and that it continued to build relationships with the community sector and encourage relationship building within that sector.

# 2.6 Key Evaluation Questions addressed

This chapter brings together evidence reported in the preceding chapters on the Qualitative Impact Evaluation (QIE) and relates it to Key Evaluation Questions (KEQs) that have been identified by the Department and that this study is asked to address. The QIE has been designed to provide insights and answers to the KEQs over the two waves of evaluation fieldwork. In fact, some of the KEQs can only be answered over two (or indeed more) waves of interviewing as they seek to establish evidence of change, some of which can only be reasonably expected to become observable after some considerable time and may even be beyond the capacity of this evaluation to capture fully. For this reason, in this Initial report on the evaluation, the reporting on KEQs will be limited to those questions for which the evaluation could be reasonably expected to obtain some early indications of change.

In practice, this means, after this first round of interviews, our reporting on the KEQs focuses on observations of early operational implementation and NDIS plan development processes, and much less on the wellbeing outcomes for NDIS participants. The assessment of such long term changes would also benefit from cross referencing with the large scale quantitative surveys, where, at least in the case of the NDIS Survey and the NDIS Survey of Families and carers, the inclusion of a comparison group allows for a more robust change assessment.

In order to report on progress made with respect to the KEQs, this chapter breaks with the tradition of the previous ones to report findings not by population group, but by the KEQ supported by contributions from population specific interviews. Table 2.5 below illustrates the range of KEQs upon which this chapter will comment drawing on findings from interviews with people with disability, disability service providers, workforce stakeholder organisations and the NDIA.

**Table 2.5: Key Evaluation Questions** 

KEQ Number	Key Evaluation Question	People with disability, and their families and carers	Disability Service Provider s	Workforce stakeholder organisations	NDIA staff
2	To what extent has the NDIS contributed to changes in social and economic participation (including employment, education and the ability to express wishes and have them respected) for people with disability, their families and carers?	Yes			Yes
4	To what extent has an NDIS enabled people with disability, their families and carers to have increased choice and control over their supports?	Yes			Yes
5	To what extent did people have increased choice and control over the development and implementation of their plan?	Yes			Yes
8	How have people responded to increased choice and control?				Yes
9	To what extent has there been an appropriate balance between choice and control and safeguards for vulnerable people?				Yes
11	To what extent has an NDIS enabled people with disability to gain confidence that their 'reasonable and necessary' needs will be addressed?	Yes	Yes		
14	To what extent have people with disability, their families and carers seen NDIS review and dispute resolution processes as effective and fair?	Yes			
15	To what extent have people with disability, their families and carers been able to manage their funding on their own, customise creative sets of options for themselves, or find suitable brokers, depending on their preferences?	Yes	Yes	Yes	Yes
17	For people with disability who previously received supports, to what extent has an NDIS contributed to changes in their patterns and use of supports?	Yes	Yes	Yes	
19	For whom has an NDIS worked well or less well? Where possible, consider: (20) <i>Indigenous status,</i> culturally and linguistically diverse status, socio-economic status, proximity to services, age, gender, disability type and functional capacity, and age at onset of disability.	Yes			Yes
22	What sort of assistance do people with disability (or their families and carers, if they are managing the care) require to gain more control and navigate the system?	Yes			
24	To what extent has an NDIS helped people with disability, their families and carers during major life transitions such as starting preschool or school, leaving school, starting tertiary education, starting work, leaving home, leaving state care, leaving the workforce, and entering the aged care system?		Yes	Yes	

KEQ Number	Key Evaluation Question	People with disability, and their families and carers	Disability Service Providers	Workforce stakeholder organisation	NDIA staff
31	Have there been any other changes, including unintended changes (anticipated and unanticipated, positive and negative), in the experiences of people with disability, their families and carers as a result of the scheme?	Yes			
32	What has been the impact of an NDIS on the overall provision and quality of disability services?		Yes	Yes	Yes
33	Are clients satisfied that their supports are tailored to their individual needs and well-coordinated?				
34	What has been the impact of an NDIS on the disability sector, including the relevant government agency in each jurisdiction and advocacy organisations?		Yes	Yes	
35	Consider impacts on workforce (skills, retention rates, capacity, satisfaction, workforce culture, composition and proportion of occupation types).		Yes	Yes	
36	Consider impacts on supply and diversity of disability supports (particularly sustainability, ability to respond to choice and control, and service capacity).		Yes	Yes	
37	To what extent has the supply of disability services responded to demand?		Yes	Yes	
38	To what extent has an NDIS contributed to an increase in the provision of early interventions from disability services?		Yes	Yes	
39	To what extent has an NDIS contributed to more effective interface with mainstream services for people with disability, at an individual and a systemic level?				Yes
47	How well is an NDIS interfacing with education, health and public housing and how are these impacting on the capacity of an NDIS to deliver on its key goals?				Yes
56	What were barriers to the success of an NDIS? (Consider emerging and potentially significant barriers as well as actual barriers.)		Yes	Yes	Yes

# 2.6.1 Findings relating to Key Evaluation Questions

This section presents the evidence relating to each KEQ in turn and in the order the questions were assembled by the Department of Social Services. As some KEQ are closely related, some overlap of evidence may be unavoidable.

**KEQ 2:** To what extent has the NDIS contributed to changes in social and economic participation (including employment, education and the ability to express wishes and have them respected) for people with disability, their families and carers?

The strongest indications that the NDIS was making some difference to social and economic participation came from people with disability, and their families and carers themselves. Although qualitative evidence of this kind cannot be generalised per se, among those people with disability included in this qualitative study, most felt that their participation in social and everyday activities had indeed increased and that, as a result, many were learning new skills and enhancing existing capabilities. However, there were marked geographical variations in the extent to which these changes were reported to have been taking place, as particularly those living in regional areas felt opportunities to engage in social and economic activities were limited. For those in the metropolitan areas access to more diverse support arrangements helped to improve participation chances.

The larger and more dependable funding that the NDIS provided to NDIS participants, in particular to those with no or little previous support planning, was described as a main contributor to greater independence, which in turn helped to enhance engaging in social activities.

Unlike social participation, there were few instances of reported increased participation in paid or unpaid work. NDIS participants and NDIA staff argued that more needed to be done to develop effective guidance, supports and linkages to employers in order to open up labour market opportunities for people with disability. The study also came across a few instances of family members and carers regaining a footing in the labour market (paid or unpaid) after having been freed from some of their caring responsibilities as a result of support financed through the NDIS.

**KEQ 4:** To what extent has the NDIS enabled people with disability, their families and carers to have increased choice and control over their supports?

NDIS participants typically felt that the NDIS, through its plan development processes, was contributing to people with disability gaining more choice and control over their supports. Although NDIS participants often found it challenging to reflect on their support needs in terms of goals and aspirations, and thus also to take an active role in defining provisions, initial indications from the qualitative study was that NDIS participants felt positive about this change. The realisation of 'choice and control' in the provider market, however, continued to be problematic, in particular outside the main urban centres of the trial sites. There, provisions and providers were less numerous and thus choice more restricted. Somewhat disconcerting for NDIS participants and the NDIA was that, in some areas, there were few signs of this undersupply being corrected as there was little evidence of new providers entering the market or existing providers expanding their services. Providers were still seen to be reluctant, or insufficiently prepared or informed to be able to adapt to the new, emerging service environment. Some anecdotal evidence from NDIS participants, as well as assessments by disability service providers and workforce stakeholders suggested the NDIS funding mechanisms may constrain opportunities for new market developments.

The decision to self-manage was considered to provide widest access to service providers, including those who were not registered with the NDIA. So far, however, few of the respondents in this study had opted for self-management, being wary of the extra responsibilities and bureaucracy this may involve.

The interviews also revealed that some NDIS participants did not feel they had sufficient information to choose their service providers confidently. In particular, these participants would have liked more information about services available from each provider, and help with defining factors on which to base their choice when guizzing providers.

**KEQ5:** To what extent did people have increased choice and control over the development and implementation of their plan?

As noted above, the plan development and also the plan implementation processes were novel to many NDIS participants and their families and hence challenging for some. Respondents reflected on the importance of having an understanding Planner, particularly someone who had experience with disability-specific needs. Respondents also indicated the importance of an advocate in this process.

NDIS participants reported some instances where a support plan appeared not to have reflected their understanding of the conversation with an NDIA Planner. NDIS participants generally found the process of setting goals difficult, notably because, for them, this was a new way of approaching disability support planning and making informed choices was difficult when options were unclear to participants. Some found the resources supplied by the NDIA to help prepare for planning sessions useful, while others relied on social media and advocates for extra guidance. There thus appeared to be scope for increasing choice and control during the planning stages through the provision of more information, pre-planning learning sessions (which have now started and were being welcomed) and direct support, as offered by advocacy organisations.

The implementation of the plan generally worked well where NDIS participants had been successful in obtaining funding to ensure continuity of services. Continuity of service was often the choice of NDIS participants because they were content with provisions but also because some feared the uncertainty of change. In addition, work pressures inside the NDIA also meant that existing plans and provisions were retained because the development of new plans was delayed.

**KEQ8:** How have people responded to increased choice and control?

Taking advantage of greater choice and control at the NDIS planning stage did not always translate into greater choice and control over support acquisition and utilisation as the provider market was only changing slowly. The qualitative evidence suggests that NDIS participants sought more frequent and more intensive support rather than necessarily choosing different types.

**KEQ9:** To what extent has there been an appropriate balance between choice and control and safeguards for vulnerable people?

The qualitative evidence did not encounter any great concerns about the balance between choice and control, and safeguards for vulnerable people from NDIS participants themselves. NDIA staff and disability service providers, however, expressed concern about safeguards in cases where NDIS participants had limited capacity to understand NDIA processes or might be using support providers not registered with the NDIA.

**KEQ11:** To what extent has the NDIS enabled people with disability to gain confidence that their 'reasonable and necessary' needs will be addressed?

The boundaries of what were 'reasonable and necessary' supports and what were not were often not clear and apparent to NDIS participants and thus became, for many, a cause of dissatisfaction with NDIS plans. Thus, some NDIS participants were dissatisfied with decisions about therapies and services that were not funded by the NDIA, although they had been allowed as part of pre-NDIS funding packages. The interviews with NDIS participants also suggested that the NDIA changed guidance as to what was eligible for NDIS funding and what was not in the course of the roll-out. This was seen to result in inconsistencies and indeed inequity in support provision across trial sites.

There was also confusion among NDIS participants as to whether certain support needs were to be met by the NDIS or the mainstream health and education sectors. This confusion was echoed by NDIA staff and workforce stakeholder organisations, who stressed that the division of responsibility, in particular with respect to support funding, required further clarification.

**KEQ14:** To what extent have people with disability, their families and carers seen NDIS review and dispute resolution processes as effective and fair?

Only a few NDIS participants in our study had already gone through a plan review and yet fewer had disputed support plans. Plan reviews were described as helpful and beneficial, but also plagued by — what was perceived to be — unnecessary paperwork. NDIS participants and carers had contradicting understandings of the plan review process as some believed it to be a dynamic and ongoing process, whereas others believed plans could only be changed at annual or bi-annual review meetings. In reality, several participants reported having had plans changed outside the formal review process at their request. This was particularly the case for young children whose needs for support were constantly changing.

**KEQ15:** To what extent have people with disability, their families and carers been able to manage their funding on their own, customise creative sets of options for themselves, or find suitable brokers, depending on their preferences?

The option of self-managed funding was not always fully understood by NDIS participants; nor was it always discussed in the planning meetings. Most respondents chose not to self-manage, because they perceived it as complex and incurring a large administrative burden. Those who decided to self-manage funding were positive about the benefits of doing so, principally in relation to greater choice and flexibility in accessing non-NDIS service providers.

Disability service providers and workforce stakeholder organisations confirmed that they had come across few NDIS participants who were self-managing their funding. Providers believed that self-managing funding would eventually lead to increased choice for NDIS participants, but were concerned that providers not registered with the NDIA or otherwise accredited may not have the skills or provide the quality of service that NDIS participants expected and needed. For this reason, disability service providers called for quality assurance measures to be put into place alongside safeguards to protect NDIS participants from financial exploitation and substandard services.

**KEQ17:** For people with disability who previously received supports, to what extent has the NDIS contributed to changes in their patterns and use of supports?

NDIS participants who had previously already received disability supports typically continued to access existing providers and similar supports, because they had been content with previous provisions. In some instances, however the lack of market movement meant that, de facto, few alternative providers or provisions were becoming available. Exceptions were where products could be procured from outside the NDIS participant's area of residence or range of usual providers, facilitated by more flexible funding arrangements, notably self-management of funds.

Thus NDIS participants in this study who changed supports had typically done so by adapting supply frequency or type rather than changing their source. This included increasing the hours of supports, their intensity and regularity, acquiring more appropriate equipment, or accessing a wider range of activities.

Concurrent with the accounts of NDIS participants, disability support providers reported experiencing or observing only incremental changes in the use of disability supports amongst their clients and customers since the introduction of the NDIS. Workforce stakeholder organisations argued that the types of services demanded by participants were starting to change, with a greater emphasis on facilitating social and community participation, communication, and personal care, which lends support to our initial findings reported with respect to KEQ2. However, providers and NDIS participants also reported occasions of the latter not receiving the supports that they had expected to receive which had been part of earlier support packages. This was also acknowledged by NDIA staff who pointed out that changing the itinerary of supports was sometimes seen as part and parcel of developing a more ambitious programme of supports that was aiming to lay the foundation for greater independence in the longer term. It was not clear that NDIS participants thus affected always understood and shared this perspective.

**KEQ19:** For whom has the NDIS worked well or less well? Where possible, consider: Indigenous status, culturally and linguistically diverse status, socio-economic status, proximity to services, age, gender, disability type and functional capacity, and age at onset of disability.

At this early stage, it was difficult to note more than some early impressions as to the socio-demographic equity of the NDIS, which, in any case, is better scrutinised using the (quantitative) NDIS Survey. This said, the evidence from the qualitative study does point to inequities emerging – or continuing to exist – with respect to the place of residence of NDIS participants, with those living outside metropolitan and regional centres continuing to encounter fewer service options than NDIS participants elsewhere. Moreover, NDIS participants were faced with the potentially costly decision to travel to access supports in the service centres; generating additional costs, which participants found were not covered in their support plans.

The evidence from interviews with NDIS participants and workforce stakeholder organisations also suggested that people with (often fluctuating) mental illness fared somewhat less well under the new system than those with physical support needs, who were typically better able to articulate their needs. NDIA staff themselves noted the difficulty they faced with accommodating the needs of people with mental illness and translating those needs into planned supports.

Reduced literacy among some NDIS participants and a complex, bureaucratic language used in NDIA documentation, including access and processing forms, were also described as raising communication barriers between NDIS participants and NDIA staff, leading to inequitable outcomes. NDIA staff reported challenges with respect to engaging with people from culturally and linguistically diverse or Aboriginal or Torres Strait Islander backgrounds.

**KEQ22:** What sort of assistance do people with disability (or their families and carers, if they are managing the care) require to gain more control and navigate the system?

NDIS participants criticised the often lengthy and complicated process of establishing NDIS eligibility, exacerbated by the initially unresponsive administration of the scheme on the part of the NDIA. This was reported to have resulted in delays between first and subsequent contact, feedback on access enquiries and telephone enquiries remaining unanswered. These difficulties were acknowledged by NDIA staff who also reported about their high workload, which reduced contact with individual participants and a more customised service.

NDIS participants argued that they would have welcomed more and better advice and assistance in preparation for planning meetings, including, for instance, sample copies of plans to illustrate goal setting, and lists of eligible and accessible services. They also would have liked more help in understanding the plan and how it related to their needs. All respondent groups advised the use of advocates to facilitate planning meetings.

**KEQ24:** To what extent has the NDIS helped people with disability, their families and carers during major life transitions such as starting preschool or school, leaving school, starting tertiary education, starting work, leaving home, leaving state care, leaving the workforce, and entering the aged care system?

Managing transitions into school, between school and work, and between home and independent living was a key concern for respondents from the Tasmania and South Australia trial sites. In Tasmania, almost all respondents felt that the NDIS was playing a significant part in facilitating these transitions by providing access to activities and individual support around life skills, practical skills, communication and self-confidence. As a result, many families felt more optimistic about the prospect of their child living more independently and being more fulfilled through social and economic participation in the future.

The key transition point for NDIS participants in SA was the transition to school, with fewer transitions to child care and kindergarten. While educational goals were invited and included in a child's plan, the NDIA did not fund learning and other supports that were considered to be in the domain of the Department of Education and Child Development (DECD). This separation of responsibilities was a source of frustration for parents/carers of older children who perceived their child's educational needs were not being met and that the NDIA was not advocating on their child's behalf with DECD.

**KEQ31:** Have there been any other changes, including unintended changes (anticipated and unanticipated, positive and negative), in the experiences of people with disability, their families and carers as a result of the scheme?

NDIS participants did not observe any unintended changes that were attributed to the NDIS at the time of the first round of data collection. While the process of developing a plan and obtaining funding was not an easy one, and extra administrative work and time went into the process that may not have been anticipated at first, most of the changes to the participants' and their family members and carers lives connected to the NDIS were as would have been intended and indeed foreseen.

The same could not necessarily be said about the wider disability support environment as our interviews identified two instances of potentially unintended, adverse outcomes of the trial of the NDIS. First, respondents noted the cessation of support groups and community groups, which could not operate without block funding. Second, respondents in some trial sites also reflected on a decline in the quality and availability of government funded (therapy) service provision as large numbers of staff were leaving the service in anticipation of its closure following the roll out of the NDIS.

**KEQ32:** What has been the impact of the NDIS on the overall provision and quality of disability services?

NDIS participants were more likely to report changes in the overall provision than in the quality of disability services. As most participants had decided to retain existing disability service providers, it was the frequency and intensity of supports that was most likely to have changed, not so much the quality or range of the individual provisions. Of course, the latter was typically reported to be reasonable and acceptable, which had encouraged NDIS participants to continue to stick with their current providers in the first place. Quality changes were mainly reported where the NDIS had enabled participants to source disability products more flexibly and from non-traditional sources (i.e. by shopping on the internet).

Disability service providers felt that the NDIS had improved participants' access to allied health supports and services as a result of better funding arrangements. Providers were conscious of the fact that, in order to compete successfully in the new disability services market, they would need to ensure high quality goods and services. However, along with the workforce stakeholder organisations they also felt that current NDIS pricing structures made this difficult as they did not cover the actual costs of providing support. Whereas larger providers may, at least initially, be able to address this by cross-subsidising activities, smaller organisations would not be able to do so and may be at risk of exiting the market.

Aside from support changes, disability service providers observed changes to their relationship with clients. According to some NDIS participants, service providers had become more open with clients about the types and costs of the services that they offered. This openness had typically strengthened relationships with clients; however there was some concern that the focus on financial aspects of service provision interfered with the ability of disability service providers to establish a relationship of care with the client and their family.

**KEQ33:** Are clients satisfied that their supports are tailored to their individual needs and well-coordinated?

NDIS participants did not report a change in their perceptions or assessment of the tailoring of supports other than noting that 'choice and control' remained limited as long as the provider market remained largely unchanged. The ability to increase the frequency of supports, especially in the home, was described as improving the lives and social participation opportunities of NDIS participants, and their families and carers.

**KEQ34:** What has been the impact of the NDIS on the disability sector, including the relevant government agency in each jurisdiction and advocacy organisations?

Disability service providers and workforce stakeholder organisations reported a number of impacts the NDIS trial has had on the disability sector. These included reports of some new providers, changing relationships between existing providers, and sustained concerns about the financial viability of the sector under the new funding system. NDIS staff, providers and stakeholders all confirmed the difficulty the sector was facing in switching from payment-in-advance under the old

block-funding arrangement to payment-in-arrears under the new funding system. It was doubted that smaller organisations would have the financial capacity to obtain bridge funding for supports provided in advance. In rural parts, the volume of business that providers may legitimately expect to receive was also feared to be insufficient to sustain smaller providers without significant revisions to their individual business models in the long run.

Whereas the anticipated influx of new providers to the sector had not eventuated, disability service providers did indicate that providers new to the local market were registering with the NDIA, although few were actively providing services in the trial sites. At the same time, there were no reports of disability service providers exiting the market in the trial sites.

The move to a competitive market was suggested to have resulted in changes to the relationship between existing providers, with disability service providers now being more guarded in their interaction with other, competing providers. This said, as the trial progressed, there was also evidence of some disability service providers increasing collaborations in efforts to share learnings and experiences about operating under the NDIS.

Workforce stakeholders expressed concern about the withdrawal of state government provided disability services, which left the job situation and prospect of government workers uncertain.

**KEQ35:** Consider impacts on workforce (skills, retention rates, capacity, satisfaction, workforce culture, composition and proportion of occupation types).

Disability service providers reported that the introduction of the NDIS model and its emphasis on transdisciplinary working and individualised service provision had resulted in changes to staff training and the skills sought by organisations. Some explained that they had changed their recruitment strategies and restructured the roles and functions of staff within the organisation early on in anticipation of the NDIS.

Providers reported seeking to develop a transdisciplinary skills base integrating in-home support provision, person-centred care and specialist recreation skills. Whilst articulating these ambitions, providers also reiterated their concerns about the NDIS funding model, whose reimbursement rates were deemed too low to cover auxiliary costs, such as staff training.

Low NDIS pricing was also feared to undermine providers' ability to attract additional staff to the sector through more attractive remuneration packages and improved working and staff development conditions. Providers already felt they were competing with the NDIA for staff who could expect better pay in the public sector. At the same time, the move to a more commercial, business-like model of service provision had led some providers to lose staff who had felt uncomfortable with the implied change in ethos or felt less secure in their jobs.

There remained considerable uncertainty and, in fact, scepticism amongst providers as to their capacity to break even on operational costs within the framework of the new funding regime. Several providers pointed out that they would not be able to honour conditions agreed with staff under current Enterprise Bargaining Agreements if full operating cost were not being met.

Workforce stakeholders expressed similar feelings of anxiety and uncertainty regarding future employment and working conditions among members, in particular in state-operated disability services. They felt that individualised funding could adversely affect employment conditions as employees may have to respond to growing demands for working during atypical hours or being on call, thus changing existing relationships between clients and providers, and employees and employers. Concerns were also raised by the workforce stakeholder organisations regarding the

impact of individualised funding arrangements of the NDIS on wages, employment contracts and career structures.

In the NDIA, early recruitment of staff was generally thought to have resulted in a diverse and committed workforce. However, the pressures of high workloads and changing role expectations were reported to have taken a toll on staff morale, leading to resignations in some trial sites during early trial phases.

**KEQ36:** Consider impacts on supply and diversity of disability supports (particularly sustainability, ability to respond to choice and control, and service capacity).

In this early phase of the NDIS trial, evidence of changes in the supply or diversity of disability supports were few and far between. As noted above, market changes were slow to materialise, both as a result of a slowly adapting or emerging provider sector, and as a result of NDIS participants often retaining existing provisions. In a circularly reinforcing fashion, the two phenomena were, of course, intrinsically linked.

Overall, the QIE encountered a variety of often contradictory views amongst both service providers and workforce stakeholders. In the twelve to eighteen months after the trial had begun, some respondents had observed a greater flexibility among service providers who were offering and delivering supports more closely aligned with users' requirements. Others also reported new providers entering the market, such as aged care organisations in rural areas. At the same time and in part contradicting the above, providers and workforce stakeholders repeatedly stressed the constraints that the new funding regime was imposing on the former as a result of which the provider market had not changed much. Overall, the impression gained from the interviews was that among both providers and workforce stakeholders, anecdotal insights prevailed over well informed knowledge.

**KEQ37:** To what extent has the supply of disability services responded to demand?

The accounts offered by NDIS participants suggested demand for more frequent provision of services rather than a fundamental change in their nature, although opportunities for the latter were curtailed by limited availability or limited knowledge of their availability, or both. The supply appeared to have responded positively to these changes in demand, albeit sometimes as a result of the determined initiative of NDIS participants, and their families and carers.

Both NDIA staff and disability service providers reported that providers had initially been slow to register with the NDIA, but that registrations had been picking up more recently, giving NDIS participants access to a broader range of potential providers and provisions. Disability service providers explained that they had been adding to the number of services that they were registered to deliver under the NDIS. This increase was accredited to a greater familiarity with the range of supports that could be funded under the NDIS as well as to increased demand from clients.

According to providers and NDIA staff, demand had especially increased for services facilitating greater independence in the home and in the community, shifting from group-based services to individual and community-based services. Providers said they had responded to these demands by introducing more flexible arrangements around the types of services they provide, and ensuring that the provision of those services were at times and locations that suited participants.

Workforce stakeholders had not observed this change in demand affecting workforce levels or conditions in any significant manner.

**KEQ38:** To what extent has the NDIS contributed to an increase in the provision of early interventions from disability services?

Disability service providers noted an increase in requests for, and supply of, early intervention measures, which they thought might eventually help to take pressure off other sectors, for example, the health sector by reducing the incidence of hospitalisation. Early interventions were also thought to reduce waiting lists in mainstream provisions and increase support for families with young children.

**KEQ39:** To what extent has the NDIS contributed to a more effective interface with mainstream services for people with disability, at an individual and a systemic level?

Some NDIS participants reported disputes over the funding for disability support in a school setting, with NDIA and state education departments disagreeing over who should foot the bill. NDIA staff and workforce stakeholder organisations acknowledged that more needed doing to bridge the gap between mainstream services and the NDIS, including overcoming uncertainty with respect to supporting people with mental health problems.

**KEQ47:** How well is the NDIS interfacing with education, health and public housing and how are these impacting on the capacity of the NDIS to deliver on its key goals?

As noted above, there appeared to be evidence of unresolved issues with respect to the responsibility for funding disability supports in different institutional settings. However, the qualitative study was only able to record anecdotal and sporadic evidence.

**KEQ56:** What were barriers to the success of the NDIS? (Consider emerging and potentially significant barriers as well as actual barriers.)

The most significant current barrier to a fully successful NDIS is the fast pace of the trial and anticipated roll-out, which NDIA staff found challenging. Disability service providers also found it challenging to deal with the amount of change required in order to adapt to NDIS requirements. Resulting administrative burden and costs in staff time were major concerns, in particular as changes to the funding of services were feared to impact adversely on staff training capacity and broader operational viability.

There appears to be scope for further improving communications between the NDIA and communities, including service providers, and providers of social activities or employment, to more actively promote the social and economic integration of people with disability, and their families and carers.

# 3. NDIS Survey of people with disability, and their families and carers

## 3.1 Introduction

This chapter presents large scale longitudinal data collections of people with disability, and their families and carers. This data will form part of the comprehensive evidence base we will use for the NDIS Evaluation. The data has several important attributes. First, the surveys are large data set collections with thousands of individuals sampled. The large sample size is necessary in order to ensure that the ensuing data set will be able to capture the full range of experiences the evaluation needs to measure with sufficient statistical accuracy. This is necessary for dealing with a large scale and diverse national policy. Second, the surveys approach the same individuals twice over the period in which the NDIS is rolled out in the trial sites. The repeat sampling (called a 'longitudinal' or 'panel' survey) will allow the evaluation to assess the impact of change by observing the same people over the period in which the policy change is happening.

The reader is advised to keep in mind that the evaluation is also collecting extensive qualitative evidence, asking very similar questions of very similar people but with a very different emphasis and little duplication of effort. Whilst the quantitative methodology allows the performance of a formal evaluation measuring the impact of the NDIS, the qualitative methodology brings the depth and granularity of understanding and interpretation of individual people and circumstances needed for the interpretation of the relevant policy. The two methodologies have been built into the evaluation design in a complementary way to help us measure accurately and interpret correctly the impact of the NDIS trial roll out on people with disability, and their families and carers.

Thus, the qualitative evidence collection focusses on depth of investigation, granularity of data, aiming at valuable insights that can only be gained through incisive interviewing. The quantitative evidence collection focusses on achieving as statistically robust as possible coverage of the relevant experiences and as long as possible coverage of the relevant time period when the policy change happens. The quantitative data collection has been designed to match the Difference-in-Difference evaluation methodology, as described in the Evaluation Framework (2014).

# 3.2 Design and development – the sampling process

This section provides background information to the design and development of the NDIS Survey, which consists of the NDIS longitudinal survey of people with disability (NDIS Survey) and the NDIS longitudinal survey for Families and Carers (NDIS Survey for Families and Carers). The surveys are designed to collect two waves of data by interviewing the same people twice, with an intervening period of 10-12 months between the two interviews. The first data collection we call Wave 1 is designed to be as close as possible to the start of the NDIS and the second data collection we call Wave 2 relates to the point when respondents have had at least one year's experience of life with the NDIS. The main purpose of interviewing the same people twice is in order to collect information on how things have changed following the introduction of the NDIS. As explained in the Evaluation Framework, in order to measure change due to the introduction of the NDIS, on top of the information we collect from the trial groups (the trial sample), we also collect information from respondents not included in the trial who have not been exposed to the NDIS (the comparison group). The difference between the experiences of these two groups reflects the impact of the NDIS.

## 3.2.1 Sample design by location: trial and comparison groups

The trial sample of people with disability aims for a total of 3,110 people with disability participating in the NDIS to be interviewed over the two waves. The comparison group sample aims for a total of 1,770 corresponding interviews. Both trial and comparison samplings aim to interview the families and carers of the persons with disability. Since not every person with disability necessarily has a family or a carer, the number of responding families and carers will be lower than the number of responding people with disability in both trial and comparison groups.

Table 3.1 summarises the targeted number of responses for each of the participating trial sites in the original evaluation design. This number took into account differences in the number of NDIS participants to be rolled into the Scheme during the trial phase. The distribution of the sample sizes by trial site was decided in order to optimise statistical robustness for the given total sample size. In order to achieve the (3,110 + 1,770 =) 4,880 responses in Wave 2, the starting sample needed to be considerably larger, in order to allow for attrition between waves and refusal or non-response at the various stages of the survey. Table 3.1 presents the relevant calculations based on the original assumptions that:

- (i) about 65 per cent of NDIS participants and 45 percent of people with disability in the comparison group invited to take part in the NDIS Survey would do so
- (ii) about 85 per cent of NDIS participants and 80 per cent of comparison group respondents in the first wave of interviews would also respond at Wave 2.

Table 3.1: Estimates of NDIS eligible populations and required sample sizes

Survey area	Eligible Population (age group)	Estimated Eligible Cases (by end of 2016)	Estimated sample size required at Wave 1**	Estimated response required at Wave 1*	Responses after 2 waves of interviewing (target)
South Australia	0 to 14	4,800	1,177	765	650
	years				
Tasmania	15 to 24	1,000	778	506	430
	years				
NSW (Hunter)	0 to 64	10,000	1,268	824	700
	years				
Victoria (Barwon)	0 to 64	5,000	1,194	776	660
	years				

Survey area	Eligible Population (age group)	Estimated Eligible Cases (by end of 2016)	Estimated sample size required at Wave 1**	Estimated response required at Wave 1*	Responses after 2 waves of interviewing (target)
ACT	0 to 64	6,000	1,212	788	670
	years				
TOTAL trial sites		26,800	5,629	3,659	3,110
Comparison group	n/a	n/a	4,918	2,213	1,770

Note: \* assuming response yield of 65 per cent in trial and 45 per cent in comparison group. \*\* assuming 15 per cent attrition rate in trial and 20 per cent in comparison group

The comparison group pilot study indicated clearly that a much larger sample than the originally assumed 4,918 people with disability would be required for this group. The main reasons were (i) the high proportion of incorrect contact details, and (ii) the high proportion of correct records that would be ineligible because the relevant form did not contain appropriate consent information. Cases of incarcerated people and people with violent behaviour were also removed. The final sample size that needed to be drawn in order to aim for 1,770 Wave 2 responses in the comparison group was 14,049 records.

## 3.2.2 Differences within trial sites and between trial sites

NDIS participant populations in the five trial sites were designed to be different from one another. In South Australia and Tasmania, only young people aged 0-14 and 15-24 respectively were to be transferred into the NDIS in the trial period of 2013 to 2016. In the other three sites all people aged up to 65 and living with a severe and permanent disability were deemed to be eligible to join the NDIS.

Transfers into the NDIS are conducted in phases in all trial sites. For example, South Australia targeted those aged two years or younger for NDIS participation in the first trial year. The other trial sites appear to have used a combination of institution, provider, or program-based as well as age-differentiated approaches to phase-in participants in the first year of the trial. Trial site residents whose disability is diagnosed during the trial period or who move between trial sites may enter the NDIS regardless of any phasing-in rules that may apply at the time.

Data collected by the Australian Institute of Health and Welfare suggests that differences in terms of disability arising from the non-random phasing in of the NDIS in the trial sites, may also result in marked differences in support needs and service use between the trial sites. Although such differences would be expected to even out naturally as the number of NDIS participants increases, their impact in the beginning of the roll-out could influence the picture that emerges in our statistics.

# 3.2.3 Phasing in of the NDIS trial roll out and sampling timeline implications

The fact that the NDIS trial roll out ended up being both late and not random, presented certain challenges to the survey design and implementation. The slow roll-out resulted in insufficient sample sizes in most trial sites for Wave 1 data collection. This problem is at its most acute in the Australian Capital Territory (ACT), where the roll out started in July 2014 and the realised sample sizes are well below the targets. Our general strategy for responding to the overall slow roll-out and the late ACT trial start has been the design of Waves 1a, 1b and 1c, with 1a almost complete and 1b in the field in July 2015. These 'earlier' waves are designed to include all NDIS participants who consent to being approached for research purposes, thus forming a census at the time the samples are drawn. Waves 1c and sampling in the ACT are yet to be precisely defined and implemented.

The non-randomness of the NDIS trial also presents challenges to the survey design and the design of the subsequent analysis. Although some information about the planned phasing in of NDIS participants in each trial site has been publicly available, this was too approximate and provided little insight into the socio-demographics of participants to be of practical use to the sampling. The main way in which this affected the survey has been the introduction of uncertainty as to the appropriate composition of the comparison sample. We must remind the reader that a highly desirable feature of the comparison group would be to contain people with similar type and severity of disability and, to the degree that this is possible, people who resemble the NDIS participants in their sociodemographic characteristics as well. The non-random roll out coupled with lack of precise information about the characteristics of the NDIS participants in the trial sites has made this job harder. A strategy of mixed sample design has been employed to alleviate the consequences from this lack of information in that half of the sample was based on our present knowledge on the NDIS participants and the other half on more general (population based) knowledge on how disability is distributed in Australia. We utilised the disability information in the DHS data to construct equivalent scales and appropriately stratify part of the sample, applying a strict potential eligibility selection rule which, on the one hand requires a larger initial sample from the DHS, but on the other hand can be expected to produce a better quality comparison group. The resulting data can be matched better with the NDIS sample.

# 3.2.4 Sampling for trial and for control samples

The evaluation of the impact of the trial of the NDIS using survey data is built on contrasting the experiences of NDIS participants with those of other people with similar disability. This comparison group comprises people with disability who are not (currently) eligible to join the NDIS because they do not live in a trial site or because they do not meet the age-based eligibility conditions of the NDIS trial. Therefore, the age, sex and disability of NDIS participants guided the evaluation in the determination of the composition of the comparison group.

Sampling for the NDIS Survey and the NDIS Survey for Families and Carers drew on four different administrative data sources. The sampling of NDIS participants, that is, for the trial group, relied on the participant data base prepared and made available by the National Disability Insurance Agency (NDIA), to the survey company. The survey company kept all individual information confidential in a design that guaranteed that the evaluation research team only handles records in an anonymised form. The sampling from the comparison population relied on administrative data of recipients of Disability Support Pension (DSP), Carer Payment (CP) or Carer Allowance (CA), made available by the Department of Human Services (DHS) to the survey company. The same confidentiality and anonymisation rules applied to the comparison group.

The NDIA administrative data identified the NDIS participant and, in some cases also a family member or carer. The NDIS Survey in the trial sites considered all NDIS participants who had agreed to participate in research, as eligible for the survey.

A much larger pool of potential sample members was available for the comparison group, which was able to draw on several hundreds of thousands of DSP, CP and CA recipients. The comparison group sample was drawn from DSP, CP and CA recipients living within the trial states, but not being eligible for the NDIS during the trial period. That is, they were either of a different age (in South Australia and Tasmania) or lived outside the actual trial site (in New South Wales and Victoria). Since all people with disability are potentially eligible for the NDIS in the ACT, no comparison sample was drawn from the ACT.

The comparison sample was divided into two equal halves. The first half of the comparison sample was matched on age, gender and broad type of disability to current NDIS participants, and was drawn

from a combination of DSP and CP/CA records. The latter records were used to capture young people with disability who did not receive DSP but in all other respects match young NDIS participants.

