

# Evaluation of the NDIS

## Final Report

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### **Abbreviations**

|            |  |
|------------|--|
| ACT .....  | Australian Capital Territory                       |
| CALD ..... | Culturally and Linguistically Diverse              |
| COS .....  | Continuity of Support                              |
| CRM .....  | Customer Relationship Management (software system) |
| DSS .....  | Department of Social Services                      |
| ECEI ..... | Early Childhood Early Intervention                 |
| GP .....   | General Practitioner                               |
| ILC .....  | Information, Linkages and Capacity Building        |
| LAC .....  | Local Area Coordinator                             |
| LGA .....  | Local Government Areas                             |
| NDIA ..... | National Disability Insurance Agency               |
| NDIS ..... | National Disability Insurance Scheme               |
| NSW .....  | New South Wales                                    |
| PSC .....  | Plan Support Coordinator                           |
| SA .....   | South Australia                                    |
| TAS .....  | Tasmania   |
| VIC .....  | Victoria   |

## Terminology

|  |   |
|--|---|
| All ages .....                                     | <b>Quantitative:</b> Person with disability – all ages  |
| Age 8+ .....                                       | <b>Quantitative:</b> Person with disability aged 8 years or older   |
| Age 0 - 15 .....                                   | <b>Quantitative:</b> Person with disability aged 0 to 15 years  |
| Adults .....                                       | <b>Quantitative:</b> Person with disability aged 16 years or older  |
| Trial .....  | <b>Quantitative:</b> NDIS participants  |
| Comparison .....                                   | <b>Quantitative:</b> non-NDIS participants  |
| Carers .....                                       | Family members and/or carers of persons with disability   |
| Disability service sector<br>representatives ..... | Representative from a disability service provider organisation  |
| ATET .....   | Statistical term, average treatment effect on the treated   |
| Eudaimonic.....                                    | The eudaimonic approach on wellbeing focuses on meaning and self-realisation  |
| KEQs .....   | Key Evaluation Questions  |
| Likert scale .....                                 | A survey response on a scale which allows measurement of opinion or view  |
| Mainstream.....                                    | Health, mental health, education and employment sectors; and the aged care sector   |
| NDIS Surveys .....                                 | NDIS Survey (of people with disability)<br>NDIS Survey for Families and Carers<br>NDIS Survey of Disability Support Providers   |
| Non-NDIS participants.....                         | <b>Qualitative:</b> People in trial sites who either,<br>a) did not apply for access to the NDIS, b) did not proceed after receiving access to the NDIS or c) were deemed by the NDIA not to meet the eligibility criteria. |
| NVivo.....   | NVivo is a qualitative data analysis computer software package produced by QSR International  |
| Outlets.....                                       | Service locations of disability service provider organisations  |
| QIE.....   | Qualitative Impact Evaluation   |
| Respondent .....                                   | Participant in either qualitative or quantitative component of the evaluation   |
| Self-management.....                               | An individual receives direct funding and manages all aspects of funding and acquiring supports   |
| Trial sites .....                                  | Five original NDIS trial sites (South Australia, Tasmania, the ACT, Barwon region in Victoria and the Hunter in NSW)  |
| Workforce stakeholder<br>Organisations .....       | Representatives from professional associations, unions, peak body training organisations and advocacy organisations   |

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## Research team

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

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## Executive Summary

The National Disability Insurance Scheme (NDIS) has been one of the most important social policy innovations to have been developed and implemented in Australian history. For such a major social policy to commence through a large-scale trial, which is simultaneously evaluated in a rigorous manner by an independent body of experts, is the right course of action. It supports the prudent use of public resources and is also a manifestation of respect for the many thousands of people who make the NDIS, from the people with disability and their families and carers, to the dedicated carer and support providers and workforces, and with the arrival of the NDIS, to the new dedicated NDIA workforce.

The main objective of the evaluation of the NDIS has been to offer a well-informed and independent assessment of the many impacts of the NDIS trial. The trial has taken place in South Australia (SA), Tasmania (TAS), New South Wales (NSW), Victoria (VIC), the Australian Capital Territory (ACT) and the Barkly region in the Northern Territory (NT). We consider the impacts of the trial on people with disability and their families and carers, the disability sector and its workforce, mainstream providers and services, and stakeholders and the wider community. A further objective of the evaluation has been to examine high-level processes, focusing on elements of the NDIS which contributed to or impeded the intended positive outcomes. In addition, the evaluation has provided a working template for a continuing independent longitudinal survey data collection of people with disabilities and their families and carers in Australia and of the disability support sector and its workforces. Such a survey would provide early evidence of any problems as they arise, and confirmation of where things are going well. It would thus be an objective guide as to how best to modify and strengthen the system as it unfolds and matures.

Several main findings emerge from the evaluation of the NDIS. The first finding is that the Scheme has been designed and built on sound fundamentals. This is an important confirmation of the policy. The second finding is that the NDIS has been delivering the outcomes that it was designed to deliver. This is probably the most important positive finding of the evaluation and it should be flagged as such. Given the complexity and magnitude of the undertaking, it is not unexpected that these positive findings come with qualifications. For example, some design aspects and implementation outcomes are not necessarily as person-centred as originally desired, and several outcomes are not attained at the speed that was originally expected. The evaluation identifies several such problems and offers its critical assessment. The evaluation team would invite the policy maker to consider carefully these identified problems, as many of them will need to be resolved. Equally, the team would invite the policy maker to consider carefully those aspects of the NDIS that make for its success and seek appropriate policy interventions that will reinforce them.

The evaluation has been designed to publish its results in three major reports. This Final Report is the last of these three reports. The first report presented the methodologies used for all evidence collections. The second Intermediate Report provided the first synthesis of the evidence collected up to mid-2016 from all different sources of the NDIS evaluation on a selected number of themes (supply and demand of support services; choice and control; and participation, wellbeing and aspirations). This Final Report provides a complete and comprehensive synthesis of the evidence collected from all different sources and methodologies of the NDIS evaluation. This report is presented in a thematic way in order to utilise the synergies between the depth of understanding offered by qualitative evidence and the overall representativeness achieved through quantitative survey data. Combining and integrating these different sources of data offers critical insights on the NDIS. The three reports should be considered jointly, as the evaluation's methodological foundations are explained in the Initial Report and the underpinnings of the current thematic reporting in the Intermediate Report.

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 58 such KEQs.

This Final Report draws from each element of the NDIS evaluation data collection activities in order to provide a comprehensive synthesis of the complete evaluation evidence. Following on from the Intermediate report, the Final Report uses a thematic approach, with the relevant KEQs supporting each theme. The following ten themes reflect the thematic grouping of the 58 KEQs and areas of key policy interest to the NDIS roll-out:

- Supply and demand of support services (Chapter 2)
- The disability sector and its workforce (Chapter 3)
- Choice and control (including self-management) (Chapter 4)
- Reasonable and necessary supports (Chapter 5)
- Wellbeing (Chapter 6)
- Participation (social, economic and educational) and aspirations (goals) (Chapter 7)
- Fairness, equity and access (Chapter 8)
- Mainstream interface (Chapter 9)
- Older people with disability (Chapter 10)
- NDIS in the NT (with a focus on the Barkly trial site) (Chapter 11)

The Final Report combines all data collections that were completed for the NDIS evaluation. The quantitative evidence (from large scale survey data) and the qualitative evidence (from in-depth interviews) are reported separately in order to stress the different role that each evidence source plays in building the necessary evidence base for the evaluation. Throughout the evaluation, the development of the quantitative surveys was informed by the findings of the qualitative interviews and vice versa. Our key messages about the NDIS are informed very strongly by both sources of evidence and are presented in an integrated form based on policy themes. This enables both the depth and the representativeness of the evidence to be utilised.

On the quantitative side, we report on the first and second waves of the longitudinal survey of people with disability and their carers. In addition, we report on the two waves of the survey of disability support providers, which include employers, their workers and the self-employed from SA, TAS, NSW, ACT and Queensland.

On the qualitative side, we report on the findings from two waves of interviews with NDIS participants and their carers, disability service providers, disability workforce stakeholder organisations, and NDIA staff undertaken as part of the qualitative impact evaluation in the five original trial sites. We also report on the two waves of interviews conducted with the same stakeholder groups for the evaluation of the NDIS in the Barkly Region of the NT. In addition, we report on one wave of interviews undertaken with various stakeholder groups as a part of two additional studies exploring the impact of the NDIS on (i) mainstream health, mental health, education and employment sectors and (ii) older people with disability and the aged care sector.

In each of the first seven main chapters of the report we present the quantitative and qualitative findings separately. Each chapter begins with the integration of the quantitative and qualitative findings. These integrated findings sections have been designed to be read independently from the body of the chapter and are provided to enable a reader with limited time to review these sections

rather than delve into the detail of the findings. The final three chapters in this report describe the findings of three additional qualitative studies conducted alongside the main evaluation.

In the remainder of this Executive Summary we bring together the key integrated findings from the quantitative and qualitative evidence to provide an overall assessment of the roll-out of the NDIS in each of the ten main themes.

## **Chapter 2: 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 a summary of the integrated findings relating to the broad theme of supply and demand of disability support services.

The evaluation found that the types and number of supports received by many NDIS participants increased as a consequence of their participation in the NDIS. The NDIS has led to increased hours of support, greater frequency of services, and access to a wider range of supports for many people with disability. In particular, improved access to equipment, allied health services, early intervention, support co-ordination and more tailored support services has occurred. Moreover, the average number of supports received by participants increased with time in the NDIS. The NDIS has also improved satisfaction with the quality of supports for many people with disability and their carers.

While in general the NDIS is leading to increased levels and quality of services and support, not all people with disability have experienced improved outcomes under the NDIS. People with disability who are unable to advocate for themselves or who struggle to navigate NDIS processes are at risk of receiving lower levels of services than previously and many have. The NDIS has also had a negative impact on the availability and cost of services for people with disability who are not part of the NDIS. Furthermore, access to specific supports for family members and carers was considered limited under the NDIS.

Service providers were found to be responding to the changing demand for supports brought about by the NDIS. Many providers were expanding their services, client numbers and workforces. Despite these changes, the supply of disability supports is not growing sufficiently to meet the additional demand created by the NDIS. As a consequence of these issues, many NDIS participants and their carers experienced continuing difficulties in accessing disability supports for which they receive NDIS funding. Particular shortages were noted for allied health services, early intervention supports, respite and accommodation services. The incidence of unmet demand did not reduce over the length of the evaluation.

Overall the evaluation found that the NDIS has led to improved levels of supports for people with disability participating in the NDIS. However, the demand for disability services and supports is now exceeding supply in the sector. This is leading to significant levels of unmet demand for supports.

## **Chapter 3: The disability sector and its workforce**

The NDIS will profoundly affect the disability sector and its workforce. Expectations among current and future users of the NDIS are for different and more flexible services. Service providers are beginning to modify or develop their supports, while new care services are expected to enter local provider markets. Issues of up-skilling, re-training and retention of the workforce will become increasingly important, as will shortages of skilled workers. In this section we present the key findings from the

quantitative and qualitative evaluation evidence that relate to the theme of the disability sector and its workforce.

While the disability sector response to the NDIS was fairly slow during the initial roll-out period, by wave 2 of the evaluation, considerable sector change was occurring. This included increased service specialisation, more flexible service provision, and a growth in services which supported NDIS transition. A move to more market-driven business practices and the entry of new providers in the NDIS trial sites were also observed. At the start of the evaluation, the sector viewed the NDIS in a positive light; over time, however, perceptions of the NDIS deteriorated. Whilst funding volumes had increased, the sector was far from settled by the end of the trial period. Ongoing concerns were expressed about funding, pricing structures and financial sustainability under the NDIS.

By the end of the evaluation, an expansion of the disability workforce (and particularly disability support worker roles) was under way. The full impact of the NDIS on employment in the disability sector, however, will take time to be realised. Presently the workforce is predominantly female, with low levels of vacancies and evidence of skill shortages. The evaluation found concerns about pay, staff retention, increasing levels of casualisation and the de-professionalisation of the workforce. Growing evidence of a shortage of allied health workers in the sector also emerged over time. Although issues were raised about the potentially negative impact of the NDIS on disability training, the availability of necessary training appeared to be adequate.

A new workforce - the NDIA workforce - is emerging within the disability sector. The evaluation found increasing concerns about high workloads and stress, skills and knowledge gaps, and considerable levels of turnover within the NDIA. Improved training, career opportunities, and strategies to manage workplace stress and workloads were recommended.

Overall the evaluation concluded that at the end of the trial period of the NDIS, the disability support sector was actively responding to the changes brought about by the introduction of the NDIS. However, going forward the sector still faces serious uncertainties and remains in an unsettled state, which makes all evidence as to its status more difficult to obtain and interpret.

#### **Chapter 4: Choice and control (including self-management)**

The concept of people with disability and their carers exercising more choice and control is a critical feature of the NDIS. One of the central aims of the NDIS is to support people with disability towards achieving greater choice and control to help them reach their goals and have more say in the planning and delivery of their supports.

The evaluation found that the NDIS is leading to improved satisfaction with choice and control - both over *what* supports are received and *where* these are obtained - for the majority of participants. Furthermore, these improvements with choice and control became stronger with longer time in the NDIS, and with increased familiarity with the NDIS. As a consequence, NDIS participants were increasingly requesting different types of supports and flexibility of service provision. Change of service providers was also more commonly seen as the evaluation progressed.

Despite these improvements, most NDIS participants wanted to have more choice and control over the supports they receive. Of concern, around a fifth of NDIS participants reported that they currently had little choice and control over their supports. Participants with a mental/psychosocial disability and those unable to articulate their support needs or navigate the NDIS website, experienced lower levels of choice and control. Constraints to greater choice and control included a lack of service providers, long waiting lists for services, limited information about provider options and inflexibility of service provision.

Although many carers of people with disability also reported improved choice and control over supports as a result of the NDIS, their perception of improvement was at a lower level than NDIS participants themselves reported. In particular those who cared for a child with disability or for a person with a mental/psychosocial disability reported lower than average satisfaction with their choice and control. Furthermore, around a quarter of families and carers reported that their choice and control had declined with longer time in the NDIS.

The evaluation identified that only a minority of NDIS participants chose to self-manage their NDIS funding, and that levels of uptake did not increase over time. While self-management was perceived to increase choice and flexibility over service provision, concerns were raised regarding administrative burden and a lack of safeguards to protect NDIS participants from potential fraud.

Overall the NDIS has led to improved choice and control over supports for a majority of NDIS participants and their families and carers. However, better information and assistance around planning and plan implementation processes could help more people to exercise effective choice and control over their supports.

## **Chapter 5: Reasonable and necessary supports**

The NDIS funds reasonable and necessary supports that help a participant to reach their goals, objectives and aspirations, and to undertake activities that enable social and economic participation. The NDIA makes decisions about what supports would be considered reasonable and necessary based on the National Disability Insurance Scheme Act 2013 (NDIS Act) and the rules made under this Act. Operational guidelines also provide practical guidance for NDIA staff on what supports are considered reasonable and necessary.

Throughout the evaluation, NDIS participants typically reported high satisfaction that their NDIS supports were reasonable and necessary. Aligned with better understanding of NDIS language and processes, satisfaction with supports being reasonable and necessary increased with time in the NDIS. However, perceptions of reasonable and necessary supports were found to vary according to the characteristics of the NDIS participant. People with a developmental or congenital disability were most satisfied that their supports were reasonable and necessary, while people with an intellectual or mental/psychosocial disability were least satisfied. Older NDIS participants and their carers also had lower levels of satisfaction with their supports as did those who had joined the NDIS in its earliest stages. In addition, participants who were unable to understand NDIS processes and effectively articulate their support needs, were considered to be at risk of receiving inadequate levels of supports.

Several key factors were found to contribute to perceptions that funded supports were not always reasonable and necessary under the NDIS. Dissatisfaction arose due to variability and gaps in NDIS plans and perceived inequality in the plans of participants with similar types of disability and support needs. Inconsistencies in decision-making across NDIS trial sites and a lack of transparency as to how funding decisions were made, further contributed to dissatisfaction. Variable levels of skills and experience possessed by NDIA planners were also considered to influence outcomes around reasonable and necessary supports. Particular supports which were considered to be under-funded in NDIS plans included family supports, alternative therapies, social and recreational activities, and respite.

Overall, the evaluation found that most NDIS participants were satisfied that their supports are reasonable and necessary under the NDIS. Attention needs to be paid, however, to ensuring that all NDIS participants have equity of access to supports that are reasonable and necessary.

## **Chapter 6: Wellbeing**

The NDIS aims to improve the quality of life and wellbeing of people with disability, their families and carers. A core task of the NDIS evaluation was to understand the degree to which the introduction of the NDIS has increased wellbeing. As wellbeing is a very complex concept, the strategy underpinning the NDIS evaluation was 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.

The evaluation found overall that the NDIS has led to modest improvements in the wellbeing of people with disability; this is further improving with time in the NDIS. Better wellbeing was found to be associated with increased levels of support and independence. Opportunities for greater social participation, improved skills and developmental progress also contributed to enhanced wellbeing under the NDIS.

Notwithstanding the improvements brought about by the NDIS, the evaluation noted that the wellbeing of people with disability remains at a level well below the national average for all Australians. Moreover, the wellbeing improvements caused by the NDIS are not distributed evenly among all participants, but vary according to their age and disability. For adult participants, wellbeing increased with age and was greatest for people in their mid to late 40s. In contrast, the NDIS was not found to have an impact on the wellbeing of child participants. Furthermore, NDIS participants with intellectual, developmental and mental/psychosocial disability, those living in rural areas, or with unmet demand for supports have poorer average levels of wellbeing.

The evaluation did not find evidence that the NDIS has improved the wellbeing of the families and carers of people with disability. A negative impact of the NDIS on wellbeing was reported by those caring for children with disability. Furthermore, levels of carer wellbeing fell slightly over the duration of the evaluation. The wellbeing of families and carers was strongly related to the amount of perceived control over how the carers themselves spend their time. Carers of NDIS participants with mental/psychosocial disability had lower levels of wellbeing than those caring for people with other types of disability. Anxiety about the long-term sustainability of the NDIS and the administrative burden associated with NDIS processes were found to have a negative impact on carer wellbeing.

In summary, while levels of wellbeing of people with disability have generally improved with the NDIS, wellbeing remains considerably poorer than that of the general population. Moreover, not all people with disability and their carers have experienced enhanced wellbeing as a consequence of joining the NDIS.

## **Chapter 7: Participation (social, economic and educational) and aspirations (goals)**

The NDIS aims to improve the social, educational and economic participation of people with disability, their families and carers. A core task of the NDIS evaluation is therefore to understand the degree to which the introduction of the NDIS has increased social, educational and economic participation, with the latter focussing on employment activities. It should be noted, however, that the evaluation recognises that impacts on participation are very hard to establish in the short term and that change is likely to manifest slowly. It is also acknowledged that change will happen at a different rate in these three key areas, with social participation improvement leading the way, education following, and employment that requires higher levels of qualifications probably coming last. In the context of the evaluation, some forms of participation are often the means for improving other forms of participation. For example, education is often the precursor of employment; social participation can build towards educational participation and so on. It is in this context of interconnected outcomes that the impact of the NDIS on participation must be understood.

While the evaluation found no econometric evidence derived from quantitative survey data that the NDIS has impacted on the social participation of people with disability to date, an abundance of qualitative evidence shows positive improvements in the accessing of social activities. Similarly, due to increased service provision for NDIS participants, family members and carers are also enjoying enhanced opportunities for social participation. Persistent barriers were identified which prevent the full social participation of people with disability. These barriers included cost, access, transport and communication issues. Additional challenges regarding social participation were found for people with mental health conditions, intellectual disability and Autism Spectrum Disorder.

Similar to social participation, no econometric evidence was found that the NDIS has improved levels of educational and economic participation. There is, however, evidence that both education and work are prime objectives and in the plans of many people with disability. While educational participation was high at the start of the evaluation, this appeared to decline over the duration of the evaluation. Only a fifth of NDIS participants were in paid employment (mostly on a part-time basis) and this did not change over time. Considerable barriers to participation in both education and work activities were identified in the evaluation, including the health/disability of the NDIS participants, opportunities for employment and study, and difficulties with transportation, facilities and equipment. There was no evidence that these barriers were being overcome during the course of the evaluation. More work is needed to develop job-readiness skills and open up labour market opportunities for people with disability.

On the whole, there is very little econometric evidence regarding the impact of the NDIS on all types of participation. Given the broad recognition that participation activities often take time to yield concrete results, this is not a surprising finding. Evidence was found, however, that the NDIS has been influencing the building of aspirations and the setting of goals regarding social and educational participation and, to a lesser extent, economic participation. Furthermore, the NDIS has been providing vital support to participants undergoing important transitions and life changes during the course of the evaluation.

## **Chapter 8: Fairness, equity and access**

A central aim of the NDIS is to provide equity of access to disability supports. Ensuring that those who are at the margins of eligibility for the NDIS are adequately supported is also critical. Issues of fairness and equity have arisen directly and indirectly in several other parts of the evaluation, especially when looking at choice and control, unmet demand, wellbeing and participation. In many instances the evaluation found that the NDIS has improved the lives of a majority of its participants, but at the same time it has left several minorities either in their pre-NDIS situation, or even in a worse situation. In many instances we find outcomes that could give rise to justifiable feelings of unfairness and inequity.

The report presents evidence that relates to the specific theme of fairness, equity and access. In particular the findings focus on eligibility and navigating the NDIS, review and dispute resolution processes, and equity and fairness.

The evaluation found that experiences of the transition into the NDIS were mixed. While some people with disability had had an easy transition into the NDIS, others found the NDIS eligibility processes to be lengthy and complicated and the boundaries between the NDIS and mainstream services confusing. Specific groups of people with disability – those with psychosocial disability, literacy problems, cognitive impairment, or from culturally and linguistically diverse (CALD) and Indigenous backgrounds – were identified as particularly struggling with the complexity of NDIS processes and documentation.

While compared to pre-NDIS processes, participants and carers felt it took the same or less time to find and get supports, but more time was required to do paperwork to obtain supports under the NDIS. Information about how to access disability supports was considered inadequate under the NDIS; these perceptions persisted into the later stages of the evaluation.

Most NDIS participants had undergone at least one review of their disability support plan by wave two and many were satisfied with plan review processes and the frequency and outcome of their reviews. However, around a fifth of participants expressed dissatisfaction with aspects of their plan review. The mode of review (typically in an NDIA office or by phone) was unsatisfactory to participants whose initial planning meetings had occurred in their homes. A lack of planner consistency and continuity between initial planning and review, variability of planner knowledge of disability, and delays in conducting review meetings or finalising plans, also contributed to dissatisfaction.

The evaluation explored perceptions of the fairness and equity of the NDIS. Outcomes under the NDIS were not found to be consistent for all people with disability. The NDIS was identified to work best for participants and families who were able to strongly advocate for themselves. In contrast, poorer outcomes were reported for NDIS participants with intellectual disability, psychosocial disability and complex needs or with older carers facing their own health issues. NDIS participants from CALD backgrounds and living outside urban areas were similarly considered to be disadvantaged under the NDIS. Concerns were also raised regarding the impact of the NDIS on service provision for non-NDIS participants.

While improving the supports, participation and wellbeing of many participants, the NDIS was not found to be leading to equitable outcomes for all people with disability. In order to improve fairness and equity within the NDIS, the importance of advocacy (either formal or informal and, where needed, as a funded support) was highlighted. In addition the strengthening of safeguards for vulnerable participants within the NDIS was recommended.

## **Chapter 9: Mainstream interface**

The NDIS is a new way of providing individualised support for people with disability, their families and carers. However, the NDIS is not intended to replace other mainstream supports. To be fully included in society, people with disability should be able to access mainstream systems such as education, health, and be supported to participate economically. Hence, wherever possible the NDIS assists participants to access mainstream services.

The Report presents findings arising from the Mainstream Study, which was an extension of the broader NDIS evaluation. The overall objective of the Mainstream Study was to explore the impact of the NDIS on mainstream health, mental health, education, and employment sectors. A particular focus was on the interface between the NDIS and these mainstream sectors. The Mainstream Study consisted of one wave of in-depth interviews with senior NDIA staff and representatives from mainstream providers/state government agencies. As well as addressing the impact of the NDIS on mainstream services, the interviews also uncovered mainstream sector perspectives on broader issues and impacts of the NDIS.

While clearer boundaries have emerged over time, unresolved issues remained regarding the interface between the NDIS and the mainstream sectors at the end of the evaluation period. These issues centred generally on responsibilities for funding shortfalls and, more specifically, on the support of people with complex or chronic health conditions, those requiring rehabilitation services, and supports within the school environment for children with disability. While communication channels had been established at all levels of operation, the NDIA was perceived by the mainstream sector to be largely

unresponsive and difficult to communicate with. Moreover, a lack of consultation with mainstream organisations was reported.

The supply and demand of services between the NDIS and the mainstream sectors were shown to be partly inter-related. The NDIS had led to increased demand for therapy services, early intervention services and assessments, and case management services provided by mainstream organisations. Service gaps also emerged as the roll-out of the NDIS progressed; these related to foster and out-of-home care arrangements, and mental health, prosthetic and rehabilitation services. In addition, insufficient sharing of client information between the NDIS and mainstream sector had led to service duplication, while delays in transitioning people into the NDIS was contributing to longer outpatient waiting lists and lengthier hospital admissions.

The evaluation also identified further challenges that the NDIS had brought to the mainstream sectors. New, untested and more formal referral pathways were being established between the mainstream and disability sectors as a result of the NDIS. The individualised funding model of the NDIS had also presented the mainstream sectors with new and costly administration, IT and staff training challenges.

In line with the whole evaluation, mainstream organisations felt that the NDIS was working well for most participants. However, specific cohorts (people from Indigenous and CALD backgrounds or with mental health conditions, high support needs or limited capacity to self-advocate) were considered to be experiencing poorer outcomes. The speed of the NDIS roll-out, delays due to lengthy NDIS processes and the complexity of NDIS systems were also found to be having a negative impact on the implementation of the NDIS. The mainstream sectors have been responding to these service gaps by providing interim services to people with disability, but these responses too were often considered to be inadequate.

Overall, the continuing complexity of the NDIS was found to be impacting negatively on its capacity to work well with related mainstream agencies and provider organisations. Improved collaboration, communication and information sharing between the NDIA and mainstream sectors was recommended to improve transitions into the NDIS and service provision.

## **Chapter 10: Older people with disability**

Entry into the NDIS is available to all eligible people with disability aged 65 years and under. Existing NDIS participants who reach the age of 65 years may choose to continue receiving services under the NDIS or transfer into the aged care system. People who acquire a disability after the age of 65 years are ineligible to participate in the NDIS; these individuals will instead receive support from other funding sources such as the aged care system.

This Report presents findings arising from a study of older people with disability (the Older People Study). This study was an extension of the broader NDIS evaluation and sought to compare the supports and satisfaction of older people with disability who were part of the NDIS with those who were ineligible to join the NDIS. In-depth qualitative interviews were conducted across one wave with older NDIS participants (aged 59 years and above), older people with disability who were not NDIS participants (aged 64 to 75 years), representatives from provider organisations working with older people with disability, and representatives from key disability and aged care agencies.

The Older People Study found that the NDIS is having a clearly positive impact on the supports of older participants. Funding levels under the NDIS were found to be higher than within the aged care and state disability systems. Likewise satisfaction with support quality and access, opportunities for social participation, and levels of choice and control were greater in the NDIS, giving rise to concerns about equity and fairness for older people with disability outside the NDIS.

Despite these overall positive perceptions, several areas of improvement within the NDIS were highlighted. Issues around the NDIS eligibility criteria, the availability of accessible information, and difficulties with navigating through bureaucratic and complex NDIS processes were found. Instances of unmet demand for supports were also reported due to issues with plan implementation. In addition, many aspects of the NDIS review process were perceived to need attention and fixing to ensure that reviews are age-appropriate as well as disability-appropriate.

Both the NDIS roll-out and the aged care reforms have been moving towards person-centred and consumer-directed care, making comparisons between the sectors unavoidable and inviting thinking about potential opportunities for synergies. At present, however, there is a lot of uncertainty about the way these two sectors may co-exist in the future. The extent to which the aged care sector has the capacity, skills and funding to adequately care for older people with disability was also questioned in the evaluation. Workforce training to provide specific skills to care for people who are both older and have a disability was recommended.

Concerns were expressed about the outcomes of older people with disability who may not qualify for supports under the NDIS, with much fear about those who may fall between the cracks of the disability and aged care sectors. The interface between the NDIS and mainstream sectors supporting older people with disability was a further source of uncertainty and impacted upon how services may be received. The evaluation also highlighted the positive role of charitable organisations in looking after vulnerable older Australians with disability; the need to protect the availability of these provisions into the future was recommended.

Overall, the systems which fund and provide supports to older people with disability are going through a period of change and uncertainty. While the NDIS is presenting modest improvements and some optimism, the big picture remains uncertain and precarious for some of the most vulnerable older Australians. Currently there is considerable variation in the funding and provision of supports to older people with disability across the different funding schemes. In order to address this inequity, a single funding scheme which provided funding and supports to all people with disability regardless of their age was recommended.

## **Chapter 11: NDIS in the NT (with a focus on the Barkly trial site)**

As a nationwide scheme, the NDIS covers rural and remote areas, and vast distances. People with disability living in rural and remote areas often face additional challenges that are distinctly different from those faced by people who live in metropolitan areas. It is therefore imperative that the NDIS is responsive to, and appropriate for, people with disability and their families and carers living in rural and remote areas. Furthermore, there are many challenges involved in the delivery of disability services in rural and remote areas including small populations dispersed across vast geographic regions, limited infrastructure, and difficulty in attracting skilled personnel. The NDIS recognises the need to ensure that it supports service delivery in rural and remote areas, particularly those that include a higher proportion of Aboriginal and Torres Strait Islander peoples.

This Report presents findings arising from the evaluation of the NDIS in the Barkly region of the NT. As an extension of the broader NDIS evaluation, this study sought to explore specific issues regarding the operation of the NDIS in a remote location. In-depth qualitative interviews were conducted across two waves with NDIS participants and their families and carers, non-NDIS participants, disability service sector representatives, and NDIA managers and staff. The study of the NDIS trial in the remote Barkly region focussed around seven main themes which include the supply and demand of disability support services; the disability sector and its workforce; choice and control (including self-management); reasonable and necessary supports; participation, wellbeing and aspirations; fairness, equity and access; and the interface between the NDIS and mainstream sectors.

The NDIS evaluation in the remote Barkly region highlighted that prevalence of disability and associated health and social support needs are high in the area. The number of actual participants in the NDIS, however, was felt to be an underestimate of these high levels of disability. While awareness of the NDIS presence in the NT improved during the evaluation period, understanding of the NDIS and its processes remained low throughout the course of the evaluation.

The NDIS had led to some participants receiving additional funding and supports, particularly for equipment and mobility aids. However, outcomes for NDIS participants were variable. Better outcomes were found for people with good English literacy and/or computer skills and those with strong advocates. NDIS participants living in remote Aboriginal communities were shown to have particularly limited outcomes under the NDIS. In general, a lack of adequate funding for transport, respite, support coordination and skill development was reported.

Choice and control remained an almost theoretical concept and these processes were challenged by the virtual absence of a viable disability support market. While some improvements in social and economic participation were found over time, further progress was stymied by limited local services and opportunities. Furthermore, while wellbeing was improved for some families and carers, the majority of NDIS participants did not experience greater wellbeing because of the NDIS.

Levels of unmet demand for supports were high amongst NDIS participants, particularly for allied health services and respite. This was a consequence of a historically inadequate supply of disability services in the Barkly region, which did not improve despite the additional funding brought with the introduction of the NDIS. Evidence of new providers entering the region was limited; their entry was deterred by the small numbers of NDIS participants in the trial site and an inadequate provision in NDIS pricing structures for remote service provision. The NDIS had also failed to have an impact on the size or diversity of the disability workforce in the Barkly region. Persistent shortages in the disability workforce were coupled with the NDIA workforce encountering challenges with recruitment and retention.

While attempts were made over time to adapt NDIS processes to local need, by the end of the evaluation period it was still felt that both the approach and implementation of the NDIS trial in the NT had been ineffective. In particular, the NDIS was not perceived to have adapted sufficiently to address the specific needs of the Barkly region. The adoption of a model which was more culturally sensitive and appropriate to remote needs and service delivery was recommended.

## **Concluding remarks**

The evaluation of the NDIS trial has showcased the far-reaching potential of the NDIS to improve the lives of many Australian people with disability. By generating independent and robust evidence, the evaluation shows credibly that in most of its aspects the NDIS is working well for the majority of the people that it touches, which is a major achievement. However, the NDIS also leaves a large minority (about a third) as well off as they were before, and it makes a small minority (between 10 and 20 per cent) feel worse off. These proportions come up time and again in many of the evaluation's findings. In most cases of a new policy, leaving a clear minority feeling worse off because of the policy would be a cause for concern. In the case of often highly vulnerable people with disability not clearly benefiting from the new system, such a finding points towards the need for closer monitoring and for more targeted and person-centred policy responses.

The evaluation has found that on the whole, the objectives of the NDIS and its high level design are working very well. However, hindsight suggests that the speed of implementation was too fast and that more thought needs to go into the practical aspects of the NDIS rollout. Some of the practical issues appeared to be getting solved during the three-year evaluation period, some remained largely

unchanged, and some appeared to be getting worse. Given the complexity of these outcomes, the expectation that the NDIS full roll out will happen in a timely fashion is probably unrealistic. Considering the enormous complexity and ambition of the undertaking, encountering practical obstacles should not come as a surprise: one can even argue that when a completely new major social innovation is introduced and tried out, learning on the go can be a useful part of cost- and time-efficient development. The evidence provided by this independent evaluation is indispensable for examining such adaptive learning. Each chapter contains highly condensed evidence about what works well and what does not.

Finally, this evaluation has been built with a longer-term national benefit in mind. Following the project design, in the background of this evaluation and its reporting lies a formidable body of evidence in the form of a tested and working template for a new national longitudinal data set of people with disability and their families and carers in Australia. This evidence can be utilised to monitor how the NDIS expands and adapts in the next critical years of its development.

# 1. Introduction

## 1.1 Background

In August 2011, the Australian Productivity Commission released its landmark report on disability care and support (Productivity Commission 2011). The report was highly critical of the care and support available to people with disability and their 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. 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 7th December 2012. The *National Disability Insurance Scheme Act 2013* established the National Disability Insurance Agency (NDIA) and gave birth to the NDIS.

The trial of the NDIS, originally known as DisabilityCare Australia, began in July 2013 in SA, TAS, the Barwon region in VIC and the Hunter area in NSW. The ACT and the Barkly Region in the NT joined the launch in July 2014, and Western Australia conducted and evaluated its own independent trial. The Nepean Blue Mountains area of NSW became the first NDIS site to transition to full rollout, starting in July 2015. In July 2016, the NDIS finished its trial period and the full Scheme began rolling out across Australia.

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).<sup>1</sup> The evaluation was originally planned to take place between 2013 and 2016 and cover SA, TAS, the Barwon region in VIC and the Hunter area in NSW from 2013 and the ACT from 2014. In 2014 the NDIS evaluation was extended to include the Barkly Region in the NT. Two additional studies were commissioned one exploring the impact of the NDIS on mainstream health, mental health, education and employment sectors and another exploring the impact of the NDIS on older people with disability and the aged care sector. 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 SA, TAS and the ACT, the Barwon region in VIC, and the Hunter area in NSW. Reporting on the findings of the evaluation in the Barkly NDIS is included in Chapter 11. The NDIS evaluation does not include any further NDIS trial sites.

## 1.2 Reporting Framework for the NDIS Evaluation

The NDIS evaluation has now been running for four years and this Consolidated Report is the third of three major reports. The Initial Report was delivered to DSS in December 2015 and was made publicly available in December 2016. 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. The Intermediate Report was delivered to DSS in September 2016 and was made publicly available in December 2016. The Intermediate Report provided the first synthesis of the evidence

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

collected up to mid-2016 from all different sources and methodologies of the NDIS evaluation on a limited number of themes and their related key evaluation questions (KEQs).

A separate document under the title The Evaluation Framework was published in February 2015 detailing the original design of the evaluation.

The precise objective of the NDIS evaluation was to assess the impacts of the NDIS in SA, TAS, the Hunter area in NSW, the Barwon region in VIC and the ACT on:

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

As described in Section 1.1, the NDIS evaluation also extends to the Barkly Region in the NT, and includes two additional studies that examine the impact of the NDIS on mainstream health, mental health, education, and employment sectors and on older people with disability and the aged care sector. The NDIS evaluation is also intended to evaluate high-level processes, focusing on elements of the NDIS which impacted on the intended positive outcomes.

In this report we present quantitative and qualitative 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. The combining and integrating of these numerous sources of data is a core element of evaluation's design.

### **1.3 Key Evaluation Questions, Main Themes and the Structure of this Report**

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 DSS originally identified a total of 58 such questions to be answered by the NDIS evaluation.

This Final Report draws from each source of the NDIS evaluation data collection activities to provide a synthesis of the evaluation evidence around 10 main themes. These themes form individual chapters of this report. A brief description of each is presented below and the related KEQs that underpin each theme/chapter are documented in Appendix 1.1. With Chapter 1 being the Introduction, we begin with Chapter 2.

- Chapter 2: Supply and demand of support services – this theme examines the impact of the NDIS on the demand, supply and quality of disability support services. We also identify areas of unmet demand for services and supports.
- Chapter 3: The disability sector and its workforce – as the NDIS is expected to bring wide-ranging change to the disability sector, this theme explores the current and anticipated impacts of the NDIS on provider markets, service providers and workers.
- Chapter 4: Choice and control (including self-management) – the concepts of choice and control are central to the NDIS. This theme examines the extent to which the NDIS has improved the choice and control of people with disability and their carers over the planning and delivery of their supports.

- Chapter 5: Reasonable and necessary supports – the NDIS funds reasonable and necessary supports to address the support needs and goals of participants. This theme considers the extent to which NDIS participants and their carers are satisfied that their supports under the NDIS are reasonable and necessary.
- Chapter 6: Wellbeing – the NDIS aims to improve the quality of life and wellbeing of people with disability and their carers. This theme assesses the extent to which the NDIS is achieving this aim.
- Chapter 7: Participation (social, economic and educational) and aspirations (goals) – a central focus of the NDIS is to improve the social, educational and economic participation of people with disability and their families and carers. This theme explores whether the NDIS is contributing to changes in participation. Furthermore, this theme examines the extent to which the NDIS has enabled participants and carers to achieve their goals and assisted with life transitions.
- Chapter 8: Fairness, equity and access – this theme focuses on experiences of eligibility processes, navigation of the NDIS, and review and dispute resolution processes. It also examines whether the NDIS is equitable and fair for all people with disability and their carers.
- Chapter 9: Mainstream interface – this theme explores the impact that the NDIS has had on mainstream sectors such as health, mental health, education and employment. The interface between the NDIS and mainstream services and the changes which have occurred in the provision and use of mainstream services by people with disability are examined.
- Chapter 10: Older people with disability – as entry into the NDIS is only available to people with disability under the age of 65 years, older people with disability can receive disability funding and supports from several different funding sources. This theme compares the supports and satisfaction of older people with disability who are part of the NDIS with those who are ineligible to join.
- Chapter 11: NDIS in the NT (with a focus on the Barkly trial site) – this theme presents finding from the evaluation of the NDIS in the Barkly region of the NT. It explores specific issues regarding the operation of the NDIS in a remote location including the supply and demand of disability supports, the disability sector and its workforce, and the outcomes for NDIS participants and their carers.

The reader must note that the above themes and the underpinning evaluation questions (and the chapters they are organised in) are inter-dependent and not mutually exclusive. There are several evaluation questions that are important in the context of several themes and in many instances the themes themselves can be overlapping. There is no clear-cut categorisation, so the evaluation is guided primarily by the policy questions, objectives, and concerns in a pragmatic manner.

Chapters 2 to 8 are presented in a way that bring out the differences between quantitative and qualitative evidence and then integrates them under the umbrella of the core policy questions addressed by each chapter. Each of these chapters begins with an integration of key findings. These integrated findings have been designed to be read independently from the body of the chapter and are provided to enable a reader with limited time to review these two sections rather than delve into the detail of the findings. We focus on the aggregate trends that the evaluation uncovers. We then continue with our detailed analyses: in the quantitative section we utilise sophisticated data estimation techniques and in the qualitative section we delve deeper into the respondents' narratives. These detailed analyses form the backbone of the evaluation's evidence, and we focus on those trends that are identified at the aggregate level to be experiencing either poorer or better outcomes. We do this to understand the factors that are most closely associated with more positive or negative outcomes stemming from the NDIS. Each of the first seven chapters (numbered 2 to 8) is concluded with a summary of the key findings arising from the quantitative and qualitative evaluation evidence

presented in the chapter, the objective being to highlight the differences in the evidence that is generated by the different methodologies we use.

The three final chapters in the report describe the findings of three additional stand-alone studies conducted in conjunction with the main evaluation (relating to the mainstream sectors, older people with disability and the NDIS trial in the Barkly region of the NT). As these were purely qualitative studies, these chapters do not include an integration of findings, and are instead preceded with the summary of the main findings of each of the studies.

## 1.4 NDIS Evaluation Data Sources

### 1.4.1 Overview

The NDIS evaluation is underpinned by a large evidence base collected by the evaluation team, comprising a *quantitative element* (consisting of a set of large scale surveys) and a *qualitative element* (consisting of a large number of in-depth interviews conducted with a broad range of relevant stakeholders groups). A common feature of most evidence bases for the main evaluation is that they collected information on their subjects at different points in time and more than once, in order to observe change and its impacts at the personal level. Thus, we have information at the early stages of the NDIS evaluation (typically from late 2013 to 2015) and at the later stages of the evaluation (typically late 2015 to late 2017). The Older People Study and the Mainstream Study were an exception, in that they did not utilise repeat (longitudinal) sampling, but were only conducted at a single time point, the reason being first, that difficulties in finding older people eligible for the study restricted recruitment and second, the mainstream study only became feasible at the later stages of the evaluation.

The evaluation utilises all data collections making the clear distinction about their respective strengths and weaknesses. The qualitative interviews provide evidence that is diverse and deep, and very broad ranging, but neither statistically generalisable, nor lending itself to make easy comparisons. In contrast, noting that the quantitative large scale survey evidence answers standardised questions in large numbers and is statistically generalisable lending itself to quantifiable comparisons, we recognise that it lacks the flexibility and depth offered by the qualitative evidence. The NDIS evaluation uses all evidence both separately and in an integrated manner which enables us to utilise the complementarities between quantitative and qualitative data.

On the quantitative side, we report the first and second wave of the longitudinal survey of people with disability and their carers. The sampling of people with disability and their carers covered NDIS participants, but also NDIS eligible non-participants (that is, people who would have been eligible to participate, if they were located in a trial site). This enables comparisons to be made between people with disability who are similar insofar as their disability is concerned, but different as to their ability to participate in the NDIS. In addition, we report the two waves of the survey of disability support providers, which included employers, their workers and the self-employed. The sample for these surveys included all providers irrespective of their registration status with the NDIS. In all sampling WA was excluded as a separate evaluation was conducted within that state.

On the qualitative side, we report the findings from the two waves of interviews with NDIS participants and their carers, disability service providers, disability workforce stakeholder organisations, and NDIA staff undertaken as part of the qualitative impact evaluation in the five original trial sites. We also report separately on the two waves of interviews undertaken with the same stakeholder groups for the evaluation of the NDIS in the Barkly Region of the NT; and one wave of interviews undertaken with various stakeholder groups as a part of two additional studies exploring the impact of the NDIS on mainstream health, mental health, education and employment sectors and on older people with disability and the aged care sector.

Table 1.1 summarises the samples sizes on which the evidence in this report is based. It records the number of respondents upon whom the analysis is performed. For the analysis using wave 2 data (third column), the numbers stated in Table 1 are lower than the actual final response rates to the survey (See Table 1.3) because the data collection extended to mid-November 2017 while the needed cut-off point for the data analysis to be included in the report was end September 2017. There are also a few number variations between trial and comparison groups from wave 1 to wave 2 because some people with disability joined the NDIS between wave 1 and wave 2 after being surveyed as comparison in wave 1, but we consider these statistically negligible. This explains the apparently low number of wave 2 comparison individuals, as about 220 wave 1 comparison individuals have moved to a Trial survey in wave 2 (by reporting they have become NDIS participants). We also observed a few individuals who were surveyed as Trial participants in wave 1 but who no longer identified as such in wave 2 and these were subsequently surveyed as members of the comparison group.

A brief overview of each of these evaluation components is provided below. For a more comprehensive overview of the methodologies employed please refer to the NDIS evaluation Initial Report (2015), the NDIS evaluation Intermediate Report (Mavromaras, Moskos and Mahuteau 2016) and the Appendices of this report.

**Table 1.1: NDIS evaluation sample**

| <b>Quantitative</b>  | <b>Wave 1*</b> | <b>Wave 2</b> | <b>Timing of wave 1</b> | <b>Timing of wave 2</b> |
|--|----------------|---------------|-------------------------|-------------------------|
| <b>The NDIS Survey of People with Disability</b>                     |                |               | Aug 14 - May 17         | Jun 17 - Nov 17         |
| Trial - NDIS participants  | 3,533          | 1,355         |                         |                         |
| Comparison - People with disability                                  | 2,139          | 588           |                         |                         |
| <b>Total Trial and Comparison</b>                                    | <b>5,672</b>   | <b>1943</b>   |                         |                         |
| <b>The NDIS Survey for Families and Carers</b>                       |                |               | Aug 14 - May 17         | Jun 17 - Nov 17         |
| Trial - Carers   | 2,713          | 997           |                         |                         |
| Comparison - Carers  | 1,738          | 385           |                         |                         |
| <b>Total Trial and Comparison</b>                                    | <b>4451</b>    | <b>1382</b>   |                         |                         |
| *Sample/Responses for waves 1a, 1b and 1c                            |                |               |                         |                         |
| <b>The NDIS Survey for Families and Carers</b>                       |                |               | Jun 14 - Apr 15         | Jun 17 - Nov 17         |
| Outlets  | 697            | 255           |                         |                         |
| Workers  | 2,133          | n/a           |                         |                         |
| Self-employed  | 272            | 265           |                         |                         |
| <b>Qualitative</b>   | <b>Wave 1</b>  | <b>Wave 2</b> | <b>Timing of wave 1</b> | <b>Timing of wave 2</b> |
| <b>The qualitative impact evaluation</b>                             |                |               |                         |                         |
| Interviews with NDIS participants and their carers                   | 62             | 61            | Aug 14 - Feb 15         | Aug 15 – Feb 16         |
| Interviews with disability service providers                         | 25             | 24            | Sep 14 - Nov 14         | Sep 15 - Dec 15         |
| Interviews with disability stakeholder organisations                 | 15             | 14            | Sep 14 -Dec 14          | Sep 15 - Dec 15         |
| Interviews with NDIA staff   | 46             | 39            | Oct 14 – Apr 15         | Oct 15 - May 16         |
| Interviews with non-NDIS participants                                | n/a            | 16            | n/a                     | Sep 15 - Feb 16         |
| <b>The NT NDIS evaluation</b>  |                |               |                         |                         |
| Interviews with NDIS participants and carers in the Barkly region    | 31             | 28            | Jul 15 - Mar 16         | Oct 16 - Jun 17         |
| Interviews with people with disability and carers in Alice Springs   | 13             | 12            | Mar 16 -Sep 16          | May 17 - Jun 17         |
| Interviews with disability service sector representatives            | 18             | 23            | Feb 15 - Jun 15         | Feb 16 - Oct 16         |
| Interviews with NDIA staff   | 9              | 15            | Jan 15 - May 15         | Jun 16 - Oct 16         |
| <b>The Older People Study</b>  |                |               |                         |                         |
| Interviews with older people with disability (NDIS participants)     | n/a            | 20            | n/a                     | May 17 – Jun 17         |
| Interviews with older people with disability (Non-NDIS participants) | n/a            | 26            | n/a                     | May 17 - Jun 17         |
| Interviews with aged care and disability service providers           | n/a            | 21            | n/a                     | Jan 17 - Jun 17         |
| Interviews with stakeholder organisations                            | n/a            | 13            | n/a                     | Apr 16 - Aug 16         |
| <b>The Mainstream Study</b>  |                |               |                         |                         |
| Interviews with representatives from health sector                   | n/a            | 15            | n/a                     | Nov 16 – Aug 17         |
| Interviews with representative from mental health sector             | n/a            | 4             | n/a                     | Nov 16 – Aug 17         |
| Interviews with representatives from employment sector               | n/a            | 5             | n/a                     | Nov 16 – Aug 17         |
| Interviews with representatives from education sector                | n/a            | 9             | n/a                     | Nov 16 – Aug 17         |
| Interviews with representatives from national or other sectors       | n/a            | 9             | n/a                     | Nov 16 – Aug 17         |

## 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 was 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 followed a two-wave longitudinal design and focused on information that assisted the evaluation to answer its core KEQs.

### 1.5.1 Design and development

The objectives of the survey design were as follows. First, to collect information on the changes that happened to NDIS participants in the trial sites (the trial group). Second, to collect information on the changes that happened to NDIS non-participants who were located in areas not included in the NDIS trial (the comparison group). The final objective was to compare the changes experienced by the NDIS participants with the changes 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 differences found between the experiences of the two groups can be attributed to the introduction of the NDIS.

Some of the core aspects of this data collection are explained below:

- The survey was conducted in all the trial sites and also included a comparison group which comprised 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 also differed by site.
- The survey followed a mixture of opt-out and opt-in consent rules, designed to comply with the project's ethics requirements. While these rules worked well in terms of protecting the ethical integrity of the project's design, they came 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 used a specially designed registration process to allow respondents to be approached in their personally preferred way. They were offered the possibility of a computer assisted telephone interview, an online response, a hard copy mail response, and a face-to-face interview. It is worth noting that an extremely small number of respondents chose a face-to-face interview. The registration process also allowed 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 followed the timing of the NDIS trial roll-out. The slower take-up of the NDIS in the trial sites was 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 (referred to as wave 1a) happened at the end of 2014, the second (wave 1b) in the middle of 2015, with the third (wave 1c) in the second half of 2016. This third sampling was timed to coincide with the earliest opportunity when the NDIS participation numbers would be 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. However, this was done at the expense of not achieving the originally planned second wave sample size and of shifting the completion date of the evaluation to the end of 2017.

- The survey was divided into two major linked but independently conducted components; the first one addressed people with disability and the second addressed their families and carers. The views of both were obtained through different questionnaires. Should they wish to, people with disability could answer their survey in private, as could their family members and carers.

### **1.5.2 Accessibility and design of the survey instruments**

Accessibility was 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 were as accessible as possible to complete.

- In order to facilitate completion, the questionnaires were divided into two parts: Part A and Part B. Part A dealt mainly with factual, less subjective information. Where it was necessary to use a proxy, this proxy could provide this information on behalf of a respondent. Part A included information on disability, activities undertaken, supports before and during the NDIS, and socio-demographic indicators.
- In contrast, Part B asked mainly subjective questions relating to opinions, assessments and perceptions, such as satisfaction and wellbeing. Here the survey design preferred to encourage the person with disability to answer, where they felt this was feasible and desirable. Part B questions included social, education and economic participation, wellbeing, aspirations, opinions and needs, and views on fairness and equity.
- Part B was also offered in a pictorial easy English format and both versions could be completed either with or without the support of someone else. Whether such support was used or not was recorded and informed the analysis.
- Questionnaires that were age-appropriate were designed and distributed accordingly. Children below the age of eight years were not asked to provide any direct information, their surveys were instead typically completed by their parents.
- The diversity of the respondents' categorisations was 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. Using the experience of wave 1, the number of questionnaire variants was halved for wave 2.
- The first wave of the data asked all people with disability whether they would like to give their consent to the evaluation team to access their administrative data. About 86 per cent of them consented. The evaluation tried to obtain this data from the NDIA but were unable to do so, and the work that was planned for 2016 using this data was cancelled.
- As these design elements have been reported extensively in the Initial Report and also discussed in many instances in the Intermediate Report, we do not repeat these discussions here, but refer the interested reader to these other documents.

### **1.5.3 Completed fieldwork with sample sizes and timing**

- A pilot study was conducted and has been reported in the Initial Report. An outline of the timing of fieldwork for the surveys with people with disability and their families and carers are presented below in Table 1.2.

**Table 1.2: NDIS survey fieldwork**

| <b>People with disability</b> |                               |                      |                                 |
|-------------------------------|-------------------------------|----------------------|---------------------------------|
| <b>Wave</b>                   | <b>Fieldwork</b>              | <b>Wave</b>          | <b>Fieldwork</b>                |
| <b>1a Trial</b>               | August 2014 to December 2015  | <b>1a Comparison</b> | September 2014 to December 2015 |
| <b>1b Trial</b>               | January 2015 to December 2015 |                      |                                 |
| <b>1c Trial</b>               | November 2016 to May 2017     | <b>1c Comparison</b> | November 2016 to May 2017       |
| <b>2a/b Trial</b>             | June 2017 to November 2017    | <b>2a Comparison</b> | June 2017 to November 2017      |

| <b>Families and Carers</b> |                                 |                      |                               |
|----------------------------|---------------------------------|----------------------|-------------------------------|
| <b>Wave</b>                | <b>Fieldwork</b>                | <b>Wave</b>          | <b>Fieldwork</b>              |
| <b>1a Trial</b>            | September 2014 to December 2015 | <b>1a Comparison</b> | October 2014 to December 2015 |
| <b>1b Trial</b>            | January 2015 to December 2015   |                      |                               |
| <b>1c Trial</b>            | November 2016 to May 2017       | <b>1c Comparison</b> | November 2016 to May 2017     |
| <b>2a/b Trial</b>          | June 2017 to November 2017      | <b>2a Comparison</b> | June 2017 to November 2017    |

- Fieldwork for wave 1 yielded for the trial sample 3,533 people with disability and 2,713 family members and carers and for the comparison sample, 2,139 people with disability and 1,738 family members and carers.
- Fieldwork for family members and carers 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. Also, there are some people with disability who have no identifiable family member or carer.
- The whole of wave 1 sampling was in essence a census of all NDIS participants who had consented to take part in research at the time of sampling. Wave 1c focussed on the ACT and came later (as soon as the late rollout in the ACT permitted) with 838 people with disability and 861 carers for the trial group. Wave 1c also provided a top up for the comparison group of 466 people with disability and 204 carers.
- The re-sampling of waves 1a and 1b (that is, the second wave of the longitudinal collection, referred to as wave 2a/b) commenced in 2017. The second wave was planned to have a shorter fieldwork duration, as a registration was not required. In order to allow the NDIS evaluation to be completed by the end of 2017, only the data collected by early October 2017 was used for this report. However, the fieldwork was allowed to continue to November 2017 in order to maximise the sample size for wave 2 (shown in Table 1.3).
- Table 1.3 provides information about the total response and retention rates for people with disability and their families and carers in the trial and comparison groups achieved as of October 2017.
- Wave 2 fieldwork was closed mid November 2017 with a total of 2,077 people with disability and 1,619 families and carers for the trial group and 900 people with disability and 605 families and carers for the comparison group. Wave 2c was cancelled in order to meet the completion date of the overall evaluation.
- The final response rates for waves 2a and b for the trial group were 83 per cent and 87 per cent for people and carers respectively, close to the target set by the evaluation of 85 per cent. Responses

for the comparison group (48 per cent and 40 per cent) were both much lower, which had been anticipated and factored into the design of the sampling by sending out a larger number of questionnaires to that group.

**Table 1.3: Wave 2a&b responses and retention rates**

|                | <b>Trial</b><br>People with disability | <b>Comparison</b><br>People with disability | <b>Trial</b><br>Carers | <b>Comparison</b><br>Carers |
|----------------|--|---|------------------------|-----------------------------|
| Wave 1a and b  | 2,495                                  | 1,873                                       | 1,870                  | 1,516                       |
| Wave 2a&b      | 2,077                                  | 900   | 1,619                  | 605                         |
| Retention rate | 83%                                    | 48%   | 87%                    | 40%                         |

#### **1.5.4 Estimating the impact of the NDIS: An overview of the methodology**

The analysis of the data collected was 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 we use deviates from the textbook methodology described in the Evaluation Framework (2015) in order to adapt to and utilise in full the actual data obtained, as we describe in this section.

The evaluation sought to estimate the impact of the NDIS on outcomes for people with disability and their families and carers. We try to use non-technical language, where possible, to describe how this approach was used, but this is not always feasible. The survey data design and collection worked sufficiently well to allow the use of robust statistical methodologies to derive formal impact estimates and determine direct causal interpretations. This type of estimates are the gold standard of evaluation methodology as they allow us to state formally whether the NDIS can be shown to be causing change or not.

As the data structure and timing of the collections were dependent on the actual roll-out of the NDIS, the methodology was adapted to use the data at hand. A major advantage of the survey data collected for the evaluation is that we have a very rich set of personal, demographic and socioeconomic information both at an individual and family level, which helps us with the necessary matching operation for making statistically meaningful comparisons. Another critical advantage of the data is that the opportunities and frequency of individuals self-selecting to enter the ‘trial’ group was highly unlikely – so the distinction between a trial group and a comparison person is clear cut and easy to determine in our data. In technical language, we do not need to rely as much on methodologies that control for both *unobserved heterogeneity* and *non-random selection into the trial group*, as one would have to if weaker data and experimental design were used.

### **Technical box: Estimation the NDIS impact using large scale survey data**

The way we conducted the impact estimations for the evaluation is explained below using the ‘choice and control’ Chapter 2 as our example. The impact of the NDIS on people with disability and carer perspectives of how much *choice and control* they can exert over their supports was estimated. The estimations used data collected from the following two survey questions:

- *The amount of say the person with disability has over decisions on what supports he/she receives*
- *The amount of choice the person with disability has about where to obtain these supports*

To estimate the impact of the NDIS, we first used matching techniques, to make people with disability in the NDIS trial and comparison groups comparable so that the outcomes of the NDIS participants could be properly evaluated. Following this, the average difference between the NDIS participants’ answers to the questions on choice and control and the answer they would have given had they not joined the NDIS was determined. Further, using the longitudinal dimension of the surveys of people with disability and families and carers, the incremental impact of the NDIS over time on those measures was estimated.

The analyses used both (i) a binary measure of choice and control, i.e. looking at the proportion of people with disability who reported having a lot of say/choice over their supports compared to those who did not, and (ii) a continuous measure of these outcomes, using all the points of the Likert scale answers to these questions.

Note that choice and control information, as with other outcomes such as support quality or supports being reasonable and necessary, was only elicited from adult people with disability (and not children with disability). However, the information was also elicited from the carers of people with disability across all ages. This allowed us to compare the estimated impact of the NDIS on the choice and control of adult participants as reported by people with disability themselves and their carers. Furthermore, the information collected from carers was used to estimate the impact of the NDIS on choice and control outcomes for child participants. It should also be noted that the magnitude of the estimated impact of the NDIS on choice and control was expected to vary depending on the type of measure used (i.e. binary or continuous).

## **1.6 The NDIS Disability Support Providers Surveys**

The first wave of this survey was completed early in 2015 and is fully described in the Initial Report. A brief summary is provided below:

- 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 organisations, 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 organisations and a satisfactory response rate by self-employed support providers.
- Linking workers with outlets indicated that several organisations did not provide any information at all through their workers, while several other organisations provided information through their workers, but did not themselves return their organisational questionnaire.

The second wave of providers' surveys fieldwork was completed in October 2017 but challenges in this data collection were experienced, especially in regards with the workers questionnaires where response rates were extremely low. Our understanding about the sector's very different wave 1 and 2 responses are explained in the caveats section at the end of the Introduction. In practical terms this low response rate makes comparisons between waves 1 and 2 less precise and in some instances statistically unreliable. In contrast the qualitative evidence stemming from interviews with providers has been rich and provides much detail as to the impact of the NDIS on the disability sector and its workforce. Chapter 3 presents the findings relating to the disability sector and, as a result of these issues, relies more heavily than initially designed on the qualitative evidence collected. This qualitative evidence highlights the current unsettled nature of the disability sector. Furthermore, it explains in part why providers would find it difficult in this period of considerable change to focus on a survey that looks into the future of the sector when in many individual cases the present is so uncertain.

## **1.7 The Qualitative Impact Evaluation**

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

- NDIS participants and, their families and carers
- disability service providers
- disability workforce stakeholder organisations
- NDIA managers and staff
- non-NDIS participants.

These interviews collected impressions and assessments of the progress and achievements of the implementation of the NDIS. With the consent of participants, each interview was recorded. The interviews were transcribed verbatim and analysed using NVIVO. The analysis of the interview data was informed by both deductive and inductive strategies. An initial coding scheme was developed that reflected the initial KEQs of the evaluation. This was subsequently amended and elaborated to reflect the evolving themes and sub-themes that emerged in a careful reading and re-reading of the interview transcripts. To protect respondents' identities pseudonyms are used in all references in this report.

### **1.7.1 Interviews with NDIS participants, and their carers**

Interviews were conducted with sixty-two NDIS participants, and their carers in the five trial sites. The interviews targeted people who had already moved into the NDIS and commenced or completed the NDIS plan preparation and implementation. Recruitment for the interviews sought 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 phase 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 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.

## **1.7.2 Interviews with disability service providers**

Interviews were conducted with five NDIA-registered disability service providers in each of the trial sites between September and November 2014. Interviews were undertaken with employers of Pay As You Go (PAYG) workers, brokered workers and self-employed sole providers. Selective sampling ensured that the types of disability service providers 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.

## **1.7.3 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.

## **1.7.4 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.

## **1.7.5 Interviews with non-NDIS participants**

Not all people eligible for the NDIS join and in addition not all people with disability who apply to join the NDIS are found to be eligible. Therefore, it was of central importance that the evaluation also inquired about the impact of the NDIS on people with disability who had not joined.

Interviews were conducted with 16 people with disability who were not participating in the NDIS. The interviews targeted people with disability who:

- had been determined eligible for joining the NDIS but had chosen not to do so; or
- were not eligible for the NDIS and hence were not participating. This included people supported under the NDIS Information, Linkages and Capacity Building (ILC) component (previously also known as Tier 2 of the NDIS).

To be included in the evaluation, people were required to be living in an NDIS trial site. They were also required to possess similar characteristics to the population that was eligible in their trial site although the type or severity of their disability may have made them ineligible for the NDIS (except for the ILC component).

Interviews with non-NDIS participants sought to learn about and understand:

- the context that led to non-participation in the NDIS and, if applicable, the reasoning and rationale for non-participation;
- current satisfaction with disability supports, including perceptions or experiences attributable to the NDIS;
- the experience and contact (if any) of non-participants with the NDIS; and
- any issues about disability supports and the NDIS that concern non-participants.

Respondents had a broad range of disabilities, with the largest subgroup (n=7) being people identifying as having a psychosocial disability. The sample included children, young people and adults. Pilot interviews were conducted in August 2014, and the main fieldwork occurred between September 2015 and February 2016. Each interview lasted 45 minutes on average. Most interviews were undertaken face-to-face and at the respondent's home.

## **1.8 The Evaluation of the NDIS in the Barkly Region**

The delivery of the NDIS in rural and remote communities such as those in the Barkly region is likely to differ from its metropolitan counterparts. The NT evaluation aimed to provide findings about specific issues regarding the operation of the NDIS in rural and remote communities with a particular focus on Aboriginal and Torres Strait Islander people of all ages, living with disability in a range of communities.

The evaluation of the NDIS in the Barkly region of the NT consisted of a number of in-depth interviews with:

- NDIS participants and their carers
- Disability service sector representatives
- NDIA managers and staff
- Non-NDIS participants.

Interviews were conducted with the same respondents at two time points. These interviews collected impressions and assessments of the progress and achievements of the implementation of the NDIS in a rural and remote setting. With the consent of participants, each interview was recorded. The analysis and reporting of the interview data collected as a part of the evaluation of the NDIS in the Barkly region preceded along the same lines as that adopted for the main QIE as outlined in section 1.7. To protect respondents' identities, no personal information is disclosed, pseudonyms are used in all references in the report and sources of direct quotes are de-identified.

There were many challenges of undertaking the evaluation of the NDIS in the Barkly region of the NT. These are briefly described in Appendix A1.2.

### **1.8.1 Interviews with NDIS participants and their carers**

The NDIS trial commenced in the Barkly region of the NT in July 2014. In total 31 interviews pertaining to 36 NDIS participants were conducted. Interviews were conducted with 14 people with disabilities and 20 carers and/or family members. The number of carers interviewed was higher than the number of people with disabilities as several in the latter group were under guardianship arrangements or unable to participate in interviews due to intellectual impairment or their age. Wave 1 interviews occurred between July 2015 and March 2016. The duration of interviews varied with some lasting only 15 minutes, while others were 1.5 hours in duration.

A second round of interviews with these NT NDIS participants and carers was conducted between October 2016 and June 2017. Eleven respondents who had taken part in wave 1 were unable to participate in wave 2. Replacements were found for three respondents, resulting in 28 interviews pertaining to 28 NDIS participants being conducted in wave 2.

NDIS participants included people with developmental conditions, visually impairment, congenital conditions, degenerative conditions, acquired brain injury, people who had acquired a disability through accidents and/or acute or chronic illness, and one with a primary mental health diagnosis. Participant ages ranged from three years to 62 years. While most NDIS participants were living with family or foster carers, several were in residential care under guardianship arrangements. In both waves 1 and 2, only four of the interview respondents were non-Indigenous, with the remainder being of Aboriginal and/or Torres Strait Islander background.

### **1.8.2 Interviews with disability service sector representatives**

In wave 1, 18 interviews were conducted with disability service providers (including self-employed providers) and peak bodies involved in the NDIS trial in the Barkly region in the NT. These interviews were conducted between February and June 2015. Between February and October 2016 a second round of interviews were undertaken with twenty-three disability service providers and peak bodies involved in the Barkly region. The number of interviews with disability service providers increased in wave 2 to include some new providers operating in the region since wave 1 of the evaluation. Interviews were either undertaken face-to-face or via telephone. The interviews sought to understand the change brought by the NDIS on the disability sector and its workforce in rural and remote areas.

### **1.8.3 Interviews with NDIA managers and staff**

From January 2015 to May 2015 a first round of interviews were conducted with nine NDIA staff who currently or previously worked in the Barkly trial site. Six respondents were actively involved in the Barkly region trial, of whom five were based in the region. The remaining three respondents had returned to their original trial sites but continued their involvement in the Barkly trial through participation in the 'community of practice' network.

A second round of interviews with these NDIA staff were undertaken between June 2016 and October 2016. Of the original nine participants, three declined to be interviewed in wave 2. However, another nine NDIA staff who currently or previously worked in the Barkly trial site were additionally willing to inform the evaluation. In total 15 NDIA staff were interviewed in wave 2, ten of whom were currently actively engaged in the trial site. Six of these NDIA employees were based in the Barkly region, three were based in Darwin, and the remaining respondent was based outside the NT. These interviews highlighted the experience of implementing the NDIS in rural and remote areas.

