Evaluation of the NDIS

Intermediate Report

Kostas Mavromaras
Megan Moskos
Stéphane Mahuteau

September 2016

National Institute of Labour Studies
Flinders University, Adelaide, Australia

Tables:

Figures:

Acknowledgements

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

This report is the result of a team effort from those working on the NDIS Evaluation 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 contributions.

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 NDIS evaluation.

Research Team

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

From Flinders University:

The lead authors of the report are: Kostas Mavromaras as the project's Chief Investigator, Stephane Mahuteau as the lead of the quantitative components and Megan Moskos as the lead of the qualitative components.

The remaining Flinders University team has included (in alphabetical order): Andreas Cebulla, Angela Crettenden, Caroline Ellison, Jo Flavel, Alison Goode, Lorna Hallahan, Joshua Healy, Linda Isherwood, Genevieve Knight, Deb Payne, Pammi Raghavendra, Sue Richardson, Llainey Smith, Helen Walton, Zhang Wei and Rong Zhu.

From partner organisations:

Christine Bigby, La Trobe University;
Patricia O'Brien, Centre for Disability Studies, Sydney University;
Karen Kellard, Social Research Centre.

Data Collection

Graham Challice, Darren Pennay and Sonia Whiteley, Social Research Centre;
Julia Bizdoaca and Mark Davis, I-View.

State and International Experts

Christine Bigby (Victoria), Di Chartres (South Australia); Patricia O'Brien (New South Wales); Margaret Reynolds (Tasmania); Jacinta Cummins/Christina Ryan (Australian Capital Territory).
Bruce Stafford (Nottingham, United Kingdom); Jeff Smith (Michigan, United States of America);
David Greenberg (Baltimore, United States of America).

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 2265 (d) +61 8 8201 3482
Email: k.mavromaras@flinders.edu.au
Website: www.NDISevaluation.net.au
Evaluation email: ndisevaluation@flinders.edu.au

Executive Summary

The main objective of the evaluation of the National Disability Insurance Scheme (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, on the disability sector and its workforce, on selected mainstream providers and services, and on selected stakeholders and the wider community. It is also intended to evaluate high-level processes, focusing on elements of the NDIS which contributed to or impeded the intended positive outcomes.

This Intermediate Report is the second of three reports on the NDIS evaluation. The first report presented the methodologies used for all evidence collections. The present Intermediate Report provides the first synthesis of the evidence collected to date (mid-2016) from all different sources and methodologies of the NDIS evaluation. In this report we present qualitative and quantitative evidence in a thematic way in order to utilise potential synergies between the depth of understanding qualitative evidence offers and the overall representativeness of quantitative survey data. The work of combining and integrating data is at the heart of the design of the NDIS evaluation and will continue in all further work by the evaluation team.

A central focus of the NDIS evaluation has been the list of Key Evaluation Questions (KEQs) originally identified by the Department of Social Services (DSS) as the core guide for the design of the NDIS evaluation. The list consists of a total of 56 such KEQs.

This Intermediate Report draws from each element of the NDIS evaluation data collection activities in order to provide an updated and comprehensive synthesis of the evaluation evidence as it stands in mid-2016. Unlike the first report which focussed on presenting and explaining the different methodologies used by the NDIS evaluation, with limited emphasis on the KEQs, the Intermediate Report has been arranged in a thematic way, with the relevant KEQs supporting each theme. The following three main themes (and their related KEQs) have been chosen in order to reflect areas of key policy interest to the NDIS roll-out:

- Supply and demand of support services
- Choice and control (including self-management)
- Participation (economic and educational), wellbeing and aspirations (goals).

The Intermediate Report combines all data collections that were completed between May 2013 and June 2016, as presented in Table 1 below. 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, which includes employers, specialist workers and the self-employed from South Australia, Tasmania, New South Wales, Australian Capital Territory and Queensland. On the qualitative side, we report the findings from the two waves of interviews with people with disability, and their families and carers, including NDIS participants and their family members and carers, disability service providers, disability workforce stakeholder organisations, and the NDIA. Table 1 below summarises the samples sizes on which the evidence in this report is based upon.

Table 1: NDIS Evaluation Sample

	Wave 1	Wave 2
Quantitative		
The NDIS Survey of People with Disability, and their Families and Carers		
Trial -NDIS participants	2,539	-
Trial – Family members and carers	1,835	-
Comparison - People with Disability	1,885	-
Comparison – Family members and carers	1,531	-
NDIS Disability Support Providers Surveys		
Outlets	697	-
Workers	2,133	-
Self-employed	272	-
Qualitative		-
Interviews with people with disability and their family and carers	62	61
Interviews with disability service providers	25	24
Interviews with disability stakeholder organisations	15	14
Interviews with NDIA staff	46	41

In each of the three main thematic sections of the report we present the quantitative and qualitative findings separately to provide an overview of the evidence against each of the various KEQs under investigation. In this summary we bring together and integrate the main threads of both the quantitative and qualitative evidence to provide a first overall assessment of each of the three main themes and their related KEQs.

Supply and demand of support services

The NDIS is a new way of providing care and support for people with disability in Australia. The capacity of the NDIS to achieve an appropriate market-based balance between the supply and demand of disability support services is essential for its long-term success. In this section we present integrated qualitative and quantitative evaluation evidence on the following six KEQs that relate to the broad theme of *supply and demand of disability support services*:

- KEQ 17: For people with disability who previously received supports, to what extent has the NDIS contributed to changes in their patterns and use of supports?
- KEQ 32: What has been the impact of the NDIS on the overall provision and quality of disability services?
- KEQ 34: What has been the impact of the NDIS on the disability sector, including the relevant government agency in each jurisdiction and advocacy organisations?
- KEQ 35: Consider impacts on workforce (skills, retention rates, capacity, satisfaction, workforce culture, composition and proportion of occupation types).
- KEQ 36: Consider impacts on supply and diversity of disability supports (particularly sustainability, ability to respond to choice and control, and service capacity).
- KEQ 37: To what extent has the supply of disability services responded to demand?

Demand for supports

- Both the quantitative and qualitative data indicate that the majority of respondents receive increased supports as a result of becoming NDIS participants. Increased supports comes in the form of increased hours of support, greater frequency (intensity) of service provision, and more appropriate equipment or access to a wider range of supports.
- Both data sources also indicate that most NDIS participants and their families and carers have more say and choice over the supports they received, the timing of those supports, the location of their supports, and the provision of supports (being able to use different services/providers). Most NDIS participants also experienced an increase in their satisfaction with the quality of the supports and a minority reported a decrease in their satisfaction. The qualitative data indicates that the main factors impacting on the quality of the supports are the quality of support workers, and the NDIS pricing constraints and time benchmarking.
- The evaluation finds that, while the number of supports received has increased for most NDIS participants, the majority of NDIS participants did not change providers upon joining the NDIS. The qualitative data suggests that uncertainty contributes to choosing to stay with the same provider, with evidence emerging that, as NDIS participants and carers increase their knowledge and experience of the Scheme, they become more confident about changing service providers over time.
- An important finding that emerges very clearly from both the quantitative and qualitative data is that whilst the overall picture of the NDIS trial roll-out is one of increased supports and improved outcomes, not all people with disability are achieving improved outcomes under the NDIS. Here we focus on two aspects of poorer outcomes.
    - First, qualitative reports indicate that some people with disability were experiencing poorer outcomes under the NDIS and were receiving a lower level of services than previously. These were particularly people with disability who were unable to effectively advocate for services on their own behalf, including some people with psychosocial disability and/or those people who struggled to manage the new and sometimes complex NDIS processes.
    - Second, both qualitative and quantitative evidence indicates that many NDIS participants and their families and carers experienced continuing difficulties in accessing disability supports for which they were receiving NDIS funding. Both data sources indicate that this was primarily due to lengthy waiting lists for some providers or types of support, lack of local providers, and lack of quality provision. Both data sources suggest that this type of unmet demand is experienced more by those living in rural and remote areas, in the Victorian trial site (much more so in regional parts of it), and for older NDIS participants (much more so for those living in regional areas). Both data sources also indicate that self-management reduces the incidence of unmet demand (although this may not be true for younger NDIS participants).

Supply of Supports

- Both the quantitative and qualitative data indicate that disability service providers and self-employed disability service providers are undertaking many supply-related activities in direct and indirect response to the trial and roll-out of the NDIS.
- Both the quantitative and qualitative data indicate that in response to additional consumer demand, disability service providers are increasing the proportion of their services dedicated to disability support and expanding their range of services.
- The quantitative and qualitative data appear to contradict one another when considering the reported impact of the NDIS on the disability sector.

  - The quantitative data indicates that both disability service providers and the self-employed expect that the NDIS will have little impact or a positive impact overall and in particular on employment, wage growth and overall performance.
  - In contrast, the qualitative data suggests that the NDIS has had considerable impacts for disability service providers. Reported impacts included changing business models, increased merger and acquisition activity, entry of new providers, exits from the sector, and changing (becoming more guarded) relationships between providers.
- Our evidence on the impact the NDIS has had on the disability sector workforce comes from the non-generalisable qualitative data, which has reported an expanding workforce in the midst of concerns about skill shortages, employee recruitment and retention, decreased opportunities for training, increased turnover and churn, unfunded work, more casual and less well-paid work, lower quality of provision and more. The evaluation will be able to assess the impact of the NDIS on the workforces in a statistically meaningful manner after the collection of wave 2 of the providers' quantitative surveys.

Supply and Demand viewed jointly

- Both disability service providers and NDIA staff report that, in their experience, demand for disability supports has been exceeding supply. Of concern was the indication by providers that they would start ceasing the provision of some services which were consider underfunded under current NDIA cost guidelines. Should such a market response occur, the cessation of these services could exacerbate current market shortages and, possibly, influence the prices of uncapped items and/or the quantities of price-capped items. We do not have quantitative evidence of this type of response by providers. Although it may be early days for making such assessments, these considerations should enter the relevant policy watch lists.
- Both the quantitative and qualitative data also indicate that many NDIS participants continue to access supports that are not funded in their NDIS plan. Such unfunded supports include alternative therapies and social and recreational activities. It is reported that NDIS participants and/or their family already pay out-of-pocket expenses for accessing such services.

Choice and control (including self-management)

The concept of people with disability and their families and carers exercising more choice and control lies at the heart of the NDIS. One of the central aims of the NDIS is that it will support people with disability to have choice and control to help them reach their goals and also to help them in the planning and delivery of their supports. In this section we present qualitative and quantitative evaluation evidence on the following five KEQs that relate to the broad theme of *choice and control*.

- 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?
- KEQ 5: To what extent did people have increased choice and control over the development and implementation of their plan?
- KEQ 8: How have people responded to increased choice and control?
- KEQ 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?
- KEQ 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?

NDIS participants

- Both the quantitative and qualitative evidence collected so far suggests an overall improvement in the choice and control NDIS participants experience over their supports. When it comes to choice and control, a pattern is emerging, whereby about half of all respondents indicate that they are better off, about a third that they are about the same as before the NDIS, and about 15 per cent that they are worse off.
- There is considerable diversity among those who report being worse off.
  - Both the qualitative and quantitative data indicate that people with mental health and psychosocial disability are more likely to report less choice and control over supports since becoming NDIS participants. The qualitative data further indicates that vulnerable families, those unable to navigate the NDIA website to find what services and providers were available, and those less able to articulate support needs, are less likely to experience greater choice over their supports. Exercising choice was also constrained for those living in non-metropolitan locations with fewer service providers.
  - The quantitative data indicates that those who report that they are worse off in terms of their choice and control over their supports are more likely to have experienced a decrease rather than an increase in the number of supports they receive since becoming NDIS participants. In addition, those who report that they have funding for supports which, however, they cannot access, have lower levels of satisfaction with the overall quality of their supports.
- Both qualitative and quantitative data sources also indicate that many NDIS participants would like to have more choice and control over their supports.
  - The quantitative data allows us to understand the number of supports over which NDIS participants would like more choice. On average, each person stated four types of support over which they would like more choice.
  - The qualitative data allows us to understand in more depth what increases in choice and control are desired. This data indicates that NDIS participants and carers felt they had insufficient information to choose their service providers confidently. These respondents requested more information about services available from each provider, and help with defining factors on which to base their choice when asking providers about their supports in order to make an informed choice. Several respondents described the NDIA website to be difficult to navigate, inhibiting their access to information about services. Finally, instances were reported where choice and control were restricted because of limitations in the number or capacity of service providers.
- The quantitative data also indicates that under the NDIS it takes participants (i) more time rather than less time to do the necessary paperwork and (ii) less time rather than more time to find and get supports.
- The first of these findings (on paperwork) is supported by the qualitative evidence. The second of these findings however (on finding and getting supports) is contradicted by the qualitative evidence. The qualitative data indicates plan implementation was impeded by (i) a lack of information about providers and the services they offer (ii) the amount of time and effort involved in managing and organising NDIS providers and activities and arranging payments for some services and (iii) a lack of service providers, in particular outside the main urban centres. However, it is important to note that inclusion of case management/case coordination in NDIS plans to assist with the engagement and implementation process for services and supports was more common at wave 2. Feedback from respondents suggested that for many, this was a valued service which has removed the burden and stress of communicating and co-ordinating with providers.

- Both the quantitative and qualitative evidence indicates that self-management is very uncommon. The qualitative evidence indicates that the main reason for this appears to be a reluctance to take on additional administrative activities. 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 and in the support workers that they engaged.

Family members and carers

- The quantitative data indicates that the overwhelming majority of NDIS participants need assistance on a daily basis. The most frequently mentioned person that assists NDIS participants was their own mother or father.
- The quantitative data finds that the NDIS increases the ability of family members and carers to care for people with disability and decreases their anxiety about future supports available to the person they cared for. However, the qualitative data did indicate that there were many concerns about the future sustainability of the NDIS.
- The quantitative data suggests that family members and carers report high levels of satisfaction with the amount of say they have about what supports the person with disability receives and where they obtain those supports. This finding appears to contradict the qualitative evidence which suggests that family members and carers of NDIS participants (particularly of young children) reported that their own needs and the needs of the family more broadly were not addressed in the planning process. Respondents requested greater attention to the family context.
- Both the quantitative and qualitative data indicate that many family members and or carers of NDIS participants are unable to take adequate breaks from providing support and that they cannot access carer support in a consistent manner.

Participation (economic and educational), wellbeing and aspirations (goals)

The NDIS aims to improve the quality of life, wellbeing, and social and economic participation of people with disability, their families and carers. A core task of the NDIS evaluation is to understand the degree to which the introduction of the NDIS has increased social and economic participation and wellbeing. It is recognised by the NDIS evaluation that there are many facets of participation and that wellbeing is a very complex concept that can take different meanings by different people, even when they are faced with the same circumstances, and different meanings by the same person when faced with different circumstances or over time. It is also recognised by the NDIS evaluation that the academic and policy literature offers several methods for measuring wellbeing, each of them with their strengths and weaknesses and their specific focus points and emphasis. To this purpose the NDIS evaluation does not rely on any single measure of wellbeing, but collects information on a wide range of measures and at different points in time. In this section we present qualitative and quantitative evaluation evidence on the following five KEQs that relate to the broad theme of *participation, wellbeing and aspirations*.

- KEQ 1: To what extent has an NDIS contributed to changes in wellbeing and quality of life for people with disability, their families and carers?
- 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?
- KEQ 3: To what extent has an NDIS enabled people with disability, their families and carers to achieve their goals?
- KEQ 24: 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?

- 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?

Wellbeing

- The quantitative data collected information on three separate measures of wellbeing: (i) psychological wellbeing (often called eudaimonic wellbeing in the literature); (ii) Personal Wellbeing Index (PWI); and (iii) sense of social connection.
- The quantitative evidence indicates that NDIS participants overall have a mean wellbeing index that is well below the average PWI in Australia. It will be essential for the evaluation to assess whether the NDIS improves the personal wellbeing among NDIS participants. The second wave of the quantitative survey data will enable this assessment.
- When we compare the measures of wellbeing by broad disability type we see on all three measures NDIS participants with a mental health or psychosocial disability record a mean measure of wellbeing that is considerably lower than that recorded for other disability groups.
- The quantitative data also shows that experiences of choice and control and unmet demand under the NDIS are connected with reported personal wellbeing. The more say (choice) NDIS participants have with regards to the decision on what supports they get or where they get these supports from, the higher their reported wellbeing. In addition, those who have experienced unmet demand for supports after joining the NDIS also report significantly lower levels of personal wellbeing.
- Just under half of all family members and carers report that they experienced financial hardship over the last 12 months according to at least one of the financial hardship indicators. It will be essential for the evaluation to assess whether NDIS participation ameliorates the financial hardship experienced by family members and carers of NDIS participants.
- The two waves of qualitative evidence provide early but non-generalisable indications of whether and how the NDIS may have contributed to changes in the wellbeing of NDIS participants and their families and carers.
- The qualitative evidence makes clear that on the whole the NDIS has improved the wellbeing of NDIS participants and their family members and carers. For NDIS participants, increases in wellbeing were related to having better services than previously and increased independence. Improvements in wellbeing were associated with ‘living’ better, rather than just managing or ‘surviving’, and with generally feeling happier. Since joining the NDIS many achievements were reported, relating to NDIS participants’ goals and aspirations, which subsequently impacted positively on wellbeing.
- Families and carers often reported an increased sense of positivity and wellbeing as a result of the NDIS participant being more involved in activities they enjoyed and being able to participate in wider interests outside of the home. The wellbeing of family members and carers had also generally improved as a result of reduced financial strain and increased access to supports.
- However, the negative impact of the ongoing administrative burden of NDIS was highlighted regularly. This was for many a new source of stress: some parents felt the added paperwork consumed time that was in the past usually spent as a family.

Social participation

- The quantitative data provides information about activities that NDIS participants and family members and carers have done recently and information about activities they would most like to do in the coming year.
- The quantitative data indicates that the most frequently reported activities undertaken by NDIS participants and their family members and carers was spending time with family and with friends. The most desired activity to be undertaken in the future for both NDIS participants and their family members and carers was to go on a holiday.
- The two waves of qualitative data provide early information about whether and how the NDIS may have contributed to any changes in the social participation of NDIS participants and their family members and carers. This evidence makes clear that the social participation of both NDIS participants and their family members and carers increased as a result of the NDIS.
- Many NDIS participants are now able to take part in activities independently (i.e. without the support of a family member), are able to have access to support when needed, are able to follow interests and social activities that had previously been inaccessible, and are able to visit friends and family or to have people to stay. Increases in social participation however were limited in the case of NDIS participants with mental health problems, intellectual disabilities, or with Autism Spectrum Disorder.
- Easing the care burden on family members and carers, improved their social and economic participation as it allowed them to be involved in other valued activities such as employment, social activities and quality time with other family members that would have not been possible previously.

Educational and economic participation

- Both the quantitative and qualitative data indicate that a high number of NDIS participants were currently in education.
- The quantitative data indicates that for those currently not in education, around a quarter would like to be but their own health or disability was preventing them from doing so. For most people with disability currently in education the prime objective and plan after their education is completed is to get a job.
- Very few family members and carers of NDIS participants were currently studying.
- The quantitative data indicates that around a fifth of all NDIS participants who were surveyed were currently employed and largely liked their jobs, however their employment does not appear to be stable. A large proportion of those not in employment would like to hold a job, but the reported barriers to getting a job appear to be formidable.
- The qualitative evidence suggests that while there was an increase in participation in employment related activities over time, including volunteer work, work experience, supported employment and paid work, only a few NDIS participants reported undertaking these activities. Increased economic participation amongst people with disability was considered a long term process, with time needed to develop job-readiness skills, create programs to support both participants and employers, and to change cultural beliefs about employability and opportunities for employment for people with disability. It was 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.

- Both quantitative and qualitative data indicate that caring impacted on the carers' ability to take part in paid work and on career pathways more generally. Both data sources indicated that some family members/carers had given up their careers as a result of care responsibilities and others were working part-time, having given up full-time work to provide care and support to the person with disability.
- The qualitative data provided a few examples of carers increasing their working hours, or pursuing employment activities because they now had a little more time as a result of the NDIS participant obtaining more support than previously.

Unintended consequences

- The qualitative data indicated that NDIS funding of individualised support services instead of group-based services had negatively impacted on the social participation of some NDIS participants who no longer attended programs where they had previously mixed with a range of people.
- The qualitative evidence also suggests that support for carers (within and outside of the NDIS) has diminished since the NDIS roll-out.
- The qualitative data also uncovered concerns about the impact the NDIS would have on people with disability not eligible for the NDIS. Some non-NDIS participants were reported to be receiving fewer services while others were falling through service gaps and getting no supports at all.

1. Introduction

1.1. Background

In August 2011, the Australian Productivity Commission released its landmark report on disability care and support. The report was highly critical of the care and support available to people with disability and their families and carers within Australia 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 to improve the quality and enhance the equity of disability service provisions across Australia. A series of Council of Australian Government agreements were reached between the Australian Commonwealth and State and Territory governments, which formalised transition arrangements from the old system to the new National Disability Insurance Scheme (NDIS). The Intergovernmental Agreement for the NDIS Launch was signed by the Commonwealth and all States and Territories at the Council of Australian Government meeting of 7 December 2012. The *National Disability Insurance Scheme Act 2013* established the National Disability Insurance Agency (NDIA) and gave birth to the new Australian National Disability Insurance Scheme (NDIS).

The trial of the NDIS, originally known as DisabilityCare Australia, began in July 2013 in South Australia, Tasmania, the Barwon region in Victoria and the Hunter area in New South Wales. Western Australia, the Australian Capital Territory (ACT) and the Barkly Region in the Northern Territory joined the launch in July 2014. The Nepean Blue Mountains area of New South Wales became the first NDIS early transition site, starting 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 (the NDIS Evaluation).[1] The evaluation was originally planned to take place between 2013 and 2016 and cover South Australia, Tasmania, the Barwon region 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 Barkly Region in 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, especially the late ACT roll-out.

In this report, generic references to “trial sites” refer specifically to the whole of South Australia, Tasmania and the ACT, the Barwon region in Victoria, and the Hunter area in New South Wales. Reporting on the findings of the evaluation in the Barkly NDIS trial will be included in the final report. The NDIS evaluation does not include any other NDIS trial sites.

1.2. Reporting Framework for the NDIS Evaluation

The NDIS evaluation has now been running for three years and this Intermediate Report is the second of three major reports. The draft Initial Report was delivered to DSS in August 2015. The final version of the Initial Report was delivered in December 2015 and is planned to be publicly released at a future date. The Initial Report described the first stage of the evaluation work, namely how the evaluation was put together and how the large data collection that underpinned it had commenced. A Final Report is scheduled to be completed in 2017. A separate document under the title The Evaluation Framework has already been published explaining the nature of the original design of the evaluation.

---

[1] The NDIS Evaluation was commissioned in May 2013 by the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA).

A second supporting document detailing the relationship between the Key Evaluation Questions (KEQs) and the methodologies developed by the evaluation is planned to become public at a future date.

As described in Section 1.1, the NDIS evaluation also extends to the Barkly Region in the Northern Territory. As the evaluation of this trial site is still in its early stages, it will not be included in this Intermediate Report. Furthermore, the unique character of the NDIS trial in the Northern Territory required 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 Northern Territory. 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 (one full year later than in the four original trial sites) evidence for the ACT is not as ready for reporting here. The later ACT roll-out has required that we adapt the timing of the data collections and subsequent reporting to accommodate the roll-out timing and volume.

In agreement with the Department of Social Services, reporting on the study of the impact of the NDIS on mainstream providers and services and on the study of older people with disability will not be included in this report.

1.3. The NDIS Evaluation findings reported in this Intermediate Report

The precise objective of the NDIS evaluation is to assess the impacts of the NDIS in South Australia, Tasmania, the Hunter area in New South Wales, the Barwon region in Victoria and the Australian Capital Territory on:

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

The NDIS evaluation is also intended to evaluate high-level processes, focusing on elements of the NDIS, which contributed to or impeded the intended positive outcomes.

This Intermediate Report is the second of three reports on the NDIS evaluation, conducted by Flinders University 2013-2017, and presents a synthesis of the evidence collected to date from different sources and methodologies of the NDIS evaluation. In this report we present qualitative and quantitative evidence in a thematic way in order to inform the evaluation of the potential synergies between first, the depth of understanding qualitative evidence offers and second, the overall representativeness of quantitative survey data. We 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 quantitative data collections are finalised and in order to account for the differences between the original evaluation design and the way data collection had to be implemented to account for the way the actual roll-out happened. The work of combining and integrating data is at the heart of the design of the evaluation and will follow all evidence collections.

Key Evaluation Questions

In the background of the thematic analysis and presentation of this report is the set of Key Evaluation Questions (KEQs) that the evaluation has been designed to address. The Department of Social Services (DSS) originally identified a total of 56 such questions to be answered by the NDIS evaluation.

This Intermediate Report draws from each source of the NDIS evaluation data collection activities to provide a synthesis of the evaluation evidence around three main themes (and their related KEQs):

1. Supply and demand of support 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?
    - **KEQ32:** What has been the impact of the NDIS on the overall provision and quality of disability services?
    - **KEQ34:** What has been the impact of the NDIS on the disability sector, including the relevant government agency in each jurisdiction and advocacy organisations?
    - **KEQ35:** Consider impacts on workforce (skills, retention rates, capacity, satisfaction, workforce culture, composition and proportion of occupation types).
    - **KEQ36:** Consider impacts on supply and diversity of disability supports (particularly sustainability, ability to respond to choice and control, and service capacity).
    - **KEQ37:** To what extent has the supply of disability services responded to demand?
2. Choice and control (including self-management)
    - **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?
    - **KEQ5:** To what extent did people have increased choice and control over the development and implementation of their plan?
    - **KEQ8:** How have people responded to increased choice and control?
    - **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?
    - **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?
3. Participation (economic and educational), wellbeing and aspirations (goals)
    - **KEQ 1:** To what extent has an NDIS contributed to changes in wellbeing and quality of life for people with disability, their families and carers?
    - **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?
    - **KEQ 3:** To what extent has an NDIS enabled people with disability, their families and carers to achieve their goals?
    - **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?

- **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?

The three main themes (and their related KEQs) which have been selected to be the core focus of this Intermediate Report are those for which the evaluation currently has the most comprehensive, robust and independent evidence about, and for which there is the most policy concern. It is important to note that the above KEQs are inter-dependent and are not mutually exclusive. Therefore some measures used to assess one KEQ can and should be also used to address others. Moreover, and as will be elaborated upon below, some KEQs and parts of others, because of the longitudinal nature of the evidence required to address them, will neither be addressed nor be answered completely until the second wave of quantitative data is available.

Some of the selected KEQs covered in this report were not covered in the initial report and others covered in the initial report are not covered in this report. A matrix comparing KEQs between the two of the three major reports to be delivered on the NDIS evaluation is provided at Appendix 1.1. It is important to reemphasise that a discussion of the total 56 KEQs will only become feasible once the full evaluation material has been collected and will be delivered within the Final Report.

In each of the three main sections of the report we present an overview of the quantitative and qualitative findings relating to a particular theme (and their related each KEQs). We start each by focusing on aggregate trends that the evaluation uncovers. We then focus in more depth (in the quantitative section by utilising more sophisticated data analysis techniques and in the qualitative section by delving deeper into respondents narratives) on those that are identified at the aggregate level to be experiencing poorer outcomes. We do this to understand the factors that are most closely associated with poorer outcomes, in order to provide clues as to the areas where further attention is warranted as the Scheme moves closer to full roll-out.

Each of the three main sections of the report are preceded by a key message box, which provides a précis of the key findings included in the chapter. The key message box has been designed to be read independently from the body of the chapter and is provided to enable a reader with limited time to review this box rather than delve into the detail of the findings.

Finally, each of the three main sections of the report are concluded with a summary where we bring together and integrate the main threads of both the quantitative and qualitative evidence to provide a robust assessment of each of the three main themes and their related KEQs.

NDIS evaluation data sources

The Intermediate Report utilises all data collections that were completed between May 2013 and June 2016, including the findings from wave 1 (and in some cases wave 2) fieldwork in the four initial sites: South Australia; Tasmania; the Barwon region in Victoria; and the Hunter area in New South Wales. We report on both the quantitative and the qualitative evidence collections. Because of its later launch, material from the ACT trial site is limited for the quantitative survey of people with disability.

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 findings from the two waves of interviews with people with disability, and their families and carers, including

NDIS participants and their family members and carers, disability service providers, disability workforce stakeholder organisations, and the NDIA.

A brief overview of each of these evaluation components is provided below. For a more comprehensive overview of the methodologies employed for each of these evaluation components please refer to the Evaluation Framework (2014) and NDIS Initial Report (2015).

1.4. The 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 implementation of the NDIS.

Interviews with People with Disability, and their Families and Carers

Interviews were conducted with sixty-two NDIS participants, and their 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. Wave 1 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. Most interviews were undertaken face-to-face and at the respondent's home.

A second round of interviews with these NDIS participants, family members and carers was conducted between August 2015 and February 2016. Six respondents (five in NSW and one in VIC) who had taken part in wave 1 were unable to participate in wave 2. Replacements were found for all six respondents, matched as closely as possible for age and disability type. Two NDIS participants and their carers in SA and ACT were unable to participate in a full interview in wave 2 due to their time constraints; these participants instead provided brief information by phone and were not replaced due to oversampling in these trial sites in wave 1. To protect respondents' identities pseudonyms are used in all references in this report.

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 workers, brokered workers and self-employed sole providers. Selective sampling ensured that the types of disability service providers interviewed, 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.

A second interview with a representative from each of the original disability service providers interviewed in wave 1 was conducted between September and December 2015. One disability service provider was unable to be contacted to be interviewed in wave 2.

Interviews with Disability Workforce Stakeholder Organisations

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

A follow-up interview with a representative from each of the original disability workforce stakeholder organisations was conducted between September and December 2015. One disability workforce stakeholder organisation declined to participate in the second round of interviews due to pre-existing commitments and limited involvement in the NDIS.

Interviews with NDIA managers and staff

Forty-six NDIA staff across the five trial sites were interviewed between October 2014 and April 2015, including managerial and operational staff, and practitioners. A second interview with thirty-nine of these NDIA staff were conducted between October 2015 and May 2016. Of the original wave 1 sample, three NDIA staff had left the agency and were unable to be contacted, two had left the trial site and felt they had little to comment, and two chose not to participate.

1.5. 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 build information on the lives of people with disability, and their families and carers, and how these 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 KEQs.

Design and development

The objective of the survey design is as follows. First objective is to collect information on the changes that happened to NDIS participants in the trial sites (the trial group). Second objective is to collect information on the changes that happened to NDIS non-participants in areas that are not included in the NDIS trial as yet (the comparison group). Final objective is to compare the change that was experienced by the NDIS participants with the change that was experienced by the NDIS non-participants. Provided that the subjects in the trial and comparison groups are very similar in terms of their disability, the difference between the experiences in the two groups can be attributed to the introduction of the NDIS. This method is conventionally called difference-in-difference estimation. By using this methodology we can measure the impact of the NDIS in the trial sites. Some of the core aspects of this data collection are explained below:

- 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 mixture 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 ethical integrity for future data collections.

- The survey uses a specially designed registration process to allow respondents to be approached in their personally preferred way. They are offered the possibility of a Computer Assisted Telephone Interview, 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 roll-out. The slower take-up of the NDIS in the trial sites is 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 2016. The third sampling is timed to coincide with the earliest opportunity 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 linked but independent 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. Should they wish to, persons with disability can answer their survey in private, as can family members and carers.

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 are 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, wellbeing, 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. Where such support was used or not 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 a total of 18 separate questionnaires were used in the survey, all targeted at and designed for specific sub-groups.
- The first wave of the data asks all people with disability whether they would like to give their consent to the evaluation team to access their administrative data.

Completed and planned fieldwork

A pilot study was conducted and has been reported in the Initial Report.

- Fieldwork for wave 1a and wave 1b has been completed, yielding for the trial sample 2,539 people with disability and 1,835 family members and carers and for the comparison sample, 1,885 people with disability and 1,531 family members and carers.
- Approximately 86 per cent of all responding people with disability have consented for the research team to access their administrative data information. This work is planned for the second half of 2016, in time to incorporate the information in the main evaluation calculations.
- Fieldwork for family members and carers has yielded lower numbers than that of people with disability, as the initial administrative data was not complete and extensive work was required to locate them.
- Both waves 1a and 1b were in essence a census of all NDIS participants who had consented to take part in research at the time of sampling.
- Response rates were considerably lower in wave 1b for reasons we have not managed to explain.
- Fieldwork for the remainder of wave 1 (called wave 1c) is planned to be completed during the second half of 2016 and its main purpose will be to achieve the whole of the ACT sample provided by the NDIA and also to top up the comparison sample.
- The re-sampling of waves 1a and 1b (that is, for the second wave of the longitudinal collection) is to commence mid-2016. The second wave is planned to have a shorter fieldwork duration as the registration element will not be necessary and be completed by June 2017.
- Preliminary matching work suggests that the trial and comparison groups can be adequately matched (i.e. there is sufficient “common support”).

The differences between the actual NDIS trial roll-out from the originally planned (much faster) NDIS trial roll-out have been mirrored where necessary in changes between the originally planned sampling for the NDIS evaluation data with the actual sampling that took place and the data collected. The analysis of the data collected will be appropriately adapted to utilise fully the different sub-groups in the two samples (the trial and the comparison groups) and the added variation and richness found in the data. The methodology will deviate from the textbook methodology described in the Evaluation Framework (2014) in order to adapt to and utilise in full the actual data obtained.

1.6. The 2014 NDIS Disability Support Providers Surveys

The first wave of this survey was completed early in 2015 and is fully described in the Initial Report.

- Extensive work towards locating disability support providers (from the full NDIA register, the NILS register and additional web and telephone searches) yielded a large number of outlets, but a much lower than expected number of self-employed providers.
- The first wave of the providers’ surveys had a very low response rate by workers, a moderately low rate by outlets and a satisfactory response rate by self-employed support providers.
- Linking workers with outlets indicates that several outlets have not provided any information at all through their workers, while several other outlets have provided information through their workers, but did not themselves return their outlet questionnaire.
- In a world of continually evolving disability support providers, where supports may be only one part of their business, there is no neat or clear cut way to distinguish between “NDIS providers”

and “non-NDIS providers”. Appreciating that this will only be a temporary illustrative tool we have introduced such a distinction based on the location of each outlet and self-employed provider. By matching postcodes with each outlet we divided outlets into those that are near or inside a trial area and those that are not. This is not a precise division and is only used as a rough indicator of effective demand by NDIS clients. For the cases of Victoria and New South Wales, this may be a useful distinction. We note that the disability support providers analysis will require the second wave of quantitative data collections and the linked administrative data in order to provide definitive answers about change that can be attributed to the introduction of the NDIS. Our conclusions drawn at this stage will be limited in their scope.

- The second wave of providers’ surveys fieldwork is planned for the second half of 2016 and the first half of 2017. The need for a concerted additional effort to increase response rates by outlets and their workers has been identified.