The second half was a random sample drawn from all DSP, CP and CA recipients whose disability was assumed to be sufficiently severe and long lasting to render the person potentially eligible for the NDIS if he or she had lived in a trial site and met its current conditions for eligibility. This judgement was based on information provided in the DHS sample about the person's 'impairment rating' and duration of payment or allowance receipt.

Matching trial and comparison samples on disability proved challenging as the sampling frames used different disability categories and labels. We aggregated these up to a shared platform based on the World Health Organisation's International Classification of Functioning, Disability and Health (ICF), version 10. Moreover, although the DHS sample included a claimant's impairment rating, this information was not available for all and was generally considered unreliable. A more straightforward approach to matching between trial and comparison groups had been envisaged by the design of the project, based on obtaining information from relevant administrative data sources. This approach was not pursued due to time and financial considerations.

# 3.2.5 Sampling the Family and Carer

The DHS administrative datasets used for the sampling of the comparison group, identify family members or carers for a large proportion of DSP recipients. The NDIA administrative data used for the sampling of NDIS participants contains a much smaller proportion of people with disability with information on their families and carers. To fill this gap in the sampling, additional searches and matching of NDIS participants with a family member, carer or nominee were undertaken by the NDIA on behalf of the evaluation team for the initial trial sample. Where a link to a family member, carer or nominee was established in the administrative data, these family members, carers or nominees were considered to be eligible for the NDIS Survey for Families and Carers, subject to their consenting to participate in research. In the case of NDIS participants under the age 18 for whom a family member, carer or nominee could not be identified from the administrative data, it was assumed that this person could be contacted at the same address.

Adult people with disability in the NDIS or in receipt of DSP, for whom no family member or carer was identified in the datasets, were asked to nominate a person who was then invited to participate in the NDIS Survey for Family and Carers. This lack of family and carer information is one reason a survey registration process was introduced.

For the comparison sample, family members and carers were also identified directly from the CP/CA administrative datasets. The CP/CA datasets were used to sample young people with disability who would otherwise not be captured if sampling had solely relied on DSP records.

## 3.2.6 Initial and later sampling

The first sample of NDIS participants and what we expected to become the full comparison group sample for the main fieldwork were drawn in January and February 2014. In the case of the trial group, the sample included all NDIS participants who had consented, in principle, to take part in research related to the NDIS.

At the end of 2013, some 4,052 people with disability had transferred into the NDIS, including 2,586 who had already approved support plans. Approximately 2,300 NDIS participants indicated they would consider taking part in NDIS research. Since this number left the NDIS Survey well short of the minimum sample size of 5,629 in the original project design (see Table 3.1), people with disability who joined the NDIS between January and May 2014 (and had consented to being contacted for research) were added to the sampling frame. This brought the total number of potential participants to 5,860 NDIS participants. This first sample is referred to as 'Wave 1a'.

The sample of NDIS participants was further topped up with 5,313 NDIS participants who had joined the NDIS between May 2014 and October 2014. Of these, 3,027 had consented to participating in NDIS research. The objective of this 'top up', referred to as 'Wave 1b', was to include early entrants into the NDIS in the Australian Capital Territory (ACT) that had commenced in July 2014 and to increase the sample sizes elsewhere. Registration for the NDIS Survey (see below), which began in August 2014, proved to be slower than expected and led to the precaution of the additional top-up in the initial four trial sites.

## 3.2.7 Opt-out/in

Before the fieldwork of the NDIS Survey or the NDIS Survey for Families and Carers could be conducted, two opt-in and opt-out procedures were applied. In the first instance, as already noted, only NDIS participants or DSP or CA/CP recipients, who had previously indicated that they would be willing to be considered for research, were included in the original sampling frame. This led to a significant loss in sample numbers among NDIS participants, as can be seen from Table 3.2.8 While several NDIS participants had refused consent to be part of research, others appeared to have neither given nor refused this consent. (The NDIA verified these records, re-contacting participants to seek determination.)

Table 3.2: NDIS Survey study populations and samples

	Trial site Sample Wave 1a N	Trial site Sample Wave 1a %	Trial site Sample Wave 1b N	Trial site Sample Wave 1b %	Comparison Sample Wave 1 N	Comparison Sample Wave 1 %
Study population	5,860		5,313		757,614	
Original sample	5,860	100	5,313	100	14,049	100
Sample after research consent check	4,448	75.9	3,027	57.0	n/a	n/a
Sample after opt-out*	3,948	67.4	2,724	51.2	7,832	55.7

Note: \* with contact details confirmed useable by survey company

In the case of individuals in the DHS administrative datasets, consent was not recorded for everyone and in some instances the record was deemed unreliable because the consent had been given several months or years earlier. An additional complication came from the fact that the wording of the consent question in the DHS forms has been changing over time. In order to safeguard the privacy of recipients of DHS payments and allowances, a further opt-out procedure was introduced, in which every individual in the comparison sample was written to and informed about the study. Those who did not want to participate were given an opportunity to opt-out.

<sup>&</sup>lt;sup>7</sup> National Disability Insurance Agency (2014) Quarterly Report to Disability Reform Council - 31 December 2013.

<sup>&</sup>lt;sup>8</sup> Since Waves 1a and 1b were sampled and went into field at very different times and, hence, have different levels of 'maturity', sampling statistics are reported separately for each.

For reasons of methodological symmetry, the same opt-out process was used for the trial sample. The opt-out meant that a further 12 per cent of cases were lost in the trial sites. In the comparison sample, the loss included instances where contact and case details were found to be unusable by the survey company, increasing the total post opt-out loss to 44 per cent of the comparison sample that had consented to being approached for research purposes (see Table 3.2). A comprehensive account of attrition at all relevant points of the sampling process will be presented with the analysis of the full Wave 1 data in the Intermediate Report. More details of the various attrition points will be presented after all fieldwork has been completed in the Intermediate Report scheduled for second half of 2016.

## 3.2.8 Registration

The original design of the project (July 2013) was based on the expectation that most of the presurvey information would have been provided through the relevant administrative records (including detailed data about the communication and other support needs of people with disability), along with information that would inform later analysis of the survey data (e.g. disability service use, NDIS plan content or value, onset of disability). The fact that this information was still not available by the time sampling had to commence, generated the need for the registration process, which we present here. We also discuss some gaps in the administrative data which were responsible for adding to the length of the survey questionnaire.

It is important to present the registration process in the broader context of the way the sample is constructed. The survey sample selection begins with an opt-in at the point when new NDIS participants are asked if they would agree to be contacted for research purposes. This question is not optimally placed: it is at the end of a form that often takes a long time to complete. The longer it has taken for the form to be completed the more likely it will be that this question may not be filled in as regularly as it would if it were positioned earlier and more prominently in the registration form. The selection continues with the opt-out administered by the Department of Social Services (DSS).

Following the opt-in and opt-out processes comes the survey registration process. The registration serves several purposes, including the need to determine the preferred mode of participation, that is, whether the sample members would like to participate in a telephone interview, receive a paper copy of the questionnaire, complete the survey online, or use some other method. The registration process also elicits the need for any language and translation services. Where there are gaps in the relevant administrative data, the registration is used to identify family or carers for inclusion in the NDIS Survey of Families and Carers. The registration also seeks to confirm and often improve the sample members' contact information provided by the administrative data, after the pilot studies highlighted significant gaps and invalid information, including telephone numbers.

The registration process has added to the length of the fieldwork, and equally crucially it has delayed the time it takes for the NDIS Survey to reach the potential respondent. As an additional step it has reduced the response rate of the surveys. Responses to June 2015 in Table 3.3 indicate that the registration process only yielded 54 per cent of the useable post-opt-out sample in the trial sites (Wave 1a and 1b) and 65 percent in the comparison group. On the positive side, the registration increased the number of families and carers signing up for the NDIS Survey for Families and Carers, and also indicating their preparedness to assist the person with disability in completing their survey, where necessary.

<sup>&</sup>lt;sup>9</sup> This further attrition calls for a reassessment of the need for this rule in the trial sites.

Table 3.3: NDIS Survey sample and registrations (as at 15 July 2015)

	Trial site sample 1a N	Trial site sample 1a %	Trial site sample 1b N	Trial site sample 1b %	Compariso n Sample N	Comparison sample %
Survey sample provided by DSS	3,948	100	2,724	100	7,832	100
Useable sample	3,918	99.2	2,690	98.7	7,576	96.7
Registrations	2,047	51.8	985	36.2	2,632	33.5
Registrations % of useable sample		52.2		36.6		34.7

Note: Updated 15 July 2015. Trial site sample 1b remains open for registrations.

The registration process also helped us to customise the NDIS Survey, ensuring that respondents were able to participate using their choice of survey mode, issued in standard or Easy English (see below: Accessibility and design); and that appropriate proxy interview questionnaires were used where this had been requested. All in all, we believe that the registration process is a useful tool for handling some of the complexity of the survey design and that it should be retained for this reason. It can also serve as a powerful opt-in process, possibly making part of the initial opt-in and opt-out process redundant and subject to useful simplification.

Finally we note that introducing the registration process has not managed to fully close the data gap caused by the unavailability of NDIS and disability support data from more detailed administrative data sources. Despite the useful support provided to the evaluation by administrative data, some data items are unavailable. Unless this shortcoming is addressed, it is likely to affect the extent to which the evaluation will be able to answer some of the Key Evaluation Questions (KEQ) that depend on the administrative data, notably those that relate directly to NDIS funding and NDIS-funded supports, as this type of information can be reliably obtained only through administrative data.

# 3.2.9 Completing the first wave of interviews and commencing the second wave of interviews

The first wave of interviews is still under way. Waves 1a and 1b are expected to be completed in September/October 2015. The exact timing of Wave 1c and the topping up of the ACT sample (Wave 1 ACT) are under discussion, the objective being to commence in September 2015 with the necessary opt-out and registration processes.

The second wave of the NDIS Survey and the NDIS Survey of Families and Carers is currently scheduled to commence in late 2015. The majority of respondents will be re-interviewed approximately 10 to 12 months after their first round of interviews. The possibility of streamlining the registration process for any top up sample (that is new sample members who will be interviewed for the first time in Wave 2) could be experimented with in Wave 2. Wave 2 will be largely identical in its questions to Wave 1, as this is necessary for questions to be used for the evaluation of the NDIS. The fieldwork will be far more concentrated in terms of time in the field than in Wave 1, as there will not be any phasing in problems to delay the fieldwork.

# 3.3 Accessibility and design – the survey instruments

A core objective of the NDIS Survey is to be inclusive and make it easy for NDIS participants and their counterparts in the comparison group to take part in the study. To achieve this objective, the surveys adopted a multi-modal approach and structured the questionnaire to allow an unprecedented level of user flexibility. This was achieved whilst drawing and building on validated survey questions to ensure greatest comparability of results. Allowing multiple modes of participation and designing the questionnaires to be accessible to people with various levels of disability were central to the survey and the evaluation design.

## 3.3.1 Multi-mode delivery

Reflecting the respondents' preferences recorded in the registration process, the NDIS Survey and the NDIS Survey for Families and Carers were designed and conducted as:

- a postal survey using paper copy questionnaires
- a username and password-protected web survey for online completion
- a computer assisted telephone interview.

We describe below how the various modes were tested prior to implementation. Telephone interviews were conducted by experienced interviewers, including many with previous experience of interviewing people with disability. Telephone interviewers received specialist training from the Disability and Community Inclusion Unit (DCIU) at Flinders University.

Survey respondents were free to choose their preferred mode of participation (among hard copy, telephone or online), and were also given the opportunity to request the alternative of a face to face interview.

# 3.3.2 Accessibility of questionnaires

To improve the accessibility of the NDIS Survey, the questionnaire was divided into two parts. Part A collected factual information about the person; Part B collected opinions, data on subjective well-being, social and economic activity, and personal aspirations. Part B was also provided in Easy English format with pictorial aids. Dividing the survey into two distinct halves was intended to increase the participation of people with disability who might not be able to participate in the entire survey, but were encouraged to express their personal views in Part B, whilst potentially letting their proxy answer Part A.

NDIS Survey respondents who chose to participate in a telephone interview using the Easy English format were first mailed that questionnaire and were subsequently guided through it by the telephone interviewer. The Easy English version of Part B was also available to complete online.

The surveys were also designed to reflect the completion needs for different age groups. For young people with disability under the age of 8, a proxy questionnaire was provided for completion by the responsible adult who would typically be the parent or guardian. For young people with disability aged 8 to 15, Part A of the survey was designed to be completed by the responsible adult. Respondents were given the choice for the young person to complete Part B of the survey, or for the responsible adult to do so on behalf of the young person.

Adults and young adults with disability (aged 16 and over) or, where known, their Person Responsible, were asked to indicate who was going to complete their Part A and Part B. Full proxy interviewing was also offered if a person with disability was not able to participate himself or herself.

Assisted interviewing was encouraged where this was deemed helpful or necessary. All survey participants were asked at registration to indicate if they preferred Part B to be supplied in standard or Easy English. Finally, provisions were in place at interview time to allow the survey respondents to change the mode of participation originally requested at registration.

Table 3.4 summarises the various combinations of questionnaires that were offered. Key variations were:

- Education and employment questions were asked in an age-appropriate context. For instance, people with disability under the age of 16 were not asked about employment, thus reducing the survey length and burden on the interviewee.
- No part B was offered where the NDIS participant or person in the comparison group was\_under the age of 8. In that case, the parent, guardian or Person Responsible was asked to complete Part A only; questions concerning the social participation of the NDIS participants were included in the matched NDIS Survey for Families and Carers to provide the relevant information. Respondents who were acting on behalf of an NDIS participant under the age of 8 were also asked to skip sections in the questionnaire that were concerned with daily support needs, many of which would be deemed generic for this age group. This further reduced the burden on the interviewee.
- The Easy English versions of questionnaires included pictorial aids, and simplified wording and responses, including scales. These were developed with the assistance of specialists.
- Whereas self-completion questionnaires addressed the respondent directly, the proxy interview
  questionnaires were modified to refer to the person with disability by his or her name. Naming
  the main respondent and including an introductory note in the questionnaire, the online script
  and the telephone interviews served to remind proxy respondents that the answers to Part B
  should be from the NDIS participant's or named comparison group person's perspective.
- Proxy interviewers who did not wish to complete Part B on behalf of the main respondent were
  invited to complete Part A only (and the NDIS Survey of Families and Carers, where appropriate).
  This resulted in the creation of two versions of **Proxy Part A** questionnaires as listed in Table 3.4
  (one for the trial and one for the comparison group).
- The questionnaire for NDIS participants included questions on supports received before the NDIS in Part A. It also invited a comparison of several aspects of receiving supports pre-NDIS and within the NDIS in Part B. The NDIS support sections were omitted from the comparison group questionnaires. This exclusion reduced the length of the interview for the comparison group.

The 14 different combinations and types of survey Parts A and B meant there were seven distinct hardcopy questionnaires (including two Easy English versions) each for the trial and comparison groups of people with disability. The Full (standard or Easy English) and Assisted (standard or Easy English) questionnaire listed in the first four rows of Table 3.4 did not substantially differ in their content. There are two very distinct questions at the end of Part B. The first asks the extent of assistance the person with disability had in completing the questionnaire and the second asks the significance of the person assisting in making decisions in the life of the person with disability. The nature of the two questions required different programming in the online and CATI delivery modes in order to handle appropriately the hand-over and continuation instructions between Parts A and B. It is for this reason these questions are listed separately.

**Table 3.4: Types of questionnaires** 

DV1	Questionnaire Title	Respondent Age	Type of Completion	Type of Part B
1	Full standard survey	16+	Self-Completion	Standard
2	Full EE Survey	16+	Self-Completion	Easy English
3	Assisted Standard	16+	Assisted Part A	Standard
4	Assisted Easy English	16+	Assisted Part A	Easy English
5	Partial Proxy	16+	Proxy Part A	Standard
6	Partial Proxy Easy English	16+	Proxy Part A	Easy English
7	Standard Child Proxy	8 to 15	Proxy Part A	Standard
8	Easy English Child Proxy	8 to 15	Proxy Part A	Easy English
10	Proxy Part A	8 to 15	Proxy Part A	None*
11	Proxy Part A	16 to 17	Proxy Part A	None*
9	Full Child Proxy	<8	Proxy Part A	None
14	Full Proxy	8 to 15	Proxy Part A	Proxy/Standard
15	Full Proxy	16 to 17	Proxy Part A	Proxy/Standard
16	Full Proxy	18+	Proxy Part A	Proxy/Standard

<sup>\*</sup>At registration, the Parent, Guardian or Person Responsible agreed to participate in the Survey on behalf of the child but did not give consent for the child to be interviewed.

## 3.3.3 Designing the questionnaires and the questions

The design of the questionnaire drew on a number of pre-tested and validated survey questions in order to measure social participation and well-being. It also replicated conventional survey questions relating to socio-demographics notably, the NDIS Survey included the Deakin Personal Wellbeing Index<sup>10</sup> and questions recommended in the OECD Guidelines on Measuring Subjective Well-Being<sup>11</sup>. The questionnaire design also benefited from the UK Life Opportunities Survey<sup>12</sup> which provided useful examples of how to ask about 'choice and control'.

The NDIS Survey for Families and Carers includes a set of questions designed to measure the well-being of the family of persons with disability. The questions were adopted from the Family Quality of Life Survey<sup>13</sup> developed at the University of Kansas, USA. Also included in the NDIS Survey for Families and Carers is a module, designed to elicit the current social participation of NDIS participants under the age of 8 (who were not asked to complete Part B of the NDIS Survey) and the hopes of their families and carers for their future social participation.

The wellbeing measures used Likert-type scales<sup>14</sup> for measuring agreement with sets of statements. The inclusion of pre-tested survey questions not only strengthens the validity of the survey instrument, but also increases the potential for comparative analyses.

FOR OFFICIAL USE ONLY

<sup>&</sup>lt;sup>10</sup> International Wellbeing Group (2013). Personal Wellbeing Index: 5th Edition. Melbourne: Australian Centre on Quality of Life, Deakin University

<sup>(</sup>http://www.deakin.edu.au/research/acqol/instruments/wellbeing-index/index.php)

<sup>&</sup>lt;sup>11</sup> OECD (2013), OECD Guidelines on Measuring Subjective Wellbeing, OECD Publishing. http://dx.doi.org/10.1787/9789264191655-en

<sup>&</sup>lt;sup>12</sup> http://www.ons.gov.uk/ons/about-ons/get-involved/taking-part-in-a-survey/information-for-households/a-to-z-of-household-and-individual-surveys/life-opportunities-survey/index.html

<sup>&</sup>lt;sup>13</sup> Hoffman, L., Marquis, J., Poston, D., Summers, J. A., & Turnbull, A. (2006). Assessing family outcomes: Psychometric evaluation of the Beach Center family quality of life scale. Journal of Marriage and Family, 68(4), 1069-1083

<sup>&</sup>lt;sup>14</sup> cp.http://www.socialresearchmethods.net/kb/scallik.php

# 3.3.4 Cognitive testing

Whilst drawing to a degree on pre-tested, validated questions, the NDIS Survey was also subjected to extensive cognitive testing. The evaluation team tested the survey questions, individually and as part of larger modules, for their capacity to be understood and in order to make sure that the surveys asked the correct and desired questions of the right people. In preparation for the testing, disability support providers were consulted for their advice on wording questions on opinions, judgements and aspirations in a way that would be most meaningful to the survey participants. The cognitive testing was facilitated by people with disability and their support workers who volunteered to take part in this exercise. Volunteer participants included adults with intellectual or physical disability, and young people living with disability. Experts in the evaluation team also tested and refined the survey instruments in consultation with people with disability of Indigenous background. Additional preliminary fieldwork (skirmishing) was undertaken by researchers and evaluators, who also included people with disability.

# 3.3.5 Easy English

Professional assessment and cognitive testing conducted by an expert in accessible communication led to amendments to some of the original survey questions in the Easy English version. This simplified the language and structure of the questionnaire. Various drafts of the Easy English questionnaires were produced and tested in individual and focus group settings with people with disability.

# 3.4 Pilot study

The NDIS Survey and the NDIS Survey for Families and Carers were piloted in April 2014. The initial pilot samples were intended to include 20 NDIS participants and another 10 individuals who were not participating in the NDIS, as well as matching numbers of families and carers. The Computer Assisted Telephone Interviewing (CATI) versions of the questionnaires were fully piloted, while their hard copy versions were tested in individual and small group sessions prior to the CATI pilot as part of a programme of cognitive tests.

The CATI pilot sample was drawn purposively so to include people living with different types of disability, including physical, developmental or intellectual disability, mental health problems, sensory impairment, and neurological or brain conditions. In addition, the pilot sample included young people under the age of 17 without a known proxy as well as with a proxy who would undertake the interview on the young person's behalf. Individuals drawn in the pilot sample were first offered the opportunity to opt-out. In the end, 31 people with disability and 24 family and carers of people with disability in trial sites, alongside 15 people with disability and 21 family and carers in comparison areas remained in the pilot sample (Total: 91).

The pilot succeeded in conducting 24 interviews with people with disability, including 19 in trial sites and another 5 with people in the comparison group. Four interviews were conducted with people with disability, 17 with a guardian or parent of a person with disability, one with a carer; and in two instances, interviews were conducted with a proxy who was not a family member or carer, but offered to participate on behalf of the person with disability. In addition, 18 pilot interviews were conducted for the NDIS Survey for Families and Carers, resulting in a total of 42 interviews.

Sixteen of the persons with disability were aged 16 or over, two were aged between 8 and 15 years, and the remaining 6 were less than 8 years of age. Participants in the pilot were living with a range of disabilities, including physical disability (3), developmental condition (5), intellectual disability (4), mental health problems (1), sensory impairment (4), neurological or brain condition, including acquired brain injury (5), and other not specified (2).

Interviews with people with disability in the trial group lasted an average of 44 minutes, compared with 30 minutes in the comparison group. Likewise, interviews with family members or carers in the trial group lasted an average of 35 minutes to complete, compared with 28 minutes in the comparison group. The difference in interview length between the two groups was primarily a reflection of the shorter comparison group questionnaire which does not include any questions on NDIS-specific experiences.

While the pilot survey was conducted with fewer than the originally anticipated number of respondents, it nonetheless achieved its objective of covering different age groups and people with different disabilities. The pilot was also able to test the survey instrument with carers, family members and proxy interviewees as well as people with disability.

The pilot highlighted a number of challenges and issues with the survey instrument that had to be addressed prior to the launch of the main survey:

- At the point of sampling, the pilot revealed gaps in the administrative data, including missing links between people with disability and their carers (or nominees) that are typically recorded with the source data. Interviews were intended to be conducted with family members and carers matched to people with disability also participating in the survey. Since people with disability and their family members or carers were not automatically linked in the administrative dataset that was provided to the researchers, additional data cleaning and manual linking of records was undertaken. Some carers without a caree and some carees without a carer were also included in the pilot to explore these possibilities.
- The pilot calls subsequently encountered a large number of invalid telephone numbers for sample members, while other call attempts remained unanswered and a few sample members were not available during the pilot period. In total, 31 out of 91 cases in the sample were thus affected and could not be included in the actual pilot. These problems were particularly prominent among the comparison sample. Concern about the validity of contact details was an important factor in our subsequent decision to conduct a registration process prior to the main survey fieldwork.
- The pilot showed that interviews were taking longer to complete than had been anticipated and that the survey was becoming burdensome for some participants, in particular those living with disability. In total, 15 interviews were terminated prematurely (this was in addition to the 42 fully completed interviews); three more interviews were refused. This discovery informed our subsequent decision to divide the NDIS Survey into two parts, distinguishing between a part collecting factual information (Part A) and another part focused on perceptions (Part B).

# 3.5 Fieldwork (Wave 1)

Fieldwork for the NDIS Survey and the NDIS Survey for Families and Carers finally commenced in August 2014 with the mail-out of the registration forms to NDIS participants in Wave 1a, soon after the Department of Social Services had closed the opt-out period and released the sample of people with disability in the trial and comparison groups to the survey company (in July and June 2014 respectively). Registration requests were sent out in batches commencing with adults aged 18 or older, before continuing from the youngest age group onwards. The registration mail was sent to all in the trial and the comparison samples containing:

- a covering letter, briefly explaining the purpose of the survey, ways to register (by return of post, online or by telephone) and to obtain additional information (via a dedicated telephone helpline), and stressing the importance of informed consent to participation
- an Information Sheet, providing additional detail about the survey, the intended use of the data, confidentiality and anonymity of responses, consent, and participation options
- the registration form.

Follow-up activities, which included telephone and email reminders where contact details were known, started in late August. Registration of the comparison sample commenced in September 2014, as the sample was released later than the trial. Registration of NDIS participants included in the second round of sampling (Wave 1b) commenced in January 2015.

In November 2014, the first hard copy versions of the NDIS Survey and the NDIS Survey for Families and Carers were mailed out to those in the trial and comparison group who had registered for this survey mode. Following final tests, the online and CATI instruments were opened up in batches in March 2015, reaching all registrants by the following month. Table 3.5 presents the NDIS Survey response rates as at 15 July 2015, broken down by trial state and by sample wave. Note that the comparison sample was not drawn aiming to ensure any specific representation of individual trial states; this breakdown is only included for presentational reasons.

Response rates measured as the percentage of NDIS Survey completion from amongst all NDIS participants and individuals in the comparison group who had registered by that date, is somewhat lower for the trial Wave 1b sample (19.4 per cent) than the trial Wave 1a (37.2 per cent) or the comparison sample (35.1 per cent). This is unsurprising given the more recent start of fieldwork for the Wave 1b sample. Overall, response rates are remarkably similar between trial and comparison states. Deviations from general patterns typically may appear due to smaller case numbers or due to non-random phasing in by the NDIA.

Table 3.5: Wave 1 NDIS Survey returns, by state, and response rate (as at 15 July 2015)

TRIAL Wave 1a	NDIS Survey	NDIS Survey	Response rate %
	registrants	completions	completions/registrations
ACT	0	0	0
NSW (Hunter region)	484	192	39.7
SA	418	167	40.0
TAS	211	76	36.0
VIC (Barwon area)	931	326	35.0
Other states	3	1	33.3
Total	2,047	762	37.2
TRIAL Wave 1b			
ACT	98	36	36.7
NSW (Hunter region)	209	49	23.4
SA	386	84	21.8
TAS	47	9	19.1
VIC (Barwon area)	245	49	20.0
Other states	0	0	0
Total	985	191	19.4
Comparison			
ACT	21	4	19.0
NSW	1,120	370	33.0
SA	311	107	34.4
TAS	96	42	43.8
VIC	810	312	38.5
Other states	274	89	32.5
Total	2,632	924	35.1

Note: Wave 1a and 1b excludes 42 cases originally assigned to the comparison sample, but since reassigned to the trial sample. The total number of completed surveys (1877) is higher than reported in analysis statistics as not all responses, e.g. hardcopy returns, had been scanned (where necessary), cleaned and transferred into the data file.

To date, the majority of NDIS Survey respondents have opted to complete the survey online (38.5 per cent) or by phone (23.2 per cent) (Table 3.6). Almost 4 in 10 respondents preferred to fill out the paper questionnaire (38.3 per cent). Parents, guardians or other Persons Responsible completing only Part A of the NDIS Survey on behalf of a person with disability under the age of 8 were disproportionately likely to opt for telephone interviewing (38.8 per cent versus an average of 20.6 per cent); whereas CATI was more likely to be the choice of adult self-completers (41.3 per cent versus 26.3 per cent overall). Hardcopy (paper questionnaire) completion, by contrast, was disproportionately chosen when a proxy completed Part A of the survey, but Part B was intended for completion by the person with disability.

Table 3.6: NDIS Survey responses by mode and types of questionnaire (as at end May 2015)

DV1	Questionnaire Type	Online	CATI	Hardcopy	All
	Questionnume Type	%	%	%	%
1	Full standard survey 16+ Self-Completion - Standard	16.9	41.3	26.6	26.3
2	Full EE Survey 16+ Self-Completion - Easy English	1.0	3.2	5.2	3.1
3	Assisted Standard 16+ Assisted Part A - Standard	5.3	0.7	13.1	7.2
4	Assisted Easy English 16+ Assisted Part A - Easy English	2.1	0.0	12.1	5.4
5	Partial Proxy 16+ Proxy Part A - Standard	1.3	0.7	13.5	5.9
6	Partial Proxy Easy English 16+ Proxy Part A - Easy English	0.9	0.0	4.8	2.2
7	Standard Child Proxy 8 to 15 Proxy Part A - Standard	2.8	0.7	6.3	3.6
8	Easy English Child Proxy 8 to 15 Proxy Part A - Easy English	3.3	0.7	10.1	5.3
10	Proxy Part A 8 to15 Proxy Part A - No Part B	0.3	0.0	0.6	0.3
11	Proxy Part A 16 to17 Proxy Part A - No Part B	0.1	0.2	0.0	0.1
9	Full Child Proxy <8 Proxy Part A - Part A only	38.8	24.3	0.0	20.6
14	Full Proxy 8 to 15 Proxy Part A - Proxy/Standard	11.1	8.4	2.1	7.0
15	Full Proxy 16 to17 Proxy Part A - Proxy/Standard	2.5	1.7	0.6	1.6
16	Full Proxy 18+ Proxy Part A - Proxy/Standard	13.5	17.9	5.1	11.3
N		675	407	672	1,754
% row		38.5	23.2	38.3	100

We turn briefly to the NDIS Survey for Families and Carers, which was the last of the surveys to go into the field. We are still collecting nominations from persons with disability participating in the NDIS Survey about their families and carers. Table 3.7 summarises some basic statistics. Once again we see a loss in cases as a result of unusable address information, and we also note losses due to duplicate records.

Registrations from trial site Wave 1a (44.6 per cent of the usable sample) has been close to that for the NDIS Survey in that sample. The rates of registration from the trial site sample for Wave 1b and for the comparison sample have been considerably lower; approaching the 30 per cent mark. Completion rates shown in Table 3.7 are still low as many families and carers await the completion of the NDIS Survey. Only after registrations are completed will CATI interviews or reminder calls commence, which is expected to boost response rates quickly.

Table 3.7: NDIS Survey for Families and Carers: registrations and completions (as at 15 July 2015)

	Trial site sample Wave 1a N	Trial site sample Wave 1a %	Trial site sample Wave 1b N	Trial site sample Wave 1b %	Comparisor Sample N	Comparison sample %
Survey sample provided by DSS	3,730	100	2,107	100	6,579	100
Useable sample	2,894	77.6	2,025	96.1	5,730	87.1
Registrations	1,291	34.6	590	28.0	1600	24.3
Completions	211	5.7	18	0.9	313	4.8
Registrations % of useable sample		44.6		29.1		27.9
Completions % of useable sample		7.3		0.9		5.5

# 3.6 Initial Findings

This section presents the initial findings from the first half of the trial sites data collection as it was on 15 July 2015. Wave 1a is presently in the field and is almost complete. Wave 1b has started more recently and will remain in the field until September/October 2015. In several instances the numbers we present are too low to be useful. This shortcoming is temporary and will be corrected as the sample size increases with the completion of the first part of Wave 1 and the completion of the whole second part of Wave 1 following the timelines set out in the previous section. In many instances we also report the corresponding evidence on the comparison group, noting that comparing these two samples needs considerable statistical preparation for the results to be sufficiently precise. This caveat applies to all such comparisons in this report.

The presentation of the main findings follows the layout of the questionnaires. We begin with the first part of the questionnaires, which contains primarily factual information (referred to as Part A). Then we move to the second part of the questionnaires, which contains all information on opinions, perceptions and aspirations (referred to as Part B). Children under the age of 8 are not asked to complete Part B. All respondents are given the option of answering a pictorial Part B (referred to as Easy English – EE – Part B). We begin with Part A.

# 3.6.1 Part A – Socio-demographics

The surveys collect information on age, gender, country of birth, Aboriginal or Torres Strait Islander status, first language (asking for more information for those who are not native English speakers), marital status and location of residence. We distinguish mainly by age.

Trial respondents were approximately evenly split between people with disability aged 17 and younger (51 per cent), or 18 and older (49 per cent) (Table 3.8a). In the comparison group, more respondents were aged 18 and over (57.9 per cent). Both respondent groups included a majority of male persons with disability (58.2 per cent and 61.4 percent respectively), although trial respondents aged 18 and over were somewhat more likely to include women rather than men.

Table 3.8a: Demographic composition of trial and comparison samples

Age	Trial	Trial	Comparison	Comparison	Total
(years)	Cases	Males	Cases	Males	Cases
0 to 7	333	234	169	115	502
	37.4%	70.3%	16.8%	68.0%	26.5%
8 to 17	121	73	254	169	375
	13.6%	60.3%	25.3%	66.5%	19.8%
18+	437	212	581	332	1,018
	49.0%	48.5%	57.9%	57.1%	53.7%
Total	891	519	1,004	616	1,895
		58.2%		61.4%	

Note: trial and comparison samples at all ages

Table 3.8b shows that the vast majority of survey respondents were born in Australia (93 per cent); ; spoke English as their first language (85 per cent) and, three per cent reported being of Aboriginal or Torres Strait Islander background. Fifty-eight per cent reported living in metropolitan areas, compared with just 39 per cent living in remote or rural parts of Australia. Twenty-seven percent reported being married or in a de facto relationship.

Table 3.8b: Demographic composition of trial and comparison samples

	Trial	Trial	Comparison	Comparison	Total	Total
	Cases	%	Cases	%	Cases	%
Aboriginal or Torres Strait Islander	23	3	41	4	64	3
Country of birth: Australia	842	95	912	91	1754	93
First language is English	735	82	870	87	1605	85
Metro/Urban	561	63	536	53	1097	58
Rural/Remote	311	35	437	44	748	39
Married/de facto	105	22	191	30	296	27
Total	891		1,004		1,895	

Note: trial and comparison at all ages except Married/de facto where it is only those aged 16 years and above

## 3.6.2 Part A – Disability and living arrangements

This section begins with asking for 'the name of the **main** physical or mental health condition, impairment or disability'. Respondents are free to write the precise description of their main disability. The answers are converted into the closest ICD10 code<sup>15</sup> and are used as a guide to categorise the main disability of the respondent. There are some instances where the response cannot be clearly mapped into an ICD10 code and these cases are isolated, examined on a case by case basis and allocated the closest code possible. It is recognised that in some instances the respondents will feel either that they are not sure or that they do not know the name of their disability. For these cases the survey offers a more guided and simpler set of disability categories which have been designed to be both comprehensive and sufficiently brief and clear. Table 3.9 presents the information for the trial and the comparison groups separately and then both combined. Given the detail that is contained in this table, the number of both responses is very small within some of the individual cells, but we report them nevertheless, on the understanding that the full sample will provide a more precise picture.

<sup>&</sup>lt;sup>15</sup> World Health Organisation International Statistical Classification of Diseases and Related Health Problems, version 10.

Table 3.9 suggests a clustering of people with intellectual disability, developmental or neurological conditions in both trial and comparison groups. There is also a suggestion of a sizeable minority of people with a primary physical disability.

Table 3.9: Main disability

	Trial Cases	Trial %	Comparisor Cases	Comparison %	Total Cases	Total %
Physical condition	66	7.4	141	14.0	207	10.9
Mental health condition/psychosocial disability	17	1.9	64	6.4	81	4.3
Hearing condition	20	2.2	12	1.2	32	1.7
Speech condition	15	1.7	9	0.9	24	1.3
Vision condition	22	2.5	44	4.4	66	3.5
Intellectual disability	172	19.3	123	12.3	295	15.6
Developmental condition	228	25.6	240	23.9	468	24.7
Neurological condition	151	17.0	99	9.9	250	13.2
Congenital or inherited condition	37	4.2	21	2.1	58	3.1
Other main condition	8	0.9	8	0.8	16	0.8
Condition not otherwise defined	5	0.6	23	2.3	28	1.5
Don't know	2	0.2	7	0.7	9	0.5
Skip Question	28	3.1	66	6.6	94	5.0
Missing	120	13.5	147	14.6	267	14.1
Total	891		1,004		1,895	

Note: trial and comparison all ages

The survey also records whether respondents reported having more than one disability (question: do you have 'any other long-term physical or mental health condition, impairment or disability'), with approximately half of respondents (47 per cent) reporting that they did. Only a small minority reported more than two additional disabilities (7-8 per cent)<sup>16</sup>. About 30 per cent of the respondents reported they were born with their disability, close to 36 per cent reported that the onset of their disability happened in the first seven years of their lives and the remaining 34 per cent reported a later onset.