### **1.8.4 Interviews with non-NDIS participants**

To allow comparison with the experiences of NDIS participants in the Barkly region, interviews were also undertaken with people with disability and their carers living outside of the Barkly trial site. The Alice Springs region was chosen as the comparison site. While much bigger than Tennant Creek, the cultural make up of Alice Springs is much more aligned to that of Tennant Creek than other possible control sites such as Katherine, with many commuting between the two regions. In addition, there is considerably more overlap between disability service provision within Alice Springs and Tennant Creek than disability service provision in Katherine, much of the latter being Darwin based.

In wave 1, a total of 13 interviews involving 15 people with disability were conducted. The control cohort matched, as far as possible, the profile of participants interviewed in the trial site. Interviews were conducted with five people with disability and eight carers of people with disability. People with

disability informing this component of the evaluation included people with congenital conditions, developmental conditions, intellectual conditions, and people who had acquired a disability through accidents and/or acute or chronic illness. While most participants lived with family, several lived by themselves. Participant ages ranged from three years to over 60 years. Wave 1 interviews were undertaken between March 2016 and September 2016.

A second round of interviews with the same non-NDIS participants in the NT was undertaken between May and June 2017. Two people with disability who had taken part in wave 1 had passed away; a family member of one of these respondents chose to participate in a further interview in wave 2.

## **1.9 The Older People Study**

Entry into the NDIS is available to all eligible people with disability aged less than 65 years. Existing NDIS participants who reach the age of 65 years may choose to continue receiving services under the NDIS or transfer into the aged care system. People who develop a disability from 65 years onwards are ineligible for the NDIS and will instead receive support from other funding sources such as aged care.

The overall objective of the 'Older People Study' was to evaluate the impact of the NDIS on older people with disability and the interface with the aged care sector.

The Older People Study consisted of a number of in-depth interviews with:

- older NDIS participants
- older people with disability who were not NDIS participants<sup>2</sup>
- representatives from aged care and disability support providers
- representatives from key disability and aged care agencies.

These interviews collected impressions and assessments of the impact of the NDIS on older people with disability and the interface with the aged care sector. With the consent of participants, each interview was recorded. The analysis and reporting of the interview data collected as a part of the older people study preceded along the same lines as that adopted for the main QIE as outlined in section 1.7. To protect respondents' identities, no personal information is disclosed, pseudonyms are used in all references in the report and sources of direct quotes are de-identified.

### **1.9.1 Older NDIS participants**

Interviews were undertaken with 20 NDIS participants aged 59 years and above. Participants had a wide range of disabilities including physical disability, sensory impairment, neurological conditions and psychosocial disability. Interviews were conducted between May 2017 and June 2017, and in most cases were undertaken face-to-face in the home of the participant. Interviews examined current supports (level, types, how these are funded, length of time receiving, support gaps, choice and control, quality) and assessed how these compared with any previous supports prior to the NDIS.

### **1.9.2 Older non-NDIS participants**

Interviews were also conducted with 26 non-NDIS participants who were aged between 64 to 74 years. A majority of the non-NDIS participants had one of three types of disability (visual impairment, motor neurone disease and polio). The sample was skewed in this fashion due to large mail outs advertising

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<sup>2</sup> For convenience, this group will be referred to as older non-NDIS participants.

the opportunity to participate in the evaluation undertaken by three disability organisations. Interviews were conducted between May 2017 and June 2017, and in most case were undertaken face-to-face in the home of the respondent.

### **1.9.3 Representatives from aged care and disability support providers**

Twenty one interviews were undertaken with representatives from aged care and disability support provider organisations over the period of January to June 2017. Nearly all of these interviews were undertaken over the phone and lasted between 1 and 1.5 hours. Interviews sought information regarding supports provided in the different funding systems (NDIS, aged care and non-NDIS disability sector), transfers between the systems, and any high-level process issues contributing to or impeding the effectiveness of these supports and transfers. In addition, the interviews were used to obtain support to distribute flyers and promote the opportunity to participate in the Older People Study to eligible clients.

### **1.9.4 Representatives from key disability and aged care agencies**

Thirteen consultation interviews were undertaken with 18 representatives from key disability and aged care agencies including unions, advocacy organisations, peak bodies, and national aged and disability care providers. These consultations were undertaken over the period of April to August 2016 and were conducted over the phone. Interviews typically lasted between 1 and 1.5 hours. The aim was to further inform the content and design of the study. The consultations also sought to understand the supports received by older people with disability through the NDIS and the aged care sector, and the key issues impacting upon these supports.

## **1.10 The Mainstream Study**

The NDIS is a new way of providing individualised support for people with disability. However, the NDIS is not intended to replace other mainstream supports. To be fully included in society, people with disability should be able to access mainstream systems such as school education, health, and be supported to participate economically. Wherever possible the NDIS assists participants to access mainstream systems.

The overall objective of the Mainstream Study was to explore the interface of the NDIS with mainstream health, mental health, education and employment sectors.

The Mainstream Study comprised in-depth interviews with:

- senior NDIA staff involved with the design and implementation of ILC; and
- representatives from mainstream providers/state government agencies who interact with the NDIA and/or NDIS participants.

This aspect of the evaluation targeted specific mainstream sectors in each of the trial sites as outlined below:

- SA - early school and children's health
- TAS - education with emphasis on VET and employment pathways
- ACT - early education and health, with emphasis on older people's health
- NSW - health, mental health and employment
- VIC - health, mental health and employment.

Additional health, mental health, education and employment sectors within each state and territory were included where they were identified as central to understanding the mainstream interface within the trial site.

In total 42 interviews involving 73 representatives from mainstream sectors were undertaken over the period of November 2016 to August 2017. Interview evidence arising from the main QIE highlighted the importance of delaying the mainstream study as much as we could as the interaction between the NDIS, the disability and mainstream sectors was slow to develop and a lack of understanding about the interface was apparent. Interview respondents were based in both strategic and operational level roles. Interviews were largely conducted on the phone and typically lasted between 1 and 1.5 hours. With the consent of participants, interviews were recorded. The analysis and reporting of the interview data collected as a part of the Mainstream Study preceded along the same lines as that adopted for the main QIE as outlined in section 1.7. To protect respondents' identities, no personal information is disclosed, pseudonyms are used in all references in the report and sources of direct quotes are de-identified. The results are presented in Chapter 9 of this report (Mainstream Interface).

## **1.11 The Importance of the NDIS Evaluation Data and some Caveats**

The final section of this introduction chapter outlines the strengths of the NDIS evaluation and the important contribution this evidence makes to the future implementation of the NDIS. We also highlight some of the challenges that were experienced (and mostly overcome) during the evaluation, along with the most important caveats that arose over the course of this work.

### **1.11.1 The importance of the NDIS evaluation for a healthy NDIS**

This report concludes a robust, transparent and objective evaluation conducted by independent evaluators, which is essential for the credibility of the trial of the NDIS. By advising on the strengths and weaknesses of the NDIS trial implementation, the evaluation increases the scope for its effective long-term roll-out and management. The NDIS is a major social policy development that puts Australia at the forefront of international achievement and innovation regarding disability. By implementing a rigorous evaluation design, we provide the first independent, robust and comprehensive data to enable such an assessment. Moreover, this evaluation was conducted using a multidisciplinary approach that produced a wealth of well-evidenced and informed conclusions.

The most outstanding element of the evaluation is the uniqueness of the data it created: this is the only national resource which is both informed and independent of the performance of the NDIS from the point of view of people with disability and their families and carers. This evidence is critical for a transition from block funding support provision to individualised care and supports. The second outstanding element of this evaluation is that it provides a template for the further collection of independent data. The evaluation team were contracted to start a new national longitudinal data collection for people with disability and their families and carers, in a form that could be continued into the future. The NDIS survey can also be linked with other data sources, such as the NDIA administrative data, with the consent of participants (and over the course of the evaluation, the vast majority of respondents provided this consent). As a result, the evaluation has produced the first two waves of a very cost-effective longitudinal data set, which could be used as the springboard for a sophisticated and accurate monitoring tool for the performance of the NDIS during its national roll-out and beyond.

The integration of quantitative and qualitative evidence has enabled a better-informed data design and subsequent evidence interpretation. In addition, the use of an inclusive and accessible multi-method and multi-mode approach rather than a conventional survey design enabled the participation

in the evaluation of a wide range of people with disability. As a consequence, the data collected in the evaluation is more informative and representative.

Many innovations were introduced during the course of the evaluation. An example of this was the use of three alternative quantitative wellbeing measures within the surveys supported by extensive qualitative evidence, in a manner that enabled us to determine the impact of the NDIS on levels of participant and carer wellbeing more fully and accurately. Another innovation was allowing the NDIS survey process to be completed by proxies for those parts that are easier to know objectively, but discouraging the involvement of proxies where opinions, perceptions and feelings were to be recorded. This differential treatment of proxy involvement was quantitatively implemented through the two-part questionnaires and further supported by introducing the gradual shift of the second part of the questionnaires into easier English and pictorial instruments.

The use and integration of multimethod and multi-mode data collections was necessary given the diversity of the groups of people who took part in the evaluation. The qualitative evidence has allowed more in-depth and detailed understanding of the quantitative research. The quantitative evidence meanwhile has allowed us to judge the overall prevalence of opinions and situations discussed in the interviews, especially for those who were very negative or very positive about the NDIS. The synergies that have been realised through the integration of our findings have been many and useful, and have created a higher level of understanding of the overall evaluation evidence.

### **1.11.2 Caveats**

The complexity of this evaluation has given rise to several caveats, some of them remaining unresolved at the time of reporting.

Response rates of the provider surveys were too low for comfort during the second wave of data collection. Given that the instruments we used have been tried and tested with tens of thousands of responses from the aged care sector's providers and workforces, in four different occasions in the last decade, we believe that the problem does not lie in the survey design, but in the perceptions of the sector about the usefulness of such an exercise in a time of such intense uncertainty and change. At the time of the first wave, the roll-out of the NDIS was just starting with limited impacts to date on the sector. As a consequence, many providers responded to our request to participate in the survey. However, at the time of data collection for the second wave of the survey (in mid-2017), providers were far less responsive. As we noted, the data instrument has previously been successfully developed and used by NILS in the aged care sector with very high response rates and numbers<sup>3</sup>. The disability support sector in 2017, however, was overwhelmed by change, over-researched in an inefficiently piecemeal manner (through the use of many short and different surveys and administrative data collections, which do not lead to major bodies of evidence). Unlike the aged care sector where these data collections have been guiding the development of the sector for more than a decade, key sector support was not provided (for example by the NDS encouraging their memberships) a lack that we believe has had a negative impact upon the size of the sample at wave 2. However, without going back to the field again, we will not know for certain why this exercise returned poorer results than we expected. The strength of the qualitative evidence on this front is a strong consolation and has been supporting the evaluation.

The bunched rollout of children by age group in SA, was not ideal for sampling. For the first stages of the evaluation, the information on eight to 15 year old people with disability was largely based on the

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<sup>3</sup> For further information, please see the reports for the 2012 and 2016 National Aged Care Workforce Census and Survey.

non-SA part of the sample. Our statistical work, however, suggests that this problem has not impacted on the quality of the relevant results.

The use of administrative information provided directly by the NDIA in the form of administrative individual data had been written in the design of the evaluation and the necessary ethical approvals and individual consent was obtained by people with disability. However, as the evaluation progressed it was not possible to obtain such data and the design had to be altered. In October 2017 the evaluation was provided with some tabulations to construct the necessary population weights in order to ascertain the representativeness of the NDIS survey.

The sample for the comparison group was initially intended to be collated from records held by the Department of Human Services (DHS). However, this data was in many instances either out of date or incomplete, which questioned its present accuracy. This problem was overcome by adding a registration phase to the survey of people with disability and their family and carers. Additional questions were included in the registration phase in order to compensate for the lack of administrative data from the NDIA. This approach led to a much lower response rate but now that the data is at hand, we know that the statistical intervention has worked well.

During the course of the evaluation there were several other evidence collection exercises conducted by other organisations, some large and many small, principally due to the heightened public interest in the NDIS trial. In some instances the timing of such fieldwork activities overlapped and in some others the objectives were perceived by respondents to be very similar, often leading to avoidable interviewee burden and confusion. The evaluation believes that there is a strong public good argument for more coordination of such activities.

The NDIS rollout in the ACT picked up its speed later than we anticipated. This delayed wave 1c commencement as we waited for the numbers to build before commencing fieldwork. As a consequence, the conduct of a subsequent wave 2c was impossible within the time constraints of the evaluation. The possibility of conducting this follow-up wave would be available for at least another 12 months. If this were to be undertaken, it would provide valuable further information relating to both the ACT NDIS trial group and the comparison group sample, many of whom are likely to transition into the NDIS within the next year.

The overall design of evaluation of the NDIS in the NT had to be flexible in order to be suitable to the needs and respectful of the particulars of the populations to be studied and the nature of existing service arrangements, particularly within remote Aboriginal and Torres Strait Islander Communities. It also needed to ensure that people with disability, families, groups and communities were able to have input into discussions, consistent with local practice and the commitment to inclusive and ethical research that is culturally appropriate. The evaluation of the NDIS in the NT also had to take into consideration the objectives and timelines of the project in combination with weather, remoteness and other relevant factors including travel, communication and cultural events. It is important to note the complexity and contingencies that were involved in carrying out the NT study.

## 2. Supply and Demand of Support Services

### Integrated findings

This section integrates the quantitative and qualitative findings relating to the supply and demand of disability support services. We outline the impact of the NDIS on (i) the demand and supply of disability services; (ii) the quality of these supports; and (iii) areas of unmet demand for services and support.

The evaluation finds that:

- the types and number of supports received by NDIS participants has increased and is in most cases better than before and better than what is presently received by NDIS non-participants outside the trial areas;
- the NDIS has improved satisfaction with the quality of the supports for people with disability and their family and carers;
- the benefits from additional supports have not been distributed evenly among all NDIS participants;
- concern has been voiced about the quality of supports from a minority of NDIS participants;
- the supply of supports in number and quality is not growing sufficiently to meet the additional demand created by the NDIS;
- many NDIS participants and their families and carers experienced continuing difficulties in accessing disability supports for which they were receiving NDIS funding;
- the incidence of unmet demand did not reduce over the length of the evaluation; and
- overall, the evaluation finds that demand for disability services and supports is now exceeding supply in the sector.

#### *The impact of the NDIS on types and volume of disability support services*

- 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. Over the course of the evaluation there was a modest shift away from family care and towards paid care.
- Both the quantitative and qualitative sources of evidence clearly indicated that many people with disability are receiving more disability supports as a consequence of joining the NDIS. This included increased hours of support, greater frequency of services, as well as access to a wider range of supports. The quantitative data additionally indicated that the average number of supports received increased further with time participating in the NDIS. Commonly funded supports included aids and equipment, therapy services, personal care, leisure activities, transportation and respite.
- Both sources of evidence identified that funding for support co-ordination/case management services had increased with the NDIS. While the quantitative evidence showed access to transport services had also improved, the qualitative data highlighted instances where this was not consistent and where a lack of funding for transport made it difficult and costly for participants to attend activities, especially those not in the local area. The qualitative data further suggested better access to equipment, allied health services, early intervention, and more tailored support services under the NDIS.

- Despite a key focus of the NDIS on enhancing the social and economic participation of people with disability, both sources of evidence indicate there is limited supports to access work and study.
- The quantitative evidence found that a majority of family members and carers felt that the NDIS had improved their capacity to provide support to the person with disability that they care for. The qualitative data suggested that better access to supports enabled NDIS participants to have more independence and less reliance on family members.
- Both sources of evidence found that, while the number of supports received had increased for most NDIS participants, the majority of NDIS participants did not change providers upon joining the NDIS. The qualitative data suggested that uncertainty contributed to choosing to stay with the same provider, with evidence emerging that, as NDIS participants and carers increased their knowledge and experience of the NDIS, they became more confident about changing service providers over time. Wave 2 quantitative data continued to indicate that only a minority of NDIS participants changed providers. The qualitative evidence showed, however, that by wave 2, participants were increasingly moving across service providers and demanding more flexible services.
- The qualitative data suggested that disability service providers were responding to the changing demand for supports brought about by the NDIS. Many providers were undergoing an expansion of their services, client numbers and workforces. Particular services that were experiencing expansion included individualised supports, support co-ordination, therapeutic supports, respite, and accommodation services. Some providers were also extending their hours of operation in order to enable greater flexibility around the timing of service provision.
- However, while adaptation to the impact of the NDIS on demand for supports was occurring, the sector was experiencing persistent shortages in the supply of some types of disability supports. The qualitative interviews suggested that shortages could be particularly problematic for allied health services including speech pathology, occupational therapy and psychology.
- Furthermore, the qualitative evidence revealed concerns about the future provision of disability services. These related to perceptions that some supports were underfunded by the NDIS, including one-to-one community supports, mental health services, group services, and services for people with complex needs. With the forthcoming ceasing of block funding arrangements, the future financial viability and provision of these supports was questioned.
- An important finding that emerges very clearly from both sources of evidence is that whilst the overall picture of the NDIS is one of increased services and support, not all people with disability are achieving improved outcomes under the NDIS.
- Both sources of evidence identified that access to supports for family members and carers to directly assist them in their caring role was limited under the NDIS.
- The qualitative evidence also indicated 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 and/or those people who struggled to manage the new and sometimes complex NDIS processes. NDIS participants with a psychosocial or intellectual disability were considered to be at greater risk of poorer outcomes.
- The qualitative evidence identified that the NDIS was having a negative impact on the services and supports accessed by people with disability who were not part of the NDIS. Supports were

becoming more expensive, less readily available and, at times, no longer free for non-NDIS participants.

#### *The impact of the NDIS on the quality of disability support services*

- Both sources of evidence showed that in general NDIS participants and their family members and carers were satisfied with the quality of the disability supports they were receiving under the NDIS. Moreover, their satisfaction levels were much higher compared to those of people with disability and their family members and carers outside the NDIS.
- However, the quantitative evidence shows that satisfaction with the quality of supports was not consistent across all NDIS participants. People with mental/psychosocial disability were less satisfied with the quality of their supports under the NDIS compared to participants with other types of disability. Participants who had experienced unmet demand for supports and carers of younger children were also less satisfied with support quality.
- Qualitative evidence highlighted concerns around the quality of disability support services across both waves 1 and 2, at a worker, organisational and sector level.
- The quality and skills of disability support workers was a concern, especially with regards to agency workers. A lack of funding provision for staff training within the NDIS was considered to be undermining the quality of the disability workforce. Many respondents reported that NDIA planners did not have an adequate understanding of the needs of people with disability, which was having a detrimental impact on the quality of supports funded and received by NDIS participants.
- At a provider level, NDIS participants and their family members and carers were concerned about the reliability and continuity of care provided by some organisations. Concerns were also expressed about the quality of unregistered providers who could be hired by NDIS participants self-managing their own funding. A perceived erosion of existing governance structures and a lack of regulation were felt to be negatively impacting on service quality at a sector level as the NDIS kept being rolled out.

#### *Has the NDIS created new unmet demand for disability support services?*

- Despite evidence of positive changes to the amount of disability services received by people with disability as a result of joining the NDIS, both sources of evidence indicate that many NDIS participants and their families and carers experienced continuing difficulties in accessing disability supports for which they were receiving NDIS funding. The incidence of unmet demand did not reduce over the length of the evaluation. Services that were now more challenging to access included allied health, early intervention supports, respite and accommodation.
- Both sources of evidence concurred that unmet demand was primarily a consequence of long wait times or a lack of a local provider. The quantitative evidence also shows that a lack of quality service provision contributed to unmet demand, while qualitative evidence highlighted potential difficulties accessing supports due to a continuing inflexibility of the support hours offered by service providers.
- Unmet demand for disability supports was found by quantitative evidence to vary across different cohorts participating in the NDIS. Participants with an intellectual disability, those aged seven-15 years, or those who had entered the NDIS at a later stage, were shown to experience higher levels of unmet demand. In contrast, male participants and those with a higher household income were shown to be less likely to experience unmet demand for supports. Qualitative evidence enriched

this finding by suggesting that unmet demand was more prevalent for people with disability living in rural and remote areas.

- Both sources of evidence 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. The incidence of self-funded supports increased over time. It was reported that NDIS participants and/or their family already pay out-of-pocket expenses for accessing such services.

## 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 a central focus of many of the fifty-eight KEQs of the NDIS evaluation. In this section we present quantitative and qualitative evidence relating to the KEQs which pertain to 'supply and demand of support services'. Specifically we look at NDIS participants need for assistance, type of supports previously received and the extent to which the NDIS has contributed to changes in the patterns and use of supports. The impact of the NDIS on the quality of disability services is also examined. Further, we consider the impacts on the supply and diversity of disability supports and the extent to which the supply of disability supports has responded to demand. We conclude by providing a summary of key findings pertaining to each of these three main areas.

## 2.2 Types and Volume of Disability Supports

### 2.2.1 How are NDIS participants supported? – Evidence from large scale surveys

The NDIS Survey collects detailed information on NDIS participants need for assistance in different contexts of their lives. These questions are not asked of children below the age of eight as young children have not yet developed full autonomy.

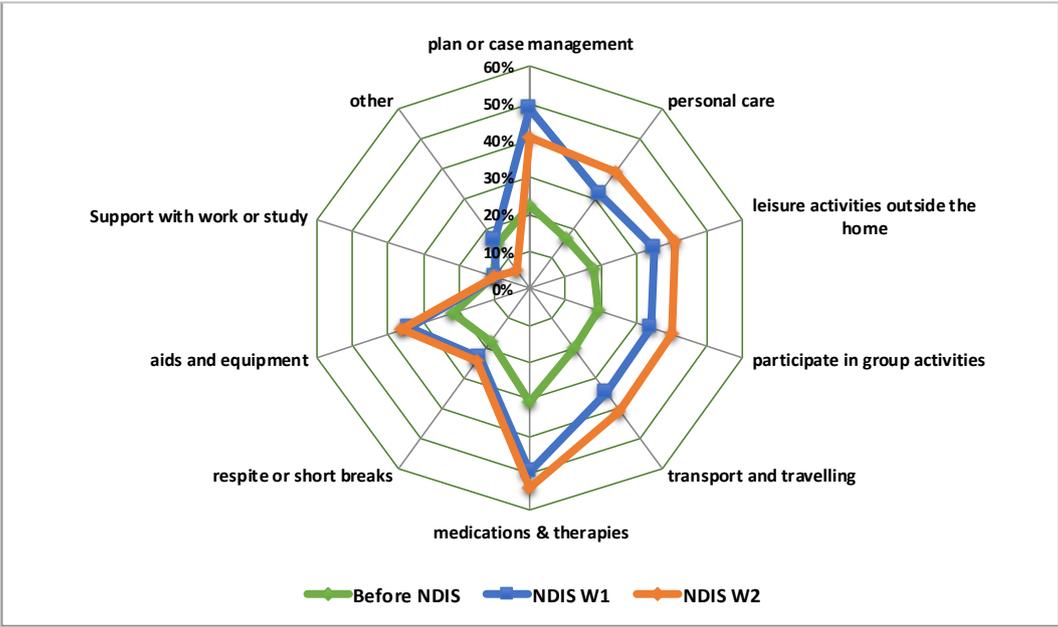
- At wave 1, 84.3 per cent of all NDIS participants aged eight years and older reported that they need assistance with daily activities (Appendix Table A2.1). The proportion reporting that they need assistance with daily activities changed little over the course of the evaluation.
- At both wave 1 and 2, the most frequently mentioned types of activity NDIS participants needed assistance with were help with doing things in the household (87.2 per cent & 87.3 per cent respectively) and help with preparing food and eating meals (74.7 per cent & 78 per cent respectively) (Appendix Table A2.2). In addition most of the other activities listed were frequently chosen. On average respondents mentioned 6.1 activities that they required assistance with in wave 1 and 6.3 activities in wave 2.
- An important aspect of support need and provision is how often this assistance is required (Appendix Table A2.3). In both waves, 85 per cent of NDIS participants needed assistance daily and 10 per cent needed assistance weekly. The remainder needed assistance less frequently or irregularly. The frequency with which support was required did not change over the course of the evaluation.
- Another important aspect of receiving support is the person who provides that support (Appendix Table A2.4). Those aged eight years and above who answered that they require assistance were then 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, a paid worker (disability support worker, personal attendant or nurse), friend, neighbour, voluntary worker or just 'someone else'. Respondents were allowed to choose more than one category. At the start of the NDIS (wave 1), mothers were the most frequent carers (75 per cent), followed by fathers (43 per cent), a paid workers (29 per cent), brothers and sisters (18 per cent), and grandparents (11 per cent).
- Wave 2 showed a small reduction in the proportion of mothers and grandparents (by -4 per cent and -3 per cent) providing assistance and an increase in paid care (by 7 per cent). This indicates a modest shift away from family care and towards paid care.

### 2.2.2 Have supports changed? – Evidence from large scale surveys

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 (Figure 2.1).

- After joining the NDIS, the range of supports accessed by participants widens. Indeed, before the NDIS 54 per cent of participants reported that they accessed only one type of support, with an average of 1.94 support types being accessed. Since participating in the NDIS, in wave 1 23 per cent of participants reported accessing only one type of support, 77 per cent accessing at least two types of support, and 58 per cent accessing at least three types. After joining the NDIS the average number of support types accessed is 3.23 (so that the total percentages in Figure 2.1 below add to more than 100).
- In wave 2, the range of supports accessed by participants widens further, with the average number of support types accessed being 5.78.

**Figure 2.1 Person with disability: Types of support received before and after joining the NDIS (Trial, All ages)**



- Figure 2.1 shows that the major change in the types of supports received by people with disability occurred once they became participants (between pre-NDIS and NDIS W1) with modest change following (between NDIS W1 and NDIS W2).
- With the exception of ‘support with work or study’ (applicable for participants 16 years 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. In the case of ‘plan or case management’, ‘transport and travelling’ and ‘leisure activities’ access had actually doubled as a result of the NDIS.
- Between wave 1 and 2, we see that with the exception of ‘support with work or study’, ‘plan or case management’, and ‘other support types’, the proportion of NDIS participants reporting access to each of the various types of disability support increased slightly or remained constant.

Early interventions are a critical aspect of the NDIS’ long-term planning and success.

- At wave 1, 29.7 per cent of NDIS participants received supports that were funded as part of an early intervention. However this decreased by wave 2 to 24.2 per cent (Appendix Table A2.5).

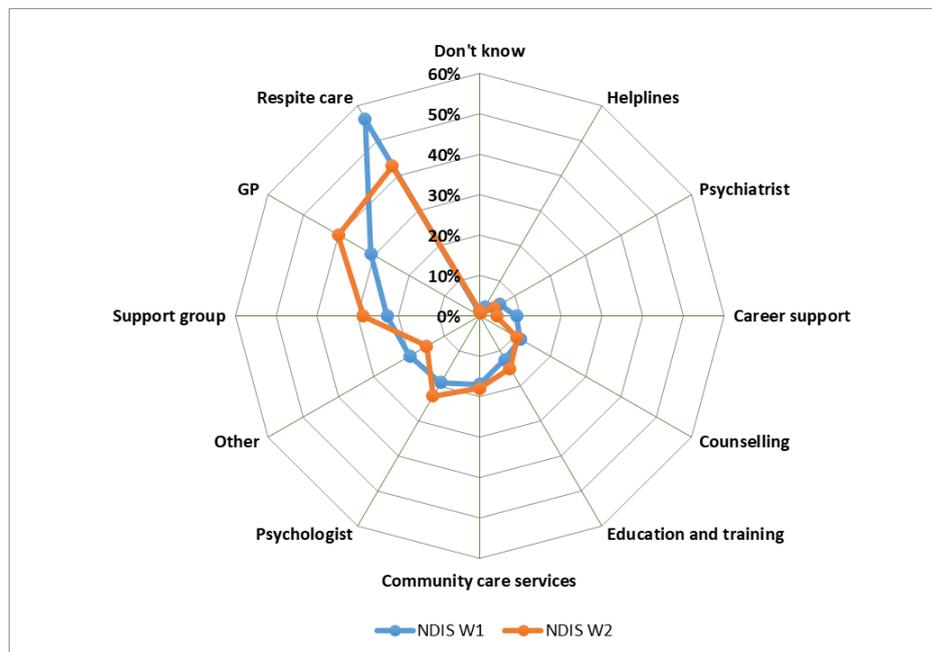
- Despite the fact that most NDIS participants reported accessing more of every type of support after joining the NDIS, only 39 per cent of NDIS participants changed provider between pre-NDIS and early NDIS (NDIS W1) and 32 per cent of NDIS participants changed providers between early NDIS (NDIS W1) and the repeat survey (NDIS W2) (Appendix Table A2.6).

### **2.2.3 Carers supporting and support for carers – Evidence from large scale surveys**

- Carers of people with disability play a key role in the life of people with disability. The NDIS evaluation is examining the impact of the NDIS on the support that carers provide directly and indirectly to people with disability and the supports they receive themselves in their carer role.
- Almost all of the carers (99 per cent) who were surveyed in both waves 1 and 2 reported that they provided emotional or practical support to a person with disability (Appendix Table A2.7).
- The quantitative data records the wide diversity of support activities provided by carers (Appendix Table A2.8). The low percentage in the support category ‘Something else’ indicates that the evaluation captured the key supports provided by carers to people with disability. Little change in the types of support provided by carers was found over the course of the evaluation.
- Understanding the intensity of support (both required and provided) is important, as it can impact on the overall and long-term capacity of carers to provide effective support (Appendix Table A2.9). The quantitative data finds that in wave 1 52 per cent of carers provided NDIS participants with support ‘24/7’, with another 19 per cent providing support for more than 35 hours per week; 17 per cent reported providing less than thirty-five hours of support per week and 12 per cent provided no information. Interestingly, in wave 2 the proportion of respondents providing support to participants 24/7 increased from 52 to 59 per cent.
- Crucial for the NDIS is that approximately 77 per cent of carers have been providing support to the person with disability since birth (Appendix Table A2.10), 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 24 per cent of carers in wave 1 reported that they themselves had a long-term health condition, impairment or disability that restricted their ability to undertake everyday activities (Appendix Table A2.11). This proportion increased to 27 per cent of carers in wave 2.
- The degree of control carers have over their own lives is of importance for understanding the impact of the NDIS on people with disability and their carers (Appendix Table A2.12). The quantitative data finds that roughly a quarter of the carers surveyed in both waves 1 and 2 indicated that they had a lot of control over how they spend their time, with 41-43 per cent indicating that they had some control, 27 per cent indicating that they had little control, and five-six per cent indicating that they had no control at all over how they spend their time. The proportion of participants in the most vulnerable categories (little or no control) remained unchanged during the evaluation period (from 32 per cent in wave 1 to 33 per cent in wave 2).
- Around a third of carers (33 per cent in wave 1 and 29 per cent in wave 2) reported that they have adequate daily or weekly breaks from providing support to NDIS participants. A similar proportion reported having less frequent breaks (30 per cent in wave 1 and 33 per cent in wave 2) and around another third of carers (30 per cent in wave 1 and 33 per cent in wave 2) reported that they are never able to take adequate breaks from providing support (Appendix Table A2.13).
- The quantitative data finds that 80 per cent of carers did not access any carer-specific supports in wave 1 (Appendix Table A2.14). The proportion of carers not accessing supports (in their role as a carer) increased to 86 per cent in wave 2.

- For those carers who did access some carer supports, the most frequently accessed supports in wave 1 were respite (56 per cent), GP supports (31 per cent) and taking part in support groups (23 per cent) (Appendix Table A2.15 and Figure 2.2). Twenty per cent of carers reported that they accessed ‘other’ supports, which suggests that there is a wide diversity of supports that matter to them. Carers accessed on average just over two supports each in wave 1.
- The proportion of carers accessing respite in wave 2 decreased substantially to 43 per cent. Our qualitative work suggests that the decrease in the numbers of people being able to access respite could reflect the unsettled use of the term ‘respite’ in the NDIS lexicon. The proportion accessing GP support increased considerably from 31 to 40 per cent, while those accessing support groups increased from 23 to 29 per cent.

**Figure 2.2 Carers: Which of these services have you used to help you as a carer in the last year? (Trial, All ages)**



- In wave 2, carers were asked to assess whether the amount of support they accessed in their capacity as a carer had increased, decreased or stayed the same (Appendix Table A2.16). Sixty per cent reported that carer supports had remained the same, 20 per cent indicated they had increased, while 13 per cent reported that they had declined.

#### **2.2.4 Is the NDIS changing the ability of carers to provide support? – Evidence from large scale surveys**

- In wave 1, 62 per cent of the carers surveyed stated that the NDIS had increased their ability to provide help, assistance or support to the person with disability that they care for (Appendix Table A2.17). A further 24 per cent reported that it made no difference to their ability to provide help and nine per cent reported that it had actually reduced their ability.
- Though once in the NDIS for some time (wave 2), further improvements in the ability to provide help, assistance or support were not apparent for many carers (61 per cent). Just under a quarter (23 per cent) reported an improvement in wave 2, while 14 per cent of carers reported a reduction in their ability to provide help, assistance or support.
- Table 2.18 explores change between waves 1 and 2. Those who report an increased ability to provide help, assistance or support between waves 1 and 2 are in the top right part of the table

above the diagonal, and those with a decreased ability are in the bottom left, below the diagonal. The diagonal running from the top left to the bottom right of the table, includes all those with no change. Change refers to the present against ‘about one year ago’ – and not exactly the time of the previous interview.

- We see that 16 per cent of those carers who in wave 1 said that the NDIS had previously increased their ability to provide care (that is, making a comparison between their pre-NDIS status and their early NDIS status in wave 1), reported a reduced ability to provide care in wave 2 (we note that this is making a comparison between their early NDIS with their later NDIS status).
- Overall, 56 per cent of carers report that the NDIS reduced their ability to provide care, 10 per cent report that the NDIS increased their ability to provide care and 34 per cent report no change.<sup>4</sup> Table 2.1 (and also Appendix Table A2.18) below shows the full detail of all individual transitions. For example, of all those who had reported that the transition between pre-NDIS and early NDIS made no difference to them, 11 per cent said that their ability was reduced between early (wave 1) and later (wave 2) NDIS, 69 per cent said there was no change and 21 per cent said there was an increase.

**Table 2.1 Carers: Transition in ability to provide help, assistance or support to person with disability - wave 1 and 2 evidence (Trial, All ages)**

| Wave 1<br>Level of ability to provide help or support |  | Wave 2<br>Level of ability to provide help or support |                    |            | Total       |
|---|--|---|--------------------|------------|-------------|
|   |  | Reduced   | Made no difference | Increased  |             |
| Reduced   |  | 21%   | 66%                | 13%        | 100%        |
| Made no difference                                    |  | 11%   | 69%                | 21%        | 100%        |
| Increased   |  | 16%   | 60%                | 24%        | 100%        |
| <b>Total</b>  |  | <b>15%</b>  | <b>63%</b>         | <b>22%</b> | <b>100%</b> |

Note that a very small number of wave 2 carers who responded to the survey are not the same carers who answered in wave 1 for the same person with disability. Excluding those carers who switched does not alter the reported proportions.

- In wave 1, 46.6 of all carers surveyed reported that the NDIS had reduced their anxiety about the future supports available to the person they care for (Table 2.2 and Appendix Table A2.19). 27 per cent reported that it made no difference, and 20.2 per cent reported increased levels of anxiety due to the introduction of the NDIS.
- Between wave 1 and 2, negative coverage about the fiscal position of the NDIS and its future sustainability increased in both general and specialised media. Wave 2 of the survey suggests that widespread concerns about the future sustainability of the NDIS were felt among carers, with 48 per cent of all carers reporting increased anxiety about future supports availability. Notably, 37.6 per cent indicated that their anxiety had stayed the same, while only 12 per cent indicated that it had decreased.

<sup>4</sup> As explained in the Introduction, reading these transition tables is not simple. To get this percentage we use the (not reported in the table) individual sample sizes to derive an overall percentage for the whole table, which shows, for example, that 56 per cent of the total went from ‘increased’ in wave 1 to either ‘made no difference’ or to ‘reduced’, or from ‘made no difference’ to ‘reduced’.

**Table 2.2 Carers: Level of anxiety about supports in the future for the person with disability by wave (Trial, All ages)**

| Level of carer anxiety | Wave 1       | Wave 1        | Wave 2     | Wave 2        |
|------------------------|--------------|---------------|------------|---------------|
|                        | Frequency    | Per cent      | Frequency  | Per cent      |
| Increased              | 501          | 20.23         | 436        | 47.96         |
| Made no difference     | 668          | 26.98         | 342        | 37.62         |
| Reduced                | 1,154        | 46.61         | 111        | 12.21         |
| Don't know/missing     | 153          | 6.18          | 20         | 2.20          |
| <b>Total</b>           | <b>2,476</b> | <b>100.00</b> | <b>909</b> | <b>100.00</b> |

Note: at wave 1 the reference point was 'Compared to before the NDIS', at wave 2 'Compared to last year'

- Table 2.3 (and Appendix Table A2.20) explores further the change that occurs between waves 1 and 2 in carers' anxiety. Those who report a reduced anxiety about supports for the person with disability between waves 1 and 2 are in the top right part of the table above the diagonal, and those with increased anxiety are in the bottom left, below the diagonal. The diagonal which runs from top left to bottom right, includes all those with no change. We see that 44 per cent of carers who said in wave 1 that their anxiety about future supports for the person with disability had reduced, reported in wave 2 that their anxiety had now increased.

**Table 2.3 Carers: Transition in level of anxiety about supports in the future for the person with disability - wave 1 and 2 evidence (Trial, All ages)**

| Wave 1<br>Level of carer anxiety | Wave 2<br>Level of carer anxiety |                    |            | Total       |
|----------------------------------|----------------------------------|--------------------|------------|-------------|
|                                  | Increased                        | Made no difference | Reduced    |             |
| Increased                        | 66%                              | 27%                | 7%         | 100%        |
| Made no difference               | 49%                              | 44%                | 7%         | 100%        |
| Reduced                          | 44%                              | 41%                | 15%        | 100%        |
| Total                            | <b>49%</b>                       | <b>39%</b>         | <b>11%</b> | <b>100%</b> |

Note: a very small number of wave 2 carers who responded to the survey are not the same carers who answered in wave 1 for the same person with disability. Excluding those carers who switched does not alter the reported proportions.

- Overall, 60 per cent of family members and carers report that their anxiety about future supports for the person with disability had increased, eight per cent report that their anxiety has decreased and 32 per cent report no change<sup>5</sup>.

## 2.2.5 What is in an NDIS plan? – Evidence from in-depth qualitative interviews

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 the plans of NDIS participants and how this has changed patterns and use of supports over time.

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<sup>5</sup> Using manual calculations from unreported frequencies

*The NDIS plan through the eyes of NDIS participants and their carers*

- Wave 1 interviews with NDIS participants and their 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 supports (including therapeutic support and social activities).
- In 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.

*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 originally 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 they were 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 in wave 2 as they did in 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 their plans 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 participants 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 and 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.
  - Therapy (psychology support, physiotherapy and speech therapy).
  - Personal care and support with independent living.
- In wave 2 funding for support coordination (including support to organise services and/or the financial management of plans) was more commonly included in plans.
- 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<sup>6</sup>.
- 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. Respondents seemed to believe that the NDIS could not afford the transportation element so it had been removed.
 

*For example, last year which was I suppose our first review, the transport costs were taken out of the plan and obviously when people have looked at that I assume after the first 12 months they realised that that was a fairly significant cost and they decided to, I won't say throw it back on the parents or the carers, but that's effectively what happened so that that wasn't available in the plan anymore. (A03C W2)*
- In wave 1, many carers of NDIS participants (particularly of young children) reported that their own needs and those 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.

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<sup>6</sup> Respite services as also funded by State and territory Governments and are not the sole responsibility of the Commonwealth.

- In 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. (D10C W2)*

- Of note, respondents also considered that items (such as complimentary movie and massage vouchers) that were 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 NDIS plan through the eyes of service providers and workforce stakeholder organisations*

- In wave 1, representatives from workforce stakeholder 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.
- In wave 2, these respondents 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 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 workforce stakeholder 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 being 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)*

- In wave 1, service providers reported introducing more flexible support arrangements, 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 NDIS progressed.
- 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. In response, 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.

*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)*

*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)*

- Wave 1 interviews with both disability service providers and workforce stakeholder organisations indicated, however, 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 in wave 2, with respondents reporting that 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 NDIS plan through the eyes of NDIA staff*

- NDIA staff reported positive changes for those participating in the NDIS and believed that the NDIS 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 NDIS, including participants with intellectual disability.

### **2.2.6 What do non-NDIS participants get? – Evidence from in-depth qualitative interviews**

#### *Disability supports and services through the eyes of people with disability not participating in the NDIS*

- Interviews with people with disability who were not participating in the NDIS indicated that one of the main reasons for choosing not to join the NDIS at all or withdrawing from the NDIS was dissatisfaction with the level of supports available to them under the NDIS and the belief that they would be worse off. This will be discussed in greater detail in chapter 5.
- Non-NDIS participants continued to access both free and fee for service disability supports outside of the NDIS, though respondents were aware that interim funding arrangements were time limited.
- Many reported that the NDIS had negatively impacted, or was expected to have a negative impact, on services and supports due to cost increases to be passed on by service providers. Others reported needing to pay for previously free services or gave examples of reduced availability of services to non-NDIS participants:

*Like I understand before there was--there was like the psychosocial rehabilitation program that I go to they had--they offered all sorts of--they used to, and they still do, offer workshops in, I don't know, being more assertive, managing money, getting ready for Christmas, communication skills. All those things were all offered, they were funded and now those things are offered more to NDIS participants. So you have to pay for them. (C03 NP)*

*I phoned up [name of provider of home help service] services to get the new path done in concrete and... the woman I spoke to said, 'But oh no, we can't help you anymore. You have to be a member of the NDIS'. (C04 NP)*

- Several non-participants noted indirect changes to their situations as a consequence of the NDIS, including perceptions that services had become less flexible as organisations moved to a 'business model'.

## **2.3 Quality of Services and Supports**

### **2.3.1 Satisfaction with the quality of supports – Evidence from large scale surveys**

The NDIS Survey collects detailed information on the satisfaction of respondents with several aspects of the quality of the supports they receive under the NDIS.

- At the start of their NDIS experience, a similar proportion of NDIS participants reported that the quality of the supports they received under the NDIS was either better (43 per cent) or had not changed (43 per cent) compared to the quality of supports they received prior to the NDIS (Appendix Table A2.21). However 13.5 per cent of all participants felt that the quality of their supports had become worse.
- The level of satisfaction with quality of supports was high throughout the evaluation period (75 per cent were very satisfied/satisfied in wave 1 and 74 per cent in wave 2). At the low end of the satisfaction spectrum, eight per cent of people with disability were dissatisfied or very dissatisfied with their supports in wave 1 compared with nine per cent in wave 2 (Appendix Table A2.22).
- Eighty-five per cent of NDIS participants also felt confident with the quality of care provided by their current disability support providers (Appendix Table A2.23). In wave 2, only a very small proportion (6 per cent) had concerns over the quality of care provided by their disability support providers.
- The quantitative data provides direct findings about the views of carers regarding the impact of the NDIS on the quality of supports accessed by the person they care for (Appendix Table A2.24). Specifically, the evaluation finds a very high level of satisfaction about the quality of these supports. In wave 1, 82.7 per cent of carers were either somewhat satisfied (35.3 per cent) or very satisfied (47.5 per cent) with the quality of supports received by the NDIS participants for whom they cared. This did not change over time, with a similar proportion of carers reporting high level of satisfaction with the quality of supports in wave 2 (80 per cent). It should be noted, however, that the proportion of carers who were very satisfied with the quality of supports reduced from 47.5 per cent in wave 1 to 39.6 per cent in wave 2.
- Table 2.4 (and Appendix Table A2.25) explores change between wave 1 and 2 in carer satisfaction with the quality of supports accessed by the NDIS participants for whom they care, with increased satisfaction in the top right of the table, above the diagonal and decreased satisfaction found below the diagonal in the bottom left of the table. The diagonal running from top left to bottom right is where there is no change.

**Table 2.4 Carers: Transition in level of satisfaction with the quality of supports of the person with disability - wave 1 and 2 evidence (Trial, All ages)**

| Wave 1<br>Level of satisfaction       | Wave 2<br>Level of satisfaction |              |  |            |                   | Total       |
|---------------------------------------|---------------------------------|--------------|--|------------|-------------------|-------------|
|                                       | Very<br>dissatisfied            | Dissatisfied | Neither<br>dissatisfied<br>nor satisfied | Satisfied  | Very<br>satisfied |             |
| Very dissatisfied                     | 5%                              | 21%          | 16%                                      | 42%        | 16%               | 100%        |
| Dissatisfied                          | 4%                              | 12%          | 20%                                      | 49%        | 16%               | 100%        |
| Neither satisfied nor<br>dissatisfied | 2%                              | 13%          | 20%                                      | 37%        | 28%               | 100%        |
| Satisfied                             | 0%                              | 6%           | 12%                                      | 53%        | 28%               | 100%        |
| Very satisfied                        | 0%                              | 3%           | 3%                                       | 36%        | 58%               | 100%        |
| <b>Total</b>                          | <b>1%</b>                       | <b>6%</b>    | <b>9%</b>                                | <b>43%</b> | <b>42%</b>        | <b>100%</b> |

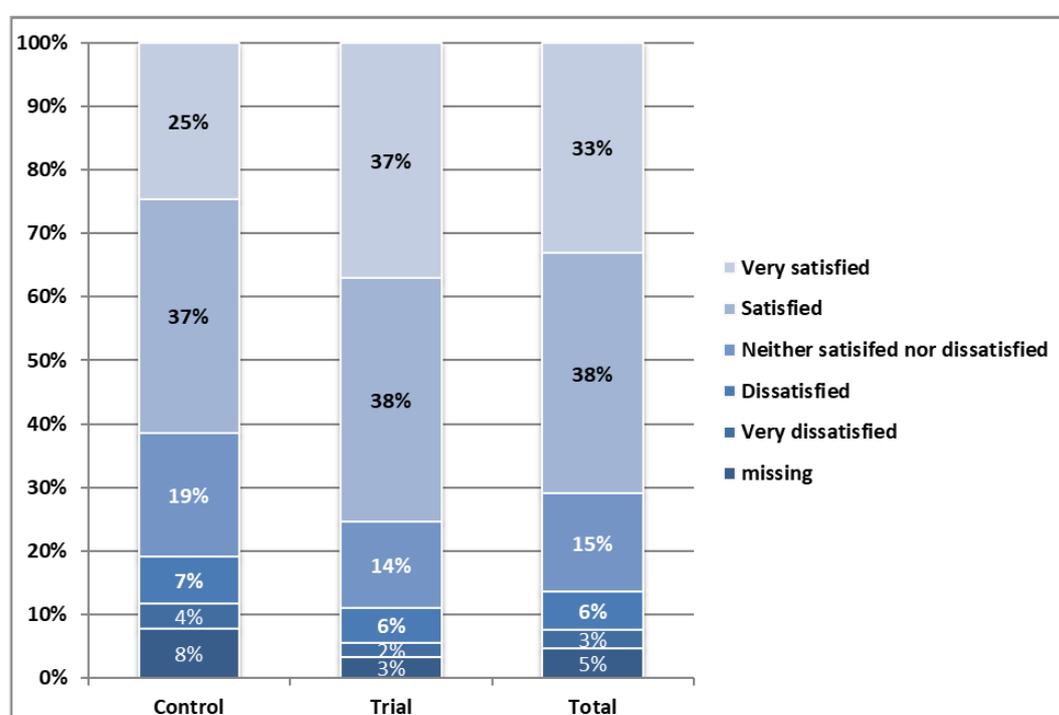
Note that a very small number of wave 2 carers who responded to the survey are not the same carers who answered in wave 1 for the same person with disability. Excluding those carers who switched does not alter the reported proportions.

- We see that nearly half (42 per cent and 49 per cent) of carers who in wave 1 said that they were very dissatisfied or dissatisfied with the quality of supports, reported in wave 2 that they are satisfied.
- Overall, 30 per cent of carers reported that the quality of supports had decreased, 21 per cent reported that the quality of supports had increased and 50 per cent reported no change<sup>7</sup>.

### 2.3.2 The impact of the NDIS on satisfaction with the quality of supports – Evidence from large scale surveys

The data on satisfaction with the quality of supports currently accessed is collected in the form of a five-category Likert scale. Figure 2.3 below presents the results of those located in the NDIS trial and those in the comparison group. It shows that differences between trial and comparison groups are concentrated at the two tails of the satisfaction distribution (the top satisfaction category and the bottom two satisfaction categories) suggesting considerably higher satisfaction levels among the NDIS participants.

**Figure 2.3 Person with disability: Satisfaction with the quality of supports (Comparison and Trial)**



Using these data we estimated the impact of the NDIS on satisfaction with the quality of supports with the following main findings:

- On average, NDIS participants were 33 per cent more likely to report that they are very satisfied with the quality of their support compared to what they would have reported had they not been rolled out into the NDIS.
- Important differences in satisfaction by disability type were also found. NDIS participants with mental/psychosocial disabilities report lower levels of satisfaction with the quality of their supports compared to NDIS participants with other types of disabilities.

<sup>7</sup> Using manual calculations from unreported frequencies.

- In addition, a significant proportion of NDIS participants with a mental disability experience a worse outcome in terms of support quality than they would have had without the NDIS.
- No significant differences by geographical location (rural versus urban) were found with regards to the impact of the NDIS on quality of supports.

*Is the NDIS improving the quality of supports? What people with disability think?*

After we account for the differences between the characteristics of the comparison group and the trial group, the impact of the NDIS on the quality of supports was estimated to be positive and statistically significant.

- When comparing the two top categories of being 'very satisfied' or 'satisfied' against all lower satisfaction categories, being in the NDIS increases the probability of being satisfied by 6.3 percentage points (with 95 per cent confidence intervals between 0.01 and 0.11). When comparing only the top category of being 'very satisfied' against all lower satisfaction categories, being in the NDIS increases the probability of being satisfied by 9.3 percentage points (95 per cent confidence intervals 0.04 to 0.15).

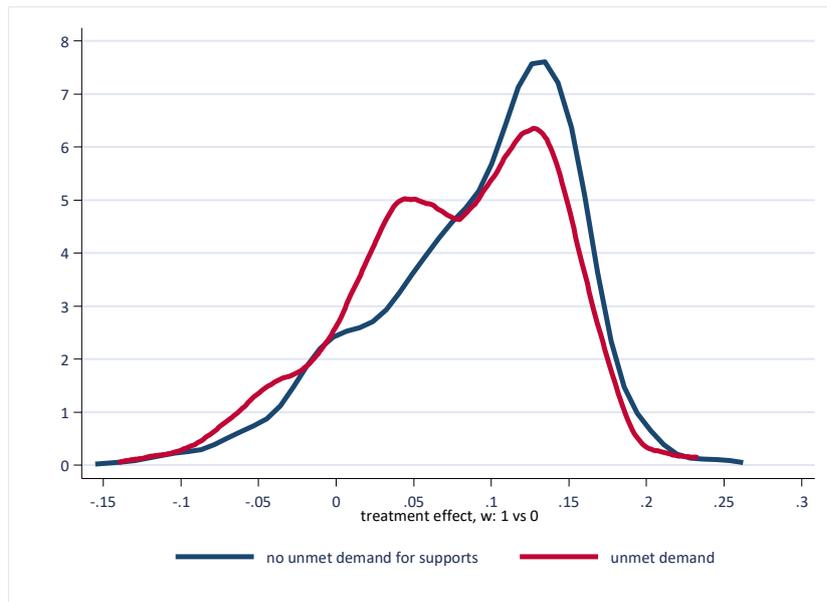
**NDIS participation increased satisfaction with quality of supports by approximately 6.3 to 9.3 percentage points**

- Using the least restrictive definition of satisfaction with the quality of supports (i.e. pooling both of the categories 'very satisfied' and 'satisfied' together) the difference between trial and comparison group is 11.3 percentage points. As described above, our analyses suggest that out of the 11.3 percentage points, 6.3 percentage points can be attributed to the impact of the NDIS and the remaining five percentage points can be attributed to the observed differences between the NDIS participants and the comparison group.
- Similarly, when we use the more restrictive definition of being satisfied with the quality of supports (only those who responded to be 'very satisfied') the difference between trial and comparison group is 11.7 percentage points. Of this, 9.3 percentage points can be attributed to the impact of the NDIS and the remaining 2.4 percentage points can be attributed to the observed differences between the NDIS participants and the comparison group. We note that the confidence intervals of the 6.3 and 9.3 percentage points estimates are overlapping but in both cases are above zero. Tables A2.26 and A2.27 in the Appendix show the detail of these estimation results.

The survey asked people with disability if they have experienced any unmet demand for supports, that is, supports that are in their approved plan, but they cannot access.

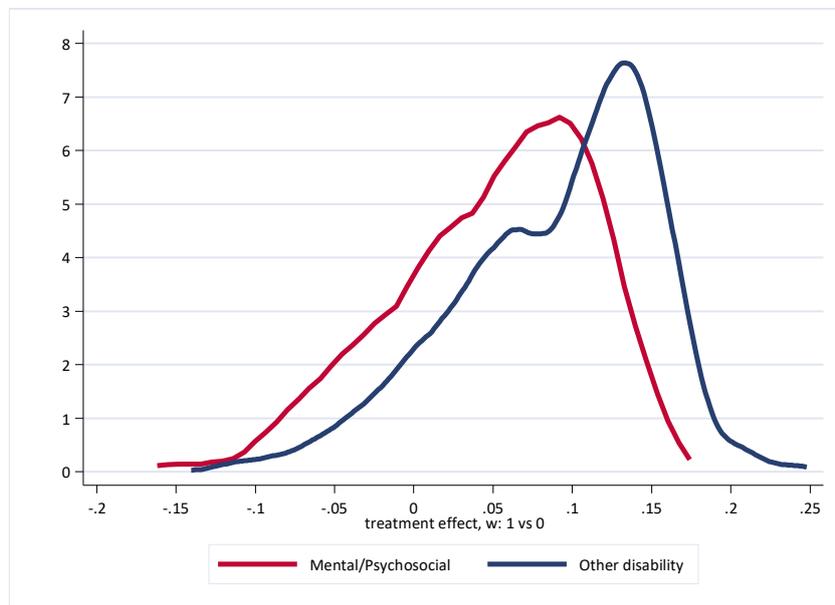
- Figure 2.4 shows how satisfaction with the quality of supports differs between those who have experienced unmet demand and those who have not. It is clear that those who experienced unmet demand were also less satisfied with the quality of the supports they actually received, indicating that these two problems are associated.

**Figure 2.4 Person with disability: Distribution of the impact of the NDIS on the satisfaction with the quality of supports by occurrence of unmet demand for supports (Trial, Adults)**



- The degree to which satisfaction with support quality was compared for people with mental/psychosocial disabilities and people with other types of disability. Figure 2.5 shows that the benefits from the NDIS are smaller for NDIS participants with mental/psychosocial disabilities, indicating that the NDIS is less able to deliver supports of satisfactory quality to people with mental/psychosocial disability than to people with other disabilities.

**Figure 2.5 Person with disability: Distribution of the impact of the NDIS on the satisfaction with the quality of supports - -mental/psychosocial disability vs. other disability types (Trial, Adults)**

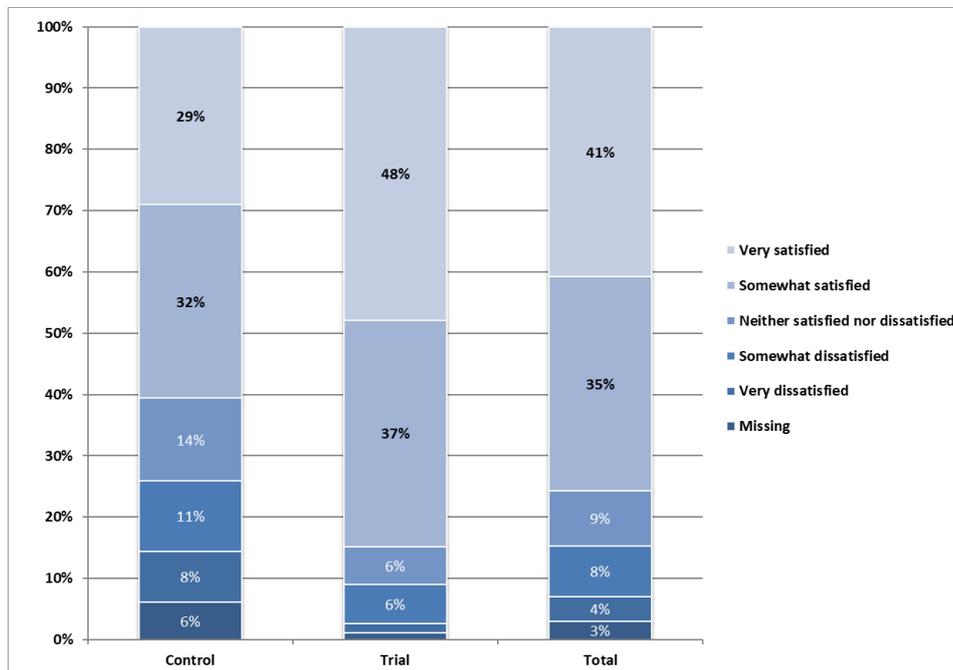


*Is the NDIS improving the quality of supports? What carers think*

- Similar questions for satisfaction with disability supports were asked of carers about the supports received by those who they care for. Figure 2.6 shows the raw data on satisfaction with quality of supports for carers in the NDIS trial (2) and the comparison (1) areas. Carers report higher

satisfaction with the quality of supports when the person with disability they care for is in the NDIS, compared to those living in comparison areas.

**Figure 2.6 Carers: Carers' satisfaction with the quality of current disability supports**



- However, estimations using a binary definition of satisfaction with the quality of supports ('very satisfied' or not) revealed a different picture. Accounting for all observed differences in the characteristics of the trial and comparison carers, satisfaction is not statistically different between the two groups of carers for adult participants and only marginally significant for child participants. The detailed results are in Tables A2.28 and A2.29 in the Appendix.
- Our estimations then used the Likert scale for satisfaction as a linear variable that takes the values of one to five in order to bring in to play the lower values of satisfaction, which appear to be considerably more frequent in the comparison group (33.2 per cent) than in the trial group (14 per cent).
- Whereas estimation using the binary definition of satisfaction ('very satisfied' or not) did not reveal any statistically significant impact of the NDIS on the satisfaction of carers, the use of the continuous form of the Likert scale suggests that the NDIS impacts positively on carers of adults (10 per cent more likely – 95 per cent confidence interval 6-14 per cent) and those of children (12 per cent more likely – 95 per cent confidence interval 8-16 per cent). The detailed estimation results are in Tables A2.30 and A2.31 in the Appendix.

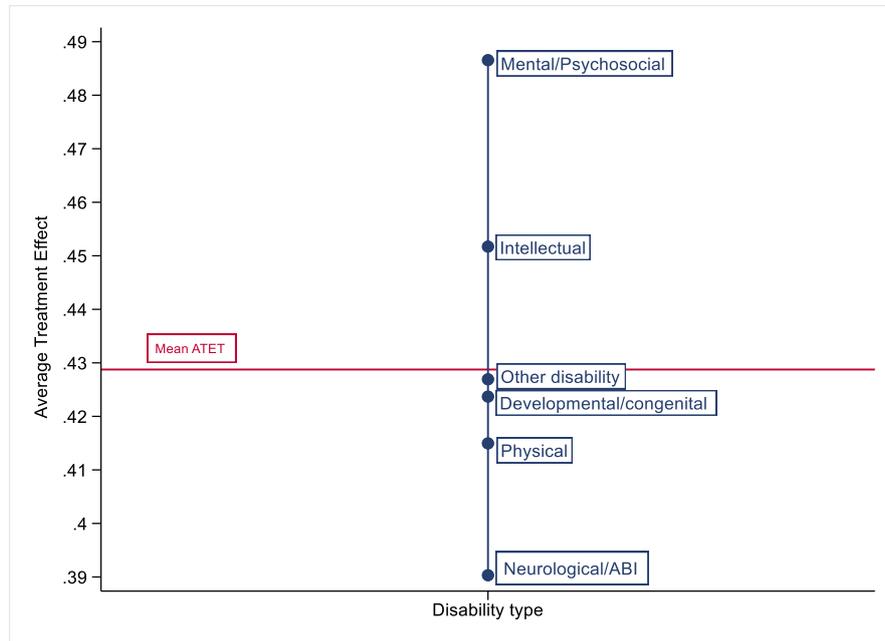
**NDIS participation increased the satisfaction of carers with the quality of supports received by the people they care for by approximately 10 per cent for adults and 12 per cent for children. The impact is more likely to be concentrated on those with lowest satisfaction levels.**

Figure 2.7 presents the estimated impact in satisfaction with the quality of supports by the disability type of the person with disability (as reported by carers).

- Those caring for a person with a mental/psychosocial disability reported the highest satisfaction with quality of supports; those caring for a people with a neurological disability had the lowest

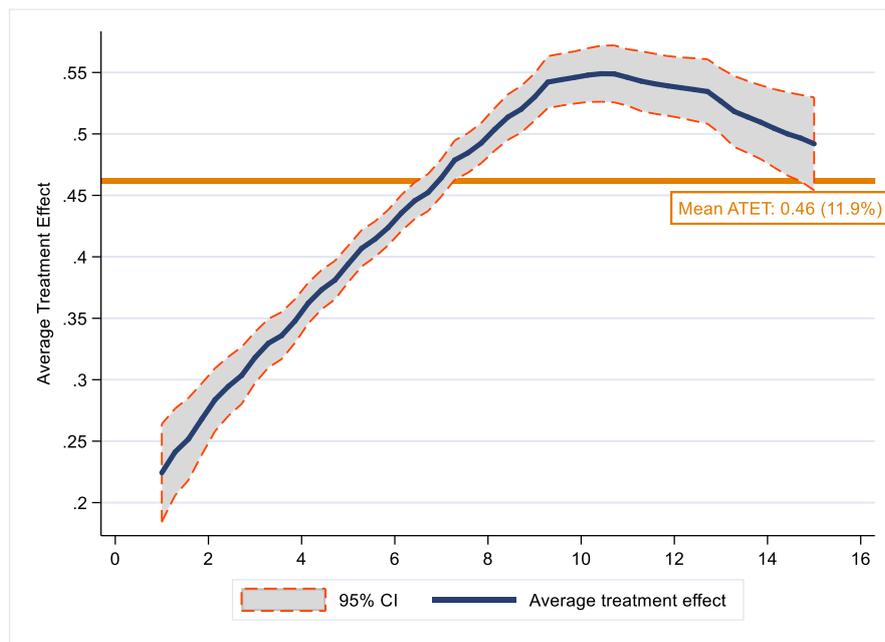
levels of satisfaction. However, as these differences are not statistically significant, the result should be taken as tentative (see Appendix Figure A2.1).

**Figure 2.7 Carers: Estimated impact of the NDIS on the satisfaction with the quality of supports by disability type**



- Age was found to be an important factor regarding the impact of the NDIS on satisfaction with the quality of supports children are receiving. The distribution of impacts by age is presented in Figure 2.8 below.

**Figure 2.8 Carers: Distribution of the estimated impact of the NDIS on the satisfaction with supports of children with disability (Age 0 – 15)**



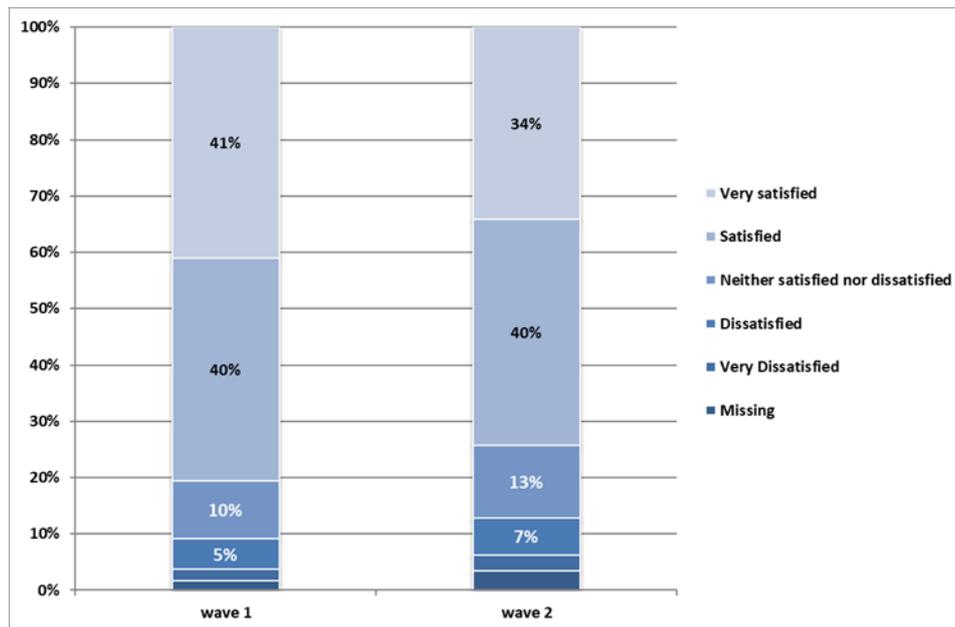
- Satisfaction with the quality of supports due to the NDIS is greater for carers with older children (with levels of satisfaction peaking at around 9 years of age).

### 2.3.3 Has satisfaction with quality of supports has changed overtime? – Evidence from large scale surveys

The next section examines how satisfaction with the quality of supports changed over time between wave 1 and 2 surveys for each individual.

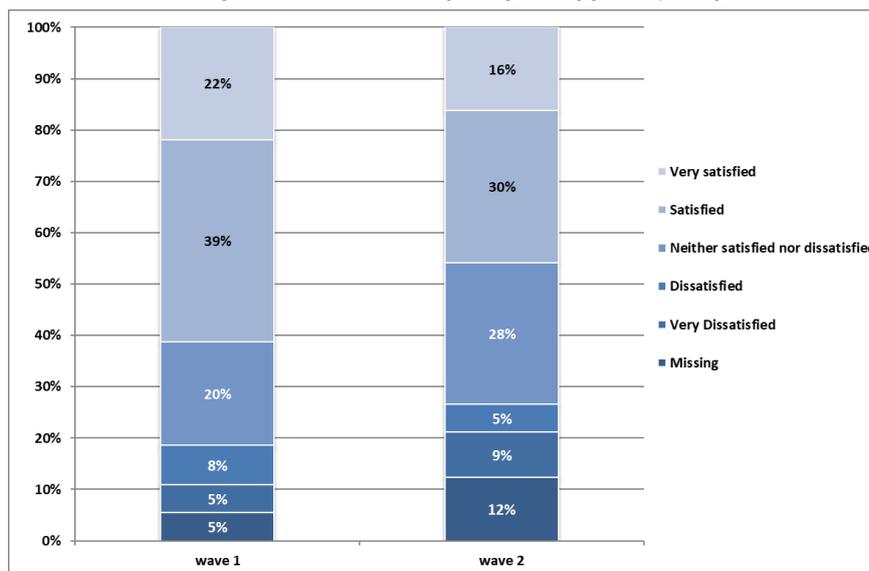
- Figure 2.9 compares the responses of NDIS participants in the trial areas between their early NDIS experiences (wave 1) and their later NDIS experiences (wave 2).