1.7. The Importance of the NDIS Evaluation data and some caveats

A robust, transparent and objective evaluation conducted by independent evaluators is essential for the credibility of the launch of the NDIS and, by advising on the strengths and weaknesses of the launch implementation, it increases the scope for its effective long-term roll-out and management. By implementing our rigorous evaluation design, we provide the first independent, robust and comprehensive data to allow such an assessment.

It will be useful at this stage to share with the reader a few thoughts about the scope and the statistical robustness of the statistical evidence we present in this Intermediate Report. By the very nature of being in the midst of an ongoing longitudinal data collection, any quantitative evidence we choose to report on will be based on the first wave of data alone and should be read in the knowledge that it could (and probably will) be usefully augmented and revised as soon as we gain access to the second wave of the quantitative data surveys. Clearly the scope of the first wave evidence we present here will be limited and some aspects of it will be preliminary. The main reason why it is presented in this early form is because of the need to inform the NDIS roll-out as early and as fully as possible. The thinking is that it is better to have the analysis of the first wave of data collection now (with all necessary caveats for its limited scope), rather than having to wait for the arrival of the second wave to obtain the full analysis. We should however, note that this caveat applies principally to the scope of the analysis and not to the statistical robustness of its results.

Despite the limited scope of the data that we use for the first wave analysis of the quantitative data, the statistical methods we use are the appropriate ones and the results we present are statistically robust. There have been several instances where we judged that the data quality or quantity was not adequate for addressing a specific question: the reader can see sections where the sub-heading “The quantitative detail” is missing. In these instances we simply have left the task of addressing the relevant questions using quantitative methodologies until the final NDIS evaluation report where the second wave of data will be available. Thus the reader should interpret the statistical results that we do present with the knowledge that while the scope of the analyses has been limited, the results are statistically robust in their present form. Given that statistical significance is not an either/or concept, but rather an indicator of the degree of confidence we have when we make a statement, it goes without saying, that when we have reservations about the statistical robustness of a result, but we still think that it is a result on an important question that is worth mentioning, we will present the results and disclose our reservations (about its statistical significance), in order to allow the readers to make their own judgement.

Having concluded on the introductory material, we now turn to the full presentation of the three main themes (and their related KEQs) of the Intermediate Report. We note that in order to allow the exposition to flow, the quantitative analyses are supported by an extensive Appendix which contains all the specific numbers and Tables on which the main text of the report is based. These are clearly marked to allow the interested reader to navigate easily.

2. Supply and demand of support services

Key Messages

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?

The quantitative detail

- The quantitative data shows considerable change in the number of services accessed, but far less change in the providers of these services.
- The quantitative data indicates that NDIS trial site participants have not been limited to retaining existing services.
- The total number of services accessed after joining the NDIS has increased, both for the "average" NDIS participant and for NDIS participants as a whole.
- The quantitative data shows clearly that the increase in types of services accessed is not spread evenly across all types of services.

The qualitative detail

The qualitative data shows clearly the multifaceted change in the supports accessed by NDIS participants and the diversity and heterogeneity of circumstances and outcomes.

- Respondents who had received supports prior to NDIS generally reported increased flexibility of supports including better access to therapies, better equipment, more tailored support (in and out of the home). This enabled greater independence and less reliance on family members to provide support.
- In general, respondents described accessing the same range of services at wave 2 as they did at wave 1. While the types of disability services and supports included in plans varied and were largely dependent on the age of NDIS participants, common supports included in plans included:
    - **aids and equipment**
    - **case management**
    - **therapy (psychology support, physiotherapy and speech therapy)**
    - **personal care and support with independent living**
    - **travel and transport assistance, and**
    - **respite.**
- Several concerns were raised.
- Many NDIS participants continued to be disappointed to see items and activities they had hoped to access not funded under their NDIS plan. These included alternative therapies and social and recreational actives. Other unfunded services and supports were related to overlaps with mainstream services, in particular education and health.

- Funding for family supports was inconsistently included in plans and limited in scope.
- There was a concern that not all NDIS participants were achieving improved outcomes under the NDIS. Those unable to effectively advocate for services on their own behalf, including some people with psychosocial disability and/or those who struggled to manage complex NDIS processes, were reported to be experiencing poorer outcomes under the NDIS and receiving a lower level of services than pre-NDIS.

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

The quantitative detail

- The amount of say over what support people access has increased after joining the NDIS.
- NDIS participants report that choice over where they obtain the supports they receive has improved since joining the NDIS.
- NDIS participants report that the quality of the disability supports they access has increased since joining the NDIS. However, 35.5 per cent reported that the quality of their supports has not changed and 15 per cent felt that it has become worse.

The qualitative detail

- There was evidence of improved flexibility in the timing of supports (offering home visits and accommodating out-of-work hour appointments), the location of support (enabling them to travel), and the provision of support (being able to use different services/providers).
- While service flexibility was reported to have increased at wave 2, providers were still reported as being reluctant to provide services on a casual “as needed basis”.
- Other concerns included the quality of the support workers, lack of communication from disability service providers, rigid structures in the NDIS claiming systems and funding for therapist travel.

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

The quantitative detail

- Some serious planning activity is reported by support providers. This is unsurprising as the full roll-out is now treated as a certainty. The sector is listening.
- Some change is recorded in who is funding disability support providers, as would be expected in the NDIS trial sites. It is early days for the evidence to represent the whole sector, but the direction of the change is our first rough indication of what could be expected at full roll-out.
- The sector reports that expectations are positive and plans are in place.
- As experience is being built and uncertainties are dispersed, there are indications that the sector had been expecting worse than what they have experienced to date.

The qualitative detail

- While some initial changes had occurred in the disability sector as a consequence of the NDIS at the wave 1 interviews, more extensive impacts were reported at wave 2. The NDIS had prompted the need for disability service providers to change their business models. In some cases this was reported to have led to less personalised service provision.
- Many disability service providers were still receiving some block funding. As such, the full financial impact of the Scheme was not yet considered to have hit the sector. However, concerns about financial viability continued.
- NDIS providers were concerned about their capacity to deliver to the same standard as before the NDIS and according to need, citing NDIS funding caps and the NDIS emphasis on prices as a constraint.
- The entry of new providers into the NDIS trial sites was widely reported at wave 2. Most new entrants were small or solo allied health practices. The emergence of new internet based labour-for-hire services led to concerns about safeguards and the future quality of disability support services.
- Increased merger and acquisition activity were also reported.
- Some exits from the sector were noted, either through closure or a decision to cease providing disability support services due to the loss of state government funding. Reports were also provided of allied health professionals disengaging from the Scheme due to issues with pricing and best practice.

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

The quantitative detail

- The quantitative data cannot provide an early assessment on the present impact of the NDIS on the disability sector workforce. The data has been designed to provide the essential baseline evidence to enable such an assessment to occur once the second wave collection has been completed.

The qualitative detail

- The workforce is reported to be expanding; however, this is in the midst of concerns about skill shortages, employee recruitment and retention, increased turnover and churn, unfunded work, more casual and less well-paid work, remote provision, lower quality of provision and more.
- Some providers were reported to be having to hire agency staff due to recruitment issues. NDIS participants expressed considerable concern about the quality of these workers and the lack of specialised training.
- NDIS participants also reported that support workers could be unreliable (i.e. not arrive on time or at all) or there was no worker continuity on different occasion of care.
- Concerns about conflict between industrial relations responsibilities and NDIA pricing constraints continued. These concerns included paying staff award rates within NDIS pricing levels, managing minimum shift hours under industrial awards against NDIS participant requests for shorter services, and also had implications for workers compensation.

- Opportunities for training, student placements and supervision had reduced within the NDIS trial sites. Concerns were also expressed about the future impact that this could have on the skilling of the workforce and the ability to attract new workers to the sector.

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

The quantitative detail

- All outlets report an increase in the proportion of their services dedicated to disability support. Proximity to a trial site does not appear to make a difference.
- More than one third of all outlets plan to expand their range of supports, again, proximity to an NDIS trial site makes little difference.

The qualitative detail

- The NDIS had led to an increased demand for disability services. There were increased reports of new providers entering the market in response to this heightened service demand. In general, however, NDIS-funded supports continued to be provided predominantly by the current pool of disability service providers, many of who were reported to be expanding their supply of supports.
- In response to changing consumer demand, some providers were expanding the range of their services. Types of services that were reported to be experiencing growth included one-on-one support services, support coordination and financial management, therapy, respite and accommodation services.

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

The quantitative detail

- The quantitative data suggests that more than a quarter (27 per cent) of NDIS participants reported that they could not access a support for which they had funding under the NDIS (unmet demand). Of those NDIS participants who could not access a support:
- 41 per cent report that it was due to the waiting time being too long, 34 per cent because of a lack of local provider and about a quarter (24 per cent) mentioned the lack of quality provision available. Only 9 per cent reported the support being too expensive as a reason.
- About one third (34 per cent) of those NDIS participants who experience unmet demand also reported accessing services that are not funded by the NDIS
- 26 per cent of all NDIS participants reported that they accessed services not funded by the NDIS. Non-funded supports were mainly paid for by the family (50 per cent) and the participant (26 per cent).
- NDIS participants reported a wide variety of services they would like to have more choice with.

The evaluation used multivariate regression analysis in order to investigate further the issue of unmet demand. The key messages are:

- There are statistically significant differences across States with regards to how likely NDIS participants are to experience unmet demand.
- On average, NDIS participants living in rural or remote areas are 15 per cent more likely to experience unmet demand for supports compared to equivalent NDIS participants living in urban areas.
- Older NDIS participants are more likely to experience unmet demand.
- Unmet demand is also strongly associated with the NDIS participant's broad type of disability.
- The wider the variety of supports currently accessed by the NDIS, the more likely they are to have funding for supports that they cannot access.

The qualitative detail

- The qualitative data indicates that all groups interviewed as a part of the NDIS evaluation reported that NDIS participants and their family members or carers experienced problems with accessing supports and with the quality of their supports.
- A number of factors were seen to be limiting access to disability supports including small numbers or low capacity of service providers in area, lengthy waiting lists for some providers or types of support, inflexibility of support hours by service providers, rigid structures in the NDIS claiming system and fixed prices for certain types of support.
- NDIS participants report that supply has not been adapting to the changing demand for services, particularly in rural/remote areas. Some providers are feared to be reaching capacity constraints.
- Providers reported shifting to individual supports, in some instances expressing concerns about their cost-effectiveness and their inability to provide at the NDIS pricing levels, resulting in cross subsidising between services. Services considered underfunded were one-to-one community participation, mental health services, group services and services for people with complex needs.
- Persistent shortages are identified in speech pathology, occupational therapy and psychology.
- NDIA staff have been identifying demand increases and the challenges they bring in terms of shortages, rural/remote provision and "transitioning out" arrangements.
- Supply constraints are reported to be real and persistent. While adaptation is happening, it is very diverse and in many cases it is incomplete and unsettled.

2.1. Introduction

The NDIS is a new way of providing care and support for people with disability in Australia. The capacity of the NDIS to achieve an appropriate market-based balance between the supply and demand of disability support services is essential for its long-term success. Understanding the supply and demand of disability support services is also a central focus of many of the 56 Key Evaluation Questions (KEQs) of the NDIS evaluation. In this section we present evidence relating to the following KEQs which pertain to "supply and demand of support services".

- KEQ 17: For people with disability who previously received supports, to what extent has the NDIS contributed to changes in their patterns and use of supports?
- KEQ 32: What has been the impact of the NDIS on the overall provision and quality of disability services?
- KEQ 34: What has been the impact of the NDIS on the disability sector, including the relevant government agency in each jurisdiction and advocacy organisations?
- KEQ 35: Consider impacts on workforce (skills, retention rates, capacity, satisfaction, workforce culture, composition and proportion of occupation types).
- KEQ 36: Consider impacts on supply and diversity of disability supports (particularly sustainability, ability to respond to choice and control, and service capacity).
- KEQ 37: To what extent has the supply of disability services responded to demand?

2.2. 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?

The quantitative detail

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

The NDIS survey of people with disability, and their families and carers collects detailed information on respondents need for assistance in different contexts of their lives. The relevant questions are not asked of children below the age of 8 as young children have not yet developed full autonomy.

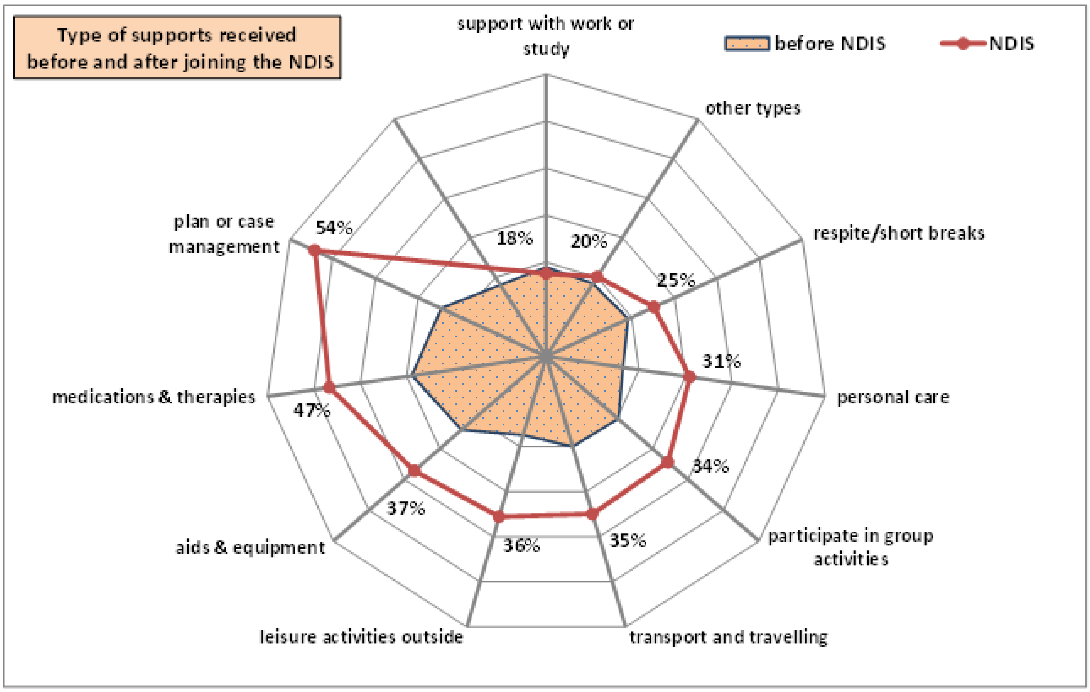
- Of the 1,134 NDIS participants aged 8 years and older, 960 (85 per cent) reported that they need assistance with daily activities (Appendix 2.2 Table 2).
- The most frequently mentioned types of activity NDIS participants needed assistance with were help with doing things in the household (89 per cent) and help with preparing food and eating meals (74 per cent) (Appendix 2.2 Table 3).
- An important aspect of support need and provision is how often it is required (Appendix 2.2 Table 4). A large majority of NDIS participants needed assistance daily, around 12 per cent needed assistance weekly, and the rest needed assistance less frequently or irregularly.
- Another important aspect of receiving support is the person who provides that support (Appendix 2.2 Table 5). Those aged 8 and above answering that they require assistance are 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”. Mothers were the most frequent carers, followed – at some distance – by fathers and partners. 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.

The quantitative data also contains information about what disability services are accessed by NDIS participants, both prior to joining the NDIS (through recall questions) and currently.

- After joining the NDIS, the range of supports accessed by participants widens. Indeed, before the NDIS 50 per cent of participants reported that they accessed 1 type of support and the average number of support types accessed was 2.02. Since participating in the NDIS, 50 per cent reported accessing 3 types of support and 75 per cent reported accessing at least 2 types of support. After joining the NDIS the average number of support types accessed is 3.3.

- The following Figure 1 shows the types of supports NDIS participants reported accessing before and after joining the NDIS.

Figure 1: Types of support received before and after joining the NDIS (Trial PWDs, all ages)



- Figure 1 makes clear that with the exception of "support with study" (16 and over only) and "other support types" the proportion of NDIS participants reporting access to each of the various types of disability support increased significantly and in the case of "plan or case management", "transport and travelling" and "leisure activities" had actually doubled.
- More than 87 per cent of NDIS participants reported that they use between 1 and 5 support providers in a typical month, with more than 60 per cent using 2 to 5 support providers (Appendix 2.2 Table 6).
- Despite the fact that most NDIS participants reported accessing more of every type of support after joining the NDIS, only a third (36 per cent) of NDIS participants have changed provider since joining the NDIS (Appendix 2.2 Table 7).

The qualitative detail

The qualitative data collected as a part of the NDIS evaluation adds to the quantitative findings presented above and allows us to understand what supports are being included or not in NDIS participant plans and how this has changed patterns and use of supports over time.

The perspective of the person with disability and their family members or carer

- Wave 1 interviews with NDIS participants and their family members and carers indicated that in the main, respondents had increased support as a result of the NDIS. This included increased hours of support, greater frequency (intensity) of service provision, more appropriate equipment, or access to a wider range of activities (including therapeutic support and social activities).
- At wave 2, respondents were generally satisfied with the supports and services included in their revised plans. The majority indicated the outcome of the review had been the "roll over" of funding from the initial plan with small upward adjustments to incorporate pricing changes or changing needs for services.

> *There's not a great deal of change. Basically, we moderated the plan to conform with Darcy's current program. The current program hadn't changed all that much from last year. So yeah, it was just titivating hours; basically, adjusting a few hours here and a few hours there. (C17C W2)*
>
> *[The plan has] got Shelley's best interests and giving her the life that she deserves and maybe we wouldn't be able to give her without the plan. (E06C W2)*

- Wave 2 evidence suggested that changed NDIA guidelines around the funding of some supports had led to items being funded that were not allowed to be funded during initial planning.

> *Grant got some equipment funded. He actually got a piece of equipment funded that I asked for Ned initially and it got denied. Which was really interesting. (D12C W2)*

- However, wave 2 interviews also showed that these changes to NDIA guidelines had led to funds being withdrawn from other, previously funded, supports:

> *In the first plan that we had, there's an ASD soccer group that Rory was attending and I was told this time no, that's not something they'd be able to fund anymore if we wanted to do that. It falls under that category of people that want to get trampolines, or pay for swimming lessons, that they kind of – basically, it's something you would pay for your child anyway and she said "we would expect that you would pay for sports or any of those sorts of things anyway as a parent, so they're not willing to fund it". (D11C W2)*

- While in a minority, several respondents expressed concern that the budget for their plan or the plan of the NDIS participant for which they cared had been adjusted downward at review. In these cases, budgets were reduced by the amount of funds not used in the preceding year. While some respondents reported being reassured that they could ask for funding to be re-instated if needed over time, others were concerned that if the plan was not utilised to its full extent then further cuts would occur and additional funding would not be accessible in the future.

> *I bought (sic.) up the fact that Darcy's has been reduced considerably a couple of times…And the impression I got from [planner] when he first came was you asked for that because if you don't ask for it you won't get it later. And because I haven't used all the funding and I didn't last time it kind of has been cut back (E13C W2)*

- In general, respondents described accessing the same range of services at wave 2 as they did at wave 1.
- The types of disability services and supports included in plans varied and were largely dependent on the age of NDIS participants.
- For younger children the types of supports included in the plan related principally to early intervention therapies (such as speech pathology, occupational therapy, physiotherapy, and psychology), though access to specific therapies was also provided for in plans of older NDIS participants. Equipment and aids were included in several plans, including funding for nappies and continence aids; communication support devices (e.g. iPads); daily living aids, and therapy aids. Some were additionally funded to access disability specific sporting or recreational activities (including swimming and horse-riding), or adapted equipment such as modified bikes. School-aged NDIS participants were also funded to engage in after-school and school holiday programmes, and for overnight respite care.
- For young adult NDIS participants, many of whom were recent school leavers, the principal services funded were day programmes or group activities and/or one-to-one supports provided by a disability support worker. Work preparation and work experience services were also common for this group.
- A range of other disability services/supports were funded without necessarily being related to a particular age group:

    - Equipment and aids were included in most plans, including funding for communication support devices (e.g. iPad), daily living aids, and therapy aids.
    - While funding for transport was commonly included in participant plans, this was not consistent. For some participants funding for transport was not part of their plan (this included instances where taxi vouchers had been removed from plans). A lack of funding for transport made it difficult and costly for participants to attend activities, especially those not in the local area.
    - As previously noted, some plans included funding for Support Coordination (including support to organise services and/or the financial management of plans). Wave 2 also saw the growth of funding for advocacy and support services related to the NDIS.
    - Several respondents noted the inclusion of respite in plans, though this was described in terms of personalised supports for the NDIS participant (e.g. assistance with daily activities, therapy support or skill development) rather than providing respite for carers.
- Whereas many respondents reported that the NDIS had helped them to increase their supports, many continued to be disappointed to see items and activities they had hoped to access not funded under their NDIS plan.
- The range of services that continued not to be funded by the NDIS at wave 2 was broadly similar to those noted at wave 1. These included alternative therapies (naturopathy, osteopathy, chiropractic treatments) and social and recreational actives (including drama classes, gym membership, camps for young people, hydrotherapy/swimming lessons, horse riding, and social groups). Other unfunded services and supports were related to overlaps with mainstream services, in particular education and health. The concept of “reasonable and necessary” continued to be used by the NDIA as a basis for not supporting these activities and services.
- Respondents mentioned that they regularly paid out-of-pocket expenses for services such as transportation (for example, bus tickets and taxi fares) and activity fees (like sporting and social participation activities) as funding for these was not included as part of their plan. Although generally these expenses continued to be paid out-of-pocket, there was some indication from respondents that the presence of these expenses discouraged participation in some of the activities.
- Similarly, other respondents were concerned that expectations by the NDIA that participants would cover costs for equipment items under $50 (e.g. physiotherapy aids and iPad apps) was problematic for people on low incomes.
- At wave 1, many family members and carers of NDIS participants (particularly of young children) reported that their own needs and the needs of the family more broadly were not addressed in the planning process. Respondents requested greater attention be paid to the family context, in particular the potential for parents/carers to require support and respite.
- At wave 2, it still appeared that funding for family supports was inconsistently included in plans and limited in scope:

> *When you look at five hours a month, it doesn’t really go very far if you wanted to actually use it for a break. You know, really, the only benefit I can see to five hours a month is using it in one hit on one day and actually going out for a big chunk because going out for an hour or two hours, sometimes just --it’s not a break. That’s me leaving them home with dad for an hour while I duck to the shops, like yeah. (D10C W2)*

- Of note, evidence was also provided that items (such as complimentary movie and massage voucher) that were previously supplied to parents/carers by disability service providers prior to the NDIS were no longer available. This furthered parents/carers’ perceptions that the NDIA’s concern for their needs was negligible.

> *The Commonwealth Carers Respite Centre was funding things for carers so recent example show tickets, movie tickets but other things as well that could be really helpful. Now if anybody rings up they say "Sorry, we've got no funding. It's gone to the NDIA." which actually isn't necessarily quite right or true but nobody's giving any support to carers respite centre anymore. They're getting nothing. They're getting the brush-off. (B02 PWD W2)*

The perspective of the service provider and key workforce organisations

- At wave 1, representatives from key workforce organisations and disability service providers observed positive changes for many clients, and, believed that on the whole, NDIS plans provided participants with the supports and services that they needed. Providers were impressed that access to allied health supports and services had increased due to individualised funding arrangements.
- At wave 2 representatives from key workforce and disability service providers found that NDIS participants had greater access to support services than in the past and overall outcomes were positive. Some were reported to be receiving more supports than before, especially around social participation, communication needs, post-school pathways and early intervention. More transdisciplinary plans had increased flexibility of service provision. The inclusion of funded case coordination services in many plans was welcomed as helping participants to implement their plans. However, many still noted the need for pre-planning support and stronger protections for vulnerable NDIS participants and families. In addition, providers were concerned that "extra" services such as community access were not included in NDIS plans.

  > *In general, all of them, or their parents, have access to far greater purchasing power, and the range of services that they are now able to access, should they wish to, compared to what existed under the (previous) system.(A01S W2)*
  >
  > *I think definitely there are people who are able to access services that couldn't before and that's been a really positive thing for them. (D05S W2)*

- The wave 2 interviews with disability service providers and representatives from key workforce organisations continued to observe an increased demand for services around increasing independence in the home and community. Respondents noted a greater focus on in-home care and community access services as well as a general move away from group-based services to individual services. Disability service providers did not see the move to individualised and community-based services as unproblematic. Group-based services were viewed as providing social opportunities both for the participants and their families as well as allowing transdisciplinary collaboration between service providers that other services did not.

  > *The opportunity for one-on-one support, and that has a positive and negative consequence, I think, so, people can very much more individually be developing skills that they need for their future, so that's great, but I also see that some people are being very isolated from friends and from contact, and that's alarming. So, we have one participant who would come here five days a week, and is an extremely social person, and now doesn't come in at all, so she's out with a support worker every day from home, so the only contact that person now has is her family and her support worker, so all of the conversation of the 30-odd people that attend here every day, the staff that walk past and say hello, and the participants that sit round and have conversations, that's all gone at the moment*. (D02S *W2*)

- By wave 2, evidence was also emerging that participants were increasingly choosing different service providers and requesting more services at weekends, after hours and for shorter periods of time.

> *They're far more assertive in saying I want the service on a particular day at a particular time, and only for one hour, and if you can't agree to all of those conditions, they very much look elsewhere until they can find it, or they might choose you if you've got the best match. (A01S)*

- Wave 1 interviews with both disability service providers and key workforce organisations also indicated that not all people with disability were achieving improved outcomes under the NDIS. Some NDIS participants were reported as not receiving all necessary supports, and in some instances previous levels of service provision had not been able to be matched under NDIS funding. There were concerns that some people with disability, particularly those unable to effectively advocate for services on their own behalf, were experiencing poorer outcomes under the NDIS and receiving a lower level of services than previously.
- These concerns persisted at wave 2, with respondents reporting that perceived NDIS funding constraints were adversely impacting support packages. They reported that some NDIS participants were receiving less supports than before the NDIS, or were having NDIS-funded supports reduced at review, and as a result, were unable to pursue more aspirational goals. Vulnerable NDIS participants and their families, including some people with psychosocial disability and/or those who struggled to manage complex NDIS processes were identified as being at risk of poorer outcomes. Additionally a lack of NDIS funding for supports such as respite, support co-ordination, behaviour management, employment skills, and psycho-social support for families was reported.

> *Some clients have found that sort of their allocation under NDIS has been dramatically cut back and I think they find that quite disempowering. I mean when that's happened it doesn't seem like they've really had any explanation as to why the allocation's been cut back so dramatically and so they're sort of left in limbo feeling like well, you know we, we had access to all of these services and now we have much less choice.(B05S W2)*
>
> *Those who do not have the time, energy, inclination … level of understanding, who are challenged by their overall family circumstances, they generally do not achieve the plans with the quantum of money, nor the degree of detail of specificity of connection between the particular goal and the disability support that's been approved. (A01S W2)*

The perspective of the NDIA staff

- NDIA staff reported positive changes for those participating in the NDIS and believed that the Scheme had improved the lives of many participants and their families. People with disability were now accessing supports which were previously not funded or available to them. However, NDIA staff considered that participants and families who were confident, educated and able to articulate support needs had better outcomes than those with less capacity to understand the Scheme, including participants with intellectual disability.

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

The quantitative detail

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

A large amount of the quantitative information that can be used to address this KEQs will also be included below in relation to KEQ4 and KEQ5.

- NDIS participants reported that their **say over what supports they receive** has increased (Appendix 2.3 Table 8). Indeed, 44 per cent of NDIS participants surveyed reported that they had more say over the supports they received once in the NDIS compared to before they joined the NDIS. The share of those experiencing a decrease in their say over what supports they received was 17 per cent, while 39 per cent reported no change.

- NDIS participants' **choice over where they obtain the supports they receive** has also improved (Appendix 2.3 Table 9). Just under half (46 per cent) reported that they had more choice over where they obtained their supports once in the NDIS compared to pre-NDIS. The share of those reporting that their choice of supports declined once in the NDIS was 16 per cent, while 38 per cent reported no change.
- Finally, satisfaction with the **quality** of disability supports is also reported to have increased after joining the NDIS (Appendix 2.3 Table 10). Just under half (49 per cent) of NDIS participants felt that the quality of supports under the NDIS was better than those supports they received prior to the NDIS, however 15 per cent of participants felt that the quality of their supports were worse. 35.5 per cent reported that the quality of supports did not change.

The quantitative detail

The 2014 NDIS Disability Support Providers Surveys

The survey of disability support providers provides only an early indication of the expected impact the NDIS will have on the disability sector.

- We identified those outlets that are located closer to the NDIS trial sites using their postcode (Appendix 2.3 Table 11). Out of a total of 697 outlets, 202 are close and the remaining 495 are not. Given that these outlets are a mix of smaller enterprises (where the postcode would be a good indicator of the location of their clients) and larger outlets (with a wider geographical reach than their postcode) a certain amount of imprecision is involved in the NDIS versus non-NDIS distinction (See section 1.6 for full discussion).
- The survey of disability support providers traces possible differences in the way quality of supports is monitored: managers are utilised 7 per cent more often and employees 5 per cent less often among outlets located near the NDIS trial (Appendix 2.3 Table 12). There does not appear to be a difference in the utilisation of performance criteria (Appendix 2.3 Table 13).

The qualitative detail

The qualitative data collected as a part of the NDIS evaluation includes much information about the provision of disability supports and views about the quality of those supports.

The perspective of the person with disability and their family and carer

- Wave 1 interviews with NDIS participants and their family members and carers indicated a lack of choice of service providers (most evident in regional areas), a lack of service flexibility and poor quality of care. Respondents also reported some service providers were reaching capacity, in particular some therapists were reported as having long wait lists.
- Wave 2 interviews with NDIS participants and their families and carers indicated improved flexibility in the timing of their supports (offering home visits and accommodating out-of-work hour appointments), the location of their support (enabling them to travel), and the provision of support (being able to use different services/providers).

> *Since the NDIS, the provider that I've been using has become more flexible and willing to have their support workers do whatever role it is that we want them to do, I guess. So they do provide Sean with support in increasing his independent skills and living skills and that works better for us. (C10C W2)*

- While service flexibility was reported to have increased at wave 2, a perceived inflexibility of the support hours offered by service providers continued. In particular providers were seen as being reluctant to provide services on a casual "as needed basis". This lack of flexibility limited NDIS participants and family member's choice, especially in the case of those who had been allocated funding for only a few hours of care. Notably, respondents usually chose another service in these instances.

  > *Male: It's always people like [Name of provider 1] that are just stuck in the old ways they will not embrace the new and change.*
  >
  > *Female: And that's what it is I'm afraid. NDIA on the right hand doing it all as best to their ability considering it's only been going for a couple of years and you've got the provider whose still living in the dark ages. (E02 PWD&C W2)*
  >
  > *That was like with one provider we don't use anymore because they wanted basically a week's notice, well who can give a week's notice of something that's going to be tomorrow. (B09 PWD W2)*

- One of the main challenges identified by respondents was the lack of choice over their support worker. This was particularly the case for NDIS participants who were new to the sector and generally, the support worker was allocated to the participant without input from the participant or their family.
- Having the ability to choose their own support worker(s) (via self-management or the use of new online platforms) provided respondents with confidence that their supports were of high quality.

  > *Yeah the quality's definitely been first rate like I couldn't have asked for anything better … they've just been amazing and… certainly take on board what's required of them. …I think that reflects on the fact that being able to make those choices ourselves has ensured that we've got that quality, because we've had that input into it or been in control of that and it's made such a big difference to the first year. (E14 PWD&C W2)*

- Some providers were reported to be having to hire agency staff due to recruitment issues. Respondents expressed considerable concern about the quality of these workers (including those providing care in respite accommodation).
- Respondents also reported that support workers could be unreliable (i.e. not arrive on time or at all) or there was no worker continuity on different occasion of care. They also questioned the lack of specialised training.

  > *And trying to get support workers to actually match your needs. There's times where you're better off going without than having the worker that they'll place in. So there's times where "Does matter who does that?" and the answer is "No it doesn't." but there's other times when you need a worker that you can match and the decent ones are so full up and they're now just getting them from the scrap heap. Basically any single person who doesn't have a criminal record is now working as a disability support because they're unemployed and so many of them don't want to be in the role. (C02 PWD W2)*

- Communication from disability services was sometimes perceived to be lacking. For example respondents reported having trouble getting information from, or even speaking to, their service provider.
- Rigid structures in the NDIS claiming system and fixed prices for certain types of support were also said to decrease choice. In addition, respondents were concerned that the presence of the NDIS had driven up prices for disability supports. That is, respondents reported receiving different quotes for services depending on whether they were an NDIS participant or not.
- Finally, funding for therapist travel continued to be a concern at wave 2. The NDIA decision to limit the amount of funding each therapist could claim for this purpose was felt to be an important

factor leading to reduced frequency of appointments for participants particularly of those living in outer metropolitan areas:

> *They've capped the travel for therapists too at $1000 now per plan per therapist and, you know, if you're living up here, that's not much. I can see their argument they don't want to be everybody's funding to be taken up with travel, but therapists aren't going to come up for free either. (D05C W2)*

The perspective of the service provider and key workforce organisations

- At wave 1, service providers reported introducing more flexible arrangements around the types of services they were providing, such as ensuring that services were provided at the times and locations that suited participants. Further innovation of service delivery, in the form of more diverse and flexible service options, was expected to occur as the Scheme progressed.
- At wave 2, in response to client demand, some providers had continued to extend their operating hours to include longer day programs, more after-hours and weekend service provision, and reducing the time their services were closed over the Christmas period.

> *Are we more flexible? Yes, because we are more likely to offer out of hours, or some weekend work. I think many participants experience us as being more flexible than we used to be. (B04S)*

- Due to NDIS pricing constraints and time benchmarks the provision of quality services was seen as being difficult under the NDIS. The perceived erosion of existing governance structures in the sector (with the withdrawal of state based services) and a lack of regulation and staff accreditation was also felt to be negatively impacting on service quality.
- The low hourly rate for supports funded by the NDIS had led to increased staff turnover and agency staff being employed without appropriate qualifications or experience.

The perspective of the NDIA staff

- NDIA staff reported that in general the quality of disability supports had improved as NDIS participants were able to exercise choice and leave providers if they were unhappy with services. However, several respondents expressed concerns about the quality of unregistered providers.

> *What I'm particularly concerned about at the moment is the quality and safeguarding with regard to incident reporting. I am not a fan of unregistered providers. I believe we should have a system where all providers have to be registered and meet a minimum standard. (B01N W2)*

- At wave 2, NDIA staff reported that people with disability had been exercising choice and seeking more flexibility in the times they accessed supports. It was observed that while some providers were responsive to these requests, others were not. Overall, there was an increase in providers offering weekend, after hours and longer day services reflecting client demand. There was also evidence of providers offering shorter shifts in line with client preferences and providing personal care needs, such as showers and assistance going to bed at times that better suited participants.