The survey collects detailed information on the need for assistance by respondents in different contexts of their lives. The relevant questions were not asked of children below the age of 8 as young children have not yet developed full autonomy. Of the 1,393 respondents aged 8 years or over, 1,089 reported that they needed assistance of one type or another and 304 that they did not. The type of assistance is presented in Table 3.10. It must be noted that more than one type of assistance can be sought so respondents were explicitly asked to report as many types as were relevant to them. The fact that only 16.6 per cent of all respondents (181 out of 1,089) reported that they needed assistance with a type of help not listed in the question 'help with something else' suggests that the survey covers the most frequently needed supports adequately.

<sup>&</sup>lt;sup>16</sup> Many people stated several disabilities when asked for their main disability. Some of them may have stated they had no other disabilities while, from their previous answer, it is obvious that they do have multiple disabilities. As the work on the data progresses, this information will be compiled with greater precision.

Table 3.10: Daily activities where assistance is needed

	Trial Cases	Trial %	Comparison Cases	Comparison %	Total Cases	Total %
Help with preparing food and eating meals	380	76.9	365	61.3	745	68.4
Help with doing things in household	438	88.7	473	79.5	911	83.7
Help with daily personal activities	305	61.7	292	49.1	597	54.8
Help with accessing or entering buildings and using facilities	249	50.4	226	38.0	475	43.6
Help with using public transport or other types of transport	366	74.1	376	63.2	742	68.1
Help with talking with being around others	258	52.2	269	45.2	527	48.4
Help with managing feelings, emotions or behaviour	289	58.5	360	60.5	649	59.6
Help with reading or writing tasks	365	73.9	383	64.4	748	68.7
Help with making appointments/arranging supports	368	74.5	410	68.9	778	71.4
Help with something else (CATI, Online only)	77	15.6	104	17.5	181	16.6
Total	494		595		1,089	

Note: trial and comparison aged 8 years or over; 'Total' indicates the number of respondents to answer this question; multiple response question; columns therefore do not add to 100.

An important aspect of support need and provision is how often it is required. A large majority of respondents who needed help (84 per cent) reported that they needed support daily, with about 9 per cent weekly and the rest less frequently or irregularly.

Another important aspect of receiving support is the person who provides that support. Those aged 8 and above and who answered that they require assistance were asked who most often helps them. The survey distinguishes between spouse or partner, daughter or son, mother, father, sister or brother, grandparent, other family member, disability support worker, personal attendant or nurse, friend, neighbour, voluntary worker or just 'someone else'. The information is in Table 3.11 and the degree to which this list is comprehensive is manifested by the low number (only 11.4 per cent) responding 'someone else'. Mothers were the most frequent carers, followed – at some distance – by fathers and partners. Paid carers were used substantially more in the trial group, but the bulk of care still came from family members.<sup>17</sup>

FOR OFFICIAL USE ONLY

<sup>&</sup>lt;sup>17</sup> We expect these percentages to be sensitive to the non-random phasing in of participants within the trial group at this initial stage of sampling, but not so for the comparison group.

Table 3.11: Who most often provides assistance with daily activities?

	Trial Cases	Trial %	Comparison Cases	Comparison %	Total Cases	Total %
Spouse/De facto partner	98	23.7	156	36.1	254	30.1
Mother (including step/adoptive/foster)	622	74.7	526	65.8	1,148	70.3
Father (including step/adoptive/foster)	386	46.3	294	36.8	680	41.7
Daughter or son (including step/adoptive)	34	8.2	53	12.3	87	10.3
Sister or brother (including step/adoptive)	161	19.3	170	21.3	331	20.3
Grandparent (including step/adoptive)	103	12.4	61	7.6	164	10.1
Other family member (cousin, uncle, aunt)	40	4.8	37	4.6	77	4.7
Disability support worker, personal attendant or nurse	242	29.1	129	16.2	371	22.7
Friend	56	6.7	67	8.4	123	7.5
Neighbour	10	1.2	21	2.6	31	1.9
Volunteer	19	2.3	16	2.0	35	2.1
Someone else	77	9.2	109	13.6	186	11.4
Total	833		799		1,632	

Note: trial and comparison aged 8 years and above and reported requiring assistance with daily activities; 'Total' indicates the number of respondents to answer this question; multiple response question; columns therefore do not add to 100.

The survey asks about living arrangements, in particular the type of accommodation, ownership, and whether there are any shared living arrangements. Table 3.12 shows that the vast majority reported living in a private dwelling (85 per cent) and a small number of respondents reported living in public housing (9.5 per cent).

**Table 3.12: Accommodation** 

	Trial	Trial	Comparison	Comparison	Total	Total
	Cases	%	Cases	%	Cases	%
A private dwelling	772	86.6	839	83.6	1,611	85.0
A residential aged care	9	1.0	7	0.7	16	0.8
Public housing	72	8.1	107	10.7	179	9.5
Self-contained supported accommodation	6	0.7	8	0.8	14	0.7
A group home	19	2.1	17	1.7	36	1.9
Out-of-home care	1	0.1	1	0.1	2	0.1
A motel, caravan park	0	0.0	4	0.4	4	0.2
Other type of accommodation	8	0.9	10	1.0	18	1.0
Don't know	1	0.1	4	0.4	5	0.3
Missing	3	0.3	7	0.7	10	0.5
Total	891	100	1,004	100	1,895	100

Note: trial and comparison all ages.

Table 3.13 shows that about 23 per cent of respondents reported living in accommodation that is owned outright, 40 per cent in mortgaged accommodation and 32 per cent in accommodation where rent or board is paid.

Table 3.13: Home ownership

	Trial Cases	Trial %	Comparison Cases	Comparison %	Total Cases	Total %
Owned outright	189	21.2	252	25.1	441	23.3
Mortgaged	393	44.1	358	35.7	751	39.6
Rented or board is paid	256	28.7	342	34.1	598	31.6
Something else	27	3.0	27	2.7	54	2.9
Don't know	8	0.9	6	0.6	14	0.7
Missing	18	2.0	19	1.9	37	2.0
Total	891	100	1,004	100	1,895	100

Note: trial and comparison all ages.

Table 3.14 shows the overall living arrangements of people with disability. The relevant question allows for multiple answers. For example, there is a total of 1,152 (60.8 per cent) people with disability who reported living with their mothers and 929 (49 per cent) living with their fathers. A smaller number of 227 (12 per cent) reported living alone. The information is sufficient to define the exact family structure of people with disability and combine it with their support and assistance arrangements. Table 3.14 shows the majority of respondents reported living within a traditional family environment, most often with parents and siblings present.

Table 3.14: Who do people with disability live with?

	Trial	Trial	Comparison	Comparison	Total	Total
	Cases	%	Cases	%	Cases	%
Alone	81	9.1	146	14.5	227	12.0
Spouse/De facto partner	105	11.8	195	19.4	300	15.8
Mother (including step/adoptive)	608	68.2	544	54.2	1,152	60.8
Father (including step/adoptive)	515	57.8	414	41.2	929	49.0
Daughter or son (including step/adoptive)	37	4.2	81	8.1	118	6.2
Foster mother	10	1.1	12	1.2	22	1.2
Foster father	8	0.9	6	0.6	14	0.7
Sister or brother (including step/adopted)	404	45.3	374	37.3	778	41.1
Grandparent (including step/adoptive)	22	2.5	36	3.6	58	3.1
Other family member (cousin, uncle, aunt)	15	1.7	20	2.0	35	1.9
Friends	17	1.9	20	2.0	37	2.0
Other people not related	29	3.3	22	2.2	51	2.7
A paid support worker	7	0.8	8	0.8	15	0.8
Total	891		1,004		1,895	

Note: trial and comparison all ages; 'Total' indicates the number of respondents who answered this question; this is a multiple response question; columns therefore do not add to 100.

Table 3.14 illustrates the importance of family within the context of the lives of people with disability. This picture however is incomplete in its present form. There are two aspects that need to be stressed. First, the sample has not yet settled sufficiently. Presently, the response rate for children is very low. As the sample grows, the family focus of the living arrangements will become more precise and will allow us to investigate the degree to which the NDIS will induce shifts in traditional care arrangements. Second, the relationships that underpin the emerging picture are too complex to be portrayed in simple two or even three-way tabulations. The picture will start to become clearer after the carer information has been examined together with that of the person with disability and the nature of the person with disability-carer relationship is analysed. For example, there may be instances where a participation or wellbeing effect stemming from the NDIS may not arise directly through an increased activity of the person with disability themselves, but indirectly from an

increased activity of the person or persons who live and interact with the person with disability. In other instances looking for wellbeing effects at the individual level may be incomplete and family wellbeing may be the appropriate outcome to look at, which cannot be done without utilising the linked person with disability-carer data. The analysis of the data for the purposes of the NDIS Evaluation and beyond will shed light on such questions.

## 3.6.3 Part A – Supports before the NDIS (NDIS participants only)

It is important for any assessment of the NDIS trial to have sufficiently detailed information for the supports that the NDIS participants were receiving before the introduction of the NDIS. The pre-NDIS supports were very different nationally, so that in order to capture the 'before situation' the survey introduces a question that asks about a wide range of potential supports, trying to capture as much of the activity as possible. For the purposes of the evaluation, this information will be used in order to define where things were when the scheme started in order to be able to measure the change that happened after its introduction. Respondents have been asked to tick all supports that applied to them before the NDIS.

Table 3.15 shows that there were a wide range of supports accessed before the NDIS and that the use of these supports was extensive. This table reveals both movement and complexity. Movement is revealed from the fact that 234 of the 891 respondents (NDIS participants) who were asked this question said that they did not receive any supports before the NDIS. This is a high percentage (26.3 per cent) of apparent newcomers in the context of disability supports. This is a part of the sample that needs to be more closely examined and followed over time. Complexity comes from the fact that only 216 of the 891 respondents reported receiving only one support before the NDIS (24 per cent), with 17 per cent receiving two supports, 11 per cent three and 20 per cent four or more (calculations not shown in the table below). How these supports will change and what the respondents think about this change will be a focus of future analyses.

Table 3.15: NDIS participants only - supports received before the NDIS

	Trial	Trial
	Cases	%
Received plan or case management	230	25.8
Received support with personal care and everyday living	149	16.7
Received support with leisure activities outside the home	173	19.4
Received support to participate in group activities in the community	187	21.0
Received support with transport and travelling	205	23.0
Received therapeutic supports or support with medication	223	25.0
Received respite or short breaks	190	21.3
Received aids and equipment	217	24.4
Received other types of support	176	19.8
Did not receive any support	234	26.3
Total	891	-

Note: trial only; 'Total' indicates the number of respondents to answer this question; multiple response question; columns therefore do not add to 100.

The survey asked if anyone self-managed any funding for supports before the NDIS. Of the 657 NDIS participants who responded to this question 32 per cent said they did, 20.1 per cent being managed by the family, 6.2 per cent by the person with disability themselves and 5.9 per cent by someone else (Table 3.16). This finding suggests that almost two thirds of the NDIS participants will have had no self-funding management experience, which could be for many reasons and could add to the

complexity of the roll out of the NDIS. Here too, for many respondents, the picture will be clearer through the analysis of the linked person with disability and their family and carer's survey data.

Table 3.16: Pre-NDIS experience with self-management of funding

	Trial	Trial
	Cases	%
Yes, person with disability did (16+ only)	41	6.2
Yes, person with disability family did	132	20.1
No	385	58.6
Yes, someone else did	39	5.9
Don't know	45	6.9
Missing	15	2.3
Total	657	100

Note: trial only receiving disability supports before joining the NDIS

## 3.6.4 Part A – Participation in the NDIS: planning and accessing supports

The following data relate to NDIS participants' experiences of the NDIS since their access request was approved. Where appropriate these responses are presented next to the comparison group responses. An important marker of the NDIS participants' data collection is the number of months between the time that the access request was approved and the time of interview. This is the time each individual survey respondent has already spent within the NDIS and has been recorded in months.

Figure 3.1 reveals a large proportion of people had already spent over a year in the NDIS at the time of their interview. The first sample of NDIS participants was not drawn until about six months into the lifetime of the NDIS. As well, the process of the selection of an NDIS participant for potential inclusion in the survey is long. It begins with the time it takes to obtain the sample from the NDIA records, followed by the opt-out consent process undertaken by the Department of Social Services and NDIA, which involves the preparation of a mail out and a three-week opt-out window. This initial mail out is followed by the preparation of the registration list by the survey company and the registration process which can last several months and finishes with the invitation to take part in the main survey which allows for several months of potential delay as well. The right skew that we observe in Figure 3.1 is the first glimpse we have on how long it actually took for the first part of Wave 1 of the survey to be completed. This information will be valuable at the evaluation estimation stage as it will allow us to know the exact timing of the response, both in calendar terms and in terms of the NDIS phase.

Number of months since access request to NDIA approved -requency Number of months since access request to NDIS approved

Figure 3.1: Number of months since access request to NDIA approved

Note: trial only

Figure 3.1 has a mean duration of just over 16 months with a standard deviation of 5 months. The first key experience for a new NDIS participant, after their access has been NDIA approved, is to meet their NDIA Planner. The vast majority of participants reported that they themselves, or someone on their behalf, had already met their Planner (Table 3.17). This is not surprising given the time these participants have already spent in the NDIS.

**Table 3.17: Meeting with the NDIA Planner** 

	Trial	Trial
	Cases	%
Yes, person with disability has	687	77.1
No, but family, carer, guardian or nominee has	168	18.9
No, no one has met with the NDIA Planner	18	2.0
Don't know	11	1.2
Missing	7	0.8
Total	891	100

Note: trial only

The numbers are too small to attach statistical importance on those who reported that no one had yet met with a Planner or did not remember if/when they met with their Planner. As the sample grows, these questions will be revisited to identify the need for NDIS participants to be assisted in making decisions about the supports they need and/or receive. Table 3.18 shows that people with disability in the trial sites who undertook planning have used on average 1.8 other people to assist them with their decisions, while in the comparison sample the average is just under 1.0.18

<sup>&</sup>lt;sup>18</sup> The 833 trial group respondents stated 1,565 different instances where "other people" had assisted them with their decision. This makes for an average of 1.8 instances of other people having assisted each person with

Table 3.18: Assisted in making decisions about supports

	Trial	Trial	Comparison	Comparison	Total	Total
	Cases	%	Cases	%	Cases	%
Family member	592	71.1	304	63.5	896	68.3
Friend	28	3.4	19	4.0	47	3.6
Guardian	150	18.0	53	11.1	203	15.5
Paid support worker	104	12.5	76	15.9	180	13.7
Nominee	57	6.8	16	3.3	73	5.6
No one	30	3.6	55	11.5	85	6.5
Local Area Coordinator	119	14.3	0	0.0	119	9.1
NDIA Planner	485	58.2	0	0.0	485	37.0
Total	833		479		1,312	

Note: trial respondents who have a support plan approved by the NDIA and comparison respondents who have a support plan arranged with a disability support provider; 'Total' indicates the number of respondents to answer this question; multiple response question; columns therefore do not add to 100.

Assistance is primarily provided by family and guardians (in 71.1 per cent and 18 per cent of cases in trial sites respectively and 63.5 per cent and 11.1 per cent in the comparison group) and the NDIA Planner and Local Area Coordinator (in 58.2 per cent and 14.3 per cent of cases in the trial sites). A substantial role is also played by support workers (13 - 16 per cent) and, albeit to a lesser extent, by nominees (3 - 7 per cent) and friends (around 3 - 4 per cent).

Comparing the trial group column with that of the comparison group in Table 3.18 shows NDIS participants reported needing and using more people to assist them with making support decisions. The support from those close to the person with disability (that is, from family members, guardians and nominees) suggests their greater involvement with NDIS participants, but we cannot know if this is part of the adjustment into the NDIS or a more long-lasting change. The next wave of information may shed light on this question.

We find that the involvement of paid support workers was marginally lower in the trial group (12.5 per cent against 15.9 per cent in the comparison group). As expected 73 per cent of NDIS participants in the trial sites received assistance from their Planner or their Local Area Coordinator (58.2 per cent and 14.3 per cent respectively). Finally, we find that in the comparison group 11.5 per cent of respondents reported receiving no assistance at all, whereas the percentage drops to 3.6 per cent in the trial group.

The overall picture is that a considerably higher proportion of NDIS participants have people assisting them in decisions related to their NDIS supports. In total the instances of help per person were more than double in the trial group and the percentage of those who managed without any assistance drops from 11.5 per cent in the comparison group to 3.6 per cent in the NDIS group. In addition to the new support received by the trial group by the Local Area Coordinator and the NDIS planner (which is not available to the comparison group), the support provided by family, guardians and nominees was also shown to be higher for the trial group.

Leaving aside the potential influence of different age profiles of the trial and comparison group samples, there are several possible interpretations of the finding that NDIS participants are receiving more support with decision-making. It could be that the NDIS provides additional assistance which is utilised by those in need, so that the same or similar supports are provided in a more informed

disability (1,535/833=1.84, rounded to 1.8). The same calculation for the comparison group suggests an average of 1.0 instances (468/479=0.98, rounded to 1.0). The instances where the answer was "No one" are excluded from this calculation (30 instances in the trial and 55 in the comparison group).

manner. It may be that the choices available have increased and the supports have improved, so that more assistance is needed to navigate the NDIS and the novelty it brings. But it could also be that the system has become more complex and the use of more assistance is simply reflecting this added complexity in the process and not necessarily an improvement in the supports. Finally, the NDIS itself generates more opportunity for multiple forms of assistance. It has created two new sources of assistance, NDIA Planners and Local Area Co-ordinators, that our data shows are being used by the NDIS participants. The data will be analysed further in order to try to isolate these potentially very different explanations of the increased assistance incidence.

Table 3.19 presents the supports that respondents are currently receiving. It suggests that the instances of supports received are much higher among the trial population than in the comparison group. In all categories of supports received, the NDIS participants reported a much higher percentage of receipt. Very broadly speaking, there are two possible explanations for this.

The first explanation would be that the NDIS has brought change in the form of more supports. The second explanation could be that comparing the two columns (containing the trial and comparison group support statistics in Table 3.19) may not be comparing like with like. This could be because (i) the non-random phasing in at the trial sites may result in a different composition of people with disability relative to the comparison areas, or (ii) the types of supports may be different between the two groups. Both of these reasons would make a comparison hard and the problem could be seriously exacerbated by the lack of the full sample size.

Notwithstanding these statistical caveats, we discuss briefly the differences in support receipt between the two samples in Table 3.19. A much higher percentage of people with disability in the trial group (55.3 per cent) receive plan or case management than in the comparison group (19.6 per cent). To the degree that this stage would be a necessary start for receiving NDIS supports, this difference presages the further observation that many more of the NDIS participants also appear to be receiving supports of all types. In most cases more than twice as many for NDIS participants than for the comparison group. This includes the 'other types of support' category at 29.8 per cent for the comparison group and 54 per cent for the NDIS trial group, indicating that the variety of supports is also different.

These are early findings and they will become much more precise as we move to the full sample and as we use multivariate methods to account for the observable differences between the trial and comparison groups. Until then, we can say that there is an emerging picture suggesting that the supports landscape is considerably different between the trial and comparison groups of people with disability.

Table 3.19: Current types of supports received

	Trial	Trial	Comparison	Comparison	Total	Total
	Cases	%	Cases	%	Cases	%
Plan or case management	493	55.3	197	19.6	690	36.4
Support with personal care and everyday living	252	28.3	179	17.8	431	22.7
Support with leisure activities outside the home	328	36.8	172	17.1	500	26.4
Support to participate in group activities in the community	317	35.6	137	13.7	454	24.0
Support with transport and travelling	344	38.6	197	19.6	541	28.6
Therapeutic supports or support with medication	398	44.7	204	20.3	602	31.8
Respite or short breaks	251	28.2	125	12.5	376	19.8
Aids and equipment	320	35.9	137	13.7	457	24.1
Other types of support	481	54.0	299	29.8	780	41.2
Support with work or study (16+ only)	84	17.9	76	11.9	160	36.4
Total	891		1,004		1,895	

Note: trial and comparison all ages; 'Total' indicates the number of respondents to answer this question; multiple response question; columns therefore do not add to 100.

An important aspect of the NDIS is its focus on early interventions. Early interventions are often longer term interventions, with benefits that may be realised in some, possibly distant, time in the future. In such cases, identifying and measuring the impact of specific early intervention supports within a short term study like the NDIS Evaluation will likely underestimate or miss benefits. Both our data collection and analysis focus on the take up rate of such supports that are classified as early interventions, as the best indicator that can be collected today. External information about the longer term potential of these supports to influence longer term outcomes could be used as an approximation of their impact until a later point in time when evidence about the actual outcomes may become measurable. Table 3.20 presents the incidence of early intervention supports differentiating by age group and trial and comparison groups for the 1,454 people with disability who reported to be receiving any supports.

Table 3.20: Respondents in receipt of an early intervention by age group

Early interventio n supports	Trial 0 to 7	Comparison 0 to 7	Trial 8 to 15	Compariso n 8 to15	Trial 16 to 17	Comparison 16 to17	Trial 18+	Comparison 18+	Trial All ages	Comparison All ages
Yes	243	61	12	21	2	6	55	36	312	124
Yes %	75.2	57.5	14.5	19.6	6.1	15.4	12.9	10.7	36.0	21.1
No	41	37	59	76	26	27	301	233	427	373
No %	12.7	34.9	71.1	71.0	78.8	69.2	70.3	69.6	49.3	63.5
Don't know	38	7	10	8	5	5	67	53	120	73
Don't know %	11.8	6.6	12.0	7.5	15.2	12.8	15.7	15.8	13.8	12.4
Missing	1	1	2	2	0	1	5	13	8	17
Missing %	0.3	0.9	2.4	1.9	0.0	2.6	1.2	3.9	0.9	2.9
Total	323	106	83	107	33	39	428	335	867	587

Note: trial and comparison all ages if currently receiving disability supports

Table 3.20 suggests very strongly that early interventions are focused on the 0-7 age group. In both trial and comparison groups, the 0-7 age group account for 75.2 and 57.7 per cent of respondents in each group respectively. The difference between trial and comparison early intervention incidence in the 8+ year old people with disability is unclear, possibly due to the high level of 'do not know' responses. Further information is collected by the survey on which of the supports received are

included as part of an early intervention. This information will allow a better understanding of the role of early interventions within the totality of supports received.

## 3.6.5 Part A – Participation in the NDIS: support providers

The success of the NDIS will depend on the presence of an adequate number of providers who will be willing and able to make the necessary provisions at a price, quality and quantity that will reflect the needs of people with disability and the capacity of the whole NDIS. The evaluation therefore collects information on the provision of supports from many different angles, ranging from the people with disability and their families and carers to the employers and employees responsible for these provisions. This sub-section presents the point of view of the people with disability. The first question asks about the number of different providers that are used in a typical month, in Table 3.21.

Table 3.21: Number of disability support providers used

	Trial	Trial	Comparison	Comparison	Total	Total
	Cases	%	Cases	%	Cases	%
1	194	22.4	213	36.3	407	28.0
2 to 5	543	62.6	248	42.3	791	54.4
6 to 10	52	6.0	23	3.9	75	5.2
More than 10	17	2.0	12	2.0	29	2.0
Don't know	55	6.3	69	11.8	124	8.5
Missing	6	0.7	22	3.8	28	1.9
Total	867	100	587	100	1,454	100

Note: trial and comparison with support plan arrangement in place

In the trial group, just over 20 per cent reported using only one provider, while a sizeable majority (62.6 per cent) reported using 2 to 5 providers, with 6.0 per cent using 6-10 and 2 per cent using more than 10. Very few people reported that they used 6-10 providers and even fewer that they used more than 10. The numbers in the present table are too small to be useful, but can be expected to grow as the full Wave 1 sample is collected. This table should be revisited at the end of Wave 1 data collection to note any change between the earlier and later sampling.

The NDIS is expected to bring much change in the way provision is carried out, but it is not as yet well understood how this will happen. Table 3.22 asks whether the survey respondents have experienced a recent change in disability support providers.

Table 3.22: Changes in disability support providers

	Trial	Trial	Comparison	Comparison	Total	Total
	Cases	%	Cases	%	Cases	%
Yes	324	37.4	120	20.4	444	30.5
No	524	60.4	432	73.6	956	65.8
Don't know	13	1.5	22	3.8	35	2.4
Missing	6	0.7	13	2.2	19	1.3
Total	867	100	587	100	1,454	100

Note: trial and comparison with support plan arrangement in place

Table 3.22 clearly shows that percentage of instances of change in providers was almost double in the trial sites than in the comparison areas (37.4 per cent against 20.4 per cent). Future analysis will provide information about the direction and other characteristics of such changes, in particular whether the change is towards new provisions from a new provider or the same provisions from a new provider. The survey also asks a question about changes that were desired and for which the funding was in place, but could not be carried out due to lack of access. This would be the case where the demand for a support is present, the NDIS approves of this demand, but, for several reasons, the supply of this support is not forthcoming. Whilst this may be recognised as a problem in the context of a NDIS trial roll out, any traces of such a problem should be treated very seriously when contemplating and planning the full NDIS roll out where provision will be needed for approximately 400,000 people. Put simply, if the supply of supports experiences problems by the change brought to it by several tens of thousands of people, what will it do when it is faced with 10 times that number?<sup>19</sup>

Table 3.23 shows that the instances where supports could not be accessed are three times as many in the trial sites than among the comparison group.<sup>20</sup> This is a part of the data that needs special care and further investigation, especially when the full sample is at hand.

Table 3.23: Could not access supports

	Trial	Trial	Comparison	Comparison	Total	Total
	Cases	%	Cases	%	Cases	%
Yes	238	26.7	83	8.3	321	16.9
No	574	64.4	815	81.2	1,389	73.3
Don't know	73	8.2	89	8.9	162	8.6
Missing	6	0.7	17	1.7	23	1.2
Total	891	100	1,004	100	1,895	100

Note: trial and comparison all ages

Reasons for not accessing the support are presented in Table 3.24, where reporting multiple reasons was allowed. The number of the overall instances is informative, and the differences between trial and comparison groups more so.

Table 3.24: Reason for not accessing support

	Trial Cases	Trial %	Comparison Cases	Comparison %	Total Cases	Total %
Support was too expensive	28	11.8	15	18.3	43	13.4
There was no local provider	94	39.5	25	30.1	119	37.1
Lack of quality provision	58	24.4	15	18.1	73	22.7
The wait was too long	103	43.3	24	28.9	127	39.6
Other reason	98	41.2	36	43.4	134	41.7
Total	238		83		321	

Note: trial and comparison all ages with funding for support but could not access that support; 'Total' indicates the number of respondents to answer this question; multiple response question; columns therefore do not add to 100.

<sup>&</sup>lt;sup>19</sup> Such imbalances between supply and demand could impact on the quality, quantity and price of the full roll-out with major budgetary and performance implications.

<sup>&</sup>lt;sup>20</sup> This conclusion, like several of the conclusions drawn in this initial report, depends on the trial area sample being similar to the comparison sample.

The first observation in Table 3.24 is that, overall, 39.6 per cent of respondents reported that the wait to access supports was too long, suggesting a stretched supply chain. A similar picture arises about a lack of local providers (37.1 per cent), again a sign of a stretched supply chain. These reasons are the most prevalent of the single reasons reported by both trial and comparison groups indicating a long standing problem, but it is worth noting that the introduction of the NDIS does not seem to have solved it. On the contrary, a visibly larger proportion of people in the trial group than in the comparison group reported that they could not access their supports because "There is no local provider" (39.5 against 30.1 per cent) or because "The wait was too long" (43.3 against 28.9 per cent). Lack of quality provision is also a high prevalence reason for not accessing supports, which is also more frequently encountered in the NDIS trial group (24.4 per cent against 18.1 per cent in the comparison group). It is noteworthy that despite these clear signs of supply constraints the price does not seem to be adjusting to a higher level which would act as a break to the demand that remains unfulfilled. In addition to evidence of unfulfilled demand, the data appears to be suggesting that the prices may not be rising to reduce demand, which may well be a desired attribute of the NDIS. We note here that in situations where price variations may not be allowed to play their core economic role (by allocating access according to capacity to pay) other mechanisms are known to take over, such as waiting times and or quality adjustments. Table 3.24 provides early evidence that such alternative adjustments may be happening and need therefore to be closely monitored.

A final observation is that the percentage of 'Other reason' answers was very high, indicating that this question could have been more detailed. This was anticipated and a box for free answers was provided, the answers to which will be further analysed.

The NDIS is not designed to cover all supports for all people with disability. There will be supports that are demanded and which are not funded by the NDIS. The surveys ask whether people with disability access supports that are not funded by the NDIS and how they access them, in order to examine how these are developing as the NDIS is rolled out. The numbers for these supports in the present sample are not large enough to report their distribution as an individual item in the data, with only 238 people in the trial sites and 83 in the comparison areas having reported accessing supports that were not funded. We will report on these supports when the full Wave 1 sample becomes available for analysis.

# 3.6.6 Part A - Education

Education and employment are widely recognised as major direct contributors towards greater social and economic participation and indirect contributors towards improving wellbeing and the general quality of life. The surveys collect information about the education level of people with disability. For those who are currently studying towards a qualification, we ask the level of that qualification. The survey also collects information about current employment status, occupation and further details. One of the aspirations of the NDIS is to increase social and economic participation and personal wellbeing, with education and employment being recognised as prime pathways towards such improvements for at least some NDIS participants. Both the collection and the interpretation of the employment and education information are heavily age-related. For the younger NDIS participants we would be looking at school participation and thinking of education as an early intervention activity aiming not only at current life quality improvements through participation, but also working towards better future outcomes, including potential employment outcomes. For the older adults, we would be looking at education and employment as participation contributors that work in tandem and where a certain (longer-term) level of achievement is already present. The question for the older adults would be whether the NDIS may be able to provide practical support to improve that longerterm status as a means of improving participation and wellbeing. For the youngest adults, the picture is mixed as they could be still at school, or in post-school education, but they can also already be in employment.

It is important that we clarify from the outset exactly how this information can be interpreted and used. The information in the first wave of the survey data will give us a baseline picture of where our respondents' levels of employment and education are at the time of interview. The information in the second wave will provide us with information about any changes that have happened between Wave 1 and Wave 2 interviews. This information will need to be interpreted differently by age, as the outcomes we can expect will be age-related. For the youngest participants, the main change would be the level of school participation and how this could influence mainly future outcomes. The 'early intervention' nature of an improvement in school participation or performance is self-evident and does not need explaining. In contrast, for the older adults we would not be looking for future outcomes. If the NDIS facilitates the enrolment and completion of, say, a Certificate IV, then we would expect that the employment outcomes should materialise soon after graduation.

Clearly, in this context the young and the old should be examined separately. However, there are other aspects where the benefit of education can be similar for both young and old. For example, attending school and attending TAFE will both result in increased social participation with obvious benefits. Given that the provision of education and achieving employment are processes with an as yet unknown influence by the roll out of the NDIS, we present the relevant statistics jointly for the trial and comparison samples.

Table 3.25 shows that at the time of the interview, 48 per cent of people in the trial and comparison groups reported they were currently studying, including almost all children between the age of 3 and 15 (97.7 per cent) and 17.1 per cent of adults.

Table 3.25: Currently studying or not

	Children	Children	Adults	Adults		
	3 to 15 years	3 to 15 years	16+	16+	Total	Total
	Cases	%	Cases	%	Cases	%
Yes	688	97.7	189	17.1	877	48.4
No	15	2.1	909	82.1	924	51.0
Don't know	0	0.0	3	0.3	3	0.2
Missing	1	0.1	6	0.5	7	0.4
Total	704	100	1,107	100	1,811	100

Note: trial and comparison aged 3 years and above

Table 3.26a shows the type of school attended and Table 3.26b shows the type of post-school education attended. The majority of children below 16 and who reported attending a school were in Pre-school/ kindergarten (16.3 per cent), in Pre Year 1 primary school (13.2 per cent) and Primary school Year 1 and above (41.7 per cent). School attendance of a secondary level or within a special school is at 13.1 per cent each for the 3-15s and for the 16+s, most are attending either a secondary school or a special school (65.9 per cent and 25.6 per cent respectively).

Table 3.26a and Table 3.26b show the type of educational establishment attended by those in education.

Table 3.26a: Attending school

	Children	Children	Adults	Adults		
	3 to 15 years	3 to 15 years	16+	16+	Total	Total
	Cases	%	Cases	%	Cases	%
Secondary school	90	13.1	54	65.9	144	18.7
Special School	90	13.1	21	25.6	111	14.4
School by distance Learning	4	0.6	3	3.7	7	0.9
Other	5	0.7	-	-	5	0.6
Pre-school/ kindergarten (0 to 15 only)	112	16.3	-	-	112	14.5
Pre Year 1 primary school (0 to 15 only)	91	13.2	-	-	91	11.8
Primary school Year 1 and above (0 to 15 only)	287	41.7	-	-	287	37.2
Home school	4	0.6	-	-	4	0.5
Missing	5	0.7	4	4.9	9	1.2
Don't know	1	0.1	-	-	1	0.1
Total	689		82		771	

Note: trial and comparison aged 3 years and above currently at school, excluding tertiary education

Moving to post-school education of adults (16+) in Table 3.26b, 15.9 per cent reported attending university, 37.4 per cent a TAFE/Technical college and the remaining 45.8 per cent reported attending several other options.

Table 3.26b: Attending post-school education

	Adults 16+	Adults 16+
	Cases	%
University	17	15.9
TAFE/Technical college	40	37.4
Post school distance learning	9	8.4
Industry skills centre/employer based training?	8	7.5
Specialist institute/college	6	5.6
Community centre	4	3.7
Other	22	20.6
Don't know	1	0.9
Total	107	100

Note: trial and comparison aged 16 years and above currently studying post-school

Table 3.27 suggests that the level of post-school qualification aimed at is diverse. Whilst the most frequently reported level is Certificate I or II (which typically confer the minimum labour market impact amongst all post-school qualifications), a substantial proportion reported attending courses that lead to a Certificate III/IV, a Diploma, a Degree or equivalent, all of which are education outcomes with a well-established relationship with future labour market success.

Table 3.27: Qualification level currently studying

Adults 16+	Adults 16+
Cases	%
37	34.6
18	16.8
11	10.3
14	13.1
3	2.8
4	3.7
1	0.9
8	7.5
6	5.6
3	2.8
2	1.9
107	100
	Cases  37 18 11 14 3 4 1 8 6 3 2

Note: trial and comparison aged 16 years and above in education (post-school)

The school year of current study is also collected as an indication of the present education status and achievement and in order to be compared with that of future samplings. Progression is an indication of successful education participation and the data presented in Table 3.28 provides us with the benchmark from which we will judge progress through the next wave of data collection. We will not only observe how each person with disability presently attending education has progressed, but will also see what other factors are more strongly associated with this progression and how people with disability perceive their education progression. It is well-established that education has a 'consumption value', in that it can also confer personal quality of life benefits (over and above labour market improvements) which make studying a worthwhile activity for people. The data we collect will allow us to make such judgements about people with disability and education. The lower the labour market prospects from an educational pathway, the more important the 'consumption value' element of it will be.

Table 3.28: What year are you currently in?

	Children	Children	Adults	Adults		
	3 to 15 years	3 to 15 years	16+	16+	Total	Total
	Cases	%	Cases	%	Cases	%
Year/Grade 1 (3 to 15 only)	106	21.9	-	-	106	18.8
Year/Grade 2 (3 to 15 only)	76	15.7	-	-	76	13.5
Year/Grade 3 (3 to15 only)	41	8.5	-	-	41	7.3
Year/Grade 4 (3 to 15 only)	39	8.0	-	-	39	6.9
Year/Grade 5 (3 to 15 only)	43	8.9	-	-	43	7.6
Year/Grade 6 (3 to 15 only)	32	6.6	-	-	32	5.7
Year/Grade 7 (3 to 15 only)	42	8.7	-	-	42	7.5
Year 7 or equivalent (16+ only)	-	-	1	1.3	1	0.2
Year 8 or equivalent	25	5.2	-	-	25	4.4
Year 9 or equivalent	22	4.5	-	-	22	3.9
Year 10 or equivalent	29	6.0	4	5.1	33	5.9
Year 11 or equivalent	10	2.1	19	24.4	29	5.2
Year 12 or equivalent	-	-	45	57.7	45	8.0
Year 13 or equivalent	-	-	4	5.1	4	0.7
Don't know	16	3.3	2	2.6	18	3.2
Missing	4	0.8	3	3.9	7	1.2
Total	485	100	78	100	563	100

Note: Note: trial and comparison aged 3 years and above in school

Another indicator of education participation is whether the study is full time or part time. Table 3.29 shows this for children and adults. About 30 per cent of adults reported attending education part time. In contrast, very few children reported going to school part time (only 3.9 per cent of the total).