**Figure 2.9 Person with disability: Satisfaction with quality of supports (Trial – waves 1 and 2)**



- Satisfaction with the quality of supports reduced with length of time in the NDIS. The proportion of NDIS participants who were ‘very satisfied’ or ‘satisfied’ with the quality of their supports decreased from 81 to 74 per cent, while the proportion who were ‘dissatisfied’ or ‘very dissatisfied’ increased from seven to 10 per cent. We note however the very high levels of satisfaction among the NDIS participants.
- Figure 2.10 presents the same statistics for the comparison group, who were not NDIS participants at the time of the surveys. This group also show a decrease in satisfaction over the quality of their supports. However, satisfaction levels for the comparison group were lower in wave 1 and decreased more between wave 1 and 2 than in the trial group.
- The reduction in satisfaction for the trial group between wave 1 and 2 could be attributed to the direct impact of the NDIS on participants. The comparison group’s reduced satisfaction originates largely from people who were either ‘satisfied’ or ‘very satisfied’ in wave 1 and then reported being ‘neither satisfied nor dissatisfied’ in wave 2. This could be a consequence of either their support quality deteriorating in the context of the national change in the supports market (i.e. a supply of supports cause), or a change in their perception of what is acceptable quality. One could speculate that this is due to higher expectations generated by the NDIS nationally (i.e. a demand for supports cause).

**Figure 2.10 Person with disability: Satisfaction with quality of supports (Comparison – waves 1 and 2)**



- To investigate exactly how changes in the level of satisfaction with the quality of supports occurred, movements between each satisfaction category in the transition from wave 1 to wave 2 are presented in Tables 2.32 and Table 2.33. These two tables should be read as previous transition tables where satisfaction increase is in the top right of the table, decrease in the bottom left and no change is in the diagonal from the top left to bottom right in the table. For example, 50 per cent of people with disability in the trial group were satisfied with their support in both waves 1 and wave 2.
- The total of movements within the trial group (Table 2.5 and Appendix Table A2.32) show that three per cent became 'very dissatisfied', seven per cent became 'dissatisfied', 12 per cent became 'neither satisfied nor dissatisfied', 42 per cent became 'satisfied' and 37 per cent became 'very satisfied'.

**Table 2.5 Person with disability: Transitions between levels of satisfaction with quality of supports by category - wave 1 and 2 evidence (Trial, Adults)**

| Wave 1<br>Level of satisfaction       | Wave 2<br>Level of satisfaction |              |  |            |                   | Total       |
|---------------------------------------|---------------------------------|--------------|--|------------|-------------------|-------------|
|                                       | Very<br>dissatisfied            | Dissatisfied | Neither<br>satisfied nor<br>dissatisfied | Satisfied  | Very<br>satisfied |             |
| Very dissatisfied                     | 0%                              | 20%          | 30%                                      | 30%        | 20%               | 100%        |
| Dissatisfied                          | 7%                              | 10%          | 17%                                      | 37%        | 30%               | 100%        |
| Neither satisfied nor<br>dissatisfied | 4%                              | 4%           | 27%                                      | 47%        | 18%               | 100%        |
| Satisfied                             | 4%                              | 6%           | 12%                                      | 50%        | 28%               | 100%        |
| Very satisfied                        | 1%                              | 7%           | 7%                                       | 33%        | 52%               | 100%        |
| <b>Total</b>                          | <b>3%</b>                       | <b>7%</b>    | <b>12%</b>                               | <b>42%</b> | <b>37%</b>        | <b>100%</b> |

- Overall 24 per cent of NDIS participants reported improvement in the quality of supports between wave 1 and 2, 46 per cent reported no change, while nearly a third (30 per cent) of NDIS participants reported that the quality of support had declined<sup>8</sup>.
- Similarly, the movements within the comparison group in Table 2.6 (and Appendix Table A2.33) show that seven per cent became 'very dissatisfied', seven per cent became 'dissatisfied', 27 per cent became 'neither satisfied nor dissatisfied', 36 per cent became 'satisfied' and 23 per cent became 'very satisfied'.

**Table 2.6 Person with disability: Transitions between levels of satisfaction with quality of supports by category - wave 1 and 2 evidence (Comparison, Adults)**

| Wave 1<br>Level of satisfaction       | Wave 2<br>Level of satisfaction |              |  |            |                   | Total       |
|---------------------------------------|---------------------------------|--------------|--|------------|-------------------|-------------|
|                                       | Very<br>dissatisfied            | Dissatisfied | Neither<br>satisfied nor<br>dissatisfied | Satisfied  | Very<br>satisfied |             |
| Very dissatisfied                     | 40%                             | 40%          | 20%                                      | 0%         | 0%                | 100%        |
| Dissatisfied                          | 18%                             | 0%           | 27%                                      | 36%        | 18%               | 100%        |
| Neither satisfied nor<br>dissatisfied | 13%                             | 9%           | 57%                                      | 17%        | 4%                | 100%        |
| Satisfied                             | 0%                              | 8%           | 21%                                      | 45%        | 26%               | 100%        |
| Very satisfied                        | 0%                              | 0%           | 10%                                      | 43%        | 48%               | 100%        |
| <b>Total</b>                          | <b>7%</b>                       | <b>7%</b>    | <b>27%</b>                               | <b>36%</b> | <b>23%</b>        | <b>100%</b> |

Satisfaction with quality of supports is considerably higher among NDIS participants than non-NDIS participants. Satisfaction has been increasing moderately for NDIS participants and declining substantially for the comparison group.

### **2.3.4 Satisfaction with the quality of supports – Evidence from in-depth qualitative interviews**

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.

*Satisfaction with quality of supports through the eyes of NDIS participants and their family members or carer*

- Generally, NDIS participants and their carers were satisfied with the quality of the services they were receiving as part of their NDIS package. Respondents noted that services were becoming more responsive to participant needs, and more flexible in their service delivery.

*We know what we're getting. We're quite happy with [Residential Service] quality of service. (E06 PWD&C)*

*Look, I'm extremely happy with our service providers. I'm extremely grateful that we have the funding to go to [Provider] and that we have... them in place to get to where we need to go. (D14C)*

<sup>8</sup> Using manual calculations from unreported frequencies.

- However, respondents also raised concerns about the quality of disability services and staff.
- Respondents reported the provision of services could be unreliable, i.e. support workers who do not arrive on time or at all, or there being no continuity of support workers on different occasion of care.
- Respondents also questioned the quality of the support workers who were referred to them, and the lack of specialised disability specific training. Others expressed considerable concern about general standard of agency provided workers.

*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 it 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. (B02 PWD W2)*

*We're actually finding we're having a lot of problems with agency based care and this is the thing... they're saying use the agencies, but... you lose all freedom. You're getting sent people who you wonder how they've got the job at times... It looks almost like they're just getting the lowest common denominator coming in because they're desperate for workers at time. (C03C W2)*

- The quality of NDIA staff was also questioned with many respondents reporting that planners did not understand the specific needs and supports required for particular disability types.

*I didn't feel that the NDIS understands mental illness still, that they've got a long way to go...it pisses me off, I feel like ... you're not hearing what my needs are for when I'm, nearly, acutely unwell. (B08 PWD W2)*

- Respondents suggested a number of reasons for their concern about the quality of the disability workforce, such as low wages and high staff turnover.
- The development and satisfaction of the relationship with support workers influenced participants and families' perceptions of service quality.

*He ended up with a really good support worker through [Name of provider], who he still has and she's very cruisy. She's more my age, she's older but she's very calm and she's nice to talk to and she gets on well with David and that's really important. (E01 PWD&C W2 W2)*

- 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)*

*Satisfaction with quality of supports through the eyes of people with disability not participating in the NDIS*

- Interviews with non-NDIS participants did not indicate any changes in the quality of disability services. However, the cultural change for organisations, in moving to a business model, was thought to have reduced the flexibility of services to some extent (for example, restricting opportunities for incidental communications with service providers and formalising arrangements around non-attendance).

*Satisfaction with quality of supports through the eyes of service provider and workforce stakeholder organisations*

- 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.

*Well I suppose price is a big concern because it'll drive quality in the long run and it drives the quality of staff, quality of what we can provide. (B01S W2)*

- NDIA pricing did not provide funding for the training of staff which was reported to undermine workforce quality.

*The industrial laws don't match the unit price. And I think that's important when you're talking about the qualified workforce... How do you maintain a qualified workforce that's trained, up to speed, within that unit price? (E01S W2)*

*Satisfaction with quality of supports through the eyes of 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 who could be hired by NDIS participants who were self-managing their funding.

*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)*

## **2.4 Unmet Demand for Services and Support**

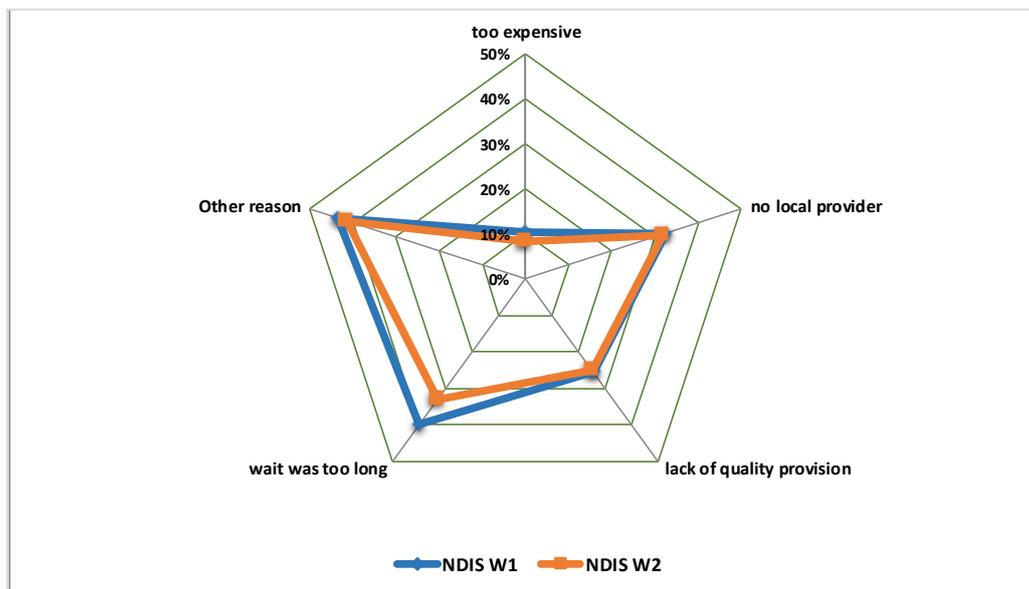
### **2.4.1 How has supply responded to demand? – Evidence from large scale surveys**

The quantitative data includes specific measures of unmet demand and these can be used to assess the extent to which the supply of disability services has responded to changes in demand brought by the introduction of the NDIS.

- In wave 1, 32 per cent of NDIS participants reported that they could not access some of the supports for which they had funding under the NDIS (Appendix Table A2.34). In contrast, only six per cent of people with disability who were not part of the NDIS trial reported they were unable to access funded supports.

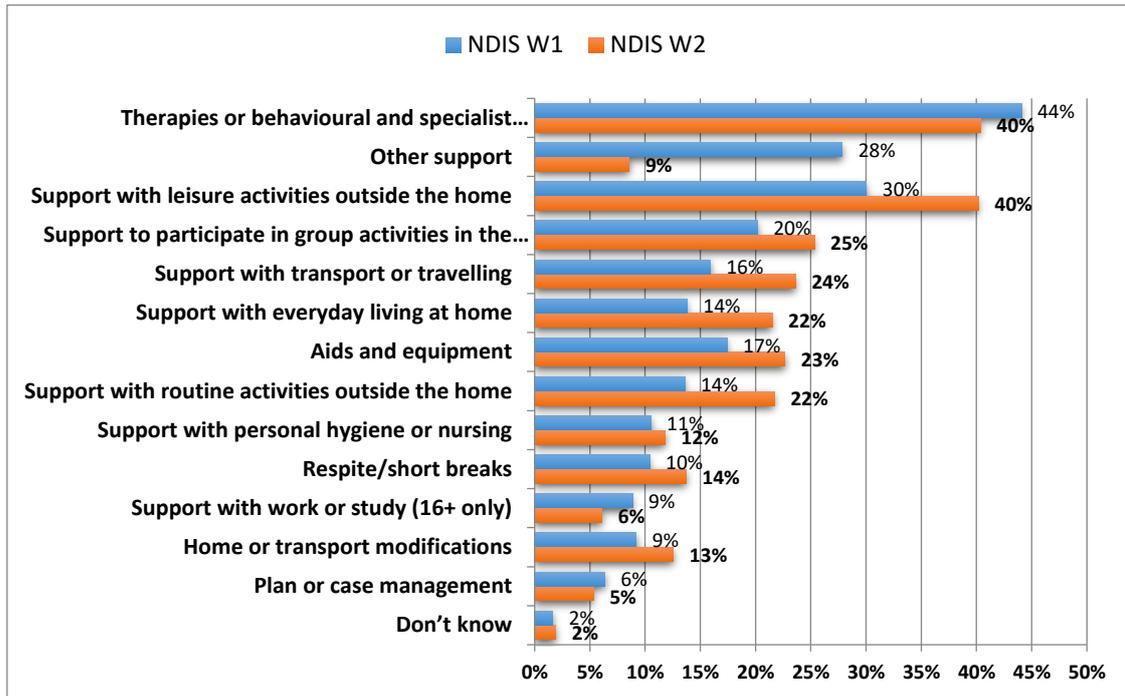
- The incidence of unmet demand did not decrease overtime. In wave 2, a similar proportion of both NDIS participants (33 per cent) and people with disability who were not part of the NDIS (7 per cent) reported that they could not access some of the supports for which they had funding.
- The reasons why some people with disability could not access their funded supports are presented in Figure 2.11 below for both waves 1 and 2. Most NDIS participants report that it was due to wait times or a lack of a local provider (33 per cent in wave 1 and 32 per cent in wave 2). About a quarter (26 per cent in both waves) reported that an inability to access funded supports was due to the lack of quality of the available provision. Only a small proportion (10 per cent in wave 1 and 8 per cent in wave 2) reported they could not access their supports because they were too expensive.
- We note that the category ‘other reason’ in Figure 2.11 is very widely populated (around 40 per cent of all answers in both waves), 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. Further explanation of the reasons for unmet demand is provided in the qualitative findings that follow.

**Figure 2.11 Person with disability: Reason why support for which there is funding, could not be accessed (Trial, All ages)**



- In wave 1, 26 per cent of all NDIS participants accessed supports not funded through the NDIS. In wave 2 the proportion of NDIS participants accessing supports not funded through the NDIS had increased considerably to 39 per cent (Appendix Table A2.35).
- The most frequently reported non-NDIS funded supports accessed by NDIS participants in wave 1 were therapies or behaviour and specialist interventions (44 per cent of all NDIS participants who accessed non-NDIS funded supports) and support with leisure activities outside the home (30 per cent) (Figure 2.12).
- With the exception of therapies or behaviour and specialist interventions, support with work or study, and plan or case management, wave 2 saw an increase in the proportion of NDIS participants who reported accessing each type of listed supports not funded by the NDIS.

**Figure 2.12 Person with disability: Types of supports accessed, not funded through the NDIS (Trial, All ages)**



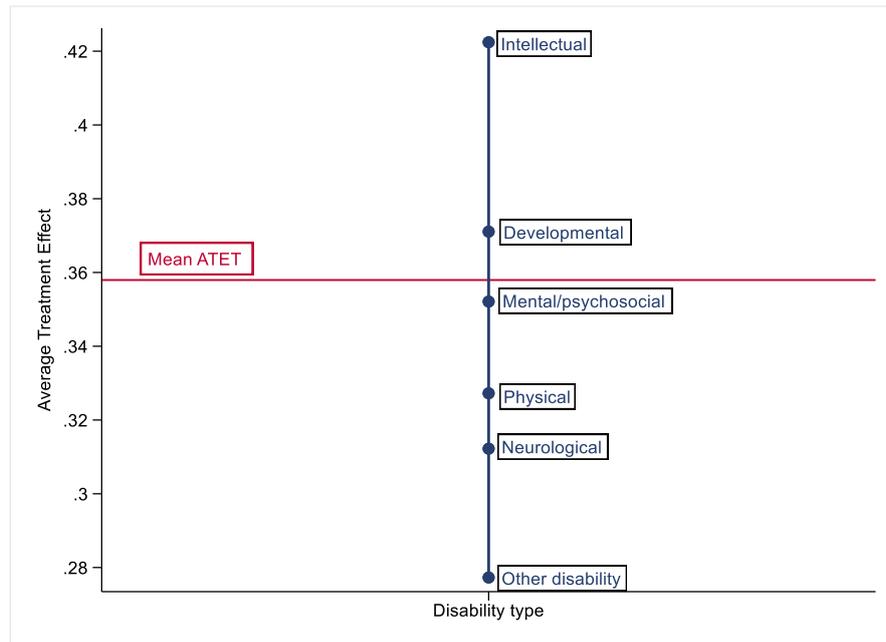
- The most frequently reported method by which NDIS participants accessed non-NDIS funded supports (Appendix Table A2.36), was either to rely on family members to pay for the supports (52 per cent of responses in wave 1 and 59 per cent in wave 2), or to pay for the supports themselves.
- A higher proportion of NDIS participants paid to access non-funded supports themselves in wave 2 than in wave 1 (36 per cent compared to 24 per cent).

#### **2.4.2 Who is more likely to experience unmet demand? – Evidence from large scale surveys**

Multivariate analysis was used in order to investigate further the issue of unmet demand for supports experienced by NDIS participants. The multivariate evidence focuses on the NDIS participants and estimates the determinants of unmet demand so as to ‘profile’ the types of NDIS participants who are more at risk of experiencing unmet demand for supports (Appendix Table A2.37). The question we ask is whether people sharing the experience of unmet demand under the NDIS have any clear identifying characteristics or other circumstances that we could use in order to reduce unmet demand. As the first wave of data collection was spread over a period of more than a year we have estimated the difference between the early, mid-way and late wave one survey participants.

- The later NDIS participants were found to be more likely to experience unmet demand (14 per cent higher probability than those joining in the early roll-out of the NDIS). In addition, children aged seven-15 years were about 7.5 per cent more likely to experience unmet demand than their adult counterparts. NDIS participants with an intellectual disability were more likely to experience unmet demand than people with other disability types.

**Figure 2.13 Person with disability: Estimated probability to experience unmet demand by disability type, (Trial, All ages)**



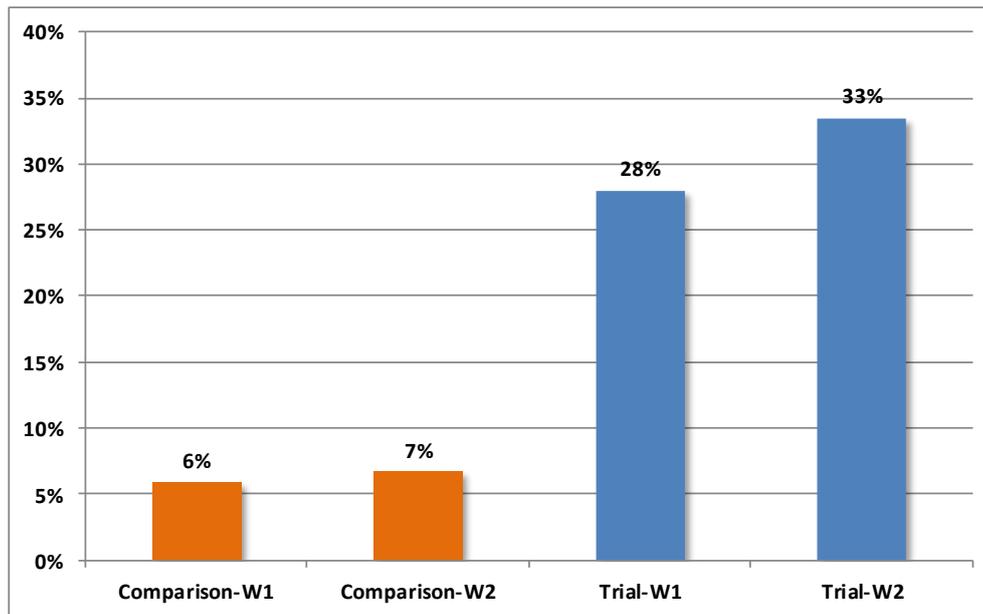
Note: Based on Table A7 regressions

- NDIS participants with a mental/psychosocial disability are more likely to experience unmet demand at the initial phase of their roll-out but as they ease into the NDIS, it appears that their probability of unmet demand decreases with time.
- In contrast, NDIS participants with an intellectual or developmental disability become more likely to experience unmet demand as the time they spend in the NDIS increases (figures A2.4 and A2.5 in Appendix). Finally, male NDIS participants are less likely to experience unmet demand as are NDIS participants who live in a household with a higher income.

### 2.4.3 Has unmet demand changed overtime – Evidence from large scale surveys

Very few people with disability outside of the NDIS reported that they thought they had funding for supports that they could not access (Figure 2.14). This does not mean that there were no supports that were demanded but not provided before the NDIS, but that the term gained a practical meaning within the NDIS context where funding became allocated to individuals who then became able to seek these supports. As the right panel of Figure 2.14 shows a large proportion of people with the necessary funding were unable to access the supports they planned to purchase and that the proportion of 28 per cent in wave 1 increased to 33 per cent in wave 2.

**Figure 2.14 Person with disability: Experience of unmet demand by treatment status - changes over time - wave 1 and 2 evidence (Trial and Comparison, All ages)**



- For the NDIS participants we examined further the individual changes that occurred between wave 1 and 2. Overall, 26 per cent of those who did not experience unmet demand for supports in wave 1, experienced unmet demand in wave 2 (Tables A2.38). Those who report unmet demand at wave 1 and no unmet demand at wave 2 are in the top right of the table. Those who report no unmet demand at wave 1 and unmet demand at wave 2 are in the bottom left, and those who gave the same answer in both waves are in the diagonal running from top left to bottom right.
- Among those who reported that they experienced unmet demand in wave 1, 57 per cent remain in this situation while 43 per cent no longer face unmet demand for supports (Table 2.7 and Appendix Table A2.38).

**Table 2.7 Person with disability: Transition in having funding for supports but not being able to access these supports- wave 1 and 2 evidence (Trial, All ages)**

| Wave 1<br>Access to supports | Wave 2<br>Access to supports |                           |              |                 |              |             |
|------------------------------|------------------------------|---------------------------|--------------|-----------------|--------------|-------------|
|                              | No unmet demand<br>Frequency | Unmet demand<br>Frequency | Total        | No unmet demand | Unmet demand | Total       |
| No unmet demand              | 539                          | 192                       | 731          | 74%             | 26%          | 100%        |
| Unmet demand                 | 137                          | 178                       | 315          | 43%             | 57%          | 100%        |
| <b>Total</b>                 | <b>676</b>                   | <b>370</b>                | <b>1,046</b> | <b>65%</b>      | <b>35%</b>   | <b>100%</b> |

Note: Balanced panel data. Wave 2 data provisional and subject to change

Unmet demand is very prevalent and persistent over time among NDIS participants. However, it is changing in the right direction, with more cases resolved than new ones appearing in the data.

#### 2.4.4 How is unmet demand experienced? – Evidence from in-depth qualitative interviews

The qualitative interviews highlighted areas of unmet demand for services and supports. Representatives from disability service providers and workforce stakeholder organisations also provided evidence about the extent to which the supply of disability services have responded to the demand.

*Unmet demand through the eyes of NDIS participants and their family members or 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 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] 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 in 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 of factors related to this including wait lists for therapy services, the 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, 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)*

#### *Unmet demand through the eyes of people with disability not participating in the NDIS*

- Several of the non-NDIS participants expressed a desire to receive more disability support than that which was currently available to them, for example: one-to-one assistance, counselling, and privately offered therapeutic programmes.
- Non-NDIS participants also noted an underlying problem with the availability of disability services and supports especially in regional areas. It was also highlighted that the NDIS had increased demand for disability services, particularly for early intervention therapies, and may be outstripping availability of services for NDIS participants and non-participants alike.
- Those who had joined the NDIS but had not yet had their plan implemented, reported having to pay for support services themselves in the interim.

*I'm frustrated because I know that they've got a job to do and the government has given them a criteria of, you know, like who you can help, but on paper it looked like [child's name] seeing God knows amount of people, but realistically he's receiving no support, he's seeing these people for a number of issues, but there's no support. Like, the doctor's your doctor, your paediatrician is your paediatrician, but there's no speech, no OT. We have to source that ourselves. (D03C NP)*

#### *Unmet demand through the eyes of service provider and workforce stakeholder organisations*

- As anticipated in 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.
- In wave 2, workforce stakeholder 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)*

- In wave 2, workforce stakeholder 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)*

- In 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 subsidisation but advised this was not sustainable long term. In addition, NDIA pricing was reported to not cover travel for staff. This was seen to impact directly on the types of services that could be provided and on participants' access to these services.
- In 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. A lack of funding for respite and employment services was particularly noted. 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 also continued to be a concern in 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)*

#### *Unmet demand through the eyes of NDIA staff*

- In wave 1, NDIA staff (particularly Local Area Coordinators (LACS) 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 direct 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)*

- NDIA staff concluded that overall, demand for disability services and supports now exceeded supply in the sector.

*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)*

## 2.5 Summary of Key Findings

We provide below a summary of the key findings arising from the evaluation evidence assessing the impact of the NDIS on (i) the demand and supply of disability services; (ii) the quality of these supports; and (iii) areas of unmet demand for services and support.

### 2.5.1 Types and volume of disability supports

*Evidence from large scale surveys*

- The total number of services accessed by NDIS participants increased both after joining the NDIS and with time in the NDIS. The average number of supports received increased from 1.94 supports pre-NDIS to 3.23 in wave 1, and 5.78 in wave 2.
- This increase in the number of services accessed was not spread evenly across all types of services. While access to plan/case management, transport services and leisure activities doubled as a result of the NDIS, access to supports with work and study declined.
- Although providing considerable levels of informal care to NDIS participants, a majority of carers did not access any carer-specific supports (76 per cent in wave 1 and 83 per cent in wave 2).

*Evidence from in-depth qualitative interviews*

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 the NDIS generally reported increased levels of supports including better access to therapy services and equipment, as well as 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 in wave 2 as they did in 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:
  - aids and equipment;
  - therapy (psychology support, physiotherapy and speech therapy);
  - personal care and support with independent living; and
  - respite.
- The NDIS had led to an increased demand for disability services. 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.

- By wave 2, evidence was emerging that NDIS participants were increasingly choosing different service providers and requesting more flexible services.
- Several concerns were raised in both waves 1 and 2 regarding the funding and provision of supports:
  - Funding for family supports was inconsistently included in plans and limited in scope.
  - The NDIS had negatively impacted, or was expected to have a negative impact on, the services and supports accessed by people with disability not in the NDIS. These impacts included cost increases, needing to pay for previously free services and reduced availability of services.
  - A decline in group based services was viewed as decreasing social participation opportunities for NDIS participants and their families as well as limiting transdisciplinary collaborations between service providers.
  - Not all NDIS participants were felt to be 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.

## **2.5.2 Quality of services and supports**

### *Evidence from large scale surveys*

- Upon joining the NDIS, a similar proportion of participants reported that the quality of supports they received under the NDIS was either better (43 per cent) or had not changed (43 per cent) compared to prior to the NDIS. However 14 per cent of participants felt that the quality of their supports were worse.
- Once in the NDIS, a high proportion of NDIS participants were satisfied with the quality of the supports that they were receiving. This did not change over time in the NDIS.
- The impact of the NDIS on satisfaction with the quality of supports was estimated. On average, NDIS participants were 33 per cent more likely to report being very satisfied with the quality of their supports compared to if they had not joined the NDIS.
- Important differences in satisfaction with the quality of supports by disability type were found. NDIS participants with mental/psychosocial disability reported lower levels of satisfaction compared to NDIS participants with other types of disability.
- The impact of the NDIS on the quality of supports did not differ for participants living in rural or urban areas.
- Carers also reported higher satisfaction with the quality of supports when the person with disability they cared for was in the NDIS. The impact of the NDIS on support quality was 10 per cent for the carers of adults and 12 per cent for carers of children.

#### *Evidence from in-depth qualitative interviews*

- While NDIS participants and their carers were generally satisfied with the quality of the services they were receiving, concerns were raised in both waves 1 and 2 about the reliability of some services and the continuity of care provided.
- Respondents also questioned the quality of the support workers who were referred to them and the lack of specialised disability training. Others expressed considerable concern about the general standard of agency provided disability care workers.
- The quality of NDIA staff was also questioned with many reporting that planners did not understand the specific needs and supports required for particular disability types.
- Service providers and key stakeholder organisations considered staff training to be underfunded within NDIS pricing structures; this undermined workforce quality.

### **2.5.3 Unmet demand for services and supports**

#### *Evidence from large scale surveys*

- In wave 1, unmet demand was reported by 32 per cent of NDIS participants who were unable to access a support for which they had funding under the NDIS. The incidence of unmet demand did not decrease over time.
- Unmet demand was primarily due to wait times, a lack of a local provider or the lack of quality provision. Only a small proportion (around 10 per cent) reported they could not access their supports because they were too expensive.
- In wave 1, 26 per cent of NDIS participants reported accessing services that were not funded by the NDIS. This increased considerably to 39 per cent in wave 2. Non-funded supports most commonly related to therapeutic interventions and leisure activities, and were mostly paid for by the family and the participant.
- People with disability who entered the NDIS later were estimated to be 14 per cent more likely to experience unmet demand compared to those who joined in the early roll-out of the NDIS.
- In addition, children aged seven-15 years were about eight per cent more likely to experience unmet demand than their adult counterparts.
- NDIS participants with an intellectual disability were more likely to experience unmet demand compared to people with other disability types.

#### *Evidence from in-depth qualitative interviews*

- The qualitative data indicated that all groups interviewed in both waves 1 and 2 reported that NDIS participants and their carers experienced problems with accessing supports.
- A number of factors were seen to be limiting access to disability supports including small numbers or low capacity of service providers in local areas, lengthy waiting lists for some providers or types of support, and inflexibility of support hours by service providers.
- NDIS participants reported that supply had not been adapting to the changing demand for services, particularly in rural/remote areas. Some providers were feared to be reaching capacity constraints.

- The types of services that were reported to be experiencing strong demand in wave 2 included one-on-one support services, support coordination and financial management, therapy, respite and accommodation services.
- While providers reported shifting to individualised supports, concerns were expressed about financial viability. Many were unable to provide services at the NDIS pricing levels, resulting in cross-subsidising between services. Services considered underfunded by the NDIS were one-to-one community participation, mental health services, group services and services for people with complex needs. A lack of funding for respite and employment services was also noted. Organisations anticipated ceasing particular services when block funding ended.
- NDIA staff also identified that demand of supports had increased. This had led to challenges in terms of shortages, rural/remote provision and 'transitioning out' arrangements.
- Supply constraints were reported to be real and persistent. Shortages were particularly identified for speech pathology, occupational therapy and psychology services. While adaptation to unmet demand was occurring, it was very diverse and in many cases incomplete and unsettled.
- Other concerns relating to unmet demand included the quality of support workers, rigid structures in the NDIS claiming systems and funding for therapist travel.

### 3. The Disability Sector and its Workforce

#### Integrated findings

The following section integrates, and provides a summary of, the main quantitative and qualitative findings relating to the disability sector and its workforce.

The evaluation finds that:

- response to the NDIS was slow to start with evidence of lack of preparation, but change is happening now;
- overall, the sector started by viewing the NDIS positively, responding with more specialisation, more NDIS-related flexibility, and increased activities;
- perceptions deteriorated during the trial period and whilst funding volumes had increased, the sector was far from settled by the end of the trial period;
- there is concern about funding, pay structures and financial sustainability;
- the full impact of the NDIS on employment will take time to be realised. Presently the workforce is predominantly female, casual, with marked specific-skills shortages, low sector retention and dissatisfaction with conditions;
- some concerns with pay and quality of service provision are present;
- availability of the necessary training appears to be adequate;
- a new NDIA workforce is emerging with concerns about working conditions, inadequate training, high workloads and stress, and high turnover, and in need of improvement;
- the sector contrasts unfavourably with the Aged Care workforce, where after recent reforms there is less casual work, higher retention, fewer skill shortages and less overall uncertainty; and
- overall the evaluation concludes that at the end of the trial period the disability support sector still faces serious uncertainties and remains in an unsettled state.

#### *The disability sector*

- The quantitative and qualitative data provided evidence of changes that were occurring within the disability sector as the NDIS roll-out progressed.
- The quantitative evidence suggested that disability service providers were becoming more specialised with the average number of services each organisation provided declining over time, and the provision of some specific services also declining over time. A decline was particularly evident in the proportion of providers offering early intervention services and supports relating to advocacy, information and communication. Only a minority of disability service providers reported plans in wave 2 to expand their range of supports in the future.
- The qualitative evidence pointed out that while slow to adapt to the roll-out of the NDIS, by wave 2 service provision was starting to become more flexible with greater choice offered to people with disability. Moreover, a growth in services which supported NDIS transition (such as support with planning and plan implementation) was identified.

- Both the quantitative and qualitative evidence 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.
- The level of these activities (and particularly those centred on engagement with LACs, expansion of the workforce and changing staff types to meet service demand) increased over time. The qualitative data also showed that business models were changing within the sector with a move towards more market-driven practices. With the adoption of more commercial business practices, concerns were raised of a detrimental impact both on client-provider relationships and on collaboration between provider organisations.
- The quantitative and qualitative data appear to contradict one another when considering the reported impact of the NDIS on the disability sector, indicating a mix of change and uncertainty.
- Most providers participating in the quantitative survey felt that the NDIS was having a positive impact on their organisation; these positive impacts centred on employment, support charges, wage growth and overall performance. However, provider sentiment of the impacts of the NDIS became considerably more negative over time.
- In contrast, the qualitative data suggests that the NDIS has had considerable but mixed impacts for disability service providers. By wave 2, new providers were emerging in the NDIS trial sites. While these were mostly allied health practices, the emergence of new internet based labour-for-hire services was also noted. Evidence was also provided of established provider organisations moving into the NDIS trial sites. Over time some exits from the disability sector were reported as a consequence of organisational closure or a decision to withdraw from disability service provision (either completely or as a registered provider under the NDIS). Increased merger and acquisition activity was also occurring by the wave 2 interviews.
- Both data sources provided information about funding within the disability sector. The quantitative data indicated that sector funding had increased between waves 1 and 2 and as the proportion of funding from the NDIS grew, funds from other sources had declined. The qualitative interviews highlighted widespread perceptions that NDIS pricing structures did not adequately cover the full costs of service provision. However, the full impact of funding and pricing changes was yet to be realised as many disability service providers continued to receive some block funding during the transition to full NDIS roll-out. Concerns regarding the future financial viability of disability organisations persisted throughout the period of the evaluation.

#### *The disability workforce*

- While the full impact of the NDIS on the disability workforce was yet to be realised, an expansion of the workforce was observed by wave 2 in both the quantitative and qualitative data. In particular, the average number of employees in the disability organisations surveyed increased considerably over time. A majority of provider organisations reported future hiring intentions, with demand for disability and residential support workers, programme administrators and allied health staff particularly strong.
- The quantitative data provided an overview of the composition of the disability sector workforce. Disability and residential support workers form an expanding majority within the direct care workforce. The occupational profile of the remainder of the workforce changed little over time. The disability workforce is also predominantly female.

- Both the quantitative and qualitative findings highlighted a growing trend towards the casualisation of the disability workforce. However, a lack of agreement was found as to the use of agency workers within the sector. While the quantitative survey data showed that the use of agency workers was decreasing over time, some providers were noted in the qualitative interviews to be continuing to hire agency workers in order to address issues with staff recruitment. Concerns were raised about the skills of these agency workers by both disability service providers and by NDIS participants and their family members and carers. Moreover, indications that staff retention may be becoming more problematic were found at wave 2. The quantitative data showed a decline in the length of tenure of disability workers, while examples of experienced staff leaving the sector were noted in the qualitative interviews.
- Further evidence of the impact of the NDIS on working conditions in the disability sector was shown in the qualitative data. Issues relating to the ability to pay staff award rates within NDIS pricing levels, and managing the dichotomy between minimum shift hours under industrial awards and NDIS participant requests for shorten services were highlighted. Concerns were also raised about increased workloads in relation to administrative and financial aspects of the NDIS.
- Discrepancies between the two data sources were found regarding the impact of the NDIS on the training of the disability workforce. Evidence was provided in the qualitative interviews that NDIS pricing structures were negatively impacting upon opportunities for training within the NDIS trial sites. In contrast, the quantitative data indicated that access to disability training remained unchanged over time.
- Low levels of vacancies and evidence of skill shortages within the disability sector were reported in the quantitative data. However, as substantiated in both the quantitative and qualitative evidence, over time allied health workers positions became more difficult to fill. The qualitative data also found that new roles within the sector were typically being offered at lower rates of pay and skill levels than before the NDIS. This perceived de-professionalisation of the disability workforce led to concerns about the quality of service provision.
- The qualitative interviews (and in particular those conducted with NDIA staff) provided evidence about a major new workforce within the disability sector – the NDIA workforce. While the quality of the NDIA workforce was considered to be good by those working within the agency, high workloads and work stress were negatively impacting upon staff wellbeing and retention. These concerns grew over the course of the evaluation. Different occupational groups within the NDIA reported specific challenges in their work. Many planners were concerned about the high administrative burden arising from planning processes, LACs that the expected community engagement aspect of their role was not a key focus, and PSCs were struggling to undertake both plan implementation and community engagement.
- Several areas of improvement were recommended for the NDIA workforce. Respondents across all interview groups highlighted that further training was required by NDIA staff, including greater understanding of disability types and associated needs, how to better support plan implementation and self-management, and role-specific training. NDIA staff themselves also identified strategies that could better support their workforce. These included improved career opportunities, more effective management of workplace stress and high workloads, as well as specific strategies to address the support needs of NDIA staff with disability.

### 3.1 Introduction

The NDIS will profoundly affect the disability sector and its workforces. Expectations among current and future users of the NDIS are for different, more flexible services. Service providers are beginning to modify or develop their supports, while new care services are expected to enter local provider markets. Issues of up-skilling, re-training and motivating the workforce will become increasingly important, as will shortages of skilled workers. In this section we present quantitative and qualitative evaluation evidence on evaluation questions that relate to the theme of *the disability sector and its workforce*. Specifically, this chapter asks what has been the impact of the NDIS on the disability sector and its workforce. The chapter also considers the birth of a new workforce within the disability sector – the NDIA workforce. The chapter details the experiences faced by NDIA staff in rolling out the NDIS.

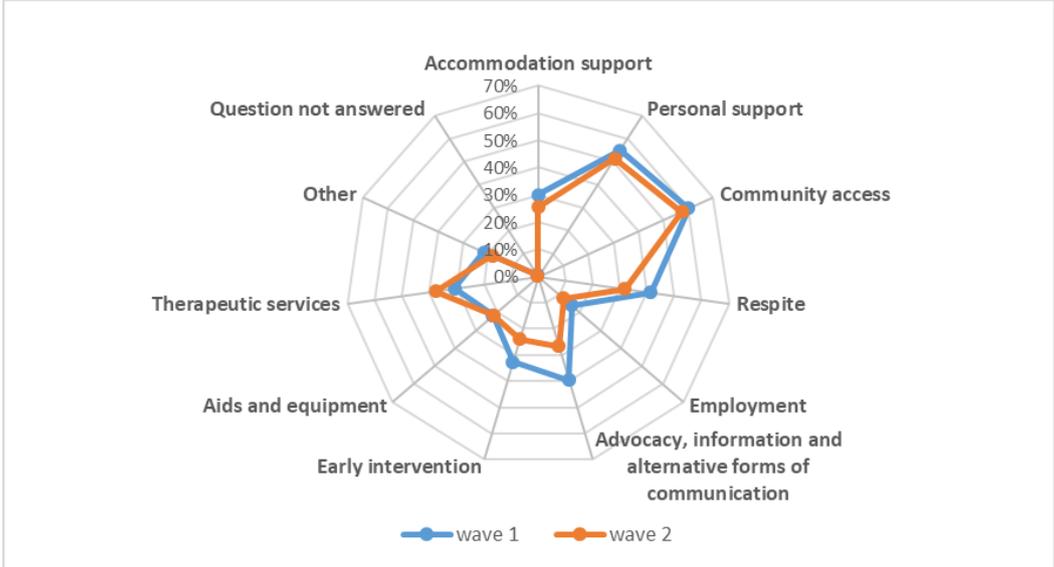
### 3.2 Disability Supports

#### 3.2.1 The supply and diversity of disability supports – Evidence from large scale surveys

The survey of disability support providers offers additional evidence on the supply and diversity of disability supports.

- Figure 3.1 (and Appendix Table A3.1) shows the proportion of organisations providing certain types of disability support. In wave one the most common service offered by disability providers was community access (60 per cent of providers), followed by personal support (55 per cent). They remain the two most prevalent services provided by disability organisation in wave 2 (provided by 57 per cent and 51 per cent of organisations). Disability employment services were the least commonly provided service in both waves 1 (16 per cent) and wave 2 (12 per cent).

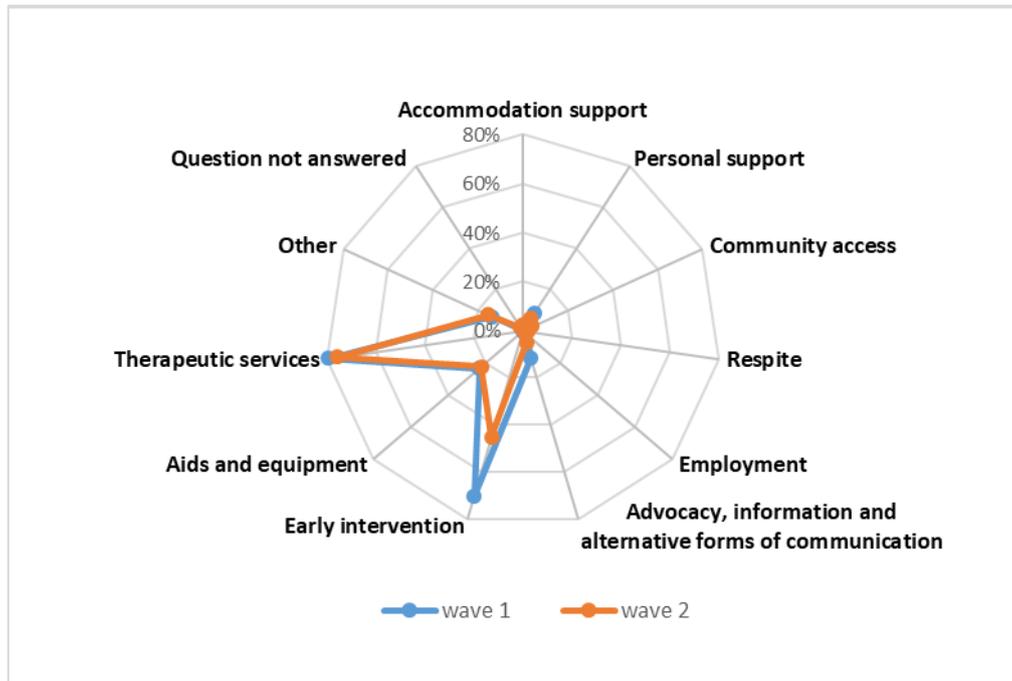
**Figure 3.1 Disability Support Provider: Types of disability support currently provided by disability support providers**



- The evaluation finds that with the exception of therapeutic services, the proportion of disability service providers providing each type of disability support has declined between wave 1 and 2. The largest declines occurred for advocacy, information and alternative forms of communication and early intervention services.
- Figure 3.2 (and Appendix Table A3.1SE) shows the proportion of self-employed providers delivering certain types of disability support. In wave 1, the most commonly services provider by

self-employed disability support providers were therapeutic services (79 per cent) and early intervention (70 per cent). These remained the two most prevalent services provided in wave 2 (76 per cent and 45 per cent respectively).

**Figure 3.2 Disability Support Provider: Types of disability support currently provided by self-employed disability support providers**



- Accommodation support, community access, respite and employment were the services least commonly provided by self-employed disability support providers in both waves 1 and wave 2 (all less than 5 per cent).
- The proportion of self-employed disability support providers delivering early intervention and advocacy, information and alternative forms of communication services declined substantially between wave 1 and 2. Little changes was noted in the other types of disability service provision.
- Appendix Table A3.2a documents the average number of services provided by disability support providers in wave 1 and 2. The proportion of organisations providing one to three types of disability services has increased from wave 1 and 2, while the proportion providing more than three types has decreased overtime. This trend is similar for the self-employed disability support providers (Appendix Table A3.2a SE).
- Overall, there was a decline in the average number of services provided by both organisation and self-employed providers (from 3.5 in wave 1 to 3.1 in wave 2 for organisations and 2.1 to 1.8 for self-employed).
- The quantitative data suggests that most of the planning to adapt to the new demand coming from the NDIS occurred in wave 1 for disability service providers, while the reverse was true for self-employed providers. In wave 1, 34 per cent of all disability service providers reported that they were planning to expand their range of supports in anticipation of the NDIS roll-out (Appendix Table A3.3). This decreased to 27 per cent of organisations in wave 2.
- Eighty-three per cent of self-employed providers at wave 1 and 78.9 per cent at wave 2 (Appendix Table A3.3 SE) did not have plans to change the range of disability supports they provided.

- The survey of disability support provider’s traces possible differences in the way quality of supports are monitored (Appendix Table A3.4). Managers or supervisors were the most common way in which the quality of supports were monitored in both waves 1 and 2 (84 per cent and 85 per cent respectively). The use of surveys of service users, external auditing, and inspectors from another part of the organisation to monitor the quality of services decreased over time.

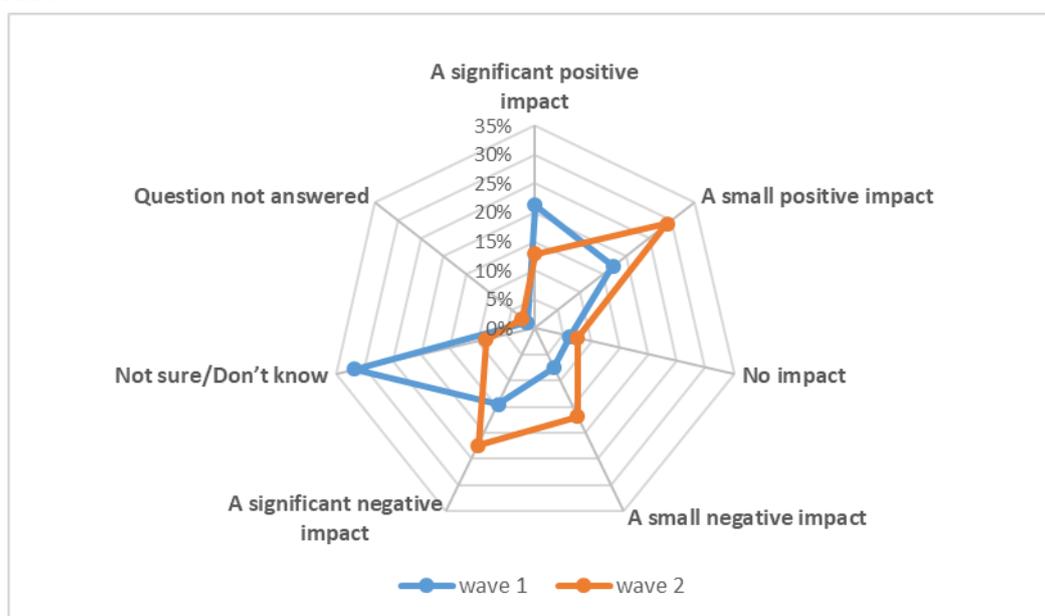
### 3.3 The Disability Sector

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

#### 3.3.1 General outlook – Evidence from large scale surveys

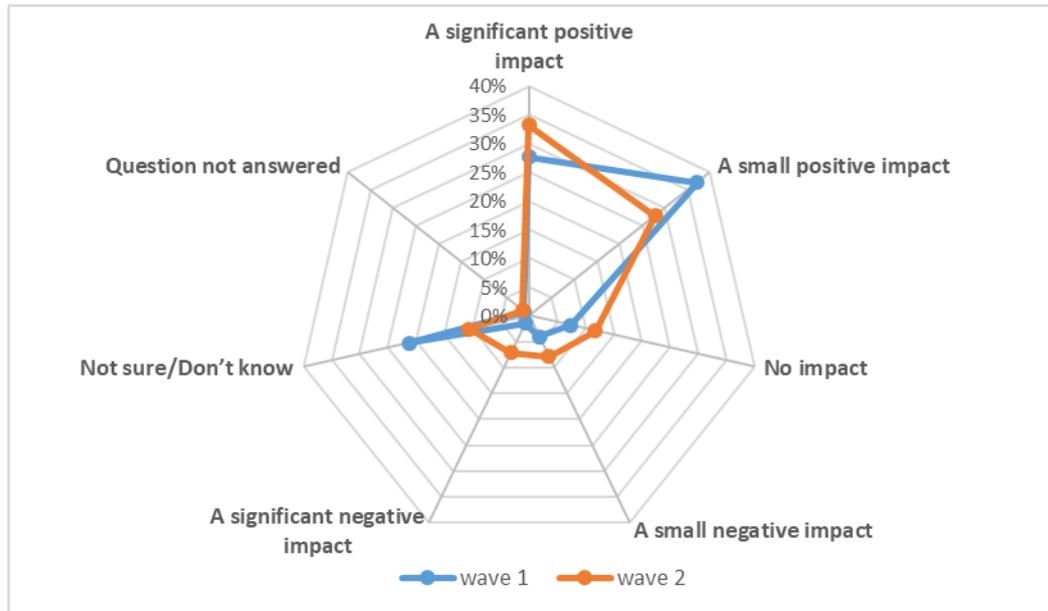
- As may be expected, providers were much more certain about the impact the NDIS had had on their organisation in wave 2 compared to wave 1 (as shown by the proportion of providers answering ‘not sure/don’t know’ reducing considerably over time in figure 3.3 and Appendix Table A3.5).

**Figure 3.3 Disability Support Provider: The general impact of the rollout of the NDIS on disability service providers**



- In both wave 1 and 2 a large proportion of outlets reported the NDIS to have had a positive impact on them (38 per cent and 42 per cent respectively). However, the proportion of providers reporting a negative impact had increased sharply in wave 2, from 22 per cent to 39 per cent of organisations.
- Self-employed disability providers were more optimistic about the impact of the NDIS than provider organisations (Figure 3.4 and Appendix Table A3.5SE). A much larger proportion reported a positive impact of the NDIS in both waves 1 and wave 2 (65 per cent and 61 per cent, respectively). However, while small, the proportion of self-employed disability providers reporting a negative impact increased sharply in wave 2 (from 6 per cent in wave 1 to 15 per cent in wave 2).

**Figure 3.4 Self Employed: The general impact of the rollout of the NDIS on disability service providers**



### 3.3.2 Will the NDIS bring change? – Evidence from large scale surveys

- Disability service providers were asked about their expectations of the changes that the NDIS would bring to the operation of their organisation (Appendix Table A3.6). In wave 1, disability service providers expected the NDIS to have a positive impact on (1) employment, (2) support charges (prices), (3) wage growth and (4) overall performance. The most commonly expected negative impact of the NDIS was on profits (reported by 27 per cent of providers).
- These reports of expected impacts in wave 1 were generally consistent with the actual impacts and the expected future impacts reported in wave 2. The impacts of the NDIS had strengthened overtime. This is reflected by the fact that the proportion of providers reporting ‘no change’ in organisational operations reduced over time on nearly all the impact aspects (Appendix Tables A3.6a and A3.6b).
- Similar trends are observed for self-employed providers. Self-employed providers expected the implementation of the NDIS to have a more positive impact on all elements of their operation – including (1) prices, (2) profits, (3) employment, (4) investment in equipment and (5) overall performance (Appendix Table A3.6SE).
- These expected impacts were consistent with the actual impacts and the future expected impacts reported in wave 2 (Appendix Table A3.6SEa and Appendix Table A3.6SEb). The current and expected impacts on all aspects of operation remained positive.
- The impact of the NDIS on operations was relatively stable overtime, with little change in the proportion of self-employed providers reporting ‘no change’.

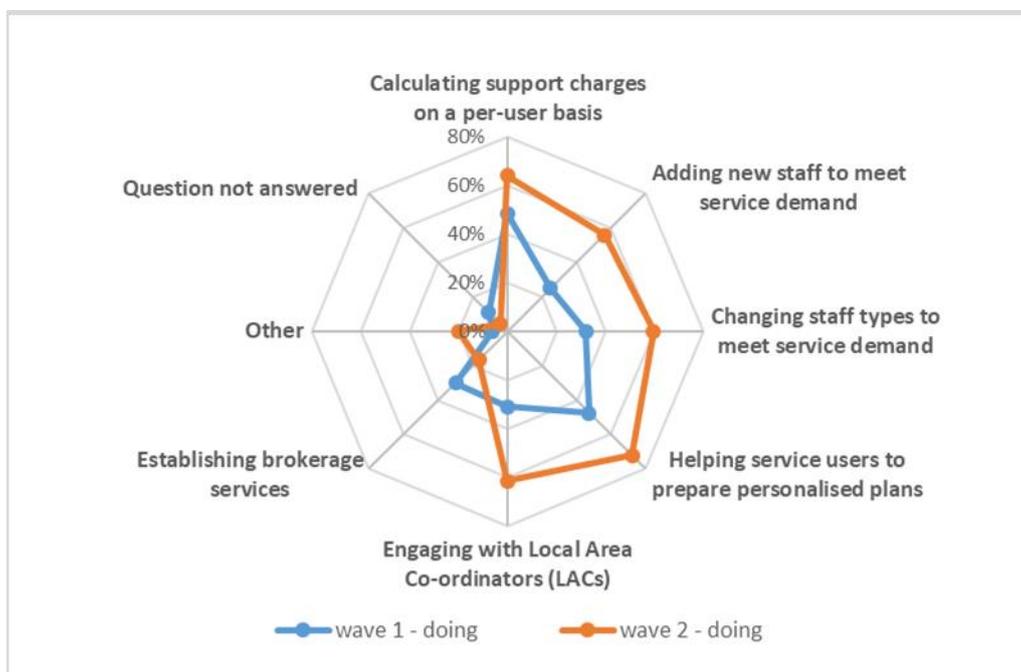
### 3.3.3 Is the sector responding to the NDIS roll-out? – Evidence from large scale surveys

- Disability support providers were asked about the activities that they were either currently or planning to undertake as a consequence of the NDIS. A much larger proportion of disability service providers reported to be acting in response to the NDIS in wave 2 compare to wave 1 (Appendix Table A3.7). While in wave 1 20.5 per cent of organisations reported that they were not doing or

planning any activities in response to the roll-out of the NDIS, all providers surveyed in wave 2 had actions and plans.

- The average number of activities being undertaken in response to the NDIS had also increased from 2.5 in wave 1 to 3.7 in wave 2.
- Disability service providers were asked about the activities they were undertaking or planning to undertake in response to the NDIS (Figure 3.5 and Appendix Table A3.8). In wave 1 the most frequent activities being undertaken by disability service providers were calculating support charges on a per-user basis (49 per cent) and helping service users prepare for individualised plans (47 per cent). The most frequent activities they were planning on undertaking was expanding their workforce (33 per cent) and engaging with LACs (34 per cent).

**Figure 3.5 Disability Support Provider: Activities of disability service provider organisations in response to the rollout of the NDIS**



- With the exception of establishing brokerage services, the proportion of disability service providers reporting undertaking activities increased for each of the activity types listed in wave 2. This was also true for the activities they were planning on undertaking.
- The activities that experienced the greatest increase over time were engaging with LACs (increased by 31 per cent) and expanding the workforce (31 per cent). The proportion of providers who were changing staff types to meet service demand also substantially increased from wave 1 by 28 per cent.

### 3.3.4 Funding sources – Evidence from large scale surveys

- Disability service providers were asked about the funding they received for disability support provision. The total funding received by disability service providers for the provision of disability support services increased significantly from wave 1 and 2 (Appendix Table A3.9).
- A large increase in disability support funding was also reported by self-employed providers (Appendix Table A3.9SE).

- For both disability service providers and self-employed providers, the proportion of funding from the NDIS had increased steadily overtime. In contrast, the proportion of funding received from government, non-government and private donations had declined (Appendix Table A3.10 and Appendix Table A3.10SE).
- The key difference between the funding sources of organisation and self-employed providers is that the proportion of funding from ‘user fees/direct payment’ was stable for organisations while that for self-employed providers had declined substantially.

### 3.3.5 Impact of the NDIS on the disability sectors – Evidence from in-depth qualitative interviews

The qualitative data collected as a part of the NDIS evaluation included a large amount of information on the perceived impact the NDIS has had on the disability sector. A summary of this information is provided below.

#### *The perspective of NDIS participants and their family members or carer*

- In wave 1, there was little evidence of changes in the supply or diversity of disability supports. Market changes were slow to materialise due to a slowly adapting or emerging provider sector, and as a result NDIS participants often retained existing provisions.
- In wave 2, there was a mixture of feedback from NDIS participants and their carers about how the disability sector had responded to the NDIS. 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 examples were also given of positive movement towards greater flexibility of service offerings and willingness to consider new and creative business models.
- A number of changes to the sector were perceived positively by respondents. In 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 new providers’ perceiving that they could be involved in NDIS for purely financial reasons and that the quality of the service being provided (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) 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 workers 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] and their profiles. I can request to book a particular 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 in wave 2 that were perceived negatively by respondents. Evidence was provided 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)*

*The perspective of the service provider and workforce stakeholder 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 in 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 in wave 1 regarding the NDIS pricing structure and a lack of adequate coverage for the full costs of service delivery continued in wave 2. Many organisations were reported to be currently operating at a loss under the NDIS. 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)*

- In wave 2, many disability service providers continued to receive some block funding. As such, the full financial impact of the NDIS was not yet considered to have hit the sector. However, concerns about financial viability continued and included issues around unfunded work such as the extra administrative work generated by the NDIS, funding for cancelled appointments, adaptation to the payment in arrears system, and the financial viability of small providers.
- Increased merger and acquisition activity had been occurring in the trial sites in 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 in 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 in 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 or into the disability sector (such as aged care organisations in rural areas) 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)*

- Exits from the sector were also noted in wave 2. 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. In addition, reports were provided of allied health professionals disengaging from the NDIS due to issues with pricing and best practice. The future of advocacy organisations remained unknown.

*We now have the institutions closing down around us so we have three lots of those that are closing. (D01S W2)*

*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 in wave 2 although as in wave 1, interactions remained guarded and there was less sharing of information due to commercial considerations. In general respondents felt that the NDIS 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 W2)*

- 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 in 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*

- In general NDIA staff considered that the disability sector was unprepared for the move from block to individualised funding, and were resistant to changing their business and practice models. Providers were reported to be slow to register with the NDIA, and disputes about pricing structures, planning processes and plan implementation had occurred.
- 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; as a result they 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 NDIS 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.

- In wave 2, NDIA staff reported that the number of providers in the trial sites had increased. In Barwon, the Hunter and SA 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 provide 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 organisational 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)*

## **3.4 The Disability Workforce**

### **3.4.1 A profile of the disability support workforce – Evidence from large scale surveys**

The surveys of disability support providers indicate that it is too early to fully assess the impact the NDIS has had on the disability service workforce. Although response rates were very low, they do, however, provide some essential baseline data that will enable future monitoring of its impact.

- Appendix Table A3.11 gives a detailed profile of the range of the size of disability service provider organisations, as measured by their number of PAYG employees. In both wave 1 and 2, there was a wide range of size, from 16 per cent in wave 1 and 14 per cent in wave 2 indicating fewer than five employees to 15 per cent with 100 employees or more. In wave 1, the most common staff size was 20 to 49 employees (20 per cent of outlets) and 10-19 employees (22 per cent of outlets) in wave 2.
- The average size of the organisations surveyed had increased from 70.6 employees in wave 1 to 84.0 in wave 2.

- The survey asked organisations about the composition of their direct care workforces. As shown in Table 3.1 (and Appendix Table 3.12), the most prevalent occupation in the disability support sector in both waves was disability support/residential support worker in both of the two waves (growing from 48 per cent of direct care employees in wave 1 to 57 per cent in wave 2). Personal care/home care worker was the second most common occupation in this sector, and comprised of 19 per cent of the direct care workforce in both of the waves. Thus, the majority of the direct care workforce (67 per cent in wave 1 and 76 per cent in wave 2) are employees who are providing intensive care services to people with disability.

**Table 3.1 Disability Support Provider: The composition of organisations' direct care workforce by occupation**

| <b>Occupation</b>   | <b>Wave 1</b> | <b>Wave 2</b> |
|---|---------------|---------------|
| Disability support/Residential support worker                   | 47.8%         | 56.7%         |
| Personal care/Home care worker                                  | 19.1%         | 19.4%         |
| Service or program administrator/Manager/Coordinator            | 7.4%          | 9.7%          |
| Social worker/Disability case coordinator                       | 4.9%          | 2.9%          |
| Employment support worker                                       | 1.9%          | 1.9%          |
| Peer support worker   | 1.1%          | 0.6%          |
| Allied health worker  | 5.2%          | 5.2%          |
| Other   | 12.7%         | 3.5%          |
| <b>Average number of direct care workers per organisation</b>   | <b>56.8</b>   | <b>53.0</b>   |
| <b>Total number of workers</b>                                  | <b>36,021</b> | <b>12,613</b> |
| <b>Total number of organisations who answered this question</b> | <b>634</b>    | <b>238</b>    |

Source: NDIS DSP outlet survey, Question B2 in wave 1 and Question B2 in wave 2.

- With the exception of the growing proportion of disability support/residential support workers, the occupational composition of the direct care workforce had not changed substantially between the two waves.
- The average number of direct care employees had declined marginally between the two waves (from 57 to 53), while the average number of PAYG employees had increased from 71 to 84 as shown in Table A3.12 above.
- Appendix Table A3.13 shows that the disability sector is a female dominant industry with three quarters of the direct care workforce being female in both of the waves.
- While females formed the majority for all occupations, the proportion varied by occupation. The highest proportion of females was among allied health workers (89 per cent in wave 1 and 87 per cent in wave 2). The lowest share of female workers were found in employment support roles (61 per cent in both of the two waves)
- The proportion of female employees was stable between the two waves.
- The proportion of permanent employment has declined largely for all occupations over time, indicating a growing trend of casualisation in this sector (Appendix Table A3.14 and A3.14a). Across all occupations the casual workforce grew from 29 per cent of employees in wave 1 to 40 per cent in wave 2.

- The largest increase in casualisation had occurred in the occupations of ‘disability support/residential support worker’, ‘personal care/home care worker’ and ‘employment support worker’, all with a decline of permanent employees by more than 10 percentage points.
- Despite these changes to working conditions, permanent employment is still the most prevalent form of employment in disability sector (accounting for 64 per cent of employees in wave 1 and 48 per cent in wave 2).
- The proportion of workers with five years or more experience has reduced for all occupational groups, an obvious consequence of a growing workforce, but also indicating that retention may be a growing issue in this sector (Appendix table A3.15 and A3.15a). While 37 per cent of workers had five or more years of tenure in wave 1, this had fallen to 32 per cent of workers in wave 2.
- The occupation with the most serious problems with regard to retention is allied health worker. The proportion of allied staff with five or more years of experience reduced by 16 per cent over time.
- As shown in Appendix Table A3.16, the use of agency workers seems to have decreased overtime. A much smaller proportion of the organisations surveyed in wave 2 used agency workers (22 out of 215 or 10 per cent) compared to wave 1 (97 out of 580 or 17 per cent). The most common role which agency staff were used to fill was disability support/residential worker.
- The average number of agency workers in an organisation has also reduced from 15.0 in wave 1 to 8.3 in wave 2<sup>9</sup>.
- Workers in the disability support sector face quite varied work conditions (Appendix Table A3.17). First, work patterns may be quite different from jobs in other industries. Over 80 per cent of disability service providers reported that their employees may have to work longer than scheduled due to unanticipated needs of service users. About 70 per cent of the organisations reported that their employees may have to experience variation in hours or location at short notice. A further 30 per cent of disability service providers also indicated that their employees have to work alone late at night.
- Sixty per cent of disability service providers indicate that their employees have to work with aggressive services users.
- In contrast, working in unsanitary conditions is relatively less likely to occur, with only four per cent of disability service providers reporting that their workers have to do this under normal circumstances and 18 per cent in exceptional circumstances.
- Contrary to the concerns voiced by respondents in the qualitative interviews, the quantitative data indicates that the NDIS is not impacting on the training provided to disability support workers (Appendix Table A3.18). Both the average number and the distribution of the type of training offered to employees was relatively stable across waves 1 and 2.
- ‘Team working’, ‘communication skills’, ‘risk identification and safeguarding’, ‘manual handling’, ‘person-centred thinking or planning’ and ‘mandatory reporting’ were the most frequently offered types of training; all had been adopted by more than half of the organisations in both waves 1 and wave 2.

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<sup>9</sup> Using manual calculations from reported frequencies

### 3.4.2 Skill shortages and staff skills – Evidence from large scale surveys

The information collected allows us to report on the types of skills used, staff skills balance, the extent of skill shortages, the factors thought to underlie the skills shortages and the kinds of responses used to deal with them. These aspects can inform existing workforce strategies and planning for the future.

- Appendix Tables A3.19 and A3.19a shows within each row, the share of outlet managers who thought their staff were under-skilled for delivering each job role. The questionnaires defined under-skilling as the situation where a worker's skills were perceived to be below those required for the job they were responsible for.
- Many outlet managers did not answer this question (as reflected in the high percentages in the 'Question not answered' column).
- Under-skilling was not seen as a substantial problem as the most frequent response among providers (that expressed an opinion) was that they had no under-skilled workers. The two roles with the highest levels of reported under-skilling (a total of some, most, all under-skilled) were disability support/residential support workers (20 per cent of outlets for both waves) and service or program administrator/ manager/coordinator (13 per cent for both waves).
- Skills shortages experienced by disability organisations are considered in Appendix Tables A3.20 and A3.20a, with each row reflecting the information about a specific worker role. The table shows skill shortages for this range of staff types during the past 12 months, where a skills shortage was defined as appropriately qualified workers not available or not willing to work under existing market conditions. As with the question about under-skilling, a large number of organisations did not answer this question in both waves. It is reasonable to infer that for those cases where the question was not answered, any skills shortage that might be faced by that respondent was not very pressing.
- The incidence of skill shortages has not changed considerably between the two waves.
- Disability support/residential support workers were the most problematic occupation in terms of skill shortages, being in shortage (either continuously or occasionally) for about 30 per cent of the organisations in both waves. 'Service or program administrator/manager/coordinator', 'personal care/home care' and allied health workers were the other occupations for which organisations reported relatively higher levels of skill shortage.
- For all occupation types, however, less than 14 per cent of outlets reported that they faced a continuous shortage of that skill. This suggests that, at the time of the survey, skills shortages were not a serious obstacle to the provision of disability services.
- Appendix Tables A3.21 and A3.21a show the reasons that were put forward by disability support providers for the reported skill shortages. Specialist knowledge required was the most commonly reported reason for skill shortages in both waves 1 and 2. While there is considerable diversity in the causes of skill shortages, the reported reasons for skill shortages did not change substantially between the two waves.
- Appendix Tables A3.22 and A3.22a show that disability service providers' responses to skill shortages are diverse. However, very few of these responses to skill shortages were adopted in all situations.
- A very small proportion of organisations (less than 5 per cent in both waves) always use a particular response.