> *People are walking up going well why can't you give me the support I need when I need it. And so as people become more proactive the response from the providers is to become more flexible and offer more options and work with people to try and maximise the way they use their plan. (D08N W2)*

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

The quantitative detail

The 2014 NDIS Disability Support Providers Surveys

General outlook:

- A large proportion of all outlets expect the NDIS to have a positive impact on them (28 per cent for non-NDIS and 30 per cent for NDIS trial areas. The expectations are more pessimistic among those who have not as yet experienced the NDIS directly (Appendix 2.4 Table 14).
- A similar difference is observed among self-employed providers. The self-employed in NDIS trial areas are more optimistic about the impact of the NDIS than their counterparts in non-NDIS areas. Around, 83.7 per cent of the self-employed in NDIS trial areas expect the implementation of the NDIS to have a positive impact on this business. A little over half of the self-employed in non-NDIS areas expect the implementation of the NDIS to have a positive impact on their business, however over a quarter are unsure what the impact of the NDIS will be (Appendix 2.4 Table 15).

Will the NDIS bring change?

- More outlets in the NDIS trial areas expect the implementation of the NDIS to have a positive impacts on (1) wage growth, (2) employment, and (3) overall performance than in non-NDIS areas (Appendix 2.4 Table 16).
- Similar differences are observed for self-employed providers. Self-employed in NDIS trial areas expect the implementation of the NDIS to have a more positive impact on (1) prices, (2) profits, (3) employment, and (4) overall performance than the self-employed in the non-NDIS areas (Appendix 2.4 Table 17)**.**

Is the sector responding to the NDIS roll-out?

- A larger proportion of outlets in the NDIS trial areas report to be acting in response to the NDIS, while a larger proportion of outlets in non-NDIS areas report to be planning to act in the next 12 months in response to the NDIS (Appendix 2.4 Table 18).

Funding outlook:

- There is little definitive evidence as yet from the quantitative data regarding the level of funding and its distribution. It appears that the total funding to all outlets in the sample dedicated to the provision of disability support services increased from the year 2013-14 to 2014-15.
- The proportion of funding provided by the NDIS specifically also appears to have increased in all outlets, but much more so among those in the NDIS trial areas. In the NDIS trial areas funding provided by the NDIS increased by 11 per cent, while funding provided by other government agencies as well as state and local governments decreased by 2.7 per cent, 5.4 per cent and 1.1 per cent respectively (Appendix 2.4 Table 19). The pattern is that of NDIS funding increasing and all types of government funding decreasing.
- The sector's reported expectations for increased funding from the NDIS to individual outlets between 2014/15 and 2015/16 was from 4.9 per cent to 15.3 per cent for those located in non-NDIS areas and from 20.7 to 27.4 for those located in the NDIS trial areas (Appendix 2.4 Table 20). Without further detailed analysis, these figures are hard to interpret.

The qualitative detail

The qualitative data collected as a part of the NDIS evaluation includes a large amount of information on the perceived impact the NDIS has had on the disability sector and its workforce.

The perspective of the person with disability and their family and carer

- At wave 1, evidence of changes in the supply or diversity of disability supports were few and far between. Market changes were slow to materialise, due to a slowly adapting or emerging provider sector, and as a result of NDIS participants often retained existing provisions.
- At wave 2, there was a mixture of feedback from NDIS participants and their carers about how the disability sector had responded to the NDIS. As noted earlier, some suggested there was still evidence of "*the old way where… these are the services that we're prepared to offer you. Take it or leave it (C17C W2)*" but there were examples also given of positive movement towards greater flexibility of service offerings and willingness to consider new and creative business models.
- Changes to the sector that were perceived positively by respondents included: changes to the provider market, most notably the entrance of online platforms for participants and carers to manage their own support workers; increased choice of services and improved quality due to a greater number of NDIS providers; and improved flexibility in service provisions with enhanced provision of individualised support.
    - At wave 2, respondents observed greater choice of some services and support and improved quality due to the existence of more registered NDIS providers and therefore more competition.

        > *There's a lot more services available now and the quality is a lot better because they're all pushing against each other to get money out of everybody … (E07 PWD&C W2)*
        >
        > *Now there is competition and I think they've sort of pulled up their socks. There is a total change in attitude… we raised an issue and it got taken right up the line and this type of a response immediately we didn't get [before] you know, they're sort of anxious to keep their clients now. (C16C W2)*

    - However, some expressed concern about the new providers, enforced by a perception that they could be involved in NDIS for purely financial reasons and that the quality of the service they are providing (particularly in relation to support workers) was less than ideal.

        > *They give you a great big wad of things. You don't know any of them. These people have all come on board because of the NDIS, they're all jumping on the bandwagon for the money. You don't know whether you've got a good one, a bad one or other. (E11 PWD&C W2)*

    - A growth in privately offered services to support NDIS transition, including support for planning and plan implementation (support or case coordination), as well as advocacy was also reported. In addition, there was evidence of carers capitalising on their own skills and experiences in the NDIS to offer planning workshops and advocacy supports to others:

        > *I went to a workshop on preparing for reviews… run privately, and the lady who ran it has a disabled child and she's actually since the NDIS came in, started running her own business…. the market is responding to a need. Like she's running a business. There's no two ways about it. She's running a business because she can see a need out there. It's not out of the goodness of her heart. She's also making money out of it. (C18C W2)*

    - The biggest change in the sector however, related to the introduction of online services allowing NDIS participants and their carers to recruit and self-employ their own disability support workers. This new approach was much desired by a number of respondents, as it was thought to provide better control over services and in particular, the ability to match support worker to the needs of the person with disability.

> *I can see all the available support workers in the Canberra region who are registered through [name of provider 2] and their profiles. I can request to book a particularly support worker. They get an email with the request. They respond to it. You get a booking. It's all done online. (C18C W2)*
>
> *I'll be able to employ the people that I want to employ, whereas at the moment, when I ask for a 21 year old male, fit, young passionate male to take Darcy to the gym, I end up with a 55 year old, obese, female smoker. It's not right. That's what I've been contending with this year. (C17C W2)*

- In contrast, there were also changes to the disability sector at wave 2 that were perceived negatively by respondents.
  - There was evidence of changing relationships between families and providers as disability services providers moved to more commercial business practices. The use of service agreements appeared to highlight the financial context in which NDIS services were provided - for example describing penalties for non-attendance at appointments.

    > *I noticed quite a shift in service providers attitudes that bothers me, that the service providers, even ones that we've dealt with for quite a time, who were very flexible and very helpful, and really treated us as part of the family… they're so fed up with it that they really are getting like "No I won't, not unless they pay." (D01C W2)*

  - For some, changed attitudes on the part of providers towards their clients with NDIS plans led to less personalised service provision.

    > *On the weeks that we paid with our private health, to when we used his care plan allowance, was - it was chalk and cheese the way you were spoken to, the way you were treated… paying with your own money you seem to get more. You're valued more than if you're using your care plan, "We don't have to do as much this week." (D17C W2)*

  - Concern was also expressed about changing models of care, reflected in some part by the greater emphasis on one-to-one supports and concern about the loss of "wrap-round service provision".

    > *I know they were hoping to get that holistic, whole team thing happening right from the beginning, but that certainly didn't happen. And I don't think my speechie and OT [occupational therapist], who were within the same organisation, ever spoke to each other about Sean or his needs. It was still very much an individual "this is your speech therapist and we do speech/this is my OT and then we do OT", even though initially there was meant to be some consultation. (C10C W2)*

  - More generally, respondents reported hearing from some providers that they were struggling financially in the new NDIS market-place, with examples given of providers reducing services and increasing prices (despite consumer push back):

    > *They said, "Oh, we're no longer going to offer respite care on weekends"…. (C08C W2)*
    >
    > *And they went very quiet, and they said, "Look under the NDIS we are struggling to make money and we have to get some revenue from somewhere." That was the bottom line. (C18C W2)*

The perspective of the service provider and key workforce organisations

- While some initial changes had occurred in the disability sector as a consequence of the NDIS at the wave 1 interviews, more extensive impacts were reported at wave 2. The NDIS had prompted the need for disability support providers to change their business models. This encompassed a move from mission to market-driven practices, the demonstration of more accountability, and greater focus on financial issues. Considerable variance was noted as to how well providers had been able to adapt to the new model of the NDIS.

  > *It's a mission-driven market. It's not a business-driven market…[but] they have had to take a market-based approach to their business practices. (10R W2)*

- Concerns raised at wave 1 regarding the NDIS pricing structure and a lack of adequate coverage for the full costs of service delivery continued at wave 2. Many organisations were reported to be currently operating at a loss under the Scheme. Providers described different ways of reconciling this - some were willing to accept temporary financial losses in the hope of future profits with full roll-out; others were cross-subsidising funding from other sources to be able to continue to operate.

  > *I haven't heard any provider yet say that they're comfortable with the level of funding they're getting in packages. They all say they're running at a loss. (08R W2)*

- At wave 2, many disability service providers continued to receive some block funding. As such, the full financial impact of the Scheme was not yet considered to have hit the sector. However, concerns about financial viability continued and included reports of unfunded work such as the extra administrative work generated by the NDIS, funding for cancelled appointments, adaptation to the payment in arrears system, and ongoing concerns about the financial viability of small providers.

- Increased merger and acquisition activity had been occurring in the trial sites at wave 2, with larger organisations taking over the operations of some smaller providers. The long-term sustainability of some disability service providers (and particularly small organisations) remained a concern. In order to protect the future sustainability of the disability service sector, it was widely recommended that the NDIA review their current pricing structures and levels. Active intervention in the market place was also highlighted as being necessary to enable small providers to survive and continue to offer services under the NDIS.

  > *An increase in the number of mergers are being reported…But I think too what we're also hearing around the merger stuff is that a lot of large organisations are being approached by smaller organisations and that when they do some of the initial due diligence work they're finding that the underlying financials for some of these smaller providers are weak, and so the merger discussions are not progressing. (05R W2)*

- While at wave 1 there had been little change in the composition of the disability provider market, the entry of new providers into the NDIS trial sites was widely reported at wave 2. While the emergence of internet based labour-for-hire services was reported, most new entrants were small or solo allied health practices. Evidence was also provided of established provider organisations moving into the trial sites in preparation for full roll-out. The emergence of new labour-for-hire services led to concerns about safeguards and the future quality of disability services. Several providers and stakeholder groups were concerned that the NDIA had still not released a quality framework to ensure quality service provision.

  > *The concern around the subcontracting Uberisation of the sector…I think will be interesting because there's a whole lot of risks there, particularly in terms of the financial risks for the, well, for workers taking on all the liabilities and the employer, but also the risk for people with disability without regulation or control and…because it kind of seems as if anyone can sign up to this. (07R W2)*

- Some exits from the sector were also noted. Some state-provided disability services in the NSW and ACT were reported to be winding down; the closure of some NGO children's services in SA and the ACT due to the loss of state government funding had also occurred. Reports were also provided of allied health professionals disengaging from the Scheme due to issues with pricing and best practice.

  > *We now have the institutions closing down around us so we have three lots of those that are closing. (D01S)*
  >
  > *An OT practice that saw a lot of people with autism has closed and so then that meant that all the other OTs at the moment have huge waiting lists because all of those people have had to go and find another OT so I don't know why that was that they closed, whether it was to do with the funding. (D05S)*
  >
  > *A lot of the private psychologists, in fact, are not signing up for the NDIS providers or are dropping out…either the money's not adequate to cover the service, or alternatively, they have real trouble getting the money because there's issues with the NDIS payment process…so it's like, oh, give up, I won't do those clients anymore, it's too hard, which is a real shame for consumers. (03R W2)*

- Providers continued to report good relationships with other providers at wave 2 although as at wave 1, interactions remained guarded and there was less sharing of information due to commercial considerations. More generally, though respondents felt that the Scheme had adversely changed the dynamic within the sector with increased competition for staff and clients occurring. However, some collaboration between providers was continuing to occur as providers adjusted to the new marketplace.

  > *I think that's been a sad sort of aspect of the NDIA. When you create a competitive marketplace it's very hard, you know, those old networks that we would have been a part of and shared ideas and things like that have kind of broken down a little bit. (C04S)*

- Several recommendations were suggested to ease the adaptation required by providers to the NDIS and to protect the future sustainability of the disability sector. As at wave 1, the NDIA was encouraged to have more of a focus on sector support and development. In particular, providers required enhanced support in developing their capabilities including assistance with adapting their business models. Respondents from trade unions also expressed the view that continued active state involvement in the sector was essential for the establishment of an effective provider market.

The perspective of the NDIA staff

- NDIA staff reported that there was a mixed response to the NDIS by disability service providers. Some providers were positive about the NDIS, willing to accept change and were responding effectively to the new environment. Some providers had engaged with their clients to ascertain service needs, created new business models, changed service programs, adapted staff roles and sought a more diverse workforce and as a result were perceived to be managing well. Other providers, however, were described as "sitting on their hands" or "burying their heads in the sand" and failing to prepare and adapt to the NDIS. Some NDIA staff attributed a lack of adaptation to the Scheme to ongoing block or in-kind funding. Moreover, it was noted that the NDIA had to ensure providers were given information about the future roll-out in a timely manner to allow them adequate time to prepare.

- At wave 2, NDIA staff reported that the number of providers in the trial sites had increased. In Barwon, the Hunter and South Australia there were reports of new large providers coming from interstate. NDIA staff noted a particular increase in the number of sole or small providers in every trial site. These were primarily therapists delivering allied health services and to a lesser extent independent support coordinators. Concerns continued to persist about deficiencies in provider markets in rural and remote locations.

> *I see that there's been an increase in the market. We have over 800 providers registered down here now. That's massive… You know so therapists, like the increase in therapists and available therapy is massive. (B01N W2)*
>
> *There's always new providers coming in. Mostly you see individuals or smaller type you know, couple of speech pathologists or a couple of people that provider the co-ordination of support. (D05N W2)*
>
> *No, (there's not enough providers to meet demand) not at the moment, not, and particularly as we kind of move forward there aren't going to be, particularly as we go regional. The more kind of out we get into the country the harder it's going to get. (D02N W2)*

- NDIA staff noted some providers exiting trial sites, either through closure or a decision to cease providing disability support services. Some evidence of mergers between providers was also reported.

> *I referred to the list this morning and there are a number that no longer exist and I think, I looked at one called [Name], that was from psycho-social people but it's very sad that's gone. That was a not-for-profit agency that relied on funding from State Government and NDIA funding doesn't provide for that organisation to exist. (B02N W2)*
>
> *Several mergers happening this year or have happened …. So yeah so half a dozen notable mergers this year I think, or thereabouts (C03N W2)*

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

The quantitative detail

The 2014 NDIS Disability Support Providers Surveys

The survey of disability support providers indicates that it is too early to assess the impact the NDIS has had on the disability service workforce. It does however provide some of the essential baseline data that will enable such an assessment when wave 2 data collections become available.

- There are some clear differences between the workforce composition of the outlets located in the NDIS trial areas and those located in the remaining non-NDIS areas. Outlets in the NDIS trial areas report a larger average number of employees in the core occupations (an average of sixty-four workers against forty-six for outside the NDIS trial areas). This may be an indication of increasing occupational concentration in the sector, presumably as a response to the NDIS roll-out. The NDIS trial located outlets are also more likely to be employing male workers in all different occupational categories (Appendix 2.5 Table 21), but the gender difference is not uniform among the various occupations.
- There are also clear differences between workers in the NDIS trial areas and elsewhere in terms of the percentage of workers in each occupational category and their contractual status – defined as being under permanent/continuing contracts or not (Appendix 2.5 Table 22).

The qualitative detail

Interviews with disability service providers and representatives from key workforce agencies indicated a number of impacts the NDIS has had on the disability sector workforce.

The perspective of the service provider and key workforce organisations

- At the time of the wave 1 interviews the full impact of the NDIS on the disability workforce was yet to be realised. Greater impacts were reported by respondents in the wave 2 interviews. While working conditions were generally being maintained in the trial sites, increased levels of precarious employment (in the form of casual and contract work) were reported for support workers. Concerns were also raised about increased staff workloads in managing the administrative and financial components of the NDIS, such as the unfunded support provided to NDIS participants in managing NDIS plans and processes. Concerns about conflict between industrial relations responsibilities and NDIA pricing constraints continued. These concerns included paying staff award rates within NDIS pricing levels, managing minimum shift hours under industrial awards against NDIS participant requests for shorter services, and implications for workers compensation.

- As had been emerging at wave 1, increased consumer demand had led provider organisations in the NDIS trial sites to experience expansion and consequently hire more staff. However, providers were reported to be offering contract or casual positions at lower rates of pay and skill levels. Some increased casualisation in the workforce was perceived to be leading to higher levels of turnover and churn in the sector and reducing the quality of services for people with disability.

  > *What they've often found is a lot of staff who are untrained, unsupervised, and casuals and that sort of stuff, so you're sort of getting bodies on deck, but the two issues for that, is one that's often for the clients or families, they actually don't know who their support worker's going to be, it's often not the same person all the time, so they're getting their weekly support, but there's a rollover of workers because people are sort of coming in and out, it's a bit transient workforce rather than investing in it, like a stable workforce. (03R W2)*

- Staff retention was also reported to be problematic. Due to continued uncertainty of future employment, state government workers and some tertiary qualified staff in provider organisations were reported to be leaving the sector, leading to the loss of experience and skills. Persisting shortages of staff, particularly for the allied health professions were also reported (particularly in rural and remote areas).

  > *We have already seen, even though the state service hasn't completely withdrawn we are seeing a number of allied health that have just left the state service. Some of them have got jobs not even in the disability space. (11R W2)*

- Challenges with staff recruitment was also evident in the sector. These challenges included a lack of experienced allied health workers and workers with specialist disability expertise. Lower wages offered by not-for-profit disability providers also made it difficult to compete with the public and private sector to attract staff. Demand for therapy staff remained high at wave 2, particularly for speech pathology, occupational therapy and psychology services where demand exceeded supply.

  > *We need more staff. That's the biggest issue for us. We're constantly, people are asking for things outside of hours, people are asking for things when we're already literally packed out, we just can't fit much more in there so we're actually having to look for more staff. (D03S)*

  > *Impossible. Almost impossible… It's always been difficult for us to find therapists who have an interest to work in private rehabilitation and also the experience. So it's nothing new, and it potentially might be getting harder for us because there are other providers out there who will snap up the same people that we want. (E03S)*

- To ensure sufficient support worker numbers, providers also sought to employ from non-traditional employee pools. For example, one provider advised they now sometimes hired older men leaving earlier careers and bringing "a whole lot of life experience and community contacts that are also really valuable" (B02S). Another provider was trying to employ support workers from the fitness industry or with music skills to match the more diverse services being requested by their clients. In response to demand from younger NDIS participants, several providers sought younger staff to work with these clients.

  > *A lot of (clients) aren't looking for people with a disability experience, they are looking for people that yeah can match their likes and dislikes. You know a lot of people are looking for*

> *younger people that want to go out on a Friday night, that sort of stuff, they're not looking for somebody that has that disability background. (D03S)*

- A perception was expressed in the wave 1 interviews that the pricing structure of the NDIS would bring change to the role of allied health professionals through encouraging the increased use of non-professional staff. By wave 2 a de-professionalisation of the disability workforce was more commonly being reported, with increasing numbers of allied health assistants in the sector. Concerns were raised about the ability and skills of these workers to provide more complex supports and the impact this could have on the quality of care and outcomes for participants.

> *We have employed a number of inexperienced people, but I believe that's starting to backfire… Just the inexperience and the lack of knowledge on how to work with behaviours or understand confidentiality, or things like professional distance and all those types of things. And we're sending inexperienced people out to work individually with people with disabilities. (D02S)*

- At wave 1 concerns were raised that NDIS pricing did not provide funding for the training of staff and this would undermine workforce quality. Moreover, the ceasing of block funding arrangements was expected to be detrimental to the availability of training and supervision in the sector. At wave 2, key workforce organisations and disability service providers reported that opportunities for training, student placements and supervision had indeed reduced within the NDIS trial sites over the previous twelve months. Concerns were also expressed about the future impact that this could have on the skilling of the workforce and the ability to attract new workers to the sector.
- As was also observed at wave 1, a lack of adequate workforce planning by both provider organisations and the NDIA to address the potential challenges of the NDIS was reported. Furthermore, concerns were raised of a lack of worker preparation and engagement about the Scheme.

The perspective of the NDIA staff

- NDIA staff reported that a lack of sufficient numbers of trained staff within the disability workforce meant that providers were struggling to meet the demand for services. Shortages of workers were particularly noted amongst support workers, therapists and support coordinators.

> *I think all disability service providers are struggling to get staff. Struggling to get staff probably with the higher level qualifications that we're needing for support work connection and coordination particularly. (B13N)*

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

The quantitative detail

The 2014 NDIS Disability Support Providers Surveys

The survey of disability support providers provides preliminary evidence on the supply and diversity of disability supports.

- The evaluation finds that compared with one year ago, all outlets report an increase in the proportion of their services dedicated to disability support. Proximity to a trial site does not appear to make a difference and increases are small (2.6 per cent for those close to the NDIS trial areas and 2.5 per cent for the rest) (Appendix 2.6 Table 23).

- While disability supports of nearly all types are higher than what they were “one year ago” in both non-NDIS and NDIS trial areas, the NDIS trial areas have experienced higher increases in all types of disability support except for early intervention (Appendix 2.6 Table 24).
- The quantitative data suggests that the sector is planning to adapt to the new demand coming from the NDIS. More than one-third of all outlets reported that they plan to expand their range of supports in anticipation of the NDIS roll-out, 38 per cent for those close to the NDIS trial areas and 33 per cent elsewhere (Appendix 2.6 Table 25).
- Compared to outlets, a much higher proportion of the self-employed providers report that they have no plans to alter their range of supports. More plans are reported to be in place among the non-NDIS located self-employed providers, possibly because those in the NDIS trials may have already made their planned changes (Appendix 2.6 Table 26). Wave 2 evidence will be needed for us to understand this distinction adequately.

The qualitative detail

The perspective of the service provider and key workforce organisations

- The wave 2 interviews observed that the NDIS had led to an increased demand for disability services. As described above, there were increased reports of new providers entering the market in response to this heightened service demand. In general, however, NDIS-funded supports continued to be provided predominantly by the current pool of disability service providers, many of who were reported to be expanding their supply of supports.
- However as at wave 1, concerns were expressed regarding the long-term sustainability of smaller disability providers. Increased merger and acquisition activity had been occurring in the NDIS trial sites over the previous year. It was feared that this would continue and the market could potentially become dominated by large disability organisations leading to reduced choice of supports for people with disability.
- Increased diversity in the types of supports requested by NDIS participants was also reported at wave 2. As a consequence some providers were expanding their range of services or developing more innovative services. Other disability service providers, however, were reported to be struggling to meet client demands.

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

The quantitative detail

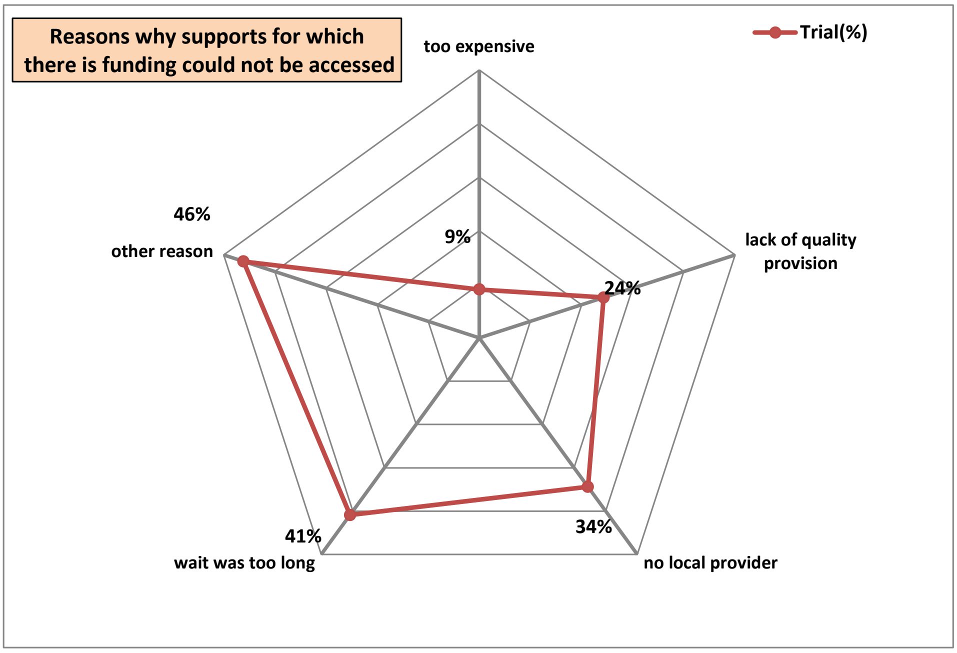
The NDIS Survey of People with Disability, and their Families and Carers

The quantitative data includes specific measures of unmet demand and this can be used to access the extent to which the supply of disability services has responded to demand.

- 27 per cent of NDIS participants reported that they could not access some of the supports for which they had funding under the NDIS (Appendix 2.7 Table 27). At only 6.4 per cent, the proportion is much lower for people with disability who were not part of the NDIS trial.
- Of those NDIS participants who could not access a support 41 per cent report that it was due to the waiting time being too long, 34 per cent because of a lack of local provider and about a quarter (24 per cent) due to the lack of quality of the available provision. Only 9 per cent reported they could not access the support because it was too expensive (see Figure 2 below).
- Figure 2 illustrates the distribution of the reasons stated by the respondents as to why they could not access some of the supports they already have funding for. We note that the category “Other” is very widely populated in this question (46 per cent of all answers), which indicates that there is

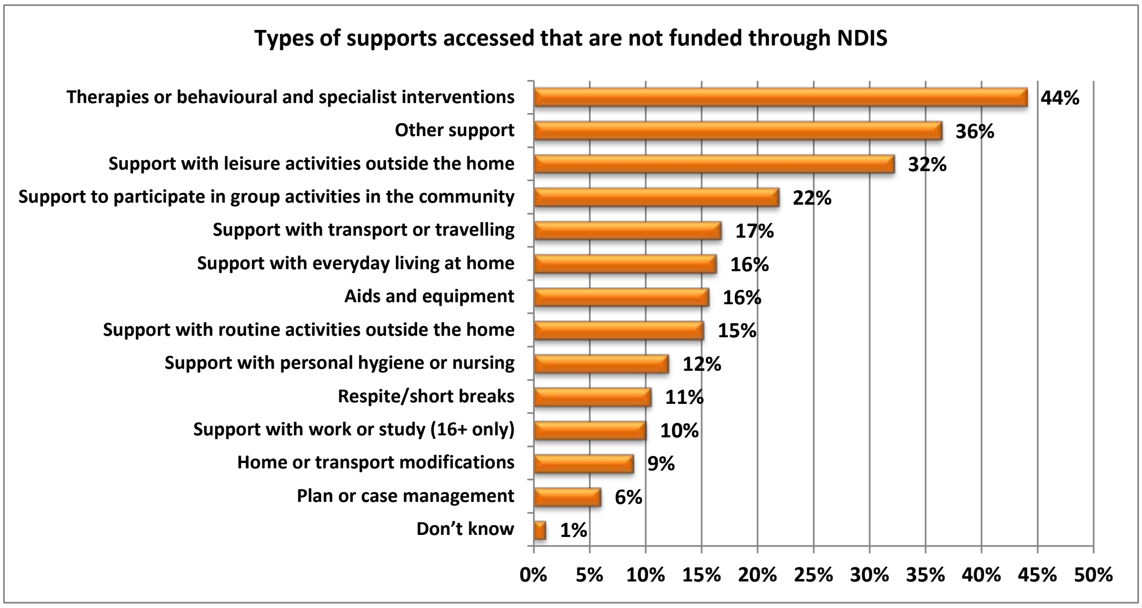
considerable diversity in the reasons why supports could not be accessed, that is not captured fully by the quantitative data. This observation is clearly borne by the qualitative findings that follow.

Figure 2: Reason why support for which there is funding could not be accessed (Trial PWDs, all ages)



- Among all NDIS participants 26 per cent accessed supports not funded through the NDIS. This proportion was a little higher for those who experienced unmet demand with (34 per cent) reporting accessing services that are not funded by the NDIS.
- Figure 3 below shows that the most frequently reported non-NDIS funded supports which NDIS participant accessed were therapies or behaviour and specialist interventions (44 per cent of all NDIS participants who accessed non-NDIS funded supports) with the next most commonly accessed being support with leisure activities outside the home (32 per cent of all NDIS participants who accessed non-NDIS funded supports).

Figure 3: NDIS participant accesses supports not funded through the NDIS (Trial PWDs, all ages)



- The most frequently reported way NDIS participants accessed non-NDIS funded supports (Appendix 2.7 Table 28), was either to rely on family members to pay for the supports (50 per cent of responses), or to pay for the supports themselves (23 per cent of responses).

We use multivariate analysis in order to investigate further the issue of unmet demand for supports experienced by NDIS participants. The question is whether people sharing the experience of unmet demand under the NDIS have any clear identifying characteristics that we could use in order to guide future policy interventions. The key messages we get from multivariate analysis are:

- There are significant differences across States with regards to how likely NDIS participants are to experience unmet demand. An NDIS participant in the Victoria trial site is, on average, 17 per cent more likely than a similar NDIS participant living in the NSW trial site to experience unmet demand for supports. This difference in the probability of experiencing unmet demand between NSW and Victoria has been estimated after we have accounted for differences between NDIS participants in terms of their individual characteristics.
- The evaluation also finds that, on average, NDIS participants living in rural or remote areas are 15 per cent more likely to experience unmet demand for supports compared to equivalent NDIS participants living in urban areas. Further analysis shows that among NDIS participants living in rural or remote areas it is the younger ones that are more likely to have unmet demand for supports, while among NDIS participants living in urban areas it is the older ones who are more likely to experience unmet demand for supports.
- As a general picture, older NDIS participants are more likely to experience unmet demand, i.e. there is a clear positive association between the age of a person with disability and their probability to experience unmet demand.
- How likely it is that one experiences unmet demand is also strongly associated with the broad type of disabilities of NDIS participants. Combining the information on disability type and age, we find that for younger NDIS participants, aged 13 and less, the highest probabilities of unmet demand are observed for those who have a developmental or congenital disability. For NDIS participants aged 15 or older, we find that those who have a physical disability experience the highest probability of unmet demand.
- Younger NDIS participants who self-manage funding are more likely to experience unmet demand compared to NDIS participants who do not self-manage funding. This association does not appear among the older NDIS participants. We note that this is an association that does not lend itself to an easy causal interpretation.
- Finally, the evaluation finds that the wider the variety of supports currently accessed by the NDIS participants (number of types of supports currently accessed) the more likely these participants are to have funding for supports that they cannot access.

The qualitative detail

Interviews with disability service providers and representatives from key workforce agencies contain information that can be additionally used to assess the extent to which the supply of disability services have responded to the demand.

The perspective of the person with disability and their family and carer

- Despite evidence of some positive changes to the overall provision and quality of services, the wave 2 interviews also indicated that many NDIS participants and their families and carers continued to experience difficulties in accessing disability supports.

- Many respondents, particularly in regional and, to a lesser extent, outer metropolitan areas, felt their choice and control over supports was impeded by the small number or low capacity of service providers in their area. This was particularly an issue for respite and employment services.

  > *No we don't have a choice. And I think there's only [Name of provider 1] anyway … for an actual service provider we've only got one. (E02 PWD&C W2)*

- Many reported waiting lists for some providers or types of support such as respite. In some cases, it was indicated that providers with specialist expertise, such as therapists, had been overwhelmed with the number of NDIS participants and had limited appointment availability. The problem of wait lists was therefore more evident at wave 2 than wave 1:

  > *There's a limited number of health professionals within South Australia and now people have got the funding to be able to go and see them, of course their availability is getting less and less and less. (D11C W2)*
  >
  > *Like take [name of social skills program], for example. That's already booked out for next year for the first six months. So if somebody comes in and had a plan and [says] I want funding for (a social skills program)… they are highly unlikely to get it. So it's all well and good to provide funding for something, but if there is no place for your child to do that particular support, it doesn't work. (D12C W2)*

- Respondents also reported that it was difficult to access disability support services, due to increased demand since the NDIS began. For example, several respondents reported that respite services had been easier to access prior to the NDIS as there had been fewer people seeking them. A similar narrative was told about physiotherapy, speech therapy, and accommodation options.

  > *Once kids go under the plan all of a sudden they're full because people have got the funding for it and they're using it….That's going to be constant because there are not enough speechies, OTs or any specialists down here now. (B11 C W2)*

- Several respondents expressed dissatisfaction that they were unable to obtain the intensity of services they would like (and were funded to receive). There were a number factors related to this, including wait lists for therapy services and limited capacity of individual providers; and staffing vacancies within the larger agencies (particularly for speech pathologists).
- Several respondents felt that the current environment in which demand for services out-stripped availability had resulted (as pre-NDIS) in a "service providers market" (C18C W2). As a consequence some providers were perceived to be not giving good value for money, or were inflexible or complacent.

  > *So there's a bit issue about providers in this town, they are still running the show, they are still acting in a cavalier way, they can do what they like. (C02 W2)*

The perspective of the service provider and key workforce organisations

- As anticipated at wave 1, the wave 2 interviews provided evidence that demand for disability supports had increased strongly in the NDIS trial sites during the subsequent 12 months. As a consequence of this increased demand many provider organisations were reported to be increasing their client numbers, services and workforces.
- At wave 2, key workforce organisations and service providers also reported that in response to changing consumer demand, some providers were expanding the range of their services. Types of services that were reported to be experiencing growth included one-on-one support services, support coordination and financial management, therapy, respite and accommodation services.

> *So we have increased our accommodation and respite services humongously this year and we had this, beginning or mid-year, we had to recruit in one successfully 60 staff. (A04S W2)*
>
> *We're definitely providing a lot more one-on-one support, definitely. People are coming in with that in their plans, everybody, everybody's getting one-on-one support in their plans.* (D02S W2)
>
> *Complex support coordination is an area where we've grown, and initially NDIS wouldn't use the word "case management" and they, so and there was no case management funded for the first six months… But I think they've recognised that that actually is a necessary support so that's one area that we have grown in, and other organisations have as well. (B02S W2)*

- At wave 2, key workforce organisations and service providers confirmed that increased demand for therapy services was creating waiting lists, particularly for speech pathology, occupational therapy and psychology services:

> *We still do have a wait list and it probably is still sitting around four to six weeks… obviously there's been growth within organisations that provide therapy services because there is a massive increase in demand especially for occupational therapy and speech and everyone's got wait lists. (B03S W2)*

- At wave 1, NDIS pricing and the viability of service provision was influencing decisions about the services organisations would provide. Employment services, supports for people with high needs, and supported holidays and camps were examples of services that were identified as being 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 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 had reassessed or ceased providing services where the NDIA price did not cover the cost of service delivery. Some large providers were absorbing financial losses 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 wave 2, providers continued to express concern about NDIA pricing which was again seen as not meeting the costs for some services. Services considered underfunded were one-to-one community participation, mental health services, group services and services for people with complex needs. Rather than ceasing to provide particular services, providers continued to absorb financial losses but were closely monitoring their financial sustainability. Several providers anticipated their organisation would need to cease particular services when block funding ended. Funding for travel continued to be a concern at wave 2.