Table 3.29: Enrolled full time/part time

	Children Cases	Children %	Adults Cases	Adults %	Total Cases	Total %
Full time	452	93.2	97	58.1	549	84.2
Part time	19	3.9	51	30.5	70	10.7
Don't know	0	0.0	8	4.8	8	1.2
Missing	14	2.9	11	6.6	25	3.8
Total	485	100	167	100	652	100

Note: trial and comparison all ages in education (school or tertiary organisation)

The next two tables show the highest achieved levels of schooling (Table 3.30) and educational qualification (Table 3.31) excluding those currently in primary or secondary education. These two measurements of educational achievement are well understood to be strong markers of, first, the likelihood that further education participation will occur and, second, the nature of present and future labour force participation and performance. It is worth noting that schooling is an indicator of the more general 'human capital' that education builds (in that school teaches people generic and skills with wider applicability and lesser occupational specificity), while post-school education is an indicator of the more specific 'occupational human capital' that education builds (in that most certificates and many degrees lead to a specific type of occupation or part of the labour market and are more easily recognised by employers in terms of the skills they offer).

Tables 3.30 and 3.31 show about half of adults had achieved 10 or more years of schooling (Table 3.30) and just over half having completed some form of qualification (Table 3.31). A little over a third (38.5 per cent) reported not having achieved any qualification.

Table 3.30: Highest year of schooling attained

	Adults 16+	Adults 16+
	Cases	%
Did/does not go to school	33	3.2
Year 7 or below	81	7.9
Year 8 or equivalent	42	4.1
Year 9 or equivalent	78	7.6
Year 10 or equivalent	197	19.1
Year 11 or equivalent	91	8.8
Year 12 or equivalent	354	34.4
Year 13 or equivalent (16+ only)	59	5.7
Prefer not to say	9	0.9
Don't know	59	5.7
Missing	26	2.5
Total	1,029	100

Note: trial and comparison aged 16 years and above not in education or in community based education

Table 3.31: Highest level of educational qualifications

	Adults 16+	Adults 16+
	Cases	%
No qualification completed	396	38.55
Year 12 certificate or equivalent	145	14.1
Certificate I or II	49	4.8
Certificate III	76	7.4
Certificate IV	39	3.8
Diploma or Advanced Diploma	69	6.7
Bachelor degree	61	5.9
Postgraduate degree	32	3.1
Other educational qualification	82	8.0
Don't know	31	3.0
Missing	49	4.8
Total	1,029	100

Note: trial and comparison aged 16 years and above not in education or in community based education

Any changes in these levels that could be attributable to NDIS participation would provide direct evidence insofar as education has its own 'consumption value' and indirect evidence insofar as education can improve other personal objectives, for example, by enabling a higher quality labour market involvement. This evidence will be used by the evaluation to judge the impact of the NDIS on present and future labour market aspirations, expectations and ultimately actual performance and the degree to which these lead to higher social and economic participation and wellbeing.

We cannot expect to see change in the highest level of education achievement between the two waves of data collection. The survey will however identify uptake of study in the sampling of the second wave. Thus the overall data picture we aim to complete by the end of Wave 2, is (i) evidence on the educational outcome for those who were studying in Wave 1, (ii) evidence on the choices to study or not in Wave 2, for those who were not studying in Wave 1. The differences in the composition of these three distinct outcome-groups will inform the evaluation.

# 3.6.7 Part A – Employment

The questions on employment are only asked of the adult survey respondents. Of the 1,107 adult respondents, 222 (20 per cent) reported being in employment with 201 (18 per cent) reporting that they were employed and were at work in the current week. Twenty-one (2 per cent) reported that they were in an employment relationship but were not at work in the current week because of holidays, sickness or any other reason (such as maternity leave or workers compensation). Of the 222 people in employment, 79 (35.6 per cent) reported that they worked in an Australian Disability Enterprise (Table 3.32).

Table 3.32: Work in an Australian Disability Enterprise

	Adults 16+	Adults 16+
	Cases	%
Yes	79	35.6
No	126	56.8
Don't know	13	5.9
Missing	4	1.8
Total	222	100

Note: trial and comparison aged 16 years and above in work

Figure 3.2 shows the distribution of hours worked. The most important statistic to look at is the mode, that is, the category that is most prevalent in the data. Figure 3.2 suggests that there is no clear mode, but rather there are two modes, one in the 11 - 15 hours per week range and another in the 36+ hours per week range. This is because, while the majority of employment is part time, there is also a sizeable minority of respondents who reported working full-time. This suggests that employment of people with disability can be very diverse and that further information should be sought. At this stage that the numbers are too small to draw any further conclusions and that we should have a better picture once the full Wave 1 information is at hand.

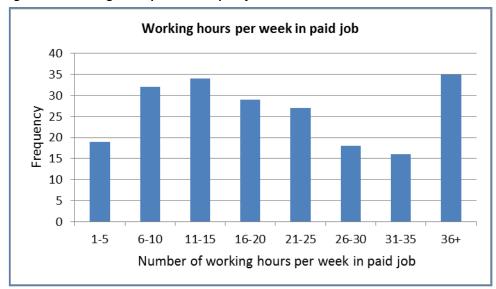


Figure 3.2: Working hours per week in paid job

Note: trial and comparison aged 16 years and above in work

The current and past occupations are recorded in a free hand fashion in the data collection and are later converted into the 6-digit ANZSCO<sup>21</sup> code. A distribution at the 1-digit level is presented in Table 3.33. It shows that the currently employed are likely to be working in manual occupations, about half of whom (Table 3.34) had their workplaces adapted to facilitate their employment. In some contrast, those not presently employed, but with previous employment, included more occupations in the managerial, professional or technical and trades occupations. However, as previously noted numbers are too small to draw any further conclusions until the full Wave 1 information is at hand.

-

<sup>&</sup>lt;sup>21</sup> Australian and New Zealand Standard Classification of Occupations

**Table 3.33: Current occupation** 

	Current occupation Cases	Current occupation %	Past occupation if presently not employed Cases	Past occupation if presently not employed %
Manager	3	1.4	22	4.0
Professionals	22	9.9	72	13.1
Technicians and Trades Worker	15	6.8	61	11.1
Community and Personal Service Worker	18	8.1	62	11.3
Clerical and Administrative Worker	30	13.5	93	16.9
Sales Worker	11	5.0	34	6.2
Machinery Operators and Driver	4	1.8	43	7.8
Labourer	88	39.6	132	24.0
Miscellaneous	3	1.4	5	0.9
Don't know	4	1.8	7	1.3
Missing	24	10.8	20	3.6
Total	222	100	551	100

Note: trial and comparison aged 16 years and above in work

Table 3.34: Work place adapted to facilitate working

	Cases	%
Yes	110	49.6
No	94	42.3
Don't know	16	7.2
Missing	2	0.9
Total	222	100

Note: trial and comparison aged 16 years and above in work

An important statistic arises from Table 3.35. When we look at all adult respondents who reported not presently working, we find a good majority (61.2 per cent) who reported that they had held a job sometime in the past. This finding is in general agreement with the employment literature where the labour force participation of people with disability is both volatile and changeable over time.

Table 3.35: If presently not employed, have ever had a job?

	Cases	%
Yes	540	61.2
No	330	37.4
Don't know	1	0.1
Missing	11	1.3
Total	882	100

Note: trial and comparison aged 16 years and above not in work

## 3.6.8 Part A - Income

Income is one of the core background pieces of information that our data collection generates. The role of income in participation is self-evident: most participation activities come at a financial cost and those with higher incomes can afford to do more than those with lower incomes. One of the core objectives of the NDIS is to make certain that people with disability who do not have high personal incomes will be able to participate through receipt of a reasonable level of supports. We elicit the different sources of income.

The income of adult persons with disability is recorded by asking for the main source of income and other sources of income. After the source of income has been established we ask for the level of total personal income in the last financial year, before tax and other deductions. Finally, we ask for the combined income of all household members of both adult and child respondents.

Table 3.36 presents the category of the main source of income of the person with disability. After listing several well established categories, we allow the respondent to write into a box if they have any 'Other Government pension or allowance'. This box could be analysed in depth. We also allow the respondent to write their 'Other' sources of income in an additional box. The two write in boxes serve two main purposes. First they provide us additional information in an almost interactive manner and in a granularity that reveals diversity that cannot be known in advance. Second, it works as a completeness check for the categories that the question includes in that, if the 'Other' category is heavily populated, we know that the list is leaving much information unchecked. The list of categories we use is a standard list that is universally applied.

Table 3.36: Person with disability main source of income

	Trial Cases	Trial %	Comparison Cases	Comparison %	Total Cases	Total %
Wages or salary	26	5.5	71	11.2	97	8.8
Disability Support Pension (paid by Centrelink)	366	77.9	378	59.3	744	67.2
Child Disability Assistance Payment	0	0.0	1	0.2	1	0.1
Carer Payment	1	0.2	3	0.5	4	0.4
Other Government pension or allowance	3	0.6	25	3.9	28	2.5
Superannuation, an annuity or private pension	13	2.8	26	4.1	39	3.5
Compensation/Insurance pay-out	4	0.9	16	2.5	20	1.8
Dividends and interest from shares	2	0.4	2	0.3	4	0.4
Other	7	1.5	14	2.2	21	1.9
Newstart allowance	0	0.0	15	2.4	15	1.4
Partner allowance	0	0.0	2	0.3	2	0.2
Australian Age Pension	2	0.4	11	1.7	13	1.2
None	13	2.8	20	3.1	33	3.0
Don't know	0	0.0	11	1.7	11	1.0
Missing	33	7.0	42	6.6	75	6.8
Total	470	100	637	100	1,107	100

Note: trial and comparison aged 16 years and above

Table 3.36 suggests that the main source of income is overwhelmingly a Disability Support Pension paid by Centrelink (67.2 per cent), the only distinct further sources of some noticeable frequency being wages or salary (8.8 per cent) and Superannuation (3.5 per cent). The proportion of respondents who left this question unanswered (missing) is 6.8 per cent, which, given the sensitivity of this type of information we consider to be very low.

FOR OFFICIAL USE ONLY

The same exercise was carried out in Table 3.37 which reports if there are any other sources of income. This question is typically not answered as frequently or as precisely as the main source of income and it is not surprising that the 'Other' categories are heavily populated. We do not consider this to be problematic. We note that the wages or salary category is sizeable at around the 5 per cent mark (there are presumably people who work part time and other supports are their main source of income). We also note that Disability Support Pension sits at the 6 per cent mark, indicating that these respondents top up their income this way.

Table 3.37: Sources of additional income of a person with disability

	Trial	Trial	Comparison	Comparison	Total	Total
	Cases	%	Cases	%	Cases	%
Wages or salary	25	5.3	30	4.7	55	5.0
Disability Support Pension (paid by Centrelink)	26	5.5	40	6.3	66	6.0
Child Disability Assistance Payment	0	0.0	1	0.2	1	0.1
Youth Disability Supplement	1	0.2	3	0.5	4	0.4
Carer Allowance	5	1.1	10	1.6	15	1.4
Carer Payment	2	0.4	8	1.3	10	0.9
Other Government pension or allowance	10	2.1	27	4.2	37	3.3
Superannuation, an annuity or private pension	11	2.3	18	2.8	29	2.6
Compensation/Insurance pay-out	2	0.4	2	0.3	4	0.4
Dividends and interest from shares	14	3.0	19	3.0	33	3.0
Other	29	6.2	38	6.0	67	6.1
Do not know	2	0.4	5	0.8	7	0.6
Prefer not to say	6	1.3	5	0.8	11	1.0
Newstart allowance	1	0.2	2	0.3	3	0.3
Partner allowance	0	0.0	0	0.0	0	0.0
Sickness allowance	0	0.0	0	0.0	0	0.0
Australian Age Pension	1	0.2	1	0.2	2	0.2
No other sources of personal income	144	30.6	206	32.3	350	31.6
Other government pension	10	2.1	27	4.2	37	3.3
Other source of income	29	6.2	39	6.1	69	6.2
Other (does not apply/missing)	152	32.3	156	24.5	307	27.7
Total	470	100	637	100	1,107	100

Note: trial and comparison aged 16 years and above

The next two Tables 3.38 and 3.39 report the level of personal and combined household income. This is asked in income brackets, as this method is known to increase the precision of the answer and the response rate, as people who may know the exact level of their income are often reluctant to reveal it and other people simply do not remember the exact figure but are familiar with the range. We have expressed the categories as annual incomes (and also presented the fortnightly equivalent). The preliminary picture we see in Tables 3.38 and 3.39 may change as the sample size increases. As well, average income statistics can conceal much diversity. The detailed picture of income will be developed in the second report which will be based on the full Wave 1 sample and will include multivariate statistical analysis of personal and household income and other related information at the personal and household level that will be developed through the linking of the person data with the family and carer data as well.

Table 3.38: Total person with disability personal income for the last year

	Trial	Trial	Comparison	Comparison	Total	Total
	Cases	%	Cases	%	Cases	%
\$1 - \$9,999 (\$1 - \$379 per fortnight)	60	13.6	101	16.6	161	15.4
\$10,000 - \$19,999 (\$380 - \$759 per fortnight)	136	30.9	177	29.1	313	29.8
\$20,000 - \$29,999 (\$760 - \$1159 per fortnight)	134	30.5	150	24.6	284	27.1
\$30,000 - \$39,999 (\$1160 - \$1539 per fortnight)	15	3.4	31	5.1	46	4.4
\$40,000 + (\$1540 + per fortnight)	15	3.4	53	8.7	68	6.5
Don't know	80	18.2	97	15.9	177	16.9
Total	440	100	609	100	1,049	100

Note: trial and comparison aged 16 years and above

Notwithstanding the need for caution, the distribution of income shows that the majority of persons with disability are recipients of very low incomes. Close to 20 per cent of all respondents reported that they do not know their income. About 75 per cent reported their before-tax annual income to be below \$30,000, with less than 5 per cent between \$30,000 and \$39,999. Very few people with disability reported an income of more than \$40,000. This income distribution should be read alongside with the main source of income being government supports (Tables 3.36 and 3.37), with the low employment rate (start of section 3.6.7 and Table 3.32) and the large proportion of those employed who work fewer than 15 hours per week (Figure 3.2).

Table 3.39 shows the combined household income and paints a different picture. About the same proportion of people reported that they do not know their household income. Now that the whole household income is taken into account, the emerging preliminary picture is that the households of people with disability are still below the national average<sup>22</sup>, but not by much. With the whole sample at hand we will examine this picture more closely.

Table 3.39: Total person with disability household income for the last year

	Trial	Trial	•	Comparison	Total	Total
	Cases	%	Cases	%	Cases	%
\$1 - \$9,999 (\$1 - \$379 per fortnight)	18	2.3	20	2.2	38	2.2
\$10,000 - \$19,999 (\$380 - \$759 per fortnight)	54	6.7	84	9.2	138	8.0
\$20,000 - \$29,999 (\$760 - \$1159 per fortnight)	99	12.4	131	14.3	230	13.4
\$30,000 - \$39,999 (\$1160 - \$1539 per fortnight)	68	8.5	90	9.8	158	9.2
\$40,000 - \$49,999 (\$1540 - \$1919 per fortnight)	58	7.2	65	7.1	123	7.2
\$50,000 - \$59,999 (\$1920 - \$2299 per fortnight)	65	8.1	47	5.1	112	6.5
\$60,000 - \$79,999 (\$2300 - \$3059 per fortnight)	72	9.0	105	11.5	177	10.3
\$80,000 - \$99,999 (\$3060 - \$3839 per fortnight)	78	9.7	71	7.8	149	8.7
\$100,000 - \$124,999 (\$3840 - \$4799 per fortnight)	54	6.7	51	5.6	105	6.1
\$125,000 - \$149,999 (\$4800 - \$5759 per fortnight)	40	5.0	32	3.5	72	4.2
\$150,000 or more (\$5760 or more per fortnight)	38	4.7	42	4.6	80	4.7
Don't know	157	19.6	177	19.3	334	19.5
Total	801	100	915	100	1,716	100

Note: trial and comparison all ages

าา

<sup>&</sup>lt;sup>22</sup> All employees average weekly total earnings \$1136.90/week (ABS 2015)

## 3.6.9 Part B - Overview

In this section, we turn to presenting the preliminary findings from the early NDIS Survey responses to the second part of the survey, Part B. Whereas Part A described above collected factual information from survey respondents, Part B is concerned with opinions, perceptions and aspirations. Specifically, Part B is divided into six sections, recording:

- social participation and wellbeing
- education aspirations
- employment aspirations
- living and housing
- past disability supports
- disability supports, including in the NDIS.

Part B questions were not asked of the 502 children less than 8 years of age as they were deemed too young to take part personally in a survey. All remaining respondents were offered the option of answering the standard Part B questionnaire 1,112 (79.8 per cent) or the Easy English questionnaire 281 (20.2 per cent). The section below begins with the description of the responses from the standard questionnaires.

## 3.6.10 Part B – Social participation and wellbeing

The NDIS aims to enhance the activities of people with disability. A core task of the evaluation is to understand the degree to which the introduction of the NDIS has increased social and economic participation and wellbeing. There are many facets of participation and wellbeing is a very complex concept.

The survey asks about the activities the respondents have done recently (Table 3.40) without reference to a specific timeline (such as 'in the last month') to improve accessibility. The survey also asks respondents to indicate from the same list which activities they would most like to do in the coming year (Table 3.41). Both questions about current and future activities include a write-in box where 'other activities' can be mentioned and commented on.

Table 3.40: Activities that you have done recently

	Trial	Comparison
	%	%
Spent time with family at home	88.1	83.2
Spent time with friends at home	33.9	36.8
Spent time with family outside the home	75.6	68.3
Spent time with friends outside the home	56.5	56.3
Used the internet for social networking and emailing	41.5	45.1
Used the internet for shopping, arranging appointments, booking meetings	17.5	17.4
Played sports, went for a walk or went swimming	54.5	52.4
Went to see a show or movie, or went out for food or drinks	64.1	54.7
Went on a holiday	22.9	20.6
Other social or leisure activities	22.2	20.4
Total	446	666

Note: trial and comparison standard questionnaire 8 years and above; 'Total' indicates the number of respondents to answer this question; multiple response question; percentages do not add to 100.

Table 3.40 presents fairly similar patterns of recent activities among the trial and the comparison groups, both reporting above all having spent time with their family inside and outside the home. More have met friends outside the home than inside; and more than half had gone out to shows, movies or meals, or had taken part in physical activities. The percentages presented here are based on a total of 4.64 responses per person.

Aspirations for future activities are also fairly similar in the trial and the comparison groups. The percentages presented in Table 3.41 are based on a total of 3.08 responses per person. It is important to understand that the fact that respondents were asked to nominate just three activities that they would most like to do in the future explains in part the lower percentage response rates for aspirations when compared to actual, past activities. However, this is not a general rule as going on holiday is by far the most frequently reported desired future activity and one of the least frequented actual experiences. Going out to shows, movie or meals, and going on holiday were reported as the most desirable future activities. The comparison of these percentages however, can be inaccurate and the only way to understand these differences will be through the analysis of data at the individual level.

Table 3.41: Activities (top three) you would most like to do in the coming years

	Trial	Comparison
	%	%
Spend time with family at home	46.4	45.1
Spend time with friends at home	17.5	20.4
Spend time with family outside the home	40.6	39.5
Spend time with friends outside the home	36.8	36.3
Use the internet for social networking and emailing	15.0	15.9
Use the internet for shopping, arranging appointments, booking meetings	4.7	5.3
Play sports, go for a walk or go swimming	36.6	33.6
Go to see a show or movie, or go out for food or drinks	52.2	38.4
Go on a holiday	52.0	49.6
Other social or leisure activities	17.7	16.4
Total number of respondents	446	666

Note: trial and comparison standard questionnaire 8 years and above; 'Total' indicates the number of respondents to answer this question; multiple response question; percentages do not add to 100.

The two questions in Tables 3.40 and 3.41 above will provide a solid benchmark about the 'starting point' of our information collection. The difference between current activities and future/planned/desired activities is reported here. Wave 2 collection will ask about the same activities and report changes in **actual** activities and also changes in the difference between actual and desired activities.

An important aspect of the NDIS is its explicit objective to remove barriers and hurdles faced by people with disability in their everyday life, presented in Table 3.42. Straight after asking for actual and desired future activities (when the juxtaposition of current wide future/planned activities is fresh in the minds of respondents) respondents are asked to think about any hurdles that may make their future activities hard to achieve. The survey offers a comprehensive list of potential hurdles and also provides the option of a write-in box to capture diversity where this may be present.

Table 3.42: Hurdles to doing things in the coming year

	Trial	Comparison
	%	%
It is not easy to get into buildings	26.7	18.5
Has no transport	23.5	21.9
It costs too much	33.2	46.1
Doesn't feel safe	24.9	22.2
Other people do not make him/her feel welcome	16.1	17.3
Other people cannot understand him/her easily	36.1	34.2
Finds it hard to understand others	23.8	23.0
It requires too much organisation	25.3	25.5
It takes too much time to arrange supports	16.8	13.4
Doesn't have anyone to support	8.1	9.9
Total	446	666

Note: trial and comparison standard questionnaire 8 years and above; 'Total' indicates the number of respondents to answer this question; multiple response question; percentages do not add to 100.

Wellbeing questions are part of a battery of validated questions incorporated into the NDIS Survey. These questions have been designed to lend themselves to aggregated analysis, where a combined score across all component statements is calculated, using a validated methodology. This allows more robust assessments of wellbeing to be formulated, and will be undertaken for the response sample after the completion of Wave 1 data collection.

The questionnaire provides a detailed set of statements where respondents are asked to rate their agreement or disagreement with a large number of wellbeing statements that fall into three broad categories:

- statements about themselves and how they feel
- questions about how happy they feel about things in their lives
- descriptions about how much support they get from other people.

These three categories are presented in Figures 3.3a - f, 3.4a - g, and 3.5a - e and are briefly discussed. These figures present responses of agreement or disagreement with a specific statement on a scale from 0 (completely disagree) to 10 (completely agree). They are all presented in a way that suggests and encourages an interpretation which would mean that 5 would be an answer implying 'indifference' or no strong opinion in either direction, but does not force it by stating this in the questionnaire. The answers to these questions are important in themselves as an indication of where we are at this present point in time, but will also be very important for measuring any improvements the NDIS may bring on this front.

## Box 3.1: Interpreting Figures 3.3, 3.4 and 3.5

The taller the bar above each possible answer, the more people have responded with this answer. A practical way to absorb the message from each of these figures is to focus on the shape of the figure as a whole and note where its weight is concentrated. It is not necessary to pay much attention on individual specific categories and their numbers in the first instance.

If the 'weight' of the bars is on the left side (a left skew), there is a lot of disagreement. If it is on the right (a right skew), there is a lot of agreement. A strong presence in the middle suggests that many people do not have strong feelings about this matter. If all categories appear to be roughly equally populated (a uniform distribution) then opinions and perceptions are very diverse without any specific category being dominant. Finally, if the far left and the far right are well-populated with an empty middle (what we call a bimodal distribution) there are strong and polarised views on this matter.

The following notes aid interpretation. First, the 0-10 'ordinal scale' cannot be interpreted as a 'cardinal' scale. That is, an (agreement strength) distance of 2 (for example between 4 and 6) is neither double as strong as a distance of 4 (for example between 5 and 9), nor equally strong as another distance of 2 (for example between 5 and 7, or 1 and 3). The scale simply says that 0 represents the strongest disagreement and 10 the strongest agreement and that the numbers 1 to 9 in between are in ascending order in terms of agreement. An implication of this is that, although the comparison group's answers are presented next to the trial ones, these are only loosely comparable. The reader should not make direct and precise comparison between any two specific such numbers. Finally, given that these answers will depend strongly on several factors, including the specific disability of the respondent, precise and specific comparisons cannot be made using the aggregated picture presented in the graphs.

### 3.6.10.1 Statements about yourself and how you feel

Statements about 'yourself and how you feel' are presented in Figures 3.3a to 3.3f. This report presents responses to individual statements only, which serves to illustrate the general patterns in the data. However these statements contain much more information when they are analysed as part of a set of validated questions. This allows for an overall assessment of wellbeing to be derived. These calculations will be undertaken for the response sample after the completion of Wave 1 data collection.

Figure 3.3a suggests that respondents felt generally very positive about themselves. Most of the answers are bunched in the right of the figure and, importantly the bottom three categories are not well populated for both trial and comparison group.

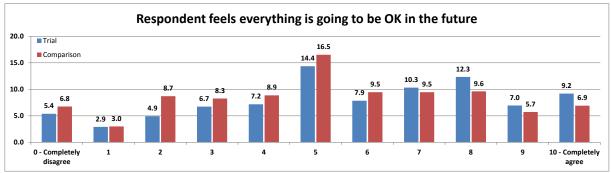
% of useable sample In general, respondent feels very positive about himself/herself 20.0 Trial 17.0 16.8 15.0 13.2 13.2 12.1 11.7 10.2 9.2 10.0 6.3 6.8 6.8 5.0 5.0 3.1 2.7 2.6 2.9 0.0 0 - Completely 3 10 - Completely

Figure 3.3a: How respondent feels

Note: trial and comparison standard questionnaire aged 8 years and above

Figure 3.3b measures the uncertainty people may be feeling about the future. Although the answers are still bunched in the right of the figure, the right bunching is weaker and there is a stronger presence of people in the bottom three categories.

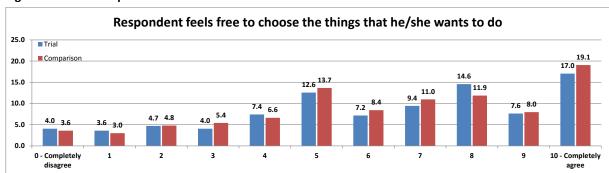
Figure 3.3b: How respondent feels



Note: trial and comparison standard questionnaire aged 8 years and above

Figure 3.3c measures the feeling of freedom felt by respondents to 'choose the things they want to do'. This picture too gives a positive message, with a notable peak at the complete agreement point.

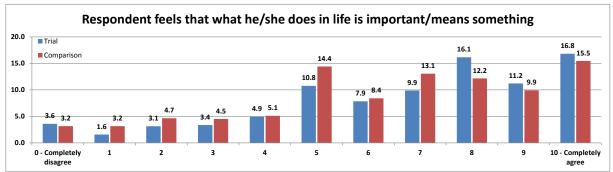
Figure 3.3c: How respondent feels



Note: trial and comparison standard questionnaire aged 8 years and above

Figure 3.3d suggests people with disability report having a very positive feeling about doing meaningful and important things in their lives. This is probably the most positive of all six statements about how respondents reported feeling.

Figure 3.3d: How respondent feels



Note: trial and comparison standard questionnaire aged 8 years and above

Figure 3.3e suggests a similar positive feeling expressed about achievement, but the difference at the very top agreement categories is notable (the feeling of purpose is much higher than that of daily achievement). This suggests a situation where people feel they lead a meaningful and purposeful life, but that high level of purpose is not equally matched by feelings of achievement.

Most days respondent senses that he/she achieved something 20.0 ■ Trial 15.7 ■ Comparison 15.0 12.1 12.0 11.1 11.1 10.0 7.9 7.1 7.2 7.4 5.6 5.9 4.5 5.3 4.9 4.8 5.0 3.4 3.5 0.0 3 5 6 7 10 - Completely 0 - Completely disagree

Figure 3.3e: How respondent feels

Note: trial and comparison standard questionnaire aged 8 years and above

A gap between having a life with purpose and a life of achievement can be related to the opportunities and the barriers that people encounter in their lives. Figure 3.3f suggests that a large majority of respondents think it takes them a long time to get over things that went wrong in their lives. The question that further analysis of this data will need to address is whether disability in general, or specific types of disability contribute to the long time to get over things that went wrong and, ultimately, if the NDIS can contribute towards changing this.

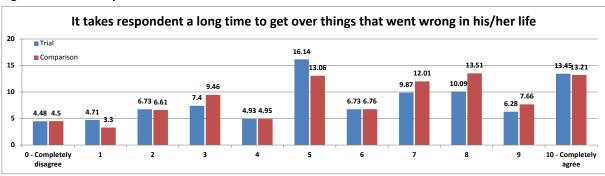


Figure 3.3f: How respondent feels

Note: trial and comparison standard questionnaire aged 8 years and above

The next set of questions is about how happy respondent feel about things in their life. The focus here remains on general feelings about wellbeing, but this time we switch to slightly more concrete matters and in some instances on matters that could even be quantified, such as money.

# 3.6.10.2 Statements about how happy respondents feel about things in their life

Figure 3.4a suggests a general high level of wellbeing being reported by respondents. We note the strong presence of the top three categories (especially the 'completely happy' one) and the very low presence in all four bottom categories.

How happy is respondent about the things he/she has 20.0 ■ Trial 17.3 16.2 ■ Comparison 14.6 15.0 13.5 13.1 <sup>11.9</sup> 11.0 11.2 10.0 6.8 5.0 1.6 2.0 1.8 0.0 0 - Not at all 2 3 5 6 7 8 9 10 - Completely happy happy

Figure 3.4a: Happiness about things in life

Note: trial and comparison standard questionnaire aged 8 years and above

Figure 3.4b presents a less positive picture about the contribution of health to the feelings of respondents about their overall wellbeing. One could argue that there are more respondents who suggested a higher level of happiness, but it is worth noting that the top two categories are visibly less populated. The most notable aspect of this Figure is that many respondents reported being not happy with their health with about a quarter being located in the bottom four categories and most notably 8 per cent reporting they are 'Not at all happy'.

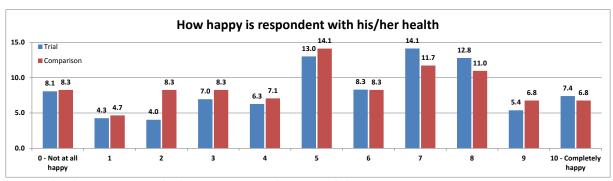
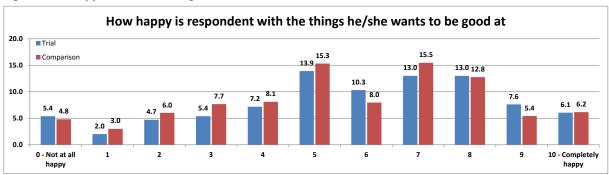


Figure 3.4b: Happiness about things in life

Note: trial and comparison standard questionnaire aged 8 years and above

Figure 3.4c suggests that few respondents were not at all or completely happy about the things they want to be good at, noting around 5 per cent reported not being happy at all. This question is in part a 'happiness with achievement' measure and responses are concentrated in the middle, with a clear weight in the moderately above average happy categories.

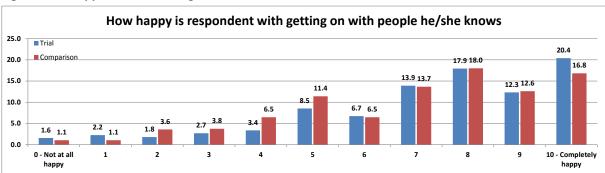
Figure 3.4c: Happiness about things in life



Note: trial and comparison standard questionnaire aged 8 years and above

Figure 3.4d suggests that respondents felt very happy with the way they get on with people they know. It is noteworthy that the top four categories are populated by approximately 75 per cent of all respondents and about 10 per cent populated the bottom four categories.

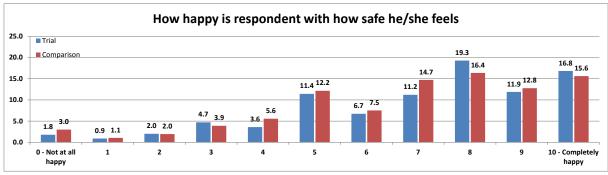
Figure 3.4d: Happiness about things in life



Note: trial and comparison standard questionnaire aged 8 years and above

Figure 3.4e suggests that respondents were generally happy about their safety, with small numbers expressing unhappiness about it and for those who do, it is mostly moderate.

Figure 3.4e: Happiness about things in life



Note: trial and comparison standard questionnaire aged 8 years and above  $\,$ 

Similarly, Figure 3.4f suggests that respondents were mostly happy about doing things away from home.

How happy is respondent about doing things away from his/her home 20.0 ■ Trial Comparison 14.8 15.0 12.9 12.6 12.5 10.8 9.6 9.0 10.0 7.2 7.4 5.0 5.0 0.0 10 - Completely 0 - Not at all

Figure 3.4f: Happiness about things in life

Note: trial and comparison standard questionnaire aged 8 years and above

Figure 3.4g presents the answers to how happy respondents feel about what might happen to them in later life. The broad picture is one of considerable unhappiness about the uncertainty of what the future may hold. There are many reasons why the future may be worrying. Worries may be related to age, family circumstances, specific disability reasons and much more. We note that many of these reasons will be inter-related which suggests that they should be examined using multivariate regression methodologies.

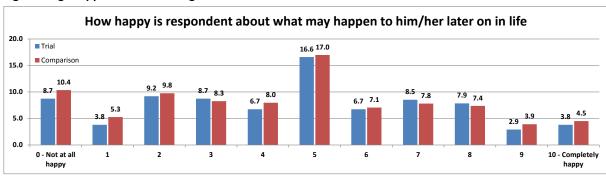


Figure 3.4g: Happiness about things in life

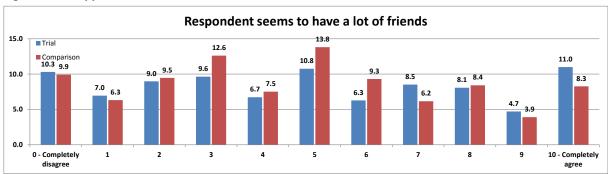
Note: trial and comparison standard questionnaire aged 8 years and above

With the exception of a large proportion of respondents reporting being unhappy about their health and being unhappy about the uncertainties they may face in later life, the overall happiness picture arising from Figure 3.4a to 3.4g is positive.

# 3.6.10.3 Statements about support respondents feel they have from other people

The people who support people with disability directly or indirectly make a vital contribution to their lives. The following suite of questions elicits the extent to which people with disability feel they have both emotional and practical support from people around them. Figure 3.5a asks if the respondent has lots of friends. The answers are probably the most variable and most evenly spread in all participation and wellbeing questions. The weight of the answers lies in the negative side - the majority of all respondents generally disagreeing with the statement that they have a lot of friends. Yet, a large minority agreed with this statement, with a notable 10 per cent of respondents completely agreeing. This is an important picture which will need to be unpacked at the analysis stage.

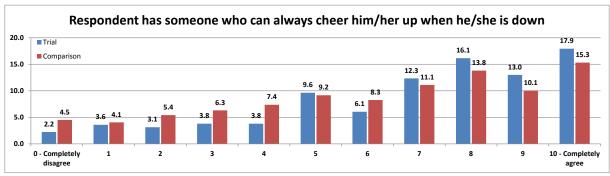
Figure 3.5a: Support from others



Note: trial and comparison standard questionnaire aged 8 years and above

Figure 3.5b suggests that, in contrast to the general statement about not having 'a lot of friends', a large majority of respondents reported that they have someone to cheer them up when down, and a small minority said that they do not.

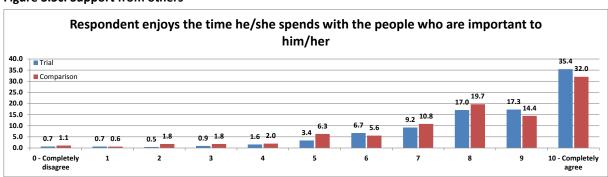
Figure 3.5b: Support from others



Note: trial and comparison standard questionnaire aged 8 years and above

Figure 3.5c clearly suggests that respondents overwhelmingly enjoy spending time with the people that are important to them.

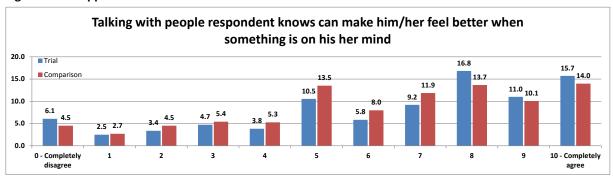
Figure 3.5c: Support from others



Note: trial and comparison standard questionnaire aged 8 years and above

Figure 3.5d shows the degree to which people with disability know that when something is on their mind, talking to people can make them feel better. This can be interpreted more as the knowledge and willingness to reach out to people, rather than the availability of people that Figure 3.5b measures. The weight of this Figure is on the right, suggesting that a large majority agree with this statement.