- The most common strategy adopted by managers in both waves is more use of on-the-job or internal training of staff followed by use of their existing workforce working longer hours and more use of external training of staff.

### **3.4.3 Vacancies – Evidence from large scale surveys**

- Job vacancies are another indicator of skill shortage or labour turnover. Appendix Tables A3.23 and A3.23a consider the number of current vacancies at outlets for each employee type, with the vacancy advertised and available to fill immediately (at date of survey during the 2014/15 financial year).
- For each type of employee, more than 60 per cent of all organisations recorded that there were currently no vacancies, however, the numbers were generally small.
- The largest number of vacancies were for disability support/residential support workers, followed by personal care/home care workers.
- Appendix Tables A3.24 and A3.24a show that there were few unfilled vacancies in each worker type across both waves. Unfilled vacancies were most commonly reported for service or program administrator/manager/coordinator (5 per cent in wave 1 and 6 per cent in wave 2) and allied health worker roles (5 per cent in wave 1 and 10 per cent in wave 2).
- The proportion of disability service providers reporting that they were unable to fill allied health worker vacancies doubled between wave 1 and 2. This corresponds to the qualitative findings which suggest that allied health workers are in shortage.

### **3.4.4 Hiring intentions – Evidence from large scale surveys**

- The hiring intentions reported by outlet managers give a sign as to whether they foresee a need to replace workers, or supplement their numbers. Appendix Tables A3.25 and A3.25a indicate the number of additional hires anticipated for each staff category together with the number of outlets that indicated this information for each worker type.
- The proportion of organisations which intend to hire worker(s) in the next 12 month has increased from 65 per cent in wave 1 to 71 per cent in wave 2.
- Each entry in a row shows the expected number of employees that outlet managers reported an intention to hire, of each worker type in the next year. For each of the listed occupations, the intent to hire will be larger if the occupation is widely employed across outlets and if the total number of such workers is relatively high. It is not surprising then to see that disability support/residential support workers were expected to be hired in the greatest number. Strong future demand for additional service or program administrator/ manager/coordinators, personal care/home care workers and allied health workers was also noted.
- Internet advertisements was the most dominant channel for recruitment in both waves 1 and wave 2, adopted by about three quarters of disability service providers (Appendix Tables A3.26).
- ‘Newspaper advertisements’, ‘recommendations from existing employees’, ‘word of mouth’ and ‘direct approach to potential recruits’ are also commonly used strategies, all of which are adopted by more than 20 per cent of the organisations.
- The distribution of the recruitment channels is similar between the two waves except for the use of ‘newspaper advertisements’, which decreased by half in wave 2.

- 'Experience' and 'motivation' are the most common attributes that organisations look for when trying to hire new employees (Appendix Table A3.27). Interestingly while a high proportion of organisations also consider 'formal qualifications' and 'references' to be important, the proportion are smaller.
- The distribution of important attributes or qualities of potential employees was similar between the two waves.

### **3.4.5 What do NDIS participants and their carers think about their support workers? – Evidence from large scale surveys**

- Seventy-two per cent of NDIS participants reported that they receive services from disability support workers (Appendix Table A3.28).
- In wave 2, NDIS participants and their carers were asked to respond to a series of statements about the disability support workers they are currently receiving services from. The question asks respondents to nominate on a scale of zero (completely disagree) to ten (completely agree) how much they agree or disagree with a set of seven statements. The statements refer to different aptitudes of disability care workers. These subjective evaluations are important indicators of how confident NDIS participants and their carers are with the disability support workers that assist with their care. Appendix Table A3.29 reports the average scores from NDIS participants for each of the statements.
- Overall, we see that NDIS participants display high levels of agreement with nearly all statements, with average scores ranging from 7.4 to 9.1. The highest average scores are in the areas of support quality and how safe they feel with their workers. The lowest average score related to the flexibility in the day and time services are provided.
- In general, NDIS participants with physical or sensory conditions reported higher average scores to each of the statements, whereas NDIS participants with intellectual disability and mental health conditions or psychosocial disability recorded the lowest average scores.
- Carers are also asked to indicate their level of agreement with a similar set of statements. Appendix Table A3.30 reports the average scores from carers for each of the statements about disability support workers.
- Overall, we see that carers displayed moderate levels of agreement with nearly all statements, with average scores ranging from 6.9 to 7.8. The highest average scores relate to the quality of care provided and the skills of support workers. The lowest average score related to the flexibility in the day and time services are provided.
- In general, carers reported much lower mean scores to the statements about disability support workers than NDIS participants.

### **3.4.6 What do disability support workers think about their work? – Evidence from large scale surveys**

- Disability sector workers were also asked to respond to a series of statements about aspects of their work in wave 1. On a scale of zero (completely disagree) to seven (completely agree), disability support workers were asked how much they agree or disagree with each statement (Table 3.2 and Appendix Table A3.31).
- The disability sector workforce agreed that they had 'sufficient skills and abilities to do the job' and were able to 'use many of their skills and abilities' (with an average score of 6.0 and 6.1,

respectively). Other statements which rated particularly highly were 'I am proud to tell people who I work for' (5.9) and 'I feel loyal to this organisation' (5.7). Two thirds of workers believed that they received adequate training and had freedom to decide how to do their work. While the average scores for the statements on pressure ('I feel under pressure to work harder in my job', mean 3.9) and stress ('my job is more stressful than I had ever imagined', mean 3.6) indicated disagreement on average, a sizeable proportion of workers felt they were under pressure (38 per cent) and stressed (30 per cent).

**Table 3.2 Disability Support Worker: Opinions about aspects of work (1-7 disagree/agree scaling)**

Row percentages are shown

| Opinions about aspects of work<br>(1-7 disagree/agree scaling)                  | Disagree<br>1-3 | Neither<br>agree nor<br>disagree<br>4 | Agree<br>5-7 | Question<br>not<br>answered | Mean |
|---|-----------------|---------------------------------------|--------------|-----------------------------|------|
| I spend enough time with each person accessing supports                         | 19.4            | 17.8                                  | 60.3         | 2.5                         | 4.8  |
| I have adequate continuity of contact with each person accessing supports       | 16.5            | 18.8                                  | 62.0         | 2.7                         | 4.9  |
| I have the skills and abilities I need to do my job                             | 2.0             | 5.9                                   | 90.7         | 1.4                         | 6.0  |
| I use many of my skills and abilities in my job                                 | 2.1             | 4.9                                   | 91.0         | 2.0                         | 6.1  |
| I have a higher qualification than the one required for my job                  | 36.2            | 19.7                                  | 42.0         | 2.2                         | 4.1  |
| I have a lot of freedom to decide how I do my work                              | 14.9            | 17.6                                  | 66.0         | 1.5                         | 5.0  |
| I feel under pressure to work harder in my job                                  | 39.1            | 21.5                                  | 37.9         | 1.5                         | 3.9  |
| My job is more stressful than I had ever imagined                               | 47.4            | 21.1                                  | 30.1         | 1.5                         | 3.6  |
| I get the respect and acknowledgement I deserve for my efforts and achievements | 18.5            | 16.4                                  | 63.7         | 1.4                         | 4.9  |
| Adequate training is available through my workplace                             | 17.8            | 14.3                                  | 66.4         | 1.5                         | 5.0  |
| I feel loyal to this organisation   | 7.5             | 11.5                                  | 79.8         | 1.2                         | 5.7  |
| I am proud to tell people who I work for  | 5.7             | 9.6                                   | 83.4         | 1.3                         | 5.9  |
| <b>Total (N=2,133)</b>  |                 |                                       |              |                             |      |

Source: 2014 NDIS DSP employee survey, Question B11.

- Disability sector employees were also asked about their job satisfaction in wave 1 with statements rated from 0 ('dissatisfied') to 10 ('satisfied'). Table 3.3 (and Appendix Table 3.32) shows that overall disability workers were highly satisfied with their job. They were particularly satisfied with the work itself (8.2) and the sense of achievement (8.1) they got from it. Workers were least satisfied with pay and job security (with an average score of 6.1 and 6.6 respectively). They were reasonably satisfied with all other factors of the job, although a significant proportion (14 per cent) had concerns about their opportunities to develop skills and abilities.

**Table 3.3 Disability Support Worker: Job satisfaction (1-10 dissatisfied/satisfied scaling)**

Row percentages are shown

| <b>Job satisfaction</b><br>(1-10 dissatisfied/satisfied scaling)   | <b>Dissatisfied</b><br><b>1-4</b> | <b>Neither</b><br><b>satisfied</b><br><b>nor</b><br><b>dissatisfied</b><br><b>5-6</b> | <b>Satisfied</b><br><b>7-10</b> | <b>Question</b><br><b>not</b><br><b>answered</b> | <b>Mean</b> |
|--|-----------------------------------|---|---------------------------------|--|-------------|
| The sense of achievement you get from your work                    | 4.7                               | 10.2  | 84.2                            | 0.9  | 8.1         |
| Your total pay   | 26.4                              | 22.6  | 50.1                            | 0.9  | 6.1         |
| Your job security  | 21.2                              | 21.2  | 56.3                            | 1.4  | 6.6         |
| The work itself (what you do)                                      | 4.0                               | 10.9  | 83.9                            | 1.2  | 8.2         |
| The hours you work   | 11.5                              | 16.8  | 70.0                            | 1.6  | 7.4         |
| The match between your work and your qualifications                | 10.2                              | 17.2  | 71.5                            | 1.0  | 7.4         |
| The opportunity to develop your skills and abilities               | 14.2                              | 18.8  | 66.1                            | 0.9  | 7.2         |
| The level of support from your team/employer                       | 11.5                              | 13.0  | 74.7                            | 0.8  | 7.6         |
| The flexibility available to balance work and non-work commitments | 11.3                              | 14.1  | 73.8                            | 0.8  | 7.6         |
| All things considered (i.e. the job overall)                       | 3.9                               | 13.1  | 82.1                            | 0.8  | 8.0         |

**Total (N=2,133)**

Source: 2014 NDIS DSP employee survey, Question B12.

### 3.4.7 Impacts of the NDIS on the disability sector workforce – Evidence from in-depth qualitative interviews

Interviews with disability service providers and representatives from workforce stakeholder organisations indicated a number of impacts the NDIS has had on the disability sector workforce. NDIS participants and staff working within the NDIA highlighted additional workforce impacts.

#### *The perspective of NDIS participants and their family members or carer*

- 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.
- 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 occasions of care. They also perceived some workers to lack specialised training.

#### *The perspective of the service provider and workforce stakeholder 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 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 working conditions.

- As had been emerging in wave 1, increased consumer demand had led some provider organisations in the NDIS trial sites to experience expansion and consequently hire more staff. However, providers were reported to be offering these roles as contract or casual positions at lower rates of pay and skill levels. As a consequence the hiring of less skilled workers was reported to be occurring within the sector. 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. (O3R 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)*

- The low hourly rate for supports funded by the NDIS was perceived to have led to increased staff turnover and agency staff being employed without appropriate qualifications or experience.
- Challenges with staff recruitment was also evident in the sector. These challenges included a lack of availability 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 sector to attract staff. Demand for therapy staff remained high in 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 W2)*

*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 W2)*

- 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 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 W2)*

- 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, this 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 W2)*

- In 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. In wave 2, workforce stakeholder 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 in 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 NDIS. Enhanced worker preparation and engagement was therefore considered necessary to improve worker readiness and understanding of NDIS principles and processes.

*What we would call workforce engagement, and that is about frontline workers being involved in discussions and decisions that an organisation makes to change or adapt in preparation for the NDIS. We are seeing quite a few organisations that are obviously concerned about the future of that organisation, how they'll position themselves, how they might need to introduce change to prepare or restructure themselves, and that's all fine for an organisation to have those processes but what we're seeing is that a lot of it is happening over an extended period of time behind closed doors and then you get that kind of, 'Oh, here's an announcement today,' with no consultation. (07R W2)*

*There needs to be a lot of work done in terms of educating the community and educating the workforce about what are the objectives of the NDIS, how will it work and what is the quality, vision and proposition for participants in the service system. (10R W2)*

### *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 W1)*

### **3.5 The NDIA Workforce: The Birth of a New Workforce – Evidence from In-depth Qualitative Interviews**

One of the chief impacts of the introduction of the NDIS has been the creation of a major new workforce within the disability sector – the NDIA workforce. The NDIA's target staffing level at full roll-out is planned to be 'below 3,000', down from the original estimate of above 10,000 (Senator Fifield, 2015). Interviews with NDIA staff allowed the evaluation to examine this workforce and their experiences of rolling out the NDIS.

- In wave 1, NDIA staff reported that the quality of their workforce was a positive aspect of the NDIS. In wave 2 NDIA staff again reflected on the high calibre of staff, and described a workforce of committed and extremely capable people. Respondents expressed the feeling that all staff were working together to achieve good outcomes.

*We've recruited some spectacular people who are incredibly skilled, and compassionate and ethical, all the things that we would want. (E01N W1)*

- The experience and diversity of staff was also reported as being of great benefit to the NDIA, particularly the requirement for knowledge, or lived experience of disability. This diverse range of staff knowledge within trial sites was viewed as providing an important and highly regarded resource for the operation of the NDIA.

*It's just unprecedented to work in an environment where you have that level of skill and experience amongst the people that you're working with, I think, and the diversity that we had to draw on with each other. (B14N W1)*

- However, managers noted the challenge of keeping 'ahead of the game' and being strategic in planning for recruitment and changes to workforce structures over time. A lack of career opportunities outside of National Office was a particular problem that was identified. One Manager reflected on the challenge of 'keeping (good staff) long enough until other opportunities open up towards the full Scheme' (C03N W1).

*As an employee I feel that I've gone backwards in my career, I've de-skilled. I think you'll find a lot of people would say that and I've also been significantly disappointed with the supposed opportunities that were meant to be here and weren't... all these changes don't necessarily you know surprise me but personally for my career it's been a disaster coming here. (D05N W2)*

- There was a concern that staff retention would be adversely affected as the NDIA evolved in the future. Retaining agency staff in local offices was becoming difficult as more NDIA sites opened up and disability sector organisations sought NDIA staff expertise.

*Well workforce is a massive challenge for me, creating, getting sticky staff as we say ... Sticky staff, staff that stick... my staff are really now becoming highly sought after by the provider sector. Because they know NDIA very well so retention will be a big issue for me. (B01N W2)*

### **3.5.1 Workload pressure – Evidence from in-depth qualitative interviews**

- NDIA staff across all trial sites and positions reported high workloads and work pressures. Role-specific responsibilities were contributing to workload pressure. For planners, work stress related to the pressure to complete plans; for LACs, the high caseloads to facilitate plan implementation; and for Business/Regional Support Officers, the administrative tasks associated with planning and plan implementation. Respondents reflected on the need to work very long days, including weekends and outside regular office hours to meet the demands of their role.

*The workload's huge. It's massive. So it's impossible to do it in a reasonable week. (E01N W1)*

*I'm taking work home, I'm doing it on the weekends, my flex is up to a week. I had 38 hours, other people had more. And people were encouraged to come in on the weekend and they were tired during the week. (E04N W1)*

- At the time of the wave 2 interviews NDIA staff were preparing for the beginning of full rollout of the NDIS in July 2016. They reported that workload pressures were intensifying as timeframes to meet targets came closer.

*We're being told that we now have to do, complete all our reviews for up until the 30th of June next year by the 31st of March. So we're back into this pressurised, pressure cooker of having to do ridiculous amounts of work in very limited time to try and get, really, to support the new offices that are about to rollout, and we're just exhausted, we're really tired, to know that we're about to actually be asked to once again, put in an enormous amounts of effort, yeah. It's challenging. (B12N W2)*

- Many staff described a perception that the KPIs for the NDIA were 'all about the numbers' rather than quality of plans. High workload contributed to feelings of not doing a good job; of increasing potential of making mistakes; and guilt for not undertaking work that was felt needed to be done but not prioritised. Work stress was linked to high rates of resignations and in some cases adverse health impacts for staff.

*There were... numerous times when I considered leaving the Agency purely because of the level of pressure and the impact that it was having on my health. (A06N W1)*

*A lot of the original cohort are now looking for jobs, and also people who've recently come are looking for jobs elsewhere, because they just can't sustain the hours that they're working and the pressure that's on them. (D02N W1)*

*There's a lot of meltdowns happening. It's just the stress. It's just very, very busy. (D06N W2)*

- Concerns regarding stress and burnout amongst NDIA staff had increased by the wave 2 interviews as the NDIS moved towards full roll-out. Staff anticipated that the difficult working environment during the trial would be continuing for some time.

*A lot of people here, of course, have really struggled with the changes over the last two and a half years. They're burnt out. It hasn't been well managed. They're at the end of themselves because this is the point at which we believed that we would actually have, now things would settle, now we'd have an understanding of what we needed to do. Now, we'd be starting to,*

*you know, be to bedding things in. In actual fact the next three years will be more chaos and it's really going to take up to five years for anything to be settled and for us to have any sort of effect there and agency maturity in terms of process and dealing with that. That's really, really, really challenging for people here. (B14N W2)*

- Respondents believed that the NDIA did not always provide the supports staff needed to manage stress and other challenges in the workplace. NDIA staff reported a lack of responsiveness by supervisory staff when support to manage workplace stress was requested. This lack of support was attributed to a high turnover of staff in supervisory positions, managerial workload pressures and some staff in these roles lacking management skills and experience. There were particular concerns that the support needs of NDIA staff with disability were not being met.

*Staff with disabilities have been let down time and time again, which is a real shame, given the agency we work for... like assistive technology not being transitioned properly, not having people on it, people not being onboarded properly. We've got staff starting on disability and their desks aren't set up for them properly. No follow up on the kind of supports that they need. Not having a good understanding of what services are out there... we should just know better. We really should, there's no excuse for it. So that's been quite challenging. (E07N W2)*

- The experience of having staff leave or continually having to support the 'on-boarding' of new people was felt to be a stressor in its own right. There was also reflection on the particular problems associated with frequent changes of management, leading to organisational instability.
- Respondents perceived that the NDIA had misjudged workload expectations such that resource modelling did not match demand.

*We've been generally under resourced in terms of being able to do a really good job... I think when the original modelling was done it was all best guess stuff so the Scheme's still working out how long does it take to write a plan or a review plan and how many should people be doing a week and all those types of things are areas that need ongoing work. (D07N W1)*

- Workload pressures were exacerbated by problems with the IT system. The system was considered time consuming and difficult to use as well as being cumbersome, slow and hard to teach new staff as it lacked logical progression or intuitive steps. These problems were increasing workloads, creating frustration and affecting service delivery and timeliness.

### **3.5.2 Role-specific challenges – Evidence from in-depth qualitative interviews**

There were a number of challenges that differentially impacted on NDIA staff depending on their role within the agency.

#### *Planners*

- The role specific challenges for planners were primarily related to workload but were also due to the high administrative burden arising from planning processes. This was in part because the time allocated for planning had substantially been reduced over time, in response to imperatives to complete plans and because of inefficient IT systems.

*We hired people on the basis that the modelling was that 60 per cent... of planner time would be working with families... That's never been true from the beginning and hasn't got a lot better, so that, it's probably more 20, 30 per cent forward facing participant time; the rest is heavily stuck at a computer doing administration. (C03N W1)*

*I am looking elsewhere... I don't think it maximises my skills and I certainly don't get stimulation from it... I feel like I'm just going to be pushing buttons on a computer and there's not going to be a lot of – a lot in it for me as a professional... it's not a long term or a medium term satisfaction role for me. (B02N W2)*

- For many planners, the tension between needing to complete plans and wanting to spend more time with participants led to perceptions that the quality of planning and resultant plans was declining, and the person-centred philosophy of the NDIS jeopardised. This contributed to a level of job dissatisfaction and disillusionment that in some cases resulted in staff leaving the organisation.

*Are we developing good plans? Are we giving enough support for the plan to be implemented? Probably no. (E05N W1)*

*One of the big reasons why people are leaving, 'cause they feel that they're not being true to the values and the sort of expectations that they have. And that is always going to be a tension, and a tension that we have to manage. (D02N W1)*

#### *Local Area Coordinators (LACs)*

- Challenges specific to the role of LACs related largely to perceptions that they were not doing what they were employed to do. Many felt the specific skills and connections to the community that they brought to the position were not being utilised. All of the LACs who were interviewed described being required to spend the largest portion of their time supporting the planning process and plan implementation. This situation led to widespread dissatisfaction and concerns of de-skilling.

*The LAC role... became very attached to the Planner role, and became all about plan implementation. And I got very quickly bored and frustrated with that and felt that my skills weren't really being used and I wasn't being stimulated or really building my expertise very much in that space. (D02N W1)*

*I have found that very difficult to cope with, in that it's been disrespect for our skillset, and our career objectives for ourselves, that we came on board with the passion and the enthusiasm for the NDIS, and what that means to people with a disability, and wanting to be in that space. But we had to put all of that aside for operational requirements, and getting these plans through... people who came in here as local area coordinators, while they've picked up other skills in other areas like planning... but for those people who wanted to fill that role of community development, they've put their career on hold for two years. (B04N W2)*

- In several trial sites, however, there was evidence that the LAC role was changing overtime. For example, in TAS and NSW in particular, LACs were undertaking more community engagement and community development activities.
- In TAS, the Local Area Coordination role was outsourced. There appeared to be different views of the success of this approach. The LACs themselves while seeing advantages to being based in community settings, acknowledged the challenge of 'having two masters' and keeping in touch with the NDIA. In contrast to the mostly positive views of LACs, other staff (managers in particular) saw problems associated with the out-sourced model.

*Most other launch sites have had the flexibility to use their, to direct the practice and exactly what Local Area Coordinators do... we have to go through a very formal process... and it takes*

*a lot of time... I think it's been demonstrated that it's not value for money. (C03N-Manager W1)*

- In VIC, an organisational re-structure led to the establishment of a specialist team tasked to undertake community engagement. This was considered positively for the most part, with one respondent explaining the drawback of the previous model which involved participants being allocated to any staff member, regardless of age, disability type, or staff expertise *'so you ended up (being) almost like a Jack of All Trades, Master of None'* (B10N W2). LAC who were not in the specialist engagement team, however, had concerns about the future of their role. As in the SA trial site, there was expectation that the planner and LAC roles would be combined into the future.

*There's talk about how the Local Area Coordination role will change into a plan support coordinator... so it's hard to work in amongst that speculation all the time when we really haven't had the opportunity to see the original model that we applied for and had a high expectation of the dream job... it's a very challenging environment to stay focused and stay positive amongst. (B04N W1)*

#### *Plan Support Coordinators (PSCs)*

- As part of the rollout of the NDIS in July 2014, the ACT and NT trial site started operation staffed with PSCs, rather than planners and LACs as in other trial sites. The principal challenges identified by staff in these roles related to the pressures of workload and in finding time to undertake plan implementation and community engagement (the LAC component of the role).

*A lot of our time is spent in that planning phase and you almost resent when people call up and need help with organising things because you just haven't got time to help them, and that's a big issue with a lot of us at the moment, that we're just feeling that we haven't got the time to fully do the job that we've been hired to do. (E02N W1)*

- Workload pressures in the ACT were leading to the outsourcing of plan implementation. Wave 2 interviews indicated that plan implementation was often left to Business Support Officers.

*The way that we're heading is to have the coordinators external to the agency... I think potentially some people may only need them for their first plan, just to help set things up and then they'll be fine from then on. (E08N W1)*

#### *NDIA staff in regional and remote areas*

- Several NDIA staff reported organisational and staff challenges for the NDIA in regional and remote locations. At an organisational level, challenges included the 'tyranny of distance', difficulties with engagement and disseminating information in small communities, and supporting NDIA teams in small regional offices. Staffing pressures and workloads were exacerbated in smaller offices as staff who were absent due to leave or assisting in new NDIA offices could not be backfilled in their absence.

*Just being able to make sure we can support people taking decent amounts of leave... in (smaller offices) we've rarely ever been able to backfill extended leave and we've had a couple of planners take up other opportunities for, you know three month stints in engagement or interstate, and when they go we can't, we have very little capacity or options for people to backfill for that length of time... for small offices it's really, really difficult and even one person not being there makes the whole office barely viable to even maintain. (C03N W2)*

- NDIA staff working in small regional offices reported isolation, difficulties seeking assistance from city based colleagues and feelings that *'you can easily get forgotten out here'* (A02N W2).

### 3.5.3 Training and supervision – Evidence from in-depth qualitative interviews

- Respondents identified areas where further training would benefit NDIA staff and improve outcomes for participants. Training deemed necessary included improving the ability of staff to identify and monitor participant capacity to implement their plan; support for self-management; and training in specific disabilities to assist with making decisions about what were reasonable and necessary supports.
- A number of respondents suggested the need for more role specific training and the availability of ongoing training.

*It's highly, highly important that the staff are adequately trained, just because of our role, just because of the demographic that we are supporting. (A08N W1)*

- The challenge though, was the lack of time for training, and also the limited availability of this. Ongoing training appeared to be principally provided 'in-house' (i.e. within trial sites), with a focus on Agency based training needs. Several staff indicated appreciation of 'lunchbox' sessions where:

*There's a whole programme of events for a couple of months so you know what's on, when it's on... (the Trial Site Manager) gets speakers or if somebody's got... expertise within our team, our group, that person then prepares it and delivers it. But they've been very, very good. (D06N W1)*

- Training and ongoing professional development activities was of particular importance for staff with an allied health staff background who needed professional development hours to maintain their professional registration. One respondent suggested the absence of professional development opportunities contributed to the problem of staff resignations:

*There's a lot of health professionals... who are looking at, you know, 'well I can do this for a couple of years, but then if I stay here too long I'm going to have to then do a two year refresher course on my allied health professional qualifications because I've pretty much let my skills lapse'. So we've also had people that are going, 'you know what, I'm not doing that, I'm getting out now'. (A06N W1)*

### 3.5.4 Factors impacting staff morale – Evidence from in-depth qualitative interviews

The final set of challenges for NDIA staff highlighted by the interviews related to factors impacting on staff morale.

- Managers in particular, were conscious of the effect of negative media on staff confidence. NDIA staff likewise considered the circulation of misinformation as a challenge for the agency and staff, especially the impact of social media.

*There's a huge amount of misinformation that goes on out into, in the community particularly on social media. I mean one of the biggest challenges for us is there is no other major agency or Government reform that has been implemented in this day of social media. So you can have somebody sitting at a planning conversation believing that somebody's said something and they can have it posted on Facebook within half an hour after their visit. You know they can be derogatory towards the planner. (A07N W2)*

*And then there's all the rampant rumours and the Facebook stuff about NDIA have run out of the money, it's just a trial so the government's going to, obviously it hasn't worked and the government's going to pull it and all those sorts of things. (A08N W2)*

- Respondents also suggested a key challenge for staff was managing their response to distressed and anxious NDIS participants and their carers. This situation was most problematic for the trial sites targeting young children with disabilities (i.e. SA and ACT during first phase-in), where parents may still be in shock and grieving following recent diagnosis.

*It was really hard for our staff, brand new, dealing with parents who were so traumatised and really hard for parents who, you know, like first cab off the rank, here they were having people talk to them about ... their child and disability services. (E01N-Manager W1)*

- Many noted an unmet need for specialist staff support and supervision to assist NDIA staff with the emotional demands of their work.

*We're dealing with people's emotions... for instance that example I gave before about the person coming in today in crisis with their child. We're dealing with that regularly; not once a day, but many times a day. And you know... any other professional... would have support (and) supervision... when you're dealing with people in a vulnerable situation. We don't have that sort of support. We might have a manager we go to discuss that, but we don't have that level of emotional support. (C05N W1)*

## 3.6 Summary

We provide below a summary of the key quantitative and qualitative evaluation evidence relating to the disability sector and its workforce.

### 3.6.1 The disability sector

*Evidence from large scale surveys*

- As the roll-out of the NDIS progressed, changes were identified in the provision of disability supports. The average number of services provided by disability support providers and self-employed providers declined over time. In particular a decrease in the proportion of organisations offering advocacy, information and communication support, and early interventions occurred.
- Community access and personal support were the two most common service types provided by disability organisations, while self-employed providers most commonly reported providing therapeutic and early intervention services. This did not change over time.
- Most of the planning by disability service providers to adapt to the new demand arising from the NDIS occurred in wave 1; only around a quarter of provider organisations were planning to expand their range of supports further in wave 2.
- By wave 2 providers were much more certain about the impact the NDIS had had on their organisation. While many providers continued to feel that this impact was positive, the proportion reporting negative impacts from the NDIS rose sharply by wave 2.
- The expected positive impacts of the NDIS reported by providers in wave 1 (on employment, support charges, wage growth and overall performance), were largely consistent with the actual and expected future impacts identified in wave 2.
- The number of activities being undertaken by providers in response to the NDIS increased over time. In particular, in wave 2 more disability service providers reported engagement with LACs, expansion of their workforce and changing staff types to meet service demand.

- The total funding received by disability service providers for the provision of disability supports had increased considerably by wave 2. Moreover, as the proportion of funding received from the NDIS increased, the proportion from government, non-government and private donations declined. Self-employed providers also experienced a decline in funding from user fees/direct payments.

*Evidence from in-depth qualitative interviews*

- Market changes were slow to materialise, due to a slowly adapting or emerging provider sector. 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 NDIS was not yet considered to have hit the sector. However, concerns about financial viability continued throughout the evaluation and included reports around unfunded work, funding for cancelled appointments, adaptation to the payment in arrears system and NDIS pricing.
- Providers were concerned about their capacity to deliver supports to the same standard as before the NDIS, citing the NDIS model of individualised funding and caps on service prices as a constraint.
- The entry of new providers into the NDIS trial sites was widely reported in 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 in the disability sector over time.
- Some exits from the sector were noted, either through organisational 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 NDIS due to issues with pricing and best practice.

### **3.6.2 The disability workforce**

*Evidence from large scale surveys*

- Most NDIS participants reported receiving services from disability support workers and were highly satisfied with the quality of care they received.
- Overall disability workers reported high levels of job satisfaction. They were particularly satisfied with the work itself and the sense of achievement gained. Disability workers were also confident that they had sufficient skills and abilities and were able to use these in their work.
- Although the size of the disability organisations surveyed varied considerably, the average organisational size increased from wave 1 to wave 2 (from 71 to 84 employees).
- The most common direct care occupations in the disability sector across both waves 1 and 2 were disability support/residential support workers. The proportion of workers in this role grew from two-thirds of the workforce in wave 1 to three-quarters in wave 2. The occupational profile of the remainder of the direct care workforce changed little over time.

- The disability sector is a female-dominated industry; three quarters of the direct care workforce in both waves 1 and 2 were female.
- Although permanent employment remains the most prevalent form of employment for the disability workforce, a growing trend of casualisation was seen over time.
- The length of employee tenure had declined by wave 2, and particularly for allied health workers. This could be indicative of growing issues with staff retention in the sector.
- The use of agency workers decreased over time. Agency staff were most commonly used to fill disability support/residential support worker positions.
- Contrary to concerns raised in the qualitative interviews, the level and type of training provided to disability support workers was relatively stable across time.
- Low levels of under-skilling and skill shortages were reported in both waves 1 and 2. Skill shortages were primarily attributed to a lack of specialist knowledge and were most commonly reported for disability support/residential support roles.
- A majority of disability service providers reported having no staff vacancies. While few unfilled vacancies were reported overall, the number of service providers unable to fill allied health worker positions doubled between wave 1 and 2. This corresponds with the qualitative evidence and suggests that allied health workers are in shortage.
- The proportion of organisations intending to hire new workers over the next 12 months increased over time. Strong future demand for disability support/residential support workers, service or programme administrators/manager/coordinators, personal care/home care workers and allied health staff was noted.
- Experience and motivation were the two most common attributes disability providers reported looking for in new applicants. These were considered to be relatively more important than formal qualifications and references.

*Evidence from in-depth qualitative interviews*

- The workforce was reported to be expanding in wave 2; however, this was occurring in the context of concerns about skill shortages, employee recruitment and retention, increased turnover and churn, unfunded work, more casual and less well-paid work, remote provision and lower quality of provision.
- 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 their lack of specialised training.
- Concerns about conflict between industrial relations responsibilities and NDIA pricing constraints were persistent throughout the evaluation. 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 working conditions.
- 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 into the sector.

### 3.6.3 The NDIA workforce

- One of the chief impacts of the introduction of the NDIS has been the creation of a major new workforce within the disability sector – the NDIA workforce. Interviews with NDIA staff allowed the evaluation to examine this workforce and their experiences of rolling out the NDIS.
- NDIA staff reported that the quality of their workforce was a positive aspect of the NDIS. Staff retention was a concern, however, and was projected to become more difficult as the NDIS roll-out progressed.
- NDIA staff across all trial sites and positions reported a high workload, which contributed to considerable work stress. Work stress was linked to high rates of resignations and in some cases negative health impacts for staff. Concerns regarding stress and burnout amongst NDIA staff increased over time as the NDIS moved towards full roll-out.
- Respondents identified areas where further training would benefit NDIA staff and provide better outcomes for participants. This included improving the ability of staff to identify and monitor participant capacity to implement their plan, support for self-management, and training about specific disability types to assist with reasonable and necessary decisions.
- There were a number of challenges that differentially impacted on NDIA staff. The role specific challenges for planners were primarily related to workload but also to high administrative burden arising from planning processes. Challenges specific to the role of LACs related largely to perceptions that they were not doing what they were employed to do. Many felt the specific skills and connections to the community that they brought to the position were not being utilised. The principal challenge identified by PSCs related to the pressures of workload, and in finding time to undertake plan implementation and community engagement.
- NDIA staff reported several areas of improvement which were required. NDIA staff wanted to be able to utilise their skills more fully and for the agency to offer improved career opportunities to enhance both job satisfaction and retention of staff. More support from supervisors to manage workplace stress and high workloads was also highlighted. Moreover improvements were required in managing the support needs of NDIA staff with disability including ensuring access to assistive technology, setting up desks appropriately and better understanding of the services available to support these staff.

## 4. Choice and Control (Including Self-Management)

### Integrated findings

This section integrates and summarises the quantitative and qualitative findings relating to choice and control and its implications about consumer directed care in the NDIS.

The evaluation finds that:

- the NDIS leads to improved satisfaction with choice and control for the majority of participants, but not for all;
- for that majority, improvements with choice and control get stronger with longer time in the NDIS;
- the evaluation identifies specific sub-groups who do not enjoy this improvement in satisfaction as fully as other, with some reporting being worse off in the NDIS;
- most families and carers also report improved choice and control, however, at a lower level than people with disability themselves report;
- those who care for children with disability also report lower satisfaction with choice and control;
- around a quarter of families and carers report that their choice and control declined with longer time in the NDIS;
- the evaluation finds that there are still many family members and carers who can exercise better choice and control, but who appear to be struggling within the NDIS and who are asking for more care for the family rather than just the person with disability;
- overall the evaluation finds that consumer directed care has increased the satisfaction of a majority of NDIS participants; and
- at the same time the evaluation finds that consumer directed care does not work as well for all NDIS participants and that for some it brings negative outcomes, which in some cases become worse with longer time in the NDIS.

### *NDIS participants*

- Both the quantitative and qualitative evidence indicated strongly that joining the NDIS leads to improvements in the choice and control people with disability have over their supports. Our surveys asked all NDIS participants about their pre-NDIS experiences regarding choice and control. The quantitative evidence shows that compared to their experiences before the NDIS, the choice and control of most participants had either improved or stayed the same. Comparisons of NDIS participants with non-participants reiterated this finding. Compared to those not participating in the NDIS, NDIS participants were considerably more likely to report that they had a greater say over which supports they received and, even more positively, about where these supports were obtained than their counterparts outside the NDIS.
- Both quantitative and qualitative evidence agree, however, that not all NDIS participants are able to exercise more choice and control over their supports. Around a fifth of NDIS participants in the quantitative data in both waves 1 and 2 felt that they had little choice and control over their supports. The impact of the NDIS on perceptions of choice and control (relating to say over which supports were received) was found to be lower for participants with a mental/psychosocial disability. Moreover, NDIS participants who felt that their supports had decreased since joining the NDIS were more likely to report poorer choice and control.

- The qualitative evidence further supports and illustrates the finding that vulnerable groups (and particularly those with intellectual disability and complex needs), those NDIS participants who were unable to navigate the NDIA website to obtain information about services and providers, and those who were less able to articulate their support needs, all experienced poorer choice and control over their supports. The qualitative interviews highlighted a consistent need for better advice and assistance around planning and plan implementation including the role of advocacy to assist in improving choice and control for all NDIS participants.
- Mixed results were found regarding the relationship between the location of the NDIS participant and perceptions of choice and control. While no significant differences were found in the quantitative evidence between NDIS participants living in urban and rural areas, the qualitative evidence showed that effective choice and control was more difficult in rural and remote areas. This was primarily due to limited numbers of service providers and the longer waiting lists outside the main urban centres in the NDIS trial sites.
- Both quantitative and qualitative evidence indicated that for many NDIS participants, further improvements in the choice and control people with disability have over their supports occurred with longer time in the NDIS. The qualitative interviews suggested that increased levels of choice and control occurred over time as a consequence of NDIS participants becoming more familiar with the NDIS and its processes and language. Increased funding of support co-ordination or case management services in wave 2 was also considered to have improved communication with service providers.
- The qualitative interviews highlighted many of the ways in which NDIS participants were utilising their enhanced choice and control. While initially NDIS participants typically sought more frequent and intensive support rather than different types of support, by wave 2 there was evidence that this had changed. With longer time in the NDIS, participants were increasingly likely to request additional types of supports and also to change service providers. A greater demand for improved flexibility in the timing, location and provision of supports was also seen.
- Both sources of evidence suggest that a majority of NDIS participants wanted to have more choice and control over the supports they receive. The qualitative evidence allows us to understand in-depth what constrained the ability of NDIS participants to exercise effective choice and control. Constraints included a lack of service providers, waiting lists for services and limited information about provider options. In addition, while increased flexibility of service provision was noted within the disability sector, some service providers were unresponsive to changing client requests. The use of service contracts to formalise support provision was considered to be a further impediment to those who sought more choice and control.

#### *Family members and carers*

- Both sources of evidence found that family members and carers reported high levels of satisfaction with the choice and control they have over the supports of the NDIS participant they care for. The quantitative evidence showed that most carers felt that their levels of choice and control had increased over time in the NDIS, around a quarter reported that their choice and control declined between waves 1 and 2.
- While the quantitative evidence indicated that the NDIS had a positive impact on carer satisfaction over their choice and control, this impact was lower than for the NDIS participants themselves. Also carers of participants with a mental/psychosocial disability reported lower levels of choice

and control (both in regards to what supports were received and where these were obtained) than carers of people with other disability types. While still positive, the impact of the NDIS on carer choice and control was less for the carers of child participants compared to those caring for an adult with disability.

- While the quantitative evidence found a small but positive impact of the NDIS on the ability of carers of NDIS participants to take adequate breaks from their caring role, both data sources indicated that many family members and carers struggle to have time away from providing support and to access adequate carer support and respite services. In particular, the qualitative evidence across the evaluation period consistently found that many family members and carers of NDIS participants (particularly of young children) wanted greater attention to be paid to the family context and carer needs in planning and review processes.

#### *Self-managed plans*

- Both the quantitative and qualitative evidence indicated that only a minority of NDIS participants had chosen to self-manage their NDIS funding and that levels of uptake did not increase over the duration of the evaluation. The qualitative evidence showed that the administrative activities associated with self-managed funding was off-putting for many NDIS participants and their family members and carers. Concerns were also raised about a lack of safeguards within the NDIS to protect against potential fraud or financial mismanagement. However, those who decided to self-manage their NDIS funding were positive about the benefits of doing so, principally in relation to having greater choice and flexibility over service provision including opportunities to access non-NDIS registered service providers and support workers.

## 4.1 Introduction

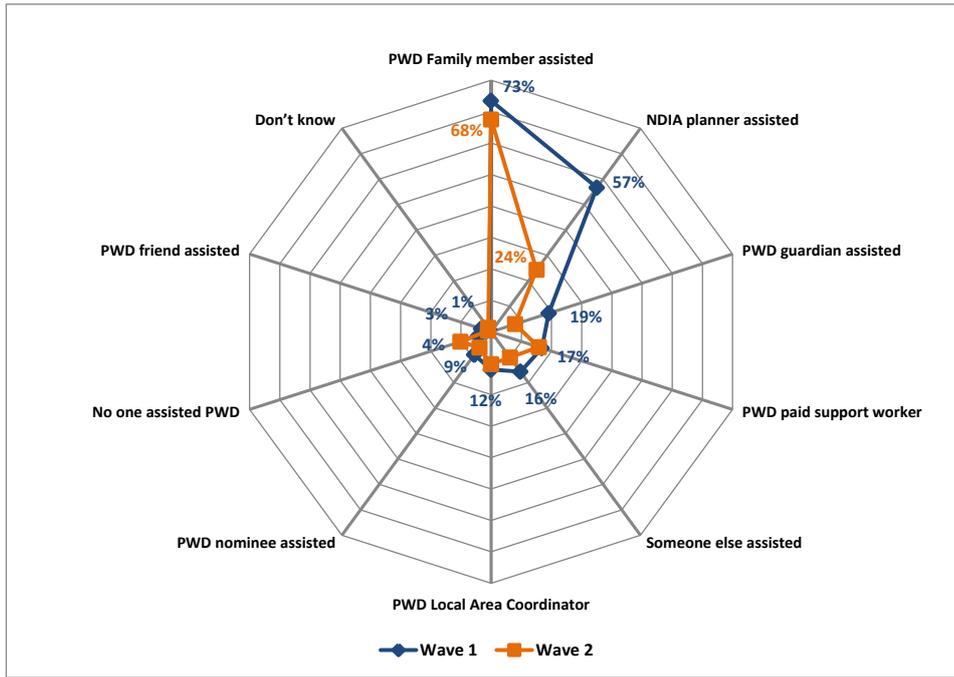
The concepts of choice and control are at the heart of the NDIS. One of the central aims of the NDIS is that it will support people with disability to have choice and control to help them reach their goals and also to help in the planning and delivery of their supports. Choice and control is also a central focus of many of the 58 KEQs which guide the NDIS evaluation. In this section we present evidence relating to KEQs which pertain to 'choice and control'. Specifically we review the extent to which people had choice and control over the development and implementation of their NDIS plans. We further assess the extent to which NDIS participants and their carers had choice and control over their supports and how this has changed over time. We also separately analyse the prevalence of self-managed plans and associated benefits and costs.

## 4.2 Development and Implementation of NDIS Plans

### 4.2.1 Making plans with the NDIS – Evidence from large scale surveys

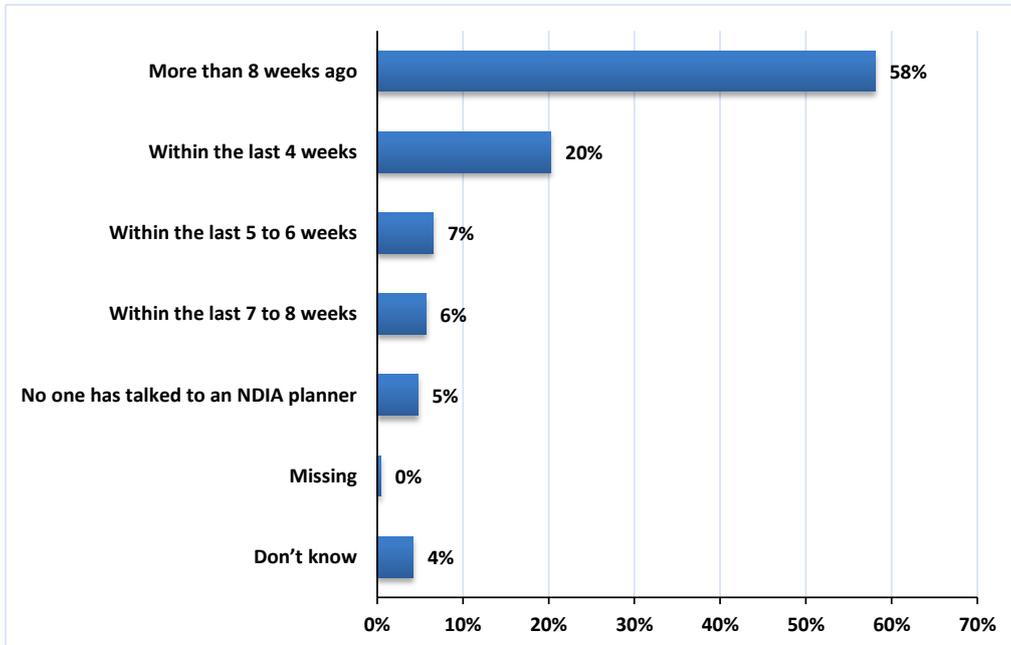
- Ninety-two per cent of NDIS participants had a support plan already approved by the NDIA at the time of completing their survey in both wave 1 and 2 (Appendix Table A4.1).
- Figure 4.1 below and Appendix Table A4.2 show the sources of assistance received by NDIS participants in making decisions about the support arrangements to be included in their plan in wave 1 and 2.
- In wave 1, 94.6 per cent of NDIS participants obtained assistance from other people in making decisions about their plan. Assistance was primarily provided by family and guardians (73 per cent and 19 per cent respectively) and by NDIA planners and LACs (in 57 per cent and 12 per cent of cases). A substantial role was also played by support workers (17 per cent) and to a lesser extent, by nominees (9 per cent) and friends (3 per cent). Sixteen per cent of NDIS participants reported that 'someone else' had assisted them in their decision-making. The qualitative evidence would suggest that the category 'someone else' would consist largely of either advocates or disability service providers.
- In wave 2, there was an increase in the proportion of NDIS participants reporting that no one had assisted them to make decisions about the support arrangements to be included in their plan (from 4 per cent in wave 1 to 10 per cent in wave 2). Also of note, there was a large decrease in the proportion of NDIS participants obtaining assistance from an NDIA planner (from 57 to 24 per cent) and from a guardian (from 19 to 8 per cent).

**Figure 4.1 Person with disability: Did any of the following people assist in making decisions about the support arrangements in the plan? (Trial, All ages)**



- In wave 2, NDIS participants were also asked about the last time they had met or spoken with their NDIA planner (Figure 4.2 below and Appendix Table A4.3). Fifty-eight per cent of participants reported that it had been more than eight weeks since contact, while a further five per cent reported that they had never talked to an NDIA planner.

**Figure 4.2 Person with disability: When was the last time that you, or someone else on your behalf, talked to an NDIA planner? (Trial, All ages)**



#### 4.2.2 The experience of plan development and implementation – Evidence from in-depth qualitative interviews

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

##### *The perspective of NDIS participants and their family members or carer*

- In 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 participant 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 2. Some respondents indicated doing a great deal of preparation for the review appointment. However, there was little mention of information or resources being provided by the NDIA to support this, and some participants felt it was more beneficial to seek advice from an external advocate (paid and unpaid).
- In wave 2, nearly all respondents said that the planning process had become easier over time, due to increased familiarity with the NDIS, 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)*

*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 existing support. In contrast during wave 2 interviews, respondents showed familiarity and comfort with identifying their goals, and their plans became more aspirational with consideration given to the future in addition to daily support needs.
- In both wave 1 and 2 the experience and personal attitudes and beliefs of the planner were reported to influence the outcomes for the types of services included in plans.
- Across both waves of interviews, 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 to address their own needs.

- In 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)*

- Of note, the wave 2 interviews indicated awareness of 'standardised' funding amounts for particular types of disability or pre-determined severity of disability.

*Apparently my plan should only be about \$12,000. That's what a child that's leaving group early intervention services and then just taking on one-on-one therapy would get a package of no more than \$12,000. That's completely generous apparently, the \$12,000. I am getting \$18,500. (C12C W2)*

- 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 in wave 2. Feedback from respondents suggested that for many, this was a valued service which removed the burden and stress of communicating and coordinating 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 coordination providers were new to the trial site and lacked knowledge of local services.
- 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 are 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 previously discussed, plan implementation was frequently impeded by a lack of service providers, in particular outside the main urban centres of the trial sites.

*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 in 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.
- For NDIS participants who had identified employment as a goal on their plans, opportunities for volunteering or support in procuring employment were limited.

#### *The perspective of the service provider and other stakeholder groups*

- In 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 wave 2 NDIA staff observed a shift in the general mindset of NDIS participants away from accepting any services and supports that were available, towards being an active consumer. 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 had 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 in wave 2. The first was the need to be able to identify and monitor whether participants had the capacity to implement their plans (or required resources including local area coordination (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 W2)*

- 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 W2).'

### **4.3 How has Choice and Control Changed for NDIS Participants? – Evidence from Large Scale Surveys**

People with disability 16 years and older in the trial group were asked several questions related to the supports they received including:

- how much of a say they had over what supports they received; and
- how much choice they had over where they obtained these supports.

The same set of questions were asked about (i) the supports they had received prior to their NDIS participation; (ii) their current supports provided under the NDIS in wave 1; and (iii) their current supports provided under the NDIS in wave 2. Parents, on behalf of children participating in the NDIS and below the age of 16 years, provided the same information in the Family and Carer questionnaire as too did carers of people with disability aged 16 years or older.

#### **4.3.1 Comparing pre-NDIS with early NDIS experiences on choice over supports**

- A similar proportion of NDIS participants reported that their choice over where they obtain the supports they receive under the NDIS was either better (40 per cent) or had not changed (45 per cent) compared to prior to the NDIS. Fourteen per cent reported that their choice of where supports were obtained worsened once in the NDIS (Appendix Table A4.4).
- Thirty-eight per cent of NDIS participants reported that their say over what supports they receive was better in the NDIS compared to before they joined the NDIS, with 48 per cent reporting their choice was about the same and 13 per cent stating it was worse (Appendix Table A4.5).
- Both measures of choice and control provide a very similar message about the impact of the NDIS. They suggest an improvement in choice and control for a sizable minority, no change for about half of NDIS participants, and a deterioration for a minority (about 13 to 14 per cent).

#### **4.3.2 Moving from early to later NDIS experiences – description of choice over supports**

- Once in the NDIS, a majority of participants in wave 1 reported that they had either a lot or some say over what supports they receive (70 per cent, Appendix Table A4.6) and where they obtain these supports (66 per cent, Appendix Table A4.7).
- There is little evidence that time in the NDIS influenced the amount of say NDIS participants have over their supports. In wave 2, similar proportions of NDIS participants reported to have either a lot or some say over what supports they received (69 per cent) and where they obtained these support (65 per cent).
- In both waves 1 and 2, however, a sizable minority of NDIS participants reported having little choice and control over what supports they receive (16 per cent in wave 1 and 18 per cent in wave 2) or where these are obtained (19 per cent and 21 per cent respectively). The fact that little change has occurred in the proportions of NDIS participants reporting little or no choice and control over their supports is of concern.

#### **4.3.3 Has the NDIS changed the number of supports? – comparing pre-NDIS with early NDIS**

- In wave 1, people with disability were also asked to recall the number of supports they accessed prior to joining the NDIS and those accessed currently via the NDIS. In wave 2, NDIS participants were asked how the number of supports they accessed has changed in the past year. The number of supports received is a rough indicator of the choices available to people with disability. The expectation is that where choice improves, the number of different accessed supports is also likely to increase.
- In wave 1, 64 per cent of all NDIS participants reported that they accessed more disability supports under the NDIS than previously (Appendix Table A4.8). A further 20 per cent of participants had the same number of supports and 15 per cent had fewer supports. We note, however, that more supports cannot and should not be taken to also mean better supports.

#### **4.3.4 Number of supports combined with quality and choice measures - comparing pre-NDIS with early NDIS**

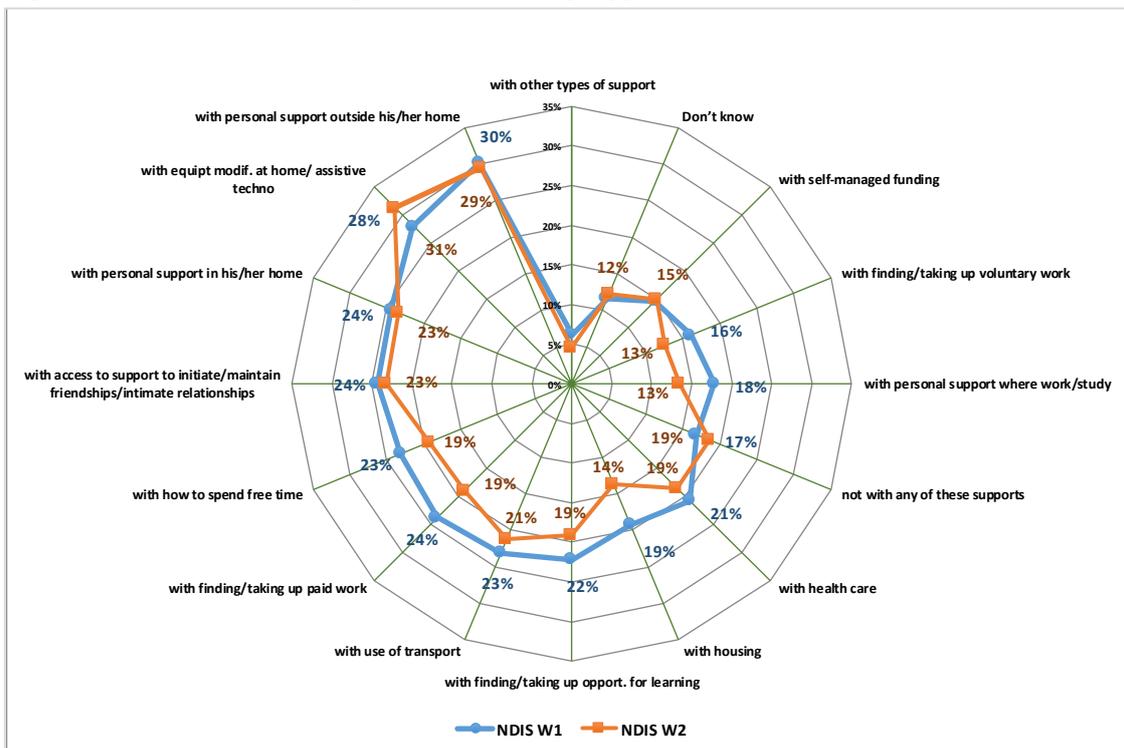
- The data on change in number of supports (pre-NDIS versus NDIS) was combined with the data on change in the two measures of choice and control (i.e. over what supports were received and where these were obtained) (Appendix Table A4.9 and Appendix Table A4.10). People with disability who reported that they were worse off in both measures of choice and control within the NDIS, were also more likely to have experienced receiving fewer rather than more supports within the NDIS. Of those participants who felt their say over what supports they received under the NDIS was worse, 16 per cent had less supports and 11 per cent had more supports. For NDIS participants with worse choice over where supports were obtained, 19 per cent had fewer supports and 12 per cent had more supports under the NDIS. The reverse relationships hold for those who reported to be better off within the NDIS in regards to both measures of choice and control.

#### **4.3.5 Areas of support where NDIS participants would wish to have more choice – comparing early and later NDIS experiences**

- A majority of NDIS participants (83 per cent in wave 1 and 81 per cent in wave 2) reported that they would like to have more choice over their supports (see Figure 4.3 and note that multiple answers were allowed in this question).

- Figure 4.3 presents the various types of supports over which NDIS participants reported they would like to have more choice. Notably, across both waves 1 and 2, there does not appear to be any specific type of support where additional choice is particularly demanded. Rather we have a picture where greater choice would be welcome for most supports by many people with disability.
- In wave 2, with the exception of supports relating to equipment/modifications at home/assistive technology there is a slight decrease in the proportion of NDIS participants reporting they would like to have more choice over each type of support.

**Figure 4.3 Person with disability: Areas of disability supports where more choice wanted (Trial, Adults)**



#### 4.4 Has Choice and Control Changed for Carers? – Evidence from Large Scale Surveys

- The quantitative data provides direct evidence of the views of carers regarding the impact of the NDIS on the choice and control they themselves have over the supports of the people with disability they care for. In both waves 1 and 2, carers reported very high levels of satisfaction regarding the amount of say they had about the supports the person with disability received (83 per cent in wave 1 and 77 per cent in wave 2, Appendix Table A4.11) and about where they were obtained (85 per cent and 82 per cent respectively, Appendix Table A4.12). A very small proportion of carers (less than 10 per cent in both waves) reported being dissatisfied with the amount of say they had over the supports of the person with disability.

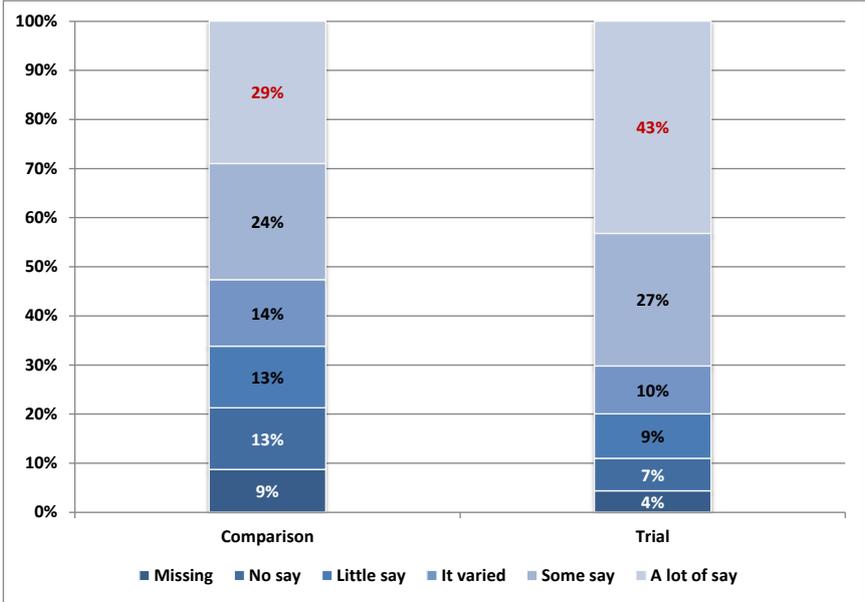
#### 4.5 The Impact of the NDIS on the Amount of Choice and Control over Supports – Evidence from Large Scale Surveys

- Further analyses were conducted to examine the estimated impact of the NDIS on the amount of say people with disability have about which supports they receive and where to obtain these supports (see Introduction section). Estimations were also conducted using longitudinal data to explore the effect of time in the NDIS on levels of choice and control.

### 4.5.1 What do NDIS participants think about choice and control?

- Figure 4.4 shows how people with disability felt about the amount of say they have over the supports they get, comparing the NDIS participant and comparison groups. In wave 1, 43 per cent of NDIS participants felt that they had a lot of say over the supports they received compared to only 29 per cent of the comparison group. This suggests that the NDIS is delivering more say to people with disability.

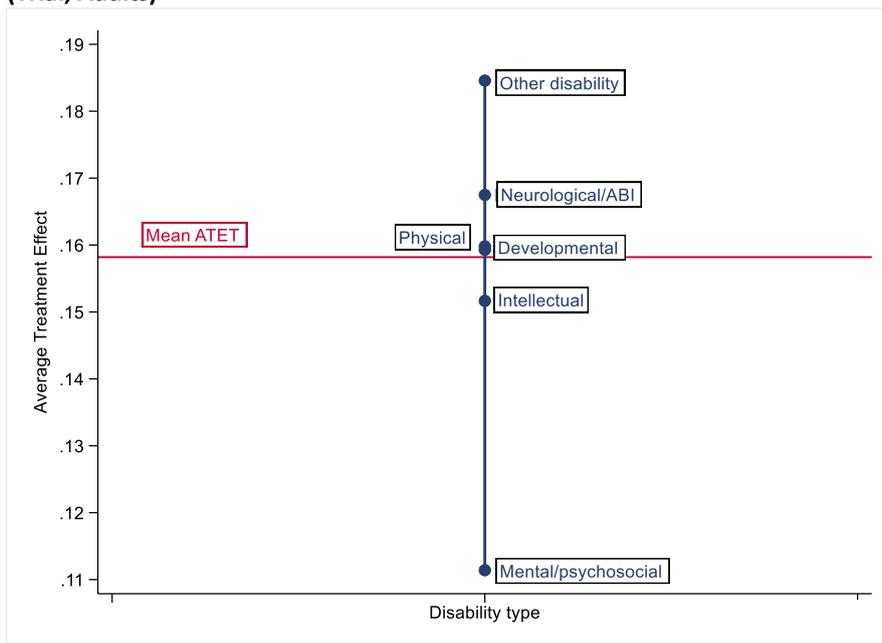
**Figure 4.4 Person with disability: Amount of say over what supports received by treatment status (Wave 1, Adults)**



- Appendix Table A4.13 reports the estimated impact of the NDIS on the choice adult people with disability feel they have over the supports they receive. Using a binary measure of choice and control, NDIS participants were estimated to be 54 per cent more likely to report that they have a lot of say about what supports they get as a result of participating in the NDIS.
- The difference in the impact of the NDIS on choice and control by type of disability (using a binary measure of choice and control) is shown in Figure 4.5 below. The average impact of the NDIS is represented by the horizontal line in the middle of Figure 4.5.<sup>10</sup> All disability categories that are named above that average do better under the NDIS than all those below the line. Adult NDIS participants with a mental/psychosocial disability (at the bottom of the Figure) were found to benefit comparatively less from the NDIS than adult participants with other disabilities. Thus we see that adult NDIS participants with a mental/psychosocial disability were about 36 per cent more likely to report having a lot of say over the supports they received (compared to those in the comparison group, that is, they were 36 per cent more likely to report having a lot of say because of the NDIS), which is much lower than the estimated average impact of the NDIS, according to which all NDIS participants are on average 54 per cent more likely to report having a lot of say *because of the NDIS*.

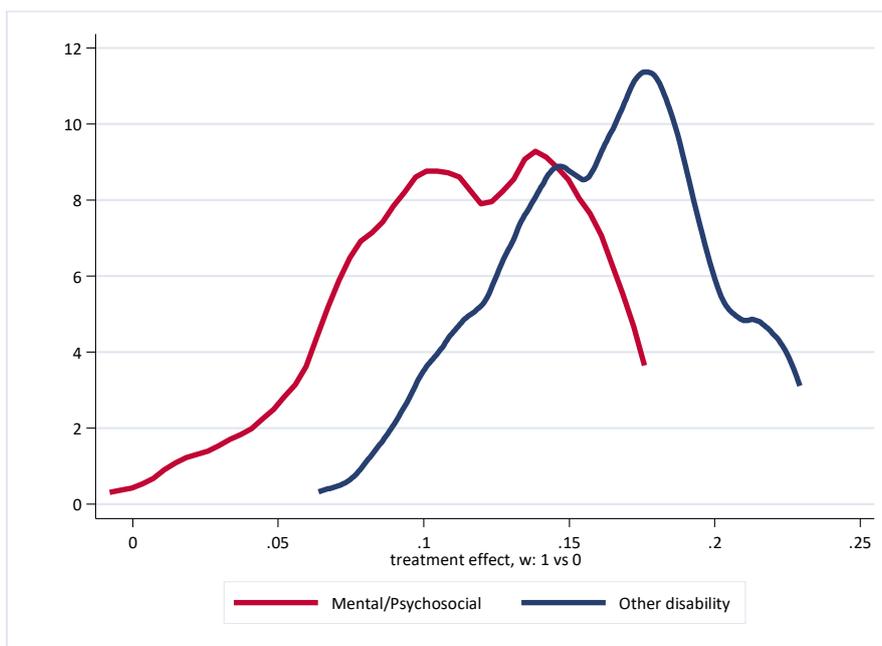
<sup>10</sup> The average treatment effect on the treated (ATET) is the scale used in these Figures. An alternative way to present the NDIS impact is in terms of the probability of being in an alternative category. In Figure 4.5 the average ATET of 0.16 can be translated into a statement that those in the NDIS have a 54 per cent higher probability of 'having a lot of say due to the NDIS' than their comparators who are not.

**Figure 4.5 Person with disability: Amount of say over what supports received - estimated conditional ATET by disability type (Trial, Adults)**



- Figure 4.6 below further illustrates the lower benefit from the NDIS on the choice and control of people with mental/psychosocial disability (compared to NDIS participants with other disability types). Poorer outcomes for people with mental/psychosocial disability were seen not only with regard to the average impact of the NDIS on choice over which supports were received, but also as to how the impacts were distributed between the two groups.

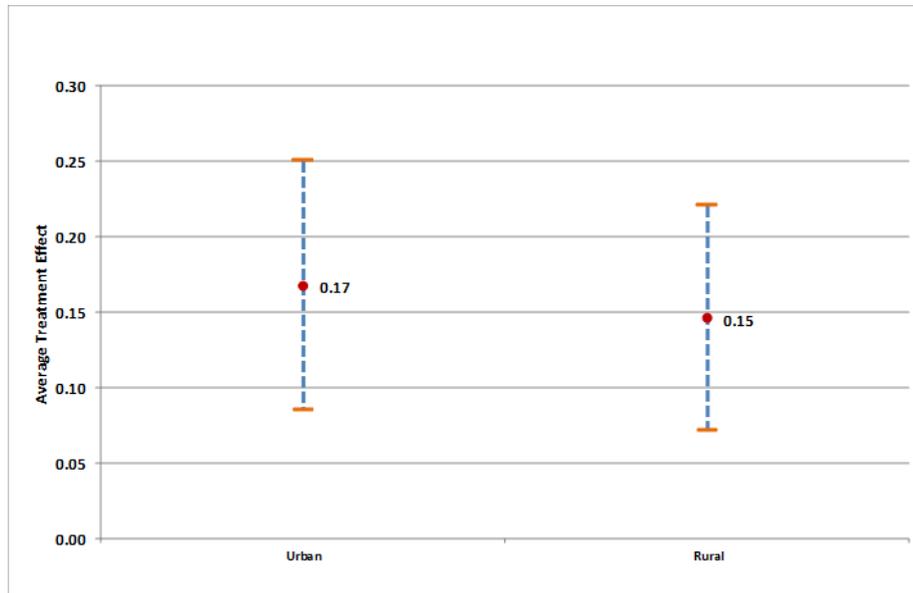
**Figure 4.6 Person with disability: Amount of say over what supports received - estimated ATET by mental/psychosocial disability vs. other disability type (Trial, Adults)**



- The estimated impact of the NDIS on say over what supports were received by geographical location is show in Figure 4.7 below. Although the positive impact of the NDIS was estimated to be

slightly smaller for NDIS participants living in a rural area, the difference is small and not statistically significant.