> *I think there are some particular pricing issues because I think someone said the price, the mental health price under the NDIS is about half the state price, so that's a major issue. (B02S)*
>
> *The group funding is, ridiculous. It's – we can't break even with group funding, pretty much whichever way we look at it, unless we go back to the old, very old model of 20 people in a centre, with two staff there, and so we're a very person centred organisation. We don't believe, in that at all. So, you know the groups are funded around that $20 an hour and that sort of stuff, which is you know great but to make it work you've got to have at least one staff for about five people. (E04S)*

The perspective of the NDIA staff

- At wave 1, NDIA staff (particularly Local Area Coordinators) described a number of challenges related to service provision. Many highlighted a lack of disability services (especially in rural areas) or gave evidence that services were reaching capacity because of increased demand.
- NDIA staff reported that some disability services had experienced growth since the NDIS while others were in shortage. Services experiencing growth included those providing early intervention, support coordination, therapies and community access. The expansion of these services was in response to increased demand by NDIS participants. Services where demand exceeded the supply included speech pathology, occupational therapy, psychology, support coordination and respite for young people.

> *We're still short of psychologists and speech therapists and OT's that specialise in children (B02N W2)*

- While the NDIS had led to an increase in the supply of disability supports, the Scheme had also led to an increase in a demand for services (and particularly therapy services); NDIA staff concluded that overall, demand now exceeded supply.

> *The NDIS has worked twofold. It's increased the amount of service available so people can see other OTs outside of what they would have been able to. But there's an increased demand. The increased demand is way above the increase of services. (C10N W2)*

- A lack of support coordination services was delaying plan implementation and once plans were implemented, waiting lists for services were delaying service provision.

2.8. Summary and Integration

In this section we presented qualitative and quantitative evaluation evidence on six KEQs that relate to the broad theme of *supply and demand of disability support services*.

Demand for supports

The quantitative data indicates that the overwhelming majority of NDIS participants need assistance on a daily basis. While most of the required assistance is provided informally by family members outside the economic market structure, just under a third of respondents also utilise market provisions.

Both the quantitative and qualitative data indicate that the majority of respondents receive increased supports as a result of becoming NDIS participants, in the form of increased hours of support, greater frequency (intensity) of service provision, and more appropriate equipment or access to a wider range of supports.

Both data sources also indicate that most NDIS participants and their families and carers report that they have more say and choice over the supports they received, the timing of those supports, the location of their supports, and the provision of supports (being able to use different services/providers). Most also experienced an increase in their satisfaction with the quality of the supports and a minority reported a decrease in their satisfaction. The qualitative data indicates that for those participants who report dissatisfaction with quality, the main factors impacting on the quality of the supports are the quality of support workers, and the NDIS pricing constraints and time benchmarking.

The evaluation finds that, while the number of supports received has increased for most NDIS participants, the majority of NDIS participants did not change providers upon joining the NDIS. The qualitative data suggests that uncertainty contributes to choosing to stay with the same provider, with evidence emerging that, as NDIS participants and carers increase their knowledge and experience of the Scheme, they become more confident about changing service providers over time. Wave 2 quantitative data and related administrative data will allow the evaluation to provide a more robust assessment of the dynamics of changing provisions and providers.

An important finding that emerges very clearly from both the quantitative and qualitative data is that whilst the overall picture of the NDIS trial roll-out is one of increased supports and improved outcomes, not all people with disability are achieving improved outcomes under the NDIS. Here we focus on two aspects of poorer outcomes.

First, qualitative reports indicate that some people with disability were experiencing poorer outcomes under the NDIS and were receiving a lower level of services than previously. These were particularly people with disability who were unable to effectively advocate for services on their own behalf, including some people with psychosocial disability and/or those people who struggled to manage the new and sometimes complex NDIS processes.

Second, both qualitative and quantitative evidence indicates that many NDIS participants and their families and carers experienced continuing difficulties in accessing disability supports for which they were receiving NDIS funding. Both data sources indicate that this was primarily due to lengthy waiting lists for some providers or types of support, lack of local providers, and lack of quality provision. Both data sources suggest that this type of unmet demand is experienced more by those living in rural and remote areas, in the Victorian trial site (much more so in regional parts of it), and for older NDIS participants (much more so for those living in regional areas). The quantitative data indicates that there is a positive association between those that experience unmet demand and self-management, but only for young NDIS participants, but it provides no guidance as to why this maybe the case. The qualitative evidence provides us with the crucial causal evidence that suggests that where there is unmet demand, people respond by self-managing.

Supply of Supports

Both the quantitative and qualitative data indicate that disability service providers and self-employed disability service providers are undertaking many supply-related activities in direct and indirect response to the trial and roll-out of the NDIS.

Both the quantitative and qualitative data indicate that, in response to additional consumer demand, disability service providers are increasing the proportion of their services dedicated to disability support and expanding their range of services.

The quantitative and qualitative data appear to contradict one another when considering the reported impact of the NDIS on the disability sector. The quantitative data indicates that both disability service providers and the self-employed expect that the NDIS will have little impact or a modest positive impact overall and in particular on employment, wage growth and overall performance.

In contrast, the qualitative data suggests that the NDIS has had considerable impacts for disability service providers. Reported impacts included changing business models, increased merger and acquisition activity, entry of new providers, exits from the sector, and changing (becoming more guarded) relationships between providers.

Our only evidence on the impact the NDIS has had on the disability sector workforce comes from the non-generalisable qualitative data, which has reported an expanding workforce in the midst of concerns about skill shortages, employee recruitment and retention, decreased opportunities for training, increased turnover and churn, unfunded work, more casual and less well-paid work, lower quality of provision and more. For the time being, the first wave of quantitative data provides us the necessary baseline information and little more. The evaluation will assess the impact of the NDIS on the workforces in a statistically meaningful manner after the collection of wave 2 of the providers' quantitative surveys.

Supply and Demand viewed jointly

Ideally, one would wish to see supply and demand balancing against one another in a way which provides the necessary supports for people with disability and their families and carers, within the overall budget that is at the disposal of the NDIS. Given that the roll-out is taking place in an uneven and non-random way within the trial sites, it is highly unlikely that any kind of "orderly" introduction of the market system will be observed by the evaluation data. The expectation is that imbalances will be common and unpredictable and the main two questions that should concern the evaluation is whether they are long-lasting (which would suggest that the newly introduced market system is not sufficiently flexible in its adjustments) and whether they are particularly damaging (by either focusing systematically on specific vulnerable groups, or by being intensely detrimental to whoever experiences them). The NDIS evaluation will be able to offer an assessment on questions of this nature through the various impact KEQs.

Both disability service providers and NDIA staff report that, in their experience from the trial areas, demand for disability supports has been exceeding supply. Of concern was the indication by providers that they would start ceasing the provision of some services which were considered underfunded under current NDIA cost guidelines. Should such a market response occur, the cessation of these services could exacerbate current market shortages and, possibly, influence the prices of uncapped items and/or the quantities of price-capped items. We do not have quantitative evidence of this type of response by providers. Although it may be early days for making such assessments, these considerations should enter the relevant policy watch lists.

Both the quantitative and qualitative data also indicate that many NDIS participants continue to access supports that are not funded in their NDIS plan. Such unfunded supports include alternative therapies and social and recreational activities. It is reported that NDIS participants and/or their family already pay out-of-pocket expenses for accessing such services.

3. Choice and control (including self-management)

Key Messages

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?

The quantitative detail

- Most people with disability report that their choice and control over supports improved once in the NDIS.
- About half the people with disability report that they access a larger number of supports since they joined the NDIS, one quarter the same, and one quarter fewer.
- In the broader context of most people with disability reporting improved choice and control over supports and higher numbers of supports accessed, there is a minority of approx. 15-17 per cent of NDIS participants who report that they are worse off in terms of their choice and control. These NDIS participants are also more likely to be going against the general trend, by accessing fewer supports than they did prior to the NDIS.
- The majority of people with disability say they would like to have more choice regarding the supports they receive, naming on average four types of supports out of a list of 14.
- In further analysis looking at the minority of NDIS participants who report that choice and control has become worse since joining the NDIS (15 per cent to 17 per cent of the NDIS participants) the evaluation finds that:
  - There is a strong association between disability type and say over what supports to obtain: people with physical and sensory disability experience the lowest dissatisfaction due to lack of say; people with neurological disabilities have near average dissatisfaction levels and mental health and psychosocial are way above the average dissatisfaction levels. No such association is found when we examine the relationship between disability type and satisfaction over where they receive the relevant supports.
  - Satisfaction with the quality of supports is considerably lower for those people with disability who report that they have the necessary funding but cannot access their chosen supports. This finding would be consistent with a situation where people with funding that cannot be used as they would best like to, may be accessing supports of lower quality, as poor substitutes of their original preferences.
  - The incidence of dissatisfaction with say over what supports focusses on two groups. First, on those who report that they need help with transport in order to access their supports and second, on those who say that they receive therapeutic services and support with medication through the NDIS.
- The family members and carers data paints a picture of support provided primarily by close family members to NDIS participants. Support is intense in that it often involves long periods of uninterrupted support activity, with long hours every day, involving many different types of supports.
- The family members and carers quantitative data finds large increases in the ability to provide help, assistance or support to the person with disability that is

cared for, with an overwhelming majority reporting being satisfied with the say that family members and carers have about what supports the person with disability receives and about where they obtain them. The only negative aspect detected in the quantitative data is that a sizeable minority of family members and carers report increased levels of anxiety about future supports due to the introduction of the NDIS.

The qualitative detail

- The qualitative evidence suggests that overall, the NDIS has increased choice and control for almost all respondents. There was evidence of increased choice as respondents became more familiar with the NDIS "world", and consequently were becoming more confident in changing service providers over time.
- Constraints to choice and control continued to be highlighted and included limited provision of information about provider options, and limitation in the number and capacity of registered service providers. The formalisation of relationships between services providers and NDIS participants via the use of service contracts was suggested to inhibit choice and control.

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

The quantitative detail

- More respondents report that it takes less time to find and get a support and more time to do the paperwork. The gains in time are focussed on people with disability (the NDIS participants themselves), while the losses in time are focussed on their family members and carers.

The qualitative detail

- The planning process seemed to be smoother for NDIS participants and their family members and carers by wave 2, which in part related to general familiarity with NDIA processes. NDIS staff appeared to be more familiar with these processes too, leading to more efficient communication among participants and the NDIA.
- Where choice and control over the development of the plan was greatest, this appeared to be primarily where participants had good advocacy/support.
- At wave 2, it was more common to have funding for support coordination or case management included in plans. For most, this was reported to be a valued service which removed the burden and stress of communicating and co-ordinating with providers. For some, however, it was reported that little benefit was experienced as a result.
- Restricted choice of providers or longer waiting lists for services reduced the amount of choice respondents felt they had over the implementation of their plan.

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

The qualitative detail

- Wave 1 evidence suggested that NDIS participants sought more frequent and more intensive support rather than necessarily choosing different types of services. By wave 2, NDIS participants and families appeared more confident in changing support providers or approaching the NDIA to request additional or different types of supports. However, this was frequently impeded by a lack of service providers and long waiting lists, in particular outside the main urban centres of the trial sites.

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 quantitative detail

- Self-management is still very uncommon and its frequency is increasing at a slow pace. The increase is driven primarily by increased family member and carer involvement, but also by individual participants taking on the task themselves.

The qualitative detail

- Self-management was uncommon, with many NDIS participants being reluctant to undertake the additional administrative work they perceived self-management would require. 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 and in the support workers that they engaged.
- While the flexibility of self-managed funding was thought to be advantageous, fears were expressed about the potential risk of fraud or mismanagement of funds by those undertaking self-management. Disability service providers, key workforce agencies and NDIA staff were concerned that the Scheme lacked sufficient safeguards.

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 had improved understanding of processes and the concepts/language used by the NDIA over time. This improved their interactions with the NDIA. However, a need for better advice and assistance (including lists of eligible and accessible services) remained. All respondent groups recommended the use of advocates (either paid or unpaid) who were familiar with the NDIS system.

3.1. Introduction

The concepts of choice and control are at the heart of the NDIS. One of the central aims of the NDIS is that it will support people with disability to have choice and control to help them reach their goals and also to help in the planning and delivery of their supports. Choice and control is also a central focus of many of the 56 KEQs which guide the NDIS evaluation. In this section we present evidence relating to the following KEQs which pertain to “choice and control”.

- 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?
- KEQ 5: To what extent did people have increased choice and control over the development and implementation of their plan?
- KEQ 8: How have people responded to increased choice and control?
- KEQ 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?
- KEQ 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?

3.2. 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?

The quantitative detail

The NDIS Survey of People with Disability - Quality and say measures, prior and current, NDIS trial areas only

People with disability over the age of 15 in the trial group and who received supports before participating in the NDIS are asked several questions related to the supports they received including:

1. how much of a say they had over what supports they received;
2. how much choice they had over where they obtained these supports; and
3. their satisfaction with the quality of these supports.

The same set of questions are asked about (i) recalling the supports they received prior to their NDIS participation and (ii) their current supports provided under the NDIS. Parents of children below the age of 15 were asked related information about their children in the family and carer questionnaire.

The link between choice and control and the first two questions is direct and self-explanatory. The link between choice and control and the quality of supports is indirect and could be interpreted as follows. Where people with disability have less choice and control over their supports, their level of satisfaction with those supports is likely to be lower as they will be (by necessity) more likely to settle for the provision of supports that they consider of lower quality.

- All three measures of choice and control provide a very similar message about the impact of the NDIS (Appendix 3.2 Table 29, Table 30, and Table 31). They all suggest an overall improvement in choice and control, with only a minority of people with disability feeling that things are not working well for them under the NDIS. Just under half of NDIS participants surveyed (44 per cent, 46 per cent, and 49 per cent) reported that, compared to before they joined the NDIS, their say over the supports they received, their choice over where they receive their supports and the quality of the supports they receive improved once in the NDIS. A sizeable minority (respectively, 39 per cent, 38 per cent, and 36 per cent) reported that they saw no change. A minority (respectively, 17 per cent, 16 per cent, and 15 per cent) reported that they felt things got worse for them. Later in this section we use multivariate regression in order to examine who these 15-17 per cent of all people with disability who find themselves worse off are. The question that needs to be addressed is whether the people who report to be worse off are a random sub-sample of all NDIS participants, or whether they have any clear identifying characteristics that would allow any desired policy intervention to address their newly encountered disadvantage.

Has the NDIS changed the number of supports?

- People with disability are also asked to recall questions about the number of supports they used to access prior to their NDIS participation and those accessed currently via the NDIS. The number of supports is a rough indicator of the choice available to people with disability and the expectation is that, at the population level, where choice improves, the number of different accessed supports is likely to increase. Our data suggests that about half of all respondents have accessed a higher number of supports, a quarter the same and a quarter fewer. We note that a higher number of supports cannot and should not be taken to also mean better supports and that further information is needed on this front.

Number of supports combined with quality and say measures

- We combined the data on change in number of supports (pre-NDIS versus NDIS) with the data on change in the three measures of choice and control (quality, say and choice) (Appendix 3.2 Table 32, Table 33, and Table 34). We find that those people with disability who reported that they are worse off in each of the three measures of choice and control within the NDIS, are more likely to have experienced fewer rather than more supports within the NDIS. For quality of supports the difference between those who were “worse” off is that 26 per cent have fewer supports versus 11 per cent having more, for say over what supports the comparison is 24 per cent versus 14 per cent and for choice over where supports are obtained it is 24 per cent versus 13 per cent. The reverse relationships hold for those who reported to be better off within the NDIS in regards to the three measures of choice and control.

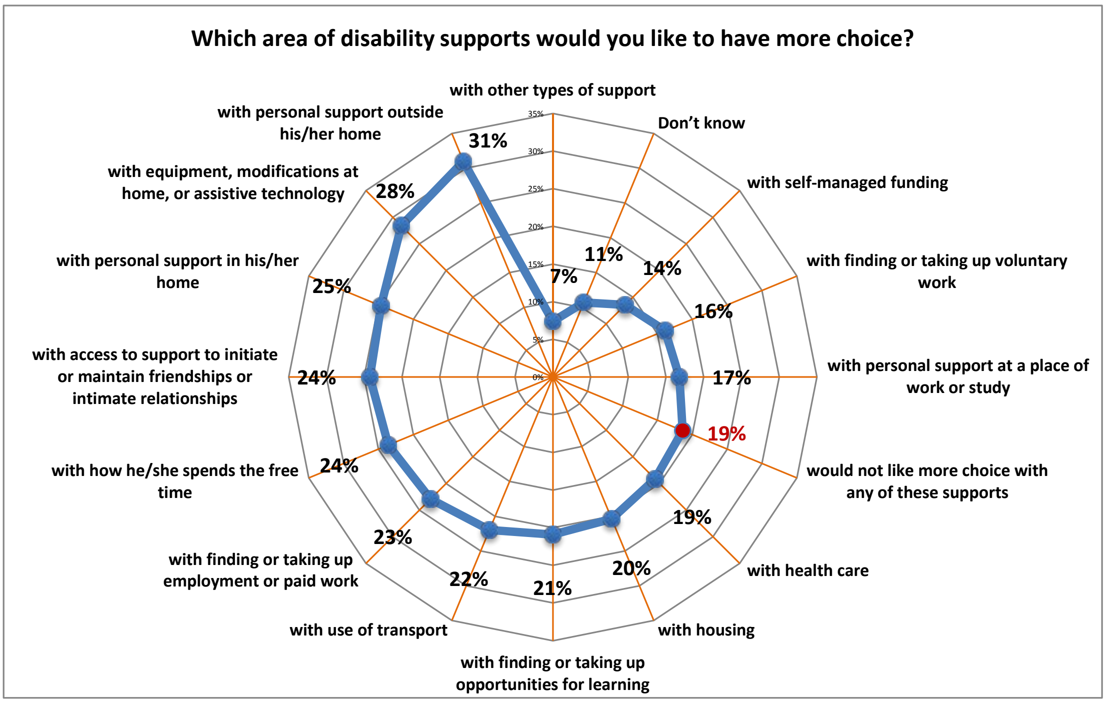
Choice and control combined with reasonable and necessary measures

- There is also an association between the reported level of choice and control (quality, say, and choice) and the degree to which the people with disability think that the NDIS supports they access are reasonable and necessary to meet their needs (Appendix 3.2 Table 35, Table 36, and Table 37). A largely positive picture emerges from the data, with a big majority reporting that they consider their supports to be reasonable and necessary. However, as with the numbers of supports, there is a small minority of people who find that their choice and control is restricted and that at the same time they do not consider that those supports they manage to access are reasonable and necessary.

More Choice?

- The quantitative data shows that (i) in the context of an observed increase in the number of accessed supports, and (ii) in the context of a general increase in perceived choice and control over accessing these supports, and (iii) in the context of the majority of respondents reporting that their supports are reasonable and necessary, it is still the case that 71 per cent of NDIS participants surveyed reported that they would like to have more choice over their supports (see Figure 4: Areas of disability supports in which NDIS participant would like to have more choice (Trial PWDs, Aged 16+)). Of those people who said that they wanted more choice, each person stated on average four different types of support over which they would like to have more choice.
- Figure 4 presents the various types of supports over which NDIS participants report they would like to have more choice. Notably, there does not appear to be any specific type of support that is drastically out of line, rather we have a picture where more choice, would be welcome for most supports, and by most people with disability.

Figure 4: Areas of disability supports in which NDIS participant would like to have more choice (Trial PWDs, Aged 16+)



The quantitative detail – looking at the choice and control of people with disability through the multivariate regression lens

Our preliminary multivariate regression findings suggest that:

- There is no discernible association between age and say over supports, or age and the choice over where to obtain the supports.
- Satisfaction with the quality of supports is lower among older people, increasingly so with age.
- Disability type and satisfaction with the quality of supports are not associated with one another among younger people with disability, but they are associated with one another among older people with disability. Neurological, Mental Health and Psychosocial disability is associated with lower levels of satisfaction with supports.
- There is a strong association between disability type and say over supports: people with physical and sensory disability experience the lowest dissatisfaction due to lack of say; people with neurological disabilities have near average dissatisfaction levels and mental health and psychosocial are way above the average dissatisfaction levels. The evaluation finds no such association when we examine the relationship between disability type and satisfaction over the choice over where to obtain the relevant supports.
- People who were in receipt of many different types of supports prior to them becoming NDIS participants reported higher levels of dissatisfaction with the quality of their supports (than their counterparts receiving fewer types of supports). An encouraging message arises, namely that their dissatisfaction with the quality of their supports that is associated with receiving many types of supports has been reduced within the NDIS.
- Satisfaction with the quality of supports is considerably lower for those people with disability who report unmet demand (in terms of having funding but not accessing the supports). This finding would be consistent with a situation where people with funding that cannot be used as they would

best like to, may be accessing supports of lower quality, as poor substitutes of their original preferences.

- The incidence of dissatisfaction with say over what supports focusses on two groups. First, on those who report that they need help with transport in order to access their supports and second, on those who say that they receive therapeutic services and support with medication through the NDIS.
- Notably any association between unmet demand (in terms of having funding but not accessing the supports) does not appear to be associated with the choice of where supports are provided. We can only trace above average dissatisfaction with where supports are provided among those who need transport help and below average dissatisfaction among those with physical and sensory disabilities.

The quantitative detail

The NDIS Survey of family members and carers of NDIS participants.

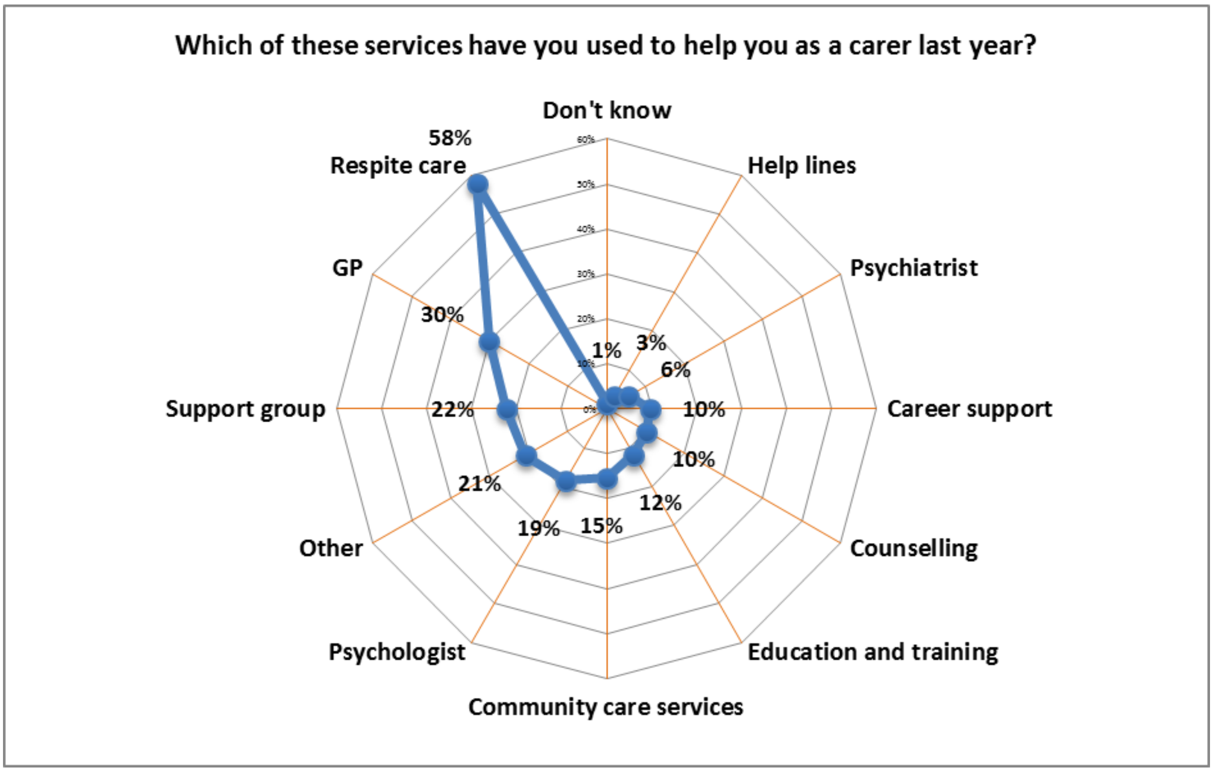
Family members and carers of people with disability play a key role in the life of people with disability. The NDIS evaluation is, therefore, examining the impact of the NDIS on the support family members and carers provide directly and indirectly to people with disability and the supports they receive themselves in their carer role.

The family members and carers support context

- Almost all (99 per cent) family members and carers who were surveyed reported that they provided the NDIS participants with emotional or practical support. The quantitative data records the wide diversity of support activities provided by family members and carers (Appendix 3.2 Table 38).
- The intensity of support (required and provided) is important, as it can impact on the overall and long-term capacity of the family members and carers to provide effective support. The quantitative data finds that over half (53 per cent) of family members and carers provided NDIS participants with support "24/7" (Appendix 3.2 Table 39), with another 20 per cent providing support for more than 35 hours per week (15 per cent reported less than 35 hours per week and 11 per cent provided no information). Crucial for the NDIS is that approx. 79 per cent of family members and carers have been providing support to the person with disability since the birth of the NDIS participant (Appendix 3.2 Table 40), but we note that up to a point, this could be due to the oversampling of children in the SA sample.
- The quantitative data finds that 25 per cent of family members and carers reported that they themselves had a long-term health condition, impairment or disability that restricted their ability to undertake everyday activities (Appendix 3.2 Table 41).
- The degree of control family members and carers have over their own lives is of importance for understanding the impact of the NDIS on people with disability and their family members and carers. The quantitative data finds that about 25 per cent of the family members and carers surveyed indicated that they had a lot of control over how they spend their time, with 44 per cent indicating that they had some control, 26 per cent indicating that they had little control, and 5 per cent indicating that they had no control at all over how they spend their time (Appendix 3.2 Table 42).
- Around 34 per cent of family members and carers reported that they have adequate breaks from providing support to NDIS participants daily or weekly, with about 30 per cent having less frequent breaks and about 29 per cent reporting that they are never able to take adequate breaks from providing support (Appendix 3.2 Table 43).

- The quantitative data finds that approx. 74 per cent of family members and carers did not access any carer supports (Appendix 3.2 Table 44).
- For the 24 per cent who did access some carer supports, the supports most frequently accessed were (i) respite (58 per cent), (ii) GP supports (30 per cent) and (iii) taking part in support groups (22 per cent). About 20 per cent of family members and carers reported that they accessed "other" supports, which suggests that there is a wide diversity of supports that matter to them. Family members and carers accessed on average just over two supports each (Figure 5).

Figure 5: Which of these services have you used to help you as a carer in the last year? (Carers of Trial PWDs, all ages)



The impact of the NDIS on family members and carers

- The NDIS increased the ability of family members and carers to care for people with disability. About 65 per cent of the family member or carers of all NDIS participants stated that the NDIS has increased their ability to provide help, assistance or support to the person with disability that they care for, 23 per cent reported that it made no difference and 8 per cent reported that it had reduced their ability (Appendix 3.2 Table 45).
- Just over half (51 per cent) of all family members and carers surveyed reported that the NDIS had decreased their anxiety about the future supports available to the person they care for, about one quarter (27 per cent) reported that it made no difference, and a minority (17 per cent) reported increased levels of anxiety due to the introduction of the NDIS (Appendix 3.2 Table 46).
- The quantitative data provides direct findings about the views of family members and carers regarding the impact of the NDIS on choice and control afforded to the people with disability they care for. Specifically, the evaluation finds a very high level of satisfaction among family members and carers about the amount of say the family members and carers themselves had about what supports the person with disability receives (52 per cent were very satisfied and 34 per cent satisfied – Appendix 3.2 Table 47) and about where they obtain them (58 per cent were very satisfied and 30 per cent satisfied – Appendix 3.2 Table 48). A very small proportion (7 per cent and 6 per cent) reported to be somewhat or very dissatisfied, which interestingly is a much lower

proportion than the direct dissatisfaction reported by people with disability themselves when asked the same questions.

The qualitative detail

The qualitative data collected as a part of the NDIS evaluation adds to the quantitative findings presented above and allows us to understand further the extent to which NDIS participants and their family members and carers had choice and control over their supports and how this has change over time.

The perspective of the person with disability and their family and carer

- In general, respondents felt they had the ability to pick their provider of choice. In particular, self-management of funding was thought to have provided greater access to service providers (including those providers not registered with the NDIA).
- Most respondents were satisfied with their pre-existing service providers and many continued with these providers once in the NDIS. For those participants who chose to retain their providers, they did so because of established relationships and a shared understanding of needs developed over many years, and satisfaction with the supports received.
- While overall there was a continuity in the service providers used by NDIS participants between wave 1 and wave 2, the wave 2 interviews indicated that NDIS participants and carers had increased their knowledge of the Scheme, and consequently were becoming more confident in changing service providers over time.
- There were a range of reasons why changes were instigated by NDIS participants and/or their families including: the support worker having moved to another provider, dissatisfaction with the assistance they were receiving, and participants no longer needing that particular type of support.
- When choosing their service providers, NDIS participants and carers used strategies of talking to fellow NDIS participants, seeking advice from disability services, and using Clickability (a website where participants can rate service providers). Social media or other networks were also an important source of information about the quality of service providers.
- However, both the wave 1 and 2 interviews with NDIS participants and carers revealed that some felt they had insufficient information to choose their service providers confidently. These respondents requested more information about services available from each provider, and help with defining factors on which to base their choice when asking providers about their supports in order to make an informed choice. There was an expectation that NDIA staff should be able to provide more guidance as to what supports and services were available to them. In particular, it was expected that NDIA Planners would draw on knowledge from the management of other NDIS participants and be more suggestive of supports and services that have proven beneficial for others with similar needs. Furthermore, several respondents described the NDIA website to be difficult to navigate, inhibiting their access to information about services.
- At wave 2, it was common for respondents to suggest that the NDIA remained reticent to suggest ideas for supports and services. One example of this is a respondent who wanted to enter the workforce being unaware of that the NDIA was able to offer support in finding employment until she was informed by an advocacy agency, despite it being one of her goals.

> *So they gave me a list of everything that NDIA funds because NDIA didn’t tell me and my support service didn’t tell me. So there's packages for people to try and get them into work but no one ever told me that it's available...But [the NDIA] don't tell you what they're offering. (B05 PWD W2)*

- Many respondents were not able to exert choice and control over some aspects of their supports due to limitations in the number or capacity of service providers. This was discussed above when we considered the supply and demand of disability support services.
- Finally, the formalisation of relationships between service providers and the NDIS participants/carers through a service contract was suggested to inhibit decisions to exert choice and control.

> *I've just signed a contract. Am I allowed to break a contract? I don't know. (D06C W2).*

The perspective of service providers and other stakeholder groups.

- Disability service providers and key workforce stakeholder groups recognised that the NDIS had impacted positively upon the ability of people with disability to exercise choice and control over their supports. Some NDIS participants were reported to be starting to change service providers and choosing different types of supports.

> *Well from what I've seen over the last year or so, oh I think that sort of the various ways in which people are empowered by sort of NDIS is going to have a really beneficial impact on people… it's not just within sort of the NDIS system but in terms of people learning that they can have choice and learning how to access services. I think that it's going to mean that people are going to have a better choice of a whole range of services.* (B05S W2)

- Providers and stakeholders however, continued to site some constraints to participants being able to fully exercise choice and control.
- At wave 1 providers and stakeholders were concerned that people with disability and their families were not always aware of the types of support services that were available or appropriate, and this constrained their choice and control. A greater role of NDIA staff in providing information about services to participants and their families was recommended. While these issues remained at wave 2, the increase in funded support coordination services included in NDIS plans had alleviated some of these concerns.

> *We still get clients who walk out with plans that they yeah don't necessarily 100 per cent meet their needs because they didn't know what they needed to ask for because they didn't know what was out there to get*. (C02S W2)

- At both wave 1 and 2, concerns were expressed about the ability of some people with disability (including those with intellectual disability and/or very high needs) to have their individual choices acknowledged and respected. Vulnerable families, those unable to navigate the NDIA website to find what services and providers were available and those less able to articulate support needs were reported to be less likely to experience greater choice over their supports. Choice was also constrained for those living in non-metropolitan locations with fewer service providers.

> *How will people with really high needs be able to navigate a system which is truly based on their choices and control, and not one that's manipulated or abused by, and determined by the choice and control actually of their guardian or relatives. So that's a real concern…whose choice and control will it really be? (07R W2)*

The perspective of the NDIA staff

- At wave 1, NDIA staff highlighted that some NDIS participants, family members and carers, were anxious and overwhelmed by being asked to make choices over supports and felt this was something that would become easier for them in time.
- Other NDIA staff thought NDIS participants were reluctant to change service providers, in part because of anxiety about the Scheme but also because of prior (sometimes long-standing) relationships with service providers.

- At wave 2, NDIA staff observed that as participants gained experience with the NDIS, they were making bolder choices around their providers and the way they utilised their supports. Some NDIS participants were now seen as being willing to "vote with their feet (B01N *W2*)" if they were unhappy with the supports they received.

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

The quantitative detail

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

We have no direct evidence as yet about increasing choice and control over the development and implementation of plans.

- As background information we note that about 93 per cent of NDIS participants had a support plan already approved by the NDIA at the time of completing their survey. About 96 per cent of NDIS participants obtained assistance from other people in making decisions about the support arrangement to be included in the plan (Appendix 3.3 Table 49). Assistance was primarily provided by family and guardians (in 71 per cent and 22 per cent of cases in trial sites respectively) and the NDIA Planner and Local Area Coordinator (in 61 per cent and 13 per cent of cases). A substantial role was also played by support workers (16 per cent) and to a lesser extent, by nominees (9 per cent) and friends (around 4 per cent). About 18 per cent of NDIS participants mentioned that someone else had assisted them in making decision about the support arrangements in their plans. The qualitative evidence would suggest that the category "someone else" would consist largely of either advocates or disability service providers.
- People with disability over the age of 15 in 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 (Appendix 3.3 Table 50).
- The same questions are asked of the family members and carers or NDIS participants (Appendix 3.3 Table 51).
- The quantitative data finds that the NDIS has impacted on how long things take for the majority of NDIS participants and their families and carers. Only between 24-29 per cent of NDIS participants and 30-40 per cent of family members and carers report that it takes them the same amount of time to find, get and do the necessary paperwork for their supports.
- The change we observe is tilted towards more respondents reporting (i) that they need less time rather than more time to find and get supports and (ii) that they need more time rather than less time for doing the necessary paperwork. The shorter time taken under the NDIS to find and get supports is more pronounced among NDIS participants than among their family members and carers. In contrast, the longer time taken under the NDIS to do the paperwork is more pronounced among the family members and carers. We cannot know the net effect of these changes, but we can see that there is a shift in the time burden away from NDIS participants themselves and towards their family members and carers who are assisting them with the necessary new paperwork.
- To the degree that shorter times to find and get the desired supports and to complete the necessary paperwork may contribute towards an increase in choice and control, we can see some

indirect evidence that the NDIS is reported to be bringing an improvement in the choice and control over the development and implementation of Plans. However, we note that this may be a tenuous link that needs further investigation.