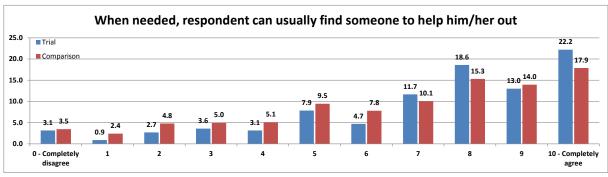
Figure 3.5d: Support from others



Note: trial and comparison standard questionnaire aged 8 years and above.

Figure 3.5e complements Figures 3.4b and 3.4d and suggests that most people were able to find someone to help them out when the need arises.

Figure 3.5e: Support from others



Note: trial and comparison standard questionnaire aged 8 years and above.

## 3.6.11 Education aspirations (children and adults reported separately)

Children and adults have been asked about their education aspirations separately. There are many common questions where this is appropriate and several differences largely reflecting the ways in which aspirations and reporting must be age-related. Children aged 8-15 were asked whether they like studying and what they would like to do after finishing their current education. Both the standard questionnaire and the Easy English questionnaire included these questions, the latter somewhat simplified, but largely comparable. The same questions were asked of those aged 16 or older and are reported later. A total of 278 children were asked these questions, 190 using the standard and 88 the Easy English questionnaire. As we presented the relevant statistics on education jointly for the trial and comparison groups in Part A, we also do so here in Part B.

Overall, children reported that they either liked school (55.7 per cent) or liked it sometimes (22.7 per cent) with 5.4 per cent reporting they did not know (Table 3.43 below). The sample size is still not large enough to look into each category in any detail, but in general the message that children like school, is clear for both types of questionnaires.

Table 3.43: Does he/she like school? (8 to 15 years)

	Standard Question Cases	Standard Question %	Easy English Question Cases	Easy English Question %	Total Cases	Total %
Yes	103	54.2	52	59.1	155	55.7
No	14	7.4	18	20.5	32	11.5
Sometimes	63	33.2	-	-	63	22.7
Don't know	2	1.1	13	14.8	15	5.4
Missing	8	4.2	5	5.7	13	4.7
Total	190	100	88	100	278	100

Note: trial and comparison aged 8-15 in education.

Table 3.44 asks the same children what they would like to do after they finish their course. The options offered are work, training, university, something else, nothing and don't know for the standard questionnaire and the same but without the 'nothing' option for the Easy English questionnaire.

Table 3.44: What would he/she like to do after finishing his/her current education? (8 to 15 years)

	Standard Question Cases	Standard Question %	Easy English Question Cases	Easy English Question %	Total Cases	Total %
Work	47	24.7	26	29.6	73	26.3
Training	23	12.1	18	20.5	41	14.7
University	31	16.3	13	14.8	44	15.8
Something else	18	9.5	9	10.2	27	9.7
Nothing	2	1.1	-	-	2	0.7
Don't know	56	29.5	21	23.9	77	27.7
Missing	13	6.8	1	1.1	14	5.0
Total	190	100	88	100	278	100

Note: trial and comparison aged 8-15 in education.

While, understandably, many children reported not knowing what they want to do (27.7 per cent), about equal proportions want to do further study or training and 26.3 per cent reported that they wanted to work after finishing school. Especially the younger cohorts in this group will have several more years at school before they have to contemplate and make decisions about their future.

The same questions are asked of the 185 adults in education, 136 using the standard and 49 using the Easy English questionnaire. Table 3.45 suggests a very similar picture as that for children, with just over half of the respondents stating that they liked studying and another 23.2 per cent that they liked studying 'sometimes'.

Table 3.45: Does he/she like studying? (Adults 16+)

	Standard Question Cases	Standard Question %	Easy English Question Cases	Easy English Question %	Total Cases	Total %
Yes	65	47.8	29	59.2	94	50.8
No	15	11	11	22.5	26	14.1
Sometimes	43	31.6	-	-	43	23.2
Don't know	6	4.4	4	8.2	10	5.4
Missing	7	5.2	5	10.2	12	6.5
Total	136	100	49	100	185	100

Note: trial and comparison respondents aged 16 and above in education.

Table 3.46 presents that most adults in education reported planning to either find work (38.4 per cent) or continue their education/training (20.5 per cent). The standard questionnaire suggests a higher proportion of intentions to work and go to university and a lower proportion of 'don't know' answers. The sample size is still not large enough to make meaningful statistical statements about this question.

Table 3.46: What would he/she like to do after finishing his/her current education? (Adults 16+)

	Standard Question Cases	Standard Question %	Easy English Question Cases	Easy English Question %	Total Cases	Total %
Work	56	41.2	15	30.6	71	38.4
Training	5	3.7	8	16.3	13	7.0
University	20	14.7	5	10.2	25	13.5
Something else	16	11.8	5	10.2	21	11.4
Nothing	4	2.9	-	-	4	2.2
Don't know	24	17.7	11	22.5	35	18.9
Missing	11	8.1	5	10.2	16	8.6
Total	136	100	49	100	185	100

Note: trial and comparison respondents aged 16 and above in education.

All respondents aged 16 and above were asked what makes it hard for them to study. Table 3.47 presents the responses. On average, each respondent mentioned four barriers that make it hard for them to study. Table 3.47 suffers from the small sample size even more than the other education tables. Notwithstanding this caveat (which will become less important once the full Wave 1 sample is at hand), it is worth noting some aspects of its contents. A notable feature of the responses is that 68.6 per cent reported their own health/disability to be an obstacle, by far the most frequently stated inhibiting factor. The remaining categories offered much detail, ranging from difficulties of a

broad and general nature (e.g. with a 'lack of opportunities' reported by 41.3 per cent) to very specific difficulties (e.g. 'difficulties with transport or parking' reported by 40.1 per cent).

Table 3.47: Do any of the following make it hard to study? (Adults 16+)

	Trial	Trial	Comparison	Comparison	Total	Total
	Cases	%	Cases	%	Cases	%
A lack of opportunities	28	45.9	43	38.7	71	41.3
Difficulties with transport or parking	25	41.0	44	39.6	69	40.1
What teachers think about people with disability	10	16.4	31	27.9	41	23.8
A lack of schooling	16	26.2	26	23.4	42	24.4
Difficulties using facilities or equipment	23	37.7	38	34.2	61	35.5
Own health/disability	42	68.9	76	68.5	118	68.6
A lack of flexible hours on offer for learning	24	39.3	34	30.6	58	33.7
A lack of personal supports	23	37.7	42	37.8	65	37.8
The need for special equipment	10	16.4	20	18.0	30	17.4
The concern that welfare benefits might be affected	12	19.7	28	25.2	40	23.3
Another reason	25	41.0	30	27.0	55	32.0
Total	61		111		172	

Note: trial and comparison aged 16 and above in current study or not in study but looking for a course to study; 'Total' indicates the number of respondents to answer this question; multiple response question; columns do not add to 100.

Education research shows that each one of these barriers can have a serious educational impact in itself and often not only on performance (how well the student does), but also on participation (whether the prospective student choses to study or not). Education research also suggests that where combined barriers are experienced by an individual student, their impact can become acute. Although the sample size is still not large enough to undertake meaningful statistical analysis about the impact of any individual such obstacle, Table 3.47 should be marked for its significant potential when the full sample sizes are available and when the full information on the person with disability will be combined with that of their family and carer in a way that will allow the necessary multivariate statistical analyses.

# 3.6.12 Employment aspirations

Table 3.48 shows that of the 919 respondents in an age group that would allow them to work, 19 per cent reported being in employment.

Table 3.48: Currently in work or not

	Cases	%
In work	178	19.4
Not in work	739	80.4
Missing	2	0.2
Total	919	100

Note: trial and comparison aged 16 and above.

The sample size of 178 is too small for the statistical examination of respondents in employment, but it is sufficient for illustrating the statistics that will be derived and used with the full sample. Table 3.49 shows that an overwhelming majority of the respondents reported liking their job (79.2 per cent).

Table 3.49: Does he/she like his/her job?

No Don't know	22 8	12.4 4.5
Missing	8 7	4.5 3.9
Total	178	100

Note: trial and comparison aged 16 and above in work.

Table 3.50 shows about one quarter of those in work reported that they would like to have a different job (27.5 per cent) but a clear majority reported they would not (56.2 per cent).

Table 3.50: Would you like to have a different job?

Yes No	49 100	27.5 56.2
Don't know	21	11.8
Missing	8	4.5
Total	178	100

Note: trial and comparison aged 16 and above in work.

Of the 49 respondents who reported being in work and said they would like to have another job (those who answered Yes in Table 3.50) a majority reported that they were not looking for another job. The numbers are too small (sample size is 49) to attach any message to the contents of Table 3.51, but the information could become important once the full sample is in place.

Table 3.51: Looking for a different job

	Cases	%
Yes	18	36.7
No	28	57.1
Don't know	2	4.1
Missing	1	2.0
Total	49	100

Note: trial and comparison aged 16 and above in work and would like a different job.

Table 3.52 asks the 739 respondents from Table 3.48 who reported that they were not working whether they would like a job. Of these 41 per cent reported they would not like to have a job while 36.7 per cent said reported they would like to work, now or later. A sizeable 17.1 per cent reported that they did not know if they would like to have a job. The second wave of data collection will reveal if the time spent in the NDIS and the supports received in that time have had an impact on the clarity of employment aspirations.

139

Table 3.52: Would like to have a job

	Cases	%
Yes	217	29.4
No	303	41.0
Yes, when I have finished my education	54	7.3
Don't know	126	17.1
Missing	39	5.3
Total	739	100

Note: trial and comparison standard questionnaire aged 16 and above not in work.

Table 3.48 reported that 80.4 per cent of all age-appropriate respondents did not work and Table 3.52 suggests that of them, about 37 per cent would like to have a job, with 7 per cent being in education aiming for a job when they finished their education. The implication is that there is a large reserve of people with disability who would wish to join the labour market. Only a small proportion of 36.7 per cent (small by general labour market standards) reported they are currently looking for a job. This is an area that will require further investigation once the full size sample is in place.

The investigation of the reasons why people with disability may not be in the employment position they would like will be studied with the help of Table 3.53. The question of what makes it hard to get a job is asked of two groups of people with disability. Respondents are asked "if they have a job but would like to have another job" and "if they did not have a job and would like to have one". The same categories of barriers and difficulties used for education allow examination of barriers and activities to employment. For example, it will be possible to examine jointly these circumstances where multiple barriers may influence jointly a specific single activity and where single barriers may be influencing several activities.

Table 3.53: Do any of the following make it hard to get a job?

	Cases	%
A lack of opportunities	177	65.8
Difficulties with transport or parking	119	44.2
What employers think about people with disability	131	48.7
A lack of schooling, training or experience	99	36.8
Difficulties using facilities or equipment	99	36.8
Own health/disability	203	75.5
A lack of flexible hours on offer for learning	78	29.0
A lack of personal supports	81	30.1
The need for special equipment	51	19.0
The concern that welfare benefits might be affected	56	20.8
Another reason	60	22.3
None of the above reasons	4	1.5
Don't know	3	1.1
Total	269	

Note: trial and comparison standard questionnaire aged 16 and above in work looking for different work or those not in work but who would like to work and are looking for a job; 'Total' indicates the number of respondents to answer this question; multiple response question; percentages do not add to 100.

On average people with disability mentioned 4.3 barriers per person. This is a very similar number as that for education. Own health/disability was the most frequently stated reason, with lack of opportunities following close behind and employers' thinking and transport and parking difficulties coming next. Information in the barriers/difficulties questions will be the subject of future in-depth analysis.

All of the employment aspirations tables presented above were based on answers provided through the standard adult questionnaire. Initial findings are based on the Easy English questionnaires. Of the 188 adults who completed the Easy English questionnaire, 44 were at work. Of the remaining 144, 104 were neither working nor studying. These 104 were asked a more accessible version of the barriers questions, which we present in Table 3.54. In an attempt to capture comprehensive information but without undue burden on the interviewees, education and employment barriers questions were combined by asking if there is 'anything stopping you from working or studying', allowing for multiple responses to the 7 categories offered.

The reasons identified were diverse. Although the sample size is not large enough to make meaningful statistical statements about the impact of any individual such obstacle, Table 3.54 has been marked for its potential significance when the larger sample sizes are available.

Table 3.54: Is there anything stopping him/her from working or studying?

	Cases	%
Hard to get into buildings	15	14.4
Hard to get to and from work/study	25	24.0
Others don't think he/she can	21	20.2
Others can't understand him/her very well	34	32.7
He/she needs special equipment	15	14.4
He/she can't find a job or course with hours to suit	17	16.4
He/she doesn't have anyone to support him	11	10.6
Another reason	37	35.6
Total	104	_

Note: trial and comparison Easy English questionnaire aged 16 and above who are neither working nor studying; 'Total' indicates the number of respondents to answer this question; multiple response question; percentages do not add to 100.

## 3.6.12 Living and housing

A large minority (42.3 per cent) of respondents reported they would like to live in a place of their own one day (Table 3.55) while 32.4 per cent reported they would not with 18 per cent reporting they did not know.

Table 3.55: Would like to live in a place of his/her own one day

	Trial	Trial	Comparison	Comparison	Total	Total
	Cases	%	Cases	%	Cases	%
Yes	81	36.2	116	47.9	197	42.3
No	85	38.0	66	27.3	151	32.4
Don't know	43	19.2	41	16.9	84	18.0
Missing	15	6.7	19	7.9	34	7.3
Total	224	100	242	100	466	100

Note: trial and comparison standard questionnaire aged 16 and above.

Table 3.56 looks further into the preferences of those who reported they would like a place of their own. Only 30.5 per cent of respondents answered they would like to do this in the next two years with a majority of 52.2 per cent reporting a preference to do it 'later' and 17.3 per cent reported they did not know when they would like to do it.

Table 3.56: When would he/she like to live on his/her own

	Trial	Trial	Comparison	Comparison	Total	Total
	Cases	%	Cases	%	Cases	%
Now	12	14.8	22	19.0	34	17.3
This year	6	7.4	5	4.3	11	5.6
Next year	8	9.9	7	6.0	15	7.6
Later	43	53.1	59	50.9	102	51.8
Don't know	11	13.6	23	19.8	34	17.3
Missing	1	1.2	0	0.0	1	0.5
Total	81	100	116	100	197	100

Note: trial and comparison standard questionnaire aged 16 and above who would like have a place of their own.

Table 3.57 shows that a very large majority of respondents (83.6 per cent) reported that where they currently live meets their needs.

Table 3.57: Where currently living meets needs

	Trial	Trial	Comparison	Comparison	Total	Total
	Cases	%	Cases	%	Cases	%
Yes	326	84.0	442	83.2	768	83.6
No	48	12.4	72	13.6	120	13.1
Don't know	3	0.8	10	1.9	13	1.4
Missing	11	2.8	7	1.3	18	2.0
Total	388	100	531	100	919	100

Note: trial and comparison standard questionnaire aged 16 and above.

For the 13.1 per cent of respondents who stated that where they live did not meet their needs, Table 3.58 presents potential issues with current housing. Although the sample size is still not large enough for making meaningful statistical statements about the impact of any individual such obstacle, Table 3.58 (like Table 3.47 in the education section and Table 3.53 in the employment section) are marked for its significant potential with the completion of Wave 1.

Table 3.58: Is there anything about where he/she lives that he/she is not happy about?

	Trial	Trial	Comparison	Comparison	Total	Total
	Cases	%	Cases	%	Cases	%
He/she needs to live nearer to shops and other facilities	10	16.1	20	22.5	30	19.9
He/she needs to live nearer to work/school	5	8.1	7	7.9	12	8.0
He/she needs to live nearer to family or friends	8	12.9	14	15.7	22	14.6
He/she needs to live nearer to support networks	5	8.1	15	16.9	20	13.3
Access to and/or moving around the house is difficult	21	33.9	26	29.2	47	31.1
He/she doesn't like the people he/she lives with	9	14.5	9	10.1	18	11.9
He/she worries about his/her safety	15	24.2	17	19.1	32	21.2
He/she is not allowed to have pets	2	3.2	2	2.3	4	2.7
There is no or little public transportation nearby	8	12.9	20	22.5	28	18.5
He/she needs accommodation	3	4.8	6	6.7	9	6.0
Another reason why not happy about where he/she lives	27	43.6	38	42.7	65	43.1
Total	62		89		151	

Note: trial and comparison aged 16 and above standard questionnaire and housing does not meet their needs; 'Total' indicates the number of respondents to answer this question; multiple response question; percentages do not add to 100.

# 3.6.13 Past disability supports

People with disability over the age of 15 in the trial group and who received supports before participating in the NDIS were asked several related questions:

- their satisfaction with the quality of these supports
- how much of a say they had over decisions about what supports they received
- how much choice they had over **where** they obtained these supports

Related information about children below the age of 15 is asked of their parents in the family and carer questionnaire, as the parents were considered to be a better source of this information. Table 3.59 indicates that many more people in the trial group reported being very satisfied or satisfied (50.5 per cent) than dissatisfied or very dissatisfied (19.4 per cent) with the quality of their supports before becoming an NDIS participant. A relatively large proportion were non-committal in their response (19.7 per cent being neither satisfied nor dissatisfied and 10.5 per cent did not answer at all).

Table 3.59: Satisfaction with quality of support before NDIS

	Cases	%
Very satisfied	70	23.0
Satisfied	84	27.5
Neither satisfied nor dissatisfied	60	19.7
Dissatisfied	42	13.8
Very dissatisfied	17	5.6
Missing	32	10.5
Total	305	100

Note: trial aged 16 and above if received supports before joining the NDIS.

Table 3.60 presents a picture of the extent of control that people with disability in the trial group felt they had over what supports they received.

Table 3.60: How much say over decisions about what support received before NDIS

	Cases	%
A lot of say	65	21.3
Some say	83	27.2
Little say	36	11.8
No say	53	17.4
It varied depending on the type of supports	37	12.1
Missing	31	10.2
Total	305	100

Note: trial aged 16 and above if received supports before joining the NDIS.

Table 3.61 suggests a similar picture as in Table 3.60, although with somewhat lower levels of control over where they obtained supports.

Table 3.61: How much choice over where obtained supports before NDIS?

	Cases	%
A lot of choice	43	14.1
Some choice	72	23.6
Little choice	65	21.3
No choice	70	23.0
It varied depending on the type of supports	31	10.2
Missing	24	7.9
Total	305	100

Note: trial aged 16 and above if received supports before joining the NDIS.

These three questions in Tables 3.59 – 3.61 offer an interesting picture. Through them we can have a base-line for NDIS participants' views about their past supports (presumably not from the NDIS). They allow us to compare how pre-NDIS supports fared in relation with their current NDIS.

## 3.6.14 Current disability supports

Both the trial and the comparison groups are asked questions on their views about their current supports. Prior to this suite of questions, the trial group are asked to compare aspects of their past (pre-NDIS) experiences with their experiences in the NDIS. We ask them 'Compared to before the NDIS, does it now take more, less or the same amount of time to...'

- get the supports that you need
- do the necessary paperwork to get the supports that you need
- find out where to get the supports that you need.

Table 3.62 reveals a lot of change in all three aspects of supports provision. Only a minority (24.3 per cent, 21.7 per cent and 28.3 per cent) reported no change. Responses indicate that finding and getting supports appears to be taking less time, while the opposite holds for doing the paperwork. The picture that emerges will be analysed in order to examine whether time savings are more or less likely for specific types of people or specific types of circumstances. These will be related to the change that follows the introduction of the NDIS as this is measured in the difference between Waves 1 and 2 of the data.

Table 3.62: Pre and post NDIS: Time to get supports, do the necessary paperwork and find out where to get the supports

	More time			Don't know	Missing
	%	%	%	%	%
Get supports	25.0	24.3	34.7	7.3	8.7
Do the necessary paperwork	34.3	21.7	25.3	8.3	10.3
Find out where to get the supports	19.7	28.3	32.7	9.0	10.3

Note: trial aged 16 and above currently receiving NDIS supports and received supports before joining the NDIS (sample size is 300 people).

The questions asked of both the trial and the comparison groups on their views of their current supports are reported below. The questions are identical to those asked of the trial group in the previous section on their past disability supports, seeking feedback about the quality of the supports, the choice of what supports they get and the choice they have over where to get the supports. As such this allows for a comparison between trial group views on their supports and those of the comparison group. It also allows for a comparison of trial group's views on their past and current supports which will be presented later.

Tables 3.63 – 3.65 present responses of both trial and comparison group's satisfaction levels with the quality of current supports; the amount of say over decisions about what supports are received; and, how much choice people with disability feel they have over where supports are obtained. Table 3.63 suggests a high level of satisfaction in the trial group, 79 per cent reporting they are either satisfied or very satisfied with the quality of their current supports. Only 7.6 per cent reported being dissatisfied or very dissatisfied and 3.4 per cent did not answer the question. A lower percentage of the comparison group reported being either satisfied or very satisfied with the quality of their current supports (60 .2 per cent) and a higher percentage reported either being dissatisfied or very dissatisfied (11.5 per cent). Almost 7 per cent of the comparison group did not answer the question.

Table 3.63: Satisfaction with quality of received supports

	Trial	Trial	Comparison	Comparison	Total	Total
	Cases	%	Cases	%	Cases	%
Very satisfied	150	39.4	74	22.8	224	31.8
Satisfied	151	39.6	121	37.4	272	38.6
Neither satisfied nor dissatisfied	38	10.0	58	17.9	96	13.6
Dissatisfied	21	5.5	20	6.2	41	5.8
Very dissatisfied	8	2.1	17	5.3	25	3.6
Missing	13	3.4	34	10.5	47	6.7
Total	381	100	324	100	705	100

Note: trial and comparison aged 16 and above currently receiving supports.

A similar picture is observed in the proportion of people with disability who reported having some or a lot of say over the decisions about what supports they received. Over 70 per cent of the trial group compared to 54 .3 per cent of the comparison group reported having either some or a lot of say over the decisions about what supports they received. Again, a higher percentage of the comparison group did not answer the question, at 7.9 per cent compared to 4.7 per cent of the trial group.

Table 3.64: How much say over decisions about what supports to receive

	Trial	Trial	Comparison	Comparison	Total	Total
	Cases	%	Cases	%	Cases	%
A lot of say	170	44.6	103	31.8	273	38.7
Some say	97	25.5	73	22.5	170	24.1
Little say	23	6.0	41	12.7	64	9.1
No say	31	8.1	27	8.3	58	8.2
It varies depending on the type of supports	42	11.0	42	13.0	84	11.9
Missing	18	4.7	38	11.7	56	7.9
Total	381	100	324	100	705	100

Note: trial and comparison aged 16 and above currently receiving supports

Table 3.65 presents how much choice respondents felt they had over where they obtained their supports and, again presents a very similar picture. Almost 66 per cent of the trial group felt they had either some or a lot of choice compared to just below 44 per cent of the comparison group. Again a higher percentage of the comparison group did not answer the question at 13.9 per cent to 4.2 per cent of the trial group.

Table 3.65: How much choice over where supports are obtained

	Trial	Trial	Comparison	Comparison	Total	Total
	Cases	%	Cases	%	Cases	%
A lot of choice	129	33.9	56	17.3	185	26.2
Some choice	122	32.0	86	26.5	208	29.5
Little choice	30	7.9	53	16.4	83	11.8
No choice	34	8.9	47	14.5	81	11.5
It varies depending on the type of supports	50	13.1	37	11.4	87	12.3
Missing	16	4.2	45	13.9	61	8.7
Total	381	100	324	100	705	100

Note: trial and comparison aged 16 and above currently receiving supports.

Comparing NDIS participants' views about their supports pre- and post- NDIS, of the 300 respondents who answered these questions, 270, 230 and 238 respondents provided directly comparable responses<sup>23</sup> to both questions that elicited their satisfaction with the quality of supports, the degree of say in the process of deciding what supports to receive they had and the degree of choice they had over where they obtained supports pre- and post- NDIS respectively. These are presented in Table 3.66 below in a summary of responses to all three questions in terms of satisfaction, say and choice being reported as worse, the same or better.

Table 3.66 suggests that a preponderance of people with disability felt either better off or that there had been no negative impact after moving into the NDIS in regards to the quality of their supports, the choice they enjoy in the process of deciding what supports to get, and where to get their

<sup>&</sup>lt;sup>23</sup> This excludes those who responded that the say (Table 3.64) or choice (Table 3.65) varied depending on the type of supports or provided no answer to one or the other question.

supports from. Notwithstanding the large proportion of respondents who reported increased satisfaction, control and choice (44.4, 44.8 and 42.0 per cent respectively), a sizeable proportion reported lower satisfaction with the quality of supports (17.2 per cent), having less say (14.4 per cent) and less choice (12.6 per cent).

Table 3.66: Pre and post NDIS: changes in satisfaction, control and choice

	Satisfacti quality of		Say over decisions about what supports to receive Choice of where to get		e to get support	
	Cases	%	Cases	%	Cases	%
Worse	48	17.2	29	14.4	30	12.6
Same	102	37.8	111	55.2	108	45.4
Better	120	44.4	90	44.8	100	42.0
Total	270	100	230	100	238	100

Note: trial aged 16 and above currently receiving NDIS supports and received supports before joining the NDIS.

Tables 3.67 to 3.69 below present the above summary changes by each pair of pre- and post-NDIS corresponding questions. We note the richness and detail of information, but this comes at the cost of very small numbers in individual cells. We will revisit these tables at the stage of analysis, where we will need to consider explicitly the trade-off between having a large enough sample size and having more detail in the analysis. For now they are included in the report for largely illustrative purposes.

Table 3.67: Pre and post NDIS comparison: Satisfaction with quality of received supports

			Post NDIS				
Pre NDIS	Very satisfied	Satisfied	Neither satisfied nor dissatisfied		Very dissatisfied	Missing	Total
Very satisfied	40	20	3	5	2	0	70
	57.1%	28.6%	4.3%	7.1%	2.9%	0.0%	100.0%
Satisfied	33	44	5	1	1	0	84
	39.3%	52.4%	6.0%	1.2%	1.2%	0.0%	100.0%
Neither satisfied nor dissatisfied	18	24	12	4	1	0	59
	30.5%	40.7%	20.3%	6.8%	1.7%	0.0%	100.0%
Dissatisfied	12	16	4	5	3	1	41
	29.3%	39.0%	9.8%	12.2%	7.3%	2.4%	100.0%
Very dissatisfied	10	1	1	1	1	1	15
	66.7%	6.7%	6.7%	6.7%	6.7%	6.7%	100.0%
Missing	10	8	3	1	0	9	31
	32.3%	25.8%	9.7%	3.2%	0.0%	29.0%	100.0%
Total	123	113	28	17	8	11	300
	41.0%	37.7%	9.3%	5.7%	2.7%	3.7%	100.0%

Note: trial aged 16 and above currently receiving NDIS supports and received supports before joining the NDIS.

Table 3.68: Pre and post NDIS comparison: How much say over decisions about what supports to receive

			Post NDIS				
Pre NDIS	A lot of say	Some say	Little say	No say	It varies	Missing	Total
A lot of say	38	16	4	2	5	0	65
	58.5%	24.6%	6.2%	3.1%	7.7%	0.0%	100.0%
Some say	33	34	2	4	7	1	81
	40.7%	42.0%	2.5%	4.9%	8.6%	1.2%	100.0%
Little say	13	17	3	1	1	1	36
	36.1%	47.2%	8.3%	2.8%	2.8%	2.8%	100.0%
No say	15	9	3	20	3	1	51
	29.4%	17.6%	5.9%	39.2%	5.9%	2.0%	100.0%
It varies depending on the type of supports	12	6	1	0	16	1	36
	33.3%	16.7%	2.8%	0.0%	44.4%	2.8%	100.0%
Missing	13	5	0	0	3	10	31
	41.9%	16.1%	0.0%	0.0%	9.7%	32.3%	100.0%
Total	124	87	13	27	35	14	300
	41.3%	29.0%	4.3%	9.0%	11.7%	4.7%	100.0%

Note: trial aged 16 and above currently receiving NDIS supports and received supports before joining the NDIS.

Table 3.69: Pre and post NDIS comparison: How much choice over where supports obtained

	Post NDIS									
	A lot of	Some	Little	No						
Pre NDIS	choice	choice	choice	choice	It varies	Missing	Total			
A lot of choice	25	11	4	2	1	0	43			
	58.1%	25.6%	9.3%	4.7%	2.3%	0.0%	100.0%			
Some choice	15	39	6	2	9	0	71			
	21.1%	54.9%	8.5%	2.8%	12.7%	0.0%	100.0%			
Little choice	18	24	9	5	5	3	64			
	28.1%	37.5%	14.1%	7.8%	7.8%	4.7%	100.0%			
No choice	20	17	6	17	6	2	68			
	29.4%	25.0%	8.8%	25.0%	8.8%	2.9%	100.0%			
It varies depending on the type of supports	8	1	1	1	18	1	30			
	26.7%	3.3%	3.3%	3.3%	60.0%	3.3%	100.0%			
Missing	7	7	0	1	2	7	24			
	29.2%	29.2%	0.0%	4.2%	8.3%	29.2%	100.0%			
Total	93	99	26	28	41	13	300			
	31.0%	33.0%	8.7%	9.3%	13.7%	4.3%	100.0%			

Note: trial aged 16 and above currently receiving NDIS supports and received supports before joining the NDIS.

The survey asked respondents where they would like to have more choice. Table 3.70 offers a rich set of options allowing for multiple responses. Respondents have suggested an average of 2.4 areas each. Notably the 'other' category is not very populated which suggests that the list provided is comprehensive. Many of the selected areas of activity are already within the scope of the NDIS to support, for example, personal supports within or outside the home. Here the suggestion would be that people are seeking more intensive support. Other areas, however, are not (directly or indirectly) covered by the NDIS, for example the initiation or maintenance of friendships, or housing and health, suggesting potential shifts in the type of demanded supports.

Table 3.70: In which areas of disability supports would you like to have more choice?

	Trial	Trial	Comparison	Comparison	Total	Total
	Cases	%	Cases	%	Cases	%
Personal support in his/her home	93	24.4	87	26.9	180	25.5
Personal support outside his/her home	101	26.5	98	30.3	199	28.2
Personal support at a place of work or study	48	12.6	71	21.9	119	16.9
Equipment, modifications at home, or assistive technology	93	24.4	79	24.4	172	24.4
Finding or taking up opportunities for learning	57	15.0	82	25.3	139	19.7
Finding or taking up employment or paid work	68	17.9	83	25.6	151	21.4
Finding or taking up voluntary work	55	14.4	44	13.6	99	14.0
How he/she spends the free time	83	21.8	79	24.4	162	23.0
Access to support to initiate or maintain friendships or intimate friendships	61	16.0	66	20.4	127	18.0
Housing	70	18.4	42	13.0	112	15.9
Use of transport	65	17.1	74	22.8	139	19.7
Health care	65	17.1	79	24.4	144	20.4
Support with self-managed funding	41	10.8	40	12.4	81	11.5
Other types of support	31	8.1	23	7.1	54	7.7
Total	381		324		705	

Note: trial and comparison aged 16 and above currently receiving supports; 'Total' indicates the number of respondents to answer this question; multiple response question; percentages do not add to 100.

The degree that support recipients are satisfied that their supports are reasonable and necessary is recorded in Table 3.71. In the trial group a large majority of 76 per cent are satisfied or very satisfied against 7 per cent who are dissatisfied or very dissatisfied. These percentages can be compared with those reported by the comparison group, but this would be a comparison of limited use. The important comparison will be that between the Wave 1 and the Wave 2 answers provided by the same people, thus measuring the degree to which living with NDIS supports for a year has or has not made a difference.

Table 3.71: Satisfaction that supports received are reasonable and necessary

	Trial	Trial	Comparison	Comparison	Total	Total
	Cases	%	Cases	%	Cases	%
Very satisfied	126	33.1	64	19.8	190	27.0
Satisfied	165	43.3	114	35.2	279	39.6
Neither satisfied nor dissatisfied	52	13.7	64	19.8	116	16.5
Dissatisfied	17	4.5	31	9.6	48	6.8
Very dissatisfied	8	2.1	17	5.3	25	3.6
Missing	13	3.4	34	10.5	47	6.7
Total	381	100	324	100	705	100

Note: trial and comparison aged 16 and above currently receiving supports.

Finally, all respondents who answered Part B, excluding children under the age of 8 years, were asked if they had received any help in filling in the questionnaires.

# 3.7 The NDIS surveys and the Key Evaluation Questions: Preliminary thoughts

In this concluding section we relate the initial findings from the NDIS surveys to the Key Evaluation Questions identified by the Department of Social Services for the purposes of the NDIS Evaluation. The findings we present come with several qualifications and caveats. First, the Initial Report is based on the first wave of the longitudinal data collection. Second, the Initial Report is the first of two reports, with the first one designed to present the first wave of data descriptively and the second to analyse the first wave of data. Third, the sample sizes of the data we present are below their targeted levels because the first wave fieldwork is yet to be completed as it has been following the delayed NDIS roll-out. We discuss these briefly in turn before we turn to the discussion of the relevant Key Evaluation Questions.

First, the very nature of evaluating a policy through the use of longitudinal information means that more often than not, the formal evaluation cannot be performed before the changes in the outcomes of the policy have been observed over a period of time. Hence, much of what this evaluation is designed to find will only become available after the second wave of data has been collected and the two waves have been appropriately analysed and compared. Some questions will only be addressed in the Final Report, which will utilise both Waves 1 and 2.

Second, there is a lot of information in the data we present. The picture that emerges is complex and the data structure reflects this. As the new data comes in, appropriate statistical analyses will continue to be performed and new understandings will continue to arise. This is a continuous process that takes time. The period between July 2015 and mid 2016 will be spent by the evaluation team assessing the first wave data collections. There are many aspects of the data that can only be understood by carrying out further cross tabulations and by applying multivariate regression to account for the data complexity and interdependence. The conclusions from our further analyses will be presented in the Intermediate Report.

Third, one has to be careful with the interpretation of our present findings for the main reason that they are based on sample sizes that we believe to be inadequate for purposes of the project. In essence this report is based on about one third of the target sample sizes the project expects to achieve. Until this happens we believe that it is possible that some of the numbers we present here may change. There are two main reasons for this. The first is that the smaller the sample sizes at hand the more likely it is that a future table based on a larger sample may differ. The second is that as the NDIS roll out makes progress, the composition of the NDIS participants will become more and more representative of the broader population of people with disability in Australia. To the degree that the roll-out has been happening in a non-random way, we can expect that the larger sample estimates will be different by virtue of having been drawn at a later point in time.

## 3.8 Summary and comments

The purpose of the NDIS surveys of people with disability, and their families and carers is to build a powerful national evidence base to evaluate the impact of the NDIS on people with disability, and their families and carers, as the NDIS is rolled out in the trial sites between 2013 and 2016.

We have reported the beginning phases of these major data collections. The data collections have been very ambitious in their objectives, as the evaluation's objectives are demanding. They have also been innovative in their design in order to accomplish these objectives and comprehensive in their scope to accommodate the diversity of their subject group. There have been many challenges, especially in the beginning of the implementation of the data collections, but overall preliminary outcomes are judged to have been successful.

The objectives were quickly recognised to be too optimistic with regards to their timing, as the data collection had to tailgate the NDIS roll-out. In many instances the NDIS surveys had to wait for teething problems to be overcome. The data design faced and had to overcome its own teething problems as it broke many new frontiers, for example, in overcoming the sampling initial difficulties created by the lack of readily available linked records, undertaken through the design of a bespoke registration process. The registration process was a lengthy and complicated exercise which has had a negative impact on response rates, but in itself provided invaluable information. By the time we got to those who responded that they are willing to take part in the survey, about half of all originally sampled people had already been lost to the survey.

The design and the development of the surveys are conceptually and technically innovative and complicated. Sampling necessarily followed the roll-out of the NDIS, the slower uptake making our initial sample a census of all NDIS participants who consented to being approached for research purposes for at least the first year. One consequence was that the sampling also followed closely the non-random attributes of the phasing in of the NDIS, including the later NDIS start in the ACT. The roll-out constraints have made it impossible to collect the complete first wave within a single fieldwork exercise. It is only now (July 2015) that NDIS participants are reaching the number that will allow the originally planned evaluation sample size to be achieved and the exact details of the remainder of Wave 1 data collections are currently being decided with the Department of Social Services. We expect the second wave to be a lot more compressed in its fieldwork duration and less complex in its implementation.