**Figure 4.7 Person with disability: Amount of say over what supports received - estimated ATET by geographical location, binary measure (Adults)**



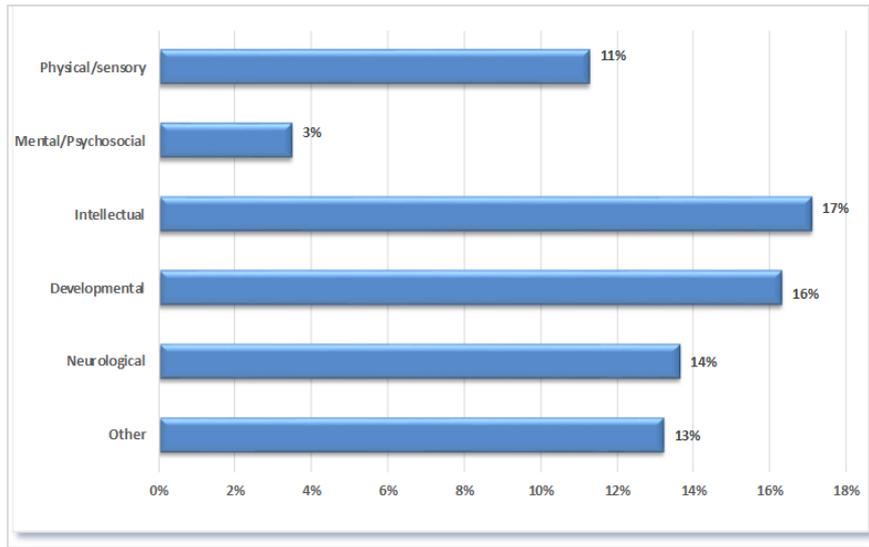
#### 4.5.2 What do carers think about choice and control?

- Since the survey for families and carers elicited information on choice and control from all carers, the impact of the NDIS on choice and control for people with disability of all ages (i.e. both adults and children) could be estimated.
- Appendix Table A4.14 and Appendix A4.15 report the estimated impact of the NDIS on the choice and control of carers of adult and child NDIS participants, respectively, using the binary measure of choice. The estimated impact of the NDIS on the say over supports that carers of adult participants have is very comparable to that found for the people with disability themselves (with an estimated impact of 46 per cent). The impact of the NDIS on the choice and control of carers of child participants was similar (41 per cent).
- The impact of the NDIS on say over supports was also found to be positive, but of a smaller magnitude when using a continuous rather than a binary measure. On average, the NDIS was estimated to have led to a 15 per cent increase in carer satisfaction about the amount of say they have over what supports the person with disability they care for received (Appendix Table A4.16). The estimated impact of the NDIS on the say of carers of children with disability was smaller (7 per cent, Appendix Table A4.17).
- Similar to the results obtained from people with disability themselves, the estimated impact of the NDIS on the reported amount of say carers of adult participants have over supports showed some heterogeneity with respect to the disability type of the NDIS participant (Figure A4.14 in Appendix). In terms of magnitude, when using a binary measure, the impact of the NDIS on choice and control for carers of adult participants with a mental/psychosocial disability was about half of that found overall (26 per cent compared to the 46 per cent for the whole sample). The impact of the NDIS

on the choice and control of carers of child participants also showed some heterogeneity according to disability type but to a smaller extent.

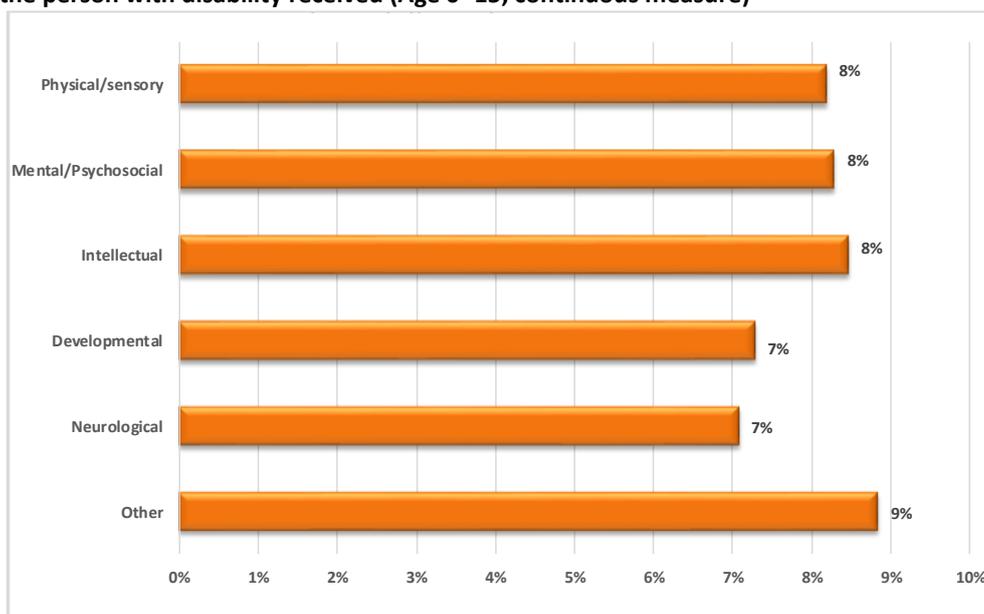
- When using a continuous measure of choice and control, carers of people with disability with physical, and more so with mental/psychosocial disability reported a smaller gain from participating in the NDIS (11 per cent and 3 per cent respectively) compared to other carers (Figure 4.8). Hence, for carers of people with a mental/psychosocial disability in particular, the benefit from the NDIS is quite negligible with respect to their ability to choose the supports they want.

**Figure 4.8 Carers: Conditional average treatment effects by disability type and the amount of say about what supports the person with disability received (Adults, continuous measure)**



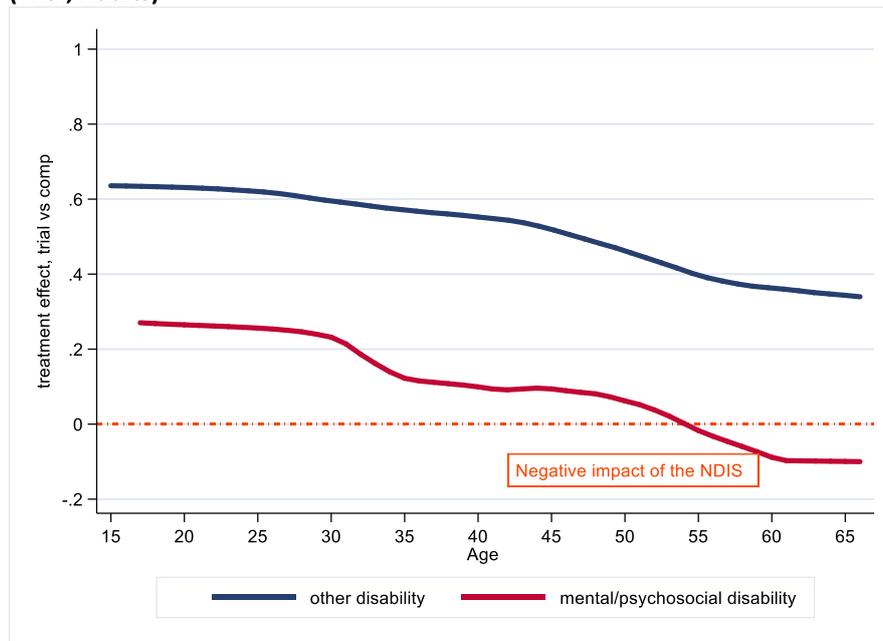
- In contrast, the impact of the NDIS for the carers of children with mental/psychosocial disability (8 per cent) did not differ greatly from the average effect found for all child NDIS participants (7 per cent, Figure 4.9). However, one must note that the estimates for the carers of children with a mental/psychosocial disability are based on a comparatively small number of observations.

**Figure 4.9 Carers: Conditional average treatment effects by disability type and amount of say about what supports the person with disability received (Age 0 -15, continuous measure)**



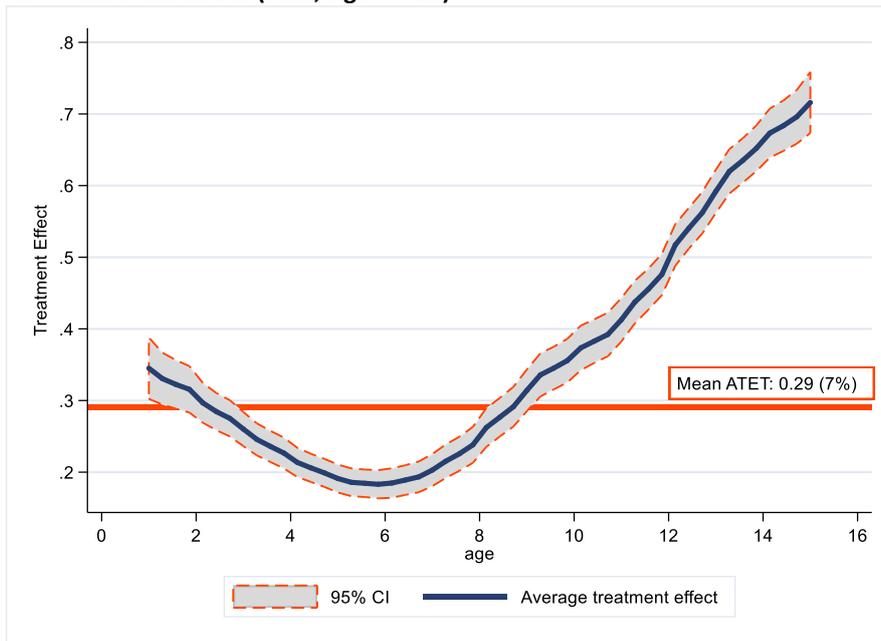
- Figure 4.10 below shows the distribution of the impact of the NDIS on carer satisfaction with say over supports according to the age of the adult person with disability. For NDIS participants with a mental/psychosocial disability, we find that the impact is negative for carers of 55 years and older people with disability. This suggests that for older people with a mental/psychosocial disability, carers either do not welcome more choice, or perceive that their ability to make choices on the type of supports received has decreased since joining the NDIS.

**Figure 4.10 Carers: Satisfaction with the amount of say on what supports people with disability receive - distribution of the conditional ATETs by person with disability age and mental/psychosocial disability vs. other disability type (Trial, Adults)**



- Figure 4.11 illustrates the relationship between the estimated impact of the NDIS on the amount of say carers have over supports and the age of their child. The estimated impact was not constant across children’s age; outcomes were lowest for the carers of children aged two to eight years old. The impact of the NDIS on say over supports increased sharply for carers whose child was aged eight years and older.

**Figure 4.11 Carers: Satisfaction with the amount of say to what supports people with disability receive - distribution of the conditional ATETs (Trial, Age 0 – 15)**

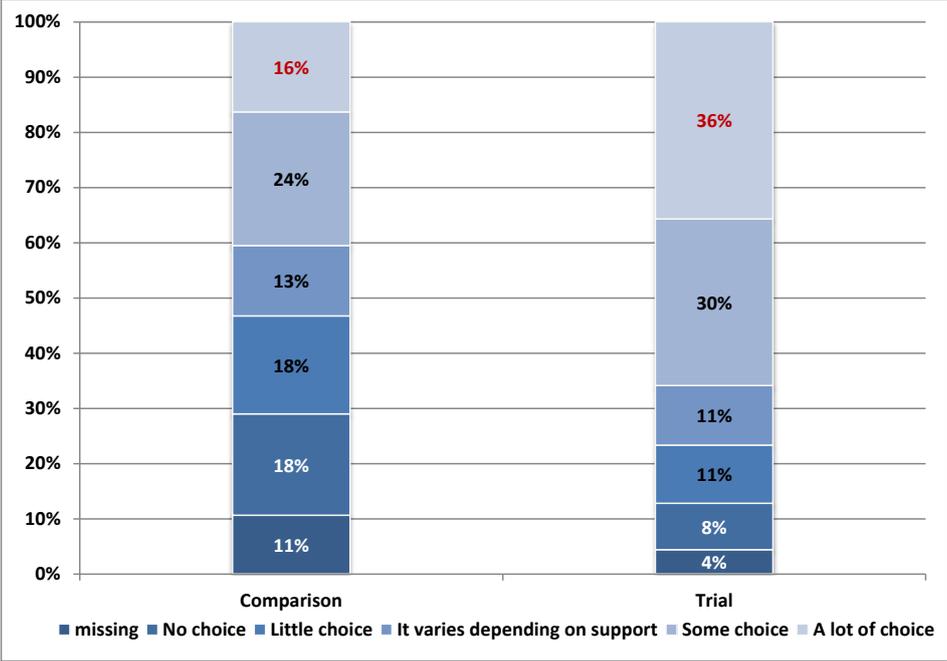


## 4.6 The Impact of the NDIS on the amount of Choice regarding where Supports are obtained – Evidence from Large Scale Surveys

### 4.6.1 What do NDIS participants think about where supports are obtained?

- Overall, the estimates of the impact of the NDIS on the amount of choice people with disability have over where they get their supports, are qualitatively very similar to those presented above on the choice they have over what supports they get.
- As observed previously with say over supports, a greater proportion of the NDIS participants report having a lot of choice regarding where they get their supports compared to the comparison group (36 per cent and 16 per cent respectively, Figure 4.12).

**Figure 4.12 Person with disability: Amount of choice about where people with disability get their supports by treatment status (Comparison and Trial wave 1, Adults)**



- Further analyses examining estimated impacts of the NDIS on choice of where supports are obtained corroborate the above observation and suggest an even greater impact of the NDIS on this outcome (Appendix Table A4.18). Using the binary measure of this outcome, NDIS participants were 114 per cent more likely to report having a lot of choice regarding where to obtain their supports compared to those not in the NDIS.
- The impact of the NDIS on choice about where supports are obtained was also estimated according to the NDIS participants’ disability type. Table 4.1 shows, for each disability type, the estimated impact of the NDIS on the NDIS participants. We do not observe significant differences in the estimates of the impact of the NDIS across disability.

**Table 4.1 Person with disability: Amount of choice about where they get their supports - Conditional average treatment effects by disability type (Trial, Adults)**

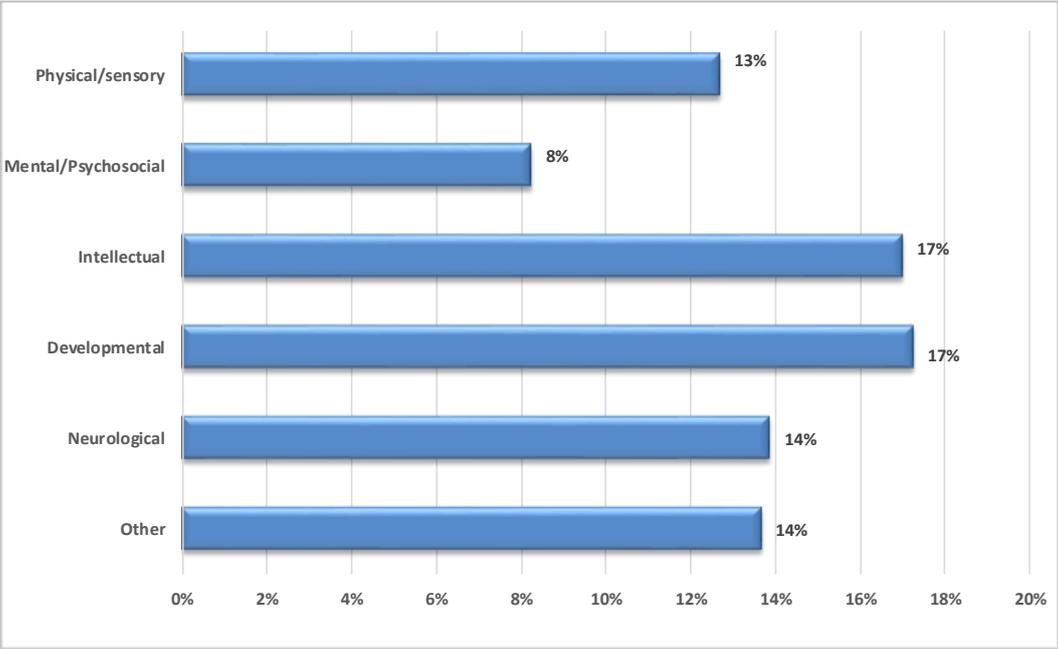
| Main disability category                        | Mean ATET | ATET expressed in per cent |
|---|-----------|----------------------------|
| Physical or sensory condition                   | 0.18      | 97                         |
| Mental health condition/psychosocial disability | 0.19      | 105                        |
| Intellectual disability                         | 0.22      | 123                        |
| Developmental or congenital condition           | 0.22      | 121                        |
| Neurological condition                          | 0.20      | 112                        |
| Other or not defined condition                  | 0.21      | 119                        |

Note: We remind the reader that an estimated impact (expressed as a percentage) of 100 per cent indicates that, based on the NDIS participants' survey answers, they are estimated to be twice as likely to report having a lot of choice under the NDIS than they would have if they had not been rolled out into the NDIS.

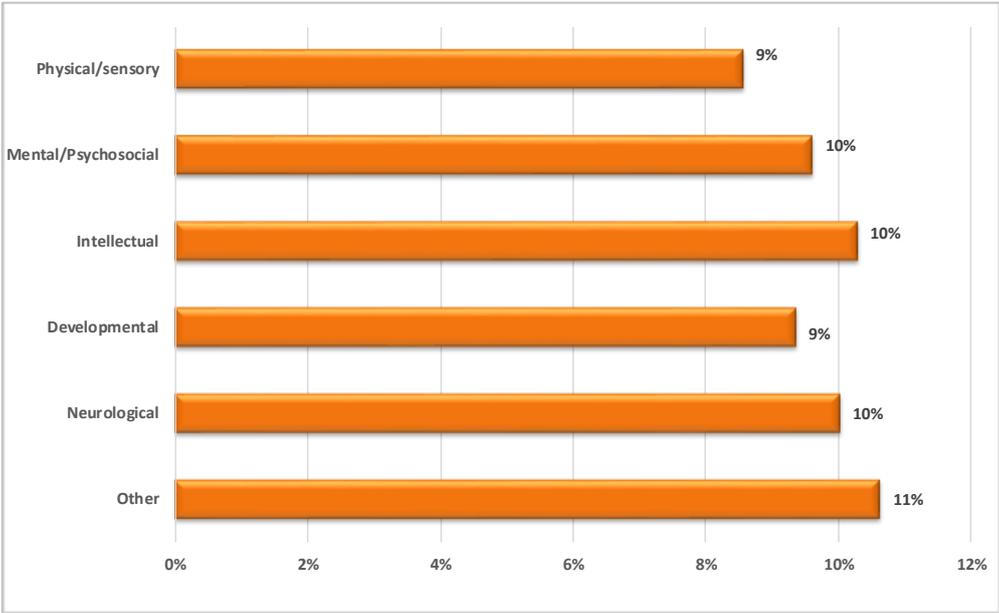
#### 4.6.2 What do carers think about where supports are obtained?

- Impact analyses were also conducted for the impact of the NDIS on the amount of choice carers have over where supports are obtained. As with the previous outcome (carer say over supports) estimation results are provided for both the binary and continuous measures of choice. Distinctions are made between carers of adults and children with disability.
- The estimation results of the impact of the NDIS on carer choice over where supports are obtained for the binary outcome indicator are reported in Appendix Tables A4.19 and A4.20. For the carers of adults (Appendix Table A4.19), the estimate of the impact of the NDIS is much smaller than the corresponding estimate obtained directly from people with disability themselves (45 per cent compared to 114 per cent). This discrepancy suggests that adult people with disability and their carers diverge in terms of their assessment of the amount of choice they have over where supports are obtained. A similar discrepancy was not observed in the analyses relating to say over what supports are received. The impact of the NDIS on choice over where supports are obtained was somewhat smaller for carers of children (about 36 per cent, Appendix Table A4.20).
- Using the continuous measure of family and carer satisfaction with the amount of choice about where people with disability get their supports, the estimated impact of the NDIS was comparable to that obtained for the previous outcome (satisfaction with the amount of say about what supports the people with disability get). The estimated impact of the NDIS was 14 per cent for the carers of adults and eight per cent for the carers of children (Appendix Tables A4.21 and A4.22 in the appendices).
- NDIS participants were not found to benefit equally from the NDIS with regards to this outcome; the impact of the NDIS on choice over where supports are obtained varied across participants' disability type. Carers of adult NDIS participants with a mental/psychosocial disability were far less likely to report having a lot of choice over their supports compared to overall (13 per cent and 45 per cent respectively, Figure A4.19 in Appendix). Using a continuous measure for choice, the estimated impact of the NDIS on carers of adult people with mental/psychosocial disability was eight per cent (Figure 4.13) and 10 per cent for carers of children with mental/psychosocial disability (Figure 4.14).

**Figure 4.13 Carers: Amount of choice about where the person with disability gets supports - Conditional average treatment effects by disability (Trial Adults, continuous measure)**



**Figure 4.14 Carers: Amount of choice about where the person with disability gets supports - Conditional average treatment effects by disability (Trial, Age 0 -15, continuous measure)**



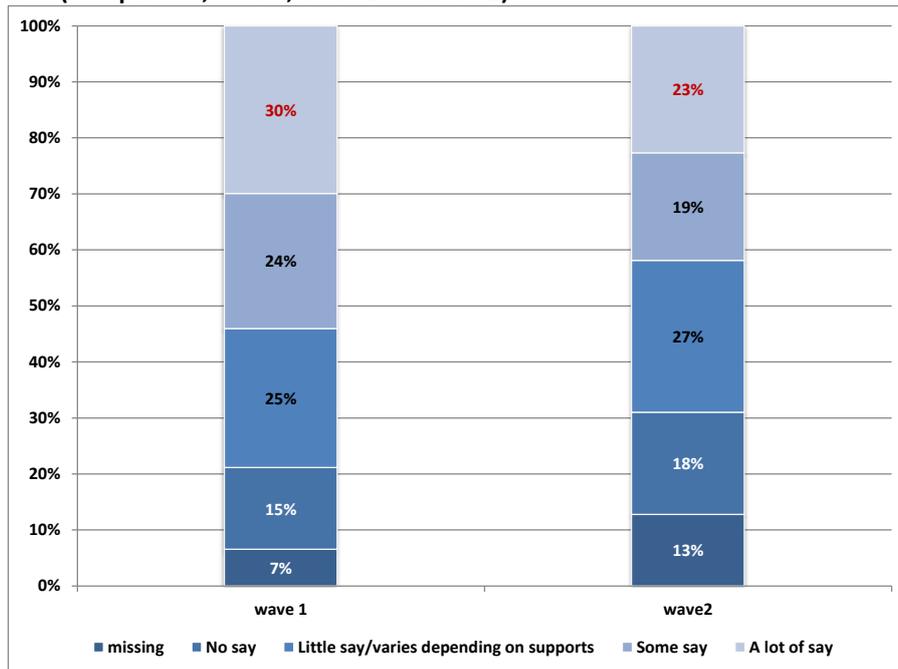
**4.7 How has Choice and Control over Supports Changed over Time – Evidence from Large Scale Surveys**

**4.7.1 Has choice and control changed over time for NDIS participants?**

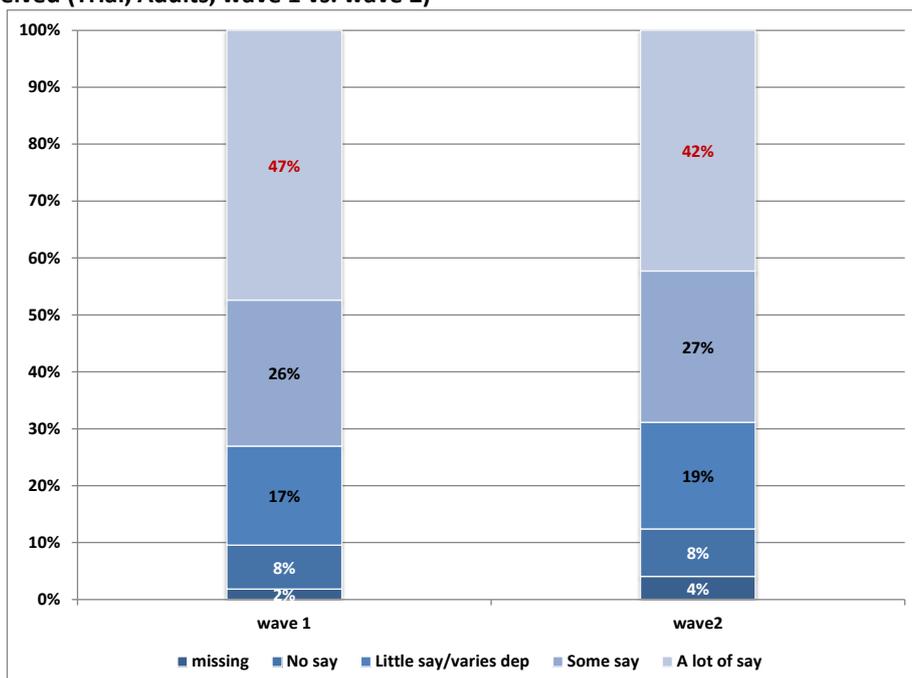
- Using the longitudinal information gathered by the surveys conducted with people with disability, changes over time in perceptions of choice and control for both the NDIS participant and the comparison groups were examined.

- Figures 4.15 and 4.16 show the levels of satisfaction reported by people with disability about the amount of say they have over which supports they receive. Each figure shows the responses in wave 1 and 2 in order to examine changes over time.
- Looking at the figures, we see that the proportion of respondents who were satisfied and very satisfied with their say over supports was smaller for the comparison group (Figure 4.15) than in the trial group (Figure 4.16), for both waves of the survey. Furthermore for both groups, the proportions of those who were satisfied/very satisfied with their say over their supports slightly decreased between wave 1 and 2.

**Figure 4.15 Person with disability: Satisfaction with the amount of say about what supports the person with disability received (Comparison, Adults, wave 1 vs. wave 2)**

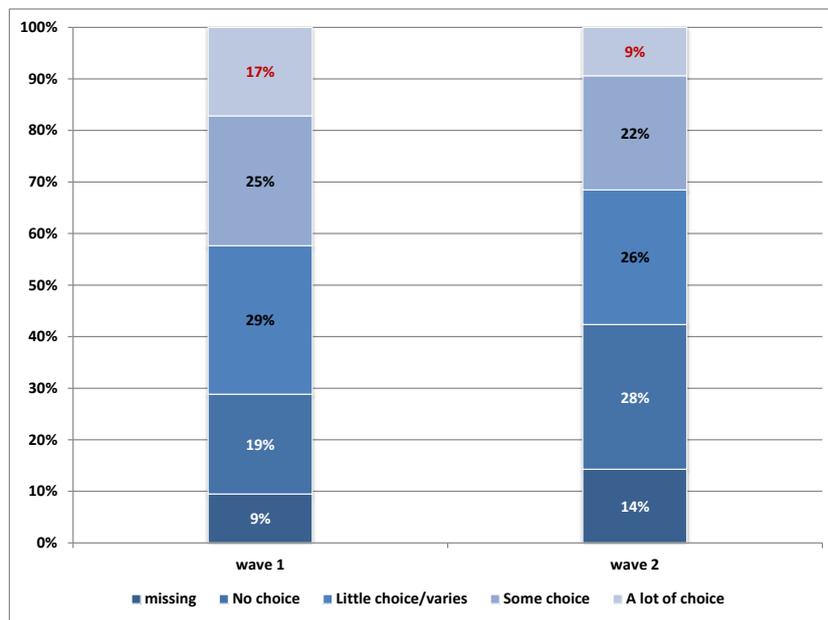


**Figure 4.16 Person with disability: Satisfaction with the amount of say about what supports the person with disability received (Trial, Adults, wave 1 vs. wave 2)**

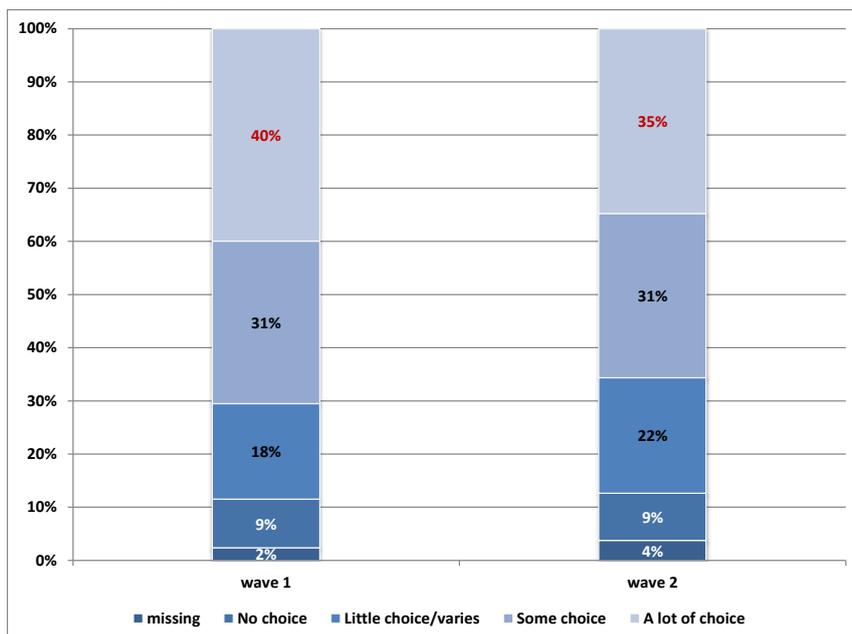


- Figures 4.17 and 4.18 show levels of satisfaction regarding the amount of choice people with disability have over where they get their supports. Again the figures reported on the wave 1 and 2 responses of the comparison and NDIS trial groups enable us to see the changes over time in these responses.
- Similar observations can be made for perceptions of choice over where supports are obtained, as made previously when exploring say over which supports are received. The proportion of people with disability who report high satisfaction is considerably lower for the comparison sample than for the trial sample across both waves (estimations of the impact of the NDIS in wave 1 show that most of these differences are due to NDIS participants joining the NDIS). In addition, the proportion of people with disability from both groups reporting high levels of satisfaction decreased between wave 1 and 2.

**Figure 4.17 Person with disability: Satisfaction with the amount of choice about where people with disability get their supports (Comparison, Adults, wave 1 vs. wave 2)**



**Figure 4.18 Person with disability: Satisfaction with the amount of choice about where people with disability get their supports (Trial Adults, wave 1 vs. wave 2)**



- The transition tables presented below document the changes that occurred in the choice and control of NDIS participants between wave 1 and 2 based on the disaggregated change experienced by each individual. It is important to note that in this data presentation, if one person moved from satisfied to very satisfied and another person moved from very satisfied to satisfied, these two movements will be recorded and presented – this is not the case in usual tabulations which would have recorded the same overall number of people in these two categories. Table 4.2 shows the transitions that occurred in perceptions of say over decisions about what supports are received, while Table 4.3 shows changes which occurred in levels of choice about where these supports are received. Those for whom the level of say or choice increased between wave 1 and 2 are to the top right of the table above the top left to bottom right diagonal of the table. Those for whom it decreased are to the bottom left, below the diagonal. The diagonal from top left to bottom right includes those who reported the same level of say in both waves.
- The transition Tables 4.2 and 4.3 document the change that occurred between the two waves, showing that 26 per cent of NDIS participants who reported having no say over decisions about the types of supports they received in wave 1, reported in wave 2 that they now have a lot of say (Table 4.2). Similarly, 22 per cent of NDIS participants who reported having no choice over where to obtain supports in wave 1, reported that they have a lot of choice in wave 2 (Table 4.3).

**Table 4.2 Person with disability: Transition in level of say over decisions about what supports received - wave 1 and 2 evidence (Trial, Adults)**

| Wave 1<br>Level of say | Wave 2<br>Level of say |                       |            |              | Total       |
|------------------------|------------------------|-----------------------|------------|--------------|-------------|
|                        | No say                 | Little say/<br>varies | Some say   | A lot of say |             |
| No say                 | 42%                    | 18%                   | 13%        | 26%          | 100%        |
| Little say/varies      | 9%                     | 32%                   | 30%        | 29%          | 100%        |
| Some say               | 2%                     | 25%                   | 39%        | 34%          | 100%        |
| A lot of say           | 3%                     | 14%                   | 22%        | 61%          | 100%        |
| <b>Total</b>           | <b>7%</b>              | <b>20%</b>            | <b>28%</b> | <b>45%</b>   | <b>100%</b> |

**Table 4.3 Person with disability: Transition in level of choice about where to obtain supports - wave 1 and 2 evidence (Trial, Adults)**

| Wave 1<br>How much choice over where you<br>currently obtain supports | Wave 2<br>Level of say |                          |                |                    | Total       |
|---|------------------------|--------------------------|----------------|--------------------|-------------|
|   | No choice              | Little choice/<br>varies | Some<br>choice | A lot of<br>choice |             |
| No choice   | 33%                    | 18%                      | 27%            | 22%                | 100%        |
| Little choice/varies  | 12%                    | 30%                      | 35%            | 23%                | 100%        |
| Some choice   | 4%                     | 25%                      | 40%            | 31%                | 100%        |
| A lot of choice   | 3%                     | 14%                      | 27%            | 56%                | 100%        |
| <b>Total</b>  | <b>8%</b>              | <b>21%</b>               | <b>33%</b>     | <b>39%</b>         | <b>100%</b> |

- At the same time, 28 per cent of NDIS participants reported a decrease in the amount of say they have over decisions regarding the types of supports they receive. A further 24 per cent of NDIS participants reported an increase in their amount of say, while 49 per cent reported no change<sup>11</sup>.
- In terms of choice over where supports are obtained, the quantitative data indicates that 30 per cent of NDIS participants reported a decrease in their level of choice between wave 1 and 2, 26 per cent reported increased choice and 44 per cent reported no change.<sup>12</sup>
- The improvements seen over time with regards to choice and control seem, however, to be concentrated in the upper end of the distribution. In other words, those who already reported having some say/choice in wave 1 see their situation improve further by the second wave of the survey. Improvements are less common amongst those who reported adverse outcomes at the first wave of the survey.
- It has been difficult to form an overall view on the combined evidence on change between wave 1 and 2 as this is presented in the Figures 4.15 to 4.18 and the transition Tables 4.2 and 4.3. The evidence is mixed as it reflects partly the fact that trial and comparison groups are exercising different choice and control over their supports, and partly that for both trial and comparison groups change is happening differently among those who are 'doing well' in terms of choice and control (that is those who answer that they are 'satisfied' or 'very satisfied' and those who are not doing as well (that is those who report 'about the same', 'dissatisfied' and 'very dissatisfied').
- In spite of these overall improvements in choice and control, we note that there remains a non-negligible proportion (about a quarter of the NDIS participants) who reported that they have no say either about what supports they get or where these are obtained. Moreover, those who reported having no or little say over what supports they receive are typically the same group of individuals who also reported having no or little choice over where they obtain these supports.
- Further econometric analyses were conducted to explore the incremental impact of the NDIS on the choice and control of people with disability. Appendix Table 4.23 shows that, overall, there was a positive effect over time for NDIS participants in both the amount of say they have over what supports they get and the amount of choice they have with regards to where they get their supports. This means that, notwithstanding the micro-evidence we have that those with the lowest choice and control do not necessarily fare better with time in the NDIS, we also have statistically robust and significant evidence that for the majority of NDIS participants more time in the NDIS has improved the amount of choice and control they are able to exert over their supports.

#### **4.7.2 Has choice and control changed over time for carers?**

- Tables 4.4 and 4.5 document the changes that occurred in the levels of satisfaction reported by carers about the choice and control they have over the supports received by the NDIS participants between wave 1 and 2. Those for whom the level of satisfaction has increased between wave 1 and 2 are to the top right part of the table. Those for whom the level of satisfaction has decreased between wave 1 and 2 are in the bottom left part of the table and those who gave the same answer in both waves are in the diagonal running top left down to bottom right in the table.
- As with the previous transition tables for the NDIS participants themselves, change over time is mixed. Of those carers who reported in wave 1 being very dissatisfied with their say over the supports received, 26 per cent were now satisfied and 21 per cent were very satisfied in wave 2

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<sup>11</sup> Using manual calculations from unreported frequencies.

<sup>12</sup> Using manual calculations from unreported frequencies.

(Table 4.4). Similarly, for those carers who in wave 1 had been dissatisfied with the amount of choice they had over where supports were obtained, 27 per cent were now satisfied and a further 20 per cent were very satisfied.

- However, some negative changes were also revealed around carer perceptions of say over supports. For example, 17 per cent of carers who reported being very satisfied or satisfied with their amount of say over the types of supports the NDIS participant received in wave 1, were dissatisfied in wave 2.
- Overall 30 per cent of carers reported a decline in their level of satisfaction with the amount of say they have over decision regarding the types of support the NDIS participants receive, 19 per cent reported an increase in their levels of satisfaction and 51 per cent reported no change<sup>13</sup>.
- In terms of carer satisfaction with the amount of choice they have about where NDIS participants obtain their supports, 26 per cent reported a decrease in satisfaction between wave 1 and 2, 20 per cent increased satisfaction and 54 per cent reported no change<sup>14</sup>.

**Table 4.4 Carers: Transition in level of satisfaction with amount of say about what supports person with disability receives - wave 1 and 2 evidence (Trial, All ages)**

| Wave 1<br>Level of satisfaction       | Wave 2<br>Level of satisfaction |              |  |            |                   | Total       |
|---------------------------------------|---------------------------------|--------------|--|------------|-------------------|-------------|
|                                       | Very<br>dissatisfied            | Dissatisfied | Neither<br>dissatisfied<br>nor satisfied | Satisfied  | Very<br>satisfied |             |
| Very dissatisfied                     | 5%                              | 32%          | 16%                                      | 26%        | 21%               | 100%        |
| Dissatisfied                          | 0%                              | 26%          | 8%                                       | 45%        | 21%               | 100%        |
| Neither satisfied nor<br>dissatisfied | 4%                              | 15%          | 13%                                      | 45%        | 23%               | 100%        |
| Satisfied                             | 0%                              | 12%          | 10%                                      | 51%        | 26%               | 100%        |
| Very satisfied                        | 0%                              | 5%           | 5%                                       | 31%        | 59%               | 100%        |
| <b>Total</b>                          | <b>0%</b>                       | <b>10%</b>   | <b>8%</b>                                | <b>39%</b> | <b>43%</b>        | <b>100%</b> |

Note that a very small number of wave 2 carers who responded to the survey are not the same care who answered in wave 1. Excluding these does not alter the proportional distribution of changes over time

<sup>13</sup> Using manual calculations from unreported frequencies.

<sup>14</sup> Using manual calculations from unreported frequencies.

**Table 4.5 Carers: Transition in level of satisfaction with the amount of say about where person with disability obtains supports - wave 1 and 2 evidence (Trial, All ages)**

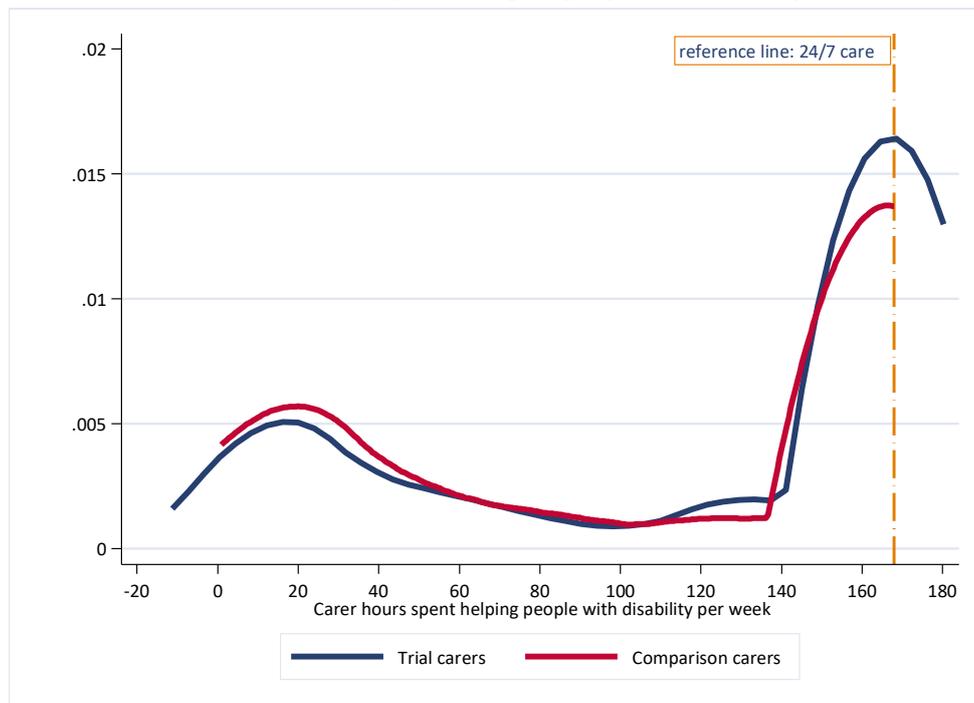
| Wave 1<br>Level of satisfaction       | Wave 2<br>Level of satisfaction |              |  |            |                   | Total       |
|---------------------------------------|---------------------------------|--------------|--|------------|-------------------|-------------|
|                                       | Very<br>dissatisfied            | Dissatisfied | Neither<br>dissatisfied<br>nor satisfied | Satisfied  | Very<br>satisfied |             |
| Very dissatisfied                     | 9%                              | 9%           | 27%                                      | 27%        | 27%               | 100%        |
| Dissatisfied                          | 0%                              | 13%          | 8%                                       | 54%        | 26%               | 100%        |
| Neither satisfied nor<br>dissatisfied | 3%                              | 5%           | 28%                                      | 40%        | 25%               | 100%        |
| Satisfied                             | 0%                              | 9%           | 11%                                      | 45%        | 34%               | 100%        |
| Very satisfied                        | 0%                              | 4%           | 3%                                       | 26%        | 67%               | 100%        |
| <b>Total</b>                          | <b>0%</b>                       | <b>6%</b>    | <b>8%</b>                                | <b>34%</b> | <b>51%</b>        | <b>100%</b> |

Note that a very small number of wave 2 carers who responded to the survey are not the same care who answered in wave 1. Excluding these does not alter the proportional distribution of changes over time

#### 4.8 Do Carers get Breaks from Providing Support? – Evidence from Large Scale Surveys

- Next we look at whether participation in the NDIS has had an impact on carers’ ability to have adequate breaks from providing support. Prior to exploring this issue, the following graph (Figure 4.19) shows the distribution of the hours spent caring among the carers surveyed. This density plot shows a small peak in the lower numbers of caring hours per week and a larger peak representing a 24/7 type of care, for both trial and comparison groups.

**Figure 4.19 Carers: Distribution of the hours spent caring for people with disability**



- Estimation analyses were conducted to examine the impact on breaks from caring. The NDIS was found to have a positive effect on the family member or carer being able to take adequate breaks

from providing support (Appendix Tables A4.24 and A4.25). The estimated impact of the NDIS on this measure was 14 per cent for carers of adult participants which, given the scale of the survey question suggests that the mean outcome would be improving from taking a break 'less than once a month' to 'once a month'. A smaller but still positive impact for the carers of child participants was also found (8 per cent). Therefore these findings indicate that while the impact of the NDIS is positive with respect to enabling carers to take adequate breaks from their caring role, the estimated impacts are small suggesting there may be room for further improvement.

#### **4.9 The Experience of Choice and Control – Evidence from In-depth Qualitative Interviews**

- 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 carers had choice and control over their supports and how this has changed over time.

##### *Choice and control through the eyes of NDIS participants and their family members or 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 most of these participants, the choice to retain their providers was because of established relationships and a shared understanding of needs developed over many years, and satisfaction with the supports received.
- While overall there was continuity in the service providers used by NDIS participants between wave 1 and 2, the later interviews indicated that NDIS participants and carers had increased their knowledge of the NDIS, and consequently were becoming more confident in changing service providers over time.
- There were a range of reasons why changes to support provision 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 participants. 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.

- In 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 was a respondent who wanted to enter the workforce being unaware that the NDIA was able to offer support in finding employment until she was informed by an advocacy agency.

*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)*

- Wave 2 interviews with NDIS participants and their families and carers indicated improved flexibility in the timing of their supports (providers accommodating requests for appointments which were outside usual working hours ), the location of their supports (offering supports both in the home and community), and the provision of supports (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 in 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 provider in these instances.

*Male: It's always people like [Name of provider] 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)*

- Many respondents were unable to exert choice and control over some aspects of their supports due to limitations in the numbers or capacity of service providers. This was discussed previously when we considered the unmet demand of disability support services.
- Respondents also reported a 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.
- Rigid structures in the NDIS claiming system and fixed prices for certain types of support were also said to decrease choice.
- Funding for therapist travel continued to be a concern in wave 2. The decision by the NDIA 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)*

- Finally, the formalisation of relationships between service providers and the NDIS participants/carers through the use of service contracts 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).*

#### *Choice and control through the eyes of service providers and other stakeholder groups*

- Disability service providers and representatives from workforce stakeholder organisations 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 NDIS is going to have a really beneficial impact on people... it's not just within 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.
- In wave 1 providers and stakeholders were concerned that people with disability and their families were not always aware of the types of support and services that were available or appropriate, and this constrained their choice and control. A greater role for NDIA staff in providing information about services to participants and their families was recommended. While these issues remained in 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)*

- In 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 without access to or 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)*

### *Choice and control through the eyes of the NDIA staff*

- In wave 1, NDIA staff highlighted that some NDIS participants 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 NDIS but also because of prior (sometimes long-standing) relationships with service providers.
- In 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.

*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)*

- 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.

### *Choice and control for people with disability not participating in the NDIS*

- While many non-NDIS participants had interim arrangements in place which enabled them to continue to access subsidised or free-of-charge services, respondents were told that this would be time limited and that in the future they would have restricted access or be required to pay, or pay more, for the same services in the future. Given most had limited financial resources, non-NDIS participants expected to have to ration or miss out on services following the full roll-out of the NDIS, when funding arrangements for organisations were understood to change. People with disabilities outside of the NDIS were therefore anticipating less choice and control over their services and supports over time.

*Then there are some really good people that work, like [psychologist] is one... she is always booked out months and months in advance and her fees are very high, but they're so high because she's excellent and she can charge that much. She can charge that much because the NDIA will pay. (C08C NP)*

- Respondents who were not participating in the NDIS also indicated that the requirement to have existing transport funding transferred to the NDIS as part of the planning process was concerning. The loss of a cash payment, and the need to self-manage claims was thought to lead to decreased choice and more stress.

*They took our mobility allowance and we had to submit receipts or we had to set aside money, it was no longer a cash payment that was given to us. I got really angry at that because my reason for receiving the mobility allowance was, in fact, that I'm a job seeker and the NDIS did not cover anything in regards to looking for work or supporting us in any capacity, way, shape or form, yet they were taking over that allowance and we were going to lose our cash payment which, you know, takes away flexibility. (B01 NP)*

#### 4.10 Self-managed Plans – Evidence from Large Scale Surveys

- The NDIS survey asked if any funding for disability supports was self-managed prior to the NDIS (Appendix Table A4.26) and under the NDIS (Appendix Table A4.27). Of the 2,512 NDIS participants who responded to the question about self-management practices prior to the NDIS in wave 1, 29 per cent said they did (20 per cent being managed by the family, 5 per cent by the person with disability themselves and 4 per cent by someone else), 64 per cent said they did not, and the remaining seven per cent did not know.
- Evidently, only a minority of people with disability entered the NDIS with prior experience of self-management. Of the 3,253 NDIS participants who responded to the question about their self-management practices under the NDIS in wave 1, 46 per cent said at least some of their funding was being self-managed (31 per cent being managed by their family, 10 per cent by the NDIS participant themselves, and 5 per cent by someone else).
- The proportion of NDIS participants who reported that their funding was being self-managed did not change over time; around half of all NDIS participants were not self-managing their plans in both waves 1 and wave 2. This finding supports the qualitative evidence presented below.
- The most frequently reported benefit of self-managing funds (Appendix Table A4.28) was that it allowed NDIS participants to employ/choose their own support workers (51 per cent), access new supports that they had not received previously (49 per cent), and access better supports than they were previously receiving (48 per cent).

#### 4.11 Self-managed Plans – Evidence from In-depth Qualitative Interviews

*The perspective of NDIS participants and their family members or carer*

- In wave 1 the option of self-managed funding was not always fully understood by NDIS participants; nor was it discussed in all 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. Some respondents who were not self-managing their NDIS funding also requested access to the portal for the same reason.

*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 in 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 in 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 NDIS resulted in decreased opportunity and increased confusion for respondents about the management of individual aspects of a plan.

#### *The perspective of service providers and other stakeholder groups*

- In wave 1, disability service providers and workforce stakeholder organisations confirmed that few NDIS participants were fully self-managing their funding. This remained the case in wave 2. While these respondents believed that the self-managing of 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.
- In 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 unregistered providers. Staff noted the risk of fraud or mismanagement of funds by those undertaking self-management and were concerned that the NDIS lacked sufficient safeguards.

## **4.12 Summary**

### **4.12.1 Development and implementation of plans – Evidence from large scale surveys**

- A large majority (92 per cent) of NDIS participants had approved support plans in both waves 1 and wave 2. Most participants reported that they received assistance from others when making decisions about their plans, primarily from family members and NDIA planners.

### **4.12.2 Development and implementation of plans – Evidence from in-depth qualitative interviews**

- 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.
- Greater attention to the family context in the planning process, in particular the potential for parents/carers to receive support and respite continued to be requested by respondents.

### **4.12.3 Choice and control over supports – Evidence from large scale surveys**

- When comparing pre-NDIS with early experiences in the NDIS, most participants felt that their choice and control (over the type of supports received and where these were obtained) had either improved or stayed the same. However, a sizeable minority (around 13 per cent) felt that their choice and control had worsened since joining the NDIS.
- Once in the NDIS, around two-thirds of NDIS participants reported having either a lot or some choice and control over their supports; little further change was seen in wave 2. However, about a fifth of all participants in both waves 1 and 2 reported having little choice and control over their support. Carers reported very high levels of satisfaction with the choice and control they were able to have over the supports of the person with disability they cared for in both waves 1 and 2.
- In wave 1, 64 per cent of NDIS participants were able to access more supports once in the NDIS than previously. Fifteen per cent of participants reported that they had fewer supports once in the NDIS. Those receiving fewer supports also reported having less choice and control under the NDIS.
- The majority of people with disability wanted to have more choice and control over the supports they receive. They said so in both waves 1 and 2.
- NDIS participants felt that they had a greater say over the supports they received compared to the comparison group. Using a binary measure of choice and control (i.e. having a lot of say over supports choice or not), NDIS participants were 54 per cent more likely than people with disability not in the NDIS to report having a lot of say over their supports.

- However, the positive impact of the NDIS on perceptions of say over supports was smaller for adults with a mental/psychosocial disability (36 per cent) than for NDIS participants with any of the other types of disability.
- No significant difference in the impact of the NDIS on say over the supports received was found between NDIS participants in urban and rural areas.
- Carers also reported that the NDIS had enabled them to increase their say over which supports the person with disability they cared for received (the impact of the NDIS was 46 per cent for carers of adult participants and 41 per cent for carers of child participants).
- The positive impact of the NDIS on say over supports, however, was lower for carers of participants (and particularly adults) with a mental/psychosocial disability. Notably, the impact of the NDIS on say over supports was negative for carers of older NDIS participants with a mental/psychosocial disability.
- With regard to choice over where supports are obtained, NDIS participants reported greater levels of choice than the comparison groups. Indeed using a binary measure for this outcome (i.e. having a lot of choice over where to obtain supports, or not), NDIS participants were 114 per cent more likely to report having a lot of choice regarding where to obtain their supports.
- No significant differences regarding the impact of the NDIS on choice about where supports were obtained were found for NDIS participants according to disability type.
- Although still positive, the impact of the NDIS on the perceptions held by carers of adult participants of their choice over where supports are obtained was less than that reported by NDIS participants themselves (45 per cent compared to 114 per cent). The impact of the NDIS on choice over supports was smaller for carers of child participants (36 per cent).
- The impact of the NDIS on choice over where supports were obtained was less for carers of NDIS participants with a mental/psychosocial disability.
- The NDIS was found to have a relatively small but positive impact on the ability of carers of adult participants (14 per cent) and child participants (8 per cent) to take adequate breaks from their caring role.
- In both waves 1 and 2, NDIS participants were more likely to report satisfaction with their choice and control (both the say they had over which supports they received and where these were obtained) than the comparison group. However, the proportion of people with disability in each group reporting satisfaction decreased slightly between waves 1 and 2.
- Examining changes in the levels of choice and control reported by NDIS participants over time, produces a mixed picture about exactly what happened between waves 1 and 2 and to whom. There are differences between waves for both trial and comparison groups, as well as differences between trial and comparison groups within each wave. When these are presented together in simple tabulations they produce an inconclusive picture which can only be resolved adequately by looking at specific subsets of the data and/ or through using multivariate estimations.
- There remains a non-negligible proportion (about a quarter of the NDIS participants) who report that they have either no say about what supports they get or where these are obtained. Those

who report having no or little say over what supports they receive are typically the same group of individuals who also report having no or little choice over where they obtain these supports.

- Estimation analyses found a positive incremental impact of the NDIS on the choice and control of people with disability. We find statistically robust and significant evidence that for the majority of NDIS participants more time in the NDIS has improved the amount of choice and control they are able to exert over their supports. This indicates that the overall impact of the NDIS has been to improve the choice and control NDIS participants are able to exert over their supports.
- Exploring changes in the choice and control of carers over time in the NDIS, again the changes observed were generally positive. However, around a quarter of carers reported that their levels of choice and control had declined between waves 1 and 2.

#### **4.12.4 Choice and control over supports – Evidence from in-depth qualitative**

- The qualitative evidence suggests that overall, the NDIS had 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.
- There was also evidence of improved flexibility in the timing of supports (providers accommodating requests for appointments which were outside usual working hours), the location of supports (offering supports both in the home and community), and the provision of supports (being able to use different services/providers).
- While service flexibility was said to have increased, providers were still reported as being reluctant to provide services on a casual ‘as needed basis’.
- 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.
- Constraints to choice and control continued to be highlighted at wave 2 and included limited provision of information about provider options, and limitations in both the numbers 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.
- 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.

#### **4.12.5 Self-managed plans – Evidence from large scale surveys**

- The proportion of NDIS participants who reported that the funding of their disability supports was self-managed increased from pre-NDIS (28 per cent) to joining the NDIS (46 per cent in wave 1). No further increases in levels of self-management were seen with time spent in the NDIS (in wave 2).

#### **4.12.6 Self-managed plans – Evidence from in-depth qualitative**

- 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, workforce stakeholder organisations and NDIA staff were concerned that the NDIS lacked sufficient safeguards.

## 5. Reasonable and Necessary Supports

### Integrated findings

The section integrates and summarises the quantitative and qualitative findings relating to reasonable and necessary supports.

The evaluation finds that:

- NDIS participants have a high satisfaction over whether they believe that their NDIS supports are reasonable and necessary;
- the satisfaction of those who joined the NDIS trial earlier was a bit lower than of those who joined it later;
- satisfaction about supports being reasonable and necessary increases with longer time in the NDIS as people understand the system better;
- however, those unable to understand the system and effectively articulate their support needs were considered to be at risk of poorer outcomes;
- satisfaction varies by disability type and the age of NDIS participants;
- there remains a minority who do not consider they are receiving reasonable and necessary supports from the NDIS and several key factors that contribute to this are identified by the evaluation;
- dissatisfaction arises due to variability and service gaps in NDIS plans, by inequality in the plans of participants with the same type of disability and needs, by funding inconsistencies across the trial sites and by lack of transparency as to how decisions are made;
- evolving guidelines were a source of concern as the NDIS kept rolling out;
- dissatisfaction also arises in instances where certain items and supports are under-funded in the NDIS plans;
- despite the initial concerns about the conceptual difficulties in forming a consensus on what is a reasonable and necessary support during the NDIS roll out, most of the difficulties recorded by the evaluation appear to have been of a practical rather than a conceptual nature; and
- overall, the evaluation finds that NDIS participants are in their majority highly satisfied about their supports being reasonable and necessary under the NDIS.

#### *Satisfaction with supports being reasonable and necessary*

- Both the quantitative and qualitative evidence suggest strongly that the majority of NDIS participants and their family members and carers were satisfied that their disability supports were reasonable and necessary. Moreover, the quantitative evidence found that being in the NDIS had a strong positive impact on satisfaction with supports being reasonable and necessary; NDIS participants were more likely to be highly satisfied that the supports they received were reasonable and necessary compared to people with disability who were not in the NDIS. Very little change was observed in these findings over waves 1 and 2.
- However, both quantitative and qualitative evidence shows that a minority of NDIS participants and their families and carers in both waves 1 and 2, did not believe that the supports they received were reasonable and necessary.

- The quantitative evidence examined which cohorts of NDIS participants and carers were more likely or less likely to be satisfied that their supports were reasonable and necessary. Satisfaction was found to vary by disability type and by the age of the person with disability.
  - NDIS participants who had a developmental or congenital disability were most likely to be satisfied that their supports were reasonable and necessary, while people with an intellectual or mental/psychosocial disability were least satisfied that their supports were reasonable and necessary. When looking at the impact of the NDIS on carer perceptions of reasonable and necessary supports, the impact was highest for carers of adult participants with an intellectual or developmental disability and lowest for those caring for a person with a mental/psychosocial disability. No discernible differences by type of disability were found for carers of child participants.
  - There is quantitative evidence that the perceptions of carers as to whether funded supports were reasonable and necessary differ by the age of the NDIS participant they care for. The impact of the NDIS on the satisfaction of the carers rose for the carers of child participants from age 0 to age 10, and declined thereafter. For the carers of adult NDIS participants, the higher ages of the participant, were associated with a lower impact of the NDIS on satisfaction that supports were reasonable and necessary. The relationship between age and satisfaction with supports was less clear among NDIS participants themselves; however, the quantitative evidence suggested that younger adults were on average more satisfied than older adults that their supports were reasonable and necessary.
- Both quantitative and qualitative evidence found that satisfaction with supports being reasonable and necessary increased with time spent in the NDIS. NDIS participants who had joined the NDIS during the early period of roll-out were less likely to report that their supports were reasonable and necessary compared to people with disability joining later. The qualitative evidence provided additional understanding of the reasons why satisfaction improved over time. With longer time in the NDIS, participants were reported to become more knowledgeable about the language and processes used in the NDIS. As a consequence some NDIS participants were able to have previously unfunded supports included in their plans at review. However, not all people with disability were seen as being equally able to develop and use this knowledge. Those unable to understand the system and effectively articulate their support needs were considered to be at risk of poorer outcomes.

#### *Concerns around reasonable and necessary supports*

- The qualitative interviews identified a number of factors which contributed to perceptions that funded supports under the NDIS were not always reasonable and necessary. These factors centred on perceived variability in supports which were funded under the NDIS and service gaps in plans.
- Variability and inequity in the plans of participants with the same type of disability and needs were reported in the qualitative interviews. Inconsistencies in funded supports were also noted across the different trial sites. In addition, variability as to whether supports received pre-NDIS would be funded under the NDIS was reported. This particularly pertained to the funding and flexibility of early intervention packages. A lack of transparency as to how decisions about reasonable and necessary supports were made by the NDIA was further noted.

- Instances of inconsistencies about whether supports were assessed as being reasonable and necessary, which influenced the decision to fund them under the NDIS, were attributed in part to the variable skills and experience of NDIA planners. In general, planners were considered to need additional understanding of specific types of disability (including mental health issues) and also knowledge of allied health roles and interventions in order to avoid such inconsistencies. NDIA staff themselves described the challenges of achieving consistency in planning processes and outcomes, especially in an environment where guidelines around reasonable and necessary supports were evolving continually.
- While overall many people with disability felt that the NDIS had led to an increase in supports, dissatisfaction that certain items and supports were not being adequately funded in NDIS plans were also evident. Supports considered under-funded included family supports, alternative therapies, social/recreational activities, respite, support co-ordination, behaviour management and employment skills. Issues were also noted around the funding of supports related to mainstream services such as education, health and recreational activities and for complex home modifications or equipment. A lack of funding for supports which were deemed not to be reasonable and necessary was shown to have contributed to decisions by people with disability to withdraw from the NDIS.

## 5.1 Introduction

The NDIS funds reasonable and necessary supports that help a participant to reach their goals, objectives and aspirations, and to undertake activities to enable their social and economic participation. The NDIA makes decisions about what supports would be reasonable and necessary based on the National Disability Insurance Scheme Act 2013 (NDIS Act) and the rules comprised in this. Operational guidelines also provide practical guidance for NDIA staff on what supports are considered reasonable and necessary. In this section we present quantitative and qualitative evaluation evidence on the KEQs that relate to the broad theme of *reasonable and necessary*. The chapter considers the extent to which NDIS participants and their carers are satisfied that their supports are reasonable and necessary and how this has changed over time.

## 5.2 Satisfaction with Supports Being ‘Reasonable and Necessary’ – Evidence from Large Scale Surveys

The quantitative data includes a measurement of the satisfaction that NDIS participants and their carers have that current disability supports are reasonable and necessary.

- In wave 1, a majority of NDIS participants (75 per cent) and their carers (84 per cent) were either satisfied or very satisfied that their current disability supports were reasonable and necessary (Appendix Tables A5.1 and A5.3). This compares to 58 per cent of people with disability in the comparison group.
- In wave 2, there was very little change in the proportion of either NDIS participants or carers who were either satisfied or very satisfied that their current disability supports were reasonable and necessary (Appendix Tables A5.2 and A5.3). The proportion of people with disability from the comparison group reporting satisfaction with their supports in wave 2, however, decreased to 45 per cent.
- A largely positive picture emerges from the data, with a majority of NDIS participants in both waves reporting that they consider their supports to be reasonable and necessary. However, as with other measures of satisfaction (e.g. the number of supports), there is a minority of people who do not consider the supports they access to be reasonable and necessary; this remained steady at about nine per cent of NDIS participants in waves 1 and 2 (Appendix Tables A5.1 and A5.2).
- Having choice and control over disability supports is strongly connected with satisfaction that these supports are reasonable and necessary.
- As shown in Appendix Tables A5.4 and A5.5 there is an association between the reported level of say that NDIS participants have over their supports and the degree to which they believe that the NDIS funded supports they access can be considered reasonable and necessary. Hence, most NDIS participants who felt that they had a lot of choice and control over their supports also reported being satisfied that these supports were reasonable and necessary.

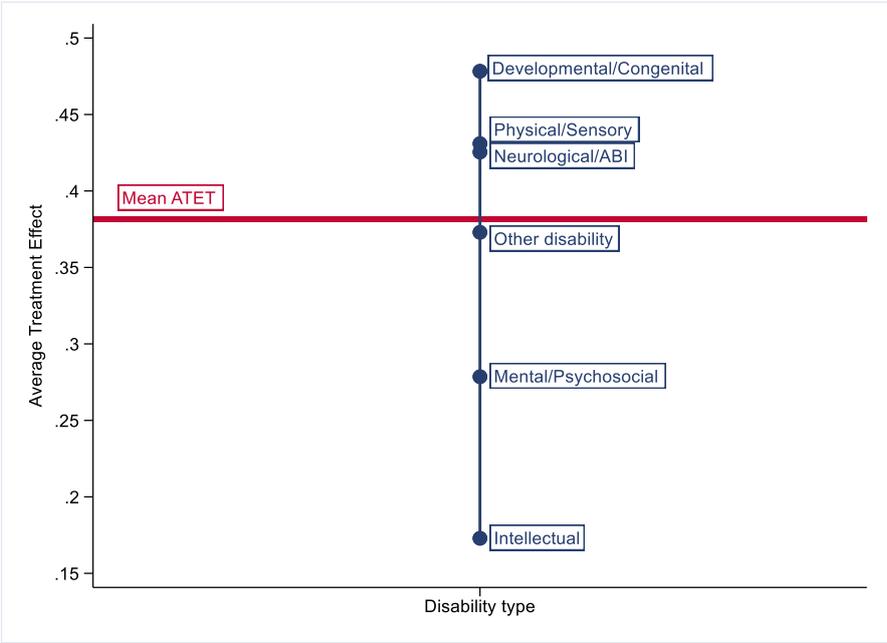
## 5.3 The Impact of the NDIS on Satisfaction with Supports Being ‘Reasonable and Necessary’ – Evidence from Large Scale Surveys

Further analyses explored the impact of the NDIS on satisfaction with supports being considered to be reasonable and necessary. The impact of the NDIS was measured by considering the difference in satisfaction among NDIS participants and the comparison group. Several estimation methods and model specifications were used to obtain robust overall results. Estimation details and results can be found in the Appendix.

**5.3.1 Reasonable and necessary: what do NDIS participants think?**

- The impact of the NDIS on satisfaction with supports being reasonable and necessary was estimated to be large and highly statistically significant. For adult people with disability, the NDIS was estimated to increase the probability of being ‘very satisfied’ that supports were reasonable and necessary by 83 per cent (or 30 percentage points as reported in Appendix Table A5.6).
- The impact of the NDIS on the satisfaction that supports were reasonable and necessary for children with disability, as reported by carers, were equally large and statistically significant with an estimated impact of 51 per cent (Appendix Table A5.9).
- People with disability who were experiencing unmet demand for supports were less likely to report that their supports were reasonable and necessary (21 per cent less likely on average) (Appendix Table A5.12 and Appendix graph A5.7 and Figure 5.8).
- The impact of the NDIS on satisfaction with supports being reasonable and necessary was the same for urban and rural adult residents. For children with disability, however, satisfaction levels were slightly higher for the urban sample.
- Estimation results (using the continuous measure of satisfaction) show some heterogeneity in the impact of the NDIS on satisfaction that supports were reasonable and necessary by disability type. Figure 5.1 illustrates this heterogeneity showing the lowest estimated impact of the NDIS to be 11 per cent for adult people with an intellectual disability followed by a 17 per cent impact for people with psychosocial disability. The estimated impact of the NDIS on perceptions that supports were reasonable and necessary was highest for people with developmental/congenital disability (29 per cent).