The qualitative detail

The qualitative data collected detailed information about the extent to which NDIS participants and their family members and carers had choice and control over the development and implementation of their plan and how this has change over time.

The perspective of the person with disability and their family and carer

Development of plan

- At wave 1, NDIS participants requested more support and preparation during the NDIS plan development stage, including help with identifying and unpacking goals and aspirations, and planning for the future (a concept that for many had not really been explored previously). Respondents would particularly have welcomed help with generating ideas about how goals could be pursued and realised.
- While some found the resources supplied by the NDIA to help prepare for planning sessions useful, others relied on social media and advocates for extra guidance.
- Most respondents were aware that interim changes could be made to their NDIS plan throughout the year. For the most part this was done to request adjustments to funding to accommodate unexpected pricing changes, or to include additional or new services including equipment repair. Overall, interim changes to plans were achieved smoothly.
- With the exception of one NDIS participants whose initial plan took much longer than usual to be completed, all respondents had experienced one or more annual plan reviews between wave 1 and wave 2. Some respondents indicated doing a great deal of preparation for the review appointment. However, there was little mention of information or resources provided by the NDIA to support this, and at least some felt it was more beneficial to seek advice from an external advocate (paid and unpaid).
- At wave 2, nearly all respondents said that the planning process had become easier over time, due to increased familiarity with the Scheme, a better understanding of their own needs and how to translate these into goals. Respondents also reported increased confidence in asking for what they wanted.

> *Just felt comfortable and I think I understood it a lot better 12 months on. (B06 PWD W2)*
>
> *The first year I struggled a bit and then people out here who are my friends and well-wishers they explain to me you have to be more expressive and you have to be more vocal and not be shy and you just have to tell them what you need and want. So as I'm staying here for more years I'm getting more and more confident in telling that no I need this or I want this. I was a bit conscious to say the things but I'm getting there. (E10C W2)*
>
> *It was a lot easier because I'd done it before and I knew what to ask, how to ask for it (D05C W2).*

- Increased comfort was also seen in respondents' approaches to goals and aspirations. That is, in wave 1 interviews, participants' plans typically focussed on day to day living, with the aim of consolidating support. In contrast during wave 2 interviews, respondents showed familiarity and comfort with identifying their goals, and their plans become more aspirational, with consideration given to the future in addition to daily support needs.
- At both wave 1 and wave 2 the experience and personal attitudes and beliefs of the planner were reported, in some cases, to influence the outcomes for the types of services included in plans.

- At both wave 1 and wave 2, family members and carers of NDIS participants (particularly of young children) reported that their own needs and the needs of the family more broadly were **not** addressed in the planning process. Respondents requested greater attention to the family context, in particular the potential for parents/carers to receive support and respite.
- At both waves 1 and 2, respondents requested more information be provided by the NDIA about providers and the services they offer, to enable NDIS participants to make informed choices about what they could include in their plan.

> *When you go into a meeting being given a choice on things that are available. There are a lot of services out there that can be provided but unless you know what they are you don't know what to ask for. So if you were given information before you went into the meeting then you could have a say in what you actually want, well at least give Charlie a heads up on what he can ask for. (E07 PWD&C W2)*

Implementation of Plan

- The implementation of plans generally worked well where NDIS participants had been successful in obtaining a continuity of funding of services.
- Having gained insights from their first year of NDIS involvement, respondents adjusted the way they implemented their plan. Some respondents (particularly parents of young NDIS participants) contacted services independently and organised their own supports, feeling in control doing so. Other respondents used funded case managers, whose role included accessing and organising the supports agreed upon in the plans. A further group of respondents reported that their primary support agencies took on an informal role of coordinating services and implementing plans on their behalf.
- The inclusion of case management/case coordination in NDIS plans to assist with the engagement and implementation process for services and supports was more common at wave 2. Feedback from respondents suggested that for many, this was a valued service which was removed the burden and stress of communicating and co-ordinating with providers. For some however, little had been gained from the funding for support coordination. In these cases it appeared expectations of the role did not match what was being offered, or that support co-ordination providers were new to the trial site and lacked knowledge of local services. Others found the process to be inefficient and lacking in flexibility, such that the carer continued to do most of the work.
- Those respondents who reported independently implementing plans expressed concern about the amount of work required. Some were overwhelmed with the task of managing and organising NDIS providers and activities and arranging payments for some services.

> *The thing that Catherine and Danielle suggested to me is that we are seeing that you trying to liaise with all the service providers and it was getting my head in, and I was just mentally drained calling one service provider to the other. So they say now the NDIS has decided to give you a co-ordinator who will handle things for you, and you know, just ease off the stress from you here. So that was one very wonderful change. So now my co-ordinator called Joanna. So from the last two times like if I can't handle something, so I just ring her up and said "Joanna, can you sort of sort this out" and she says, "Yes Keira." (E10C W2)*
>
> *I have to say, I will say very strongly that I had no idea how onerous it would be to do the case management myself.* (C02 W2)

- As at wave 1, plan implementation was frequently impeded by a lack of service providers, in particular outside the main urban centres of the trial sites. That is, there were few or no service providers to choose from or long waiting lists occurred because of high demand. This was discussed further when we considered the overall provision and quality of supports.

> *There’s been massive issues in trying to get support workers in place. So while the plan itself is not bad, it’s quite good really, being able to implement that plan is very difficult when the supports don’t exist. (B02 PWD W2)*

- It was reported that some services had “shut their doors” to new clients, so NDIS participants had limited choice of organisations to work with. Suitable and high-quality staff only appeared to have limited number of hours to give (e.g. only part-time or around other clients’ time slots) so individuals had to work within worker availability.
- Equipment provision was a challenge to plan implementation at wave 2. NDIA approval for therapist recommended items was difficult, and the need for service providers to provide quotes was time consuming and led to long delays in receiving the final product.
- Opportunities for volunteering or support in procuring employment were limited.

The perspective of the service provider and other stakeholder groups.

- At both wave 1 and 2, disability service providers and workforce stakeholder organisations perceived planning processes to be too complex for many NDIS participants and their families. Advocacy was recognised as being important for some people with disability in order to better express their needs and understand their support options. Also the time allocated by the NDIA to explore participant needs and prepare a support plan was still considered to be inadequate for some participants.

> *One of the concerns has been access in understanding the Scheme for people with disability as well, and the complexity of setting up a plan, and the importance and the need for advocacy in that process, and independent advocacy and assistance for the person with disability. (07R W2)*

- It was further recommended that plan information be shared with providers to ensure that people with disability were receiving quality services.

The perspective of the NDIA staff

- Some NDIA staff found that NDIS participants had difficulty adjusting their mindsets 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.
- In order to provide better guidance and assistance to NDIS participants, NDIA staff suggested more time and resources be provided to prepare participants for planning meetings as well as for the planning meetings themselves. NDIA staff also thought more consideration should be given to the involvement of advocacy support during plan development.
- At wave 2 NDIS staff observed a shift in the general mindset of NDIS participants away from accepting what services and supports are available, towards being "an active consumer that's got choices". However, it was acknowledged that there was still more progress that could be made in this area.

> *I think people are becoming better informed, and they are more confident about choosing their own services and supports… they've been at one service for quite some time and they've chosen to go with other service providers who better suit their needs… I've seen people be able to swap and change their supports to better suit their own circumstances. (C05N W2)*

- Beyond this there was a sense that both planners and participants have become more familiar with operating within the NDIS system since the first wave of interviews. NDIA staff observed that overall they were gaining confidence with the processes involved in planning.
- Two main challenges were identified by NDIA managers and staff around the implementation of plans at wave 2. The first was the need to be able to identify and monitor whether participants had the capacity to implement their plans (and implement resources including LAC or plan support coordination to help them build capacity if needed).

> *"…there's no point having a great plan if the family doesn't have the capacity to actually make the plan come to life (A08N)."*

- The other challenge around plan implementation, reported by a small number of NDIA staff, was the availability of services for participants to access in executing their plan. NDIA staff observed that in some cases services, particularly therapeutic services, had long waiting lists, whilst in other cases in-kind arrangements and a lack of appropriate services resulted in LACs needing to be "*creative about sometimes how to activate supports or implement supports in people's plans (A08N)."*

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

The qualitative detail

- The enhanced choice and control seen in the NDIS planning stage at wave 2 did not always translate into greater choice and control over support acquisition and utilisation as the provider market was only changing slowly. Wave 1 evidence suggested that NDIS participants sought more frequent and more intensive support rather than necessarily choosing different types of services. By wave 2, NDIS participants and families appeared more confident in changing service providers or approaching the NDIA to request additional or different types of supports. However, this was frequently impeded by a lack of service providers and long waiting lists, in particular outside the main urban centres of the trial sites.
- At wave 2 the NDIS was reported to be facilitating the ability of both participants and their families to change ways of thinking about choice and control over supports. A shift had occurred from

choice and control occurring within the confines of the pre-NDIS block-funding environment to a broader, more flexible and proactive way of thinking.

> *It does force you to be more flexible in your thinking. It does force you to go on a journey where you look at what your child with a disability can do, rather than what they can't (B10 C W2)*

3.5. 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 quantitative detail

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

- The NDIS survey asked if anyone self-managed any funding for supports prior to the NDIS (Appendix 3.5 Table 52) and currently as NDIS participants (Appendix 3.5 Table 53). Of the 1,316 NDIS participants who responded to the prior self-management question, 28 per cent said they did (19 per cent being managed by the family, 6 per cent by the NDIS participant themselves and 4 per cent by someone else), 60 per cent said they did not, and the remaining 12 per cent did not answer. Evidently, only a minority of people with disability entered the NDIS with prior experience of self-management. Of the 1,656 NDIS participants who responded to the current self-management question, 43 per cent said they did (28 per cent being managed by the family, 11 per cent by the NDIS participant themselves, and 5 per cent by someone else). The increase in self-management was attributed to two-thirds of family members and carers taking on the job (an increase from 19 per cent to 28 per cent) and one-third of NDIS participants (an increase from 6 per cent to 11 per cent).

- Notwithstanding the considerable increase in proportions, the fact remains that half of all NDIS participants do not self-manage their plans. This finding supports the qualitative evidence presented below.

The qualitative detail

The perspective of the person with disability and their family and carer

- At wave 1 the option of self-managed funding was not always fully understood by NDIS participants; nor was it always discussed in the planning meetings. By wave 2 it was evident that while NDIS participants had a greater understanding of what self-management was there remained very few self-managers. The main reason for this appeared to be a reluctance to take on additional administrative activities.
- 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 and in the support workers that they engaged. In addition, respondents mentioned that self-management allowed them to monitor how much money was being charged by service providers and for what purpose. Several respondents noticed that organisations tended to exaggerate hours of work and overcharge for services provided and that this situation could be avoided if the self-management model was taken up. Respondents who were not self-managing their NDIS funding also requested access to the portal for the same reason.

> *Yeah. And it wasn't a very good job, so when I realised that I could interview people and hire people with ABNs and do it that way I took a little bit more responsibility and got people who are now doing the job really, really well and effectively and efficiently and only charging me for the hours. I found that the organisations were charging me say for three hours and the person was only here for two. (A16C W2).*

- Feedback at wave 2 showed the increased use of financial managers, which relieved respondents of the task of paying for services but allowed them to continue to self–direct the choice of these supports.
- While the flexibility of self-managed funding was thought to be advantageous, there appeared to be little guidance provided by the NDIA on the boundaries of this flexibility. Fears were expressed about the potential risk to future funding if decisions were made which were later found to be outside of the NDIA guidelines.
- Respondents continued to report difficulties with the NDIS portal and the associated myGov website at wave 2, particularly in regard to logging in and accessing individual service invoices. This impacted the ability of NDIS participants and their families to keep track of money spent, and to plan for future expenditure.
- While respondents typically did not want the responsibility of self-managing their entire plan, it was not uncommon for them to manage discrete sections, such as transport, incontinence products or community groups. Changes to line-bundling in the second year of the Scheme resulted in decreased opportunity and increased confusion for respondents about the management of individual aspects of a plan.

The perspective of the service provider and other stakeholder groups.

- At wave 1, disability service providers and workforce stakeholder organisations confirmed that few NDIS participants were fully self-managing their funding. This remained the case at wave 2. While these respondents believed that self-managing funding would eventually lead to increased choice for NDIS participants, they were concerned that providers not registered with the NDIA or otherwise accredited may not have the skills to provide the quality of service that NDIS participants expected and needed. For this reason, disability service providers and workforce stakeholder organisations continued to call for quality assurance measures to be put into place alongside safeguards.
- At wave 2, providers identified both positive and negative outcomes for participants and families self-managing their NDIS funding. Some providers reported that self-management was working well and it could offer more flexibility and choice for some NDIS participants. However, other providers reported families struggling with the burden of self-management, including some who had been allowed to self-manage services when they lacked the capacity to do so.

The perspective of the NDIA staff

- NDIA staff reported that most participants continued to prefer that the agency managed their funding. It was suggested that many participants and families simply did not want to fully self-manage, as it was perceived to be too hard or too much work. The self-management of funding was seen as being particularly difficult for people with intellectual disability or for those without access to the internet. It was therefore reported that it was common for participants to self-manage a component of their plan rather than all their supports. Common components of plans that were self-managed included transport, therapy services, and supports provided by an unregistered provider. Staff noted the risk of fraud or mismanagement of funds by those undertaking self-management and were concerned that the Scheme lacked sufficient safeguards.

3.6. 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?

The qualitative detail

- At wave 1, NDIS participants criticised the often lengthy and complicated process of establishing NDIS eligibility, which was 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 high workloads which reduced contact with individual participants and prevented a more customised service.
- By wave 2, NDIS participants had improved understanding of processes and the concepts/language used by the NDIA. As a consequence respondents reported becoming more confident in using this knowledge in their interactions with NDIA staff. However, a need for better advice and assistance in preparation for planning and plan review meetings (including lists of eligible and accessible services) remained. All respondent groups recommended the use of advocates (either paid or unpaid) who were familiar with the NDIS system. By wave 2 some NDIS participants reported providing advice to newer entrants who were less familiar with the NDIS and the planning process.

3.7. Summary and Integration

In this section we presented qualitative and quantitative evaluation evidence on five KEQs that relate to the broad theme of *choice and control*.

NDIS participants

Both the quantitative and qualitative evidence collected so far suggests an overall improvement in the choice and control responding NDIS participants experience over their supports. When it comes to choice and control, a pattern is emerging. Looking at each facet of choice and control, about half of all respondents indicate that they are better off, about a third that they are about the same as before the NDIS, and about 15 per cent that they are worse off. There is considerable diversity among those who report being worse off.

Both the qualitative and quantitative data indicate that people with mental health and psychosocial disability are more likely to report less choice and control over supports since becoming NDIS participants. The qualitative data further indicates that vulnerable families, those unable to navigate the NDIA website to find what services and providers were available and those less able to articulate support needs, are less likely to experience greater choice over their supports. Exercising choice was also constrained for those living in non-metropolitan locations with fewer service providers.

The quantitative data indicates that those who report that they are worse off in terms of their choice and control over their supports are more likely to have experienced a decrease rather than an increase in the number of supports they receive within the NDIS. In addition, those who report that they have funding for supports which, however, they cannot access, have lower levels of satisfaction with the overall quality of their supports.

Both qualitative and quantitative data sources also indicate that many NDIS participants would like to have more choice and control over their supports. The quantitative data allows us to understand the number of supports over which NDIS participants would like more choice. On average, each person stated four types of support over which they would like more choice.

The qualitative data allows us to understand in more depth what increases in choice and control are desired. This data indicates that NDIS participants and carers felt they had insufficient information to choose their service providers confidently. These respondents requested more information about services available from each provider, and help with defining factors on which to base their choice when asking providers about their supports in order to make an informed choice. Several respondents described the NDIA website to be difficult to navigate, inhibiting their access to information about services. Finally, instances were reported where choice and control were restricted because of limitations in the number or capacity of service providers.

The quantitative data additionally indicates that under the NDIS it takes respondents (i) more time rather than less time to do the necessary paperwork and (ii) less time rather than more time to find and get supports. The first of these findings is supported by the qualitative evidence. The second of these findings however is contradicted by the qualitative evidence. The qualitative data indicates plan implementation was impeded by (i) a lack of information about providers and the services they offer (ii) the amount of time and effort involved in managing and organising NDIS providers and activities and arranging payments for some services and (iii) a lack of service providers, in particular outside the main urban centres. However, it is important to note that inclusion of case management/case coordination in NDIS plans to assist with the engagement and implementation process for services and supports was more common at wave 2. Feedback from respondents suggested that for many, this was a valued service which has removed the burden and stress of communicating and co-ordinating with providers.

Both the quantitative and qualitative evidence indicates that self-management is very uncommon. The qualitative evidence indicates that the main reason for this appears to be a reluctance to take on additional administrative activities. 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 and in the support workers that they engaged.

Family members and carers

The quantitative data indicates that the overwhelming majority of NDIS participants need assistance on a daily basis. The most frequently mentioned person that assists NDIS participants was their own mother or father.

The quantitative data finds that the NDIS increase the ability of family members and carers to care for people with disability and decreases their anxiety about future supports available to the person they cared for. However, the qualitative data did indicate that there were many concerns about the future sustainability of the NDIS.

The quantitative data suggests that family members and carers report high levels of satisfaction with the amount of say they have about what supports the person with disability receives and where they obtain those supports. This finding appears to contradict the qualitative evidence which suggests that family members and carers of NDIS participants (particularly of young children) reported that their own needs and the needs of the family more broadly were **not** addressed in the planning process. Respondents requested greater attention to the family context.

Both the quantitative and qualitative data indicate that many family members and or carers of NDIS participants are unable to take adequate breaks from providing support and that they cannot access carer support in a consistent manner.

4. Participation (social, economic and educational), Wellbeing, and Aspirations (goals)

Key Messages

KEQ 1: To what extent has an NDIS contributed to changes in wellbeing and quality of life for people with disability, their families and carers?

The quantitative detail

- The quantitative data collected information on three separate measures of wellbeing: (i) psychological wellbeing (often called eudaimonic in the literature); (ii) PWI; (iii) and sense of social connection.
- NDIS participants overall have a mean wellbeing index that is well below the average PWI in Australia. It will be essential for the evaluation to assess whether the NDIS improves the personal wellbeing among NDIS participants. The second wave of the quantitative survey data will enable this assessment.
- When we compare the measures of wellbeing by broad disability type we see on all three measures NDIS participants with a mental health or psychosocial disability record a mean measure of wellbeing that is well below that recorded for other disability groups.
- The experiences of choice and control and unmet demand under the NDIS are connected with reported personal wellbeing. The more say (choice) NDIS participants have with regards to the decision on what support they get, or where they get them from, the higher their reported wellbeing. In addition, those who have experienced unmet demand for support after joining the NDIS also report significantly lower values of personal wellbeing.
- The wellbeing measures for family members and carers paint a very diverse picture regarding the supports that make a difference in their life as carers. Carers have very high satisfaction with some aspects of their lives (e.g. with their relationships to the relevant service providers and with the support provided to people with disability to make progress at home). At the same time they have high dissatisfaction with other aspects of their lives (e.g. with family support necessary to relieve stress, availability of outside help to take care of the special needs of all family members, time of family members to pursue their own interests, and having friends or others who provide support).
- Just under half of all family members and carers report that they experienced at least one indicator of financial hardship over the last 12 months.

The qualitative detail

- The two waves of qualitative evidence provide an early indication of whether and how the NDIS has contributed to any changes in wellbeing of NDIS participants and their families and carers.
- There was an increase in overall sense of wellbeing. Many NDIS participants described evidence of improved skills and developmental progress as a result of the NDIS. This included increased participation in society and recreational activities, being able to do things that had hitherto been unavailable or inaccessible, and observable happiness in being able to be more active.

- Families and carers often reported an increased sense of positivity and wellbeing as a result of the NDIS participant being more involved in activities they enjoyed and being able to participate in wider interests outside of the home.
- The wellbeing of family members and carers had also generally improved as a result of reduced financial strain and increased access to supports.

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 quantitative detail

- The quantitative data provides information about activities that NDIS participants and family members and carers have done recently and information about activities they would most like to do in the coming year.
- The quantitative data indicates that the most frequently reported activities undertaken by NDIS participants and their family members and carers was spending time with family and with friends. The most desired activity to be undertaken in the future for both NDIS participants and their family members and carers was to go on a holiday.
- When people with disability were asked to think about those hurdles that could make their future activities hard to achieve, at the top of the list were "costing too much" (42 per cent) and "understanding" (others understanding the person with disability, and the person with disability understanding others). The data shows that there are several severe hurdles related to buildings access, transport, safety, organisation, timing and other, each of which could make things harder for the person with disability.
- A sizeable proportion of our sample consists of young people with disability in education. There is preliminary evidence (primarily due to low numbers) that working in a job is the most preferred post-education objective of these people and that going on with further education or training is the second most preferred objective. Just over a quarter of the sample report that they do not know what they would like to do after they complete their qualification.
- A majority of adults do not wish to study any further. For the rest the main obstacle to education is their own health/disability, but there are also sizeable practical barriers relating to transport and parking, facilities and equipment, personal supports, hours flexibility and other. This appears to be an area of much complexity.
- Only a small proportion of all family members and carers are presently in education.
- Around one-fifth of all NDIS participants aged 16 years or older (20 per cent) were currently employed, 77 per cent part-time, 52 per cent had their workplaces, hours or conditions adapted to enable them to work, with 86 per cent liking their job and 60 per cent not wanting a different job.
- The quantitative data uncovers an unstable picture of past employment. Of those who were not currently employed, over half (53 per cent) had previously had a paid job, and 45 per cent never had a paid job. Those who were not currently employed were fairly evenly distributed between those who wanted a paid job (40 per cent) and those who did not currently want a paid job (42 per cent). Of

those who were not working, but currently wanted to work, only a quarter were actively seeking employment (25 per cent).

- Severe barriers to employment participation for people with disability are evident. The most frequently mentioned barrier to getting a job by people with disability was their own health/disability (80 per cent). Other barriers were a lack of opportunities (69 per cent), what employers think about people with disability (55 per cent), difficulties with transport or parking (48 per cent), difficulties using facilities or equipment (46 per cent) and lack of schooling, training or experience (41 per cent).
- Formal employment of carers is severely reduced because of their caring responsibilities. About a third of family members and carers are in employment, half of them full-time and the other half part-time. About a quarter gave up work altogether for caring and a fifth gave up full-time for part-time work because of caring. Half of those who are not in employment would like to work.

The qualitative detail

- The strongest indications that the NDIS was making some difference came from people with disability, and their families and carers themselves. Although qualitative evidence of this kind cannot be generalised per se, among those included in the qualitative study, most felt that NDIS participants' engagement in social and everyday activities had indeed increased. As a result, many participants 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 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.
- Unlike social participation, there were few instances of reported increased participation in paid or unpaid work. Only a small number of NDIS participants were engaged in ongoing (mostly supported) employment, ranging from full-time to part-time hours at wave 1. While there was an increase in participation in employment related activities including volunteer work, work experience, supported employment and paid work by wave 2, still only a few NDIS participants reported undertaking these activities.
- Easing the care burden on family members and carers improved their social and economic participation as it allowed them to be involved in other valued activities such as employment, social activities and quality time with other family members that would previously not been possible.
- There were a few examples of carers increasing their working hours, or pursuing employment activities at wave 2 because they now had a little more time as a result of their child participating in more activities than previously.

KEQ 3: To what extent has an NDIS enabled people with disability, their families and carers to achieve their goals?

The qualitative detail

- Goals and aspirations were mainly related to the transition into school, enrolling in further study, gaining employment or volunteer work, gaining more independence, increasing social skills and to live independently (or continue to do so).

- Since joining the NDIS many achievements related to NDIS participants' goals were made. Many young children had transitioned into school. Other NDIS participants had enrolled in TAFE or university.
- Employment-specific goals were included in many of the participants' plans, which aimed to assist with integration into the workplace. As noted above, the achievement of employment related goals had been limited.

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?

The qualitative detail

- In general, almost all NDIS participants and their families and carers, had experienced some type of life change or transition between the wave 1 and 2 interviews. Some NDIS participants had transitioned into their first year of school, from school to further studies, or from further studies to employment related activities.
- In almost all instances, the NDIS was reported to have assisted participants with these major life transitions.

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?

The qualitative detail

- It was thought that NDIS funding of individualised support services instead of group-based services had negatively impacted on the social participation of some NDIS participants who no longer attended programs where they had previously mixed with a range of people.
- Some NDIS participants and their family members reported that support for carers (within and outside of the NDIS) has diminished since the NDIS roll-out.
- Considerable concerns about the impact the NDIS would have on people with disability not eligible for the NDIS, were evident. Some non-NDIS participants were reported to be receiving fewer services while others were falling through service gaps and getting no supports at all.

4.1. Introduction

The NDIS aims to improve the quality of life, wellbeing, and social and economic participation of people with disability, their families and carers. A core task of the NDIS evaluation is to understand the degree to which the introduction of the NDIS has increased social and economic participation and wellbeing. It is recognised by the NDIS evaluation that there are many facets of participation and that wellbeing is a very complex concept that can take different meanings by different people, even when they are faced with the same circumstances, and different meanings by the same person when faced with different circumstances or over time. It is also recognised by the NDIS evaluation that the academic and policy literature offers several different methods for measuring wellbeing, each of them with their strengths and weaknesses and their specific focus points and emphasis. Resolving these differences would be a major research task and lies well beyond the scope of this evaluation. The strategy underpinning the NDIS evaluation is to not rely on any single measure of wellbeing, but to collect information on a wide range of measures and at different points in time. We thus collected wellbeing information that is akin to what is collected by the Household Income and Labour Dynamics in Australia Survey (see for example Qu, L., et al. 2012). We also collect information that is akin to the wellbeing information collected by the Organisation for Economic Co-operation and Development (OECD 2013) and information on the well-known PWI devised by the International Wellbeing Group (2013).

In this section we present qualitative and quantitative evaluation evidence on the following five KEQs that relate to the broad theme of *participation, wellbeing and aspirations*.

- KEQ 1: To what extent has an NDIS contributed to changes in wellbeing and quality of life for people with disability, their families and carers?
- 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?
- KEQ 3: To what extent has an NDIS enabled people with disability, their families and carers to achieve their goals?
- KEQ 24: 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?
- 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?

4.2. KEQ 1: To what extent has an NDIS contributed to changes in wellbeing and quality of life for people with disability, their families and carers?

The quantitative detail

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

The quantitative data collected information on three separate measures of wellbeing: (i) psychological wellbeing (often called eudaimonic in the literature); (ii) PWI; (iii) and sense of social connection. We do not rely on any single measure. Rather we examine all of the evidence and form a quantitative judgement as to the overall message that arising regarding wellbeing and specific aspects of the NDIS.

The NDIS Survey of People with Disability, and their Families and Carers: Psychological (Eudaimonic) wellbeing measure - statements by people about themselves and how they feel (OECD 2013).

- The psychological measure contains six questions on different aspects of people's psychological functioning. It aims to measure a range of different concepts that are sometimes described as the "eudaimonic" (or "Aristotelian") notions of wellbeing[2]. Respondents are asked to rate on a scale of 0 to 10 (where 0 means "completely disagree" and 10 means "completely agree") to say how they have been feeling this week.

---

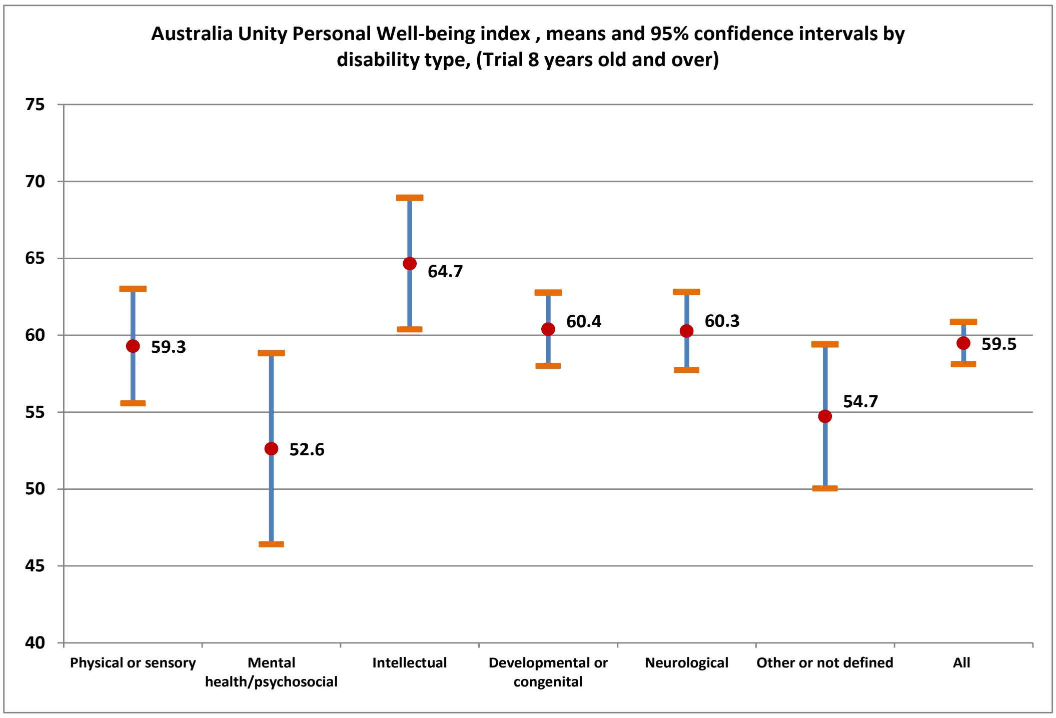
[2] The questions in the eudaimonic wellbeing block are relatively diverse and cover a range of different mental attributes and functioning's that are thought to constitute mental "flourishing". OECD 2013

- In Appendix 4.2 Table 54 to Table 58 present the mean value of responses to each of the six questions that make up the psychological wellbeing block by broad disability type. The six measures are presented in this manner, as they are intended to be used independently by the evaluation in order to enable the separate investigation of different aspects of (psychological) wellbeing.
- Overall we see that the mean responses of the NDIS participants to the six measures range from 5.9 to 7.
- In order to interpret these current observations of wellbeing, two broad comparisons are of interest. The first is a comparison between current and previous levels of wellbeing. This comparison will only be made directly once wave 2 data is at hand.
- The second is the comparison between different subgroups within the NDIS population group. When we compare the measures of wellbeing by broad disability type we see that NDIS participants with a mental health or psychosocial disability record a mean measure of wellbeing that is well below that recorded for other disability groups. We also observe that for those NDIS participants, the mean responses on all positively-keyed items are lower. They are larger for the negatively-keyed item. Conversely, we observe comparatively higher psychological measures for NDIS participants with intellectual disability.

The NDIS Survey of People with Disability, and their Families and Carers: Australia Unity PWI - questions about how happy People with disabilities feel about things in their lives (International Wellbeing Group 2013)

- Respondents are asked to report on a series of seven questions, each corresponding to a particular life domain: standard of living, health, achieving in life, relationships, safety, community-connectedness, and future security. Respondents are asked to rate on a scale of 0 – 10 (where 0 is very unhappy and 10 is very happy) how they have been feeling this week.
- 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 as it provides a cardinal measure of wellbeing.
- Figure 6 below displays the mean personal wellbeing index for NDIS participants by broad disability type along with the corresponding 95 per cent confidence intervals. It indicates that NDIS participants overall have a mean wellbeing index of 59.5. This is well below the average PWI in Australia which sits at around 75 (but has fluctuated over the years). It is worth noting that it is not only the mean (average) values of the PWI that is different from that of the broader Australian population, but also the way the answers range from 0 to 10 within each category (i.e. the distribution of wellbeing with each type of disability category). The figures reported in Appendix 4.2 show this rather forcefully and warn us to avoid making any direct comparisons between the NDIS survey averages and those of the broader Australian population.

Figure 6: Australian Unity Personal Well-being Index, mean and 95% confidence intervals by disability type (Trial PWDs, Aged 8+)



- Australian unity who are the architects of the PWI measure point out that "…if a person's PWI is below 60 and stays that way over time, it is a signal their homeostatic response is failing and they are at risk of depression". (2015: 5). When we consider the result by broad disability type we see that people with mental health/psychosocial disabilities are extremely low on the PWI, well below the "minimum threshold" defined by Australia Unity. For most other disability types, the reported PWI sits at around that minimum threshold.
- It will be essential for the evaluation to assess whether the NDIS improves the personal wellbeing among this group. Wave 2 survey data may enable such an assessment, but the strength of this change would be subject to the speed at which NDIS changes happen and the speed at which their impacts can be felt by the new NDIS participants. For some of the longer-run potential NDIS impacts, the time elapsed between wave 1 and wave 2 may not be sufficient for clear impacts to be measured.
- The interpretation of these measures would benefit from further methodological research, which however, would lie beyond the scope of this evaluation.
- Figure 8 combine the information on NDIS participants' PWI and the answer they gave to the questions of choice and control over their support. Like the previous Figure 6 they show the mean wellbeing index and corresponding confidence intervals for each of the answers given to, respectively, (i) the question about how much say NDIS participants had with the decision about what support they get under the NDIS, and, (ii) the question about how much choice the NDIS participants had about where to find their supports. Figures 5 and 6 show that the experiences of choice and control of NDIS participants are clearly associated with their reported personal wellbeing. The more say (choice) they have had with regards to the decision on what support they get or where they get them from, the higher their reported wellbeing. The relationship is more obvious between the amount of say about what supports NDIS participants get and their wellbeing than with the choice about where they get those supports. We report in the Appendix (Figure 15 to Figure 18) the distributions of the answers to the PWI according to the categories of the choice and control variables. These distributions confirm the picture of heterogeneity among NDIS participants with regards to the association between their NDIS experience and their wellbeing

and reinforce our warning about making direct comparisons with similar measures on the broader Australian Population.