The project has been breaking new ground in many methodological aspects by designing and delivering a questionnaire through several modes, in two distinct parts, to a very diverse group of people in the trial sites and the broader comparison group. The questionnaires were split into two parts to allow for the elicitation of diverse types of information, ranging from relatively straightforward demographic information in Part A to reported perceptions and feelings in Part B. The introduction of pictorial Easy English is an innovation in this type of large scale data collection. First indications suggest that it has been received very favourably. Strong efforts were made in piloting and in developing accessible instruments in an age-appropriate manner. The desire to minimise the involvement of proxy respondents and maximise the direct voice of people with disability, but without undue burden, has underpinned the overall survey design.

Response rates have been lower than expected. We are still to form a concrete opinion as to the response rates that we can expect to get for the remainder of the data collections. The registration process and the rest of the opportunities for non-response to happen, appear to be taking the final expected response rate to about 20 per cent of the original sample (Trial and Comparison), which we consider low and would like to increase. However, cases of incomplete records (missing values) and unusable information are minimal. The first part of Wave 1 which is almost completed appears to have been more productive than the second part which is approximately half way through its fieldwork.

In contrast with the qualitative evidence collection, the large surveys take a much longer time to start producing seriously useable information. We are reporting only Wave 1 of a two-wave data collection, where for many of the questions the relevant information is neither the content of Wave 1, nor of Wave 2 answers, but the difference between the two waves. This is because the evaluation will be driven by measuring the change that happened to each individual when they were introduced to the NDIS (which is captured by the direction and size of the difference between Waves 1 and 2, and not by the diversity we observe within each of the two waves). The implication is that by design the Wave 1 data collection cannot be expected to answer Key Evaluation Questions in a satisfactory manner. It is best to treat this information cautiously as both preliminary and incomplete.

We are reporting only part of Wave 1, hence we expect that we will see changes in the reported statistics once Wave 1 has reached its intended size. The likelihood that we will end up with a different statistic at the end of Wave 1 will be higher for the less well populated categories of data. We are only reporting the data on people with disability but not the data on their families and carers. The information about the people with disability along with that provided by their families and carers will add valuable dimensions to the data. The data will be richer by looking at similar matters through different lenses (and comparing them) and by providing the views of families and carers about themselves and their own circumstances, which are of great importance not only in their own right, but also for the people with disability who they may care for.

Although we are reporting the trial sites data next to the data from the comparison group, a direct comparison is not advisable. This is because the composition of the two sub-samples may not be sufficiently similar. This is only a temporary problem and will not affect the comparisons the evaluation will be making. Once we have all the data at hand, we will be able to "control" for the differences between the trial and the comparison sub-samples (using the appropriate multivariate methodologies) in order to allow for meaningful analyses to be conducted. For now and at the present preliminary stage, comparisons should only be made with caution.

Notwithstanding the caution suggested by these caveats, there are valuable findings that are already visible.

First and foremost, we have seen that the design of the data collection works well. The individual sections of each of the questionnaires appear to have been completed correctly. The quality checks we have carried out have not identified any major problem areas. We provided commentary below each table, which we will not repeat here.

The next stage of the work will be in several major directions. First, we will continue with the data collection in order to complete Wave 1. We will continue the fieldwork of families and carers and conduct the linking between data on people with disability with data on their own matched families and carers. We will add the second part of the comparison group sample to reach the necessary sample size. We will complete the remaining fieldwork for Wave 1 with the objective to reach the target sample size and in consultation with the Department of Social Services regarding the sampling alternatives, including the target size for the ACT sample.

Second, we will continue with the quality checking as the data comes in and the sample size increases. We will be checking for the robustness and consistency of the data in all relevant dimensions, primarily at the three levels (i) the person with disability; (ii) the families and carers; (iii) the relationship between persons and families. We will also begin with the intensive analysis of the data through appropriate cross tabulations and through multivariate regression methodologies. The objective is to understand the data and make sure that we have the necessary high quality information to be addressing the evaluation questions.

Third, we will organise a workshop for the cross examination of information generated through the qualitative and the quantitative evidence collection teams. This will help the evaluation as a whole to explore potential improvements in either of the two methodologies and highlight where there may be new opportunities and synergies in the way the data is interpreted and understood.

Finally, we will be making the necessary preparations for the collection of Wave 2. The main task will be to identify the questions that do not need to be asked again and remove them, and to introduce new questions that may arise as we examine the data more closely and we also compare the qualitative evidence with the Wave 1 quantitative collection. The longitudinal data needs of the evaluation require that we make minimal changes to questions between waves.

# 4. The 2014 NDIS Disability Support Providers Surveys

## 4.1 Introduction

A brief description is provided here of the purpose of the 2014 NDIS Disability Support Providers Surveys (subsequently 2014 NDIS DSP surveys), their design, development and fieldwork. This is followed by the main findings for each of the three surveys: of the individual outlets of DSP, their workforce and of self-employed service providers. A brief summary with some interpretation is offered at the end of each section.

# 4.1.1 The purpose of the 2014 NDIS DSP surveys

The focus of the 2014 NDIS DSP surveys was on understanding the current operations of disability support providers and on workforce issues. A major part consisted of trying to understand whether there will be sufficient workforce capacity to meet the growing and changing demands that will accompany the full NDIS rollout. In the 2014 NDIS DSP surveys the focus was on forming a baseline of understanding for the current operations of disability support providers and the current dimensions of the disability sector workforce. A second round of surveys is planned to commence in late 2015.

# 4.1.2 2014 NDIS DSP surveys design, development and fieldwork

A chief challenge of the DSP surveys was to define the population of disability support providers and achieve adequate coverage of them. It was difficult to accurately identify and locate outlets that delivered disability supports: no comprehensive list of this group existed, nor does one currently exist. As a result, it was difficult to know with satisfactory accuracy how representative the sample of respondents was. Our responses to this challenge are set out below.

A sample list was constructed of disability support providers in the initial trial states of the NDIS, i.e. New South Wales (NSW), Victoria, South Australia (SA), Tasmania, and the Australian Capital Territory (ACT; in the ACT a staged introduction of the NDIS started in July 2014). While Queensland (QLD) is not a trial site, it was later added as a new component of the NDIS Evaluation. The scope of the 2014 NDIS DSP surveys did not include providers from Western Australia (WA) or the Northern Territory (NT). At the time of the NDIS Evaluation initiation, the nature and timing of Western Australia participation in the NDIS was undecided. Due to its small population size, the Northern Territory is being treated separately and studied mainly via qualitative methods. All data collections have been designed for two waves of data, where the same outlets and the same self-employed providers will be interviewed twice (once in 2014 and once in 2015), with the exception of Queensland which will only take part with a one-off 2014 survey. The fieldwork for the surveys was sub-contracted to I-view.

Within the six included jurisdictions, a sample list was constructed of current disability support providers. It was not a requirement that an organisation provide disability services exclusively.

The main source of sample was a list of 'registered providers' maintained by the National Disability Insurance Agency (NDIA), which included those that had been approved by the agency to provide supports to people with disability funded by the NDIS. All registered NDIS providers were included in the sampling list for the NDIS DSP surveys. However, the broader nature of the sample scope meant that the NDIA register could not be the only source to provide the survey sample for the NDIS DSP surveys.

To increase the coverage of the sampling list additional sources were used. These were the disability service provider sample list from the NILS 2009 Community and Disability Services Ministerial Advisory Council project (CDSMAC)<sup>24</sup>; lists of providers from peak organisations, in particular National Disability Services (NDS); lists of providers from specific programs, especially the Better Start for Children initiative, which included details for significant numbers of smaller organisations and self-employed providers; location searches through the websites of particular larger organisations; and advice from the NDIS Evaluation State Experts.

The NDIS Evaluation design required DSP data collection at outlet/service location level, so in all cases an attempt was made to identify the locations and contact details of specific outlets within larger (multi-site) organisations. In the resulting 2014 NDIS DSP outlet survey, 17 organisations did not provide information at this level but only for their entire organisation.

Three questionnaires were developed for the 2014 NDIS DSP surveys data collection:

- a questionnaire to be completed by specialist DSP outlet managers, covering information on behalf of their whole service location about workforce composition, hiring practices, funding, and preparation for the NDIS. The managers are also asked to distribute the employee surveys (see below) to a random sample of employees in their outlet, based on the workforce size of the outlet
- a questionnaire to be completed by a random sample of employees in the DSP outlets, providing
  information on their own characteristics, qualifications, earnings, career pathways and views
  about their satisfaction with elements of their work and their current workplace
- a questionnaire to be completed by self-employed providers. This drew on elements of both the above two questionnaires. The main difference was that self-employed providers were not asked to provide the same level of detail about their workforce composition, based on the assumption that they have few or no employees.

The questionnaires were adapted from previously tested NILS questionnaires used for similar data collections in the aged care<sup>25</sup> and disability community care workforce settings<sup>26</sup>, and with additional input from a range of disability sector experts, survey experts, and external stakeholders. Additional relevant questions were also sourced or adapted from other major surveys, including:

- ABS Business Longitudinal Database (BLD), which has a set of skill shortage questions
- UK Workplace Employment Relations Survey (WERS)
- Australian Chamber of Commerce and Industry (ACCI) Business Expectations Survey.

Finally, survey expertise and guidance was provided by the ABS Statistical Clearinghouse.

Questionnaires were supplied in hardcopy by mail to the sample list and were available for completion in hardcopy format and online. A series of survey materials were created to complement the questionnaires. These materials were collated with one questionnaire per service (e.g. 1 x Specialist Outlet) and for the pilot six Specialist Employee questionnaires and inserted into a

<sup>&</sup>lt;sup>24</sup>Martin, B & Healy, J 2010, 'Who Works in Community Services? A Profile of Australian Workforces in Child Protection, Juvenile Justice, Disability Services and General Community Services', Community and Disability Services Ministerial Advisory Council (CDSMAC).

<sup>&</sup>lt;sup>25</sup> King, D. et al. (2013)

<sup>&</sup>lt;sup>26</sup> Martin, B. and Healy, J. (2010)

questionnaire pack for mail distribution. An appropriate number of reply-paid envelopes were provided (in this example this would be one for the outlet reply and six for the employees invited to respond, making a total of seven).

The other survey materials included:

- a loose covering letter addressed to the service or organisation receiving the questionnaire package. The letter introduced the project as being conducted for DSS by NILS, explained the contents of the questionnaire package, the benefits of completion, how to participate in the study and how to distribute the surveys. The covering letter also advised of the 1800 Helpline that the recipient could call if they had any queries (there were eight calls received in the pilot outcomes)
- a survey covering letter the first page of each questionnaire. The covering letter explained the
  purpose of the survey and provided the recipient with a unique username and password to
  complete the survey online
- a survey inside covering letter the second page of the questionnaire. The inside covering letter
  provided additional, more detailed information, about the study and benefits of completion
  including information about ethics and privacy, tips on how to complete the questionnaire
  accurately and a series of key definitions. The survey inside covering letter also advised of the
  1800 Helpline that the recipient could call if they had any queries regarding the study.

The initial questionnaire packages were mailed out in March 2014. Pilot testing occurred mainly in March and April 2014, and was completed in June 2014. The purpose was to check on the questionnaire content, the lists for survey mail-out and response, and the processing of responses received.

The pilot led to the inclusion of a pre-call stage (in the form of an initial contact by telephone) in the main stage fieldwork. Prior to starting the main survey mail fieldwork, the consolidated sample list was thoroughly checked through the telephone calls (the 'pre-calls') to all listed organisations. In this initial pre-call telephone fieldwork, a number of aspects of the list sample (such as eligibility, contact details, and outlet information, including the number of people employed at the given establishment) were clarified.

For this initial pre-call stage, NILS supplied a sample list to I-view (see above for details of how this sample list was initially defined). The sample list consisted of 4,207 DSP outlets and 853 Self-employed DSP (5,060 cases in total).

The fieldwork period for the telephone pre-calls occurred over a 23 day period from early June 2014 to early July 2014. Telephone contact was achieved with 3,415 cases (5,060 cases in total). Of these 3,415 cases that completed the pre-call questions, 2,996 indicated that they were eligible to participate in the full survey. These were the cases taken forward to the mainstage fieldwork, where three different questionnaire types were sent out. They were essentially the same as those used for the pilot, with several small changes around wording and dates.

The three mainstage questionnaires were designed for:

- DSP outlet managers
- DSP outlet employees within those outlets
- self-employed DSP

The DSP outlet direct care employees were sampled within their establishments and each outlet was sent a variable number of employee questionnaires, depending on the pre-call stage information collected about establishment size. An NDIS Evaluation information sheet was included in each survey pack.

A series of survey materials were created to complement the questionnaires, similar to those in the pilot phase. These materials were collated for DSP outlets with one questionnaire per service (e.g. 1 x Specialist Outlet) and a set of outlet employee questionnaires, and inserted into a questionnaire pack for mail distribution. The number of outlet employee questionnaires was determined by reference to the employee size of the firm gathered in the pre-call stage. As in the pilot phase, questionnaires were supplied in hardcopy by mail to the sample list and were available for completion in hardcopy format and online.

The sample list provided to the survey company I-view for the mainstage mail out contained 2,996 cases. Duplicate cases and those for which no separate outlet mailing address was available were then removed. The final sample consisted of 2,323 DSP outlets with 11,299 associated employee surveys, and 495 self-employed DSP.

Fieldwork started in August 2014 and was completed at the end of May 2015. During the fieldwork, inquiries were received from four outlets and seven self-employed providers that had heard about the study and wanted to take part. Their details were added to the sample list, and information regarding the study was sent to these providers via email.

A 1800 Helpline was hosted by I-view during fieldwork. Respondents were asked to call the helpline if they had any questions regarding the surveys. Throughout the fieldwork a total of 311 voice messages were left by outlets and call backs were made to each of these. A small number of calls (4) were also made directly to Flinders University's Ethics helpline instead of the 1800 Helpline; these were mostly about ethics issues and were dealt with appropriately on a case-by-case basis.

Reminder calls were made to 1,712 outlets, starting in early September 2014. These calls were made to encourage those as yet non-responding organisations to complete and return their questionnaires. During these reminder calls email addresses were collected and reminder emails were sent subsequently, containing information on the project, how to participate, the link to the survey, and their corresponding usernames and passwords to access the unique questionnaire.

Towards the end of the reminder call period it was decided that further contact should be made with the DSP outlets and self-employed DSP. These calls started in early January 2015 and continued until the end of May 2015.

The three survey groups were targeted with further reminder calls to gather updated information on questionnaire completion status and to encourage them to take part. The plan for further targeted follow-up activities was devised based on the response patterns in the December 2014 data, and implemented from early January 2015. This involved making and prioritising telephone calls to providers based on which of the partial response/non-response categories they belonged to in the December 2014 data. These targeted calls produced improvements in response rates.

The fieldwork period produced responses which cover approximately 40 weeks/ten and half months of the 2014/15 financial year. In total, there were 697 responses from DSP outlets, 2,133 responses from employees and 272 from self-employed providers. The response rates when the survey was closed were: DSP outlets - 30 per cent from 2,323 invited to participate; employees of specialist DSP outlets - 18 per cent from 11,299 invited to participate; self-employed DSP - 54 per cent from 495 invited to participate.

## 4.1.3 The achieved sample

In order to check the profile of the achieved sample compared to that of the sample list from which it was developed, analysis on outlet size was undertaken for the outlet survey and the outlet employee survey. It was not possible to do comparable analysis for the self-employed providers since no size information had been collected. The respondents matched closely the sample from which they were derived, on the characteristics for which comparison was possible.

# 4.2 Initial findings for DSP outlets

In this section we provide an overview of where outlets were located, how they were structured, what disability services they delivered and to which age groups, their recruitment needs and strategies, and their use of non-PAYG workers and volunteers in delivering disability services. Surveys were sent to 2,323 DSP outlets and valid responses were received from 30 per cent or 697 from 2,323 invited to participate. The respondents matched closely the sample from which they were derived, on the characteristics for which comparison was possible.

## 4.2.1 A profile of DSP outlets

Table 4.1 shows the profile of State/Territory location of outlets, ownership type and the associated number of employees in these outlets. A total of 47,913 employees were reported by the 678 outlets following a headcount of PAYG employees on their payroll records.

Among respondents, the rank order of number of outlets in each jurisdiction matched their rank order by population size (and, hence, the expected size of people with disability populations). The jurisdictions with the highest number of outlets providing disability supports were, in decreasing order, New South Wales, Victoria, Queensland, South Australia, Tasmania and the Australian Capital Territory.

The same cannot be said for the number of employees. The rank order for total number of PAYG employees by jurisdiction was Victoria, South Australia, New South Wales, Queensland, Tasmania and the Australian Capital Territory. The average number of employees per outlet varied from a high of 131 (11,534/88) in South Australia to a low of 41 (8,520/210) in New South Wales. While the average number of employees per outlet was low in New South Wales taken as a whole, it was higher (1,776/29=61) in the Hunter region NDIS trial site.

The outlet type is also shown in Table 4.1, and the most common form of outlet type was not for profit or charitable (75 per cent). Most disability service employees (72 per cent) were also found in not for profit or charitable entities. While the fewest outlets were public (8 per cent) these accounted for a higher proportion of workers (20 per cent) than would be anticipated by their number.

This table also shows that slightly under one third of the surveyed disability support provider outlets (29 per cent) were servicing NDIS trial areas, which was a very different picture to that found for self-employed providers (See Table 4.44: 43 per cent).

Table 4.1: Distribution of outlets and all PAYG employees by State/Territory and ownership type

	Total outlets	Number of employees	Number of outlets reporting their number of employees
New South Wales	218	8,520	210
Hunter region of New South Wales	29	1,776	29
Rest of New South Wales	189	6,744	181
South Australia	90	11,534	88
Tasmania	48	2,511	48
Victoria	179	17,810	174
Barwon area of Victoria	16	1,475	16
Rest of Victoria	163	16,335	158
Australian Capital Territory	19	985	19
Queensland	143	6,553	139
Question not answered (number of employees)			19
Not for profit or charitable	516	34,364	506
Privately owned, for profit	121	4,147	114
Public	59	9,389	57
Question not answered (ownership type)	1	13	1
Total	697	47,913	697

Source: 2014 NDIS DSP outlet survey, Questions A5 and B1.

Table 4.2 gives a more detailed profile of the range of outlet sizes, as measured by the number of PAYG employees. Across outlets, there was a wide range of size, with 16 per cent indicating fewer than 5 employees but also 15 per cent with 100 employees or more. The most common staff size was 20 to 49 employees (20 per cent of outlets).

Table 4.2: Distribution of PAYG employees in outlets

Number of employees	%
0 to 4	15.6
5 to 9	17.9
10 to 19	15.9
20 to 49	20.2
50 to 99	12.5
100 or more	15.1
Question not answered	2.7
Total number of outlets 697	100

Source: 2014 NDIS DSP outlet survey, Question B1.

Table 4.3 shows the proportion of outlets currently delivering particular types of disability support to users. Outlets were asked to indicate every type of service they provide. There appears to be some specialisation in service provision as shown by the fact that no service was offered by all 697 of the outlets. On average, outlets provided 3.5 out of a possible 10 types of service. The service most commonly offered was community access (offered by 60 per cent of outlets), followed by personal support (55 per cent). The remaining eight types of service were provided by fewer than half of outlets. Employment was the service least commonly offered (16 per cent of outlets). There is some suggestion that the more capital intensive types of support (accommodation, therapeutic services, aids and equipment) were less frequently offered. It is possible, although cannot be known from this

table alone, that the less frequently offered services were also the ones for which there was less demand.

Table 4.3: Types of disability support currently provided

		Per cent of outlets
ommodation support		30.0
onal support		54.9
munity access		60.1
pite		41.2
loyment		16.1
ocacy, information and alternative forms	of communication	39.6
y intervention		32.6
and equipment		21.8
rapeutic services		30.7
er		21.7
stion not answered		0.6
stion not answered Il number of outlets 697		

Source: 2014 NDIS DSP outlet survey, Question A9.

Note: Multiple responses allowed.

Table 4.4 considers the users of the outlets' disability services, in terms of their age and primary disability type. Again this was a multiple response question, and each entry can be up to 100 per cent. There are ten disability types listed and five age groups. To illustrate how to read the table, consider the first cell, with the number 22.2. This says that 22.2 per cent of facilities had among their client group children aged 0-4 years who had a physical disability as their primary disability type. Similarly, when considering psychiatric disability, 27 per cent of outlets had clients with this condition and who were aged 25-64 years. The bolded row 'any type of disability' shows a construct which in each entry reflects whether outlets recorded 'users with any type of disability are provided services in this age group'. Similarly the bolded column 'users with this disability type of any age' shows whether outlets recorded that services were provided for this disability type for any age group.

Some outlets reported rarely working with people of a certain age with particular disability types (judged as 15 per cent or less of outlets currently deliver services to these client groups). These included children (aged 0-4 years) with a mental health/psychosocial, psychiatric or visual disability; children (aged 5-14 years) with a mental health/psychosocial, psychiatric, hearing or visual disability; young people (aged 15-24 years) with a hearing or visual disability; and older people (aged 65 years and older) with a psychiatric, hearing, speech, visual, developmental or congenital disability. This likely reflected the proportion of people in each age group within the population with these disability types.

The disability types for which outlets least commonly gave provision (i.e. servicing to this disability type for any age group delivered by fewer than 50 per cent of outlets) were: psychiatric, hearing, speech and visual disabilities. Outlets most commonly worked with people with physical, intellectual, neurological and mental health disabilities. The age groups for which outlets least commonly gave disability support provision (i.e. servicing to any disability type for this age group delivered by fewer than 50 per cent or less of outlets) were for children (0-4 years and 5-14 years) and older people (65 years plus).

Table 4.4: Primary disability types and ages of the current users of the outlet's supports Percent of outlets recording current user age group, for each disability type listed

Primary disability type	0 to 4 years %	5 to 14 years %	15 to 24 years %	25 to 64 years %	65+ years %	Users with this disability type (all ages) %
Physical	22.2	28.6	34.9	50.9	22.1	66.1
Mental health/psychosocial	9.0	14.8	29.6	45.1	19.2	55.1
Psychiatric	1.9	5.2	16.4	26.7	11.9	29.4
Hearing	10.3	11.0	12.8	18.7	9.0	30.3
Speech	19.2	20.7	18.5	23.8	9.2	41.0
Visual	9.8	10.9	13.2	21.4	10.0	31.6
Developmental	29.6	32.9	29.8	28.3	9.3	56.7
Other learning or intellectual	22.5	31.4	40.7	46.5	17.2	64.1
Neurological, including acquired brain injury	16.4	21.4	31.7	45.5	18.7	58.4
Congenital or inherited conditions	22.2	25.3	27.3	32.7	13.2	50.8
Users with any type of disability for this age	38.0	49.5	66.0	77.0	41.5	
Question not answered						2.7

**Total number of outlets 697** 

Source: 2014 NDIS DSP outlet survey, Question A13.

Note: Multiple responses allowed.

## 4.2.2 Skill shortages and staff skills

The information collected allows us to report on the types of skills used, staff skills balance, extent of skill shortages, the factors thought to underlie the skills shortages and the kinds of responses used to deal with them. These aspects can inform existing workforce strategies and planning for the future.

The information was collected with specific regard to each of the range of disability support worker roles: disability support/residential support worker; personal care/home worker; service or program administrator/manager/co-ordinator; social worker/disability case co-ordinator; employment support worker; peer support worker; allied health worker. Hence in reading the tables in this section, if allied health workers, for example, are of particular interest, then the figures in this row reflect information about this role.

Table 4.5 shows within each row, the share of outlet managers who thought their staff were under-skilled for delivering each job role. The questionnaires defined under-skilling as the situation where a worker's skills were perceived to be below those required for the job they were responsible for. Many outlet managers did not answer this question (as reflected in the high percentages in the 'Question not answered' column).

Under-skilling was not seen as a substantial problem as the most frequent response among outlets (that expressed an opinion) was that they had no under-skilled workers. The two roles with the highest levels of reported under-skilling (a total of some, most, all under-skilled) were disability support/residential support workers (20 per cent of outlets) and service or program administrator/manager/coordinator (13 per cent).

Table 4.5: Proportion of outlets reporting under-skilling

		Some	Most		Question not
	None	(<50 per cent)	(50+ per cent)	All	answered
	%	%	%	%	%
Disability support/residential support worker	35.2	17.4	1.2	1.0	45.3
Personal care/home care worker	25.4	6.9	0.4	0.4	66.9
Service or program administrator/manager/coordinator	58.0	10.9	0.9	0.7	29.6
Social worker/disability case coordinator	32.3	3.7	0.3	0.3	63.4
Employment support worker	17.7	3.7	0.3	0.6	77.8
Peer support worker	17.9	1.9	0.3	0.7	79.2
Allied health worker	33.4	3.0	0.1	0.1	63.3
Other	23.1	2.3	0	0.1	74.5

Total number of outlets 697

Source: 2014 NDIS DSP outlet survey, Question C5.

Note: Row percentages are shown.

Skills shortages experienced by outlets are considered in Table 4.6, with each row reflecting the information about a specific worker role. Table 4.6 shows skill shortages for this range of staff types during the past 12 months, where a skills shortage was defined as appropriately qualified workers not available or not willing to work under existing market conditions. As with the question about under-skilling, a large number (around one third of all asked) did not answer this question. We think that it is reasonable to infer that for those cases where the question was not answered, any skills shortage that might be faced by that respondent was not very pressing.

Disability support/residential support workers were the most problematic occupation in terms of skill shortages, being continuously in shortage for 8 per cent of outlets, and occasionally in shortage for a further 21 per cent of outlets. Managers, personal care/home care and allied health workers were the other occupations for which outlets reported higher levels of skill shortage. For all occupation types, however, less than 10 per cent of outlets reported that they faced a continuous shortage of that skill. This suggests that, at the time of the survey, skills shortages were not a serious obstacle to the provision of disability services.

Table 4.6: Proportion of outlets reporting skill shortages in past 12 months

	Yes continuously	Yes occasionally	No	Question not answered
	%	%	%	%
Disability support/residential support worker	8.2	21.2	46.6	24.0
Personal care/home care worker	4.5	11.9	51.1	32.6
Service or program administrator/manager/coordinator	3.2	15.1	65.6	16.2
Social worker/disability case coordinator	2.3	7.6	57.5	32.6
Employment support worker	1.7	5.2	53.8	39.3
Peer support worker	1.6	3.7	55.7	39.0
Allied health worker	5.2	9.9	53.8	31.1
Other	2.3	4.4	55.8	37.4

Total number of outlets 697

Source: 2014 NDIS DSP outlet survey, Question C6.

Note: Row percentages are shown.

Table 4.7 shows that several reasons were put forward for the reported skill shortages. To illustrate how to interpret this table, consider the top left hand cell: it says that 16.1 per cent of facilities reported that specialist knowledge was never a cause of skill shortage. The next cells across the row show that 30 per cent reported that it was a cause some of the time, 7.6 per cent most of the time and 4.7 per cent always. When we look at Table 4.7 as a whole, we see that no single reason was reported to be never present (minimum at 16.1 per cent for specialist knowledge and maximum 29.8 per cent for wage/salary costs), showing considerable diversity in the causes of skill shortages. Multivariate analysis is required to unpack this evidence and relate it to the overall sector workforce picture.

Table 4.7: Reasons for skill shortages

	Never %	Some of the time %	Most of the time %	Always %	Question not answered %	Not applicable %
Specialist knowledge required	16.1	30.0	7.6	4.7	17.6	24.0
Geographic location of the outlet	25.1	22.7	6.2	2.9	19.2	24.0
Wage/salary costs too high for the outlet	29.8	18.8	4.7	1.7	20.9	24.0
Lack of availability of adequate training	29.1	21.2	4.2	1.3	20.2	24.0
Unsure of long-term demand for services provided	26.0	22.7	5.5	1.9	20.1	24.0
Recruitment too slow	25.4	24.2	5.9	1.9	18.7	24.0
Other	30.6	3.2	1.9	1.1	39.6	23.7

Total number of outlets 697

Source: 2014 NDIS DSP outlet survey, Question C7.

Note: Row percentages are shown.

Table 4.8 shows that the outlet responses to skill shortages were diverse: very few of these responses to skill shortages were adopted in all situations (less than 5 per cent of outlet managers always made use of a particular measure, the most common being on-the-job or internal training of employees). However, 46 per cent of managers used this strategy at least some of the time and only 11 per cent said they never used this strategy to respond to skill shortages.

Other strategies that had been adopted in the last 12 months by more than a third of outlets were more use of external training of employees (37 per cent at least some of the time) and their existing workforce working longer hours e.g. overtime (37 per cent at least some of the time).

The strategies used to deal with skill shortages centred on development of and more extensive use of their existing workforce. Managers reported that it was relatively uncommon to supplement their workforce with agency staff or volunteers, sub-contract or outsource work, or reduce the amount of service provision. The implication of these types of responses is that, should outlets be faced in the future with substantially higher levels of skills shortage, presumably due to increased demand for some or all of their services, it is likely that they would face limitations from their current preferred strategies and would have to look to make use of a broader range of strategies. This finding is mirrored in the hiring expectations reported in Section 4.2.4.

Table 4.8: Outlet responses to skill shortages

	Never	Some of the time	Most of the time	Always %	Question not answered	applicable
	%		, -		%	%
More use of external training of staff	18.2	31.7	4.6	1.1	20.4	24.0
More use of on-the-job or internal training of staff	10.8	23.7	17.6	4.9	19.2	23.8
Existing workforce worked longer hours (e.g. overtime)	19.4	26.0	7.7	2.9	20.1	24.0
Made greater use of non-PAYG staff (e.g. agency staff)	37.4	13.9	3.0	0.6	21.1	24.0
Made greater use of volunteers	38.9	13.6	1.6	1.3	20.8	23.8
Sub-contracted or outsourced work to other outlets	39.7	13.2	1.4	0.9	20.8	24.0
Employed staff on short-term contract basis	29.8	23.4	1.1	1.1	20.5	24.0
Wages, salaries and/or working conditions increased	33.0	17.6	2.7	1.3	21.4	24.0
Reduced the amount of service provision	34.4	18.5	1.9	0.9	20.4	24.0
Reduced the range of services provided	40.5	12.5	1.0	0.9	21.2	24.0
Other	33.3	0.6	0.0	0.6	41.5	24.1

### Total number of outlets 697

Source: 2014 NDIS DSP outlet survey, Question C8.

Note: Row percentages are shown.

### 4.2.3 Vacancies

Job vacancies are another indicator of skill shortage or labour turnover. Table 4.9 considers the number of current vacancies at outlets for each employee type, with the vacancy advertised and available to fill immediately (at date of survey during the 2014/15 financial year).

For each type of employee, more than 60 per cent of all outlets recorded no vacancies and where there were vacancies the numbers were generally small. The largest number of vacancies were for disability support/residential support workers (20 per cent of outlets reported at least one vacancy), personal care/home care workers (12 per cent) and allied health workers (9 per cent). As we show in a later section of this report (Table 4.18), disability support/residential support workers accounted for 48 per cent of the whole direct care workforce, and it is thus not surprising that they also represented a high proportion of all vacancies.

Table 4.9: Number of current vacancies by occupation

				Three or	Question not
	None	One	Two	more	answered
	%	%	%	%	%
Disability support/residential support worker	60.8	5.2	5.3	9.5	19.2
Personal care/home care worker	61.8	2.4	3.0	6.3	26.4
Service or program administrator/manager/coordinator	77.2	6.5	0.7	1.0	14.6
Social worker/disability case coordinator	68.4	4.3	1.3	0.6	25.4
Employment support worker	67.9	1.4	0.3	0.4	30.0
Peer support worker	67.7	1.0	0.7	0.7	29.8
Allied health worker	67.1	5.7	1.7	1.3	24.1
Other	63.6	1.4	1.0	0.9	33.1

Total number of outlets 697

Source: 2014 NDIS DSP outlet survey, Question C9.

Note: Row percentages are shown.

This information aligns well with that provided for each employee type for Tables 4.6 (skills shortages in the past 12 months) and 4.11 (additional employees to hire in the next 12 months).

Table 4.10 shows that there were few unfilled vacancies, with at most 5 per cent of outlets recording that a vacancy advertised in the last six months was not filled for any of these disability services worker types. Unfilled vacancies were most commonly reported for service or program administrator/manager/coordinator (5 per cent) and allied health worker roles (5 per cent).

Table 4.10: Whether the most recent vacancy was filled

	Yes	No	Question not answered	Not applicable
	%	%	%	%
Disability support/residential support worker	38.9	2.9	17.6	40.6
Personal care/home care worker	18.7	2.7	23.5	55.1
Service or program administrator/manager/coordinator	33.4	5.0	15.2	46.3
Social worker/disability case coordinator	15.9	3.3	22.8	58.0
Employment support worker	7.9	2.2	27.0	63.0
Peer support worker	6.9	1.9	28.0	63.3
Allied health worker	17.2	4.9	23.8	54.1
Other	8.8	2.7	31.3	57.2

Total Humber of outlets 037

Source: 2014 NDIS DSP outlet survey, Question C10.

Note: Row percentages are shown.

## 4.2.4 Hiring intentions

The hiring intentions reported by outlet managers give a sign as to whether they foresee a need to replace workers, or supplement their numbers. The tables in this section, as for the earlier information on skills and vacancies, are presented by worker type.

Table 4.11 indicates the number of additional hires for each staff category together with the number of outlets that indicated this information for each worker type. Each entry in a row shows the expected number of employees that outlet managers reported an intention to hire, of each worker type in the next year. For each of the listed occupations, the intent to hire will be larger if the occupation is widely employed across outlets and if the total number of such workers is relatively high. It is not surprising then to see that disability support/residential support workers were expected to be hired in the greatest number. Strong future demand for additional service or program administrator/ manager/coordinators, personal care/home care workers and allied health workers was also noted.

Also shown in the final column of Table 4.11 is the calculation across outlets of the average number of employees that managers expected to hire. This shows an average of five additional disability support/residential support workers and three personal care/home care workers (Table 4.11: total number of additional employees of this type divided by number of outlets reporting).

This estimate reflects the fact that almost two thirds of outlet managers foresaw hiring at least one worker of these types in the coming year (at least one additional worker across all occupations, 65 per cent). Although disability support /residential support workers were expected to be the most commonly sought worker type, almost half of all outlet managers did not foresee hiring any staff of this type over the next year (49 per cent). For all of the other staff types more than half of outlet managers did not have intentions to hire in the next year.

Table 4.11: Hiring intentions in next 12 months

	Number of new hires by occupation across all outlets	Per cent of outlets with no expected new hires of workers of this type	Per cent of outlets expecting new hires of 1 or more workers of this type	Average number of expected new hires per outlet
Disability support/residential support worker	3,014	49.2	35.3	5.1
Personal care/home care worker	1,752	60.8	19.3	3.1
Service or program administrator/manager/coordinator	266	62.1	20.2	0.5
Social worker/disability case coordinator	158	66.4	11.3	0.3
Employment support worker	121	70.4	5.9	0.2
Peer support worker	124	71.7	5.2	0.2
Allied health worker	298	63.6	17.9	0.5
Other	84	65.4	5.6	0.2
For all occupations	5,817	28.1	65.4	8.9

Source: 2014 NDIS DSP outlet survey, Question C3.

Note: The average number of employees to hire per outlet is the number of employees to hire across all outlets divided by the total number of outlets answering the question; it includes intending to hire zero employees. Row percentages are shown.

Further detail is presented in Table 4.11a, which shows that most of the expected additional hiring was intended by the larger outlets—particularly those with 100 or more employees (in considering all occupations, outlets with more than 100 or more employees made up 44.8 per cent of the total number of employees to be hired). Whilst overall outlets reported that they were most likely to hire disability support/residential support workers, administrators/managers/ coordinators, and allied health workers, variation was seen in the hiring intentions by worker type across the different sizes of outlets. For example outlets with 20 to 49 and 100 or more staff reported that they were most likely to hire disability support/residential support workers, while smaller outlets with less than 20 staff most commonly wished to hire new allied health staff. Interestingly given the emphasis of the NDIS on the economic participation of people with disability, the hiring intention of employment support workers was most often found amongst outlets with more than 20 employees.

Table 4.11b shows the proportion of each outlet size that intends to hire workers of any occupational type in the next 12 months. Reported intentions for growth are universally spread, but they are at their lowest among outlets that employed less than 10 employees and appeared very vigorous in all outlets with 10 or more employees. There appears to be considerable diversity in the occupation of growth, which will be a subject for analysis in the Intermediate Report.