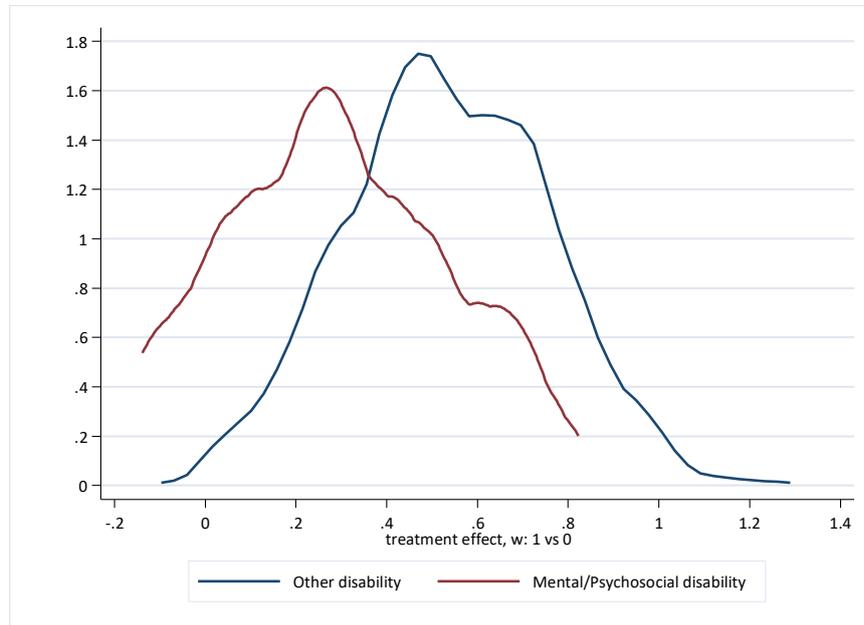
**Figure 5.1 Person with disability: Impact of NDIS on satisfaction that supports are ‘reasonable and necessary’ by broad disability category (Trial, Adults)**



- Figure 5.2 compares the estimated individual impact of the NDIS on perceptions of reasonable and necessary supports for people with mental/psychosocial disability with those with another disability type. This is illustrated by comparing the distribution of the impact collectively for each

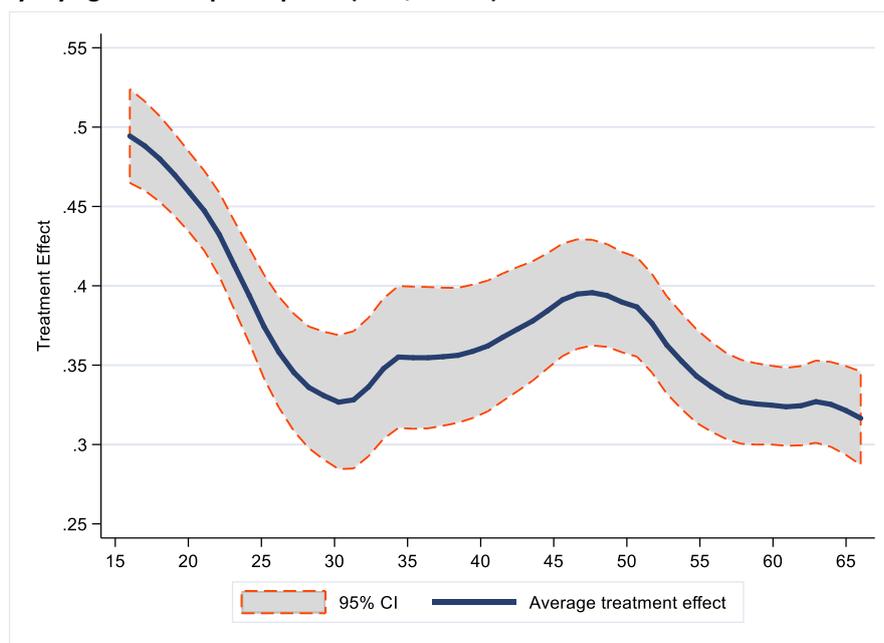
group. The mean impact of the NDIS on satisfaction with supports being reasonable and necessary was significantly lower for participants with a mental/psychosocial disability.

**Figure 5.2 Person with disability: Impact of NDIS on satisfaction that supports are ‘reasonable and necessary’ by disability type (Trial, Adults)**



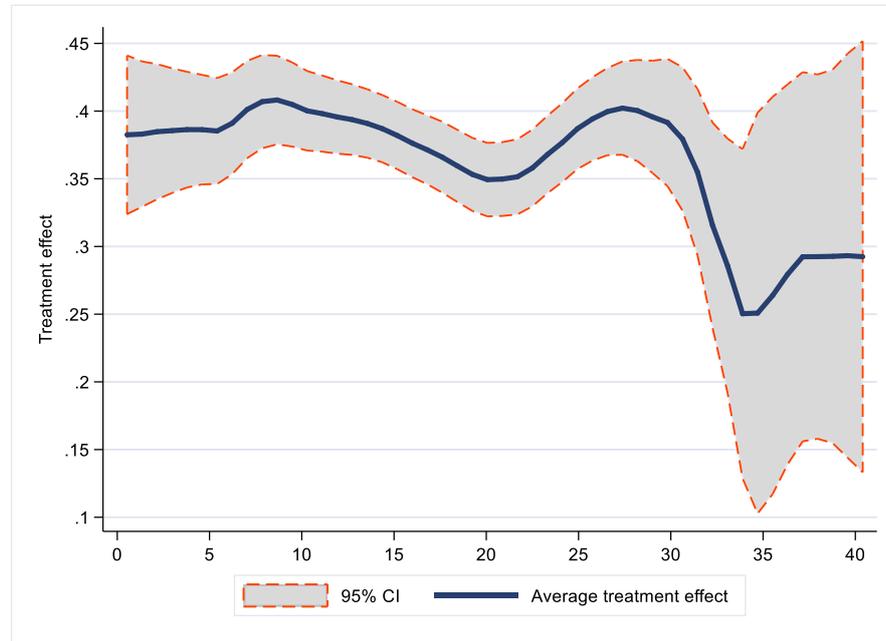
- The impact of the NDIS on satisfaction that supports were reasonable and necessary (as shown by the blue line in Figure 5.3) differed by the age of the NDIS participant. In particular, the impact of the NDIS was greatest for teenage participants. The dotted red line in the figure represents the estimated 95 per cent confidence intervals of this impact.

**Figure 5.3 Person with disability: Estimated impact of NDIS on satisfaction that supports are ‘reasonable and necessary’ by age of NDIS participants (Trial, Adults)**



- Figure 5.4 shows that the impact of the NDIS on perceptions of reasonable and necessary supports varied by how long the NDIS participant has been participating in the NDIS. Beyond about 30 months of participation, however, this estimate becomes unreliable as the very broad confidence intervals suggest.

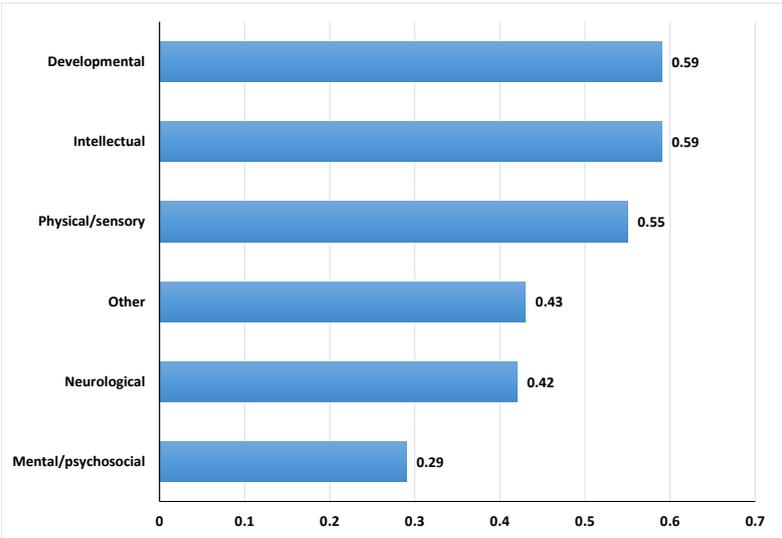
**Figure 5.4 Person with disability: Estimated impact of NDIS on satisfaction that supports are ‘reasonable and necessary’ by the length of NDIS participation (Trial, Adults)**



### 5.3.2 Reasonable and necessary: what do carers think?

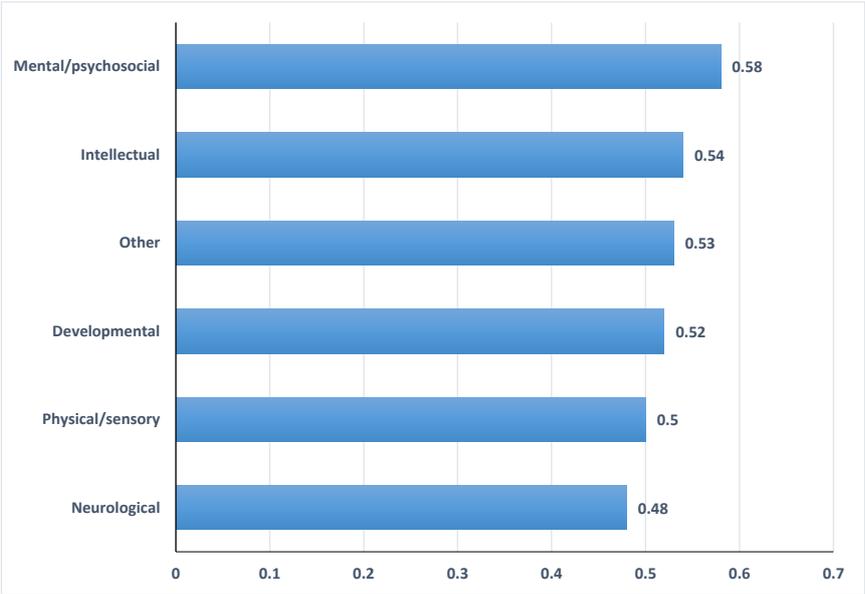
- The impact of the NDIS on the satisfaction of carers that supports are reasonable and necessary is somewhat smaller than that estimated for people with disability themselves; the estimated impact, however, is still clearly strong and statistically significant (Appendix Tables A5.8 and A5.9 on the binary measure, and, Appendix tables A5.10 and A5.11 on the continuous measure).
- We then examined the impact of the NDIS on carer satisfaction of supports being reasonable and necessary according to the main disability type of the adult person with disability they care for (Figure 5.5). The highest impact was found for carers of adults with intellectual and developmental disability and the lowest for those caring for a person with mental/psychosocial disability.

**Figure 5.5 Carers: Impact of NDIS on carer satisfaction that supports are ‘reasonable and necessary’ by disability (Trial, Adults, continuous measure)**



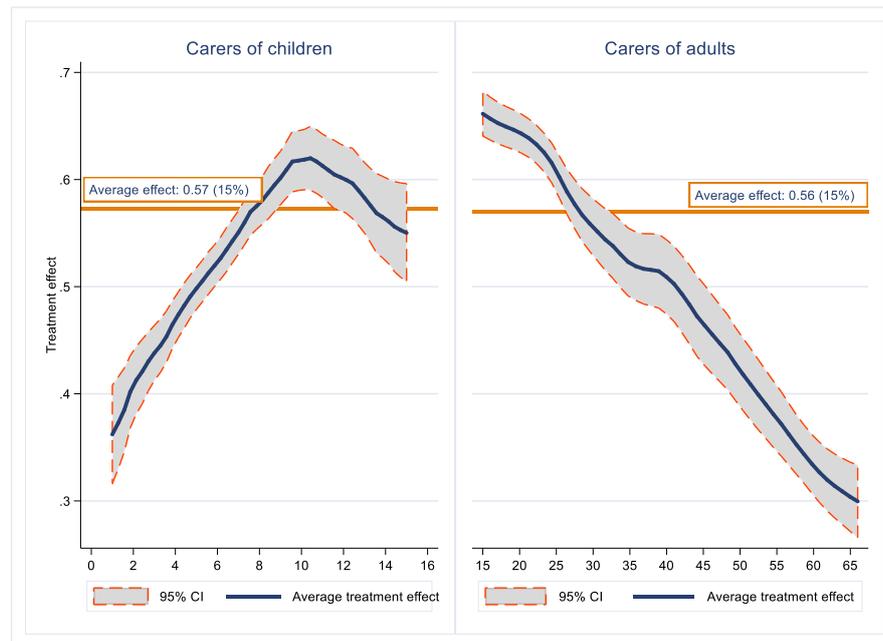
- The impact of the NDIS on supports being considered reasonable and necessary by carers according to the main disability type of the child they care for is presented in Figure 5.6. Unlike with adult participants, there no discernible differences by type of disability.

**Figure 5.6 Carers: Estimated conditional ATET for carers of people with disability (Trial, Age 0 – 15, continuous measure)**



- The impact of the NDIS on the satisfaction of carers that supports are reasonable and necessary was positive regardless of the age of the person with disability they cared for (Figure 5.7). Positive impacts on carer satisfaction increased for NDIS participants up to the age of 10 years and decreased thereafter (left panel of Figure 5.7). For the carers of adult participants (right panel of Figure 5.7), the higher the age of the participant, the lower the impact of the NDIS was on satisfaction with supports being reasonable and necessary. The lowest impacts overall were seen for carers of NDIS participants who were aged 60 – 65 years.

**Figure 5.7 Carers: Impact of NDIS on carer satisfaction by person with disability age group (continuous measure) (Trial)**



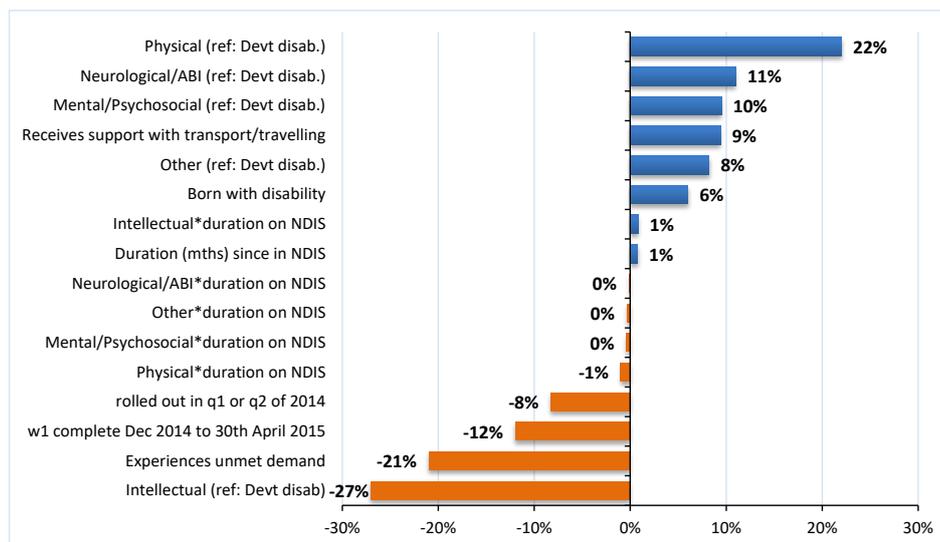
### 5.3.3 Reasonable and necessary: duration in the NDIS and different cohorts of participants

We then examined two further questions about satisfaction with supports being reasonable and necessary. First, does satisfaction increase with time spent in the NDIS? This is a ‘duration’ question about whether each individual participant is achieving improved outcomes as they become more familiar with the NDIS and the NDIS becomes more familiar with their needs. This process will be reflected through differences captured between the earlier and the later outcomes of each participant. Second, are the later cohorts of participants entering the NDIS more likely to find their supports to be reasonable and necessary than the earlier cohorts? This is a ‘cohort’ question about whether the NDIS is evolving as it gains more experience; this evolution is reflected in the difference between the outcomes of earlier and later new participants. These two questions can be confused as the earlier ‘cohorts’ will also be the ones with the longest ‘duration’. In order to disentangle this issue, multivariate regression approaches were used. The key findings from these analyses are presented below (Figure 5.8 and Appendix Table A5.12).

- People with disability who joined the NDIS early (in the first half of 2014) were less likely to report that their supports are reasonable and necessary. No further ‘cohort’ effects were found in the data.
- The longer that NDIS participants are in the NDIS, the more likely they are to be satisfied that their supports are reasonable and necessary (about 9 per cent more likely with each year spent as an NDIS participant).
- The full results of the multivariate regression are depicted in Figure 5.8 below. These estimated effects should be interpreted as estimates of association and not as causal estimates. The horizontal axis measures the effect of each factor included in the estimation; those in blue (to the right) are positively associated with satisfaction, while those in orange (to the left) are negatively associated with satisfaction.

- Differences by disability type and unmet demand experiences were statistically significant. NDIS participants with a physical, neurological or mental/psychosocial disability were especially more likely to be satisfied that their supports were reasonable and necessary, while those with an intellectual disability or experiencing unmet demand for supports were less satisfied.
- Those who were born with their disability were more likely to say that their supports under the NDIS are reasonable and necessary.

**Figure 5.8 Person with disability: Estimating the probability to be satisfied with reasonable and necessary (Trial, Adults)**

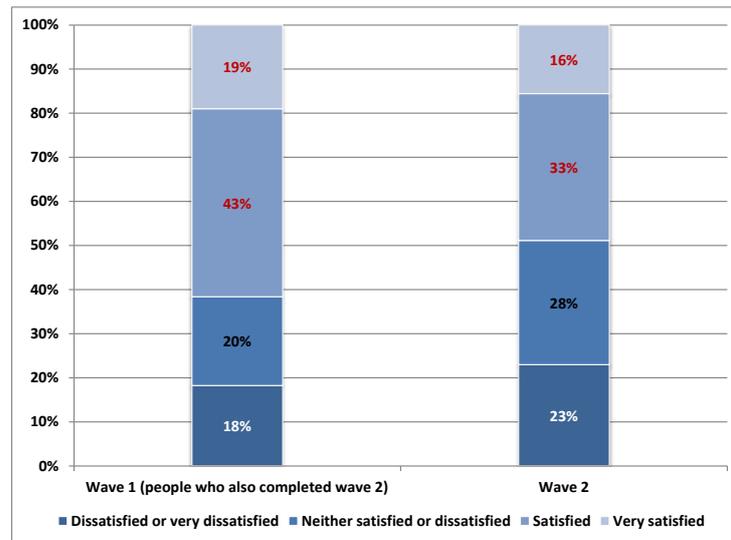


#### 5.4 Has Satisfaction with Supports being ‘Reasonable and Necessary’ Changed over Time? – Evidence from Large Scale Surveys

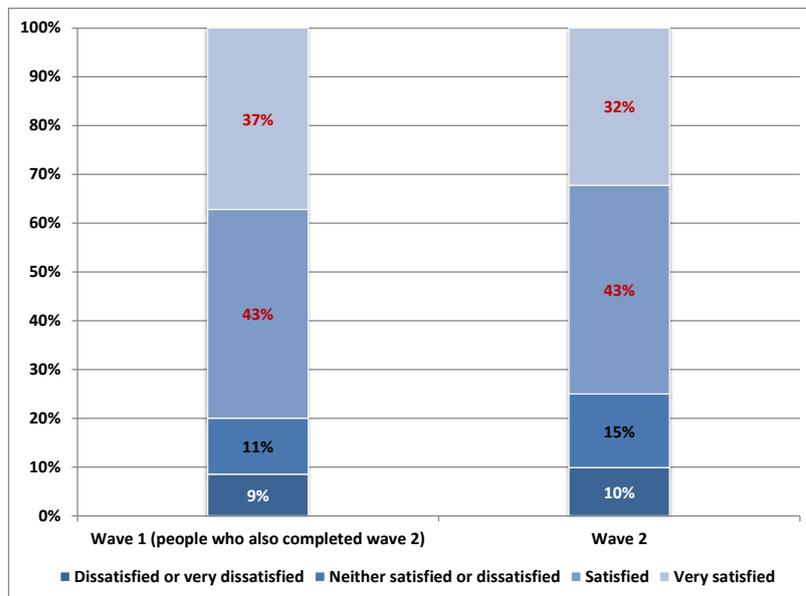
Satisfaction with supports being reasonable and necessary changed over the NDIS rollout period (Figures 5.9 and 5.10 below and Appendix Table A5.13). Levels of satisfaction were compared for NDIS participants (Figure 5.10) and people with disability who were not part of the NDIS (the comparison group, Figure 5.9). The data used for these analyses were restricted to those who answered these questions in both waves.

- The proportion of NDIS participants who reported being very satisfied/satisfied that their supports were reasonable and necessary remained the same over time. In contrast, the proportion of those who were very satisfied or satisfied decreased among the comparison group.
- Thus the widening gap found in levels of satisfaction between the trial and comparison groups stems from a reduction in satisfaction among the comparison group rather than an increase in the satisfaction of NDIS participants.

**Figure 5.9 Person with disability: Satisfaction with supports being reasonable and necessary (Comparison, Adults, waves 1 and 2)**



**Figure 5.10 Person with disability: Satisfaction with supports being reasonable and necessary (Trial, Adults, waves 1 and 2)**



- Table 5.1 documents transitions in the satisfaction levels of NDIS participants between waves 1 and 2. Hence we can identify whether people who reported a poor/good outcome in the first wave move on to a better/worse outcome, or stay the same in wave 2. It also enabled us to establish the amount of change in satisfaction over time, as well as who sees his/her outcome improve or worsen.
- As with all transition tables in this report, the top right triangle identifies those whose satisfaction improved, the diagonal line from top left to bottom right represents those whose satisfaction remained the same, and the bottom left triangle shows those whose satisfaction deteriorated.
- Overall 25 per cent of NDIS participant reported an increase in their satisfaction that their supports were reasonable and necessary over time, while 27 per cent reported a decrease in satisfaction and 48 per cent reported no change.

**Table 5.1 Person with disability: Transition in level of satisfaction that supports are reasonable and necessary to help meet needs – wave 1 and 2 evidence (Trial, Adults)**

| Wave 1<br>Level of satisfaction       | Wave 2<br>Level of satisfaction |              |  |            |                   | Total       |
|---------------------------------------|---------------------------------|--------------|--|------------|-------------------|-------------|
|                                       | Very<br>dissatisfied            | Dissatisfied | Neither<br>dissatisfied<br>nor satisfied | Satisfied  | Very<br>satisfied |             |
| Very dissatisfied                     | 22%                             | 33%          | 33%                                      | 11%        | 0%                | 100%        |
| Dissatisfied                          | 3%                              | 7%           | 23%                                      | 50%        | 17%               | 100%        |
| Neither satisfied nor<br>dissatisfied | 3%                              | 3%           | 33%                                      | 41%        | 20%               | 100%        |
| Satisfied                             | 1%                              | 6%           | 14%                                      | 54%        | 25%               | 100%        |
| Very satisfied                        | 1%                              | 5%           | 5%                                       | 35%        | 54%               | 100%        |
| <b>Total</b>                          | <b>2%</b>                       | <b>6%</b>    | <b>14%</b>                               | <b>44%</b> | <b>34%</b>        | <b>100%</b> |

- Further analyses using multivariate regression techniques to estimate the longitudinal impact of the NDIS on satisfaction with supports being reasonable and necessary, did not produce any statistically significant results.
- The estimated impact of the NDIS on satisfaction with reasonable and necessary support provision showed a slight decrease in satisfaction (the estimated effect was  $\downarrow 0.45$ ). However this estimate was not statistically significant and is relatively small in size in the context of the actual satisfaction scores.
- The longitudinal evidence on satisfaction with supports being reasonable and necessary therefore suggests that the impact of the NDIS seems to be plateauing with no real further improvement to satisfaction over time and, a possible worsening of satisfaction levels may occur if all other conditions remain unchanged.

## 5.5 Concerns around Reasonable and Necessary Supports – Evidence from In-depth Qualitative Interviews

The qualitative data indicates that all groups interviewed as part of the evaluation expressed concerns around the concept of ‘reasonable and necessary’ supports and the variability in the range and quantity of support services included in NDIS plans.

### 5.5.1 Concerns around reasonable and necessary supports for NDIS participants and their family members or carer

- In general, respondents thought that their NDIS plan covered reasonable and necessary supports. However, the boundaries of what were ‘reasonable and necessary’ supports were a principal cause of dissatisfaction with plans for many NDIS participants and their carers.

*They talked so much about what’s reasonable and necessary. I said to the lady, ‘I am sick and tired of hearing that b\*\*\* phrase.’ (D13C W2)*

- A number of factors were identified as contributing to this dissatisfaction in both waves 1 and 2, including:

- Variability in plans between participants with the same diagnosis or condition and inconsistency both within and between trial sites in the types of support services that were being funded in participants plans;
- Variability with plans accessed by participants under previous funding agreements; and
- Perceived gaps in plans.

#### *Variability in plans*

- Respondents reported that because of the prevalence of information sharing between NDIS participants (via social media or support groups), it was very apparent when a participant with the same diagnosis or condition received different services or a larger (or smaller) funding package. This led to anxiety for some respondents, contributing to feelings that they were 'missing out' on funding or services.
- The experience and personal attitudes and beliefs of NDIA staff was reported to influence what was thought of as 'reasonable and necessary'. For example, one mother of a son with intellectual disability thought that funding for her son's accommodation was reduced because their second planner thought that it was the family's role to provide that support.
- Respondents also reported inconsistencies between trial sites in what was and what was not being funded in participant plans.

#### *Variability with pre-NDIS plans*

- Respondents with previous experiences of funded services tended to report that their new NDIS plan compared favourably with pre-NDIS plans. There were, however, some exceptions to this positive comparison and this contributed to dissatisfaction with current NDIS plans.
- For example, several respondents considered previous early intervention funding packages to be more flexible than that allowed under their child's NDIS plan, such that parents/carers had greater choice and flexibility over how they could use money to purchase services and equipment.
- As stated earlier, funding for family supports was also considered to be inconsistently included in plans.

#### *Gaps in plans*

- Whereas many respondents reported that the NDIS had helped them to increase their supports, others 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 in wave 2 was broadly similar to those noted in wave 1. These included alternative therapies (naturopathy, osteopathy, chiropractic treatments) and social and recreational activities (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.
- Of note, advocacy was not explicitly included in plans, though it appeared some providers were prepared to take on this role. The lack of funding for advocacy was framed as an equity question for many respondents.

*In a way I feel as if that when someone goes into a meeting and they're clearly not very good at advocating for themselves, there needs to be a third party advocate that kind of is there. .... it really should be like an ability to go to a third party that can make sure that there is equality and there is equity. (A10PWD W2)*

- 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. There was some indication from respondents that the presence of these expenses discouraged participation in some of the activities.

#### *Change over time*

- It should be noted that NDIA processes and procedures evolved over time. Feedback from NDIS participants in wave 2 showed evidence that the NDIA had changed their policies around some items (for example iPads) such that they were now funded.
- In wave 2, there was a perception among respondents that NDIS planners were making decisions about reasonable and necessary care based on formulas or standardised plans for particular diagnoses rather than considering individuals' support needs. On occasion when participants' needs were different to those standard plans, they reported having the services denied.

*The only thing that I really want is to have funded gym. They give people with physical disabilities gym memberships because it's a physical disability but they have this blanket rule now, initially people with mental illness could get a gym membership now they've decided to veto it. (B05 PWD W2)*

- Respondent anxiety about the potential for plans to be 'capped' at review led several carers to use guidelines about what was reasonable and necessary to successfully argue their case for the continuation of services and supports for their child.

*I have letters of support from each practitioner and I said to her, 'You funded all of this indirectly in the first 12 months. You have letters of support. You've got evidence of how it's helping him. It is critical to his health and wellbeing. If you don't fund it for the next 12 months there's going to be big issues.' And she just said, 'Well leave it with me. I'll talk to my superiors. My gut feeling is how can we say no when we've already funded you for 12 months?' (C18C W2)*

- There was also evidence that over time NDIS participants had become knowledgeable about using the language and philosophy of the NDIA to include unsupported services and supports in plans. This respondent suggested she had obtained funding for respite in her son's plan by having it described as 'therapy support', and also negotiated funding for a disability support worker to develop his 'life skills' with the (embedded) aim of building basic literacy skills:

*What I've learnt over the last year rather than pushing, this sounds terrible, rather than pushing a point I'll just change it. I'll just change it so it fits...What I did was then ask for a support worker to help build his independence skills, teaching life skills, catching a bus, working out change, telling the time and that got approved. (C14C W2)*

- Concerns were raised about whether all people with disabilities had the same capacity to develop and use their knowledge and understanding of the NDIA to access services and supports that may be otherwise deemed not 'reasonable and necessary'.

- Several respondents suggested the ‘reasonable and necessary’ guideline may discriminate against NDIS participants and their families and carers living in less affluent circumstances, who could not afford to self-fund recreational or social 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.

### **5.5.2 Concerns around reasonable and necessary supports for people with disability not participating in the NDIS**

- Several non-participants expressed concerns that the services and supports that they considered or had experienced to be most helpful were not funded by the NDIS, because they were deemed not to be ‘reasonable and necessary’. In all cases this contributed to decisions to withdraw from the NDIS (either before or after planning).

*I was told they wouldn't be paying for a colour sensor because it wasn't deemed what was necessary and she said, 'Well you know, you've survived up until now without a colour sensor' and you know, 'There's probably other means, we'll get an OT to have a look. There's probably other means of you identifying your clothes' and it just seemed to me as though it was basically they were going to come up with the most cheap method which was not necessarily going to meet my needs and I find it offensive that they - I'm the expert in my life. I know what works for me and what doesn't and I can't shop independently if I don't have a colour sensor and they don't consider this stuff. It takes away - they're not recognising my disability for what it is and it's what they deem is necessary. (B01 NP)*

*They said to me 'What sort of things would make a difference in your life' and I said 'Well I'm using a manual 1960s brail machine so things like a new brail machine would be great'. I said 'Other than there's not a lot that I need'. 'Oh brail's obsolete' was the response. No it's not. Not by any means. (B02 NP)*

### **5.5.3 Concerns around reasonable and necessary supports for the service provider and other stakeholders**

- In both wave 1 and 2, disability service providers and representatives from workforce stakeholder organisations observed considerable variability in the range and quantity of support services included in NDIS plans. A lack of transparency in how these funding decisions were made and what supports were considered to be reasonable and necessary was reported.

*So between one planner and the next, one planner would respond to a priority goal, for example, of supports to enable a child to have independent communication... one planner might assign \$5,000 to that, the next planner might assign \$1,000 to that, without any kind of rhyme or reason, or rationale behind it, and there would be hundreds of examples of that kind of variability both, within each office and then across the offices, as well. (A01S W2)*

- This variability was attributed to the differing levels of knowledge and expertise amongst NDIA planners and varying levels of capacity among NDIS participants or their family to understand the system and adequately advocate and articulate their support needs.

*It still does depend a little bit on, or quite a bit actually, on how savvy the person is or their advocate... And that could be their family. We're still seeing variations in plans based on that. (B01S W2)*

*I think the knowledge of the planners is probably one of our primary concerns. The inconsistency of answers that we get, that our clients get, that come out across the country, I just, I guess it's the quote/unquote level of fairness. (A03S W2)*

- Concerns continued to be raised regarding the considerable level of skills and experience required by planners to understand the needs of different cohorts of people with disability. Understanding of disability, mental health issues, and allied health roles and interventions were considered to be necessary for planners in order to improve the quality of plans. Many did not view current NDIA planners as having these requisite skills.

*Issues to do with the awareness of planners around allied health and when and how to bring allied health into the picture around what we can offer in the range of supports....allied health needs to be brought into the equation in the planning stage so that they can much more adequately help somebody understand right upfront what are realistic options. (11R W2)*

*The people making plans don't have skills and experience in mental health. (08R W2)*

- Problems with NDIA staff knowledge extended beyond inconsistency in plans to other aspects of the planning process. The lack of disability specific knowledge within the NDIA was perceived to result in NDIS staff providing inappropriate advice to participants and families about which therapists they should engage. Concerns about NDIA staff offering clinical advice were also reported.

*One of the things we're finding is that NDIS doesn't seem to understand the fact that we're specialists. So we're not just speech pathologists here but we're speech pathologists who understand what hearing loss does to a child... they're just telling people well just go to your local speech pathologist because then you're saving on travel costs and, you know, a speechie is a speechie is a speechie. And it's not true... but no-one at NDIS seems to get that, they just think well, you know, you work with kids with disabilities, you'll be right. (A03S W2)*

- In both wave 1 and 2, Allied health organisations were concerned that a lack of planning guidelines contributed to inconsistent decision-making. Concerns about perceived cost containment within the NDIS and the impact this was having on funded supports were also raised.
- A lack of funding for particular supports was also reported by disability service providers and representatives from workforce stakeholder organisations. These included respite, support co-ordination, behaviour management, employment skills, and psycho-social support for carers.

*Very few plans, worryingly, include anything about employment skills, even though the purpose of the Scheme is to increase someone's social and economic participation. (08R W2)*

#### **5.5.4 How NDIA staff make decisions about reasonable and necessary supports**

- In both wave 1 and 2, NDIA staff reported that the use of reasonable and necessary as a concept was working well, and that most participants and their families or carers were understanding of both the need for decision-making about funded supports and how judgements were made.
- NDIA staff described the challenges of achieving consistency in planning processes and outcomes across trial sites, planners, and over time, as the NDIS developed. Guidelines to help planners make decisions about reasonable and necessary supports were not immediately available when the NDIS was initially rolled out, but were established relatively early and were reported to be in ongoing development.

- Several NDIA staff acknowledged inconsistencies in plans, and gave examples of occasions where planners who were new to disability or lacked knowledge of a particular disability type could have different perceptions of what could be funded. Staff continued to identify the need for more training pertaining to specific disabilities to assist with reasonable and necessary decisions.
- In wave 2, NDIA staff reported how reasonable and necessary decision making was supported in local offices, including seeking advice from colleagues and convening group meeting to discuss cases and assist with decision making.

*We've got a culture that if we don't know the answer we will take it to a group... We also have what we call a Reasonable and Necessary Group, so planners who have a decision regarding reasonable and necessary that they just can't work through on their own, or they're in two minds about something, whether something fits the rules or not, they bring that, it's like a case review... we'll talk through it at all levels and come to a decision. (E01N W2)*

- Examples were given of the most contentious items for NDIS funding. For child participants these related principally to equipment such as iPads, additional school supports such as tutoring, and requests for funding for mainstream recreational activities such as swimming lessons. For older participants, examples of disputed items included requests for funding for holidays, home modifications, and high end mobility equipment.
- The introduction of the new catalogue of supports and a more streamlined plan template in wave 2 were met with mixed response. A few NDIA staff indicated that the bundles of support made plans easier for participants and disability support providers to understand. More commonly though, NDIA staff observed that the move to bundles of support and more streamlined plan templates increased confusion in interpreting plans and decreased the flexibility of plans.

*My gut is that we will go back to something similar to what the State offered in individual packages for people. So you come in with a disability and say you've got Down Syndrome so this is how I feel like we're going, and you'll get – they'll say okay you can have six sessions of therapy, you can have a social activity once a month, but it will be set templates for people like TAC [Transport Accident Commission] do. (B02N W2)*

## 5.6 Summary

The final section in this chapter summarises the key quantitative and qualitative findings relating to reasonable and necessary supports.

### 5.6.1 Evidence from large scale surveys

- In wave 1, the majority of NDIS participants (75 per cent) and their carers (84 per cent) were either satisfied or very satisfied that their current disability supports were reasonable and necessary. These levels of satisfaction changed very little over time.
- A minority of NDIS participants did not consider the supports they access to be reasonable and necessary (about 9 per cent in both waves 1 and 2).
- The impact of the NDIS on satisfaction with supports being reasonable and necessary was estimated to be large and highly statistically significant. For adult people with disability, the NDIS was estimated to increase the probability of being 'very satisfied' that supports were reasonable and necessary by 83 per cent. For children with disability, the impact of the NDIS was 51 per cent.

- There was heterogeneity in the estimated impact of the NDIS on satisfaction that supports were reasonable and necessary by disability type. The lowest impact of the NDIS was for adults with an intellectual disability followed by those with a mental/psychosocial disability. The highest impact was found for people with a developmental/congenital disability.
- Although the impact of the NDIS on the satisfaction of carers that supports are reasonable and necessary was somewhat smaller than that estimated for people with disability themselves, the impact was still strong and statistically significant.
- Positive impacts on satisfaction increased for carers of child participants up to the age of 10 years and decreased thereafter. For the carers of adult participants, the higher the age of the participant, the lower the impact of the NDIS on satisfaction that supports were reasonable and necessary.
- People with disability who joined the NDIS during the early roll-out (in the first half of 2014) were less likely to report that their supports are reasonable and necessary compared to those who entered the NDIS later.
- Satisfaction with supports being reasonable and necessary increased with time spent in the NDIS. Therefore the longer an NDIS participant spends in the NDIS, the more likely they are to be satisfied that their supports are reasonable and necessary.
- When comparing individual responses in waves 1 and 2, some change in satisfaction that supports were reasonable and necessary was observed over time. Overall 25 per cent of NDIS participants reported increased satisfaction, 27 per cent reported decreased satisfaction and 48 per cent reported no change from wave 1 to wave 2.

### **5.6.2 Evidence from in-depth qualitative interviews**

- The qualitative data adds a more nuanced understanding around how respondent groups perceived the concept of 'reasonable and necessary' and what contributed to their satisfaction and dissatisfaction with NDIS funded supports.
- All groups interviewed as part of the evaluation expressed concerns around the concept of 'reasonable and necessary' supports as evidenced by the variability in the range and quantity of support services included in NDIS plans.
- Variability was thought to be attributable to a number of factors including:
  - NDIA planners applying different rules to what was eligible for inclusion or not and planners' variable levels of skills and experience in the disability sector. These were seen to result in inconsistencies and inequity in support provision between participants with the same diagnosis or condition.
  - Variability over whether therapies and services that had been allowed as part of pre-NDIS funding packages would continue to be funded by the NDIS.
  - Perceived gaps in plans - 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 activities. Other unfunded services and supports were related to overlaps with mainstream services, in particular education and health.

- In wave 2, respondents reported that NDIS planners were making decisions about reasonable and necessary care based on formulas or standardised plans for particular diagnoses rather than considering individuals' support needs.
- Having services and supports not funded by the NDIS because they were deemed not to be 'reasonable and necessary' contributed to decisions to withdraw from the NDIS (both before and after planning).
- NDIA staff understood and described the challenges of achieving consistency in planning processes and outcomes, particularly when guidelines about reasonable and necessary supports were under ongoing development.
- NDIA processes and procedures evolved over time during the period of the evaluation. There was evidence that NDIS participants had become more knowledgeable about using the language and philosophy of the NDIA in order to include previously unsupported services and supports in their plans.
- Concerns were present about whether all people with disability had the same capacity to develop and use their knowledge and understanding of the NDIA to access services and supports that may be otherwise deemed not 'reasonable and necessary'.

## 6. Wellbeing

### Integrated findings

This section integrates and summarises the quantitative and qualitative findings relating to the wellbeing and quality of life of people with disability and their families and carers.

The evaluation finds that:

- the NDIS has led to a modest improvement of the wellbeing of people with disability, which is improving with time in the NDIS;
- despite the improvements brought by the NDIS, the wellbeing of Australian people with disability remains extremely low, at a level well below the national average for all Australians;
- the NDIS impact on wellbeing is age- and disability-type related;
- a minority of people with disability report lower levels of wellbeing since the NDIS, for a large number of different reasons;
- no statistically significant evidence has been traced that the NDIS has improved the wellbeing of the families and carers of people with disability, with the exception of a modest negative impact reported by families and carers of children with disability;
- the evaluation describes and analyses in detail many aspects of disability care that have changed because of the NDIS and documents the way these changes have impacted on the wellbeing of people with disability; and
- on the whole, the wellbeing of people with disability is improved by the NDIS, however, the wellbeing levels of people with disability remain extremely low, and the benefits from the NDIS are not spread evenly among all NDIS participants.

#### *Wellbeing of NDIS participants*

- Although wellbeing is not a precisely defined and exactly measured concept, it is recognised in the social and life sciences to be very strongly associated with a broad range of easily measured objective life-outcomes. Wellbeing is not only recognised as a measure of outcomes that have happened, but also as a good predictor of opportunities and future outcomes and as such it has been treated by the evaluation with the importance it deserves.
- The evaluation recognised that measuring wellbeing is not an exact science and employed three nationally and internationally recognised methodologies to ask the same important questions in different ways and from different angles. This way, the evaluation does not attempt to resolve the debate of how to measure wellbeing, but to collect robust evidence on a question that is critical for all public policy: ‘is the wellbeing of people improving as a result of this policy?’ To a reassuringly high degree, all different measures utilised by the evaluation present a very similar picture on the impact of the NDIS, hence the presentation of the evaluation results does not focus on the comparison between the different measures, these being left for more technical methodological future investigations.
- Both quantitative and qualitative evidence demonstrates that the NDIS had a positive impact on the wellbeing of its participants. The quantitative evidence showed that this impact was small to begin with, but was followed with further modest increases observed with longer time in the NDIS. However, compared to levels of wellbeing in the general Australian population, NDIS participants

and non-participants alike report much poorer wellbeing, which had remained well below national averages even after the NDIS-induced improvements in wellbeing had occurred.

- The qualitative interviews explored in-depth the ways in which the NDIS was impacting on the wellbeing of people with disability. 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. Opportunities for increased participation in social and recreational activities, improved skills and developmental progress were found to have led to enhanced levels of wellbeing.
- The quantitative evidence however, revealed that not all NDIS participants had experienced improvements in their wellbeing since joining the NDIS. In particular, NDIS participants with a mental health/psychosocial disability consistently reported lower levels of wellbeing than people with other types of disability. Further quantitative analyses found that NDIS participants with intellectual and developmental disability also reported poorer wellbeing.
- Quantitative evidence showed that the impact of the NDIS on wellbeing depended on the age of the NDIS participant. For adult participants, the positive impact of the NDIS on wellbeing increased with age, reaching its peak in their mid to late 40s and then consistently falling as participants aged. The NDIS was not found to have an impact on the wellbeing of child participants.
- Quantitative evidence also showed that NDIS participants living in urban areas reported higher levels of wellbeing than those in rural areas, and that those who experienced unmet demand for supports reported poorer wellbeing.

#### *Wellbeing of families and carers*

- A mixed picture emerged from the quantitative and qualitative evidence on the impact of the NDIS on the wellbeing of families and carers of NDIS participants. While the qualitative interviews showed that families and carers had experienced increased wellbeing as a result of the NDIS, the quantitative evidence cannot trace a statistically significant improvement in carer wellbeing. Indeed, for carers of younger participants aged 8-15 years, the NDIS was found to have a small negative impact on wellbeing.
- Although the quantitative evidence showed that carer levels of wellbeing were much higher than for the NDIS participants themselves, average wellbeing was still lower than that for the general Australian population. Moreover, levels of reported carer wellbeing fell slightly over the duration of the evaluation.
- The quantitative evidence indicated that the wellbeing of families and carers was strongly related to the amount of perceived control they have over how they spend their time. On average, carers with a lot of control over their time reported the highest levels of wellbeing, while those with no control had very low levels of wellbeing. The quantitative evidence also showed that carers of NDIS participants with mental/psychosocial disability have lower levels of wellbeing than the carers of NDIS participants with all other disability types.
- Both quantitative and qualitative evidence contributed to the evaluation's broader understanding of the factors influencing the wellbeing of carers of people with disability. The quantitative

evidence showed that carers reported particularly high levels of satisfaction with their relationships with service providers and also with the supports provided to the person with disability to make progress at home. This latter point was reinforced by the qualitative interviews, with families and carers reporting increased wellbeing as a result of the NDIS participant having more opportunities to participate in activities they enjoyed, and of being able to participate in wider interests outside of the home.

- The qualitative evidence suggested that enhanced service provision under the NDIS can have a positive impact on carer wellbeing, by allowing greater opportunities for self-care and for spending time with other family members. It also suggested that the NDIS provided carers with greater confidence around the future plans, activities and supports of the person with disability they cared for.
- Both evidence sources identified factors through which the NDIS had impacted negatively on the wellbeing of family members and carers. In the quantitative survey, carers reported high levels of dissatisfaction with family support to relieve stress, the availability of outside help to take care of all family members, opportunities to pursue their own interests, and the availability of friends or other people to provide support. The qualitative interviews went deeper highlighting the anxiety of many families of people with disability about the long-term sustainability of the NDIS. The NDIS was seen as imposing an administrative burden which led to stress and negatively impacted on the wellbeing of some families.
- Both sources of evidence report frequently the presence of financial stress among families and carers of people with disability. Although the evaluation found financial stress to have decreased somewhat with involvement in the NDIS, a large proportion of family members and carers continued to report financial stress at the later stages of the evaluation.

## 6.1 Introduction

The NDIS aims to improve the quality of life and wellbeing 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 wellbeing. It is recognised by the NDIS evaluation 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.

The evaluation collected wellbeing information using the well-known Personal Wellbeing Index (PWI) devised by the International Wellbeing Group (2013). We also collected information that is akin to the wellbeing information collected by the Organisation for Economic Co-operation and Development (OECD 2013) and information similar to that collected by the Household Income and Labour Dynamics in Australia Survey (see for example Qu, L., et al. 2012).

In this section we present quantitative and qualitative evaluation evidence to assess the extent to which the NDIS is changing the wellbeing and quality of life for people with disability and their families and carers.

## 6.2 Wellbeing of People with Disability – Evidence from Large Scale Surveys

The quantitative data collected information on three separate measures of wellbeing: (i) wellbeing information based on the well-known Personal Wellbeing Index (PWI) devised by the International Wellbeing Group (2013); (ii) wellbeing information that is akin to what is collected by the Organisation for Economic Co-operation and Development (OECD 2013) often referred to as the psychological wellbeing (often called eudaimonic) index and (iii) wellbeing information similar to that collected in the Household Income and Labour Dynamics in Australia Survey index. We therefore do not rely on any single measure. Rather we examine all of the evidence to form a quantitative judgement as to the overall message that arises regarding the wellbeing and specific aspects of the NDIS.

### 6.2.1 Psychological (Eudaimonic) wellbeing measure - statements by people with disability about themselves and how they feel (OECD 2013)

- This 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' notions of wellbeing<sup>15</sup>. Respondents are asked to rate how they have been feeling this week on a scale of 0 to 10 (where 0 means 'completely disagree' and 10 means 'completely agree').
- Appendix Tables A6.1 - A6.6 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.

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<sup>15</sup> The questions in the eudaimonic wellbeing block are relatively diverse and cover a range of different mental attributes and functioning that are thought to constitute mental 'flourishing'. (OECD 2013)

- Overall, we see that the mean responses of the NDIS participants to the six measures range from 5.9 to 6.7 in wave 1 and 5.8 to 6.8 in wave 2.

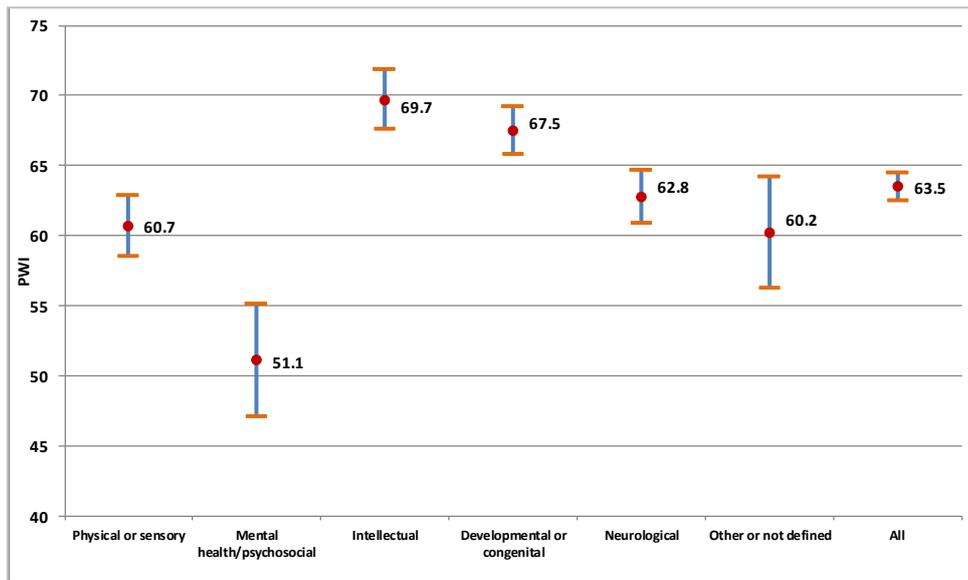
Two broad comparisons are of interest:

- First is the comparison between wave 1 and 2 levels of wellbeing. With the exception of the third and last wellbeing items (free to choose the things that I want to do myself and recovery time after adverse events), the mean responses show a modest improvement in the wellbeing of NDIS participants.
- Second is the comparison between different subgroups among NDIS participants. Comparing wellbeing by broad disability type, NDIS participants with a mental health or psychosocial disability reported the lowest wellbeing and NDIS participants with physical and sensory disorders reporting the highest wellbeing.
- The improvement in wellbeing between wave 1 and 2 holds for all main disability categories. The largest improvement is among NDIS participants with a mental health or psychosocial disability.

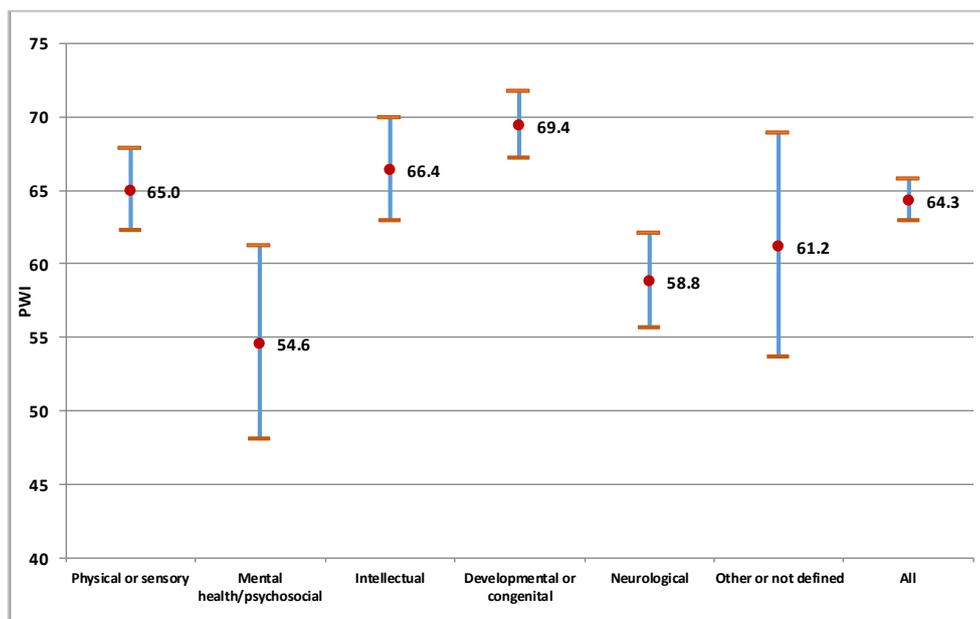
### **6.2.2 The Australia Unity Personal Wellbeing Index (PWI) - questions about how happy people with disability feel about things in their lives (International Wellbeing Group 2013)**

- Respondents are asked to report how they have been feeling this week 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. Answers are on a scale of 0 – 10 (0 is ‘very unhappy’ and 10 is ‘very happy’).
- These questions have been designed to lend themselves to aggregated analysis, where a combined score across all component statements can be calculated, using a validated methodology. This allows more robust assessments of wellbeing to be formulated as it provides a cardinal measure of wellbeing, especially at the extremely low responses which have been found to be associated with depression.
- Figures 6.1 and 6.2 below display the mean PWI for NDIS participants in wave 1 and 2 by broad disability type along with the corresponding 95 per cent confidence intervals. NDIS participants overall had a mean PWI of 63.5 in wave 1, and 64.3 in wave 2, both measures being well below the average PWI in Australia which fluctuates around 75.

**Figure 6.1 Person with disability: Australian Unity PWI mean and 95 per cent confidence intervals by disability type wave 1 (Trial, Adults)**



**Figure 6.2 Person with disability: Australian Unity PWI, mean and 95 per cent confidence intervals by disability type wave 2 (Trial, Adults)**



- Australian Unity who are the architects of the PWI, advise that ‘there is a wide so-called normative range, between 60 and 90, as people are inherently different, some more positive, others less so. However 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’ (Australian Unity, 2015: 5). When we consider the result by broad disability type we see that people with mental health/psychosocial disability have the lowest mean score on the PWI in both waves 1 and 2, well below the ‘minimum threshold’ defined by Australia Unity. NDIS participants with a neurological condition recorded a decrease in their PWI between wave 1 and 2, and in wave 2 also fell below the ‘minimum threshold’ defined by Australia Unity.
- It will be essential for an ongoing independent evaluation and monitoring to assess whether the NDIS improves the personal wellbeing among these two vulnerable groups.

### **6.2.3 Sense of social connection - descriptions about how much support they get from other people (HILDA measure)**

- The final measure of wellbeing that we collect measures a person's sense of social connection. Respondents are asked to report on a set of questions about their connection with others in the community, as 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 how they have been feeling this week with several aspects of their life on a scale of 0 - 10 (0 is 'completely disagree' and 10 is 'completely agree').
- Appendix Tables A6.7 – A6.11 present the mean value of responses to each of the five questions that make up the 'social connection' responses for both waves 1 and 2, 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.
- Responses range from 5.0 to 8.3 in both waves 1 and 2. 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 to the statement 'I enjoy spending time with the people who are important to me'. There is very little evidence of change in 'social connection' between waves 1 and 2.
- Comparing responses by broad disability type we see that people with mental health/psychosocial disability report lower levels of social connection on all measures in both waves 1 and 2.

### **6.2.4 The impact of the NDIS on wellbeing (people with disability)**

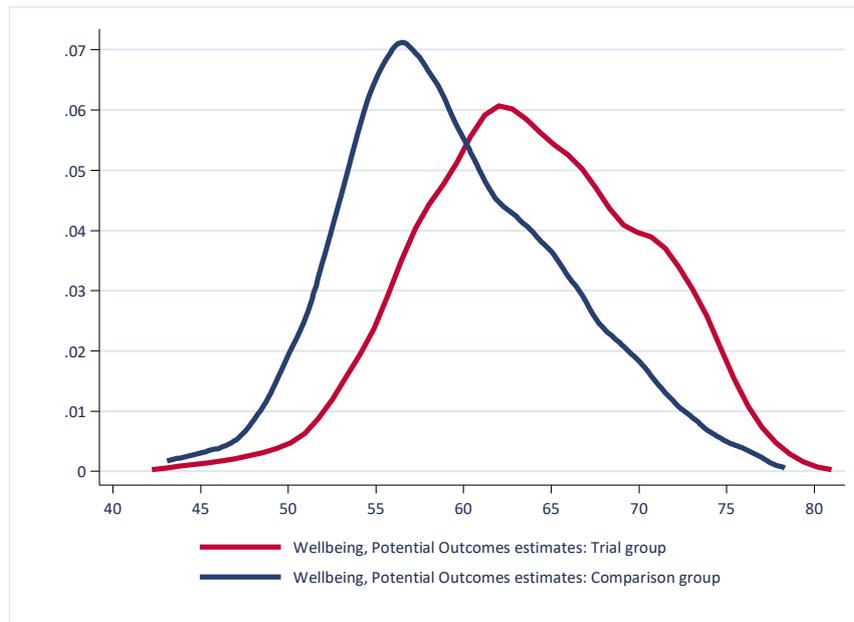
In the following section we report on the estimated impact of the NDIS on the wellbeing of people with disability using each of the three different wellbeing measures presented. Before we look at these findings, it is worth reiterating that, unlike the analyses above using the 'raw' survey data, the estimations are able to control for many socioeconomic and demographic differences between sub-groups of participants.

The strongest indication for a positive impact of the NDIS on participant wellbeing was found when using the Australia Unity PWI (International Wellbeing Group 2013), and less so when the OECD and the HILDA measures were used.

Below is a summary of the important results from the multivariate analysis of wellbeing (using the PWI)

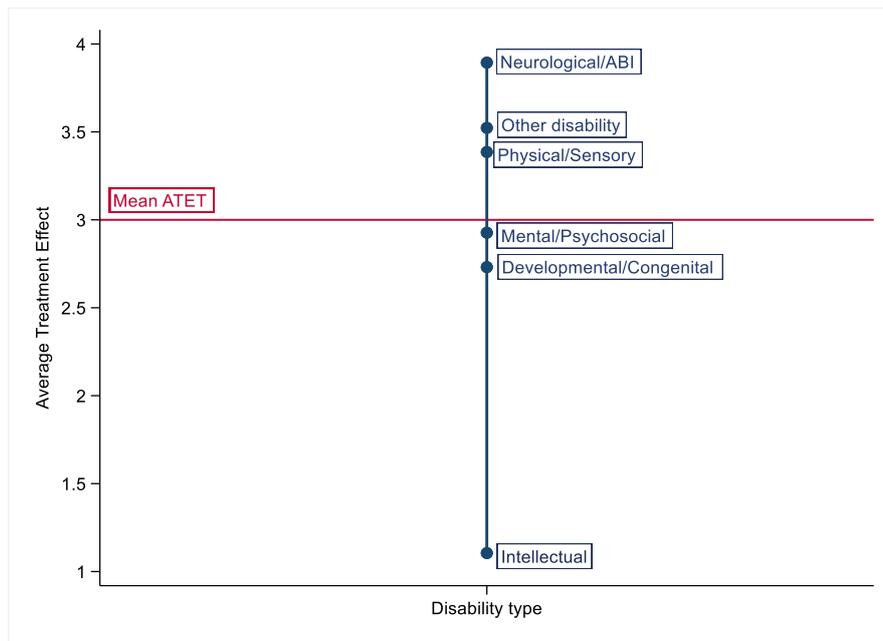
- The PWI (Deakin wellbeing index) measure suggests that the NDIS has improved participant wellbeing by 3.04 points (with a 95 per cent confidence interval from 1.30 to 4.78; Appendix Table A6.12). However, the effect is modest with an estimated treatment effect of three points on the PWI scale which represents about a five per cent increase in overall wellbeing.
- Our analyses also examined the difference in wellbeing between NDIS participants and the comparison group (Figure 6.3) The horizontal axis measures the wellbeing (which we see lies largely between 40 and 85) and the vertical axis shows how frequently each level of wellbeing is encountered. The figure indicates that NDIS participants (in red) experience greater levels of wellbeing than those not participating in the NDIS (in blue).

**Figure 6.3 Person with disability: Distribution of estimated potential outcome by treatment status (Trial and Comparison, Aged 8+)**



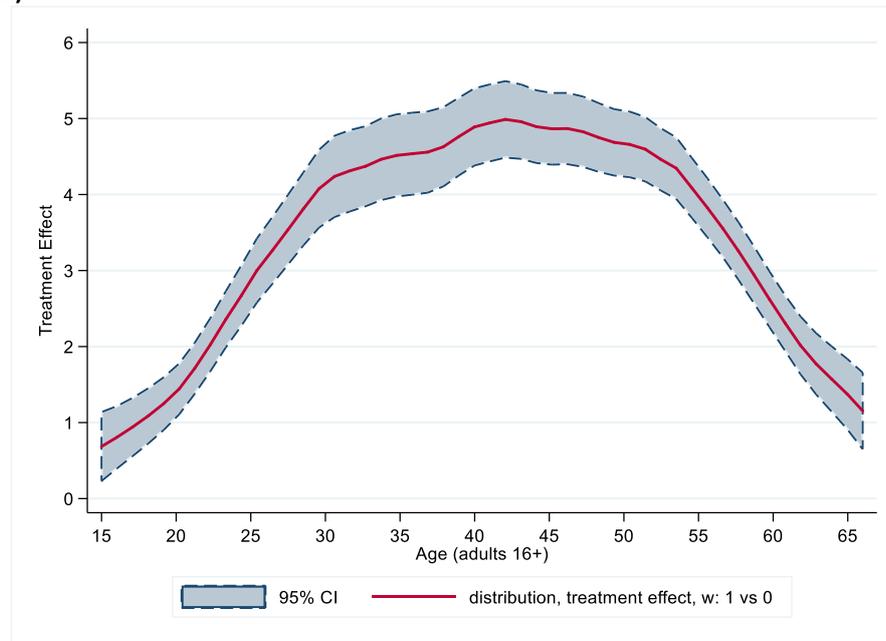
- The analyses show that the impact of the NDIS on wellbeing differed according to NDIS participants' disability type (see Figure 6.4). The NDIS was found to have the greatest impact on the wellbeing of people with a neurological condition. In contrast the impact of the NDIS on wellbeing is below the average for NDIS participants with mental/psychosocial, developmental/congenital and intellectual disabilities; for example, the estimated impact is as low as 1.5 per cent for people with intellectual disability.

**Figure 6.4 Person with disability: Estimated impact of the NDIS on wellbeing by main disability type (Trial, Aged 8+)**



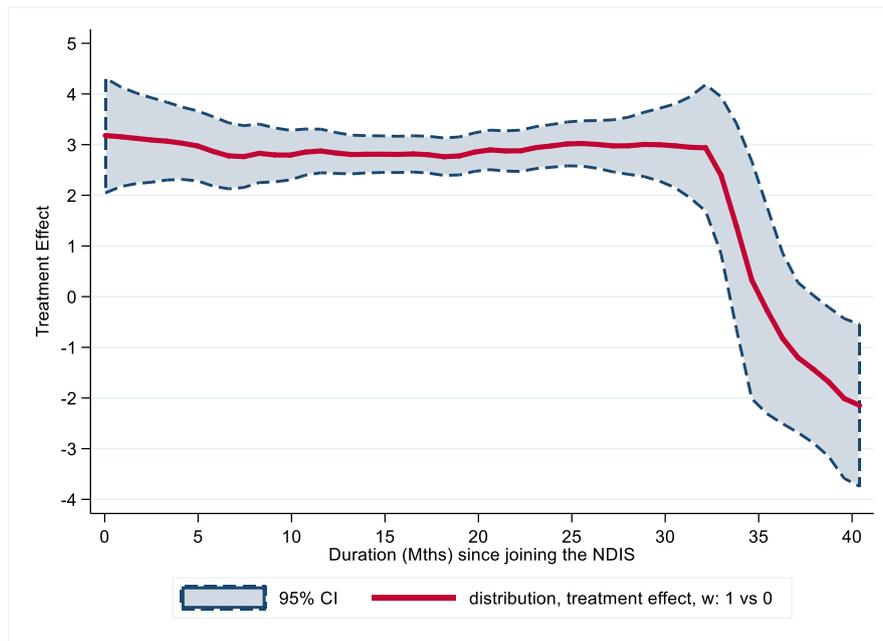
- The impact of the NDIS on wellbeing was found to vary with the NDIS participants' age, with the youngest and the oldest benefiting the least from the NDIS (Figure 6.5). The positive impact of the NDIS on wellbeing increased with age up to the person with disability reaching their early to mid-40s. After this point, wellbeing was then found to fall at an increasing rate.
- When looking at the wellbeing of NDIS participants aged 8-15 years, only a modest increase in wellbeing of 0.65 points was found, which is not statistically significant (Appendix Table A6.13).

**Figure 6.5 Person with disability: Distribution of the estimated impact of the NDIS on wellbeing by age (Trial, Adults)**



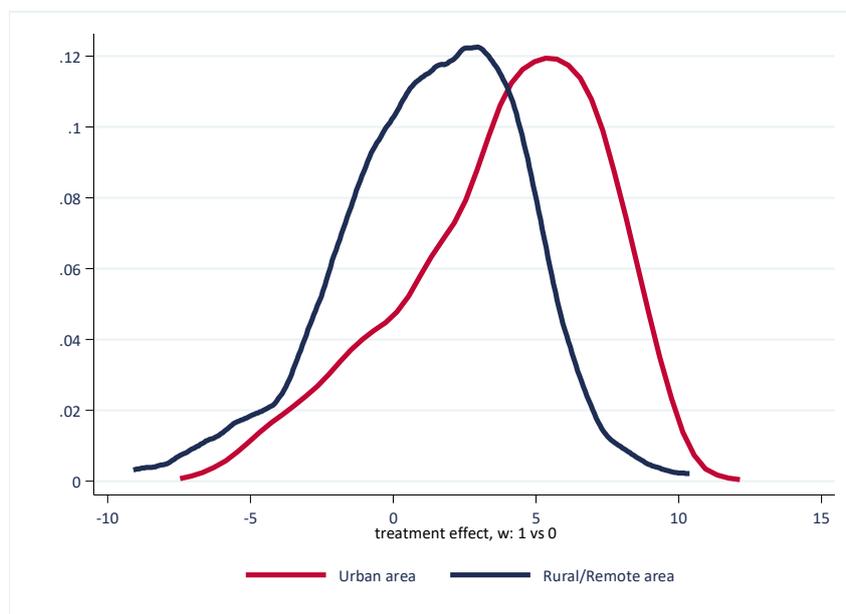
- The duration that a participant has spent within the NDIS is recorded and is plotted below against the estimated NDIS impact (Figure 6.6). The impact of the NDIS on participants' PWI did not seem to be impacted by the length of time people had participated in the NDIS. It should be noted that while a decrease in wellbeing for people who had been rolled out for the longest was observed, this may be due to smaller number of observations.

**Figure 6.6 Person with disability: Distribution of the estimated impact of the NDIS on wellbeing by duration (months) of participation in the NDIS (Trial)**



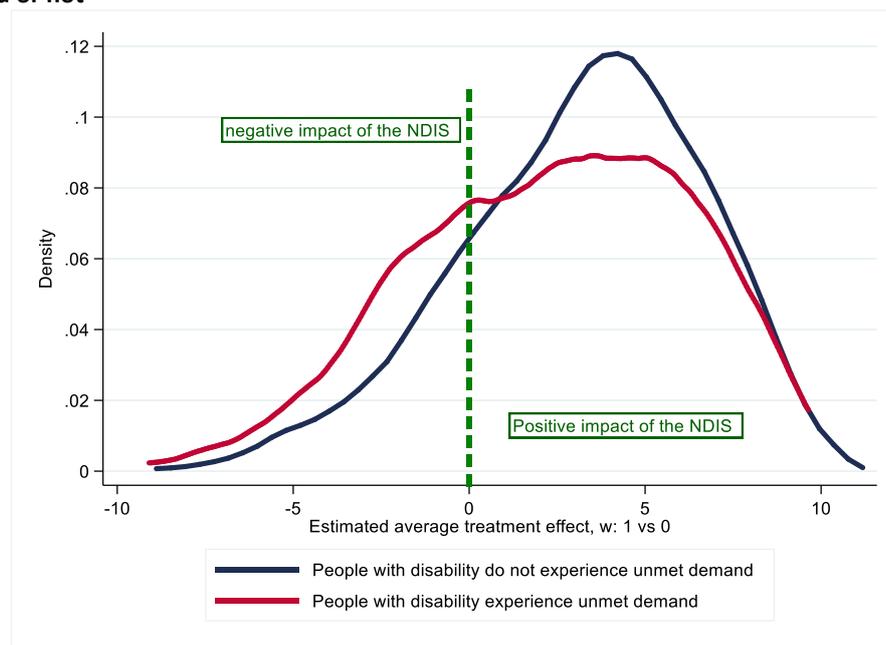
- The impact of the NDIS on wellbeing was more positive for NDIS participants living in urban areas as opposed to those living in rural areas (Figure 6.7). There are many more people who are estimated to experience a decrease in their wellbeing (the part of the two lines that lies to the left of the 0 point on the horizontal axis) in the rural areas than in the urban areas.

**Figure 6.7 Person with disability: difference in impact of the NDIS on wellbeing by urban vs. rural area**



- As shown in Figure 6.8, those NDIS participants who experienced unmet demand appear to also experience a lower impact on their wellbeing. It is not intended to assume a direct causal relationship here, but simply to remark that, after controlling for the individual characteristics of NDIS participants, those with lower wellbeing were more likely to also have problems with getting the supports they had funding for. This is a very complex relationship worth further investigation.

**Figure 6.8 Person with disability: Difference in impact of NDIS on wellbeing by whether unmet demand is experienced or not**



Overall, our analyses using the PWI measure of wellbeing, suggest that the NDIS has been making people with disability happier. However, we also have a stark warning of the inequalities that this overall positive impact of the NDIS brings with it in terms of age, type of disability, location and other. The quantitative data includes many such facets that could and should be studied in detail to guide the further development of the NDIS.