Figure 7: Australian Unity Personal Wellbeing Index, mean and 95% confidence intervals by amount of say about what supports received under the NDIS (Trial PWDs, Aged 8+)

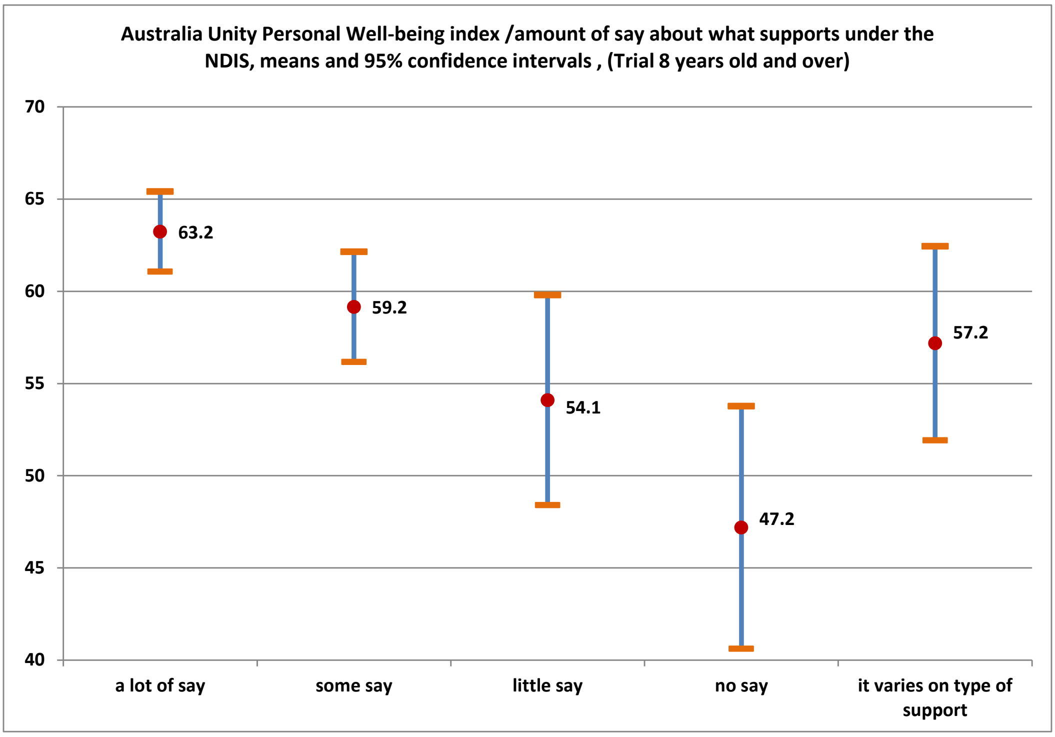
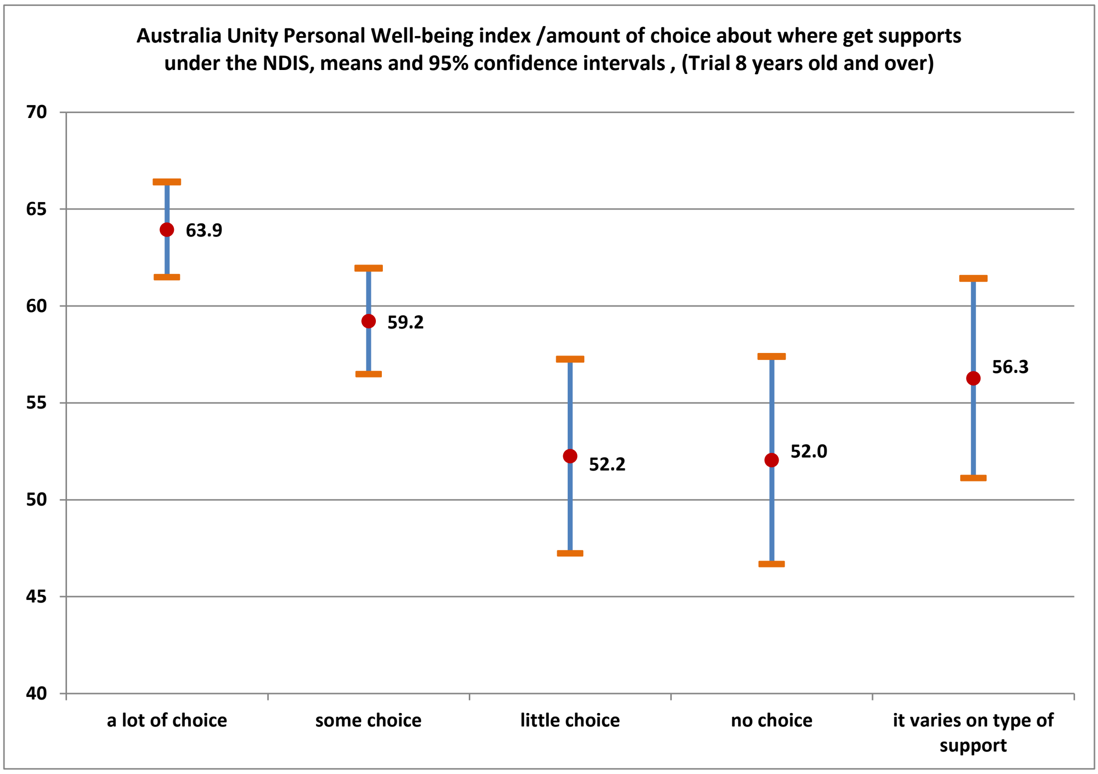
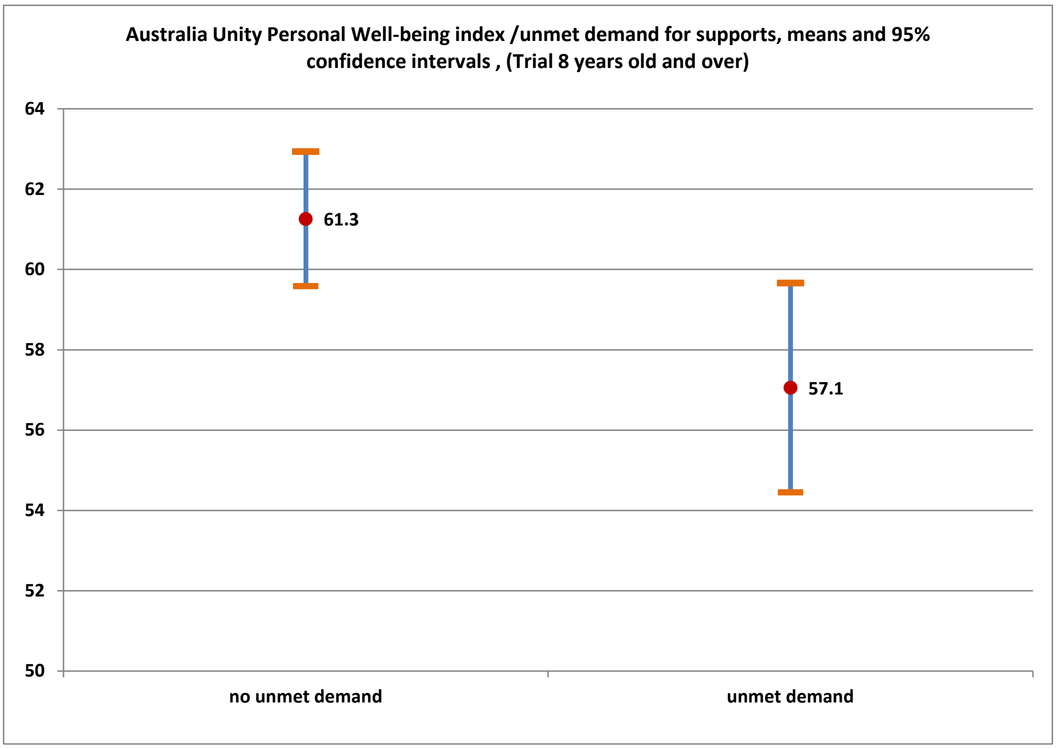


Figure 8: Australian Unity Personal Wellbeing Index, mean and 95% confidence intervals by amount of choice over where obtain supports received under the NDIS (Trial PWDs, Aged 8+)



- Figure 9 below shows the observed differences in terms of reported wellbeing between NDIS participants who experienced unmet demand (defined as those participants who had funding for support but could not access some of these funded supports). We observe that NDIS participants who have experienced unmet demand for support after joining the NDIS also report significantly lower values of personal wellbeing. The reader should note here that we are only reporting an association between unmet demand and lower wellbeing and that we do not make at this stage a causal statement. It could be that those who experience unmet demand suffer a reduction in their wellbeing (that is, unmet demand makes people unhappy), or it could be that unhappy people do not manage their supports as well and they experience more unmet demand (that is, being unhappy makes people less able to utilise services and supports that are in principle available to them) or it could be that there is another underlying reason that influences both unmet demand and people's wellbeing. We urge the reader to avoid over-interpretation of this and other similar results. Further investigation using both waves of the quantitative data will shed a lot more light on these possibilities as the evaluation data collection and analyses progress.

Figure 9: Australian Unity Personal Wellbeing Index, mean and 95% confidence intervals by unmet demand under NDIS (Trial PWDs, Aged 8+)

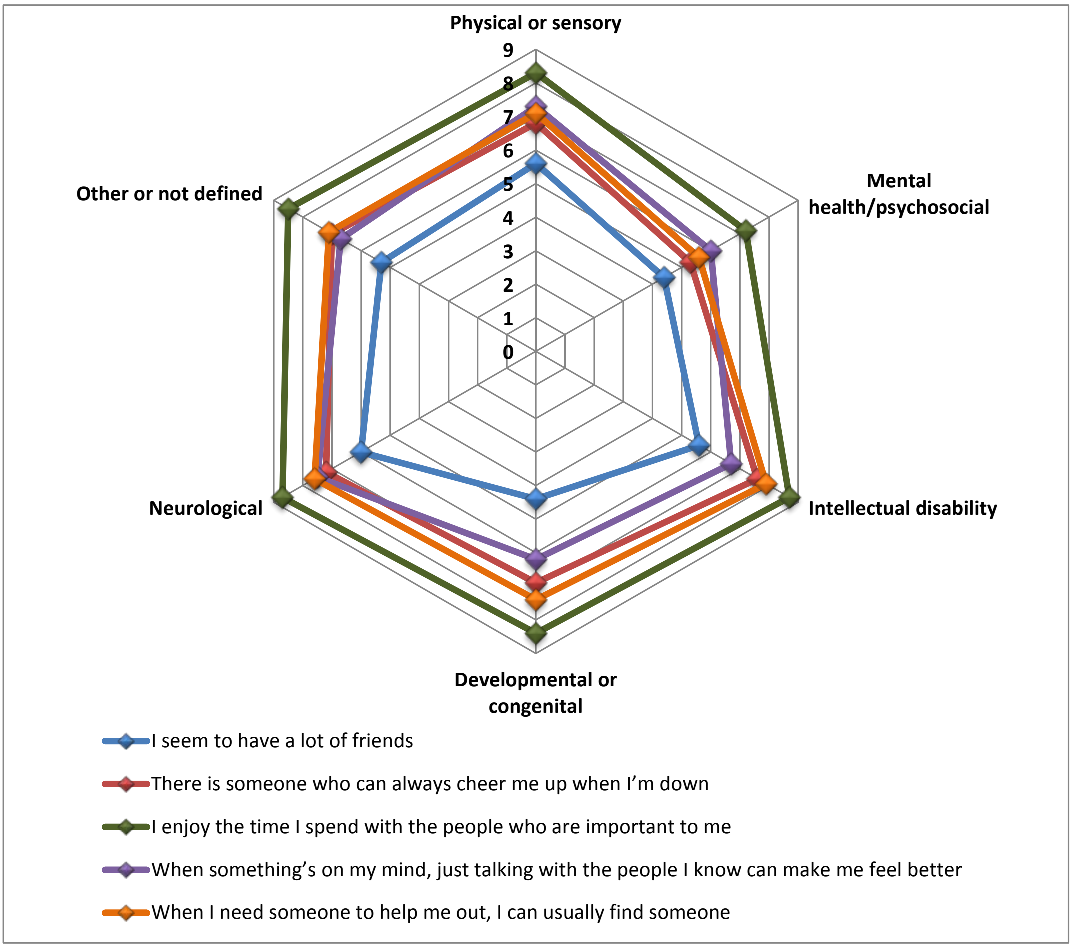


The NDIS Survey of People with Disability, and their Families and Carers: Sense of social connection - descriptions about how much support they get from other people (Household Income and Labour Dynamics in Australia Survey see for example Qu, L et al. 2012).

- The final measure of wellbeing that we collect uses a set of questions to measure a person's sense of social connection. Respondents are asked to report on a series of questions concerned with their connection with others in the community. These data are an indicator of social capital and social inclusion. The questions are concerned with levels of perceived loneliness, sufficiency of friends and visitors, and the perceived level of help available. Respondents are asked to rate on a scale of 0 - 10 several aspects of how they have been feeling this week (where 0 is completely disagree and 10 is completely agree).

- Appendix 4.2 Table 59 to Table 63 present the mean value of responses to each of the five questions that make up the "social connection" wellbeing block, by broad disability type. The five measures are presented this way as they are intended to be used independently in order to investigate different aspects of social connection. We summarise the information contained in these tables into a radar graph (Figure 10) to provide an overview that allows for clear comparisons between each of the aspects of these measures of wellbeing.
- The responses of NDIS participants to the five measures of social connection range from 5.2 to 8.4. NDIS participants report lower levels of agreement to the statement "I seem to have a lot of friends". Comparatively, they report higher levels of agreement with the statement "I enjoy spending time with the people who are important to me".
- When comparing responses by broad disability type we see that people with mental health conditions/psychosocial disorders report lower levels of social connection on all measures. People with developmental or congenital conditions report low levels of agreement to the statement "I seem to have a lot of friends".
- The radar graph in Figure 10 highlights that for all disability types, NDIS participants seem to record a higher score to the questions about "I enjoy the time I spend with the people who are important to me". Also, the graph highlights that the answers to the first question "I seem to have a lot of friends" are associated with lower scores for each disability type. For other questions we see a bit of variability between disability types with regards to which question receives higher scores but these variations appear to be too small to be statistically significant. With the availability of wave 2 data, we will be able to look at changes between the two waves and be more informative as to the impact of the NDIS on the wellbeing of people with disability.

Figure 10: Sense of social connection, mean by disability type (Trial PWDs, Aged 8+)



The NDIS Survey of People with Disability, and their Families and Carers: Family Members and Carers Perspective

- The wellbeing of the family members and carers of people with disability is another important factor on which the evaluation focuses. Families and carers are asked a series of questions to rate their level of satisfaction with various aspects of life (Appendix 4.2 Table 64).
- The majority of family members and carers in the trial sites are either satisfied or very satisfied with the various aspects of their lives they are asked to report on. However, there is diversity. We note that a significantly large proportion of family members and carers report to be either dissatisfied or very dissatisfied with some aspects of their lives. These appear to be mostly aspects that have to do with the amount of support family and carers can count on, with more than 20 per cent of family & carers reporting to be dissatisfied or very dissatisfied with (i) family support necessary to relieve stress, (ii) availability of outside help to take care of the special needs of all family members, and (iii) time of family members to pursue their own interests. The first conclusion that one can reach is that for a significant proportion of families and carers, activities centred around caring for the person with disability can be an all-consuming part of their lives, and one where the ability to rely on additional support from third persons is needed but often lacking.
- Another measure of wellbeing included in the NDIS survey is financial hardship (Appendix 4.2 Table 65). This question is only asked of family members and carers of NDIS participants and asks about seven separate indicators that could be taken as potential manifestations of financial hardship. 42 per cent of family members and carers of NDIS participants that were surveyed reported that they experienced at least one indicator of financial hardship over the last 12 months. The financial hardship most commonly reported indicator was that a carer or family member could not pay bills on time (26 per cent) and/or that they asked for financial help (25 per cent). The numbers reported in Table 65 are pointing towards those family members and carers in the sample who may be finding themselves in serious disadvantage. These family members and carers will be examined further once wave 2 data become available.

The qualitative detail

Disability, whether intellectual or physical, present since birth or acquired later in life, was reported as having a major impact on both the life of the person with the disability, and on their family members and/or carers. These impacts occurred across the spheres of health and wellbeing; social, economic and educational participation; finances; and the household and family relationships. The two waves of qualitative evidence allows us to understand how the NDIS has contributed to changes in health and wellbeing; and the social and economic participation of NDIS participants and their family members and carers.

The perspective of the person with disability and their family and carer

For the NDIS participant

- At the time of the wave 1 interviews, positive impacts of participating in the NDIS were beginning to emerge for most participants. The main impacts reported were related to having better services than previously and an improved coordination of services (particularly for households with more than one NDIS participant). Evidence was provided of increased independence, of "living" rather than just managing or "surviving", and of generally feeling happier.
- At wave 2, there was an increase in overall sense of wellbeing. However, in some cases the NDIS participant's wellbeing and behaviour had declined (for reasons not necessarily related to the NDIS).
- Many respondents described evidence of improved skills and developmental progress as a result of the NDIS. This included increased participation in society and recreational activities, being able

to do things that had hitherto been unavailable or inaccessible, and observable happiness in being able to be more active.

- At wave 2, as at wave 1, many parents of young NDIS participants gave examples of the physical and, to a lesser extent, social and emotional progress made by their child, achieved with the support of NDIA funding. There was some suggestion that increased intensity of intervention, a direct consequence of the higher level of funding provided by the NDIS, was accelerating developmental progress.
- The wave 2 interviews described changing relationships with families and carers as NDIS participants became less reliant on them for caring roles. This was said to alleviate some pressures and allow more positive familial relationships to develop.

> *Yeah I guess so like just being able to go down [to my mother's place] and it's been easier to stay, that's been more enjoyable and I guess it's built a better relationship as well possibly being able to get down there a bit more. (B16 C W2)*
>
> *I'm his mum again, or I'm in the process of becoming his mum again, not his carer. (C08C W2)*

For their family member and or carer

- At wave 2, families and carers often reported an increased sense of positivity and wellbeing as a result of the NDIS participant being more involved in activities they enjoyed and being able to participate in wider interests outside of the home.

> *It's good because David is much happier. He's a heck of a lot easier to live with because he's happier within himself, you know and he knows there's a future out there for him and he's looking forward to it and it makes me happy too. (E01 PWD&C W2)*

- The wellbeing of family members and carers had also generally improved as a result of reduced financial strain and increased access to supports.

> *It's given a peace of mind. It has taken some of the financial - the worry, out of knowing that we're doing what we can to get him set and not having to worry, "How am I going to pay for this? Can I do this? Can I do that?" (D17C W2)*

- Many carers reported a lessening of carer load with the additional help of disability support workers. This improved wellbeing as it allowed more opportunity for self-care and to spend time with other family members, notably the siblings of NDIS participants.

> *For us it's so significant to have him out and about active. And he's happy to go, there's none of this yelling and screaming, kicking. That is so good for the rest of our family. It's so good for his younger brother to have three hours of just mum and dad on a Saturday instead of dragging Dennis off to appointments or it all being about Dennis. Yeah so he gets quality time with us. (A23C W2).*
>
> *On top of that, like there's enough things. I love my Tuesdays because I actually get to spend the day by myself. Not that I don't love you but … he's off doing fun stuff with his friends and I get to spend the day just doing stuff for me (E01 PWD&C W2)*

- Family members and/or carers often spoke about having worried about the future of the NDIS participant. There was evidently a sense of relief that the NDIS had come along, in particular among parents/carers of young NDIS participants. Many reported that the NDIS had given them some control over the future, in terms of setting up plans, activities and supports for the person they cared for. However, there was also high levels of ongoing anxiety related to the longer term sustainability of the Scheme.

- The ongoing administrative burden of the NDIS was often highlighted. This was sometimes a new source of stress, so much so that some parents felt the added paperwork consumed time usually spent as a family.

4.3. 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?

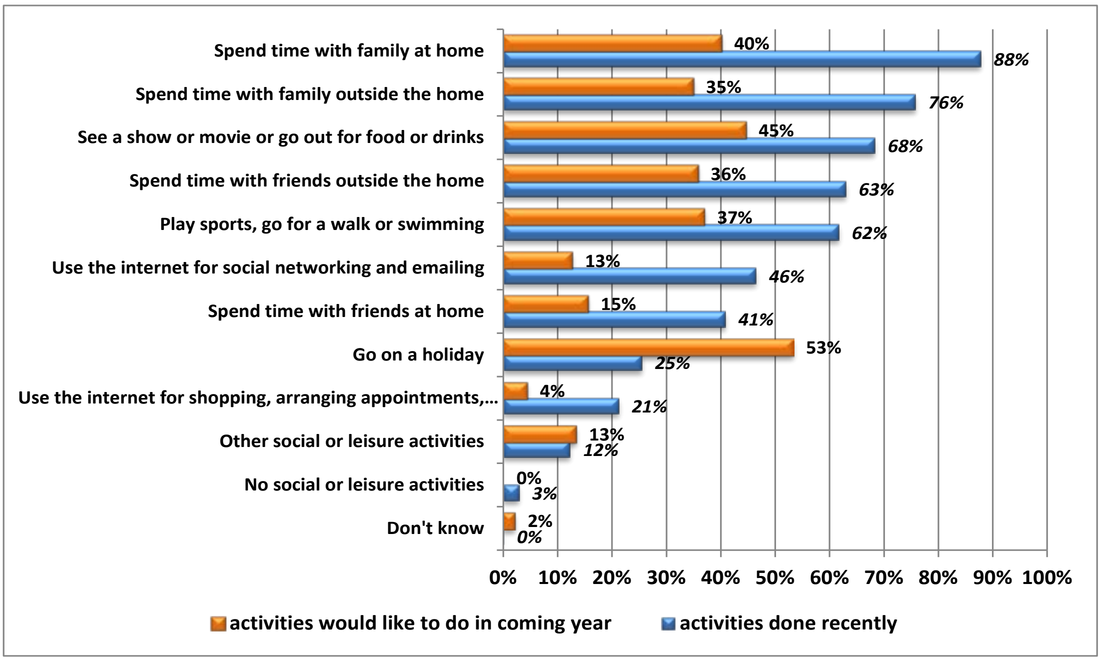
The quantitative detail

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

The NDIS participant – Social Participation

- The NDIS survey asks about the activities the NDIS participant have done recently without reference to a specific timeline (such as “in the last month”) in order to simplify and question and 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. 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. Figure 11 summarises the information contained in both questions and allows a direct comparison between what NDIS participants have done recently and what they would like to do in the next year.
- We see that above all, NDIS participants have spent time with family within and outside of the home (88 per cent and 76 per cent respectively). More have met friends outside than inside the home; and more than half went to see a show, movie or meal (68 per cent), or had taken part in physical activities (62 per cent).
- Respondents are asked to nominate just three activities that they would most like to do in the future (also in Figure 11). Going on holiday is by far the most frequently reported desired future activity and one of the least frequently actually experienced. Going out to shows, movie or meals, and going on holiday were reported as the most desirable future activities.

Figure 11: Activities the NDIS participants have done recently and would like to do in the coming year (NDIS participants, 8 years old and over)

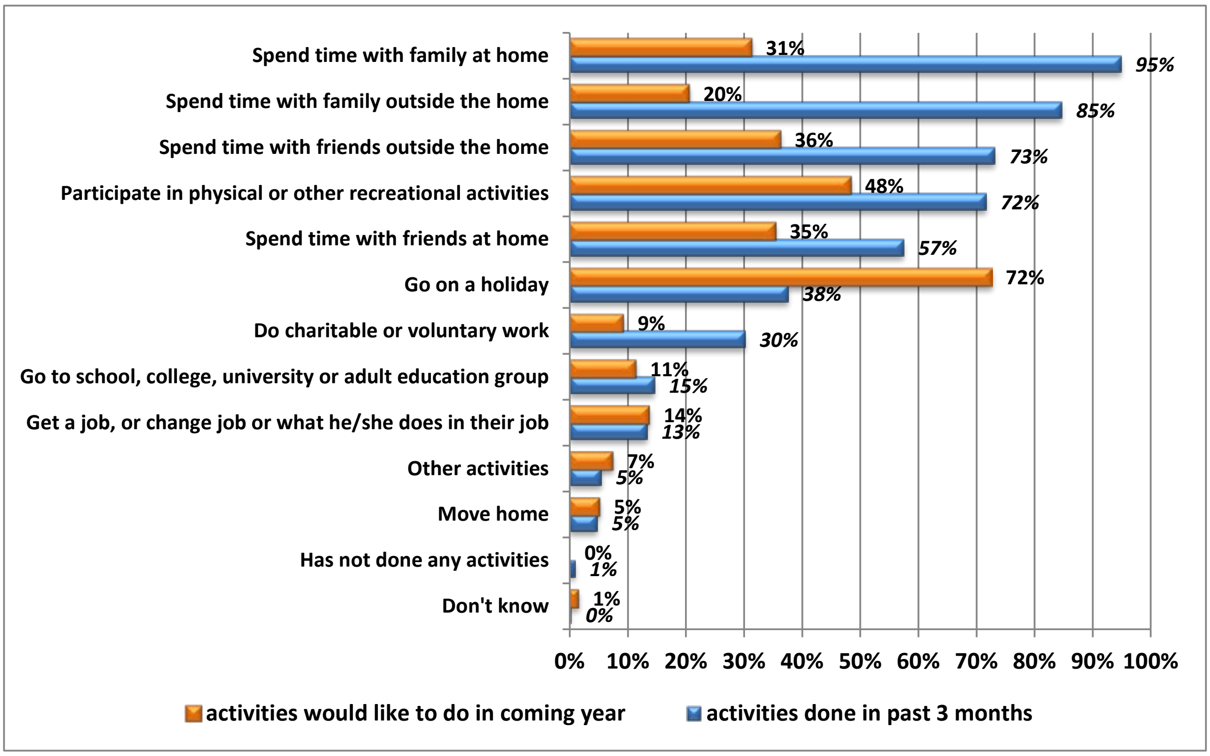


- An important aspect of the NDIS is its explicit objective to remove barriers and hurdles faced by people with disability in their everyday life. Straight after asking for actual and desired future activities respondents are also asked to think about any hurdles that may make their future activities hard to achieve (Appendix 4.3 Table 66). The most frequently mentioned hurdle was the high cost associated with undertaking social or leisure activities (41.6 per cent). Almost as frequently (41.2 per cent) reported was the hurdle that "other people cannot understand the person with disability".

The family members and carers – Social Participation

- The NDIS survey asks a similar set of social participation questions of the family members and carers. The information is summarised in Figure 12 below and gives rise to the following three main observations. First, carers report to be undertaking more social and leisure activities than the person that they care for. Second, the most frequently reported activities undertaken and desired to be undertaken in the future by family members and carers are similar to those reported by NDIS participants (i.e. meeting with family and friends and participating in physical activity). Third, compared to NDIS participants, a higher proportion of carers desired to go on a holiday in the future.

Figure 12: Activities the Family and Carers have done recently and would like to do in the coming year (Carers of Trial participants)

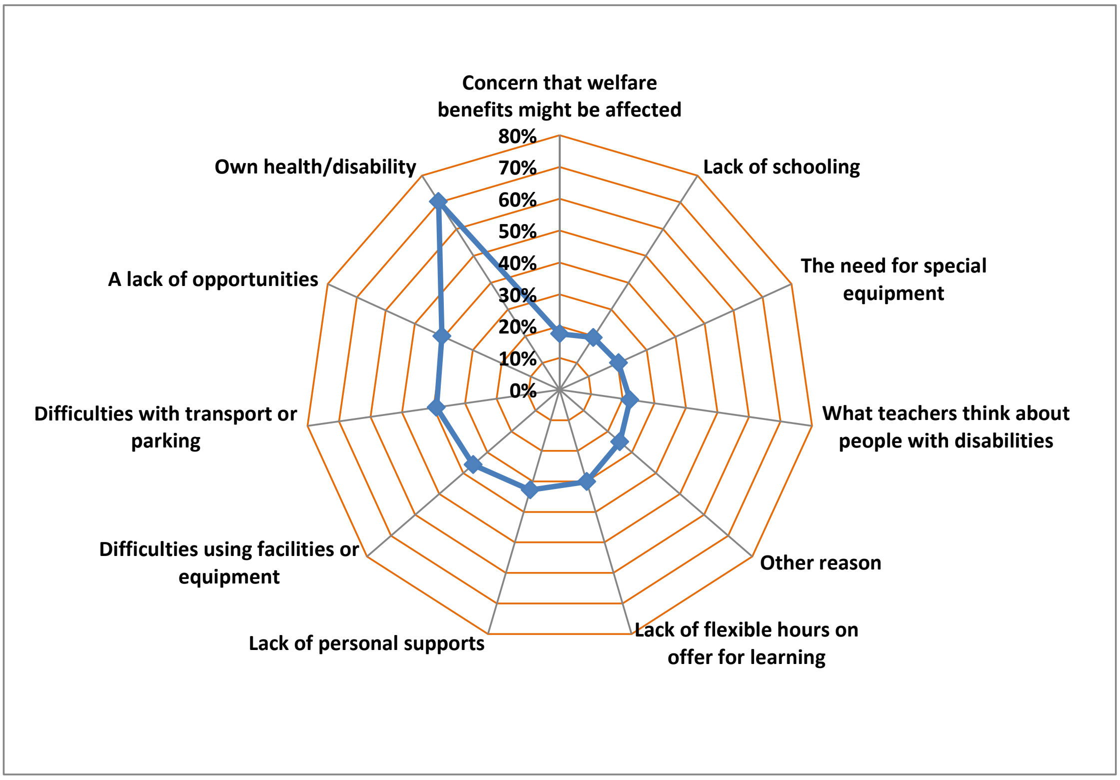


The NDIS participant – educational participation

- Education is widely recognised as a major direct contributor towards greater social and economic participation and an indirect contributor towards improving wellbeing and the general quality of life. The NDIS survey collects information about the education level of people with disability. The present sample contains 850 people with disability who are currently studying towards a qualification. We ask for the level of the aimed qualification. We note that the sample composition is skewed towards a higher proportion of younger people, principally because of the intentional design of the NDIS trial in SA to contain only 0-15 year olds and Tasmania 16-24 year olds, while the other trial sites span across all ages (which means that they also include a fair number of younger people).
- Appendix 4.3 Table 67 shows the type of educational establishment attended by those in education. The majority of children below 16 and who reported attending a school were in Pre-school/ kindergarten (19 per cent), in Pre Year 1 primary school (14 per cent) and Primary school Year 1 and above (34 per cent). School attendance of a secondary level or within a special school is at 8.5 per cent and 9 per cent respectively. Around 5 per cent are attending TAFE.
- Another indicator of education participation is whether the study is full-time or part-time. More than 80 per cent of reported attending education full-time (Appendix 4.3 Table 68).
- NDIS participants are asked what they would like to do when they complete their education (Appendix 4.3 Table 69). This question is only asked of those who are aged 8+ years. Just under 70 per cent of those asked give an answer that indicates that they have a plan for the future. Over a third report that they would like to work in a job (35 per cent), with 11 per cent planning to go to University and 12 per cent to do some further course or training. It is about a quarter (27 per cent) who report that they do not know what they would like to do and only 6 per cent who do not answer. It is important to note that the numbers are too low for making conclusions at this stage.

- NDIS participants who are aged 16 years and over and who are not currently in education, are asked if they would like to study. 23 per cent report that they would (Appendix 4.3 Table 70). Of those, around 40 per cent are looking for a course to study (Appendix 4.3 Table 71).
- We asked all those who did not definitively reject the wish to study and who were not presently studying, about what in their view makes it hard to study. Their answers are presented in Figure 13 for an easy overview. The most frequently mentioned barrier to educational participation by people with disability was their own health/disability (70 per cent). Other commonly mentioned barriers were a lack of opportunities (41 per cent), difficulties with transport and or parking (39 per cent), difficulties using facilities or equipment (36 per cent) and lack of personal supports (33 per cent).

Figure 13: What makes it hard to study (Trial PWDs, aged 16+)



Family members and carers – educational participation

- 11 per cent of NDIS participant's family members and or carers were currently studying. Nearly all on a part-time basis (Appendix 4.3 Table 72)

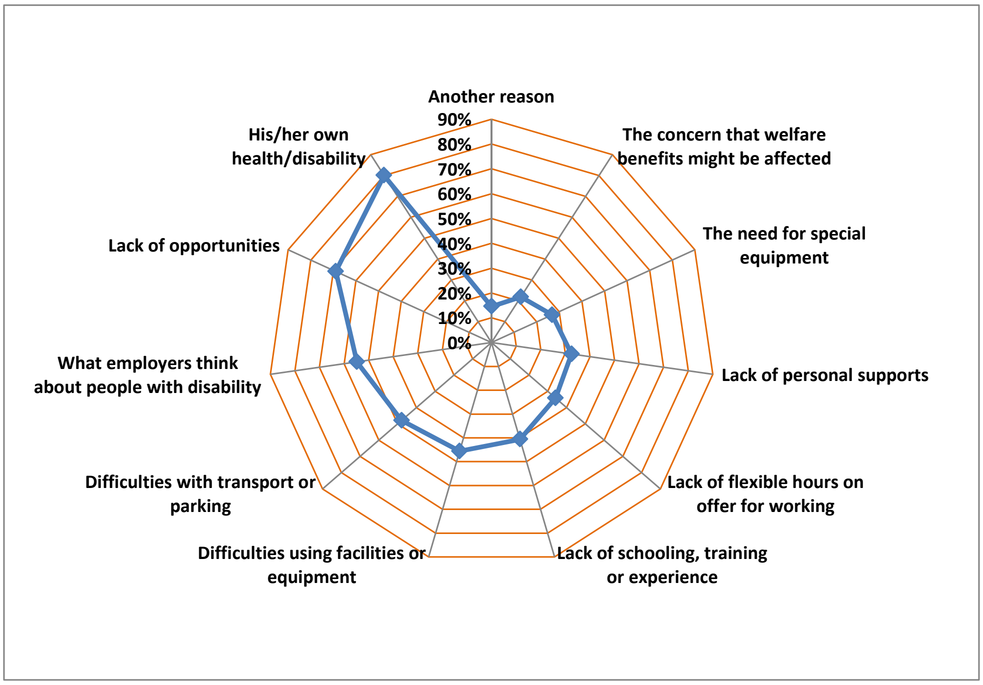
The NDIS participant – economic participation

The survey also collects information about the current employment status of NDIS participants and their family members and carers. The questions on employment are only asked of the adult survey respondents and they are probably the questions that will need the longest length of time between wave 1 and wave 2 observations for the evaluation to detect any employment changes that may follow the NDIS roll-out.

- The overall picture that emerges (Appendix 4.3 Table 73 to Table 78) is relatively clear, but the exact numbers are still tentative and require further analysis. We see that a minority of people with disability over the age of 16 are employed (20 per cent), their employment being mostly part-time (77 per cent) and that often their workplace, hours and conditions have been adapted to enable them to work (56 per cent). Overwhelmingly, they like their job (86 per cent) and did not want a different job (60 per cent).

- Of those who were not currently employed, over half (53 per cent) had previously had a paid job, and 45 per cent never had a paid job (Appendix 4.3 Table 79). They were fairly evenly distributed between those who wanted a paid job (40 per cent) and those who did not currently want a paid job (42 per cent) (Appendix 4.3 Table 80). Of those that were not working, but currently wanted to work, only a quarter were actively seeking employment (25 per cent) (Appendix 4.3 Table 81).
- We asked all those who were not employed, about what in their view makes it hard to get a job and present their answers in Figure 14 for an easy overview. The most frequently mentioned barrier to getting a job by people with disability was their own health/disability (80 per cent). Other commonly mentioned barriers were a lack of opportunities (69 per cent), what employers think about people with disability (55 per cent), difficulties with transport or parking (48 per cent), difficulties using facilities or equipment (46 per cent) and lack of schooling, training or experience (41 per cent). The overall picture that emerges is a familiar one of severe barriers to employment participation for people with disability.