Table 4.11a: Intentions to hire in next 12 months as a proportion of total number of new hires by occupation and outlet size

	Size of outlet										
	0 to 4 employees %	5 to 9 employees %	10 to 19 employees %	20 to 49 employees %	50 to 99 employees %	100+ employees %	Missing %	Total number of new hires by occupation	Number of outlets answering question		
Disability support/residential support worker	5.4	1.5	3.7	20.9	17.7	48.4	2.4	3,014	589		
Personal care/home care worker	8.7	1.3	3.3	16.8	20.4	45.0	4.5	1,752	558		
Service or program administrator/manager/coordinator	10.9	6.4	6.0	18.4	16.9	39.8	1.5	266	574		
Social worker/disability case coordinator	0.6	6.3	13.3	17.7	24.1	36.1	1.9	158	542		
Employment support worker	6.6	9.1	1.7	19.0	21.5	42.1	0.0	121	532		
Peer support worker	4.8	8.1	9.7	12.9	32.3	31.5	0.8	124	537		
Allied health worker	11.4	11.1	18.8	11.1	17.8	28.5	1.3	298	568		
Other	9.5	7.1	19.0	29.8	1.2	25.0	8.3	84	495		
For all occupations	6.9	2.7	5.1	18.9	18.8	44.8	2.9	5,817	652		
Total cases	109	125	111	141	87	105	19		697		

Source: 2014 NDIS DSP outlet survey, Questions C3 and B2.

Note: Row percentages are shown.

Table 4.11b: Hiring intentions in next 12 months by outlet size (per cent of outlets by size hiring any workers)

Size of outlet										
	0 to 4	5 to 9	10 to 19	20 to 49	50 to 99	100+	Missing	Total		
	employees	employees	employees employees		employees	employees	iviissiiig	TOtal		
Percent	39.4	54.4	70.3	74.5	80.5	77.1	57.9	65.4		
Total	109	125	111	141	87	105	19	697		

Source: 2014 NDIS DSP outlet survey, Questions C3 and B2.

Note: Percentages of total cases are shown.

Table 4.12 shows that overall a little more than two thirds of outlet managers expected their hiring plans not to change the outlet's current mix of support activities (Total column, 68 per cent). Hence this reflects that hiring intentions were more likely to relate to the replacement of staff to maintain current service levels planned for the year ahead, or an increase in the scale, but not character, of the services they offered.

However, for a quarter of outlet managers, their hiring plans would increase the focus of the outlet on disability support. Extremely few outlet managers expected the hiring plans to result in reduced outlet disability support activities (only 2 per cent). Expectations about whether the hiring plans would change the outlet's current mix of support activities were similar for outlets of small or large size. A minority (23 per cent of small and 28 per cent of large outlets) expected to increase their outlet focus on disability with their hiring intentions.

Table 4.12: Whether hiring plans change the outlet's current mix of support activities by outlet size (per cent)

	Small outlet	Large outlet	Total
	up to 18 staff	19 staff or more	Total
No	70.8	65.8	67.9
Yes, will reduce the focus on disability	1.5	1.8	1.6
Yes, will increase the focus on disability	23.0	28.0	25.4
Question not answered	4.7	4.4	5.2
Total	100	100	100

Source: 2014 NDIS DSP outlet survey, Questions B1 and C4.

Notes: An outlet is defined as small if it has 18 or fewer employees and as large if it has 19 or more employees. This classification leads to 339 small outlets and 339 large outlets, while 19 outlets did not report their size.

### 4.2.5 Agency, brokered and self-employed

In addition to those employed directly by outlets, workers may also be sourced from employment agencies (contracted from the agency and the outlet is responsible for their supervision), other disability service providers (contracted from other outlets), or through networks of independent care workers (self-employed workers with their own ABN). These non-PAYG workers are defined here as 'agency', 'brokered' and 'self-employed'. These workers augment the employer's disability services workforce.

Table 4.13 shows the use of non-PAYG workers by the disability service providers in this sample. As for the earlier sections, information for a particular worker type is reflected within a row.

Although most outlets relied on their own (PAYG) workforce, Table 4.13 shows that for a small share of outlets, some alternative employment terms were used for workers of certain types.

Across all occupation types, 14 per cent of outlets used agency workers, 11 per cent used self-employed workers, and 8 per cent employed brokered staff.

These employment terms were more common for certain types of workers: agency working was used by 9 per cent of outlets for disability support/residential support worker roles; self-employed allied health workers were reported by 6 per cent of outlets; brokered staff were used by 5 per cent of outlets for disability support/residential support workers and 4 per cent for personal care/home workers.

Table 4.13: Use of non-PAYG workers by type of worker (per cent of outlets)

	No Agency workers	Agency workers 1 or more	Question not answered	No Brokered workers	Brokered workers 1 or more	Question not answered	No Self-employed	Self-employed 1 or more	Question not answered
Disability support/residential support worker	69.2	9.2	21.7	71.9	4.7	23.4	74.0	1.9	24.1
Personal care/home care worker	70.6	3.7	25.7	68.6	4.2	27.3	71.7	0.9	27.4
Service or program administrator/manager/coordinator	75.2	2.7	22.1	75.9	0.3	23.8	75.3	1.3	23.4
Social worker/disability case coordinator	71.5	2.3	26.3	72.0	0.2	27.8	71.9	0.7	27.4
Employment support worker	71.5	1.0	27.6	71.6	0.0	28.4	71.7	0.0	28.3
Peer support worker	71.6	0.6	27.8	71.0	0.1	28.8	71.3	0.0	28.7
Allied health worker	71.5	1.4	27.1	70.7	1.4	27.8	68.2	5.6	26.3
Other	67.1	1.2	31.7	67.1	0.3	32.6	66.1	1.9	32.0
All occupations	69.3	13.9	16.8	72.2	8.2	19.7	71.0	10.9	18.1

## Total number of outlets 697

Source: 2014 NDIS DSP outlet survey, Questions D1.

Note: Row percentages are shown. Each row sums to 100 within 'agency', within 'brokered' and within 'self-employed'.

### 4.2.6 Volunteers

Some DSP outlets use volunteers within their workforce to augment service delivery. This section reflects information about the number of volunteers and the hours they contributed within outlet services. Outlet managers were asked to record this information for the previous week when completing the survey. Table 4.14 shows that about half of outlets had no volunteers in the previous week. Around a quarter of outlets reported having one to five volunteers. A total of 21.2 per cent of all outlets received the equivalent of at least 20 hours of voluntary work in the last week.

The number of volunteers and the weekly hours they worked was also explored by distinguishing between large and small outlets (small defined as up to 18 staff and large as 19 or more staff, see notes for Table 4.12 earlier). This further analysis (not shown) indicates that about half of both small and large outlets had volunteers. The numbers tended to be small, although 12 per cent of the larger outlets had 11 or more volunteers.

Table 4.14: Number of volunteers and voluntary hours in the outlet last week

	Per cent with volunteers	Per cent with voluntary hours	
	with volunteers with voluntary		
0	53.7	50.4	
1 to 5	23.7	6.3	
6 to 10	6.5	7.0	
11 to 20	4.7	7.9	
21 or more	7.6	20.7	
Question not answered	3.9	7.7	
Total number of outlets 697	100	100	

Source: 2014 NDIS DSP outlet survey, Questions B1 and D3.

## 4.2.7 Expected changes

We have some evidence of how outlets expected to be affected by the NDIS and how they were responding, or were planning to respond. The outlets were asked to look forward 12 months and this time horizon did not embrace the scheduled full rollout of the NDIS. A majority of the outlets surveyed were not within the NDIS trial sites. It would be surprising if these were making complete and concrete changes to their operations at this stage. But they were likely to have views about how the full rollout might affect their operations, to be planning how to respond and even to be making some current structural changes to help them adapt when the full rollout happens. Further information about how outlets expect to adapt to the changes that might be expected to follow the full rollout of the NDIS will be asked in the next survey of outlets, when the rollout is closer and hence more pertinent to their current operations and planning.

Outlets were asked how the types of disability support they provided at the time of the survey (between August 2014 and May 2015) differed from what they were providing 12 months prior to that date. This does not directly link any change to the introduction of the NDIS, but it does give a background level of change. In aggregate, every specific type of disability support was offered by more outlets at the time of the survey than it was a year prior. The increases, though, were small of the order of 2-3 per cent. The services with the greatest expansion were community access, respite, accommodation support and advocacy/information. The picture that emerges is that while only

modest changes in services were reported for the past 12 months, outlets were actively changing their businesses and planning further changes, in anticipation of the full NDIS rollout.

Table 4.15 shows these actions and plans. Outlets had been particularly active in revising the basis on which they charged for services, and in meeting the specific requirements of the NDIS to prepare personalised plans, engage with Local Area Co-ordinators and provide brokerage services. One third of outlets had already altered their staff profile in order to provide these new services. Collectively, outlets planned to do still more of all these things, with the greatest emphasis on adding new staff and engaging with Local Area Co-ordinators.

Table 4.15: What outlet is already doing/planning to do in response to full NDIS rollout

	Already doing	Planning to do
	%	%
Calculating support charges on a per-user basis	48.5	24.1
Adding new staff to meet service demand	25.0	32.7
Changing staff types to meet service demand	32.0	29.1
Helping service users to prepare personalised plans	47.3	24.5
Engaging with Local Area Co-ordinators (LACs)	31.0	33.9
Establishing brokerage services	30.0	22.5
Other	6.0	5.9
Question not answered	10.9	10.9
Total (N=697)		

Source: 2014 NDIS DSP Outlet survey, Question A24.

Notes: Multiple responses allowed. Per cent of outlets reporting what they are doing or planning to do each listed action.

A broad question was asked about whether outlets expected the NDIS to have a positive or negative effect on their operations. The answers to this question are set out in Table 4.16.

Almost one third of respondents did not have a view about the likely impact. Of those that did have a view, a majority of 38 per cent expected the impact to be positive. But it is worth noting that 22 per cent thought that it would have a negative impact, two thirds of whom thought it would be a significantly negative impact. It is surprising and almost counter-intuitive that providers faced with an expected large rise in demand for their services would view this demand rise in such a negative way. It raises questions about the reasons why they felt threatened by this rise. This will be explored more fully in subsequent quantitative and qualitative work.

Table 4.16: Anticipated general impact of NDIS

	%
A significant positive impact	21.2
A small positive impact	17.2
No impact	6.2
A small negative impact	7.5
A significant negative impact	14.5
Not sure/don't know	31.7
Question not answered	1.7
Total (N=697)	100

Source: 2014 NDIS DSP Outlet survey, Question A22.

Table 4.17 gives more detail about the types of impacts that outlets expected the NDIS would have on the way that their businesses operate, in the 12 months following the date of the survey. One way to read the table is to focus on the column headed 'no change'. For each category, more outlets expected no change than expected either an increase or decrease. Many were therefore not taking steps in the near future to anticipate the changes that would come with the full rollout of the NDIS.

Outlets expected the smallest impacts to be on their use of overtime and investment in buildings. The biggest expected impacts were on the prices that they charge, the number of workers that they employed, wages and their overall performance. In each case, the weight of impact was that these would be higher as a result of the NDIS. In contrast, 27 per cent (somewhat lower 17.1 per cent and much lower 9.5 per cent) expected that the NDIS would cause a fall in their profits (10 per cent expected an increase, somewhat higher 9 per cent, much higher 0.9 per cent). This expected fall in profits was likely to be one reason for the pessimism about the impacts of the NDIS.

The level of expected adaptation that is revealed in Table 4.17 is unlikely to be sufficient to manage the large task ahead. However responses referred only to the next 12 months, and it is reasonable that they would accelerate as the full rollout approaches.

Table 4.17: Expectations about how NDIS will change outlet's operations in next 12 months

	Much higher	Somewhat higher	No change	Somewhat Iower	Much lower	Question not answered
	%	%	%	%	%	%
Wage growth	4.2	23.4	52.9	7.0	2.9	9.6
Support charges (prices)	6.6	26.1	42.0	9.3	5.0	10.9
Profits	0.9	9.0	51.1	17.1	9.5	12.5
Employment	4.6	30.1	43.5	9.5	2.6	9.8
Overtime utilisation	3.0	11.8	65.9	4.3	2.2	12.9
Investment in buildings and structures	1.7	11.3	61.1	7.0	6.0	12.8
Investment in plant and equipment	1.3	16.4	56.7	7.6	5.3	12.8
Overall performance	4.2	30.0	42.3	8.6	3.6	11.3

Total (N=697)

Source: 2014 NDIS DSP Outlet survey, Question A23.

Note: Row percentages are shown.

The evidence above suggests that change is anticipated, but the evidence about its expected shape is not clear. The first Wave of data has much information which will be explored in the forthcoming Intermediate Report using multivariate analysis in order to improve our understanding about the way change was happening. Whilst it is reasonable to expect that change will be at its strongest within the NDIS trial sites, it cannot be known much about the speed at which this change will spread and exactly what shape it will take. For example, change may come through the growth of existing providers or through the entry of new providers in the sector. It may come through the growth of presently small providers or through the expansion of presently large providers. The shape of the market that will emerge during the NDIS full rollout cannot be forecast with much accuracy from the present data. The importance of these remaining questions surrounding the disability services sector supports the view that the second Wave of the providers surveys should include a top up sample in order to capture not only the way present providers develop, but also the way new providers may enter the market and allow the NDIS Evaluation to form a complete view of the change in the services sector.

# 4.2.8 A brief summary of findings for DSP outlets

The principal purpose of this chapter is to set out information about the providers of disability services and their thoughts and facts about their workforce. These are important as a baseline for understanding the capacity of providers and their workers to adapt to the large changes that are likely to occur as a result of the full rollout of the NDIS.

There was a rich mixture of providers—large and small, mainly not for profit, with some smaller for profit providers and a modest number of large public providers. About 28 per cent employed 50 or more people while 34 per cent employed fewer than 10. There was clear evidence of specialisation in the types of disabilities that were supported, and the types of services that were offered. The diversity in size, ownership and services suggests that the sector has the capacity for resilience, adaptability and growth.

By far the largest occupation among the direct care workers was disability support/residential support worker, followed by personal care/home care worker (see later Table 4.18 in section 4.3.2). Both these occupations are critical in the provision of regular care. But they are occupations that can be learned relatively quickly. If there is a sufficient reservoir in the population of people who have a willingness to provide hands-on care for others, then it should be possible to expand this component of the disability workforce as needed. That is, with a little planning it need not provide a bottleneck to the expansion of disability services. In saying this, the data gives no insight into whether it would be necessary to raise the pay of these occupations in order to expand the supply. Almost a third of the support workers were men (Table 4.18 in section 4.3.2). The fact that this component of the workforce is able to draw on both sexes expands the pool of potential workers and supports the view that the supply has good potential for expansion.

On the whole, managers thought that their workforce had the skills that it needed to do the job. While they had some concern on this front for their disability support/residential support workers, this may simply reflect the size and turnover of this section of their workforce. Since the main way that outlets said they dealt with skills shortages was to increase their in-house and/or external training, the solution to under-skilling of their existing support and care workers or difficulty in recruiting people with adequate existing skills was largely in their own hands. Managers did report some difficulty in finding the skills they wanted among program administrators/managers/coordinators and allied health workers. They were more dependent on recruitment rather than on their own training to obtain these higher level skills, which suggests that shortages could be aggravated by a rapid expansion in demand. The evidence on vacancies and intentions to hire supports this view.

Agency and brokered workers were used by less than one third of outlets. Self-employed workers were mainly allied health professionals and supplemented the direct employment of these skills for a minority of outlets. Consistent with their share in the total workforce, most agency and brokered workers were disability support/residential support and personal/home care workers. The motivation for using this form of employment is not clear, since it was not cited as a major way of responding to skills shortages. However, there is potential for further evidence collection in the second Wave of qualitative and quantitative data.

The first Wave of the Providers Survey has provided useful information about the sector. However, our findings are relatively low key and do not suggest the level of intense activity that one may have expected from an anticipated strong expansion of the sector.

# 4.3 Initial findings for disability support workforce

#### 4.3.1 Introduction

In this section, data from the 2014 NDIS DSP survey of outlet employees is used to provide an overview of workforce characteristics and their work, career paths, and their experiences of working in disability support.

Responses were received from 2,133 employees covering 669 outlets, out of a possible 11,299 invited employees in 2,323 outlets. Thus the employee response rate was 18 per cent. The DSP outlet employees were sampled within their establishments and outlet managers were sent a variable number of DSP outlet employee questionnaires, depending on the precall information collected about establishment size. The questionnaire was to be completed by a random sample of specialist disability support employees employed in the DSP outlets. Instructions were given to managers on a way to conduct the random sampling by using employee birthdates. The questionnaire collects information on the employees' demographic characteristics, qualifications, earnings, career pathways and views about their satisfaction with elements of their work and their current workplace.

### 4.3.2 Main workforce characteristics

Table 4.18 presents the reported occupational and gender composition of the DSP workforce. It is a headcount (i.e., numbers of people, not hours worked) of the DSP PAYG employees that provided disability care or support to users. It is important to note that these figures do not include outlet employees who did not provide direct disability support, such as clerical or maintenance staff, volunteers or other unpaid staff, or non-PAYG staff such as agency or self-employed workers (for the total number of payroll employees of outlets see Table 4.1).

The total column per cent entries (shown in the final column) show the proportion of each type of worker role in the workforce. The most common occupation in disability services was the disability support/residential support worker role, which accounted for 48 per cent of the employees among those outlets that responded to this survey. A further 19 per cent of the direct care workforce was personal care/home care workers. Thus two thirds (67 per cent) of the direct care workforce provided direct hands on care and had only modest formal education requirements. A Certificate III in disability care can be obtained within six months of fulltime study and a Certificate IV takes 12 months. In some instances the duration may be shorter, especially where relevant prior learning is recognised. Many people in these jobs did not have a formal qualification in disability care.

This is a female dominated industry: three quarters of all employees were female and females also formed the majority for all occupation types. Variation according to gender occurred, however, across occupations. The highest share of females was found in allied health roles (89 per cent). Significantly, males comprised 30 per cent of the largest occupation group - disability support/residential support workers.

Table 4.18: Composition of outlets' total workforce by occupation and gender: number employed and per cent for each occupation

Occupation	Males	Females	Total
Disability support/residential support worker	5,070	12,051	17,121
	56.9%	45.1%	48.0%
Personal care/home care worker	992	5,610	6,602
	11.1%	21.0%	18.5%
Service or program administrator/manager/coordinator	567	2,136	2,703
	6.4%	8.0%	7.6%
Social worker/disability case coordinator	370	1,417	1787
	4.2%	5.3%	5.0%
Employment support worker	249	384	633
	2.8%	1.4%	1.8%
Peer support worker	150	324	474
	1.7%	1.2%	1.3%
Allied health worker	196	1,657	1853
	2.2%	6.2%	5.2%
Other	1319	3,162	4,481
	14.8%	11.8%	12.6%
Total	8,913	26,741	35,654

Source: 2014 NDIS DSP outlet survey, Questions B2.

Notes: Headcount reported by the 669 outlets that responded to this question. Column percentages are shown.

The age composition of the disability support workforce is shown in Table 4.19, based on the information in the employee survey sample. It shows that the disability support sector had a significant proportion of older employees: more than 40 per cent of the employees were aged 45 years or older. The median age of the disability support workforce was 43 years (therefore half of the workforce was aged 16-43 years with the remaining half older than this). This was higher than the equivalent for the whole Australian workforce (for example, the median age in the HILDA<sup>26</sup> 2014 data was 39 years) but much lower than that of the aged care workforce in 2012 (median age was 50 years for community care employees and 48 years for residential care employees, King et al. 2013)<sup>27</sup>. A more comprehensive comparison with national data will be attempted in the Intermediate Report analyses and a better picture will be built after the Wave 2 data collection.

<sup>&</sup>lt;sup>26</sup> The Household, Income and Labour Dynamics in Australia Survey (HILDA) is a household-based longitudinal survey (HILDA). The HILDA Project was initiated and is funded by the Australian Government Department of Social Services (DSS), and is managed by the Melbourne Institute of Applied Economic and Social Research (Melbourne Institute). The findings and views reported in this paper, however, are those of the author and should not be attributed to either DSS or the Melbourne Institute.

<sup>&</sup>lt;sup>27</sup> King, D, Mavromaras, K, Wei, Z, He, B, Healy, J, Macaitis, K, Moskos, M & Smith, L 2013, 'The aged care workforce, 2012', Canberra, Australian Government Department of Health and Ageing.

Table 4.19: Age distribution of the disability support workforce

	%
16 to 24	7.3
25 to 34	22.6
35 to 44	24.4
45 to 54	26.0
55 to 64	16.4
65 or above	2.1
Question not answered	1.2
Total (N=2,133)	100
Median	43

Source: 2014 NDIS DSP employee survey, Question A2.

Table 4.20 shows the country of birth composition of the disability support workforce, based on the information in the employee survey sample.

Slightly more than three quarters of the disability support workforce was Australian born (Table 4.20 77 per cent). This represents a higher proportion of Australian born workers than the 72 and 65 per cent, respectively found in the community and residential aged care workforce (see *King et al. 2013*, p.p. 76 and 14). Among those who were born overseas, 73 per cent had been in Australia for more than 10 years and most were from English speaking countries. The disability care workforce was not one that draws much on recent migrants.

Table 4.20: Country of birth of the disability support workforce

	%
Australia	77.3
UK	4.6
New Zealand	3.0
India	0.8
Ireland	0.8
South Africa	0.8
Germany	0.6
China	0.5
Other	7.9
Question not answered	3.7
Total (N=2,133)	100

Source: 2014 NDIS DSP employee survey, Question A3a.

The self-reported English skills of outlet employees are shown Table 4.21. Given the country of birth information in Table 4.20 which shows a very high proportion of native English speakers in the disability workforce, it is not surprising to see that nearly all the workers were highly confident in their skills in all of the three facets of English literacy. Extremely few rated their skills in English as 'not very good' or 'not at all'. Of course, one should note that those with poor English would be less likely to respond to a survey, so this is an aspect where the NDIS Evaluation could attempt to get further information through the qualitative evidence collection.

Table 4.21: Self-reported English language skills (per cent)

	Not at all	Not very good	Good	Very good	Question not answered
Speaking English	0	0.4	7.8	91.5	0.4
Reading English	0	0.4	7.9	90.5	1.2
Writing English	0	0.7	11.1	87.1	1.2
Total (N=2.133)					

Source: 2014 NDIS DSP employee survey, Question A5c.

Note: Row percentages are shown.

A standard ABS measure of self-assessed health levels which uses a rating of health as excellent, very good, good, fair or poor, is shown for outlet employees in Table 4.22.

Two-thirds of employees reported they were in excellent or very good health, which was higher than that of the general Australian workforce (55 per cent: HILDA<sup>28</sup> 2014) and also higher than reported for the Aged care residential or community workforce 2012 (around 60 per cent, see King et al. 2013). Only six per cent of respondents considered their health to be fair or poor. These figures are not age adjusted. Adjusting for age would remove some bias and result in an even more favourable picture for the health of the sector's workforce in comparison with the wider Australian workforce.

Table 4.22: Self-reported health of the disability support workforce

<u> </u>	<del>-</del>
	%
Excellent	26.7
Very good	40.1
Good	26.8
Fair	5.3
Poor	0.8
Question not answered	0.4
Total (N=2,133)	100
<u> </u>	

Source: 2014 NDIS DSP employee survey, Question A12.

Table 4.23 considers another aspect of health: long term limitations to day to day activities expected to last at least 12 months. Only 14 per cent of the workforce reported their day-to-day activities were limited a little because of a long term health problem or disability with a further two per cent of employees indicating that their activities were 'limited a lot'.

Table 4.23: Self-reported health problem or disability limiting day to day activities of the disability support workforce

	%
No	84.3
Yes, limited a little	13.8
Yes, limited a lot	1.5
Question not answered	0.5
Total (N=2,133)	100

Source: 2014 NDIS DSP employee survey, Question A13.

The formal education levels of employees are shown in Table 4.24. Formal levels of education were high: more than 90 per cent of the workforce had post-school qualifications, including 36 per cent with a Bachelor degree, 34 per cent with a Certificate IV, and 26 per cent with a Certificate III. Most

21

<sup>&</sup>lt;sup>28</sup> Op cit.

of these qualifications (87 per cent) were obtained in Australia. These high levels of qualification are rather remarkable for a workforce that is predominantly employed in hands-on caring roles for which there is no formal educational requirement. In this context there could well be some response bias, towards the more educated, among the sample of workers who completed the survey. For comparison, in 2012, 80 per cent of the direct care aged care residential workforce had post-school qualifications, with 86 per cent in the equivalent community workforce [op cit. p.17 and p.79]. The qualifications composition will be further scrutinised and examined in more depth in the Intermediate Report analyses.

**Table 4.24: Level of qualifications** 

	%
Postgraduate Degree	10.2
Bachelor Degree	35.6
Diploma or Advanced Diploma	29.6
Certificate IV	34.1
Certificate III	25.7
Certificate I or II	6.4
Other	6.9
No formal qualification	6.5
Question not answered	1.9
All Bachelor degrees and above	40.4
All Diplomas and Certificates	63.2
Total (N=2,133)	

Source: 2014 NDIS DSP employee survey, Questions A7a and A7b. Note: Multiple responses allowed, column will not sum to 100.

The field of study of employees' highest and of their most relevant qualification is shown in Table 4.25. 'Disability/Disability Studies', 'Community Work/Community Services/Welfare Services/Care Work' and 'Allied Health' were the top three fields of study in terms of both the highest level and the most relevant qualifications (these three fields made up 44 per cent of the highest qualification held and 56 per cent of the most relevant qualification held). Other fields of qualifications commonly held in the sector were psychology/counselling, social work, nursing and business/business management. This suggests that a high share of the disability services workforce has specialised qualifications, and that these qualifications are of direct relevance to their current job.

Table 4.25: Field of study of the highest and most relevant qualification for current role

	Highest qualification	Most relevant qualification
Social Work	5.6	6.0
Disability/disability studies	18.7	26.6
Nursing	5.1	4.5
Psychology/counselling	6.9	6.6
Community work/community services/welfare services/care work	14.3	17.8
Youth work/youth services	0.7	0.6
Children's services	1.8	1.5
Allied health (e.g. physiotherapy, podiatry, speech therapy)	11.0	11.3
Administration	1.5	1.7
Business/business management	5.0	3.3
Law/legal studies	0.5	0.3
Information Technology	0.4	0.3
Other	13.8	7.7
Question not answered	8.6	5.9
Not applicable	6.2	6.0
Total (N=2,133)	100	100

Source: 2014 NDIS DSP employee survey, Questions A7d and A7e.

While the formal qualification level of the workforce has already been shown to be high, Table 4.26 indicates that a significant share (21 per cent) of employees was currently studying for further qualifications. Nearly all of those who are studying (502 employees) were undertaking studies at the level of Certificate III or above (90 per cent), with 33 per cent studying at Bachelor degree level or above.

Table 4.26: The highest level of qualification currently studying for

-	
	%
Not currently studying	78.9
Studying	20.6
Question not answered	0.5
Total (N=2,133)	100
Of those studying:	%
Postgraduate degree (e.g. Masters)	11.0
Bachelor degree	22.1
Diploma or Advanced Diploma	23.5
Certificate IV	22.1
Certificate III	11.4
Certificate I or II	1.0
Other	5.8
Question not answered	3.2
Total (N=502)	100

Source: 2014 NDIS DSP employee survey, Questions A8a and A8b.

Table 4.27 shows that about a quarter of those currently studying were studying in the field of 'disability/disability studies' and 15 per cent 'community work/community services/welfare services/care work', which were also the most prevalent fields of qualifications that the workforce already held. Psychology/counselling (11 per cent) and social work (9 per cent) were also popular fields of current study, yet among the workforce only seven per cent, and six per cent of workers respectively held qualifications in these fields.

In addition to formal education, most (88 per cent) employees reported that they had undertaken at least one type of training during the previous 12 months (from Question B10, table not shown). The training might have been provided internally or externally, but at a minimum it required that the employee be given time off normal duties to attend the training.

Table 4.27: The field of study currently studying for

	%
Not currently studying	78.9
Studying	20.6
Question not answered	0.5
Total (N=2,133)	100
Of those studying:	%
Social work	9.0
Disability/disability studies	24.6
Nursing	3.8
Psychology/counselling	10.5
Community work/community services/welfare services/care work	14.7
Youth work/youth services	0.6
Children's services	1.1
Allied health (e.g. physiotherapy, podiatry, speech pathology)	4.2
Administration	1.7
Business/business management	7.4
Law/legal studies	1.5
Information Technology	0.6
Other	17.0
Question not answered	3.4
Total (N=476)	100

Source: 2014 NDIS DSP employee survey, Questions A8a and A8c.

# 4.3.3 Main characteristics of the disability services work

In this section the structural features of disability services work (working conditions, career paths and experiences of working in the sector) are described.

## **Working conditions**

The employment arrangements and hours worked within the disability sector are indicators of the level of flexibility required by employers and employees.

Table 4.28 reflects the reported headcount of DSP PAYG employees that provide disability care or support to users. It is important to note that these figures do not include outlet employees that do not provide direct disability support, such as clerical or maintenance staff, unpaid staff, or non-

PAYG staff such as agency or self-employed workers (for total payroll employees of outlets see Table 4.1).

The types of employment arrangements of PAYG employees reported by managers indicate about two thirds of disability support workers (64 per cent) were employed on permanent terms. A significant proportion of disability support workers (29 per cent) were employed on a casual basis. This casual employment share is higher than the corresponding figures for the whole Australian workforce (22 per cent, HILDA 2014). There were also fewer permanent staff in disability support than in the aged care workforce of 2012 (36 per cent of disability support workers were casual or fixed term compared to 27 per cent of community and 19 per cent of residential aged care workers, King et al. 2013).

Table 4.28: Form of employment of the PAYG disability support workforce

	Per cent of employees reported		
	by outlet managers		
Permanent	63.8		
Fixed-term	7.5		
Casual	28.7		
Number of employees	33,577		

Source: 2014 NDIS DSP outlet survey, Question B5.

Notes: 665 Outlet managers responded to this question. Calculations based on headcount number of employees reported with permanent ongoing employment with paid annual and sick leave; fixed term contracts of limited duration with paid annual and sick leave; casual workers without paid leave entitlements.

The current and preferred work schedule for employees is shown in Table 4.29. Amongst those employees who supplied information on their work schedule, slightly more than 80 per cent were employed on regular daytime shifts. The distribution of the preferred work schedule appeared similar to that for the current work schedule, though fewer employees preferred an irregular schedule and more preferred a regular daytime shift. The first three rows of Table 4.29 suggest an unmet demand for regular shifts against irregular schedules, as 83.1 per cent were currently in regular shifts against 88 per cent who would prefer to be in regular shifts.

Table 4.29: Current and preferred work schedule

	Current work schedule	Preferred work schedule
	%	%
A regular daytime shift	81.9	85.2
A regular evening shift	0.9	1.7
A regular night shift	0.3	1.1
A rotating shift (predictable changes of time)	6.0	6.2
A split shift (two distinct periods per day)	1.8	1.0
On call	1.0	0.6
An irregular schedule (unpredictable changes of time)	6.8	2.1
Other	1.4	2.1
Total	100	100
Number of employees answering	1,879	1,748

Source: 2014 NDIS DSP employee survey (N=2,133), Question B7.

Table 4.30 considers what hours the employees currently worked and would like to work. While the majority of workers (around 70 per cent) worked between 16 to 40 hours a higher proportion of employees (86 per cent) would have preferred to work these hours. Very low proportions of workers preferred to work 1 to 15; or 40 hours or more.

Table 4.30: Total working hours per week and preferred total work hours per week (per cent)

	Total working hours per week	Preferred hours per week
1 to 15 hours	6.4	4.6
16 to 34 hours	31.9	38.8
35 to 40 hours	36.9	47.5
40 or above hours	23.5	6.8
Question not answered	1.3	2.3
Total (N=2,133)	100	100
Mean	35.8	34.0
Median	38.0	35.0

Source: 2014 NDIS DSP employee survey, Questions B2a and B2b.

Note: The calculations for 'Total working hours per week' are based on 2106 employees who reported at least 1 hour of work in a normal week; the calculations for 'Preferred hours per week' are based on 2085 employees who reported at least 1 hour of work per week as preferred hours per week. Groups of hours in the following table formed from reported number of hours. The mean and median values are calculated from the raw data, not the grouped intervals shown in the table.

Table 4.31 indicates that overall, the disability workforce was somewhat over-employed, i.e. the total actual working hours were larger than preferred hours. Only 38 per cent of workers were happy with the hours they currently work (i.e. preferred the same hours). The proportion that was happy with their hours was much lower than that reported for the general Australian workforce (60 per cent, HILDA 2014) and also lower than that reported for the aged care workforce in 2012 (49 per cent for community care workers and 56 per cent for residential care workers, King et al. 2013). Almost double the number of workers preferred to work fewer hours (40 per cent) compared to those who preferred to work more hours (21 per cent). This is mainly driven by the large proportion—almost a quarter—who reported working 40 or more hours per week: only 7 per cent said that they wanted to work this many hours. Despite the high prevalence of 'over work', for the whole workforce there was only a small difference in the average hours that people said they wanted to work (34), and the average hours that they did work (36). This arises because, while many people who worked long hours (more than 40) wanted to work fewer hours, many people who worked short hours (less than 35) wanted to work more hours. This suggests that there was an imbalance between actual and desired hours.

Table 4.31: Total working hours per week against preferred total work hours per week

	%
Prefer more hours	21.5
Prefer the same hours	38.3
Prefer less hours	40.2
Total (N=2,065)	100

Source: 2014 NDIS DSP employee, Questions B2a and B2b.

The calculations are based on 2,065 cases who reported both 'Total working hours per week' and 'Preferred hours per week'.

### **Earnings**

Table 4.32 reports calculations of the reported employee weekly earnings before tax by occupation. Workers in professional or managerial occupations (service or program administrator/manager/coordinator, social worker/disability case coordinator and allied health worker) earned much higher pay than care/support workers (personal care/home care worker; disability support/residential support worker; employment support worker; peer support worker). Personal care/home care workers had the lowest reported average and median wage, and their average earnings were considerably lower than the pay conditions reported for other occupations. The table reports weekly earnings, and that 38 per cent of the workforce worked part-time. The similarity of the mean and the median suggests that there was not a substantial tail of either very low or very high reported earnings.

Table 4.32: Weekly earnings before tax by occupation

	Mean \$	Median \$	Number of workers
Disability support/residential support worker	787	800	596
Personal care/home care worker	610	600	122
Service or program administrator/manager/coordinator	1,073	1,073	470
Social worker/disability case coordinator	1,041	1,006	165
Employment support worker	832	886	42
Peer support worker	776	873	27
Allied health worker	1,036	1,036	206
Other	1,002	980	237
Total	926	920	1,865

Source: 2014 NDIS DSP employee, Questions B4a and B4b.

Notes: The weekly earnings mean and median are calculated for zero to \$10,000 per week reported earnings to exclude outliers. Weekly figures calculated from reported job role, most recent pay and pay period. Entries rounded to the nearest dollar.

Table 4.32 confounds hours worked with wages, in that people who work longer hours would have higher earnings, principally because they worked longer, not because their work was valued more. There are several reasons why this distinction is pertinent in the context of the NDIS rollout. First, wages are a very accurate market signal of how the labour market moves, and in the context of the NDIS it is important to know in which direction wages are moving. Second, part-time employment can be an indication of excess or underutilised capacity, which is important to know in the context of potential increases in demand for services. To understand this difference Table 4.32 has been split into Tables 4.32a (full time employed) and 4.32b (part-time employed) and presents the earnings of the two groups of employees.

Table 4.32a: Weekly earnings before tax by occupation, full-time employees

	Mean \$	Median \$	Number of workers
Disability support/residential support worker	950	903	286
Personal care/home care worker	767	800	27
Service or program administrator/manager/coordinator	1,160	1,150	369
Social worker/disability case coordinator	1,098	1,100	126
Employment support worker	920	969	31
Peer support worker	913	954	16
Allied health worker	1,189	1,172	128
Other	1,210	1,117	141
Total	1,090	1,046	1,124

Source: 2014 NDIS DSP employee, Questions B2a, B4a and B4b.

Notes: The weekly earnings mean and median are calculated for zero to \$10,000 per week reported earnings to exclude outliers. Weekly figures calculated from reported job role, most recent pay and pay period. Entries rounded to the nearest dollar.

Table 4.32b: Weekly earnings before tax by occupation, part-time employees

	Mean \$	Median \$	Number of workers
Disability support/residential support worker	635	650	305
Personal care/home care worker	566	535	94
Service or program administrator/manager/coordinator	752	729	100
Social worker/disability case coordinator	843	826	36
Employment support worker	583	600	11
Peer support worker	378	600	11
Allied health worker	773	793	75
Other	686	674	93
Total	672	670	725

Source: 2014 NDIS DSP employee, Questions B2a, B4a and B4b.