- As with the previous estimations using the PWI, a positive impact of the NDIS on participant wellbeing was also found with respect to the OECD measurement tool. The estimated impact of the NDIS on wellbeing found with this measure was greater; with an estimated 6.3 per cent increase in participant wellbeing due to the NDIS.
- The analysis of the impact of the NDIS on each component of this wellbeing measure shows slight variability depending on the question analysed, but, altogether, the differences are not statistically significant.
- A positive impact of the NDIS on participant wellbeing was also found with respect to the HILDA measure of wellbeing. In this instance the estimated impact of the NDIS was similar to that found for the PWI.

### 6.3 Wellbeing of Families and Carers – Evidence from Large Scale Surveys

The wellbeing of the carers of people with disability is a major focus of the NDIS. Their opinions are well informed and very important for the successful care and support of people with disability. The wellbeing of carers were captured using two measurement tools- the OECD psychological measure of wellbeing and the Deakin wellbeing index PWI.

#### 6.3.1 Psychological (Eudaimonic) wellbeing measure - statements by people about themselves and how they feel (OECD 2013).

- Overall, responses of the carers of NDIS participants to the six measures of wellbeing range from 4.6 to 7.8 in wave 1 and 4.6 to 7.7 in wave 2 (Appendix Table A6.18).

- As with people with disability, two broad comparisons are of interest.

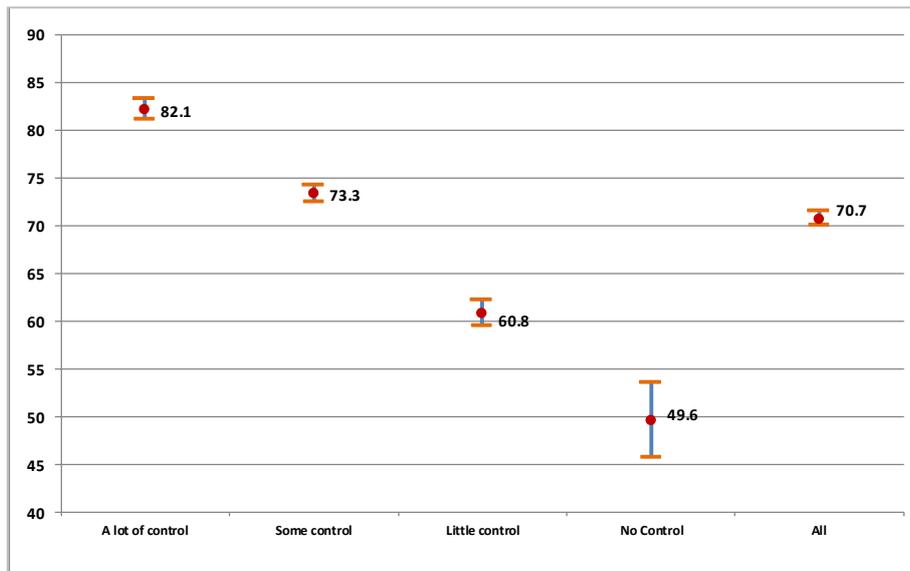
The first comparison is between wave 1 and 2 levels of wellbeing. Wellbeing increased very slightly for two facets, 'In general, I feel very positive about myself' and 'I get a sense that I have achieved something', and remained unchanged or decreased for all others. Overall, however, carers wellbeing seems to have changed little as a result of the NDIS.

- The second type of comparison is between different subgroups and circumstances. Wellbeing levels relating to how much control carers report to have over how they spend their time were compared (Appendix Tables A6.19 – A6.24). Wellbeing across all domains is negatively associated with a lack of perceived control in both waves 1 and 2.
- The wellbeing of carers who reported no control over their time in wave 1 declined further by wave 2. For all other groups there has been a general increase or no change in wellbeing over time.

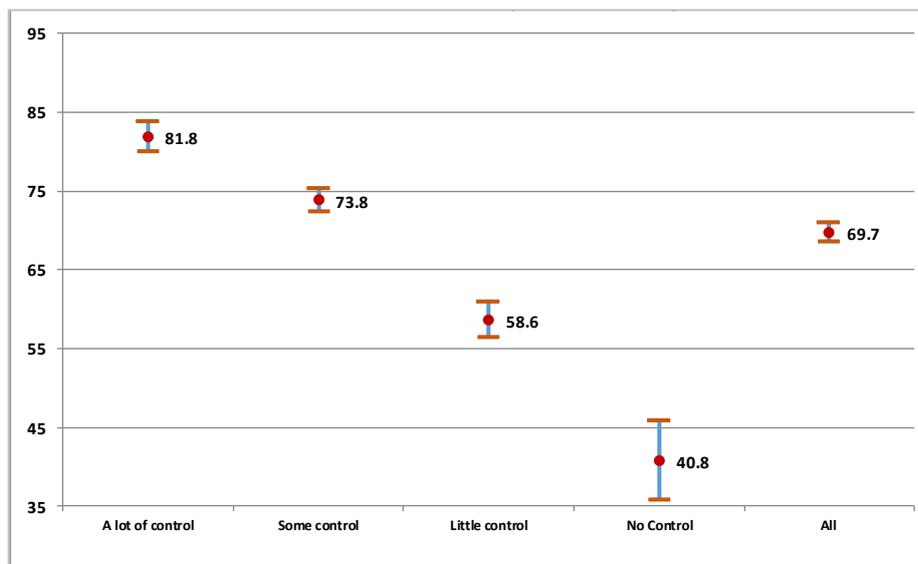
### **6.3.2 Australia Unity PWI - questions about how happy people with disabilities feel about things in their lives (International Wellbeing Group 2013)**

- Respondents are asked to report how they have been feeling this week 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. Answers are on a scale of 0 – 10 (0 is 'very unhappy' and 10 is 'very happy'). The answers were then aggregated to provide an overall personal wellbeing index (PWI).
- Figures 6.9 and 6.10 below display the mean PWI for carers of NDIS participants in wave 1 and 2 by the amount of control they report to have over their time; the corresponding 95 per cent confidence intervals are also shown. Carers overall had a mean wellbeing index of 70.7 in wave 1. Wellbeing decreased slightly over time with carers recording a PWI of 69.7 in wave 2.
- While carers wellbeing is much higher than that of the NDIS participants that they care for, their reported PWI is still well below the average for Australia (which sits at around 75).
- When we consider the result by the amount of control carers have over their time we see that carers with no control are extremely low on the PWI in both waves 1 and 2 (and well below the 'minimum threshold' of 60 as defined by Australia Unity). Carers who have only a little control over their time are also at risk with their PWI falling to just below 60 in wave 2.
- Among these groups, despite the introduction of the NDIS very little control was realised over their own time, which as we see here comes at high cost in terms of their wellbeing. It will be essential for ongoing independent evaluation and monitoring to assess whether the NDIS improves the personal wellbeing of these carers.

**Figure 6.9 Carers: Australia Unity PWI (mean and 95 per cent confidence intervals) by carer’s control over own time, (Trial, wave 1)**



**Figure 6.10 Carers: Australia Unity PWI (mean and 95 per cent confidence intervals) by carer’s control over own time, (Trial, wave 2)**



- Carers were also asked a series of questions to rate their level of satisfaction with various aspects of their life (Appendix Table A6.25).
- In both waves 1 and 2, the majority of carers in the trial sites were 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 carers report to be either dissatisfied or very dissatisfied with certain aspects of their lives relating to the amount of support family and carers can count on. In particular, more than 20 per cent of carers in both waves 1 and 2 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, (iii) time of family members to pursue their own interests and (iv) having friends or others who provide support. This suggests 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 others is needed but often lacking.

- Another measure of wellbeing included in the NDIS Survey is financial hardship (Appendix Table A6.26). This question asked about seven separate indicators that could be taken as potential manifestations of financial hardship.
- In wave 1, 42 per cent of the carers of NDIS participants surveyed reported that they experienced at least one indicator of financial hardship over the last 12 months. The financial hardships most commonly reported was that a carer or family member could not pay bills on time (25 per cent) and having to ask for financial help (25 per cent).
- In wave 2, the proportion of carers reporting that they experienced at least one indicator of financial hardship over the last 12 months declined to 36 per cent. However, this still represents a large proportion of carers of NDIS participants reporting financial stress. With the exception of family members being unable to heat their home, there was a general decline in the proportion of carers nominating each of the remaining indicators of financial hardship.

### 6.2.3 The impact of the NDIS on wellbeing (families and carers)

- Further analyses were undertaken to estimate the impact of the NDIS on the wellbeing of carers. The raw difference in wellbeing found between carers of NDIS participants and carers of people with disability not participating in the NDIS was very small, with the mean score for each group being a little over 70 (on a scale of 0 to 100). Our estimations of the impact of the NDIS on the wellbeing of the families and carers of people with disability aged 16+ found the impact to be very small (0.36 points) and not statistically significant (Appendix Tables A6.27 and A6.28). This suggests that the NDIS has not had a direct effect on the wellbeing of the families and carers of people with disability, as measured by the PWI. For the carers of people with disability aged 8-15 years it was found that the NDIS has had a small, but statistically significant negative impact on the wellbeing of families and carers (Appendix Tables A6.29 and A6.30). Both wellbeing measures (the PWI and OECD tools) led to the same results for carers of both age groups.

#### *The family quality of life outcomes for families and carers*

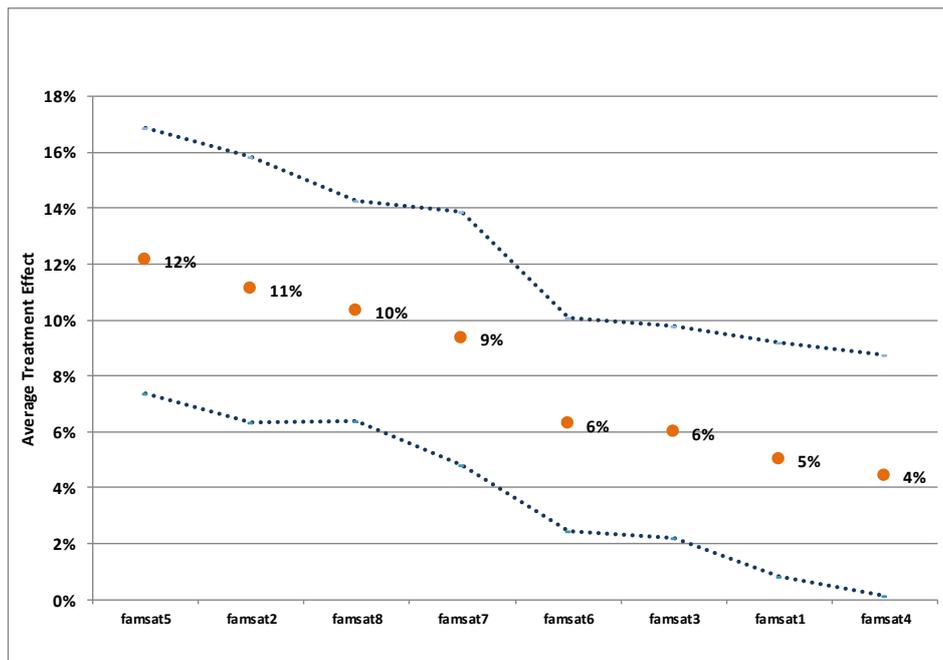
- Several aspects of quality of life were then examined, comparing carers in the NDIS trial group with the comparison group. The third column of Table 6.1 below sums up the main differences between trial and comparison groups in terms of wellbeing.

**Table 6.1 Carers: Summary of estimation outcomes on family quality of life – Trial vs. Comparison**

| Variable | Question  | Outcome               |
|----------|---|-----------------------|
| Famsat1  | ‘Your family has the supports it needs to relieve stress’   | Trial better off      |
| Famsat2  | ‘Your family has outside help available to you to take care of the special needs of all family members’     | Trial better off      |
| Famsat3  | ‘Family members have some time to pursue their own interests’   | About the same        |
| Famsat4  | ‘Family members have friends or others who provide support’   | About the same        |
| Famsat5  | ‘Person with disability has support to accomplish goals at school or at work’                               | Trial much better off |
| Famsat6  | ‘Person with disability has support to make progress at home’   | Trial much better off |
| Famsat7  | ‘Person with disability has support to make friends’  | Trial better off      |
| Famsat8  | ‘Your family has good relationships with the service providers who provide services and support to him/her’ | Trial much better off |

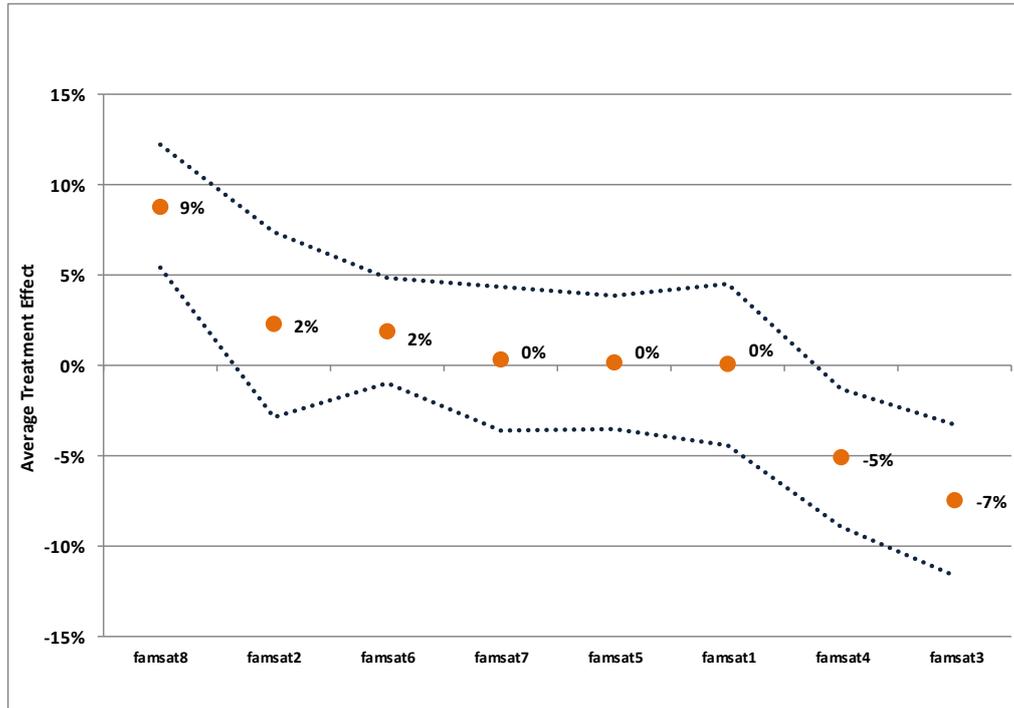
- Estimates of the impact of the NDIS on each of these quality of life statements are now presented (with detailed estimates contained in Appendix Graph A6.1 to Graph A6.10). First the average estimates for carers of people with disability aged 16+ years are shown in Figure 6.11.
- The mean estimated impacts of the NDIS on each of the quality of life outcomes of families and carers in the NDIS ranges from four per cent to 12 per cent. The highest impact of the NDIS related to whether the person with disability they care for has support to accomplish goals at school or at work. The impact of the NDIS was also high for satisfaction with accessing outside help to take care of the special needs of all family members (an estimated impact of 11 per cent) and their relationship with disability service providers (10 per cent).

**Figure 6.11 Carers: Satisfaction with family quality of life, Estimated ATETs (Trial, Adults)**



- The results on the quality of life outcomes of families and carers of children aged 8-15 years paint a very different picture (Figure 6.12). The estimated treatment effects are statistically significant for only three of the eight measures of family quality of life, namely (i) 'your family has good relationships with the service providers' with a positive estimated impact of the NDIS of nine per cent (very similar to the effect estimated for the carers of adults), (ii) 'family members have some time to pursue their own interests' with a negative estimated impact of the NDIS of seven per cent which is at odds with the results obtained on the carers of adults (+6 per cent), and, (iii) 'family members have friends or others who provide support', with a small negative estimated impact (-5 per cent).

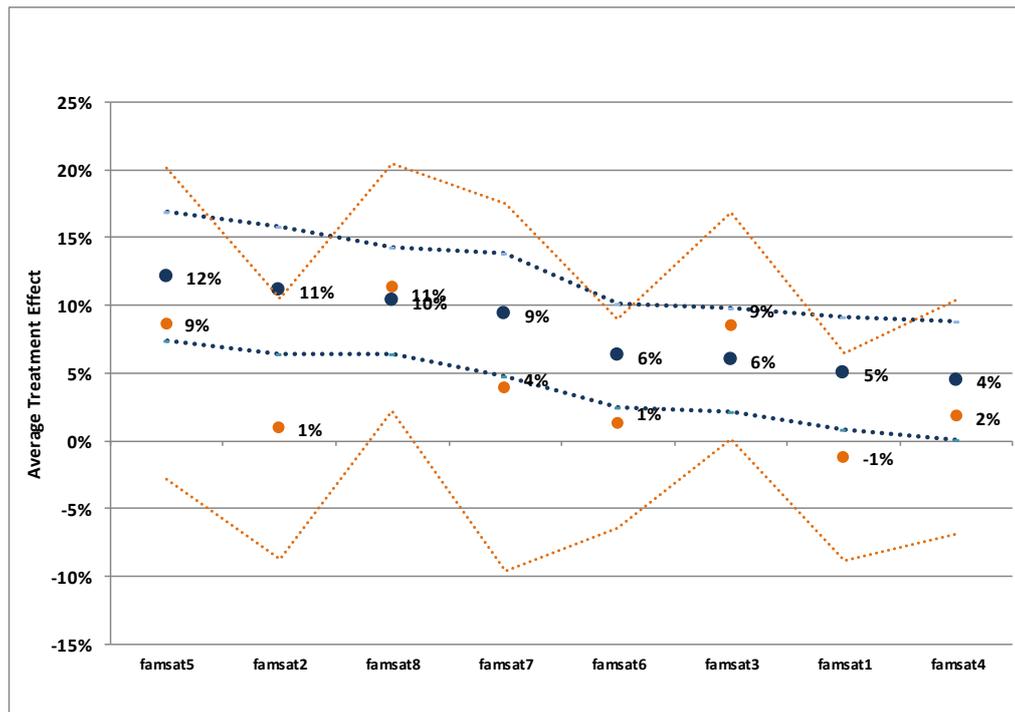
Figure 6.12 Carers: Satisfaction with family quality of life, Estimated ATETs (Trial, Age 8-15)



- Carers of people with a mental/psychosocial disability systematically experience a smaller positive impact of the NDIS. In Figure 6.13 we superimpose the estimated NDIS impacts for each family wellbeing indicator for those caring for a person with a mental/psychosocial disability (the orange dots), and for those caring for a person with any other disability type (the blue dots).<sup>16</sup>
- Overall the impact of the NDIS on the quality of life of those caring for a participant with a mental/psychosocial disability were lower. Only with regard to (i) *satisfaction with the family having good relationships with the service providers*, and (ii) *satisfaction with the family members having time to pursue their own interests* was the impact of the NDIS greater for carers of a person with a mental/psychosocial disability compared to those caring for a person with another type of disability.
- The largest differences in NDIS impacts are estimated for the statement ‘*family having outside help available to take care of the special needs of all the family members*’ with more than 10 percentage points (11 per cent versus one per cent), and in the ‘*family having the supports it needs to relieve stress*’, at six percentage points (five per cent versus -1 per cent).

<sup>16</sup> 95 per cent confidence intervals are coloured accordingly

Figure 6.13 Carers: Impact of the NDIS on family quality of life by mental/psychosocial vs. all other disabilities (Trial)



## 6.4 Wellbeing of People with Disability and Families and Carers – Evidence from In-depth Qualitative Interviews

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 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 carers.

### 6.4.1 Wellbeing of 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.
- In wave 2, an increase in overall sense of wellbeing was reported by many participants. However, in a few cases the NDIS participant’s wellbeing and behaviour had deteriorated (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 social 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.

- In wave 2, as in 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 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.

*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)*

#### 6.4.2 Wellbeing of families and carer

- In 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 including participation 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 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)*

- While acknowledging that the NDIS was principally about the person with disability, the addition of respite/disability support worker hours to plans, and the capacity to access in-home supports and psychological counselling also contributed to improved carer wellbeing.

*Well I'm not so stressed because I'm not with [Son's Name] all the time. Like I've got some adults around me now. Whereas before, it was just [Son's Name] constantly. He just chatters nonstop and gets into everything. (D8C W2)*

*I ended up seeing someone... for maybe eight months... It wasn't every week or anything. But that just really helped... keeping me grounded. (D12C 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 were also high levels of ongoing anxiety related to the longer term sustainability of the NDIS.
- The ongoing administrative burden of the NDIS was often highlighted. This was sometimes a new source of stress, so much so that some felt the added paperwork consumed time usually spent as a family.

### **6.4.3 Wellbeing of people with disability not participating in the NDIS**

- The assumption that an NDIS would necessarily lead to improved wellbeing and quality of life for all people with disability was challenged by the non-NDIS participant cohort, some of whom had actively opted out from the NDIS because they believed that their needs would not be met, or that they would become worse off by taking part in the NDIS. However it was also the case that many non-participants were optimistic of the potential of the NDIS to improve their lives if found eligible and able to access the NDIS.

## **6.5 Summary**

In this final section we provide a summary of the key quantitative and qualitative findings relating to the wellbeing and quality of life of people with disability and their families and carers.

### **6.5.1 Wellbeing of people with disability – Evidence from large scale surveys**

- NDIS participants overall have lower levels of wellbeing compared to the general Australian population. Modest improvements were seen in the wellbeing of NDIS participants from wave 1 to wave 2.
- People with a mental health/psychosocial disability report on average lower levels of wellbeing and social connection than people with other types of disability.
- We estimated impact of the NDIS on the wellbeing of people with disability using each of the three different wellbeing measures.
- The estimated impact of the NDIS on the wellbeing of people with disability was positive but modest (being in the NDIS was found to increase wellbeing by around 5 per cent).
- However, not all NDIS participants experienced enhanced wellbeing. Inequities were found for participants depending on their age, type of disability, location, and whether they were experiencing unmet demand for services. These factors should be studied in further detail to guide the development of the NDIS and ensure that the NDIS also improves the wellbeing of particularly vulnerable groups.

### **6.5.2 Wellbeing of families and carers – Evidence from large scale surveys**

- While the wellbeing of families and carers was much higher than that of the NDIS participants that they care for, their reported wellbeing was still well below the average for Australia. Levels of wellbeing decreased slightly over time in the NDIS.

- 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).
- While the proportion of carers experiencing at least one indicator of financial hardship declined over time (from 42 per cent to 36 per cent), this still represents a large proportion of carers of NDIS participants reporting financial stress.
- The estimated impact of the NDIS on the wellbeing of carers of adult participants was very small and not statistically significant. This suggests that the NDIS has not had a direct effect on the wellbeing of this group.
- For the carers of participants aged 8-15 years it was found that the NDIS has had a small, but statistically significant negative impact on their wellbeing.
- These findings suggest that the NDIS is not leading to improvements in the wellbeing of families and carers. It is essential that ongoing evaluation and monitoring occurs to assess the future impact of the NDIS on their levels of wellbeing and to identify the factors contributing to reduced wellbeing.

### **6.5.3 Wellbeing of people with disability and their families and carers – Evidence from in-depth qualitative interviews**

- An overall increase in wellbeing was reported by NDIS participants. Many respondents described evidence of improved skills and developmental progress as a result of the NDIS. This included increased participation in social and recreational activities, being able to do activities 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 (including participation in wider interests outside of the home).
- Reduced financial strain and more opportunity for self-care and to spend time with other family members also improved carer wellbeing.
- Many carers 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 were also high levels of ongoing anxiety related to the longer term sustainability of the NDIS.

## 7. Participation (Social, Economic and Educational), and Aspirations (Goals)

### Integrated findings

This section integrates and summarises the quantitative and qualitative findings relating to participation (social, economic and educational), goals and aspirations, and transitions.

The evaluation finds that:

- there is no large-scale evidence that the NDIS has already impacted on the social participation of people with disability, but an abundance of qualitative evidence is suggesting that change is occurring;
- There is some evidence that families and carers are already enjoying enhanced social participation opportunities due to the NDIS, but also that some carers had given up their careers altogether and others were working part-time in order to provide care;
- Persistent barriers prevent social participation, including cost, access, transport and communication;
- there are additional challenges regarding social participation for specific types of disability;
- there is no large-scale evidence that the NDIS has already improved educational and economic participation, but there is evidence that both education and work are prime objectives and in the plans of many people with disability and their families and carers;
- there are persistent barriers for both education and work activities and there is no evidence that these barriers were being overcome during the course of the evaluation;
- educational participation was high at the start of the evaluation, but appeared to decline over the duration of the evaluation;
- a third of people with disability were actively seeking work, but few get jobs: severe barriers were identified by both sources of evidence;
- more is needed to open up labour market opportunities for people with disability;
- there is a broad recognition that participation activities often take time to yield concrete results;
- on the whole, there is very little large-scale evidence regarding the impact of the NDIS on all types of participation, but given the long leads involved in these activities, this is not a surprising finding;
- in contrast the NDIS has been influencing the building of aspirations and the setting of goals regarding social participation, social skills and educational participation, but less so regarding economic participation; and
- the NDIS has been providing support for important transitions and life change during the course of the evaluation.

### *Social participation*

- Mixed results were found in the quantitative and qualitative evidence as to the impact of the NDIS on the social participation of people with disability and their families and carers.
- No significant differences in the social participation of NDIS and non-NDIS participants were found in the quantitative evidence. The quantitative data indicated that the most frequently reported activities undertaken by both NDIS participants and their family members and carers was spending

time with family and friends. The most desired activity to be undertaken in the future for both groups was to go on a holiday. Furthermore, little change was observed in patterns of social participation with longer time spent in the NDIS.

- In contrast, the qualitative interviews provided evidence that engagement in social and everyday activities was increasing for NDIS participants. 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.
- Qualitative interviews also found that, as a consequence of increased service provision for the NDIS participant, family members and carers also enjoyed enhanced opportunities for social participation, including spending quality time with family and friends.
- However, both quantitative and qualitative evidence identified persistent barriers which prevented the social participation of NDIS participants. Barriers to social participation identified in the quantitative evidence included the cost of activities, access to buildings, transport and communication issues.
- The qualitative interviews highlighted the additional challenges faced by people with mental health issues, intellectual disability or Autism Spectrum Disorder in participating in social activities and developing friendships. A need for better community engagement to improve the integration and acceptance of people with disability in mainstream activities was also highlighted in the qualitative interview evidence.

#### *Educational participation*

- As with social participation, the quantitative evidence found that the NDIS has not had a significant impact to date on the educational participation of people with disability or their families and carers. While the quantitative evidence showed that a relatively high proportion of NDIS participants were currently studying, this proportion decreased over the duration of the evaluation. For most of the NDIS participants in education, their primary objective after their current study was completed was to get a job or to undertake further training or education.
- Of those NDIS participants not currently in education, around a fifth would like to study in the future. However, barriers to educational participation were reported including the health/disability of the NDIS participant, opportunities for study and difficulties with transportation, facilities and equipment. There was little evidence that these barriers were being broken down over time.
- Very few family members and carers of NDIS participants were studying at either wave 1 or 2.

#### *Economic participation*

- Both quantitative and qualitative evidence indicated that levels of economic participation were low for NDIS participants and did not change over time. The quantitative evidence found that around a fifth of NDIS participants were in employment in both waves 1 and 2. Most were in part-time employment with a growing proportion employed in an Australian Disability Enterprise.
- While the quantitative evidence indicated that many NDIS participants express a preference to work, only around a third were actively seeking employment. Severe barriers to the labour force participation of people with disability were evident in the quantitative and qualitative data. These barriers were similar to those adversely impacting upon educational participation and did not

appear to be reducing over time. The qualitative interviews concluded that in addition to the development of job-readiness skills, more liaison with employers needed to occur to improve labour market opportunities for people with disability.

- The qualitative evidence suggested that while over time there was an increase in participation in employment-related activities 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 the quantitative and qualitative evidence showed that caring responsibilities impacted upon the ability of family members and carers to take part in paid work and on their career pathways more generally. Both data sources indicated that some carers had given up their careers altogether and others were working part-time in order to provide care and support to the person with disability.
- Mixed evidence was found as to the impact of the NDIS on the economic participation of family members and carers. The quantitative data identified no significant impact of the NDIS on the employment of family members and carers. In contrast, the qualitative evidence showed that some positive changes were beginning to occur; by wave 2 a few examples were provided of family members and carers being able to seek work or increase their working hours as a result of greater levels of funded support received by the person they cared for.

#### *Goals and aspirations*

- The qualitative data provided evidence about the goals and aspirations of NDIS participants and whether these had been achieved over time in the NDIS. The goals and aspirations of younger NDIS participants were primarily related to developmental progress and education. For adult participants, goal and aspirations centred on education, work, developing independence and increasing social skills. By the wave 2 interviews, while progress had been made towards educational goals, limited achievement of goals relating to economic participation was observed.

#### *Transitions*

- The qualitative interviews showed that almost all of the NDIS participants and their families and carers had experienced a transition or life change between waves 1 and 2. These were primarily related to educational transitions, health and behavioural issues, and changes in accommodation. In general, the NDIS was reported to have assisted participants through these processes and support plans were adapted to reflect their new circumstances.

## 7.1 Introduction

The NDIS aims to improve the social, educational 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, educational and economic participation. We thus examine social participation, education participation and economic participation, with the latter focussing on employment activities. The NDIS evaluation recognised from its outset two main points: First, impacts on participation are very hard to establish in the short run. Change will manifest slowly, primarily because of the long lags that are involved for outcomes to be achieved in these areas. Second, that change will happen at a different rate in these three key areas, with social participation improvement leading the way, education following, and employment probably coming last. The logic is clear: some social participation changes can happen quickly, while education outcomes will take at least as long as educational qualifications take to be completed. In the context of the evaluation, some forms of participation are often the means for improving other forms of participation. For example, education is often the precursor of employment; social participation can build towards educational participation and so on. It is in this context of interconnected outcomes that this section must be understood.

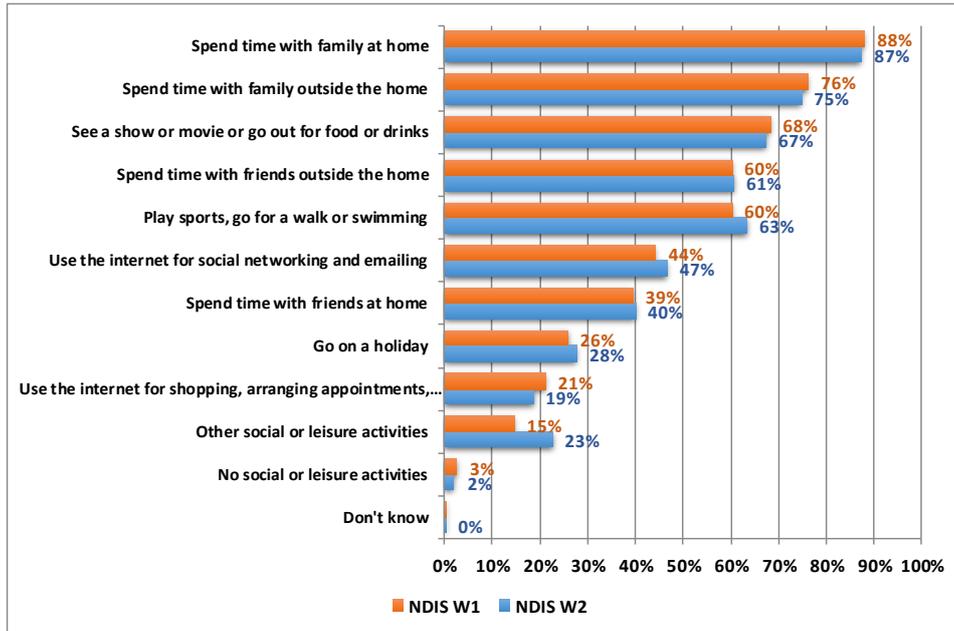
In this section we present quantitative and qualitative evaluation evidence to examine the extent to which the NDIS has contributed to changes in social, educational and economic participation for people with disability, their families and carers. We further examine the extent to which the NDIS has enabled people with disability and their carers to achieve their goals. We also consider how effective the NDIS has been in helping people to anticipate and plan for transitions such as entering school, moving from school to further education or employment or moving away from the family home.

## 7.2 Social Participation and the NDIS – Evidence from Large Scale Surveys

### 7.2.1 Social Participation of people with disability

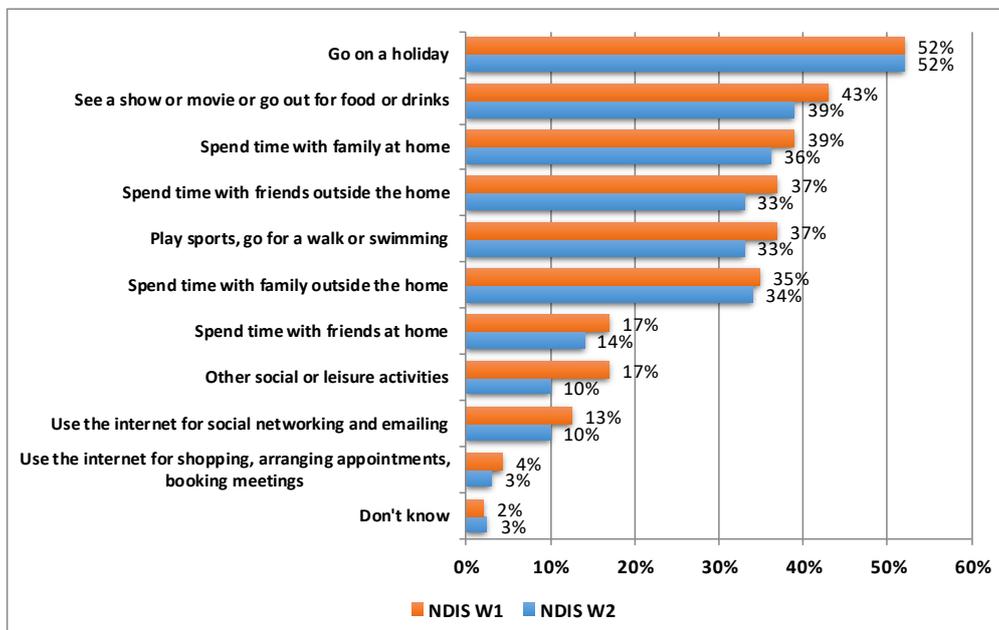
- The NDIS Survey asks about the activities the NDIS participants have done recently without reference to a specific timeline (such as ‘in the last month’) in order to simplify the question and improve accessibility. The survey also asks respondents to indicate from the same list three activities that they would most like to do in the coming year. The difference between current activities and future/planned/desired activities is reported here.
- Responses to both questions about actual current and desired future social participation activities of NDIS participants in wave 1 and 2 are summarised in Figure 7.
- NDIS participants most frequently spent time with family within (88 per cent in wave 1, 87 per cent in wave 2) and outside of the home (respectively 76 and 75 per cent). Other popular social activities included seeing a show, movie or have a meal (68 and 67 per cent), taking part in physical activities (60 and 63 per cent), and meeting friends outside the home (60 and 63 per cent). Three per cent of NDIS participants in wave 1 (2 per cent in wave 2) reported that they had not participated in any social or leisure activities in recent time.
- With regard to activities that they would most like to do in the future (Figure 7.2), wanting to go on holiday was 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 spending time with family were reported as the next most desirable future activities.
- Using the internet for entertainment or for shopping is among the least desired activities as is meeting friends at home rather than out of the home.

**Figure 7.1 Person with disability: Activities respondent has done recently (Trial, Age 8+, waves 1 & 2)**



- Wave 2 responses suggest very little change over time in the social participation patterns of current activities of NDIS participants (Figure 7.1).
- We can also compare the activities desired to be undertaken by NDIS participants in wave 1 and compare with their statement in wave 2. The pattern remains very constant and can be used as an indication of the direction change in disability support provision may need to take.

**Figure 7.2 Person with disability: Activities would like to do in the coming year, (Trial, Age 8+, waves 1 & 2)**



- An important aspect of the NDIS is its explicit objective to remove barriers and hurdles faced by people with disability in their everyday life. After asking about actual and desired future activities, respondents were also asked to think about any hurdles that may make their future activities hard to achieve (Appendix Table A7.1). The most frequently mentioned hurdles reported in both waves 1 and 2 were that social or leisure activities ‘cost too much’ (43.7 per cent in wave 1 and 39 per

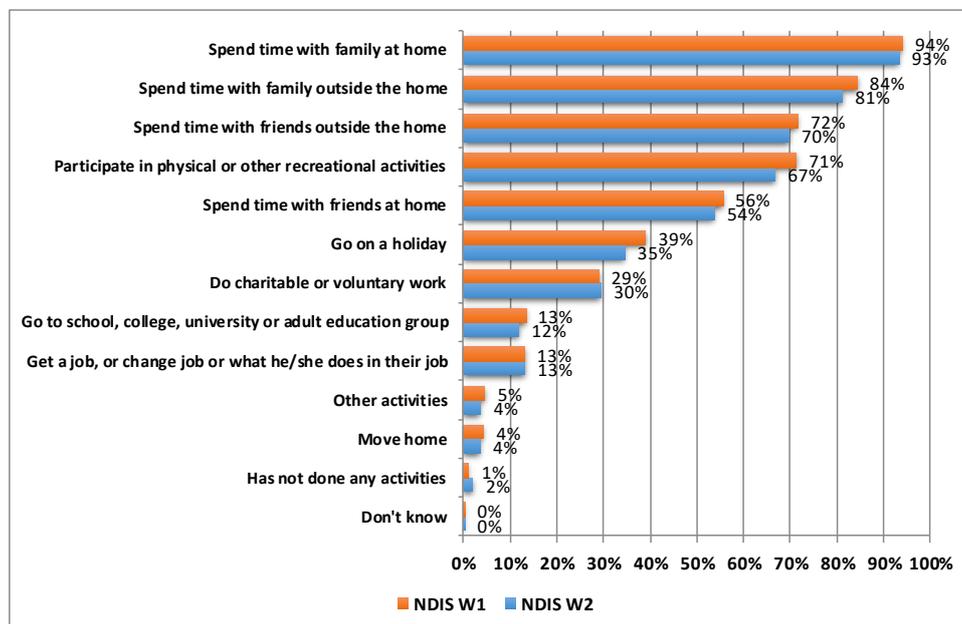
cent in wave 2) and that ‘other people cannot understand the person with disability’ (42 per cent and 40 per cent).

- There has been an overall reduction in the proportion of all other barriers reported by NDIS participants. Transport in particular seemed to pose less of a hurdle in wave 2 (19 per cent) than in wave 1 (25 per cent). The single exception to this change is that ‘being hard for a person with disability to get into buildings’ was reported slightly more frequently as a barrier. This negative finding needs further unpicking as it may be the result of increased attempts to pursue activities in the community which are subsequently frustrated due to access restrictions.

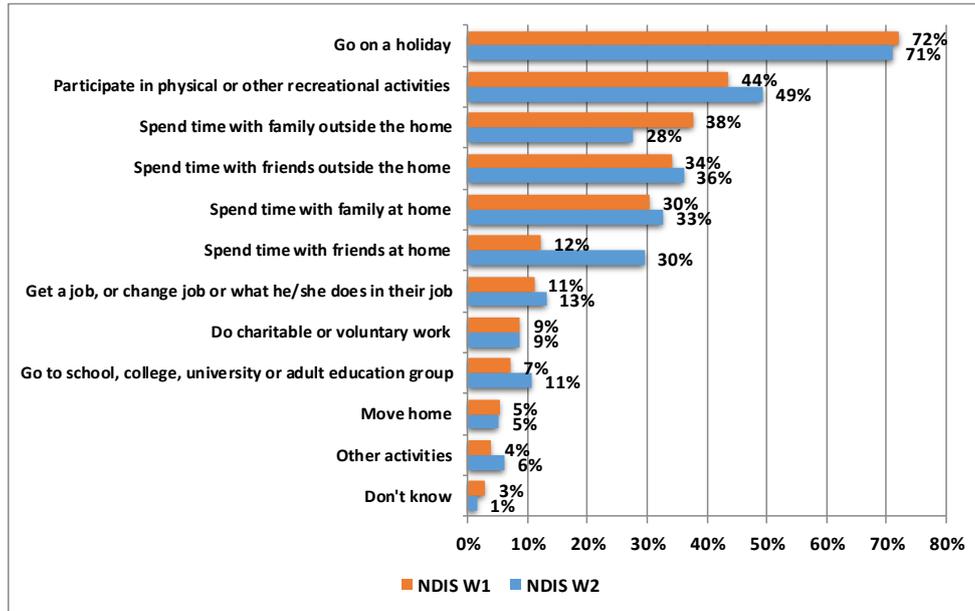
## 7.2.2 Social Participation of families and carers

- The NDIS Survey asks a similar set of social participation questions of the carers of NDIS participants. The information is summarised in Figures 7.3 and 7.4 and gives rise to the following three main patterns that have changed little over time.
- 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 carers are similar to those reported by NDIS participants (i.e. meeting with family and friends and participating in physical or recreational activities).
- Third, compared to NDIS participants, a higher proportion of carers desired to go on a holiday in the future.

**Figure 7.3 Carers: Activities respondent has done recently (Trial waves 1 & 2)**



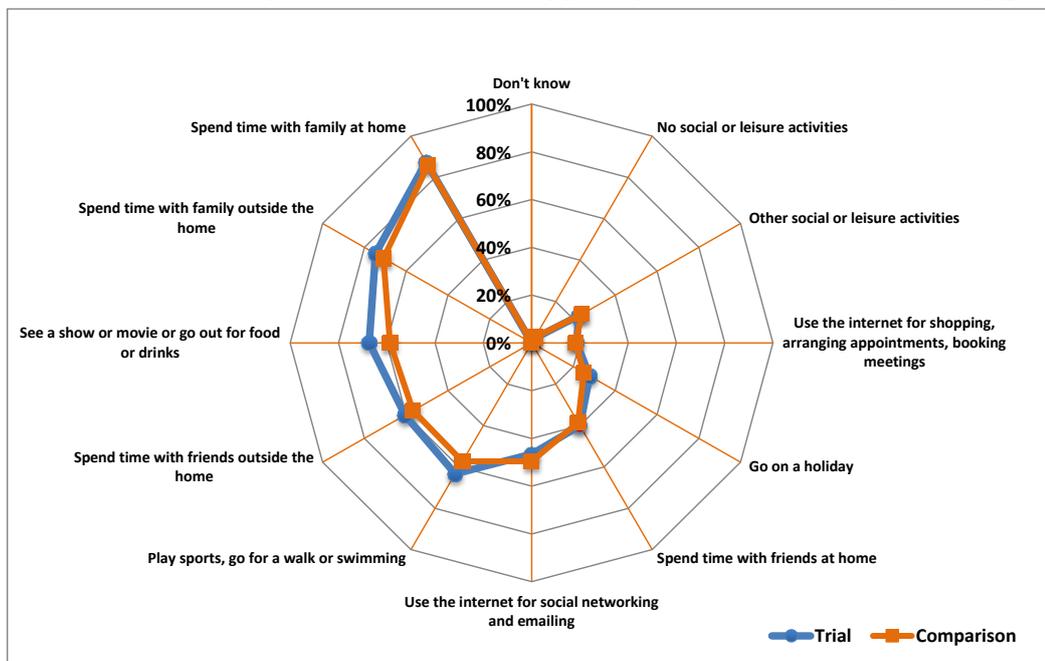
**Figure 7.4 Carers: Activities respondent would like to do in the coming year (Trial, waves 1 and 2)**



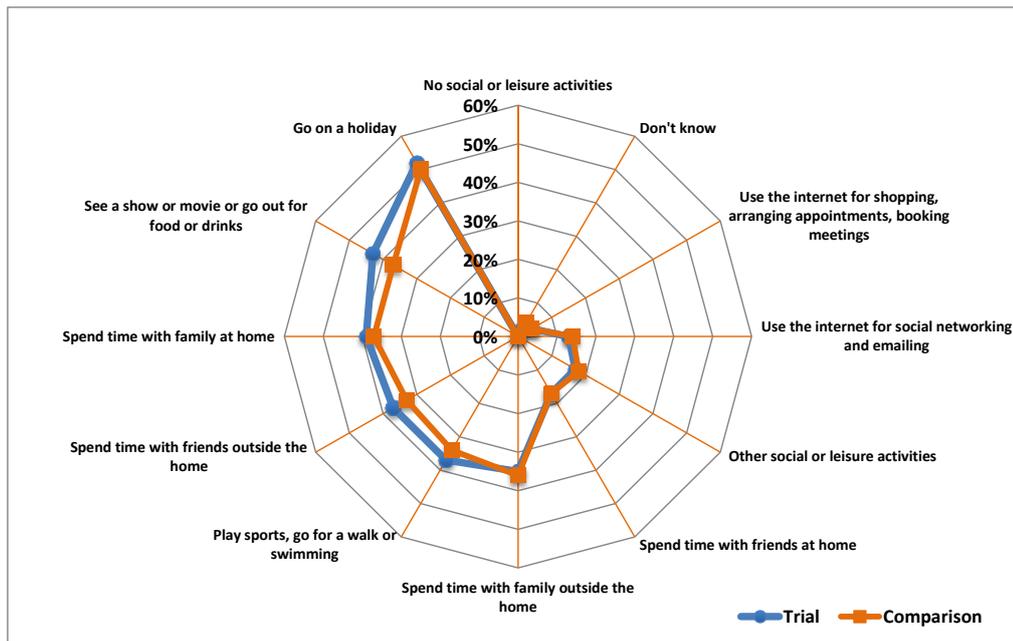
*Differences between the trial and comparison samples – social participation*

- Further analyses were conducted to compare the social activities undertaken and desired to be undertaken in both trial and comparison groups (Figures 7.5 and 7.6), with very little differences observed both in terms of activities undertaken and future aspirations.
- When we estimated the impact of the NDIS on these activities and aspirations using both waves of data, we corroborated these observations by finding no statistically significant impact of the NDIS. It is probably too early for such changes to manifest themselves in the context of large-scale quantitative data, and a longer observation period is required.

**Figure 7.5 Person with disability: Social activities recently participated in - Trial vs. Comparison (Age 8+)**



**Figure 7.6 Person with disability: Social activities would like to do in the coming year - Trial vs. Comparison (Age 8+)**



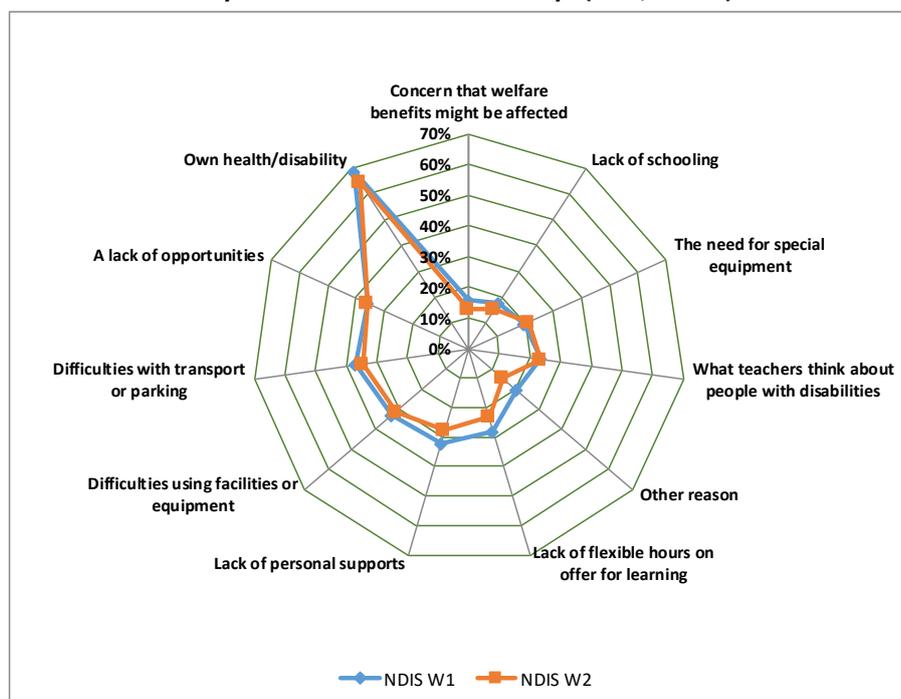
## 7.3 Educational Participation and the NDIS – Evidence from Large Scale Surveys

### 7.3.1 Educational participation of people with disability

- 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 collected information about the education level of people with disability and their educational aspirations. We note that by design the sample contains a higher proportion of younger people, principally because of the intention of the NDIS trial to focus only on 0-15 year olds in SA and only on 16-24 year olds in TAS. Also while the other trial sites cover all ages they also include a fair number of younger people.
- The proportion of NDIS participants currently studying decreased by eight per cent between wave 1 and 2 (Appendix Table A7.2).
- Appendix Table A7.3 shows the type of educational establishment attended by those in education in wave 1 and 2.
- In wave 1, most of the children under 16 years attended school; in pre-school/kindergarten (15 per cent), in pre Year 1 primary school (10 per cent) and Primary school Year 1 and above (38 per cent). School attendance of a secondary level or within a special school was at 14 per cent and 10 per cent respectively and five per cent of NDIS participants in education were attending vocational education.
- Wave 2 showed an increase in those attending primary school Year 1 and above (from 38 to 48 per cent). This seems to be largely a result of preschool children shifting into the primary school setting. The proportion reporting to be attending secondary school declined, while those attending a special school increased from 10 per cent to 14.6 per cent.

- Another indicator of educational participation is whether the study undertaken is full-time or part-time. Almost 90 per cent of those in education in both waves 1 and 2 reported that they were enrolled on a full-time basis (Appendix Table A7.4).
- NDIS participants were asked what they would like to do when they completed their education (Appendix Table A7.5). This question was only asked of those who are aged eight years or older. Around a third reported that they would like to work in a job (32 per cent in wave 1 and 28 per cent in wave 2), with 13-15 per cent planning to go to University and four-five per cent to do some further course or training. A quarter (26 per cent) reported in wave 1 that they did not know what they would like to do when they finished their education, and this proportion increased to almost a third of all students (32 per cent) in wave 2.
- NDIS participants who were aged 16 years and over and who were not currently in education, were asked if they would like to study. Twenty-three per cent in wave 1 and 20 per cent in wave 2 reported that they would (Appendix Table A7.6). Of those, 38.8 per cent were looking for a course to study in wave 1, a proportion which increased to 51.2 per cent in wave 2 (Appendix Table A7.7).
- 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 for them to study (Figure 7.7).
- The most frequently mentioned barrier to educational participation by people with disability was their own health/disability (69 per cent in wave 1 and 65 per cent in wave 2). Other commonly mentioned barriers were lack of opportunities (36 per cent in both waves 1 and 2), difficulties with transport and or parking (37 per cent and 35 per cent respectively), difficulties using facilities or equipment (33 per cent and 31 per cent respectively), and lack of personal supports (32 per cent and 28 per cent respectively).
- As little change occurred in the factors regarding what makes it hard for people with disability to study between waves 1 and 2, there is little evidence that these barriers are being overcome.

**Figure 7.7 Person with disability: What makes it hard to study? (Trial, Adults)**



### *Differences between the trial and comparison samples – Education Participation*

- There is a higher rate of educational participation among the NDIS participants than among the comparison group. However, as with social participation, our estimations did not find a statistically significant impact of the NDIS on the educational activity of people with disability or of their families and carers. From these findings, and as with social participation, we conclude that this evidence will take some time to emerge from the large quantitative data and that for now the best policy guide is the qualitative evidence gathered for this evaluation.

### **7.3.2 Educational participation of people with disability**

- An important objective of the NDIS is to also support the capacity of families and carers of people with disability to improve their own education, which can bring direct and indirect benefits to the whole family including the person with disability.
- Eleven per cent of the carers of NDIS participants were currently studying in wave 1, 82 per cent of whom were on a part-time basis (Appendix Table A7.8). There was little change in wave 2, save a modest decline in those in part time education.

## **7.4 Economic Participation and the NDIS – Evidence from Large Scale Surveys**

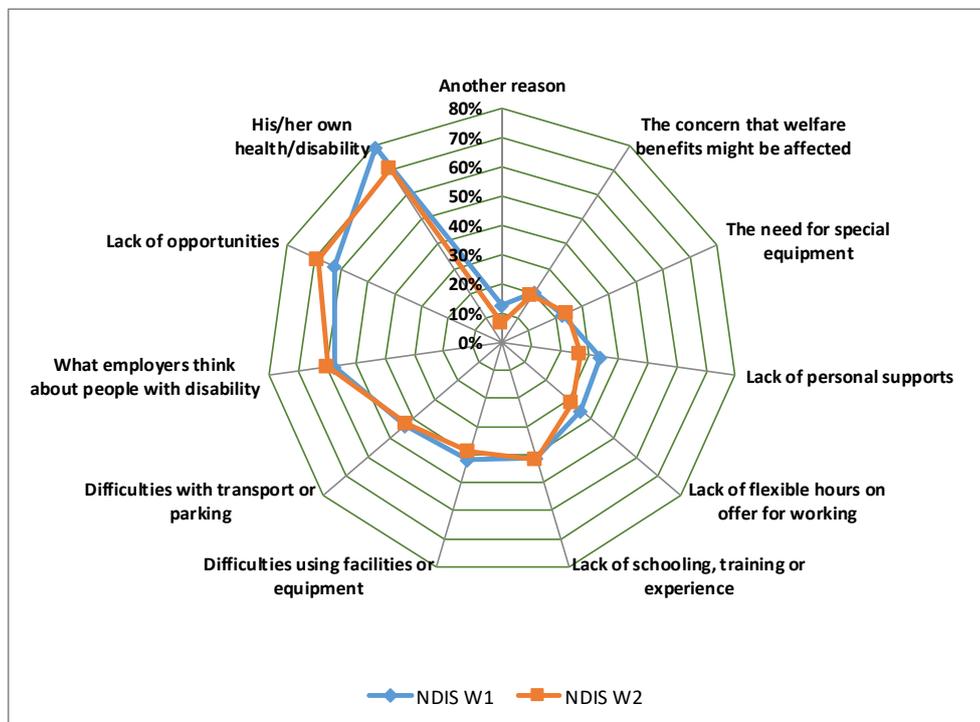
### **7.4.1 Economic participation of people with disability**

The NDIS Survey collected information about the current employment status of NDIS participants and their carers. The questions on employment were only asked of the adult survey respondents. Employment changes due to the NDIS are expected to take a long time to manifest themselves, in all likelihood longer than the timeframe of this evaluation. An improvement in employment prospects and outcomes due to the NDIS is also likely to be impacted on by preceding improvements in social and education participation. Further, improvements in employment participation will also depend on how workplaces respond to the broader call for better and more appropriate job design.

- Only a minority of people with disability over the age of 16 years were employed in wave 1 (22 per cent) (Appendix Table A7.9). This did not change over time (21 per cent in wave 2). Many were employed in an Australian Disability Enterprise (ADEs) and this proportion increased over time from 44 per cent to 52 per cent of those in employment (Appendix Table A7.10).
- Employment was predominantly part-time (75 per cent in both waves 1 and 2) (Appendix Table A7.11) and half reported that their workplace, hours and conditions had been adapted to enable them to work (52 per cent in wave 1, increased to 58 per cent in wave 2) (Appendix Table A7.12).
- Overwhelmingly, NDIS participants like their job (86 per cent in wave 1 and 90 per cent in wave 2) and did not want a different job (57 per cent and 55 per cent respectively) (Appendix Tables A7.13 and 7.14).
- Of those NDIS participants who were not currently employed, 53 per cent in wave 1 and 50 per cent in wave 2 had previously had a paid job. (Appendix Table A7.15).
- NDIS participants who were not working in wave 1 were evenly distributed between those who wanted a paid job (42 per cent) and those who did not currently want a paid job (39 per cent). However, the proportion of NDIS participants that did not want to have a paid job increased by six per cent in wave 2. The NDIS does therefore not appear to be increasing the aspirations of people with disability for economic participation (Appendix Table A7.16).

- Of those that were not working, but currently wanted to work, only 30 per cent in wave 1 and 28.5 per cent in wave 2 were actively seeking employment (Appendix Table A7.17).
- We asked all those who were not employed, about what in their view makes it hard to get a job (Figure A7.8). The most frequently mentioned barrier to getting a job by people with disability was their own health/disability (79 per cent in wave 1 and 71 per cent in wave 2). Other commonly mentioned barriers were a lack of opportunities (62 per cent and 69 per cent respectively), what employers think about people with disability (57 per cent and 59 per cent respectively), difficulties with transport or parking (44 per cent and 43 per cent respectively), difficulties using facilities or equipment (42 per cent and 39 per cent respectively) and lack of schooling, training or experience (41 per cent and 42 per cent respectively).
- These findings suggest that there are multiple and severe barriers to employment participation for people with disability. There is little evidence that these barriers are being overcome over time by NDIS participants with little change occurring between wave 1 and 2.

**Figure 7.8 Person with disability: What makes it hard to get a job? (Trial, Adults)**



*Differences between the trial and comparison samples – labour market participation*

- Estimations of the impact of the NDIS on the employment of carers did not produce any statistically significant results. From this, we can conclude that there is no significant evidence as yet to show that the NDIS makes a difference in the employment of family and carers. This could be due to the short investigation period between waves 1 and 2, but it could also be a consequence of the small number of observations in this specific aspect of the NDIS Survey.

## 7.4.2 Economic participation of families and carers

- Just over half of all carers were employed (54 per cent in wave 1 and 51 per cent in wave 2) (Appendix Table A7.18).
- In wave 1, 18.6 per cent of carers were working full-time and 35 per cent part-time. The proportion working full time declined slightly in wave 2 (15.4 per cent).
- In wave 1 21.4 per cent of carers of NDIS participants reported that they had given up work to provide care and support to the person with disability. The proportion declined slightly in wave 2 (19.5 per cent).
- A further 19.5 per cent at wave 1 and 18.3 per cent in wave 2 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.
- Of those currently not in employment, 72 per cent had previously been in paid employment in wave 1, and this increased to 78 per cent in wave 2 (Appendix Table 7.19).
- In wave 1, 51 per cent of carers ( ) reported that they would like to have a paid job (Appendix Table A7.20); this proportion decreased by eight per cent in wave 2.
- Of those who desired paid employment, but were not currently employed, 79 per cent reported that their caring role was the main barrier precluding them from them having paid work (Appendix Table A7.21). While this declined in wave 2, still over two thirds of carers of NDIS participants reported that their caring role was the main barrier to them obtaining employment.

## 7.5 Social, Educational and Economic Participation and the NDIS – Evidence from In-depth Qualitative Interviews

### 7.5.1 Social, educational and economic participation of NDIS participants

- There was evidence of increased social participation of NDIS participants in wave 1. This continued in 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, follow interests and social activities that had previously been inaccessible, and visit friends and family or having people to stay.
- Taking part in social activities had additional benefits for some participants as these activities, were helping them to learn and develop new social and 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]. 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 and less pronounced. Concerns were raised by these respondents about the difficulties they had in participating socially and developing friendships; 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 in 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, this was limited with only a few NDIS participants reported undertaking these activities.
- Several respondents were clearly aware that their opportunities for participation in paid employment were currently too limited to be actively pursued.

*The bottom line is, my goal can be employment until the cows come home. Getting someone to employ you is absolutely another matter, at my age with my disabilities, whatever. So I do not want to be locked into having to succeed at that, no matter how much I might try. (C02 W2)*

- 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.

### **7.5.2 Social, educational and economic participation of family member and or carer**

- Easing the care burden on carers improved their social participation as it allowed them to be involved in other valued activities such as 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 responsibilities 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 respondents 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 in wave 2 because they now had a little more free 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 - 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 NDIS funded support to 30 hours per week restricted the family's participation in the workforce, as flexibility was required to work around the hours their child was cared for.

### **7.5.3 Social, educational and economic participation through the eyes of the service provider**

- As was the case in 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 in wave 1, service providers were still more likely to observe increased social participation amongst NDIS participants than increased economic participation. Evidence of the positive impact of the NDIS on the economic participation of participants and their family members or carers remained limited in wave 2.
- Several disability service providers gave examples of how the NDIS was supporting economic participation for some families or carers of NDIS participants. Greater levels of funding for supports for these NDIS participants meant family members were freer to pursue or increase employment. The extension of hours of operation 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)*

### **7.5.4 Social, educational and economic participation through the eyes of NDIA staff**

- In 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 presented as 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.

- In 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 carers yet to be explicitly addressed.

## 7.6 Is the NDIS Changing Goals and Aspirations – Evidence from In-depth Qualitative Interviews

### 7.6.1 Goals and aspirations of NDIS participants and their family members or carer

- Goals and aspirations varied between each individual participant and were influenced by the age and disability of the person. For younger NDIS participants, goals and aspirations were mainly related to maximising age appropriate developmental capabilities and the transition into to childcare, kindergarten or school (including moving from a home-school situation to a mainstream primary school). The goals and aspirations of adult participants centred on enrolling in further study, gaining employment or volunteer work, developing more independence (with budgeting, transport, and cooking), increasing social skills and living independently (or continuing to do so).
- The development of goals was initially difficult for NDIS participants as many had not previously had the opportunity to construct personal and life-long goals. However, by wave 2 many respondents felt that the process had become easier as they had adjusted to the NDIS ethos and processes.
- A few of the respondents noted that over time their mindset had changed to embrace the opportunity to create goals for themselves. This was contrasted to the ‘institutionalised’ way of thinking that respondents and their families had been accustomed to, prior to the arrival of the NDIS.

*And what is starting to happen I'd say with most people that I know on their first plan they accepted the status quo and were, 'yes let's just carry on with what we're doing'. And as that year progressed and they started to see, 'hang on a minute we can change this', their second plans tended to reflect that we want change, we can start to make choices and we can start to do things differently. And the third plans are even more, 'hang on', and we're starting to see as individuals not that institutionalised thinking that's been put into all of us. We're all institutionalised to a certain extent. (B03 PWD&C W2)*

- 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 themselves. 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' educational goals. Many young children had transitioned into school with the assistance of therapy and early intervention. Other NDIS participants had enrolled in vocational education 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 and not an urgent need. 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 goals focused on obtaining work experience so that the NDIS participant 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, however, the achievement of employment related goals had been limited. There was a need for enhanced support for participants to achieve these goals. For example, for many of those who ultimately desired to be able to find paid work, initially gaining work experience and work placements was paramount. Respondents wanted to be in a workplace environment, learning new skills, interacting with others and perhaps earning an income. However, according to some there was limited support in this area; providers were struggling to find employment opportunities for NDIS participants, and were not actively supporting them in taking the next steps once a work activity/experience had ended.

## **7.7 Life Transitions and the NDIS – Evidence from In-depth Qualitative Interviews**

### **7.7.1 Transitions for NDIS participants and their family members or 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. Others had experienced a deterioration of health or behavioural issues throughout the year. A further group of participants had moved accommodation (or were preparing to move) either to an area outside of their current NDIS trial site 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. Generally, the NDIA was approached and discussions were arranged to determine whether plans were flexible enough to adapt to new circumstances.

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

- However, there also appeared to be complexities in moving from different support services coupled with transitioning to NDIS. An example here was given by a parent of a young child who was transitioning from existing funding to NDIS funding for speech therapy. Because there was an apparent disagreement as to whether the support should be school-based or not, the funding had ceased for almost a year, which meant that the child had had no support during that time.

### **7.7.2 Transitions through the eyes of NDIA staff**

- There were mixed reports from NDIA staff as to how well the NDIS manages key life transitions. 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.
- Challenges included time constraints and a lack of planner experience which often led to NDIA staff taking a 'hands off' approach to supporting participants through key life transitions.

- NDIA staff noted that the primary mechanism by which the NDIA could provide support at key transitions occurred both during the development of the plan, where funded items such as coordination of supports, transdisciplinary packages, and transitional supports could be included, and through plan reviews and amendments.

## **7.8 Summary**

### **7.8.1 Social participation – Evidence from large scale surveys**

- The quantitative data provides information about activities that NDIS participants and carers have done recently and those activities they would most like to do in the coming year.
- For both groups, the most frequently reported activities that had been undertaken were spending time with family and friends. The most desired future activity was to go on a holiday. Little change over time was observed in patterns of social participation.
- The most common barriers to social participation which were reported by people with disability in both waves 1 and 2 were that activities ‘cost too much’ and that ‘other people cannot understand the person with disability’.
- While there was an overall reduction in the proportion of all other barriers reported by NDIS participants in wave 2, the data shows that there are several considerable hurdles (related to buildings access, transport, safety, organisations and timing) which impact on the social participation of people with disability.
- Comparison of the social participation of NDIS and non-NDIS participants, did not identify any statistically significant differences. As the NDIS is still relatively new, a longer observation period may be required in order to identify proper impacts of the NDIS on social participation.

### **7.8.2 Social participation – Evidence from in-depth qualitative interviews**

- NDIS participants’ engagement in social and everyday activities increased over time. As a result, many participants were learning new skills and enhancing existing capabilities.
- However, it was notable that for participants with mental health problems, intellectual disability 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; this had not improved with the NDIS.
- Easing the care burden of carers improved their social participation as it allowed them to be involved in other valued activities such as quality time with other family members that would previously not have been possible.

### **7.8.3 Educational participation – Evidence from large scale surveys**

- The proportion of NDIS participants currently studying decreased by eight per cent between wave 1 and 2. The majority of those participating in education were children who were studying full-time in a school setting.
- Working in a job and undertaking further education or training were the most preferred post-education objectives of young people with disability in both waves 1 and 2. A further group of students (26 per cent in wave 1 and 32 per cent in wave 2) did not know what they wanted to do when they finished their education.

- In both waves 1 and 2, a fifth of adult participants reported that they would like to study in the future. While the main perceived obstacle to education was the health/disability of the person with disability, many other barriers were reported. These included opportunities for study, transport and parking, facilities and equipment, personal supports and flexible study arrangements. Little evidence was found in wave 2 that these barriers to educational participation are being overcome by NDIS participants. This appears to be an area of much complexity and one requiring further attention.
- Only a small proportion (11 per cent) of all carers were in education at either wave 1 and 2. This was primarily on a part-time basis.
- The NDIS was not found to have a statistically significant impact on the educational activity of people with disability or of their families and carers. This evidence will take some time to emerge and outcomes should be monitored in the future.
- One-fifth of all NDIS participants aged 16 years or older (22 per cent) were employed in wave 1, and this did not change over time.
- Most worked part-time and many had had their workplaces, hours or conditions adapted to enable them to work. Of those in employment, many worked in an Australian Disability Enterprise (44 per cent in wave 1 and 52 per cent in wave 2).
- Overwhelmingly, NDIS participants liked their job and did not want a different job.
- NDIS participants who were not working in wave 1 were fairly evenly distributed between those who wanted a paid job and those who did not currently want a paid job. However, the proportion of NDIS participants who did not want paid work increased in wave 2.
- Of those that were not working, but currently wanted to work, only 30 per cent in both waves 1 and wave 2 were actively seeking employment.
- Severe barriers to the labour force participation of people with disability are evident. The most common barrier reported by people with disability in both waves 1 and 2 was their own health/disability. Other barriers included a lack of opportunities, employer perceptions of people with disability, difficulties with transport or parking, difficulties using facilities or equipment, and a lack of schooling, training or experience.
- There was little evidence that these barriers were being overcome with time and, unless addressed will continue to impact negatively on the economic participation of people with disability.
- The formal employment of carers of people with disability was shown to be severely impacted upon by their caring responsibilities. In waves 1, 54 per cent of carers were in employment, 19 per cent working full-time and 35 per cent part-time. The proportion of carers in full time employment declined slightly in wave 2.
- About a fifth of carers in both waves 1 and 2 reported that they had given up work to provide care and support to the person with disability.
- In wave 1, half of the carers surveyed reported that they would like to have a paid job; this proportion decreased by eight per cent in wave 2. Their caring role was perceived as being the main barrier precluding them from obtaining paid employment.