Figure 14: What makes it hard to get a job? (Trial PWDs, Aged 16+)



The NDIS participant family members and carers – economic participation

- Around 30 per cent of family members and cares were currently employed, equally distributed between those working full-time and those employed on a part-time basis. About 23 per cent of family members and carers of NDIS participants had given up work to provide care and support to the person with disability. A further 20 per cent were currently employed part-time as a result of having to give up full-time work to provide care and support to the person with disability (Appendix 4.3 Table 82).
- Of those currently not in employment, 73 per cent had previously been in paid employment (Appendix 4.3 Table 83) and more than half (56 per cent) would like to have a paid job (Appendix 4.3 Table 84).
- Of those who desire paid employment, but were not currently employed, 80 per cent reported that their caring role was the main barriers precluding them from them having paid job (Appendix 4.3 Table 85).

The qualitative detail

The perspective of the person with disability and their family and carer

For the NDIS participant

- There was evidence of increased social participation of NDIS participants at wave 1. This continued at wave 2 with most NDIS participants further increasing their ability to take part in aspects of daily life that had been difficult for them before the NDIS. Many NDIS participants were now able to participate in activities independently (i.e. without a family member), have access to support when needed, able to follow interests and social activities that had previously been inaccessible, and be able to visit friends and family or having people to stay.
- Taking part in social activities such as meeting socially benefited some participants through increased social skills, doing fun and recreational activities and learning and developing general communication skills.

> *I've probably become more sociable and I've made new friends that I wouldn't have because I was up at [Name of provider 3]. I've become more confident with my money skills, my life skills, just become happier. (E02 PWD&C W2)*
>
> *It's good now. I've got a camp I can look forward to. Instead of me sitting in a chair thinking "oh woe is me, nothing nice ever happens"… (B16 PWD W2)*

- However, it was notable that for participants with mental health problems, intellectual disabilities or with Autism Spectrum Disorder, impacts related to social participation were more mixed. Concerns were raised by these respondents about the difficulties they had in participating socially, and developing friendships, and this had not improved with the NDIS. Others in this participant group observed that whilst they may have been able to engage more in social activities, these were often with people with similar types of issues (for example, others with mental health issues) rather than in more "mainstream" activities or in the general community.

> *I have funding for a mental health support service activity but what I found is that it's great if you go because at least you're accepted and you can share about mental illness but if you're wanting to recover and reintegrate into the community it doesn't really meet those needs, for me it doesn't meet those needs… (B05 PWD W2)*

- Unlike social participation, there were few instances of reported increased participation in paid or unpaid work. Only a small number of NDIS participants were engaged in ongoing (mostly supported) employment, ranging from full-time to part-time hours at wave 1. While there was an increase in participation in employment related activities including volunteer work, work experience, supported employment and paid work by wave 2, still only a few NDIS participants reported undertaking these activities.
- 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.

For their family member and or carer

- Easing the care burden on family members and carers improved their social and economic participation as it allowed them to be involved in other valued activities such as employment, social activities and quality time with other family members that would previously not been possible. Examples given included a carer who was able to "*join a gym and get a bit more on a healthy lifestyle" (C01C W2)*.
- Caring impacted on the carers' ability to take part in paid work and on career pathways more generally. Many parents/carers who were interviewed were unable to participate in paid work

because of care commitments. Several family members/carers noted that they had given up their careers as a result of care responsibilities, which had consequently impacted on their wellbeing and self-worth. Others felt their time out of work created further obstacles to returning to employment. For those that were in paid employment, many worked part-time and all noted caring responsibilities to have impacted on their work arrangements (i.e. leading them to work out-of-hours or on weekends, working from home, or being unable to pick up additional hours of work).

- There were a few examples of carers increasing their working hours, or pursuing employment activities at wave 2 because they now had a little more time as a result of their child participating in more activities than previously.

> *I need support to go to work which I do get, so thanks to them I get care for him when I need to go for work, so that makes me feel relaxed that he is being taken care of while I am going to work (E10C W2)*

- Some respondents intended to use their experiences with the NDIA to change career pathways - in the SA trial site several had started businesses to provide advocacy and case management (lead agent) services for other parents.
- One respondent raised a matter of concern new to wave 2, where they felt that capping the NDIS support hours at 30 restricted the family's participation in the workforce, as flexibility was required to work around hours their child was cared for.

The perspective of the service provider

- As was the case at wave 1, disability service providers continued to report varied impacts of the NDIS on the economic and social participation of people with disability and their families and/or carers. Some providers cited examples of increased social participation while others reported that only very limited supports were being provided in NDIS plans to facilitate social participation.

> *Assistance for community access, the NDIA is far more frequently approving that compared to in the first year, so I guess a sign of they have listened to the participant community on that.* (*A01S W2*)

- As at wave 1, service providers were still more likely to observe increased social participation amongst NDIS participants than increased economic participation. Evidence of the NDIS increasing the economic participation of participants and/or their family members or carers remained limited at wave 2.
- Several disability service providers gave examples of how the NDIS was supporting economic participation for some families or carers of NDIS participants. Funding supports for the NDIS participants meant family members were freer to pursue or increase employment. The extension of hour of operations of day services that was attributed to the NDIS, also freed up family members to pursue or increase employment:

> *Probably where we're seeing the economic participation would be around family members, carers, returning to work… There's respite… there's individual support within a community or in-home support or there's support for their family member or loved one to be able to get up in the morning around their personal care requirements which is enabling them to return to work. (B03S W2)*

The perspective of the NDIA staff

- At wave 2, NDIA staff advised that while social participation had increased for people with disability under the NDIS, it would take time before greater economic participation was evident. NDIA staff considered that levels of inclusivity in the community needed to develop to allow people with disability to be accepted and integrated, particularly into mainstream activities.
- NDIA staff reported mixed evidence of increased economic participation amongst NDIS participants. Those cited were individual examples rather than any evidence of systemic change. Increased economic participation amongst people with disability was considered a long term process, with time needed to develop job-readiness skills, create programs to support both participants and employers, and to change cultural beliefs about employability and opportunities for employment for people with disability. There was some evidence of transition to employment programs beginning in several trial sites.
- However, at wave 2, examples were frequently cited of the NDIS creating opportunities for families or carers to return to work or increase their hours of employment. This is despite the fact that planning meetings still focused almost exclusively on the needs and aspirations of people with disability, with those of family members and carers yet to be explicitly addressed.

4.4. KEQ 3: To what extent has an NDIS enabled people with disability, their families and carers to achieve their goals?

The qualitative detail

The perspective of the person with disability and their family and carer

- Goals and aspirations varied between each individual participant and were influenced by the age and disability of the person. Goals and aspirations were mainly related to the transition into school, enrolling in further study, gaining employment or volunteer work, gaining more independence, increasing social skills and to live independently (or continue to do so).
- Changes to participants' goals between wave 1 and 2 appeared to be minor. Through their experience of the review process some respondents were able to finely tune their goals to be more specific to the individual. Other respondents, however, felt that the planners had not been sufficiently flexible in the plan review to fully meet their needs or aspirations.

> *I was told "It's too hard, we don't know how to do that, maybe down the track we can try and look at it but for now it's way too hard to do that". I'm like "Okay so are you meeting my needs? No". (B08 PWD W2)*

- Since joining the NDIS many achievements were reported related to NDIS participants' goals. Many young children had transitioned into school with the assistance of therapy and early intervention. Other NDIS participants had enrolled in TAFE or university, with some evidence of course completion. Living independently was a major aspiration for many participants, however, this appeared to be seen as a goal to be addressed in the future, not an urgent need, and hence, developing living and independence skills had the greater focus in participant's plans.
- Employment-specific goals were included in many of the participants' plans, which aimed to assist with integration into the workplace. Some were to arrange work experience for the NDIS participant so they could develop their skills and increase employability. For others, who had already had work experience opportunities, the goal was to evolve temporary or voluntary positions into more permanent, full-time roles. As noted above, the achievement of employment related goals had been limited.

4.5. 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?

The qualitative detail

The perspective of the person with disability and their family and carer

- In general, almost all NDIS participants and their families and carers, had experienced some type of life change or transition between the wave 1 and 2 interviews.
- Some NDIS participants had transitioned into their first year of school, from school to further studies, or from further studies to employment related activities. Some participants had experienced a deterioration of health or behavioural issues throughout the year. Others had moved accommodation (or were preparing to move) either to an area outside of the current NDIS trial sites or from the family home into supported accommodation. In almost all instances, the NDIS was reported to have assisted participants with these major life transitions.

> *It was very good, the transition was very good. And the NDIS they did a lot of work to help … (A17C W2).*

The perspective of the NDIA staff

- There were mixed reports from NDIS staff as to whether the NDIA manages key life transitions well. Some NDIA staff believed that transitions were handled well with plans including appropriate supports and services. The inclusion of case coordination was viewed to assist with life transitions. However, some NDIA staff reported that the agency did not always plan for key life transitions nor were they able to respond quickly to crisis events.

4.6. 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?

The qualitative detail

The perspective of the person with disability and their family and carer

- 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.
- At wave 2 however, NDIS participants identified a number of unintended consequences.
- Respondents felt the move to personalised services, had led to both NDIS participants and their family members and carers feeling more isolated and unsupported – mostly because the individualised model provided less opportunity for engagement with other people with disability and carers to that which were available to them pre-NDIS.

> *When your child is at school at least you've got like a P&C that you can talk to people about, but when they leave school you're on your own, you've got to work out what other services and other people that can help you with things. And that has changed a bit too with the NDIS because there was a group with the Samaritans group, and they were funded by DADAC, and now they're not, and that was for older parents as well. So at least you could*

> *talk to people, but that's not there now. And I think that's what it is. And of course the older you get, if you don't have contact with other people with disability, it's very, very difficult and you don't know where to go to (A13C W2).*

- Some NDIS participants and their family members reported that support for carers (within and outside of the NDIS) has diminished since the NDIS roll-out. This was seen as either a result of funding for carers services being redirected to the NDIA or because NDIS plans focused on the participant with the disability, providing only indirect support to their family and carers.
- Finally, feedback suggested the trial of the NDIS had unexpectedly strained relationships: between families and providers; and between providers and the NDIA. NDIS participants and carers were resentful about price increases for allied health services following roll-out such that there were different prices for those in the NDIS, from those outside of the Scheme.

The perspective of the service provider and key workforce organisations

- Interviews with disability service providers and representatives from workforce organisation identified four instances of potentially unintended, adverse outcomes of the trial of the NDIS:
- At wave 1, respondents noted the cessation of support groups and community groups, which could not operate without block funding. Further closures of this type of groups were observed at wave 2.
- Respondents at both wave 1 and 2 reflected on a decline in the quality and availability of government funded (therapy) service provision as large numbers of staff were leaving these services in anticipation of expected closures following the roll-out of the NDIS.
- At both waves, providers suggested that NDIS funding of individualised support services instead of group-based services had negatively impacted on the social participation of some NDIS participants who no longer attended programs where they had previously mixed with a range of people.
- Considerable concerns were raised in the wave 2 interviews about the impact the NDIS would have on people with disability ineligible for the NDIS. Some non-NDIS participants were reported to be receiving fewer services while others were falling through service gaps and getting no supports at all. It was feared that more of these individuals would be affected if state governments continued to withdraw from the provision of disability services. Inequity in the funding of supports across sectors was also noted.

> *All the money for mental health at the Commonwealth level is being thrown into the NDIS bucket, but only one-fifth of the clientele are going to be in the NDIS….There's a huge risk that access to services will be greatly reduce to people with mental health issues as an unintended consequence of the roll-out of the NDIS without any government or government agency actually a deliberate decision to do that. (08R W2)*

4.7. Summary and Integration

Wellbeing

Disability, whether intellectual or physical, present since birth or acquired later in life, was reported as having a major impact both on the life of the person with the disability, and on the life of their family members and carers. These impacts were present across the spheres of health and wellbeing; social, economic and educational participation; finances; and household and family relationships. In this section we presented qualitative and quantitative evaluation evidence pertaining to five KEQs that relate to the broad theme of *participation, wellbeing and aspirations*.

The quantitative data collected information on three separate measures of wellbeing: (i) psychological wellbeing (often called eudaimonic in the literature); (ii) Personal Wellbeing Index (PWI); and (iii) sense of social connection.

The PWI provides the only measure which would in principle allow comparison to the broader Australian population. The quantitative evidence indicates that NDIS participants overall have a mean wellbeing index that is well below the average PWI in Australia, but we have noted certain caveats against making such unconditional comparisons. In contrast, over-time comparisons based on individual observations are a more fruitful avenue for understanding the impact of the NDIS. It will be essential for the evaluation to assess whether the NDIS improves the personal wellbeing among NDIS participants. The second wave of the quantitative survey data will enable this type of over-time comparison to be made.

At this stage of the data development we can also make comparisons between different subgroups within the NDIS population, but we cannot make over time comparisons within any subgroup. When we compare the measures of wellbeing by broad disability type we see on all three measures NDIS participants with a mental health or psychosocial disability record a mean measure of wellbeing that is well below that recorded for other disability groups.

The quantitative data also shows that experiences of choice and control and unmet demand under the NDIS are connected with reported personal wellbeing. The more say (choice) NDIS participants have with regards to the decision on what support they get or where they get these supports from, the higher their reported wellbeing. In addition, those who have experienced unmet demand for support after joining the NDIS, also report significantly lower levels of personal wellbeing.

Just under half of all family members and carers report that they experienced at least one indicator of financial hardship over the last 12 months. Again, it will be essential for the evaluation to assess whether the NDIS ameliorates the financial hardship experienced by family members and carers of NDIS participants.

The two waves of qualitative evidence provide an early indication of whether and how the NDIS may have contributed to any changes in the wellbeing of NDIS participants and their families and carers.

The qualitative evidence makes clear that on the whole NDIS has improved the wellbeing of NDIS participants and their family members and carers. For NDIS participants increases in wellbeing were related to having better services than previously and increased independence. Improvements of wellbeing were associated with “living” rather than just managing or “surviving”, and with generally feeling happier. Since joining the NDIS many achievements were reported, relating to NDIS participants’ goals and aspirations, which subsequently impacted positively on wellbeing.

Families and carers often reported an increased sense of positivity and wellbeing as a result of the NDIS participant being more involved in activities they enjoyed and being able to participate in wider interests outside of the home. The wellbeing of family members and carers had also generally improved as a result of reduced financial strain and increased access to supports.

The negative impact of the ongoing administrative burden of NDIS was often highlighted. This was for many a new source of stress, so much so that some parents felt the added paperwork consumed time that was in the past usually spent as a family.

Social participation

The quantitative data provides information about activities that NDIS participants and family members and carers have done recently and information about activities they would most like to do in the coming year. This information provides a solid benchmark about the “starting point” of our information collection.

The quantitative data indicates that the most frequently reported activities undertaken by NDIS participants and their family members and carers was spending time with family and with friends. The most desired activity to be undertaken in the future for both NDIS participants and their family members and carers was to go on a holiday.

The two waves of qualitative data provides early but non-generalisable information about whether and how the NDIS may have contributed to any changes in the social participation of NDIS participants and their family members and carers. This evidence makes clear that the social participation of both NDIS participants and their family members and carers increased as a result of the NDIS.

Many NDIS participants were now able to take part in activities independently (i.e. without the support of a family member), were able to have access to support when needed, were able to follow interests and social activities that had previously been inaccessible, and were able to visit friends and family or having people to stay. Increases in social participation however were mixed in the case of NDIS participants with mental health problems, intellectual disabilities or with Autism Spectrum Disorder, where only limited increases in social participation were reported.

Easing the care burden on family members and carers, improved their social and economic participation as it allowed them to be involved in other valued activities such as employment, social activities and quality time with other family members that would have previously not been possible.

Educational and economic participation

Both the quantitative and qualitative data indicate that a high number of NDIS participants were currently in education.

The quantitative data indicates that for those not currently in education, around a quarter would like to be, but their own health or disability was preventing them from doing so. For most in education, the prime objective and plan after their education is completed is to get a job.

Very few family members and carers of NDIS participants were currently studying.

The quantitative data indicates that around a fifth of all NDIS participants who were surveyed were currently employed and largely liked their jobs, however their employment does not appear to be stable. A large proportion of those not in employment would like to hold a job, but the barriers to getting a job appear to be formidable.

The qualitative evidence suggests that while there was an increase in participation in employment related activities including volunteer work, work experience, supported employment and paid work over time, only a few NDIS participants reported undertaking these activities. Increased economic participation amongst people with disability was considered a long term process, with time needed to develop job-readiness skills, create programs to support both participants and employers, and to change cultural beliefs about employability and opportunities for employment for people with disability. It was 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. There appears to be high complementarity between the quantitative and qualitative evidence on education and employment.

Both quantitative and qualitative data indicate that caring impacted on the carers’ ability to take part in paid work and on their career pathways more generally. Both data sources indicated that some family members/carers had given up their careers as a result of care responsibilities and others were working part-time, having given up full-time work to provide care and support to the person with disability.

The qualitative data provided examples of carers increasing their working hours, or pursuing employment activities because they now had a little more time as a result of their child participating in more activities than previously.

Unintended consequences

The qualitative data indicated that NDIS funding of individualised support services instead of group-based services had negatively impacted on the social participation of some NDIS participants who no longer attended programs where they had previously mixed with a range of people.

The qualitative evidence also suggests that support for carers (within and outside of the NDIS) has diminished since the NDIS roll-out.

The qualitative data also uncovered concerns about the impact the NDIS would have on people with disability not eligible for the NDIS. Some non-NDIS participants were reported to be receiving fewer services while others were falling through service gaps and getting no supports at all.

References:

Australian Unity (2015), *What Makes us Happy Third Edition*, Australian Unity Limited, Melbourne.

International Wellbeing Group (2013), Personal Wellbeing Index: 5th Edition. Melbourne: Australian Centre on Quality of Life, Deakin University (http://www.deakin.edu.au/research/acqol/instruments/wellbeing-index/index.php)

National Institute of Labour Studies (NILS) (2014), Evaluation of the launch of the National Disability Insurance Scheme: Evaluation Framework. Adelaide: Flinders University. http://ndisevaluation.net.au/information/ndis-evaluation-framework.cfm

National Institute of Labour Studies (NILS) (2015), Evaluation of the NDIS: Initial Report. Adelaide: Flinders University.

OECD (2013), OECD Guidelines on Measuring Subjective Well-being, OECD Publishing. http://dx.doi.org/10.1787/9789264191655-en

Qu, L., Baxter, J., Weston, R., Moloney, L., & Hayes, A. (2012), *Family-related life events: Insights from two Australian longitudinal studies* (Research Report No. 22). Melbourne: Australian Institute of Family Studies.

Appendix:

Appendix 1.1

Key evaluation questions addressed in Initial Report and Intermediate Report

	KEQ	Initial Report	Intermediate Report	Theme
1	To what extent has the NDIS contributed to changes in wellbeing and quality of life for people with disability, their families and carers?		Quant and Qual evidence	Participation
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?	Qual evidence only	Quant and Qual evidence	Participation
3	To what extent has the NDIS enabled people with disability, their families and carers to achieve their goals?		Qual evidence only	Participation
4	To what extent has the NDIS enabled people with disability, their families and carers to have increased choice and control over their supports?	Qual evidence only	Quant and Qual evidence	Choice & control
5	To what extent did people have increased choice and control over the development and implementation of their plan?	Qual evidence only	Quant and Qual evidence	Choice & control
8	How have people responded to increased choice and control?	Qual evidence only	Quant and Qual evidence	Choice & control
9	To what extent has there been an appropriate balance between choice and control and safeguards for vulnerable people?	Qual evidence only		
11	To what extent has an NDIS enabled people with disability to gain confidence that their "reasonable and necessary" needs will be addressed?	Qual evidence only		
14	To what extent have people with disability, their families and carers seen NDIS review and dispute resolution processes as effective and fair?	Qual evidence only		
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?	Qual evidence only	Quant and Qual evidence	Choice & control
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?	Qual evidence only	Quant and Qual evidence	Supply & demand
19	For whom has the NDIS worked well or less well? Where possible, consider: (20) 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.	Qual evidence only		

	KEQ	Initial Report	Intermediate Report	Theme
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?	Qual evidence only	Qual evidence only	Choice & control
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?	Qual evidence only	Qual evidence only	Participation
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?	Qual evidence only	Qual evidence only	Participation
32	What has been the impact of an NDIS on the overall provision and quality of disability services?	Qual evidence only	Quant and Qual evidence	Supply & demand
33	Are clients satisfied that their supports are tailored to their individual needs and well-coordinated?		Quant and Qual evidence	Supply & demand
34	What has been the impact of an NDIS on the disability sector, including the relevant government agency in each jurisdiction and advocacy organisations?	Qual evidence only	Quant and Qual evidence	Supply & demand
35	Consider impacts on workforce (skills, retention rates, capacity, satisfaction, workforce culture, composition and proportion of occupation types).	Qual evidence only	Quant and Qual evidence	Supply & demand
36	Consider impacts on supply and diversity of disability supports (particularly sustainability, ability to respond to choice and control, and service capacity).	Qual evidence only	Quant and Qual evidence	Supply & demand
37	To what extent has the supply of disability services responded to demand?	Qual evidence only	Quant and Qual evidence	Supply & demand
38	To what extent has an NDIS contributed to an increase in the provision of early interventions from disability services?	Qual evidence only		
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?	Qual evidence only		
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?	Qual evidence only		
56	What were barriers to the success of an NDIS? (Consider emerging and potentially significant barriers as well as actual barriers.)	Qual evidence only		

Appendix 2.2

Table 2: NDIS participant needs help with daily activities (Trial PWDs, Aged 8+)

Needs help with daily activities	Frequency	%
Yes	960	84.66
No	152	13.40
Don't know/Missing	22	1.94
Total	**1,134**	**100.00**

Table 3: Which activities NDIS participant needs help or assistance with (Trial PWDs, Aged 8+)

Which Activities NDIS participant needs help or assistance with	Cases	%
Help with preparing food and eating meals	709	73.93
Help with doing things in the household	849	88.53
Help with daily personal activities	579	60.38
Help with accessing or entering buildings and using facilities	465	48.49
Help with using public transport or other types of transport	669	69.76
Help with talking with and being around others	492	51.30
Help with managing feelings, emotions or behaviour	558	58.19
Help with reading or writing tasks	664	69.24
Help with making appointments or arranging supports with health, disability and other services	683	71.22
Needs help with something else	133	13.87
Don't know	2	0.21
Total	**959**	

Table 4: How often needs help with these activities (Trial PWDs, Aged 8+)

How often needs help with these activities	Frequency	%
Daily	800	83.33
Weekly	111	11.56
Monthly	11	1.15
Yearly	1	0.10
As needed/in an emergency	24	2.50
Don't know/Missing	13	1.35
Total	**960**	**100.00**

Table 5: Who most often helps or assists you with your activities (Trial PWDs, All Ages)

Who most often helps or assists you with your activities	Cases	%
Spouse or partner (16+ only)	171	10.61
Mother (including step/adoptive/foster)	1168	72.50
Father (including step/adoptive/foster)	676	41.96
Daughter or son (including step/adoptive/foster((16+ only)	74	4.59
Sister or brother (including	268	16.64
Grandparent (including	167	10.37
Other family member (cousin, uncle, aunt)	59	3.66
Disability support worker, personal attendant or nurse	468	29.05
Friend	110	6.83
Neighbour	26	1.61
Voluntary worker	31	1.92
Someone else	163	10.12
Total	**1,611**	

Table 6: Support providers that help NDIS participant under NDIS plan in typical month (Trial PWDs, all ages)

Support providers that help NDIS participant in a typical month	Frequency	%
1	412	24.14
2-5	1,075	62.98
6-10	91	5.33
More than 10	24	1.41
Don’t know	91	5.33
Missing	14	0.82
Total	**1,707**	**100.00**

Table 7: NDIS participant changed support providers since becoming NDIS participant (Trial PWDs, all ages)

NDIS participant changed support providers	Frequency	%
Yes	622	36.44
No	1,046	61.28
Don’t know	29	1.70
Missing	10	0.59
Total	**1,707**	**100.00**

Appendix 2.3

Table 8: How much say over what supports received Pre and Post NDIS (Trial PWDs, Aged 16+)

How much say over what supports compared to pre NDIS	Frequency	%
Worse	93	17.38
Same	209	39.07
Better	233	43.55
Total	**535**	**100.00**

Table 9: How much choice over where getting supports Pre and Post NDIS (Trial PWDs, Aged 16+)

How much choice over where getting supports compared to pre NDIS	Frequency	%
Worse	87	16.26
Same	204	38.13
Better	244	45.61
Total	**535**	**100.00**

Table 10: Transition in Satisfaction with Quality of Support Pre and Post NDIS (Trial PWDs, Aged 16+)

Quality of support compared to pre NDIS	Frequency	%
Worse	81	15.06
Same	191	35.50
Better	266	49.44
Total	**538**	**100.00**

Table 11: Number of outlets

	Outlets
Non-NDIS	495
NDIS	202
Total	**697**

Table 12: What are the three most important methods used to monitor the quality of supports provided in this outlet (per cent)

	Non-NDIS	NDIS
Managers or supervisors monitor quality	82.0	89.1
Inspectors from another parts of the organisation monitor quality	13.3	12.4
Individual employees monitor quality	39.6	34.2
Keep records of feedback or complaints from service users	67.3	61.4
Surveys of service users	54.5	55.5
External auditing (e.g. third-party inspectors)	47.7	45.1
Other	4.4	2.0
Question not answered	0.4	0.5

Note: the distinction between NDIS and non-NDIS outlets is only indicative.

Table 13: Does this outlet have targets for any of the following performance criteria? (per cent)

	Non-NDIS	NDIS
Volume of supports provided	55.8	49.0
Total operating costs	57.0	56.4
Profits or return on investment	18.4	22.3
Unit labour costs	24.2	24.3
Productivity	26.1	28.7
Quality of service to users	69.7	65.4
Labour turnover	17.2	17.3
Absenteeism	15.8	15.8
Workforce training	43.8	42.6
Employee job satisfaction	47.7	53.0
Service user satisfaction	65.9	63.9
Other	3.8	5.0
Question not answered	7.7	9.9

Note: the distinction between NDIS and non-NDIS outlets is only indicative.

Appendix 2.4

Table 14: In general, do you expect the implementation of the NDIS to have a positive or negative impact on this outlet? (per cent)

	Non-NDIS	NDIS
A significant positive impact	21.4	20.8
A small positive impact	16.6	18.8
No impact	4.2	10.9
A small negative impact	6.3	10.4
A significant negative impact	16.0	10.9
Not sure/Don't know	33.5	27.2
Invalid multiple response	0.4	0.0
Question not answered	1.6	1.0

Table 15: In general, do you expect the implementation of the National Disability Insurance Scheme to have a positive or negative impact on this business? (per cent)

	Non-NDIS	NDIS
A significant positive impact	17.4	41.0
A small positive impact	32.9	42.7
No impact	9.0	5.1
A small negative impact	4.5	3.4
A significant negative impact	1.9	0.9
Not sure/Don't know	32.3	6.8
Invalid multiple response	0.7	0.0
Question not answered	1.3	0.0

Table 16: Outlets - In what ways do you expect the implementation of the National Disability Insurance Scheme to change the following areas of this outlet's operations in the next 12 months? (per cent)

NON-NDIS	Much higher	Somewhat higher	No change	Somewhat lower	Much lower	Question not answered
Wage growth	3.2	21.6	53.7	7.9	3.4	10.1
Support charges (prices)	7.9	25.9	43.0	8.5	3.6	10.7
Profits	1.2	7.9	52.3	17.2	9.1	12.3
Employment	4.0	26.3	46.3	9.9	3.2	10.1
Overtime utilisation	3.0	10.9	66.3	4.4	2.8	12.5
Investment in buildings and structures	1.6	11.3	61.0	6.9	6.5	12.7
Investment in plant and equipment	1.4	15.8	56.4	8.5	5.5	12.5
Overall performance	3.4	29.1	43.6	9.1	3.2	11.3
NDIS						
Wage growth	6.4	27.7	51.0	5.0	1.5	8.4
Support charges (prices)	3.5	26.7	39.6	11.4	8.4	9.9
Profits	0.0	11.9	48.0	16.8	10.4	12.9
Employment	5.9	39.6	36.6	8.4	1.0	8.4
Overtime utilisation	3.0	13.9	64.9	4.0	0.5	13.9
Investment in buildings and structures	2.0	11.4	61.4	7.4	5.0	12.9
Investment in plant and equipment	1.0	17.8	57.4	5.5	5.0	13.4
Overall performance	5.9	32.2	39.1	7.4	4.5	10.9

Table 17: Self-employed - In what ways do you expect the implementation of the National Disability Insurance Scheme to change the following areas of this business's operations in the next 12 months? (per cent)

	Much higher	Somewhat higher	No change	Somewhat lower	Much lower	Question not answered
NON-NDIS						
Support charges (prices)	0.7	14.2	71.0	5.8	1.9	6.5
Profits	0.0	16.1	65.2	9.7	3.2	5.8
Employment	0.0	11.6	74.2	4.5	1.9	7.7
Investment in equipment	0.0	12.9	74.8	1.9	1.3	9.0
Overall performance	0.7	22.6	63.2	5.8	1.3	6.5
NDIS						
Support charges (prices)	2.6	31.6	53.9	3.4	0.9	7.7
Profits	2.6	42.7	48.7	4.3	0.0	1.7
Employment	2.6	22.2	69.2	0.0	0.0	6.0
Investment in equipment	2.6	34.2	58.1	0.0	0.0	5.1
Overall performance	6.8	35.0	50.4	2.6	0.0	5.1

Table 18: Outlets - Which of the following things is this outlet doing, or planning to do in the next 12 months, in response to the launch and proposed roll-out of the National Disability Insurance Scheme? (per cent)

	Doing		Planning to do	
	Non-NDIS	NDIS	Non-NDIS	NDIS
Calculating support charges on a per-user basis	48.7	48.0	25.1	21.8
Adding new staff to meet service demand	21.8	32.7	35.2	26.7
Changing staff types to meet service demand	30.5	35.6	30.5	25.7
Helping service users to prepare personalised plans	46.9	48.5	26.7	19.3
Engaging with Local Area Co-ordinators (LACs)	25.1	45.5	38.6	22.3
Establishing brokerage services	31.5	26.2	22.4	22.8
Other	5.7	6.9	5.9	5.9
Question not answered	9.9	13.4	9.9	13.4

Table 19: What percentage of the outlet's funding for providing disability support came from each of the following sources in the past financial year (2013-14) and in the current financial year (2014-15) (per cent)

	Non-NDIS			**NDIS**			**Difference**
	2013-14	**2014-15**	**Change (ΔN)**	**2013-14**	**2014-15**	**Change (ΔNN)**	**Change (ΔN-ΔNN)**
National Disability Insurance Scheme (NDIS)	3.7	4.9	**1.2**	9.8	20.7	**10.9**	**9.7**
Other Government agency	25.7	25.2	**-0.5**	16.1	13.4	**-2.7**	**-2.2**
Grants and contracts – Commonwealth government	18.2	18.3	**0.1**	24.9	24.3	**-0.6**	**-0.7**
Grants and contracts – State government	49.3	48.0	**-1.3**	49.6	44.2	**-5.4**	**-4.1**
Grants and contracts – Local government	1.5	1.5	**0.0**	2.2	1.1	**-1.1**	**-1.1**
Non-government funding (e.g. charities)	3.4	3.3	**-0.1**	5.8	5.0	**-0.8**	**-0.7**
Private donations	2.7	2.7	**0.0**	4.0	3.7	**-0.3**	**-0.3**
User fees/direct payment	13.9	13.6	**-0.3**	7.3	7.5	**0.2**	**0.5**
Other	8.4	7.7	**-0.7**	10.3	10.6	**0.3**	**1.0**

Table 20: What percentage of its funding does this outlet expect to receive from the NDIS in the next financial year (i.e. 2015-16)? (per cent)

	Non-NDIS	**NDIS**
2014-15	4.9	20.7
2015-16	15.3	27.4

Appendix 2.5

Table 21: How many male, female, and total employees are there in each of the following classifications?