Notes: The weekly earnings mean and median are calculated for zero to \$10,000 per week reported earnings to exclude outliers. Weekly figures calculated from reported job role, most recent pay and pay period. Entries rounded to the nearest dollar.

Further analysis of the Wave 1 information using multivariate methods would increase understanding (e.g. are part-time employees happy with the hours they work? Are there significant occupational differences by part/full time?). However, the most important information will become available with the arrival of Wave 2 data where it will be possible to observe change in both earnings and part/full time status between Wave 1 and Wave 2 employees. This change will give a measure of the impact of the NDIS on the relevant workforce structure.

### 4.3.4 Career paths

Table 4.33 indicates the current disability support workforce came into the sector through very diverse pathways. Disability support was the first sector of employment for only six per cent of the employees. A significant proportion of employees reported that they had previously worked in very different sectors (e.g. salesperson, clerical or administrative worker, hospitality worker). In contrast, a very small proportion had previously worked in a different health or social care sector (e.g. welfare worker or aged care). Reflecting this diversity in pathways, 29.1 per cent of all respondents chose the 'other paid employment' category as their preferred response. Only 7 per cent said that their previous job was in aged care. This suggests that there was a surprisingly small

overlap between two of the main sectors of care employment. The diverse pathways into disability care imply that there is quite a wide scope for expanding employment in disability services as the sector did not appear to rely on a narrow pipeline of potential workers.

Table 4.33: Last paid job before started working in the disability support sector

	%
No previous paid employment	6.1
Welfare worker in another setting (e.g. counsellor, social worker)	6.9
Aged care worker	6.5
Carer in another setting (e.g. personal care attendant)	2.5
Salesperson	8.6
Teacher	4.6
Clerical or administrative worker	9.6
Hospitality worker (e.g. chef)	10.4
Cleaner	1.6
Professional or manager in another setting	9.2
Other paid employment	29.1
Question not answered	4.9
Total (N=2,133)	100

Source: 2014 NDIS DSP employee survey, Question C4.

The age at which employees started work in disability support is shown Table 4.34. A high proportion of disability care workers started working in the sector at a middle stage in life with about half 30 years or older when they joined the sector. The disability sector therefore appears to be an attractive work environment for older people, including those with previous experience in other fields. This may also reflect the high formal qualifications level held by employees if work started after these qualifications were achieved.

Table 4.34: Age at which began working in the disability support sector

	%
21 or under	19.7
22 to 29	28.3
30 to 39	21.8
40 to 49	19.5
50 or above	8.7
Question not answered	1.9
Total (N=2,133)	100

Source: 2014 NDIS DSP employee survey, Question C2.

Note: Column per cent is shown.

The desire to help others and to do something worthwhile were the dominant reasons for working in the disability support sector (Table 4.35). Around three quarters of workers cited these two factors as key motivations. A number of other work characteristics in the sector, such as, work being valued and appreciated, variety in tasks and learnings, training and the application of skills were also reported as significant reasons for wanting to work in the sector. The traditional concerns of job security and attractive pay were not among the most important sources of motivation for working in disability care. Pay was reported as the least important factor for employees choosing to work in this sector, with only 16.6 per cent of workers citing it as an important motivating factor. The suggestions emerging from Table 4.35 are that people worked in this sector despite the pay

and conditions, rather than because of them and that they were primarily motivated by the opportunity this sector gave them to do a worthwhile and valued job.

Table 4.35: Reasons to work in the disability support sector

	%
Desire to help others	79.5
Desire to do something worthwhile	72.1
Work being valued and appreciated	41.4
Supportive co-workers and management	25.0
Flexibility in working hours or shifts	30.3
Independence/autonomy and responsibility in work	31.5
Variety in tasks	42.9
Learnings, training and the application of skills	41.7
Job security	22.7
Pay	16.6
Career prospects	26.1
Other	9.0
Total (N=2,133)	

Source: 2014 NDIS DSP employee survey, Question C3.

Note: Multiple responses allowed, column will not sum to 100.

Table 4.36 examines the reasons employees gave for leaving their last job in disability support, if they had held other paid disability support sector jobs. A house or location move appears to be the most prevalent reason why they left the previous job in this sector (17.2 per cent). A variety of work conditions and work roles, e.g. a desire to find more challenging work, to achieve higher pay, the job was too stressful, contract ended or funding ceased, getting the working hours or shifts they wanted and avoiding managers they did not get along with, are also factors contributing to the churn within the sector. Given the strong motivation to care that respondents reported, it is encouraging to see that very few reported not having enough time with service users as their main reason for wanting to change employer.

Table 4.36: The main reason for leaving one's last job in the disability support sector

	%
To achieve higher pay	8.4
To avoid co-workers I did not get along with	0.9
To avoid managers I did not get along with	5.6
The job was too stressful	8.4
Not able to spend enough time with service users	1.4
To get the working hours or shifts I wanted	6.7
To be closer to home	4.7
To fulfil caring responsibilities (including having children)	3.7
To find more challenging work	13.0
To find easier work	0.5
Made redundant or retrenched	4.7
Contract ended or funding ceased	8.1
Moved house or location	17.2
Other	17.2
Total (N=917)	100

Source: 2014 NDIS DSP employee survey, Question C10. Of the 2,133 cases, 761 were not in the sector in their previous job and 454 did not answer the question.

Table 4.37 shows three different measures of length of experience in the disability sector. The first column reports the answer to the question 'For how many years in total have you worked in the disability support sector?' The second column shows how many years people have worked for their current employer. The third column shows how many years people have worked in their current job and for their current employer. There is a clear and unsurprising pattern. By definition, people had worked longer in the sector than they had for their current employer, and longer for their current employer than in their current job (the question is by how much). Over one third (38 per cent) had worked in the sector for 10 years or more while less than half that proportion (15 per cent) had done the same job for that length of time. Table 4.37 shows that there was some movement between employers and between jobs, within the disability support sector: while 34 per cent had been in the sector for less than 5 years, 59 per cent had been in their current job for less than 5 years.

Table 4.37: Tenure with current employer and tenure in current job

	Tenure in the sector %	Tenure with current employer %	Tenure in current job %
1 year or less	11.1	16.7	26.2
2 to 4 years	22.4	33.1	33.1
5 to 9 years	26.9	25.1	24.0
10 or more years	38.1	20.8	14.6
Question not answered	1.6	4.3	2.1
Total (N=2,133)	100	100	100

Source: 2014 NDIS DSP employee survey, Questions C1, C5 and C6.

Table 4.38 shows that only 13 per cent of disability support workers were looking to leave their current position and were actively seeking work with another employer. For a roughly similar question content, in the Aged Care 2012 survey of community direct care workers a roughly similar share (82 per cent) were expecting to be working in aged care, in the same outlet, in 12 months.

Table 4.38: Whether actively seeking work with another employer

	%
No	85.8
Yes	12.9
Question not answered	1.3
Total (N=2,133)	100

Source: 2014 NDIS DSP employee survey, Question C8.

Table 4.39 shows that the majority of workers (72.4 per cent) expected to be working for their current employer in 12 months' time, although 10.2 per cent of them intended to change their job with the same employer. Of the remaining, 13.4 per cent were unsure what they will be doing in a year. Around six per cent of the workforce intended to look for work with a new disability service employer. Tables 4.38 and 4.39 show a high level of stability in the workforce. Only five per cent expected to leave the sector in the coming year to work elsewhere and almost none stated that they expect to retire in the next 12 months, despite the fact that 18.5 per cent of the respondents were above the age of 55 (see Table 4.19).

Table 4.39: Expected activity in 12 months' time of the disability support workforce

	%
With the same employer as now, and in the same job	62.2
With the same employer, but in a different job	10.2
In the disability support sector, but with a different employer	5.8
In the paid-care sector, but not in the disability support sector	1.2
In a different area of work altogether	4.9
Not in paid employment at all	0.9
Unsure	13.4
Question not answered	1.5
Total (N=2,133)	100

Source: 2014 NDIS DSP employee survey, Question C9a.

# 4.3.5 Experiences of working in disability support

Table 4.40 shows that overall disability support workers were highly satisfied with their job. They were particularly satisfied with the work itself and the sense of achievement they got from it. Workers were least satisfied with pay and job security with an average score of 6.1 and 6.6 respectively (in a 1-10 Likert scale). This is consistent with the information in Table 4.35 which shows that people were not motivated to work in disability care by the pay or job security that it offered. They were reasonably satisfied with all other factors of the job, although a significant proportion (14 per cent) had concerns about their opportunities to develop skills and abilities.

Table 4.40: Job satisfaction [1-10 dissatisfied/satisfied scaling] (per cent)

	Dissatisfied		Satisfied	Question not	
	1 to 4	5 to 6	7 to 10	answered	Mean
The sense of achievement you get from your work	4.7	10.2	84.2	0.9	8.1
Your total pay	26.4	22.6	50.1	0.9	6.1
Your job security	21.2	21.2	56.3	1.4	6.6
The work itself (what you do)	4.0	10.9	83.9	1.2	8.2
The hours you work	11.5	16.8	70.0	1.6	7.4
The match between your work and your qualifications	10.2	17.2	71.5	1.0	7.4
The opportunity to develop your skills and abilities	14.2	18.8	66.1	0.9	7.2
The level of support from your team/employer	11.5	13.0	74.7	0.8	7.6
The flexibility available to balance work and non-work commitments	11.3	14.1	73.8	0.8	7.6
All things considered (i.e. the job overall)	3.9	13.1	82.1	0.8	8.0

Total (N=2,133)

Source: 2014 NDIS DSP employee survey, Question B12.

Note: Row percentages are shown.

Table 4.41 reports employee opinions of their work. The disability support workforce agreed that they had 'sufficient skills and abilities to do the job' and that the job 'used many of their skills and abilities' with an average score of 6.0 and 6.1 (out of 10) respectively. Also, a large proportion reported that they had a higher qualification than required for the job (42 per cent, which was higher than the norm of between 20 and 30 per cent). Two thirds of workers believed that they received adequate training. The average scores for the statements on pressure ('I feel under pressure to work harder in my job', mean 3.9) and stress ('my job is more stressful than I had ever imagined', mean 3.6) were slightly below 4 indicating disagreement on average, however a large proportion of workers felt they were under pressure (38 per cent) and stressed (30 per cent). About

60 per cent of workers agreed that they had 'enough time with each person accessing supports' and 'adequate continuity of contact with each person accessing supports'. About two thirds of workers agreed that they had 'a lot freedom to do their work' and receive respect and acknowledgment ('I get the respect and acknowledgement I deserve for my efforts and achievements'). The disability care workforce showed a high level of loyalty and pride in their workplace, with an average score of 5.7 ('I feel loyal to this organisation') and 5.9 ('I am proud to tell people who I work for') respectively.

Table 4.41: Opinions about aspects of work [1 to 7 disagree/agree scaling] (per cent)

	Disagree		Agree	Question not	
	1 to 3	4	5 to 7	answered	Mean
I spend enough time with each person accessing supports	19.4	17.8	60.3	2.5	4.8
I have adequate continuity of contact with each person accessing supports	16.5	18.8	62.0	2.7	4.9
I have the skills and abilities I need to do my job	2.0	5.9	90.7	1.4	6.0
I use many of my skills and abilities in my job	2.1	4.9	91.0	2.0	6.1
I have a higher qualification than the one required for my job	36.2	19.7	42.0	2.2	4.1
I have a lot of freedom to decide how I do my work	14.9	17.6	66.0	1.5	5.0
I feel under pressure to work harder in my job	39.1	21.5	37.9	1.5	3.9
My job is more stressful than I had ever imagined	47.4	21.1	30.1	1.5	3.6
I get the respect and acknowledgement I deserve for my efforts and achievements	18.5	16.4	63.7	1.4	4.9
Adequate training is available through my workplace	17.8	14.3	66.4	1.5	5.0
I feel loyal to this organisation	7.5	11.5	79.8	1.2	5.7
I am proud to tell people who I work for	5.7	9.6	83.4	1.3	5.9

Total (N=2,133)

Source: 2014 NDIS DSP employee survey, Question B11.

Note: Row percentages are shown.

Table 4.42 shows that only 38 per cent of workers spent more than two thirds of their shift actively caring for people. About 30 per cent of workers spent more than two thirds of their shift on administration tasks. The high levels of job satisfaction reported in Table 4.41 coupled with a clear division of labour reported in Table 4.42 suggest that administrative and direct care work was distributed among employees in accordance with their preferences without imposing excessive burden to them.

Table 4.42: Time allocation in current disability support job

	Actively caring for people	Administration tasks
	%	%
Less than one-third of your time	27.5	39.2
Between one-third and two-thirds of your time	25.8	24.1
More than two-thirds of your time	38.0	29.5
Question not answered	8.7	7.2
Total (N=2,133)	100	100

Source: 2014 NDIS DSP employee survey, Question B8a.

Note: Column percentages are shown.

Table 4.43 examines relationships between workers and their managers, co-workers and service users. It shows that more than 90 per cent of workers thought the relationships between employees and clients were particularly good. Most workers also reported very good relationships with their co-workers, with three quarters of staff also having positive relationships with their managers.

Table 4.43: Relationship between the following groups in the outlet [1 to 7 bad/good scaling] (per cent)

	Bad 1 to 3	4	Good 5 to 7	Question not answered	Mean
		<u> </u>			
Employees and their manager	12.1	12.7	74.3	0.9	5.3
Employees and their co-workers	4.5	8.7	85.7	1.2	5.7
Employees and the people for whom they provide care and support	1.2	4.8	92.7	1.3	6.0
Total (N=2,133)					

Source: 2014 NDIS DSP employee survey, Question B13.

Note: Row percentages are shown.

# 4.3.6 A brief summary of the nature of the disability support workforce

The information provided by employees presents a positive picture. The workforce was highly educated – mostly with relevant qualifications - healthy, fluent in English, with a good distribution of different ages and, while it was predominantly female, it had a sizeable representation of men. From a workforce planning perspective, it drew on a wide demographic. It is also helpful that people working in the sector came from a wide range of previous occupations. Both these factors suggest that there could be a substantial pool of people currently working in other areas of the economy who could potentially be attracted into disability care. The workforce placed a strong emphasis on job satisfaction as a motivation and less on pay, job security and opportunities for promotion. The distinctive caring character of the job might be one reason why intention to leave, for both the job and the occupation, was quite low. Of note, only six per cent of employees came to disability care from aged care: they seemed to be quite distinct work forces.

Employees had a high level of confidence in their ability to do their job well, get on well with their co-workers and very well with their clients; they were not quite so happy with their managers. Fully 83 per cent agreed that 'they are proud to tell people who they work for'. About 39 per cent reported feeling under pressure to work even harder and 42 per cent believed that they were overqualified for their job.

# 4.4 Initial findings for self-employed DSP

#### 4.4.1 Introduction

This section provides an overview of self-employed providers of disability care and supports using the data from 272 respondents to the 2014 NDIS DSP survey of self-employed providers. It looks at their role as independent businesses and employers, as well as their experience as workers within their own businesses. Surveys were sent to 495 DSP self-employed providers and valid responses were received by 272 of them (a 54 per cent response rate). Self-employed provider networks of independent care workers reflect self-employed workers with their own ABN.

# 4.4.2 A profile of self-employed DSP

To understand the self-employed component of the disability workforce, it is important to appreciate that overwhelmingly they were professionals. As shown in Tables 4.51 and 4.52 later, 93 per cent had a Bachelor degree or above; 71 per cent had their highest qualification in allied health and 13 per cent had their highest qualification in psychology/counselling.

Table 4.44 shows the location of the self-employed providers and whether they were located within an NDIS trial site. Amongst the 272 providers surveyed, nearly a third were from Victoria (32 per cent), followed by a quarter in New South Wales (24 per cent) and in Queensland (23 per cent), and about a fifth in South Australia (18 per cent). Very few in the sample were servicing Tasmania or the Australian Capital Territory. This table also shows that slightly under half of the surveyed self-employed service providers (43 per cent) were servicing NDIS trial areas, which was a very different picture to that found for NDIS participating outlets (Table 4.1, 29 per cent).

Table 4.44: Distribution of self-employed providers by state and region

	%
New South Wales	23.9
Hunter region of New South Wales	8.8
Rest of New South Wales	15.1
South Australia	18.0
Tasmania	2.2
Victoria	32.0
Barwon area of Victoria	13.2
Rest of Victoria	18.8
Australian Capital Territory	0.7
Queensland	23.2
Total (N=272)	100

Source: 2014 NDIS self-employed DSP survey.

Table 4.45 shows the number of employees hired by the self-employed providers. Nearly three quarters of the self-employed worked as the sole trader for their businesses (74 per cent). One in ten hired one employee, and one in six (16 per cent) had more than one employee working for them.

As expected, in comparison to outlets, the self-employed businesses were very small in size, with 83 per cent of them hiring zero or one employee. In comparison the vast majority of the 697 outlets surveyed (82 per cent) had 5 or more employees, with only 16 per cent hiring zero to four

employees (see Table 4.2 in the Outlet Section). In some cases, the self-employed worked as independent contractors for outlets. As seen in Table 4.13, 6 per cent of outlets engaged one or more self-employed allied health workers.

Table 4.45: Number of employees of self-employed providers

Total (N=272)	100
Question not answered	0.7
More than 1	15.8
1	9.9
0	73.5
	%
	%

Source: 2014 NDIS self-employed DSP survey, Question B5a.

Table 4.46 shows the proportion of self-employed businesses providing certain types of disability support. Providers were asked to report on all types of services delivered. The most common were therapeutic services (79 per cent) and early intervention (70 per cent), while accommodation support (2 per cent), respite (1 per cent) and employment (1 per cent) were the least commonly provided. This reflects the allied health and psychology/counselling specialisation among the self-employed sample. In contrast outlets surveyed had a more even distribution over service types (see Table 4.3).

Table 4.46: Self-employed DSP types of disability support provided

	%
Accommodation support	1.5
Personal support	8.8
Community access	2.9
Respite	0.7
Employment	0.7
Advocacy, information and alternative forms of communication	11.4
Early intervention	70.2
Aids and equipment	23.5
Therapeutic services	79.4
Other	13.6
Total (N=272)	

Source: 2014 NDIS self-employed DSP survey, Question B7.

Note: Multiple responses allowed.

Table 4.47 focuses on the primary disability types and the age of the clients of the self-employed providers. The services were not evenly distributed across the ten listed disability types. Three out of four self-employed providers (76 per cent) catered to clients with developmental problems. In contrast, services for people with psychiatric disability were least commonly provided with one in ten providers (10 per cent) tending to this group of clients.

The self-employed providers particularly cared for children, with a concentration on 0-4 years old (74 per cent) and 5-14 years old (80 per cent). As the clients' age increased, the self-employed were less likely to provide services for these groups: only 29 per cent of providers catered to clients who were aged 65 years or older. This pattern also applied to the individual disability types, with the exception of psychiatric disability. It is recognised that the high level of early intervention may be due to the particular shape of the NDIS rollout, especially the very young children rollout in South Australia. Again this contrasts to outlets, where there was smaller variation in the proportions that provided services across each disability type. In addition, the services were most commonly

provided for people aged 25-64 in the outlets (77 per cent), and not as commonly for the old and the very young, with 42 per cent of outlets providing services for those 65 years or older, and 38 per cent of outlets providing services for 0-4 year olds. The question that arises from the comparison between outlets and self-employed is the degree to which the differences observed may be due to the possibility that the self-employed may find it easier to respond to increased demand by moving to the NDIS trial sites, than whole establishments would. The second Wave of data collection will shed light to such considerations.

Table 4.47: Primary disability types and ages of the current users of the business's disability supports of self-employed providers (per cent)

Primary disability type	0 to 4 years	5 to 14 years	15 to 24 years	25 to 64 years	65+ years	Users with this disability of any age
Physical	30.5	34.2	15.4	16.2	12.5	46.0
Mental health/psychosocial	22.4	29.8	18.0	12.5	9.9	38.2
Psychiatric	2.6	5.1	6.6	6.3	5.9	9.9
Hearing	13.6	13.2	2.6	1.1	2.6	20.6
Speech	40.4	40.8	15.4	10.7	9.9	46.3
Visual	10.7	9.9	2.6	1.8	2.9	13.2
Developmental	66.2	66.5	20.2	8.5	5.1	75.7
Other learning or intellectual	48.2	53.3	27.6	12.5	7.0	62.1
Neurological, including acquired brain Injury	29.4	29.0	19.9	20.6	15.4	47.1
Congenital or inherited conditions	46.3	46.7	22.4	15.4	9.6	56.6
Users with any type of disability for this age	74.3	79.8	44.5	35.7	28.7	

Source: 2014 NDIS self-employed DSP survey, Question B9.

Note: Multiple responses allowed.

About half of the self-employed providers in the disability sector were aged 44 or above (Table 4.48: The median age of 44 years for self-employed providers is similar to that of 43 years for outlet employees).

Extremely few of the self-employed were aged less than 24 years compared to 7 per cent of employees. This reflects at least in part the high levels of education and work experience possessed by the self-employed service providers.

Table 4.48: Age distribution of self-employed providers of disability care and supports

	%
16-24	0.4
25-34	18.4
35-44	33.1
45-54	29.8
55-64	15.8
65 or above	2.6
Total (N=272)	100
Median (years)	44

Source: 2014 NDIS self-employed DSP survey, Question A2.

The vast majority of self-employed providers (80 per cent) were Australian born (Table 4.49). Among those who were born overseas, most were from English speaking countries. The patterns for country of birth are similar to that for employees. Even more than employees, the self-employed were native born or if migrants, had been in Australia a long time; this was not a workforce that draws on recent migrants. Virtually all reported very good English language skills (Table not shown).

Table 4.49: Country of birth self-employed providers of disability care and supports

	%
Australia	80.1
UK	5.5
South Africa	2.6
New Zealand	1.8
Other	9.9
Total (N=272)	100

Source: 2014 NDIS self-employed DSP survey, Question A3.

More than 80 per cent of self-employed providers reported they were in excellent or very good health (Table 4.50), which was higher than that of employees (67 per cent), the general Australian workforce (55 per cent, HILDA 2014) and the aged care workforce of 2012 (around 60 per cent<sup>29</sup>). Ten per cent of self-employed providers reported their day-to-day activities limited a little because of a health problem or disability that had lasted or was expected to last at least 12 months, but none indicated the existence of significant limitations.

Table 4.50: Self-reported general health of self-employed providers of disability care and supports

	%
Excellent	46.7
Very good	34.6
Good	15.8
Fair	2.6
Poor	0.0
Question not answered	0.4
Total (N=272)	100

Source: 2014 NDIS self-employed DSP survey, Question A11.

Virtually all self-employed providers reported formal post-school qualifications (Table 4.51). An extremely high share of self-employed (93 per cent) had a university degree in contrast to 40 per cent for employees (shown earlier in Table 4.24). This reflects the formal qualification requirements for allied health and psychology roles which the majority performed. A low share (18 per cent) had a vocational qualification compared to 63 per cent for employees. The vast majority (90 per cent) of self-employed providers completed their highest qualification in Australia.

\_

<sup>&</sup>lt;sup>29</sup> King et al.(2013)

Table 4.51: Level of qualifications completed of self-employed providers of disability care and supports

	%
Postgraduate degree	29.8
Bachelor degree	76.1
Diploma or advanced diploma	13.2
Certificate IV	7.0
Certificate III	2.2
Certificate I or II	2.6
Other	5.5
No formal qualification	1.1
Bachelor degrees and above	93.0
Diplomas and Certificates	18.0
Other	5.5
No formal qualification	1.1
Total (N=272)	

Source: 2014 NDIS self-employed DSP survey, Questions A7a and A7b.

Note: Multiple responses allowed.

Table 4.52 shows that more than 80 per cent of self-employed providers had qualifications in either 'allied health' (71 per cent) or 'psychology/counselling' (13 per cent). These were also the qualifications that were most relevant for their work.

This was quite different from the diversity for outlet employees. Only 11 per cent of employees had allied health or psychology/counselling as their highest qualification (see Table 4.25). The top two prevalent fields of study for outlet employees were 'Disability/Disability Studies' and 'Community Work/Community Services/Welfare Services/Care Work', which accounted for one third of their qualifications. These differences suggest that the outlets and self-employed providers offered different services.

Table 4.52: Field of study of the highest and the most relevant qualification of self-employed providers of disability care and supports

	Highest qualification	Most relevant qualification
	%	%
Social work	1.5	1.8
Disability/disability studies	1.5	1.5
Nursing	0.7	0.4
Psychology/counselling	12.9	12.9
Community work/community services/welfare services/care work	0.4	0
Allied health (e.g. physiotherapy, podiatry, speech therapy)	71.0	76.5
Business/business management	1.5	0.4
Other	8.5	4.4
Question not answered	1.5	1.1
Not applicable	0.7	1.1
Total (N=272)	100	100

Source: 2014 NDIS self-employed DSP survey, Questions A7d and A7e.

Table 4.53 shows that on average, self-employed providers worked fewer hours than employees (mean of 32.2 against 35.8 for employees). Also compared to employees (Table 4.30), they were much more likely to have worked short hours (1-15), with 19.1 per cent against only 6 per cent for employees. More than 50 per cent of self-employed providers worked part-time (<35 hours a week) and 19 per cent worked for 15 hours or less. A large proportion of self-employed (28 per cent) worked for 40 hours or more a week and a relatively small proportion (16 per cent) worked for 35-40 hours a week.

Table 4.53: Self-employed DSP normal weekly working hours in the business

%       1 to 15     19.1       16 to 34     36.4       35 to 40     16.2       40 or above     28.3       Total (N=272)     100       Hours       Mean     32.2       Median     30.0		
16 to 34       36.4         35 to 40       16.2         40 or above       28.3         Total (N=272)       100         Hours         Mean       32.2		%
35 to 40 16.2 40 or above 28.3 Total (N=272) 100  Hours  Mean 32.2	1 to 15	19.1
40 or above       28.3         Total (N=272)       100         Hours         Mean       32.2	16 to 34	36.4
Total (N=272)         100           Hours         32.2	35 to 40	16.2
Mean Hours 32.2	40 or above	28.3
Mean 32.2	Total (N=272)	100
		Hours
Median 30.0	Mean	32.2
	Median	30.0

Source: 2014 NDIS self-employed DSP survey, Question C5.

The self-employed providers reported mean and median weekly gross income are shown in Table 4.54. The median shows that half of the reported incomes were lower than \$627 a week, however the mean was higher at \$939 because a significant proportion of self-employed providers recorded much higher incomes.

Table 4.54: Self-employed DSP Weekly gross income

	Weekly gross income \$
Mean (N=247)	939.3
Median (N=247)	627.9

Source: 2014 NDIS self-employed DSP survey, Question B11.

Note: this is based on 247 self-employed people who provided a valid answer (i.e. a number that equals to or greater than 0) and their reported income was not over \$10,000 a week. 4 observations with reported income over \$10,000 per week are excluded.

Table 4.55 reflects the age at which self-employed providers started working in disability support. Most self-employed providers started working in the sector when they were less than 30 years of age. This was different from employees, of whom a large proportion joined the sector at a middle stage in life. It is likely that many of the 29 per cent who started work in the sector at age 21 years or less did so while they were also studying to get their professional degree.

Table 4.55: Age at which self-employed providers began working in the disability support sector (per cent)

	%
21 or under	29.4
22-29	49.3
30-39	9.9
40-49	7.7
50 or above	2.2
Question not answered	1.5
Total (N=272)	100

Source: 2014 NDIS self-employed DSP survey, Question C2.

The number of years that self-employed providers had been working in the disability support sector is shown in Table 4.56. The large majority of providers (around 80 per cent) had been working in the sector for 10 years or more. Fewer than 10 per cent had been working in the sector for less than 5 years. Self-employed providers, on average, had much longer experience in this sector than employees. The picture that emerges was one where few newcomers were present, with 8.8 per cent of the current workforce having joined the sector in the last four years. This was not the picture of change that may be necessary in preparation for a large rollout of new services.

Table 4.56: Total number of years spent working in the disability support sector by self-employed providers

%
2.9
5.9
13.6
20.2
15.1
41.5
0.7
100

Source: 2014 NDIS self-employed DSP survey, Question C1.

Table 4.57 considers the reasons these providers had for undertaking a self-employed disability support role. 'To achieve greater control/autonomy over work' was the dominant reason for becoming a self-employed provider of disability supports (24 per cent). Some also reported seeking higher pay, more discretion over time use and the ability to spend more time with clients. The future analysis of this information will consider asking the self-employed whether they would have preferred to be an employee but could not, hence they became self-employed.

Table 4.57: The main reason for becoming a self-employed provider of disability supports

	%
To achieve a higher income	7.4
To avoid managers I did not get along with	1.1
Previous job was too stressful	0.7
To be able to spend more time with service users	7.4
To get the working hours or shifts I wanted	4.8
To achieve greater control/autonomy over my work	23.5
To achieve greater flexibility in time management	7.7
To be closer to home	2.6
To find more challenging work	2.2
Made redundant or retrenched	0.4
Contract ended or funding ceased	0.7
Other	9.2
Question not answered	32.4
Total (N=272)	100

Source: 2014 NDIS self-employed DSP survey, Question C4.

Table 4.58 shows that even more than for employees, the 'desire to help others' and 'desire to do something worthwhile' were the dominant reasons for self-employed providers working in the disability support sector with more than three quarters of providers citing these two factors for working in the sector. It is interesting to note that pay, job security and career prospects were even less motivating for the self-employed than they were for employees. Again results show the strong motivation to do work that was valued and worthwhile, rather than to gain the more material aspects of employment.

A number of other work characteristics, such as, work being valued and appreciated, variety in tasks and learnings, training and the application of skills were also reported as significant reasons to work as a self-employed provider in the disability sector. Almost all self-employed providers (97 per cent) expected to still be doing the same sort of work 12 months from now (Table not shown).

Table 4.58: Reasons for self-employed providers to work in the disability support sector

	%
Desire to help others	83.1
Desire to do something worthwhile	76.5
Work being valued and appreciated	51.8
Supportive co-workers and management	14.3
Flexibility in working hours or shifts	22.1
Independence/autonomy and responsibility in work	35.3
Variety in tasks	46.0
Learnings, training and the application of skills	44.9
Job security	15.1
Pay	10.7
Career prospects	18.4
Other	7.4

Source: 2014 NDIS self-employed DSP survey, Question C3. Note: Multiple responses allowed, rows will not sum to 100.

Even more than was the case for employees (shown earlier in Table 4.40), Table 4.59 shows that the self-employed were highly satisfied with the work that they did and the sense of achievement it brought. The self-employed providers were also very satisfied with the match between the work they did and their qualifications. As with employees, they were relatively less satisfied with their income and the level of support they received at work. Despite the higher levels of part-time work in this group, they were less satisfied than employees with the hours that they worked. One possible explanation is that they would like to be working more hours, which would suggest that there was a degree of underemployment (that is, self-employed would like to work and get paid for more hours than they currently do). Further analysis will be needed to unpack this relationship.

The self-employed were reasonably satisfied with most facets of their jobs, though a significant proportion of them (17 per cent) were not satisfied with flexibility available to balance work and non-work commitments.

Table 4.59: Job satisfaction of self-employed providers [1 to 10 dissatisfied/satisfied scaling] (per cent)

	Dissatisfied		Satisfied	Question not	
	1 to 4	5 to 6	7 to 10	answered	Mean
The sense of achievement you get from your work	1.1	4.8	93.4	0.7	8.5
Your income from doing this work	13.2	23.9	62.1	0.7	6.8
Your likelihood of having ongoing work	5.1	16.9	77.2	0.7	7.7
The work itself (what you do)	1.1	5.5	92.3	1.1	8.6
The hours you work	20.2	18.8	59.9	1.1	6.7
The match between your work and your qualifications	2.2	4.4	92.6	0.7	8.6
The opportunity to develop your skills and abilities	5.5	16.5	77.2	0.7	7.7
The level of support given to your work	14.7	29.4	53.7	2.2	6.5
The flexibility available to balance work and non-work commitments	16.5	15.4	67.3	0.7	7.1
All things considered (i.e. the work overall)	0.7	8.1	89.7	1.5	8.2
Total (N=272)					

Total (N=272)

Source: 2014 NDIS self-employed DSP survey, Question C8.

Note: Row percentages are shown.

Table 4.60 shows that similarly to employees, self-employed providers also had very high level of agreement regarding statements on sufficient skills and abilities they had for the job and the sufficient utilisation of their skills and abilities in the job, with an average score of 6.3 and 6.5 out of 7 respectively. Just over half (57 per cent) believed there were plenty of training opportunities available to them. However, a large proportion (32 per cent) reported that they had a higher qualification than required for the job. Also a considerable proportion of the self-employed workers felt under pressure (61 per cent) and stressed (34 per cent).

In almost all respects, the self-employed in Table 4.60 reported somewhat higher levels of agreement than did employees (see Table 4.41) with the positive statements about the listed aspects of their work. This might be because of the professional nature of their work, or it could arise from the autonomy they had as self-employed, which would imply that they had the opportunity to choose what they did more than their employee counterparts. Apart from the indicator of stress and pressure to work harder, they were very positive about their work. An extraordinary 96 per cent said they were 'proud to tell people who I work for' (for the self-employed, this was themselves).

Table 4.60: Opinions about aspects of work of self-employed providers [1 to 7 disagree/agree scaling] (per cent)

	Disagree 1 to 3	4	Agree 5 to 7	Question not answered	Mean
I spend enough time with each person accessing supports	18	11.8	68.4	1.8	5.2
I have adequate continuity of contact with each person accessing supports	14.3	9.9	73.9	1.8	5.2
I have the skills and abilities I need to do my work	0.7	3.3	94.9	1.1	6.3
I use many of my skills and abilities in my work	0.4	1.8	96.7	1.1	6.5
I have a higher qualification than the one required for my work	46	20.6	32.4	1.1	3.6
I have a lot of freedom to decide how I do my work	3.7	9.6	85.3	1.5	5.9
I feel under pressure to work harder in my business	21	17.3	60.7	1.1	4.8
My work is more stressful than I had ever imagined	43	22.1	33.8	1.1	3.7
I get the respect and acknowledgement I deserve for my efforts and achievements	12.5	22.4	64.0	1.1	4.9
There are plenty of training opportunities available to me	20.2	21.3	57.4	1.1	4.7
I feel loyal to the organisations and people I work with	2.6	10.3	85.7	1.5	5.9
I am proud about the work I do	1.1	1.5	96.3	1.1	6.5

Total (N=272)

Source: 2014 NDIS self-employed DSP survey, Question C7.

Note: Row percentages are shown.

Table 4.61 shows that only 40 per cent of self-employed providers spent more than two thirds of their shift actively caring for people. This was similar to the share of time spent caring indicated for employees (see Table 4.42).

In contrast to the picture of employees, only 8 per cent of self-employed providers spent more than two thirds of their shift on administration tasks. The corresponding figure for employees is 30 per cent. These figures may indicate that while substantial time was devoted to administration by self-employed providers, there was not as much time spent on administration as by outlet employees. It may also simply indicate that there was a division of labour within larger establishments, whereby fewer employees did more administrative work while others did less.

Table 4.61: Time allocation at work of self-employed providers

	Actively caring for people %	Administration tasks %
Less than one-third of your time	14.3	52.9
Between one-third and two-thirds of your time	42.3	35.7
More than two-thirds of your time	40.4	7.7
Question not answered	2.9	3.7
Total (N=272)	100	100

Source: 2014 NDIS self-employed DSP survey, Question C6a.

## 4.4.3 A brief summary of self-employed DSP

Self-employed workers in the disability care sector were overwhelmingly professionals in the allied health fields and in psychology or counselling. Their main work in the present sample was with children, typically with developmental disability. They were highly educated, predominantly with Australian qualifications, and few were recent migrants. Most were sole operators, and had been working in the disability sector for many years. More than employees, the self-employed worked short hours. Despite their autonomy, the self-employed providers were not particularly happy with the hours that they worked, but they felt fully equipped in terms of skills and qualifications to do their job well.

Even more than employees, the self-employed providers were highly motivated to provide care and support for vulnerable people and to do a job that was valued and worthwhile. The self-employed workers obtained their job satisfaction from the intrinsic rewards of the job rather than from the material rewards and opportunities. Overwhelmingly, they were proud of what they did.

The sample of the self-employed providers came a lot more from the NDIS trial sites than did the outlets and their employees' samples. This may be a reason for their much higher response rate to the survey. It may also be a reason for their specific occupational composition and other possible sample biases. The low overall sample size makes the effort to obtain a Wave 2 'top up' (that is additional sample which will only be interviewed in Wave 2) an important consideration for understanding this part of the sector's workforce.