	Non-NDIS		NDIS	
	Male (%)	**Total**	**Male (%)**	**Total**
Disability support/Residential support worker	28.3	11644	32.4	5477
Personal care/Home care worker	14.8	5015	15.8	1585
Service or program administrator /Manager/Coordinator	18.5	1784	25.8	919
Social worker/Disability case coordinator	20.6	1397	21.0	390
Employment support worker	31.3	371	50.8	262
Peer support worker	26.0	315	42.8	159
Allied health worker	10.3	1100	11.0	753
Other	20.3	1034	32.2	3447
All	21.3	22660	29.0	12992

Table 22: Percentage of permanent employees

	Non-NDIS			NDIS		
	Permanent (%)	**Proportion (%)**	**Total**	**Permanent (%)**	**Proportion (%)**	**Total**
Disability support/Residential support worker	59	50	10290	64	43	5593
Personal care/Home care worker	56	20	4211	31	12	1564
Service or program administrator/Manager/ Coordinator	78	10	2030	89	7	870
Social worker/Disability case coordinator	64	7	1438	82	3	385
Employment support worker	82	2	475	84	2	248
Peer support worker	48	1	276	66	1	167
Allied health worker	86	5	1014	83	7	849
Other	74	4	871	67	25	3296
All	68	100	20605	71	100	12972

Appendix 2.6

Table 23: Percentage of this outlet's service activity in disability support today, compared with one year ago (per cent)

	Non-NDIS	NDIS
Service activity in disability support today	71.0	62.8
Service activity in disability support one year ago	68.5	60.2

Table 24: Types of disability support provided today and one year ago (per cent)

	Non-NDIS			NDIS			Difference
	Today	One year ago	Change (ΔNN)	Today	One year ago	Change (ΔN)	Change (ΔN-ΔNN)
Accommodation support	29.0	28.1	0.9	30.2	25.7	4.5	3.6
Personal support	54.3	52.7	1.6	56.4	53.5	2.9	1.3
Community access	59.0	56.0	3.0	62.9	58.9	4.0	1.0
Respite	41.8	39.2	2.6	39.6	38.6	1.0	1.6
Employment	13.9	13.7	0.2	21.3	19.3	2.0	1.8
Advocacy, information and alternative forms of communication	40.0	38.0	2.0	38.6	35.2	3.4	1.4
Early intervention	35.6	33.5	2.1	25.3	24.8	0.5	-1.6
Aids and equipment	23.0	22.4	0.6	18.8	17.8	1.0	0.4
Therapeutic services	34.1	32.7	1.4	22.3	20.3	2.0	0.6
Other	22.6	21.4	1.2	19.3	18.3	1.0	0.2
Question not answered	0.40	0.40	0.0	1.0	1.0	0.0	0.0

Table 25: Outlets - In the next 12 months, any plans to change the outlet's current range of disability support (per cent)

	Non-NDIS	NDIS
Invalid multiple response	0.4	0.5
Question not answered	0.2	0.5
No plans to change the range of support	63.0	58.9
Yes, plans to reduce the range of support (i.e. more specialisation)	3.2	2.5
Yes, plans to expand the range of support (i.e. less specialisation)	33.1	37.6

Table 26: Self-employed - In the next 12 months, are there any plans to change the business's current range of disability support (per cent)

	Non-NDIS	NDIS
No plans to change the range of support	79.4	86.3
Yes, plans to reduce the range of support (i.e. more specialisation)	5.8	3.4
Yes, plans to expand the range of support (i.e. less specialisation)	13.6	10.3
Question not answered	1.3	0.0

Appendix 2.7

Table 27: Proportion of NDIS participants who have funding for supports that they cannot access. (Trial PWDs, all ages)

	Trial		**Comparison**		**Total**	
NDIS participant has funding for support that could not be accessed	Frequency	%	Frequency	%	Frequency	%
Yes	477	27.0	93	6.4	570	17.6
No	1,146	64.9	1,226	83.8	2,372	73.4
Missing	13	0.7	19	1.3	32	1.0
Don’t know	131	7.4	125	8.5	256	7.9
Total	**1,767**	**100**	**1,463**	**100**	**3,230**	**100**

Table 28: How NDIS participant accesses supports not funded by the NDIS (Trial PWDs, all ages)

How NDIS participant accesses supports not funded by NDIS	Cases	%
Accesses supports by paying for them (16+ only)	103	22.99
Accesses supports relying on family to pay for them	222	49.55
Accesses supports relying on charitable organisations	43	9.60
Accesses supports relying on family or friends providing support	77	17.19
Accesses supports through existing support plan (Trial only)	59	13.17
Other ways	101	22.54
Don’t know	4	0.89
Total	448	

Appendix 3.2

Table 29: How much *say* over what supports received Pre and Post NDIS (Trial PWDs, Aged 16+)

How much say over what supports compared to pre NDIS	Frequency	%
Worse	93	17.38
Same	209	39.07
Better	233	43.55
Total	**535**	**100.00**

Table 30: How much *choice* over where getting supports Pre and Post NDIS (Trial PWDs, Aged 16+)

How much choice over where getting supports compared to pre NDIS	Frequency	%
Worse	87	16.26
Same	204	38.13
Better	244	45.61
Total	**535**	**100.00**

Table 31: Satisfaction with *quality* of support pre and post NDIS (Trial PWDs, Aged 16+)

Quality of support compared to pre NDIS	Frequency	%
Worse	81	15.06
Same	191	35.50
Better	266	49.44
Total	**538**	**100.00**

Table 32: Quality of support compared to pre NDIS by change in number of supports compared to pre NDIS (Trial PWDs, Aged 16+)

Quality of support compared to pre NDIS	Change in Number of Supports			
	Fewer	Same	More	Total
Worse	33	17	31	81
	(25.78)	(15.60)	(10.73)	(15.40)
Same	50	50	87	187
	(39.06)	(45.87)	(30.10)	(35.55)
Better	45	42	171	258
	(35.16)	(38.53)	(59.17)	(49.05)
Total	**128**	**109**	**289**	**526**
	(100.00)	**(100.00)**	**(100.00)**	**(100.00)**

Table 33: How much say over decisions on what supports compared to pre NDIS by change in number of supports compared to pre NDIS (Trial PWDs, Aged 16+)

How much say over decisions on what supports compared to pre NDIS	Change in Number of Supports			
	Fewer	Same	More	Total
Worse	30	21	42	93
	(23.62)	(19.81)	(14.29)	(17.65)
Same	57	42	105	204
	(44.88)	(39.62)	(35.71)	(38.71)
Better	40	43	147	230
	(31.50)	(40.57)	(50.00)	(43.64)
Total	**127**	**106**	**294**	**527**
	(100.00)	**(100.00)**	**(100.00)**	**(100.00)**

Table 34: How much choice of where getting supports compared to pre NDIS by change in number of supports compared to pre NDIS (Trial PWDs, Aged 16+)

How much choice of where getting supports compared to pre NDIS	Change in Number of Supports			
	Fewer	Same	More	Total
Worse	31	17	39	87
	(23.85)	(16.04)	(13.40)	(16.51)
Same	53	48	99	200
	(40.77)	(45.28)	(34.02)	(37.95)
Better	46	41	153	240
	(35.38)	(38.68)	(52.58)	(45.54)
Total	**130**	**106**	**291**	**527**
	(100.00)	**(100.00)**	**(100.00)**	**(100.00)**

Table 35: Reasonable and Necessary (row) by Satisfaction with quality of supports

	Dissatisfied or very dissatisfied	Neither satisfied or dissatisfied	Satisfied	Very satisfied	Total
Dissatisfied or very dissatisfied	35	5	12	5	57
	(58.33)	(6.10)	(4.11)	(1.58)	(7.60)
Neither satisfied or dissatisfied	13	39	31	5	88
	(21.67)	(47.56)	(10.62)	(1.58)	(11.73)
Satisfied	10	32	200	96	338
	(16.67)	(39.02)	(68.49)	(30.38)	(45.07)
Very satisfied	2	6	49	210	267
	(3.33)	(7.32)	(16.78)	(66.46)	(35.60)
Total	**60**	**82**	**292**	**316**	**750**
	(100.00)	**(100.00)**	**(100.00)**	**(100.00)**	**(100.00)**

Table 36: Reasonable and Necessary (row) by How much say over what supports

	No say	Little say/varies	Some say	A lot of say	Total
Dissatisfied or very dissatisfied	16	21	13	8	58
	(22.86)	(15.56)	(5.35)	(2.72)	(7.82)
Neither satisfied or dissatisfied	14	31	30	14	89
	(20.00)	(22.96)	(12.35)	(4.76)	(11.99)
Satisfied	19	61	148	106	334
	(27.14)	(45.19)	(60.91)	(36.05)	(45.01)
Very satisfied	21	22	52	166	261
	(30.00)	(16.30)	(21.40)	(56.46)	(35.18)
Total	**70**	**135**	**243**	**294**	**742**
	(100.00)	**(100.00)**	**(100.00)**	**(100.00)**	**(100.00)**

Table 37: Reasonable and Necessary (row) by Choice over where supports

	No say	Little say/varies	Some say	A lot of say	Total
Dissatisfied or very dissatisfied	16	21	13	8	58
	(22.86)	(15.56)	(5.35)	(2.72)	(7.82)
Neither satisfied or dissatisfied	14	31	30	14	89
	(20.00)	(22.96)	(12.35)	(4.76)	(11.99)
Satisfied	19	61	148	106	334
	(27.14)	(45.19)	(60.91)	(36.05)	(45.01)
Very satisfied	21	22	52	166	261
	(30.00)	(16.30)	(21.40)	(56.46)	(35.18)
Total	**70**	**135**	**243**	**294**	**742**
	(100.00)	**(100.00)**	**(100.00)**	**(100.00)**	**(100.00)**

Table 38: Which of the following do you help NDIS participant with? (Carers of Trial PWDs, Aged 8+)

Which of the following do you help NDIS participant with?	Cases	%
Preparing food and eating meals	867	83.45
Doing things in the household		
Daily personal activities	906	87.20
Managing feelings, emotions or behaviour	648	62.37
Reading or writing tasks	1001	96.34
Appointments or arranging supports with health, disability, and other services	732	70.45
Representing, speaking on behalf of PWD or standing up for PWDs interests	925	89.03
Helping PWD consider, understand and decide about his/her options	935	89.99
Something else	935	89.99
Preparing food and eating meals	170	16.36
Total	**1,039**	

Table 39: Typical hours spent caring per week (Carers of Trial PWDs, all ages)

Typical hours spent caring per week	Frequency	%
Less than 35 hours per week	280	15.18
35 hours or more per week	372	20.16
24/7	984	53.33
Don't know	185	10.03
Missing	24	1.30
Total	**1,845**	**100.00**

Table 40: How long have you been providing this support? (Carers of Trial PWDs, all ages)

How long have you been providing this support?	Frequency	%
Since PWD birth	1,460	79.13
Less than 6 months	5	0.27
6 months to 2 years	55	2.98
3 to 9 years	173	9.38
10 to 19 years	68	3.69
20+ years	75	4.07
Don't know	6	0.33
Missing	3	0.16
Total	**1,845**	**100.00**

Table 41: Do you have any long-term health condition, impairment or disability that restricts your ability to do everyday activities? (Carers of Trial PWDs, all ages)

Carer long term health condition	Frequency	%
Yes	459	24.55
No	1,349	72.14
Don't know	26	1.39
Missing	36	1.93
Total	**1,870**	**100.00**

Table 42: Carer control over how he/she spends his/her own time

Carer control over how he/she spends his/her own time	Frequency	%
A lot of control	461	24.65
Some control	817	43.69
Little control	484	25.88
No control	88	4.71
Don't know/Missing	20	1.07
Total	**1,870**	**100.00**

Table 43: Thinking about his/her current support needs, how often do you have adequate breaks from providing support? (Carers of Trial PWDs, all ages)

How often do you have adequate breaks from providing support?	Frequency	%
Never	528	28.62
An annual break	101	5.47
Less than once a month	176	9.54
Once a month	158	8.56
A couple of times a month	141	7.64
Weekly	349	18.92
Daily	282	15.28
Don't know	87	4.72
Missing	23	1.25
Total	**1,845**	**100.00**

Table 44: Do you access any services that support you as a carer? (Carers of Trial PWDs, all ages)

Carer accesses carer supports	Frequency	%
Yes	452	24.17
No	1,377	73.64
Don't know	28	1.50
Missing	13	0.70
Total	**1,870**	**100.00**

Table 45: Has the NDIS increased/decreased Carer ability to provide help, assistance or support to NDIS participant? (Carers of Trial PWDs, all ages)

Has the NDIS increased/decreased Carer ability to provide help, assistance or support to NDIS participant	Frequency	%
Increased	1,113	65.32
Made no difference	399	23.42
Reduced	128	7.51
Don’t know/Missing	64	3.74
	1,704	**100.00**

Table 46: Has the NDIS increased/decreased Carer anxiety about NDIS participant supports in the future? (Carers of Trial PWDs, all ages)

Has the NDIS increased/decreased Carer anxiety about NDIS participant supports in the future	Frequency	%
Increased	291	17.08
Made no difference	454	26.64
Reduced	862	50.59
Don’t know/Missing	97	5.69
Total	**1,704**	**100.00**

Table 47: Overall, how satisfied are you with the amount of say you have had about what supports he/she receives? (Carers of Trial PWDs, all ages)

Overall, how satisfied are you with the amount of say you have had about what supports he/she receives?	Frequency	%
Very satisfied	926	52.38
Somewhat Satisfied	608	34.39
Neither satisfied nor dissatisfied	91	5.15
Somewhat Dissatisfied	88	4.98
Very dissatisfied	44	2.49
Missing	11	0.62
Total	**1,768**	**100.00**

Table 48: Overall, how satisfied are you with the amount of say you have had about where he/she obtains these supports? (Carers of Trial PWDs, all ages)

Overall, how satisfied are you with the amount of say you have had about where he/she obtains these supports?	Frequency	%
Very satisfied	1,034	58.48
Somewhat Satisfied	528	29.86
Neither satisfied nor dissatisfied	80	4.52
Somewhat Dissatisfied	73	4.13
Very dissatisfied	41	2.32
Missing	12	0.68
Total	**1,768**	**100.00**

Appendix 3.3

Table 49: Did any of the following people assist in making decisions about the support arrangements in the plan? (Trial PWDs all ages)

Did any of the following people assist in making decisions about the support arrangements in the plan?	Cases	%
Family member assisted	1,155	70.95
Friend assisted	59	3.62
Guardian assisted	351	21.56
Paid support worker	264	16.22
Nominee assisted	150	9.21
Local Area Coordinator	211	12.96
NDIA planner assisted	996	61.18
Someone else assisted	286	17.57
No one assisted	63	3.87
Don’t know	10	0.61
Total	**1,628**	

Note: trial respondents who have a support plan approved by the NDIA; “Total” indicates the number of respondents to answer this question; multiple response question; % columns therefore do not add to 100.

Table 50: Pre and post NDIS: Time to get supports, do the necessary paperwork and find out where to get the supports (Trial PWDs aged 16+)

	More time %	Same amount of time %	Less time %	Don’t know/Missing %
Get supports	**24.26**	**25.65**	**38.47**	**11.62**
Do the necessary paperwork	**32.41**	**24.09**	**28.08**	**15.43**
Find out where to get the supports	**23.05**	**29.12**	**33.45**	**14.38**

Note: trial aged 16 and above currently receiving NDIS supports and received supports before joining the NDIS.

Table 51: Pre and post NDIS: Time to get supports, do the necessary paperwork and find out where to get the supports (Carers of Trial PWDs, all ages)

	More time %	Same amount of time %	Less time %	Don’t know/Missing %
Get supports	25.59	39.03	28.76	6.63
Do the necessary paperwork	39.44	29.69	23.77	7.10
Find out where to get the supports	25.35	40.08	28.05	6.52

Note: Family and Carers.

Appendix 3.5

Table 52: Self-managed funding for support before NDIS (Trial PWDs, all ages)

Self managed funding of support pre NDIS	Frequency	%
No	788	59.88
Yes, PWD did (16+ only)	76	5.78
Yes, PWD family did	238	18.09
Yes, someone else did	53	4.03
Does not apply	26	1.98
Don’t know/Missing	135	10.25
Total	**1,316**	**100.00**

Table 53: Self-manages funding for support under the NDIS (Trial PWDs, all ages)

Family or someone on PWD behalf self-manage any funding for supports under the NDIS	Frequency	%
No	845	51.03
Yes, PWD does (16+ only)	174	10.51
Yes, PWD family does	466	28.14
Yes, someone else does	79	4.77
Don’t know/Missing	92	5.55
Total	**1,656**	**100.00**

Appendix 4.2

Table 54: In general, I feel very positive about myself (Trial PWDs, Aged 8+)

Main disability category, broad	Mean	Standard deviation
Physical or sensory disability	6.3	2.4
Mental health/psychosocial disability	4.9	2.9
Intellectual disability	7.3	2.1
Developmental or congenital disability	6.4	2.5
Neurological disability	7.0	2.4
Other or not defined disability	6.0	3.0
Total	**6.5**	**2.6**

Table 55: I am free to choose the things that I want to do myself (Trial PWDs, Aged 8+)

Main disability category, broad	Mean	Standard deviation
Physical or sensory disability	7.0	2.7
Mental health/psychosocial disability	5.8	3.3
Intellectual disability	7.2	2.7
Developmental or congenital disability	6.6	2.5
Neurological disability	7.0	2.7
Other or not defined disability	6.2	2.9
Total	**6.8**	**2.7**

Table 56: I generally feel that what I do in my life is important/means something (Trial PWDs, Aged 8+)

Main disability category, broad	Mean	Standard deviation
Physical or sensory disability	7.0	2.6
Mental health/psychosocial disability	6.0	2.9
Intellectual disability	7.7	2.4
Developmental or congenital disability	6.9	2.4
Neurological disability	7.2	2.5
Other or not defined disability	6.4	2.7
Total	**7.0**	**2.5**

Table 57: I get a sense that I have achieved something (Trial PWDs, Aged 8+)

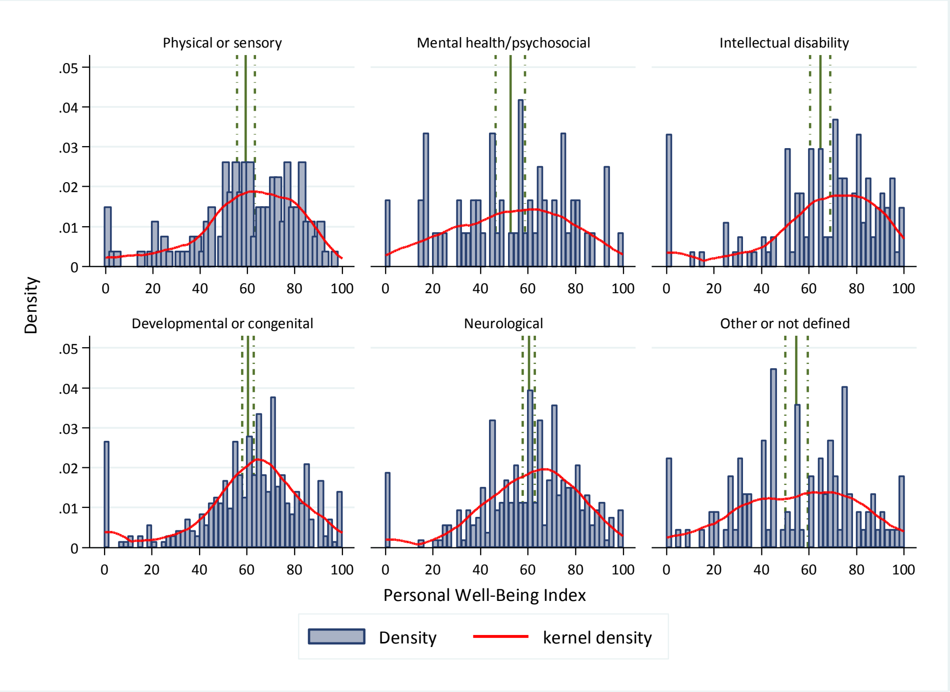
Main disability category, broad	Mean	Standard deviation
Physical or sensory disability	6.2	2.6
Mental health/psychosocial disability	5.2	3.0
Intellectual disability	7.1	2.3
Developmental or congenital disability	6.2	2.4
Neurological disability	6.4	2.5
Other or not defined disability	5.7	3.0
Total	**6.2**	**2.6**

Table 58: When things go wrong in my life it generally takes him/her a long time to get over it (Trial PWDs, Aged 8+)

Main disability category, broad	Mean	Standard deviation
Physical or sensory disability	5.4	3.1
Mental health/psychosocial disability	6.6	2.8
Intellectual disability	6.1	3.1
Developmental or congenital disability	6.3	3.0
Neurological disability	5.2	3.0
Other or not defined disability	6.0	3.3
Total	**5.9**	**3.1**

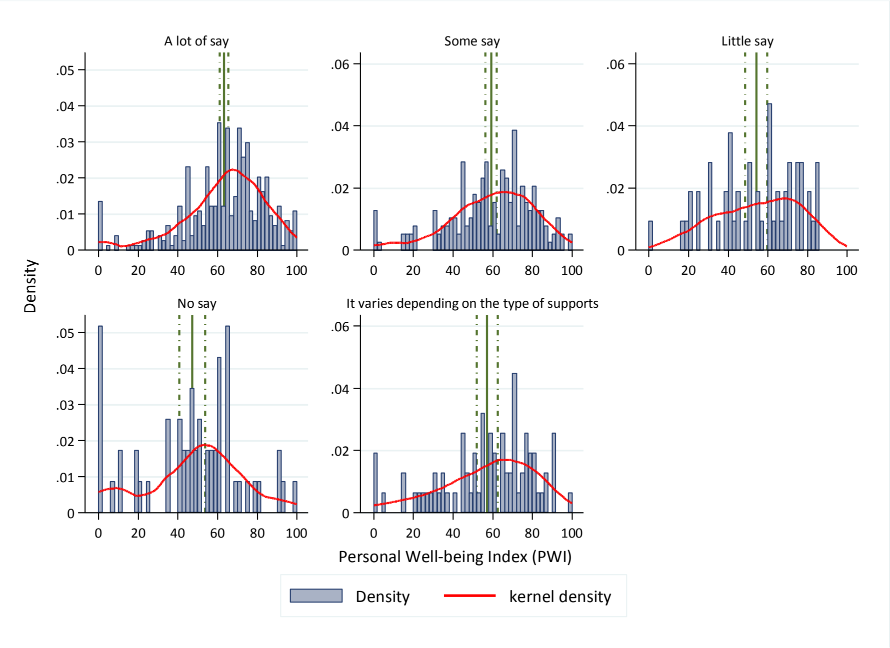
- Distribution of the NDIS' participants' PWI by disability type (8 years old and older). Green vertical lines correspond to the sample means (continuous lines) and 95 per cent confidence interval thresholds (doted lines). The red lines correspond to the kernel density of each distribution. They illustrate the heterogeneity of the answers to the questions forming the PWI by disability type and how skewed some of them are compared to a Normal distribution.

Figure 15: Distribution of NDIS participants' PWI by disability type



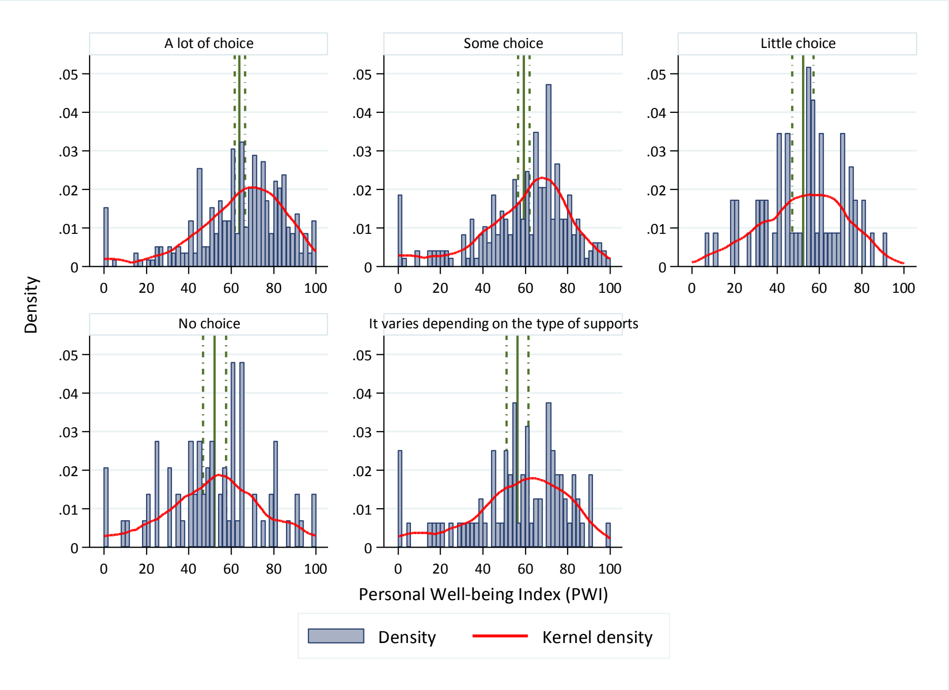
- Distribution of the NDIS' participants' PWI according to answers to the question as to whether NDIS participants have some say about the decisions on what supports they got under the NDIS.

Figure 16: Distribution of NDIS participants' PWI according to choice over supports



- Distribution of the NDIS' participants' PWI according to answers to the question as to whether NDIS participants have some choice about the where to find the supports they have under the NDIS.

Figure 17: Distribution of NDIS participants' PWI according to control over supports



- Distribution of the NDIS' participants' PWI according to whether NDIS participants experienced unmet demand for supports.

Figure 18: Unmet demand and distribution of NDIS participants' PWI

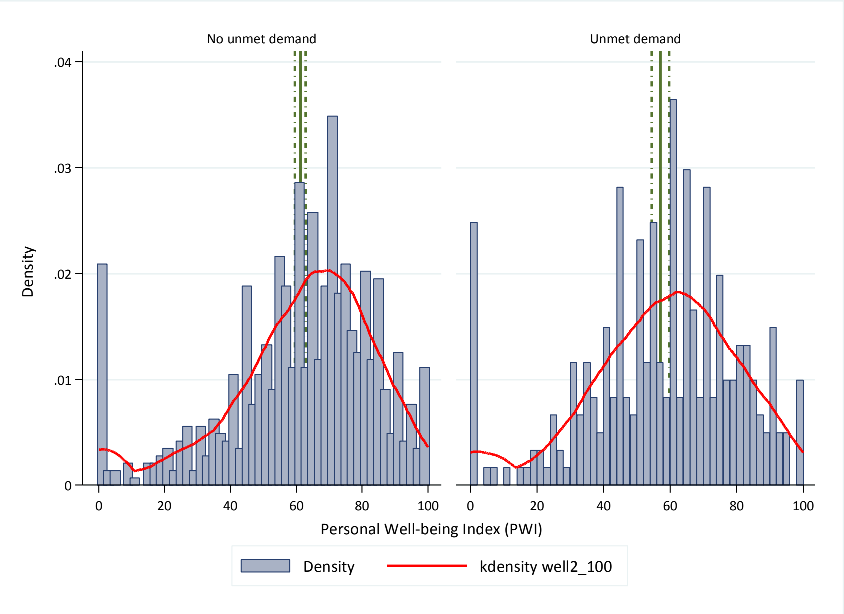


Table 59: I seem to have a lot of friends (Trial PWDs, Aged 8+)

Main disability category, broad	Mean	Standard deviation
Physical or sensory condition	5.6	3.2
Mental health condition/psychosocial disability	4.4	3.4
Intellectual disability	5.6	3.2
Developmental or congenital condition	4.4	3.0
Neurological condition	6.0	3.1
Other or not defined condition	5.3	3.4
Total	**5.2**	**3.2**

Table 60: There is someone who can always cheer me up when I'm down (Trial PWDs, Aged 8+)

Main disability category, broad	Mean	Standard deviation
Physical or sensory condition	6.8	2.7
Mental health condition/psychosocial disability	5.3	3.6
Intellectual disability	7.6	2.4
Developmental or congenital condition	6.9	2.6
Neurological condition	7.2	2.7
Other or not defined condition	7.0	2.6
Total	**7.0**	**2.7**

Table 61: I enjoy the time I spend with the people who are important to me (Trial PWDs, Aged 8+)

Main disability category, broad	Mean	Standard deviation
Physical or sensory condition	8.3	2.2
Mental health condition/psychosocial disability	7.2	2.7
Intellectual disability	8.7	1.6
Developmental or congenital condition	8.4	1.8
Neurological condition	8.7	1.5
Other or not defined condition	8.5	2.0
Total	**8.4**	**1.9**

Table 62: When something's on my mind, just talking with the people I know can make me feel better (Trial PWDs, Aged 8+)

Main disability category, broad	Mean	Standard deviation
Physical or sensory condition	7.3	2.7
Mental health condition/psychosocial disability	6.0	3.3
Intellectual disability	6.7	3.1
Developmental or congenital condition	6.2	2.9
Neurological condition	7.5	2.2
Other or not defined condition	6.7	3.0
Total	**6.8**	**2.8**

Table 63: When I need someone to help me out, I can usually find someone (Trial PWDs, Aged 8+)

Main disability category, broad	Mean	Standard deviation
Physical or sensory condition	7.1	2.8
Mental health condition/psychosocial disability	5.6	3.3
Intellectual disability	7.9	2.3
Developmental or congenital condition	7.4	2.4
Neurological condition	7.6	2.4
Other or not defined condition	7.1	3.0
Total	**7.3**	**2.6**

Table 64: Statements about satisfaction with things important for quality of life (Carers in Trial sites, all ages)

	Very satisfied %	Satisfied %	Neither satisfied or dissatisfied %	Dissatisfied %	Very dissatisfied %	Don't know/ Missing %
Family support necessary to relieve stress	14.25	39.12	22.63	15.34	6.20	2.45
Availability of outside help to take care of the special needs of all family members	13.60	38.41	20.67	17.90	6.58	2.83
Time of family members to pursue their own interests	14.36	42.17	18.50	16.92	5.66	2.39
Having friends or others who provide support	14.53	42.55	18.01	15.67	6.26	2.99
PWD support to accomplish goals at school or work	28.18	42.27	11.26	6.86	3.92	7.51
PWD support to make progress at home	30.90	50.87	9.03	4.90	1.80	2.50
PWD support to make friends	22.85	42.93	16.21	10.66	3.97	3.37
Relationships to service providers who provide services and support to PWD	43.14	40.64	8.38	3.37	1.74	2.72

Table 65: In the last year, did any of the following happen to you because of a shortage of money? (Carers of Trial PWDs, all ages)

In the last year, did any of the following happen to you because of a shortage of money?	Cases	%
Could not pay bills on time	487	26.04
Unable to heat home	140	7.49
Asked for financial help	466	24.92
Could not pay the mortgage or rent on time	166	8.88
Pawned or sold something	254	13.58
Went without meals	113	6.04
Asked for help from welfare/community organisations	173	9.25
Total	**1,870**	

Appendix 4.3

Table 66: What things will make it hard to do these activities in the coming year (Trial PWDs, Aged 8+)

What will make it hard to do these activities in the coming year?	Cases	%
Hard for PWD to get into buildings	262	28.35
PWD has no transport	245	26.52
It costs too much	384	41.56
PWD doesn't feel safe	264	28.57
Other people do not make PWD feel welcome	203	21.97
Other people cannot understand PWD	381	41.23
PWD finds it hard to understand others	279	30.19
It requires too much organisation	276	29.87
It takes too much time to arrange supports	196	21.21
PWD doesn't have anyone to support them	107	11.58
Other reason	176	19.05
Activities won't be hard to do	98	10.61
Don't know	29	3.14
Total	**924**	

'Total' indicates the number of respondents to answer this question; multiple response question; % columns, therefore, do not add to 100.

Table 67: NDIS participant attends school/university/TAFE (Trial PWDs, Aged 3+)

NDIS participant attends school/university/TAFE	Frequency	%
Pre-school/ kindergarten (0-15 only)	161	18.94
Pre Year 1 primary school (0-15 only)	120	14.12
Primary school Year 1 and above (0-15 only)	287	33.76
Secondary school	72	8.47
Special school (e.g. School for the Deaf)	80	9.41
Home school	4	0.47
School by distance Learning	4	0.47
University (16+ only)	14	1.65
TAFE/Technical college (16+ only)	40	4.71
Post school distance learning (e.g. university or TAFE)	5	0.59
Industry skills centre/employer based training	6	0.71
Specialist institute/college (16+ only)	21	2.47
Community centre (16+ only)	5	0.59
Other (please specify)	23	2.71
Don't know/Missing	8	0.95
Total	**850**	**100.00**

Table 68: NDIS participant enrolled full-time or part-time (Trial PWDs, Aged 3+)

Enrolled full time or part time	Frequency	%
Full time	453	82.97
Part time	62	11.36
Don't know/Missing	31	5.68
Total	**546**	**100.00**

Table 69: What NDIS participant would like to do when they finish their education (Trial PWDs, Aged 8+)

What NDIS participant would like to do when they finish their education	Frequency	%
Work in a job	95	35.32
Do an apprenticeship or traineeship	12	4.46
Go to a TAFE college (16+ only)	6	2.23
Go to University	30	11.15
Do some other course or training elsewhere	15	5.58
Something else	16	5.95
Nothing	5	1.86
Don’t know	73	27.14
Missing	17	6.32
Total	**269**	**100.00**

Table 70: NDIS participant would like to study (Trial PWDs, Aged 16+)

Would like to study	Frequency	%
Yes	159	23.28
No	423	61.93
Don’t know	74	10.83
Missing	27	3.95
Total	**683**	**100.00**

Table 71: NDIS participant is looking for a course to study (Trial PWDs, Aged 16+)

Looking for a course to study	Frequency	%
Yes	63	39.62
No	85	53.46
Don’t know/Missing	11	6.72
Total	**159**	**100.00**

Table 72: Are you currently studying for any qualification (s)? (Carers of Trial PWDs, all ages)

Currently studying for any qualification(s)	Frequency	%
Yes, full time	45	2.41
Yes, part time	169	9.04
No	1,644	87.91
Don’t know/Missing	12	0.64
Total	**1,870**	**100.00**

Table 73: Did NDIS participant do paid work in a job, business or farm during the last 7 days (Trial PWDs, Aged 16+)

Did NDIS participant do paid work in a job, business or farm during the last 7 days (16+ only)	Frequency	%
Yes	195	20.42
No	755	79.06
Missing	5	0.52
Total	**955**	**100.00**

Table 74: Does NDIS participant work in an Australian Disability Enterprise (Trial PWDs, Aged 16+)

Does NDIS participant work in an Australian Disability Enterprise (16+ only)	Frequency	%
Yes	98	47.80
No	95	46.34
Don’t know/Missing	12	5.86
Total	**205**	**100.00**

Table 75: Part-time/Full-time hours worked in paid job (Trial PWDs, Aged 16+)

How many hours does he/she usually work in this paid job	Frequency	%
0 hours	1	0.49
Part time (<35 hours per week)	157	76.59
Full time (35+ hours per week)	36	17.56
Don't know	11	5.36
Total	**205**	**100.00**

Table 76: Has workplace, hours or conditions been adapted to enable them to work (Trial PWDs, Aged 16+)

Has his/her workplace, hours or conditions been adapted to enable him/her to work (16+ only)	Frequency	%
Yes	107	52.20
No	86	41.95
Don’t know/Missing	12	5.85
Total	**205**	**100.00**

Table 77: Do you like your job? (Trial PWDs, Aged 16+)

Does NDIS participant like their job?	Frequency	%
Yes	148	86.05
No	10	5.81
Missing	14	8.14
Total	**172**	**100.00**

Table 78: NDIS participant would like a different job (Trial PWDs, Aged 16+)

NDIS participant would like a different job	Frequency	%
Yes	40	23.26
No	103	59.88
Don’t know	22	12.79
Missing	7	4.07
Total	**172**	**100.00**

Table 79: NDIS participant has ever had a paid job (Trial PWDs, Aged 16+)

NDIS participant has ever had a paid job (16+ only)	Frequency	%
Yes	401	53.47
No	335	44.67
Missing	14	1.86
Total	**750**	**100.00**

Table 80: NDIS participant would like to have a job (Trial PWDs, Aged 16+)

NDIS participant would like to have a job	Frequency	%
Yes, now	218	34.12
Yes, when I have finished my education	39	6.10
No	266	41.63
Don't know	91	14.24
Missing	25	3.91
Total	**639**	**100.00**

Table 81: NDIS participant is looking for a job (Trial PWDs, Aged 16+)

NDIS participant is looking for a job	Frequency	%
Yes	61	25.10
No	148	60.91
Don't know	6	2.47
Missing	28	11.52
Total	**243**	**100.00**

Table 82: Which of the following best describes your circumstances? (Carers of Trial F&C, all ages)

Carer work status	Frequency	%
Currently in full time paid work (35 hours or more per week)	275	14.71
Gave up full time work for part time work (1 to 34 hours per week) to care for PWD	366	19.57
Currently in part time paid work for other reasons	273	14.60
On extended leave, e.g. maternity leave or long service leave (paid or unpaid)	26	1.39
Gave up work altogether to care for PWD	432	23.10
Retired	157	8.40
Not in paid work for other reasons	188	10.05
Other	105	5.61
Missing	48	2.57
Total	**1,870**	**100.00**

Table 83: Have you ever had a paid job for two weeks or more (Carers of Trial PWDs, all ages)

Carer ever had a paid job for two weeks or more	Frequency	%
Yes	192	72.73
No	55	20.83
Don't know/Missing	17	6.44
Total	**264**	**100.00**

Table 84: Would you like to have a job? (Carers of Trial PWDs, all ages)

Carer would like to have a job	Frequency	%
Yes	484	56.34
No	294	34.23
Don't know	65	7.57
Missing	16	1.86
Total	**859**	**100.00**

Table 85: Is your caring role the main barrier to having paid work? (Carers of Trial PWDs, all ages)

Caring role main barrier to having paid work	Frequency	%
Yes	389	80.37
No	84	17.36
Don’t know/Missing	11	2.27
Total	**484**	**100.00**