#### **7.8.4 Educational participation – Evidence from in-depth qualitative interviews**

- 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 in 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.
- A few examples were also provided in wave 2 of families or carers increasing their working hours, or pursuing employment activities. This was a consequence of having a little more free time as a result of the NDIS participant being involved in more supervised activities than previously.

#### **7.8.5 Goals and aspirations - Evidence from in-depth qualitative interviews**

- For younger NDIS participants, goals and aspirations were mainly related to maximising age appropriate developmental capabilities and the transition into childcare, kindergarten or school (including moving from a home-school situation to a mainstream primary school).
- The goals and aspirations of adult participants centred on enrolling in further study, gaining employment or volunteer work, developing more independence (with budgeting, transport, and cooking), increasing social skills and living independently (or continuing to do so).
- Since joining the NDIS many achievements related to NDIS participants' educational goals were made. Many young children had transitioned into school, while other NDIS participants had enrolled in vocational education 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, however, the achievement of employment related goals had been limited in wave 2.

#### **7.8.6 Life Transitions - Evidence from in-depth qualitative interviews**

- 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.

## 8. Fairness, Equity and Access

### Integrated findings

This section integrates and summarises the quantitative and qualitative findings relating to fairness, equity and access. In particular the findings focus on eligibility and navigating the NDIS, review and dispute resolution processes, and equity and fairness.

The evaluation finds that:

- the experiences of the transition into the NDIS were mixed;
- difficulties were mostly encountered by those who could least 'fend for themselves';
- the eligibility process could be lengthy and complicated;
- the boundaries between the NDIS and mainstream services were often confused;
- compared to pre-NDIS processes, it took less time to get the supports, but more time to do the paperwork, the difference covered by the families and carers who often had to step in;
- information about access to supports was often considered inadequate and this persisted into the later stages of the evaluation;
- satisfaction with the processes was variable, about half found them better within the NDIS, one third about the same, and about one in seven felt they were worse off;
- most were satisfied with the frequency and outcome of their plan reviews, but about one fifth found aspects of them unsatisfactory;
- the review and planning process has been changing, causing much dissatisfaction and frustration;
- the NDIS works best for those who can advocate for themselves, causing fairness concerns; and
- a wide range of concerns was raised, many right from the start of the NDIS and many still remaining unresolved or getting worse at the later stages of the evaluation.

#### *Eligibility and navigating the NDIS*

- The qualitative evidence shows that the experiences of people with disability who join the NDIS and those of their families and carers were mixed. Some respondents had experienced an easy transition into the NDIS; these were typically people with disability who had received formal assistance to enrol, or had other family members in the NDIS, or were seeking services for the first time. In contrast, others raised concerns that the process of establishing eligibility for the NDIS could be lengthy and complicated. Administrative issues, additional assessments being required to establish diagnoses, and high workloads within the NDIA had contributed to delays.
- Specific cohorts of people with disability were identified in the qualitative interviews as particularly struggling with the complexity of NDIS processes and documentation. These included people with psychosocial disability, those with literacy problems or cognitive impairment, and people from CALD or Indigenous backgrounds. Concerns also persisted across the evaluation, that people with psychosocial disability were experiencing higher rates of ineligibility and consequently had lower levels of NDIS participation. In addition, unclear boundaries between the NDIS and mainstream sectors (and the health sector in particular) were seen as adding to confusion around the eligibility of some people with disability.
- The quantitative evidence explored the perceptions of NDIS processes, in particular the time taken for support arrangements to be put in place under the NDIS. While NDIS participants commonly

reported that (compared to before the NDIS) it now took less time to find and get supports, many carers felt that the time taken for these activities was unchanged. In contrast, NDIS participants and their carers typically reported that it took more time under the NDIS than previously to complete the necessary paperwork to obtain supports. In general these perceptions did not change with longer time spent in the NDIS.

- The quantitative evidence at the later stages of the evaluation (wave 2) found that a majority of NDIS participants and their carers still felt that they needed more information about how to access disability supports. Indeed a sizeable minority of participants and carers reported that they had very little current understanding of how to access supports.

#### *Review and dispute resolution processes*

- The quantitative evidence shows that most of the NDIS participants surveyed had undergone at least one review of their disability support plan by wave 2. While a majority of participants were satisfied with the review process and the frequency and outcome of reviews, a fifth of NDIS participants expressed dissatisfaction with aspects of their plan reviews.
- The qualitative interviews provided further detail of participant and carer experiences of the plan review processes. Inconsistencies were found about understanding whether the review processes were conducted on a fixed schedule or whether they were dynamic and ongoing. The experience of reviews was often different to the initial planning, as review meetings were typically conducted in an NDIA office or by phone (rather than at a home visit). Moreover, the often encountered lack of consistency of NDIA planners between the initial planning and the review was perceived to disrupt established relationships and understanding of support needs. As with the concerns expressed about the experiences of initial planning, the variability of planner knowledge about particular disability types remained an area of concern. Frustration was also commonly expressed about delays in conducting review meetings, or the time it took for plans to be finalised following the review.

#### *Equity and fairness*

- The need for equity and fairness is a fundamental ethical underpinning of the NDIS and has been expected to be present in the design and the working of the NDIS. This is particularly difficult to implement in the context of creating a new system of individualised provisions for a large group of people with very diverse needs. Mistakes are bound to be made, but the main question that needs to be answered is if the system has been able to learn and correct these mistakes. The findings from the evaluation are mixed on this front, as we have found many problem areas have been corrected and other areas have not. It is in this context that the performance of the NDIS must be judged.
- Factors contributing to perceptions of the fairness and equity of the NDIS were explored in the qualitative interviews. The NDIS was considered to work best for participants and families who were able to strongly advocate for themselves. In order to ensure equitable access to funding for all participants, the importance of advocacy (either formal or informal) was highlighted. Concerns were raised, however, about a lack of funding for formal advocacy support under the NDIS.
- The qualitative evidence found further concerns relating to the equity and fairness of the NDIS. Inconsistencies across plans for people with similar disabilities and support needs were observed. Moreover, NDIS participants with intellectual disability, psychosocial disability and complex needs; those from CALD backgrounds; and participants with older carers facing their own health issues were considered to be particularly at risk of being allocated lower levels of funded supports. NDIS participants living in regional and remote areas were also considered to be at a disadvantage

compared to their urban counterparts in terms of limited service availability. Safeguards within the NDIS were still perceived to require strengthening in order to protect vulnerable participants.

- Considerable concerns were also raised in the wave 2 qualitative interviews regarding service provision for people with disability who were outside the NDIS. As a consequence of reduced state government disability service provision, some non-NDIS participants were found to be receiving fewer services than before, with others reported to be receiving no services at all. Without active intervention, it was feared that outcomes for people with disability who were ineligible for the NDIS would deteriorate further.

## 8.1 Introduction

A central aim of the NDIS is to provide equity of access to disability supports. Ensuring that those who are at the margins of eligibility for the NDIS are adequately supported is also critical. Issues of fairness and equity have arisen directly and indirectly in several other parts of the evaluation, especially when looking at choice and control, unmet demand, wellbeing and participation. In many instances the evaluation finds that the NDIS has improved the lives of a large majority of its participants, but at the same time it has left several minorities either in their pre-NDIS situation, or even in a worse situation. In many instances we find outcomes that could give rise to justifiable feelings of unfairness and inequity.

In this section, we present quantitative and qualitative evaluation evidence that relates to the specific theme of *fairness, equity and access*. Specifically we examine the evaluation evidence around the experience of determining eligibility to enter the NDIS and navigating NDIS processes and procedures. We also examine experiences of, and satisfaction with, the NDIS review and dispute resolution processes. Finally we assess the extent to which the NDIS has contributed to equity and fairness, paying particular attention to the question of whom the NDIS has worked well or less well for, and the system's safeguards for when things go wrong.

## 8.2 Eligibility and Navigating the NDIS System

### 8.2.1 Comparing the NDIS to previous systems – Evidence from large scale surveys

- People with disability over the age of 15 years in the trial group were asked in wave 1 to compare aspects of their past (pre-NDIS) experiences with their experiences in the NDIS. Specifically we asked them the question '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 Table A8.1).
- The same questions were asked of the carers of NDIS participants (Appendix Table A8.2).
- The same questions were replicated in wave 2, but here we asked NDIS participants and their carers 'Compared to last year, does it now take more, less or the same amount of time to...' (Appendix Tables A8.3 and A8.4).
- The wave 1 quantitative data found that with regard to support arrangements and provision, the NDIS has impacted on how long things take for the majority of NDIS participants and their families and carers (Appendix Tables A8.1 and A8.2).
- In wave 1 NDIS participants were more likely to report that under the NDIS it now takes less time rather than more time to find (33 per cent) and get supports (30 per cent).
- In contrast, more than a third of carers (38 per cent) reported that it takes around the same amount of time to find and get supports under the NDIS as it did previously.
- Both NDIS participants and their carers reported that it took more time under the NDIS rather than less time to complete the necessary paperwork for supports (36 per cent and 43 per cent respectively).

- The majority of both NDIS participants and carers experienced little change over the time they have been in the NDIS in terms of how long it takes to get supports, do the necessary paperwork, and find out where to get supports (Appendix Tables A8.3 and A8.4).
- Sixty-eight per cent of NDIS participants, and 12-13 per cent of their carers report a lessening of the time taken to get supports, do the necessary paperwork, and find out where to get supports in wave 2. In contrast, a higher proportion (24-27 per cent and 28-30 per cent respectively) reported an increase in the amount of time taken to get supports, do the necessary paperwork, and find out where to get supports in wave 2.

### **8.2.2 Has eligibility and navigation within the NDIS changed overtime? – Evidence from large scale surveys**

- Further analyses were conducted regarding the changes that occurred in the timing of support arrangements between wave 1 and 2. Appendix Tables A8.5 - A8.7 document these changes for NDIS participants. It enables exploration (among those who participated in both waves of the survey) of whether people who reported a bad/good outcome in the first wave move on to a better/worse outcome in the second wave.
- Those who report decreased time pressures between waves 1 and 2 are in the top right part of the table, and those with increased time pressures in the bottom left. The diagonal from the top left corner down to the bottom right corner in the table, includes all those with no change.
- Of concern is that over a quarter of NDIS participants who reported in wave 1 that it took them less time to find (29 per cent) and get supports (29 per cent) and do the necessary paperwork (28 per cent) in wave 2 now reported that it now takes more time to do all these tasks.
- A much smaller proportion of NDIS participants (8 – 9 per cent) who in wave 1 felt that their supports took more time to arrange under the NDIS now reported that these took less time.
- Appendix Tables A8.8 - A8.10 show the changes that occurred in support time pressures between wave 1 and 2 for carers of NDIS participants. Similar to the tables relating to NDIS participants, those carers for whom time pressures have decreased between wave 1 and 2 are in the top right part of the table above the diagonal, and those with increased time pressures in the bottom left, below the diagonal. The diagonal from the top left corner down to the bottom right corner in the table, are those with no change.
- For those carers who reported in wave 1 that organising their support arrangements took less time under the NDIS, 28 per cent now felt it took more time to get supports, 25 per cent to do paperwork or find out where to get supports.
- In contrast, carers who in wave 1 felt that their supports took more time to arrange under the NDIS, nine per cent now felt that it now took less time to get supports, 10 per cent to do paperwork and 13 per cent to find out where to get supports.
- Overall the Appendix tables indicated the following<sup>17</sup>:
  - Thirty-five per cent of carers reported an increase in the time it takes to get supports between wave 1 and 2, 22 per cent report decreased time and 42 per cent report no change.

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<sup>17</sup> Using manual calculations from unreported frequencies.

- A similar proportion of carers reported an increase (28 per cent) or a decrease (30 per cent) in the time taken to do the necessary paperwork between wave 1 and 2, and a further 42 per cent reported no change.
- Thirty-seven per cent of carers reported an increase in the time it takes to find out where to get supports between wave 1 and 2; 23 per cent reported decreased time and 40 per cent reported no change.
- In wave 2, NDIS participants and their carers were asked how informed they were about how to access funded disability supports. Thirty-one per cent of all NDIS participants felt very well informed and had all the information they required (Appendix Table A8.11). A slightly higher proportion (35 per cent) considered themselves to be informed but requiring more information. Of concern, nearly a fifth of NDIS respondents did not feel well informed at all and did not know where to find information about funded disability supports.
- The carers who were surveyed in wave 2, reported higher levels of understanding of how to access funded disability supports compared to the NDIS participants themselves (Appendix Table A8.12). However, while over a third (36 per cent) of carers felt very well informed about access to funded disability supports, half of respondents (50 per cent) reported that they needed more information. A minority (12 per cent) of carers felt they had very little understanding of how to help the NDIS participant to access supports and did not know where to find the information.

### **8.2.3 Experience of entering the NDIS and system navigation – Evidence from in-depth qualitative interviews**

*The perspective of NDIS participants and their family members or carer*

- The experience of entering the NDIS varied greatly, with some people with disability and their family members or carers describing the process as positive and straightforward, while others commented on various difficulties they encountered.
- Respondents who had an easy transition into the NDIS were generally those who had a service provider or paid advocate who assisted them with enrolling in the NDIS, had other family members already in the NDIS, or were seeking services for the very first time.
- The most commonly reported difficulty related to a lack of responsiveness by the NDIA. Many respondents had to follow-up first contact from the NDIA due to problems with receiving paperwork or having paperwork mislaid and needing to complete multiple applications. Difficulties communicating with the NDIA more broadly, and frustrations resulting from this, were commonly described.

*Our forms kept getting lost and they'd be sent to the wrong office, for some reason we kept being put through to the national office, they'd try to direct us to [local office]... Yeah, it took three or four goes, in the end we photocopied the forms and actually drove them down to the office. (D17C W1)*

- The complexity of processes and paperwork to establish eligibility for the NDIS and undertake planning was also frequently noted. Respondents reported frustration with additional assessments being needed to establish a diagnosis for eligibility for the NDIS or for the funding of specific supports. They described that previous assessments done by agencies such as Centrelink were given to the planners, but these were often disregarded and repeated, costing respondents time, money and frustration.

*The NDIS decided that everyone [who was transitioning into supported accommodation] should have an occupational therapy report as to what their abilities and capacities were. So we had to have that done and then there was an argument about whether that was a good assessment, and what was done as a result of that assessment. It didn't do anything about looking at goals and outcomes. (B10C W1)*

- Respondents reported that the NDIA staff members' understanding of their disability and needs influenced their transition into the NDIS. If staff were knowledgeable of these, respondents described feeling supported. In contrast, others had met with NDIA staff whom they perceived as having little knowledge about their disabilities. These situations had a number of implications for transition into the NDIS, including the need to have multiple meetings with different NDIA staff, extended uncertainty over eligibility, and contributed to concerns over whether or not support needs would be adequately met under the NDIS.
- Wave 2 findings suggested NDIS participants and their family and carers had improved understanding of the processes and concepts/language used by the NDIA. Consequently they were becoming more confident in using this knowledge in interactions with NDIA staff.
- Despite this, difficulties communicating with the NDIA were still apparent, with examples given of continued 'clumsiness' around processes for communication with the NDIA. Respondents expressed particular frustration about phone calls being relayed through the National Office, the misdirection of paperwork, and confusion relating to the transfer of families to new offices.

*If you don't work it out yourself, that's your problem. Because if you ring up you'll ask the person there, and they say I don't know anything about that because I'm only the receptionist. And then they can't put you on to anybody who does know. Same as when we went into the planner, he doesn't get there and say when you're self-managing, I've had to learn everything myself by reading and doing it. (A11C W2)*

- The NDIA's provision of information via electronic newsletters was questioned by many NDIS participants. There was concern that many people with disability did not have access to computers or have the time to sort through emails, or open/read attachments.
- The decision to co-locate new offices with other government services was problematic for some respondents. For example, the presence of a security guard upon entering new NDIS offices which had been co-located with Centrelink, was both confusing and off-putting.

*I'm not going to go in there and do anything bad, but it doesn't exactly fill you with confidence either, you know. (D11C W2)*

#### *The perspective of people with disability not participating in the NDIS*

- Non-NDIS participants were broadly divided between those who (1) had not applied to the NDIS, and (2) those who had submitted an application for eligibility to the NDIS. Appendix 8.2 provides further information about why some actively chose not to participate in the NDIS; and the experiences of those who were not part of the NDIS either because of circumstances or having been deemed ineligible.
- For those who made a formal application to the NDIA to determine eligibility for the NDIS, a range of issues were reported.

- Lack of guidance around the application process contributed to incomplete applications and decisions of ineligibility. In some cases, respondents considered that were hindered by not knowing the 'language' of the NDIS.

*You have to have the special code words to go through their programme, you've got to say it's - oh, what is it they told me? Someone told me 'psychosocial disability' or something... so you can't even say what it is as a mental illness, you have to know these special code words, which makes it hard for anyone to get through because, if you don't know the special code words, you can't even get through the front door, so to speak. (A11 NP)*

- Confusion existed about the relationship between the NDIA and Centrelink for those respondents who had a Disability Support Pension. Some assumed automatic eligibility to the NDIS for those with a pension, while others expected that reports submitted to obtain the pension would be accessed by the NDIA to determine eligibility for the NDIS, particularly in context of co-located offices in some trial sites.

*You know, they can access all my Centrelink information and reports which, you know, date back to high school even, because I used to be on the disability pension, so they have all the reports from school about everything. (A11 NP)*

- A perception that NDIA staff lacked knowledge and understanding of disabilities led some respondents to believe that their personal situations were not being considered; others (in particular those with a mental health diagnosis) felt they had to work much harder to establish disability and that their problems were downplayed by NDIA staff.

*Not only did I have to answer the questions like 'Who gets you out of bed in the morning?' to which I replied 'I do' and the person asking the questions was a bit shocked (but also questions such as) 'Do you use (name of disability service provider)?' 'No I don't.' 'Why?' 'Because I don't need them' 'But but but why?' Those sort of – those sort of assessments, as if it was a shock and a horror that here I am living independent. (B02 NP)*

*I think I even said that to the lady, you know, do I have to be in a wheelchair or something to access this, and she sort of went yeah pretty much, that's the kind of thing that we support. And I'm like 'oh wow okay'. So I felt as if I was in a completely different category, but I also felt as if everything that I have is kind of just yeah, minimised away, 'to get over myself' kind of thing. (C07 NP)*

- Unclear boundaries between the NDIS and mainstream sectors clouded the process of establishing eligibility to the NDIS.

*And it's a back and forth game where - sorry, I've been going to try and get help from the NDIS then they say, 'Go to Mental Health' and Mental Health say, 'No, apply for NDIS' and it's back and forth, back and forth, and it's just frustrating because you never get anywhere. (A11 NP)*

#### *The perspective of the service provider and workforce stakeholder organisations*

- Disability service providers and representatives from workforce stakeholder organisations raised concerns about the responsiveness of the new system and whether it in fact added to the burden that people living with disability were already experiencing when navigating the disability supports environment. There was also concern that NDIA processes created barriers to accessing the NDIS which could result in some people with disability (particularly those with psychosocial disability or English as their second language) being excluded from service provision.

- Two years into the NDIS roll-out, respondents continued to report the negative impact of bureaucratic processes within the NDIS on people with disability and their families. Those considered particularly vulnerable were NDIS participants with limited personal capacity or support to manage NDIA processes and those with psychosocial disability. It was believed that the information provided by the NDIA was not appropriate for diverse populations.
- Several barriers to the engagement of people with psychosocial disability with the NDIS were identified in wave 1. First, the language of permanent disability used in the NDIS was contradictory to the recovery model of the mental health sector. Second, acknowledgement of their condition and the need for support was an issue for some people with psychosocial disability: *'there are a lot of clients who don't even recognise they've got a mental illness. They're not going to go to the NDIA'* (B04S W1). Third, mental health service providers were concerned about the capacity of this cohort to navigate the various NDIA processes effectively, particularly plan development, noting that *'those that most need it will find the process extremely difficult'* (E01S W1).
- In wave 2 mental health service providers reported some positive outcomes for people with psychosocial disability participating in the NDIS including more access to services. However, there were still concerns from both providers and workforce stakeholder organisations that higher rates of ineligibility and lower levels of participation persisted for people with psychosocial disability. The co-location of NDIS offices with Centrelink was also considered to further undermine engagement with the NDIS. A comprehensive approach to address these issues was not perceived to be occurring and a lack of consultation with mental health stakeholders was reportedly continuing.

*There is really significant concern from mental health providers that the structure and the philosophy of the Scheme doesn't fit well with mental health and I know there's peak body work going on at that level and you know some views about the fact that mental health should remain outside the Scheme. (O4R W2)I was appalled when I heard that the NDIA were going to set up in every Centrelink office. Now, for people with a mental health issue who are feeling slightly paranoid, that's not going to work. Turning it into a much more bureaucratic stuff that is associated with their income, it just means that the sickest people are going to fall through the gaps. And those people are going to end up back in emergency departments, and in these hospitals.... the NDIS isn't built to focus on those people. (B04S W2)*

- In wave 1 a number of improvements were suggested. These include more support for people with disability around the process of transitioning into the NDIS and greater access to support coordination and stronger protections for their most vulnerable clients. Improvements specific to support services for people with psychosocial disability included the development of specialist support clusters which worked with the recovery model utilised in the mental health sector; processes to accommodate participants who did not recognise that they had a psychosocial disability; and dedicated support services for the families of people with psychosocial disability.
- In wave 2 providers welcomed the funding of support coordination in many NDIS participant's plans. Concerns remained, however, about insufficient safeguards to protect the most vulnerable NDIS participants. At the time of the wave 2 interviews, improvements specific to mental health support clusters were being reviewed by the NDIA.
- As in wave 1, concerns about poor communication from the NDIA to providers persisted, in particular the timeliness and amount of information provided to the sector about future directions and changes to the NDIS. Many provider organisations continued to attend monthly forums and quarterly meetings facilitated by the NDIA or National Disability Services (NDS). While providers continued to value a collaborative partnership approach with the NDIA, many expressed ongoing concerns that the NDIA was not open to advice or feedback from the sector.

- Organisations felt that the information shared by the NDIA was risk averse and lacking in transparency. It was also noted that reports produced on behalf of the NDIA had not been published and this had led to concerns of a duplication of work.

*The communication from the NDIA is appalling. The public communication, the stuff in press releases and so forth, is very dumbed down: it's lots of pictures of people in wheelchairs looking happy and I'm sure there's a role for that and the department needs to do that kind of thing, but...there's a very risk-averse culture in that bureaucracy, you know, they're paranoid about criticism in public and so they'll err on the side of releasing less information rather than more at the very time that sectors like ours and our members are begging for information to resolve the uncertainty. (O8R W2)*

*At one point [our colleague] looked at, counted up all the research and demonstration work that the agency was doing and out of 50 projects there'd been reports from three or four of them or something. I mean, he just was making the point that there's so much work that we haven't had any results from. (O5R W2)*

- Further criticisms about the information provided by the NDIA to providers included a lack of specific information regarding outcomes, quality and safeguards, and market positions.

*I don't think the Agency's thinking what data would the sector like or need, for example...different therapy professions have been bundled together now in a catalogue pricing item, and presumably that's going to make it extremely difficult to disaggregate demand and supply, and volume of work paid for and so on by specialist, different specialisations...if we can't look at what's happening to demand for speech therapy in Barwon as opposed to occupational therapy. You know, that's a real problem. (O5R W2)*

- A considerable number of providers across the trial sites noted in wave 1 that the NDIS had created an 'administrative burden' (D04S W1) for providers including extra paperwork and processes, and time spent managing problems with the NDIS portal. Simpler and less bureaucratic processes were recommended. In particular, improvements to the IT system, especially the provider portal, were seen as necessary in order to alleviate the administrative burden the NDIS imposed on providers.
- Providers continued to report similar examples and concerns about administrative burden due to the NDIS in wave 2 and NDIS processes continued to add to staff workloads.

#### *The perspective of the NDIA staff*

- NDIA staff reported that the NDIS had overestimated participants' capacity to complete paperwork, and perceived the planning documents to be too complicated for some people with disability to complete on their own. Various examples were provided of people with literacy problems or cognitive impairments struggling to understand the various forms:

*It's clear that they haven't been designed with people with disability. They're unintuitive, hard to read, you know, they're probably a bit long... I would struggle to complete, to be honest. They're really government forms. (B11N W1)*

- In wave 1, eligibility decisions for the NDIS were still being determined at the local trial site level. The national access team was in the process of being established but had not yet begun to operate. By wave 2, NDIA staff advised that the national access team had been operating for some time, providing a centralised eligibility process with the aim to increase consistency of decision.

- NDIA staff reported a number of concerns with the national access team. Several advised that the national access approach had resulted in a slowing down of eligibility processes. Others observed that centralising the eligibility process resulted in contextual, trial site specific knowledge being absent in decision-making around eligibility.

## **8.3 Are NDIS Review and Dispute Resolution Processes Working Well? – Evidence from Large Scale Surveys**

### **8.3.1 Plan reviews**

In the second NDIS survey of people with disability, and their families and carers detailed information about NDIS participant's experience of the plan review process was collected.

- As shown in Appendix Table A8.13, around 92 per cent of all NDIS participants reported that they currently had an NDIS support plan.
- Nearly half of all NDIS participants that were surveyed (49 per cent) reported that they had had more than two reviews of their support plan since joining the NDIS (Appendix Table A8.14). A further third (33 per cent) reported that they had had one or two plan reviews and around eight per cent had not yet undertaken a review of their support plan.
- NDIS participants who had undertaken a plan review were asked about their level of satisfaction with the plan review process, the frequency with which they were able to have their plan reviewed, and the outcome of their last plan review (Appendix Tables A8.15-A8.17).
- Around 40 per cent of all NDIS participants reported that they were either satisfied or very satisfied with the plan review process (41 per cent), the frequency with which they were able to have their NDIS plan reviewed (46 per cent), and with the outcome of their plan review (49 per cent).
- Of concern, is that around a fifth of NDIS participants were either dissatisfied or very dissatisfied with the plan review process (22 per cent), the frequency with which they were able to have their plan reviewed (20 per cent), and the outcome of their last plan review (19 per cent).

### **8.3.2 Experience of plan review process – Evidence from in-depth qualitative interviews**

*The perspective of NDIS participants and their family members or carer*

- There were inconsistencies in how participants and carers understood the plan review process; some believed it to be a dynamic ongoing process while others believed plans could only be changed at annual or bi-annual review meetings. Many plans, however, had been changed outside of formal review but there was dissatisfaction with the level of paperwork involved in making even small changes to plans.
- With the exception of one NDIS participant whose initial plan took much longer than usual to be completed, all respondents had experienced one or more annual plan reviews. The outcomes of the review process have been discussed in chapter 3 and 4. Here we consider the experience of the review process for participants and their families.
- For most respondents the experience of review was different from initial planning. Home visits were generally not offered. Most respondents noted visiting the NDIA office for the review appointment and several reviews were conducted by phone.

- For many there was considerable anxiety in advance of the plan review appointment. Concerns related to fears that plans would be required to fit within a standardised (capped) amount based on their severity of disability. Fears were also expressed that that unused funds would result in the down-sizing of packages regardless of reasons for this having occurred.

*So that's one concern that I've got is that if he doesn't use his allocation this year then we don't want to be penalised the next year because the next year could have been like last year when he used all his allocation. So that's a concern I have. (A17C W2)*

- Plan reviews were generally undertaken by a different planner to the one that had put together the initial plan. This appeared in part due to high NDIA staff turnover and staff movement between NDIA offices. In the majority of cases this was unwelcome as it disrupted previously established relationships. In a few cases, however, having a new planner led to a more positive process.

*The thing is when you set up, start with a planner and you let them into your home and your life and to do that all again with someone different in 12 months is not really a good thing I don't think... but I didn't have any choice. There was no choice in the matter. There was no are you okay with that Dani, you know? It was this is what's happening. (C14C W2)*

- NDIA staff experience and knowledge of particular disability types was again raised as being an important factor that influenced satisfaction levels in the plan review process.

*I don't believe I would have had to push for that with my original planner, she would have been absolutely, that's definitely what you need. Again, she comes from a background of understanding early intervention. I feel that's the difference with planners. I feel like grilling them, where have you come from, how did you get this gig? But I don't. (C12C W2)*

- As previously mentioned, most participants stressed the importance of preparing for the review to ensure the development of an appropriate and beneficial plan. Preparation appeared to be effective in assisting respondents to understand what supports they needed, to develop achievable goals and in justifying these to the NDIA at the time of the review. Some of the preparation tasks that respondents mentioned were discussing the participant's needs and support services with relevant stakeholders (including therapists, advocates and case managers) and prompting therapists' assessment reports to be completed prior to the review date.

*And that's what I often say to anyone who's going in, 'Go prepared, know what you want'. If you don't know what you want you won't get it and you can't guarantee coming in four weeks or six weeks or eight weeks later saying I thought of something else. (B11 C W2)*

*I was a bit more prepared and confident in myself with dealing with them because I'd gone to two workshops that [Name of provider] had held about your plan and what to ask for if you're up to it and break it down. They empowered us on what our rights are. (B08 PWD W2)*

- A commonly reported challenge related to plan review processes in wave 2 was the experience of long delays for reviews to be held and plans to be finalised or that revised plans were not efficiently finalised by the NDIA. This caused frustration on the part of respondents, strained relationships with service providers who were not being remunerated in a timely manner, and in extreme cases prevented access to funding for services because a finalised plan had not been received.

*So no plan came by the end of November. I had service providers saying 'We've now provided into early December. We're providing services for your son. Your plan's expired. What's happening with your new plan?' So I would write to [the planner] and nothing would come from it. And so it went on. We didn't get a new plan until mid-January, by which time the service providers were a bit cross. (B10 C W2)*

- Another challenge in the review process related to obtaining assessment reports from therapists as per NDIA's evidence requirements. Respondents reported therapists were slow to provide assessment reports. There also appeared to be an inconsistency over who paid for these reports; the respondent or the NDIA.

*But they hadn't written their reports so trying to hassle them to get their reports in time I guess. Especially the OT report which we managed to get the day of the plan review. (B02 PWD W2)*

- Several respondents had disputed decisions in their own or their child's plan, following initial planning. Many NDIS participants had sought help from an external advocate and felt this had been beneficial, while in other cases disputes were satisfactorily mediated by senior NDIA staff. For some though, the process of resolving disputes was more difficult and took time.

#### *The perspective of people with disability not participating in the NDIS*

- None of the non-NDIS participants reported participating in NDIS dispute resolution processes because they were unhappy with their support plan or with being found ineligible for the NDIS. One respondent reported receiving advice from the NDIA that a re-application would be easier than appealing an 'ineligible' decision. This appeared to be reinforced by the number of non-participants who reported making multiple applications to enter the NDIS.

#### *The perspective of the service provider and workforce stakeholder organisations*

- Evidence was provided of clients who had at first been very satisfied with their NDIS plan but had then had their plans and funding cut considerably at review with little or no explanation as to why.

*So we have people that go look my first was fantastic, I got what I needed, I felt supported, I went back for the review and I got someone who was useless and they decided to take away money, they didn't explain to us really why. (A03S W2)*

- Some providers suggested that the NDIA were under pressure to cut back funding and supports which meant that the funding levels in initial plans in the trial sites would be reduced to ensure the NDIS remained sustainable in the future.

*I think a big question exists as to the overall system's long-term sustainability, and I suspect that the quantum of money that is assigned to each plan over time will reduce. (A01S W2)*

#### *The perspective of the NDIA staff*

- Efficiencies in the NDIS planning and review process had been introduced between the wave 1 and 2 interviews. Efficiencies included reviews conducted by telephone rather than face-to-face and the move to biennial rather than annual reviews of participants' plans.
- One of the main challenges with the plan reviews was NDIA staff workload. planners were not only engaged in conducting reviews for participants, they were concurrently also working with new participants on plan development; with the review process often being just as labour intensive for the planner as developing initial plans. In many instances this resulted in plan reviews being conducted by any planner available at the time of review rather than the original planner.

*You know when we first started, I think I said to you last year we had said that, 'You'll have a PSC [Plan Support Coordinator] who'll be your PSC, you'll see initially and you'll see at review and they'll be with you for your NDIS journey.' That's not happening at all. It's basically, whoever is available to do the review does the review. (E05N W2)*

- Inefficiencies in the computer system, which required double entry of data, further exacerbated the workload for NDIA staff engaged in planning and review.
- Difficulties around interpreting and reviewing plans developed by another planner/PSC were also reported.

## 8.4 Does the NDIS promote Fairness, Equity and Accessibility?

In both wave 1 and 2, NDIS participants and their family members or carers provided feedback about the equity and fairness of the NDIS. An overview of the key findings are provided below. In Appendix 8.3 we provide three composite case studies to show variability in 'typical' outcomes for different groups of NDIS participants. The three composite case studies illustrate the characteristics of those who typically record: 'positive' experiences; 'middle way' experiences; and 'negative' experiences of the NDIS.

### 8.4.1 Equity and fairness for NDIS participants and their family members or carer

- In both wave 1 and 2 respondents felt that those with limited literacy skills, minimal experience with the sector or lacking capacity to self-advocate would struggle to get the best out of the opportunity presented by the NDIS.

*If people have been in group homes and parents haven't had the opportunity to learn maybe some of the stuff I've learnt, then are they asking - especially when the individual can't speak for themselves - are they asking for something that's actually going to give this person a better life? Do they know that they could have? (C11C W2)*

*These people that I know that haven't bothered with the NDIS or are leaving, it's because they can't speak up, they can't write well... they can't speak the language, they can't be bothered. (C12C W2)*

- Perceptions of fairness were also based on continued observations of ongoing inconsistencies across plans for people with equivalent disabilities.

*No, [it's] absolutely not [fair]. Because I know how much I got for Robbie first time around and I know the children... from his early intervention group didn't even get half of what I got. (C12C W2)*

- The importance of advocacy (whether by a formal advocate or a parent/carers) to ensure that all participants achieved equitable access to funding was highlighted at both time points. However, advocacy was not being funded under the NDIS.

*As soon as you bring an advocate in the standard of service you get improves vastly. (B05 PWD W2 PWD)*

*I think the parents who jump up and down and send things back for reviews... get more. (C03C W2)*

- The role of the advocate ranged from requesting services to address participant needs, suggesting new ideas to respondents, and acting as a conduit for communication between the participant and NDIA representatives. The following carer described how she thought the content and quality of NDIS plans was largely determined by the extent of advocacy:

*And one of the things that the whole plans come down to is advocacy. If you haven't got a good advocate to make the plans, you're in trouble. So whether you're advocating for yourself or you have somebody advocating for you, you've got to have that advocacy in there. If you haven't got that you can't speak up and say what your needs are, or have someone who really knows you say what your needs are, you're going to get a very ordinary plan. (B03C)*

- Respondents represented a broad range of socio-economic circumstances, including living in metropolitan and regional centres. As previously noted, the primary concern for those living in regional areas was the limited availability of services. Respondents were faced with the potentially costly decision to travel to access supports elsewhere, or to wait until services could be sourced locally.
- The sample also reflected a mix of participants with different diagnoses. The main observable differences related to those with psychosocial disability who appeared to have poorer outcomes than respondents with physical support needs, who were typically better able to articulate their needs.
- Feedback from respondents in wave 2 also indicated broad concern about the situations of low income families, and the potential for children in such families to 'miss out' on social and recreational activities because their parents were not in a position to pay for these.

#### **8.4.2 Equity and fairness for people with disability not participating in the NDIS**

- Non-participants considered that people with physical disability had easier pathways into the NDIS. People with mental health problems (psychosocial disabilities) were more likely to receive advice that they would be ineligible for the NDIS, or to have applied to the NDIS and been found ineligible. While this may reflect a selection bias of those choosing to take part in the evaluation interviews, it also appeared there was confusion among NDIA staff about the boundaries between health and disability services for people with psychosocial disabilities, and less understanding of the support needs of this cohort.
- Concerns were expressed that people with disability who are unable to participate in the NDIS may have less access to disability services and supports in the future, and would, therefore, receive fewer services than those who are part of the NDIS. This suggests the potential for inequity and points to the need for additional supports to ensure decisions of eligibility to the NDIS are based on full and complete information. It is of concern that most respondents had no knowledge of the potential of the NDIS to help them access mainstream and community services as part of ILC.

#### **8.4.3 Equity and fairness through the eyes of the service provider and workforce stakeholder organisations**

- As in wave 1, the NDIS was widely considered by providers and workforce stakeholder organisations to be working particularly well for articulate English-speaking participants and their families who were able to express and assert their needs. Particular client groups who were thought to be having good outcomes under the NDIS, included people with physical disability, acquired brain injury, and prosthesis needs. NDIS participants with access to formal advocacy services were also noted to achieve better outcomes.

*If you're educated, middle-class, white person, it's fine, it works well, you can pick your services, pick what you want and it's very empowering. (O3R W2)*

*The ones that do well are the articulate ones, the assertive ones, and the ones who invest time, energy and potentially their own resources in doing a lot of pre-plan research, pre-plan discussion with service providers, and also potentially engaging their own advocate to be with them in the planning sessions. (A01S W2)*

- However, the NDIS was not seen to be having positive outcomes for all participants.

*When it works it works well but it's not working well enough. (16R W2)*

- Those more vulnerable to poorer outcomes included participants with intellectual disability and/or complex needs; from CALD communities; those experiencing mental health, substance abuse, or forensic issues; and older carers who were socially isolated and had their own health issues. These vulnerable groups were considered to receive less funded supports in their NDIS plans than others with similar support needs and to struggle with NDIS processes.

*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)*

- Considerable concerns were raised in wave 2 regarding service provision for people with disability who were not part of the NDIS. A reduction of state-provided disability services was reported to be occurring and this was having an adverse impact on the services for this cohort. Some existing disability clients were noted to be receiving fewer services than previously, while others were falling through gaps in service provision and were 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.

*The state disability services have been reducing and pulling back so they can wind down and so what's happened is there's a group of people that have had services that, because the therapy providers are no longer there, they are not getting what they used to get and in fact may not end up with very much at all. (11R W2)*

- Several respondents also noted inequity in service provision across sectors; older people with disability outside the NDIS were reported to be receiving significantly different services to their younger counterparts in the NDIS and were less likely to have their needs met.

*People that are outside of 65 years of age are already starting to receive significantly different services...The gap that's in the state scheme in terms of funding is now very clear, what those differences are going to be. Their goals are less likely to be met. (12R W2)*

- Finally, respondents were not satisfied that safeguards to protect vulnerable NDIS participants were effective. Several providers were concerned that the NDIA had still not released a quality framework to ensure quality service provision by providers. Advocacy services were considered important to safeguard NDIS participants but some providers suggested that these services were more likely to be utilised by those for whom the NDIS was already working well rather than more vulnerable NDIS participants and families.

*Often it's the more articulate, confident people who actually have the confidence to access advocacy. Often really vulnerable people don't have the confidence... you actually have to be quite empowered to actually go through that process. (B02S W2)*

*Even accessing advocacy is another one of those situations where you've got to articulate your needs. (C04S W2)*

#### **8.4.4 Equity and fairness through the eyes of NDIA staff**

- NDIA staff considered that those participants and families who were confident, educated and able to articulate their support needs had better outcomes than those with less capacity to understand and navigate the NDIS. This latter group included participants with intellectual disability and some older participants. Also considered disadvantaged were participants with less obvious disability, and those for whom the NDIS design fit less well such as those involved in the criminal justice system and some people with psychosocial disability of an episodic nature.
- Various safeguards were reported to have been put in place for vulnerable participants. These included the provision of assistance in implementing plans by LACs and PSCs. Respondents also identified the use of advocacy services, informal supports and mainstream services as possible safeguards around decision-making. In addition, some NDIA staff advised that risk assessments were conducted by agency staff for participants and appropriate safeguards were put in place. There were also reports of ongoing projects around supported decision making being conducted within the NDIA.
- NDIA staff identified a range of hurdles to meeting the needs of, and working with, participants from Aboriginal and Torres Strait Islander and CALD backgrounds. These ranged from a lack of direction from national office 'around how you work in a culturally appropriate or sensitive way (D02N)' to poor NDIS take up among people with disability from Aboriginal and Torres Strait Islander or CALD backgrounds. Further barriers included the lack of translated and culturally appropriate resources, and limited staff awareness of cultural understandings of disability and cultural preferences around supporting these cohorts.
- Some respondents noted problems in accessing interpreters to take part in planning sessions, and of working with interpreters who were unable to communicate with participants effectively. Several respondents reported the low percentage of staff within the NDIA who themselves identified as being from CALD or Aboriginal and Torres Strait Islander backgrounds. This was considered to be a barrier to engaging these communities. The location of the NDIA offices in some trial sites (which were associated with government departments such as Centrelink) was viewed as creating further barriers to effective engagement with these populations groups.
- In wave 2 NDIA staff reported a number of strategies which had been implemented to improve engagement with Indigenous people with disability. These included liaising with organisations that had established relationships with Aboriginal and Torres Strait Islander groups, provision of training for staff around working with Indigenous populations, and developing working groups dedicated to assisting participants who identify as Indigenous.

### **8.5 Summary**

This final section of the chapter provides a summary of the key quantitative and qualitative findings relating to fairness, equity and access. In particular the findings focus on eligibility and navigating the NDIS, review and dispute resolution processes, and equity and fairness.

#### **8.5.1 Eligibility and navigating the NDIS system – Evidence from large scale surveys**

- As shown in wave 1, the NDIS has impacted on how long support arrangements take for the majority of NDIS participants and their families and carers.

- Compared to before the NDIS, NDIS participants and their families and carers reported that it takes more time under the NDIS to complete paperwork for supports. While NDIS participants were most likely to report that under the NDIS it takes less time to find and get supports, carers did not believe that the time taken for these activities had changed.
- Over time in the NDIS, the majority of participants and carers experienced little change regarding how long it takes to find supports, do the necessary paperwork, and to get the supports.
- The carers who were surveyed in wave 2, reported higher levels of understanding of how to access funded disability supports compared to the NDIS participants themselves. Despite this, 50 per cent of carers reported that they needed more information about supports. In addition, around a fifth of NDIS participants and 12 per cent of carers felt that they had very little understanding of how to access supports.

### **8.5.2 Eligibility and navigating the NDIS system – Evidence from in-depth qualitative interviews**

- There was a concern held by all groups interviewed about the accessibility of the NDIS (particularly for people with psychosocial disability and of CALD or Aboriginal and or Torres Strait Islander backgrounds).
- Respondents (including NDIA staff) noted the complexity of NDIA processes and documentation. Various examples were provided of people with literacy problems or cognitive impairment struggling to understand and complete the requisite forms.
- Concerns were also held in regard to the responsiveness of the new system with respondents providing examples of the negative impact of bureaucratic processes. These included respondents having to follow-up initial contact with the NDIA due to problems with receiving paperwork or having paperwork mislaid, and needing to complete multiple applications. Respondents also reported that additional assessments were often required to establish a diagnosis for eligibility for the NDIS.
- NDIS participants criticised the often lengthy and complicated process of establishing eligibility. This was reported to have been exacerbated by administrative issues within the NDIA which resulted in delays between first and subsequent contact. These difficulties were acknowledged by NDIA staff who also reported high workloads which reduced contact with individual participants and prevented a more customised service.
- There were still concerns in wave 2 that higher rates of ineligibility and lower levels of participation persisted for people with psychosocial disability. The co-location of NDIS offices with Centrelink was also considered to further undermine their engagement with the NDIS.

### **8.5.3 Review and dispute resolution processes – Evidence from large scale surveys**

- The majority of NDIS participants in both waves 1 and 2 had a current support plan in place. Of these, only eight per cent had not yet undertaken a review of their plan in wave 2.
- NDIS participants who had undergone a plan review most commonly reported being either satisfied or very satisfied with the process (41 per cent), the frequency with which they were able to have their NDIS plan reviewed (46 per cent), and with the outcome of their plan review (49 per cent).
- Around a fifth of NDIS participants, however, were either dissatisfied or very dissatisfied with aspects of plan reviews: the plan review process itself (22 per cent), the frequency with which they were able to have their plan reviewed (20 per cent), and the outcome of their last plan review (19 per cent).

#### **8.5.4 Review and dispute resolution processes – Evidence from in-depth qualitative interviews**

- There were inconsistencies in how participants and carers understood the plan review process; some believed it to be a dynamic ongoing process while others believed plans could only be changed at annual or bi-annual review meetings.
- The experience of review was different from initial planning. Home visits were generally not offered. Most respondents noted visiting the NDIA office for the review appointment and several reviews were conducted by phone.
- Plan reviews were generally undertaken by a different planner to the one that had put together the initial plan. This appeared to be in part due to high NDIA staff turnover and staff movement between NDIA offices. A lack of planner consistency was largely unwelcome as it disrupted previously established relationships.
- NDIA staff experience and knowledge of particular disability types was again raised in wave 2 as being an important factor that influenced satisfaction levels in the plan review process.

#### **8.5.5 Equity and fairness – Evidence from in-depth qualitative interviews**

- Respondents continued to report that the NDIS worked best for those participants and their carers who were strong advocates for themselves or their child. Some also considered that outcomes were dependent on disability type and planner knowledge or understanding.
- Perceptions of fairness were also based on continued observations of inconsistencies across plans for people with equivalent disabilities and support needs.
- The importance of advocacy (whether a formal advocate or a parent/carer) to ensure that all participants achieved equitable access to funding was highlighted at both time points. However, the fact that funded advocacy is unavailable under the NDIS, raises concerns about the future fairness and equity of the NDIS.
- The primary concern for those living in regional areas was the limited availability of services. Respondents were faced with the potentially costly decision to travel to access these elsewhere, or to wait until services could be sourced locally.
- Outcomes for NDIS participants with psychosocial disability appeared to be poorer than for those with physical support needs, who were typically better able to articulate their needs.
- Considerable concerns were raised in wave 2 regarding service provision for people with disability who were not part of the NDIS. A reduction of state-provided disability services was reported to be occurring and this was having an adverse impact on services for this cohort. Some existing disability clients were noted to be receiving fewer services than previously, while others were falling through gaps in service provision and were 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.
- Finally, respondents were not satisfied that safeguards to protect vulnerable NDIS participants were effective. Many were concerned that the NDIA had still not released a quality framework to ensure quality service provision.

## 9. Mainstream Interface

### Summary of findings

This section summarises the qualitative findings relating to the interface between the NDIS and the mainstream sectors.

The evaluation finds that:

- the interface between the NDIS and related mainstream sectors is taking time to be defined, with many uncertainties remaining at the end of the evaluation period;
- despite the many communication channels already established, the NDIA was perceived by mainstream sectors to be largely unresponsive and difficult to communicate with;
- the supply and demand in the two sectors are partly inter-related. For example NDIS emphasis on early intervention, increases demand for related mainstream provisions, but there are also concerns about cost-shifting and other adverse impacts;
- insufficient sharing of information between the NDIS and mainstream sectors leads to both services duplication and gaps and longer waiting lists, through uncertain sector boundaries and responsibilities, and unduly complicated processes;
- the NDIS is forcing mainstream sectors to use new, untested and more formal referral pathways;
- the individualised funding model of the NDIS has presented the mainstream sector with new and costly administration and staff training challenges;
- in line with the whole evaluation, the NDIS is working well for most who use it, but at the same time it is making specific minorities worse off, particularly the most vulnerable;
- the ability of the NDIA to be responsive to mainstream problems is questioned, with the rollout speed and the associated uncertainties often being mentioned as the causes;
- the mainstream sector has been responding, but these responses too are often considered to be inadequate;
- overall, the continuing complexity of the NDIS is impacting negatively on its capacity to work well with related mainstream providers.

#### *Interface between mainstream sectors and the NDIS*

- The interface between the NDIS and the mainstream sectors was not perceived to have been a priority (at least initially) for the NDIA. While clearer boundaries about sector responsibilities had developed over time, unresolved issues remained at the end of the evaluation period. These were primarily around responsibilities for funding shortfalls and, for the health sector, about the support of people with complex or chronic health conditions and those requiring rehabilitation services. Greater clarity was also required within the education sector about the funding of school transport, personal care in schools and the provision of allied health services during school hours.
- Communication was occurring between the NDIS and mainstream sectors across all levels of operation. Interagency and intergovernmental communications had been valuable in the provision of information and exploring unresolved issues. At a local level, most mainstream organisations had a dedicated individual or team who managed the interface with the NDIS.

- Challenges in communication with the NDIA were noted by many mainstream organisations including difficulties contacting the NDIA (and particularly head office) and in receiving timely responses. A lack of consultation with mainstream organisations and ongoing changes to NDIA policies and staffing also hampered effective communication.

#### *Changes in supply and demand of mainstream services*

- The NDIS had led to changes in service provision by mainstream organisation, particularly in the health and education sectors. Increased demand for therapy services and early childhood early intervention (ECEI) services and assessments were noted. Moreover, education organisations reported an increased demand for therapy provision within the school environment. However, many schools had ceased allowing in-school therapy due to concerns of the adverse impact on student education.
- Child protection organisations reported an increased demand for case management services to assist their clients to navigate the NDIS. While employment organisations were yet to experience a change in the demand for their services, it was anticipated that the NDIS would have a greater impact in the future.

#### *Service gaps*

- Several services gaps had emerged as the roll-out of the NDIS progressed. These included concerns around the ability of children with disability to remain in foster care after the age of 18 years without their foster parents having to become registered NDIS service providers. A lack of funding for accommodation for children living in voluntary out-of-home care was also identified. Service gaps were also noted relating to mental health services, prosthetic services, and rehabilitation for people with brain injury. Moreover, people with disability who were ineligible for the NDIS were reported to be experiencing increasing issues accessing services.
- A lack of shared information around client participation in the NDIS had led to duplication of service provision. Within the health sector, delays in transitioning people with disability into the NDIS was perceived to be contributing to longer waiting lists for outpatient services and lengthier hospital admissions.
- Several factors were identified by mainstream organisations as contributing to these service gaps. These factors included uncertainty regarding sector boundaries and responsibilities, poor communication between the NDIS and mainstream organisations, and NDIA processes contributing to delays in referral and access to services. In order to minimise the impacts of these service gaps, mainstream organisations were continuing their in-kind service agreements with the NDIA beyond the length of the original agreement.

#### *Impacts on referral pathways*

- Prior to the NDIS, referral pathways from mainstream organisations to disability services were described as being largely informal but effective. These pathways had been dissolved with the introduction of the NDIS and had hampered the transition of clients between the mainstream and disability sectors. However, mainstream organisations reported that relationship building with the NDIA and the re-establishing of these referral networks was taking place to ensure that collaboration could again occur.

### *Individualised funding*

- The individualised funding model of the NDIS had led to additional work for administrative and frontline staff within mainstream organisations. Moreover, organisations who were registered service providers under the NDIS, reported that gaining access to the NDIA portal had necessitated costly changes to their IT systems.
- The activities of mainstream provider organisations had also changed with the individualised funding approach of the NDIS. There was now a greater emphasis on case management activity including assisting clients to navigate NDIA processes and advocating for clients around their funding and support needs. Some mainstream sector staff had had to upskill their knowledge of working with people with disability and around NDIS processes.

### *Equity, fairness and navigating the NDIS*

- Although the impact of the NDIS was perceived by mainstream organisations to be largely positive, the NDIS was seen to be working less well for particular cohorts of people with disability. These cohorts included participants from Indigenous and CALD backgrounds, those with high support needs or limited capacity to advocate for themselves, and individuals who were new to the disability sector. As a consequence of limited service provision and difficulties engaging with the NDIA due to limited access to the internet, NDIS participants living in regional and remote areas were also identified as having poorer outcomes under the NDIS.
- The ability of the NDIS to be responsive to the needs of people with mental health issues and psychosocial disability was also questioned by mental health organisations.
- The speed of the NDIS roll-out was considered to have had a negative impact on the implementation of the NDIS. Delays due to NDIS processes (around eligibility and planning) were leading to longer waiting lists, bottlenecks in mainstream services, and were contributing to gaps in services. A further area of concern was that NDIS systems were too complex for many people with disability to effectively navigate.
- As a result of delays in NDIS planning processes, mainstream organisations reported that they were providing interim services to people with disability. However, it was acknowledged that mainstream staff often lacked disability specific skills to deliver quality services. In addition, disability service provision to people with complex needs was felt to be lacking, leading to these clients inappropriately ending up in mainstream health services. To address these concerns, a need for greater quality control and regulation of the disability provider market was highlighted.
- Mainstream organisations recommended improved collaboration, communication and information sharing between the NDIA and mainstream sectors. This would assist the transitions of clients into the NDIS and also future transitions into education, employment and health/mental health services. Improved education and assistance for people with disability and their families was also recommended to aid understanding and navigation of NDIS processes. This included having better access to plan management support to assist in the implementation of services.

## 9.1 Introduction

The NDIS is a new way of providing individualised support for people with disability, their families and carers. However, the NDIS is not intended to replace other mainstream supports. To be fully included in society, people with disability should be able to access mainstream systems such as education, health, and be supported to participate economically. Hence, wherever possible the NDIS assists participants to access mainstream services.

In this chapter we present key findings arising from the Mainstream Study, an extension of the broader NDIS evaluation. The overall objective of the Mainstream Study was to explore the impact of the NDIS on mainstream health, mental health, education and employment sectors. A particular focus was on the interface between the NDIS and these mainstream sectors. The Mainstream Study consisted of one wave of in-depth interviews with senior NDIA staff involved with the design and implementation of ILC and interviews with representatives from mainstream providers/state government agencies who interact with the NDIA and/or NDIS participants.

Interviews with NDIS participants and their carers, disability service providers, representatives from workforce stakeholder organisations, and NDIA staff conducted for the main evaluation also discussed mainstream interface issues. The information collected in these interviews, however, was very similar to the feedback provided by representatives from mainstream organisations, with no unique issues uncovered. To assist readability, this chapter focuses solely on the findings of the interviews conducted with mainstream organisations.

As a standalone study, the Mainstream Study addressed specific KEQs relating to the impact of the NDIS on mainstream services (see section 1.3). The interviews, however, also uncovered mainstream sector perspectives on broader issues and impacts of the NDIS. While these findings are similar to those presented in preceding chapters relating to our interviews with other respondent groups for the main evaluation, they are included separately here for two reasons. The findings highlight the specific experiences of these issues for the mainstream sector and, furthermore, they show the systemic nature of many issues experienced with the roll out of the NDIS.

This chapter explores several areas relating to the impact of the NDIS on the mainstream sectors. First, the interface between the NDIS and mainstream services is examined to understand how effective the interface is, and the extent to which it has been clearly delineated. Second, we explore changes in the use of mainstream services by people with disability and whether areas of duplication are apparent or if service gaps have emerged. Third, we consider how well the individualised funding model of the NDIS aligns with the program funding model of mainstream services. Finally, this chapter presents the views of mainstream organisations of the impact of the NDIS on people with disability, the lessons learned from the NDIS roll-out and areas for future improvement.

## 9.2 Interface between Mainstream Sectors and the NDIS

- Most mainstream organisations observed that the interface between the NDIS and mainstream sectors was not a priority for the NDIA, particularly during the earlier phases of the roll-out. They noted that high level interagency and intergovernmental communications between departmental heads had been successful in providing information about the NDIS and developing escalation pathways for unresolved operational issues or systemic challenges. However it was observed that these meetings were tailing off and the NDIA was becoming less collaborative and more insular.
- Meanwhile, at the local level, most mainstream organisations had a key person or team that had primary responsibility for managing the interface, communicating with local NDIA contacts and for educating staff. Forums were evolving as the NDIS roll-out continued; these included local

organisational or interagency implementation committees, working groups, meetings with representatives from different mainstream sectors and involvement in the Disability Reform Program Steering Committee.

- A number of challenges were identified in relation to the interface between mainstream organisations and the NDIS. Communication with the NDIA, particularly with head office, was a primary challenge identified by mainstream organisations. Difficulties in communication included contacting the NDIA, a lack of NDIA staff knowledge of the NDIS, delays in obtaining responses from the NDIA in relation to the outcome of client referrals, a lack of consultation with mainstream organisations, and frequent changes to NDIA policies.
- The use of the national 1800 NDIS number was noted by several participants as being problematic, particularly when making referrals from the mainstream sector. Several respondents mentioned the value of having direct phone access to NDIA managers, but also noted their hesitation to overuse these to escalate individual cases.

*Trying to contact that person, knowing who they are can be really difficult to get through to because of the way their phone systems operate. So even if they give you a direct number, going through a national line and you can be on hold, so most of my communication I have to resort to email; I can't just pick up the phone and get the person I want at the other end. (MS 21 ACT E)*

- Many respondents considered that there was a lack of consultation and limited collaborative practice from NDIA Head Office around the development of protocols relating to the boundaries between the NDIS and other mainstream sectors. The lack of consultation meant that expert guidance from the various mainstream sectors had not been utilised and could prevent effective cross-sector approaches to support people living with disability.

*I've got to tell you I get a little bit angry when I think about those processes... because the NDIA do it in isolation. They are deciding what the interface between the Health and the NDIA looks like, from their perspective ... I've had numerous conversations. I can't say that I've ever got anywhere with them, but where it's a one size fits all approach, always, for the NDIS. This is the model. It was imposed. There was very little, well there was no consultation about how it was going to work. It was just 'Here you go, do it'. No nuanced sort of flexibility for a State like South Australia, which is fairly small [I] suppose again that just reflects this one way communication a lot of the time. We are always seeking information from them trying to, we're following up. It doesn't come in reverse very easily. (MS 05 SA H)*

- Other challenges for the interface between mainstream organisations and the NDIS included the perceived inflexibility of the NDIA, the overall complexity of NDIA processes, the increasing amount of bureaucracy within the system, and a disconnect between NDIA policies and how they are applied at the operational level by local NDIA staff.

*And the thing is, they are the NDIA; we don't know any individuals. It's this big, amorphous group [...] It's worse than Centrelink, and that's saying something. (MS 09 SA H)*

- These interface challenges were compounded by the regular turnover of NDIA staff:

*I've been dealing with head office in Geelong and I've just had the run around. Mainly because people have left. I get a relationship with someone and I've got a commitment we could develop some case studies that would kind of highlight the intersection between the post-secondary education and the agency. And they put some guidelines in place, but I kept not keeping the contacts, because they move. (MS 32 TAS E)*

*There has been quite a change in leadership at a regional manager level, so I think in the ACT there's now been three or four different people come and go in that manager role. So every time you feel like you've built a relationship and you're starting to make progress we feel like we're going back to square one. But at that operational level we've had some great connections with senior planners, and that's working very well; it's the relationship with the Agency is really difficult. (MS 21 ACT E)*

- Mainstream organisations reported that overall there were clear boundaries between the responsibilities of their sectors and the NDIS. However some unresolved issues remained, in particular around which sector is responsible for funding shortfalls.
- For the health sector uncertainty was expressed about what should happen in complex cases and chronic health conditions where there are grey areas around responsibility, and who is responsible for rehabilitation services. For example, there was limited clarity about the funding responsibilities for the various services associated with ongoing support of clients who presented initially with health problems (e.g. the supply of medical equipment, personal care and learning supports in schools and other services such as medication management and nutrition):

*There's a number of grey areas still, which there's still a lot of discussion about, and I think the burns rehab, obviously the acute treatment of a burns patient, I don't think there's any discussion. Everyone agrees that's a Health responsibility. But the long term rehab and equipment that might be needed to allow a child post a significant burn to attend school, they might need some specialist equipment for hand writing or a laptop or something like that. Whose responsibility is that? (MS 08 SA H)*

*So the challenges come down to definition as to whether it's a disability support and when it's a health support. So the example that we talk about commonly are nutrition and the provision of feeds and consumables associated with feeds, or continence equipment and the provision of consumables associated with continence equipment. There's a list of sort of six or eight regular medication management, those sort of things come up. (MS 20 NSW H)*

- Issues with boundaries were also identified in the mental health space where confusion persisted around whether rehabilitation for psychosocial disability should be seen as a process of recovery or long term support.
- Areas for confusion were also highlighted by respondents from the education sector. Most significantly was the lack of clarity in relation to funding school transport, personal care in schools and allied health services for students during school time:

*We're trying to work through with the agency where we say, 'Well, here's our eligibility for special needs transport, and it seems quite in line with your reasonable and necessary but there may be some differences, and what does that mean for the long-term viability of the service if you're not [going to] fund a whole heap of kids? And we've committed a certain amount of in-kind funding around the fact that we think it's this many students, if you're going to sort of cut that in half and not give transport to half of them, what does that mean?' So, it's all those things. It's a bit up in the air. (MS 11 ACT E)*

- These boundary issues were exacerbated by a perception that NDIA staff lacked understanding of mainstream organisations, a lack of shared language between mainstream sectors and the NDIA, and inflexibility from the NDIA around these boundary issues.

### 9.3 Change in Supply and Demand of Mainstream Service

- Since the introduction of the NDIS, it was observed that some state governments had withdrawn from disability service provision as had some mainstream organisations. In part this was attributed to the cashing out of services and to the feasibility of continuing service provision, given that it is not the core function of these organisations. Another consideration for mainstream providers was difficulty of NDIS processes for registering as a provider.

*As we've progressed through our registration process for becoming a provider I found that if there's a problem with the application or information that's missing there's no, the communication is not two way. So I put our application in, I understood it to be complete, based on the work that I'd done. And heard nothing and heard nothing and heard nothing and heard nothing. And spent the best part of the last six months of last year chasing. It took from July, June until November to get our first registration through and that was the dietetics one and that was a very straightforward registration. It didn't require any registration under the Disability Services Act, or any accreditation. That's through now, but that, nobody could tell me why it hadn't been processed and nobody returned my calls. (MS27 VIC H)*

- Overall, most mainstream organisations continued to provide some services under the in-kind arrangements set out in the bi-lateral agreements between the NDIA and the state governments. A number of these organisations acknowledged that the NDIA had exerted pressure to end in-kind arrangements. This was despite practical problems associated with doing this including maintaining the continuity of service provision for those not eligible for the NDIS.

*So there's been a certain amount of pressure to cash out. Because the dollars have been promised or have gone. (MS06 SA H)*

*More recently, equipment schemes across the country, including ours, have been requested by the NDIA to buy our governance arrangements, so around the provision of equipment. (MS14 ACT H)*

- A number of challenges in managing in-kind arrangements were noted by mainstream organisations. These included changes to the portal that impeded the ability to monitor in-kind arrangements. A lack of communication from the NDIA about the transition from in-kind to cashed-out arrangements was reported and organisations were therefore unaware that they were no longer operating under the in-kind arrangements. In-kind arrangements were also evidenced to result in a duplication of services when NDIS participants were not aware of the services they were receiving as a part of their plan.

*Some clinicians were saying that they, there was also a lack of understanding on the client's behalf about what they were receiving from who and so sometimes they would go to their NDIA planner and say 'Well I get this from Health' and so it would be left out of their plan, when in actual fact the service that Health was providing was on behalf of the NDIA. And so that we've actually had to instigate plan reviews to be able to say 'Well actually you've left this out. It's not a Health service that they were receiving. It was actually an NDIA service that Health provides on behalf of the NDIA'. (MS05 SA H)*

*The way the in-kind model should work is that we draw down on the money on paper, and as each child transitions that bit of money goes, and you don't lose the whole lot at once. But we have only had less than 25 per cent of the children on plans. So the reasons for that have been: the slow transition of children to the Scheme; the lack of awareness or understanding of families that they need to even put this on their plan, so there's been a lot of education, contacting families, explaining to them 'When you do your plan you need to ensure this*

*program is on it'. We are continuing to deliver these programs even if they're not on the plan so these children can get to school and so on, but strictly speaking if we were to cash out we could not provide the service. And the third problem is that the planners themselves don't know that the program needs to be on the plan. (MS06 SA H)*

- A number of changes in service provision from mainstream organisations were observed, particularly by those in the health and education sectors.
- Demand for sole provider therapy services were observed to have increased under the NDIS, in part driven by the closure of some state disability services. Mainstream health organisations also reported that some of their own staff had left or reduced their hours to establish sole provider therapy services.

*A lot of support was provided to help the staff there to transition to move out of [GOVERNMENT DISABILITY PROVIDER]. A lot of them have gone into private practice to support the client group they were previously seeing and are working for private industry now. (MS17 ACT H)*

*There's also a temptation though for our staff to go and set up private practices as well. We've had a number of our staff leave or reduce their hours to go and set up private practice, that number has increased. (MS08 SA H)*

- Mainstream health organisations had also experienced an increase in demand for services, especially ECEI services and assessments, particularly in regional areas. As a result of this increased demand, concerns were raised about the crowding out of other clients from accessing mainstream services.

*I think where they were just taking on more than what they would have, and what that actually meant is that other people who would, other children who didn't have a disability, who would have had some sessions of therapy or whatever in outpatients, weren't getting a service. (MS05 SA H)*

- Education organisations experienced increased demand for therapy provision within schools.
- This level of demand for therapy provision created conflict for schools, whose priority was to maintain their duty of care and their educational obligations for students. Having these providers on site in schools introduced an administrative burden for staff both around managing these visits and ensuring that the provider had all the necessary security clearances to work with children. It also stretched already constrained space resources. In addition, taking students out of class for therapy sessions decreased the time available for their education and was disruptive not only to the student receiving therapy services but also to others in the class. As a result some schools were opting to cease allowing therapy provision.

*Space in school is sometimes at a premium and then if they are using an office space that then can't be used by one of our own school psych's or speech and language pathologists and the costs around that sort of access need to be considered. (MS39 TAS E)*

*Look to my mind it's probably the access of NDIA funded therapists, and I'm predominantly speaking about allied health professional wanting to access students during school hours and on school grounds. So it's the role that those therapists play. And it sometimes comes down to, well there's obviously legal issues at play around supervision, the purpose of the therapy, and whether the school really is the most appropriate place for it to occur, and then obviously*

*the school's obligations around duty of care not for that, just to that student but also to all other kids in the school. (MS31 VIC ED)*

- In addition, higher education organisations reported an increase in demand for modifications and equipment to enable students with disability to access their services.
- Meanwhile child protection organisations described an increased demand for case management to assist their clients to navigate the NDIS. However concerns were raised that the skills required for this form of case management were outside the skill set of most of the social workers who typically provided this service.
- Employment organisations observed that they were yet to experience any real change to the demand for their services as a result of the NDIS, as employment was not yet a focus for most NDIS participants. However, they expected that this would change in the future as participants progressed through the NDIS.
- Although no evidence was collected about how the NDIS had impacted upon demand for crisis services, several barriers were identified in relation to accessing these services. First, delays in NDIA processes had resulted in a bottleneck of participants in the acute hospital system, placing pressure on already constrained resources. Second, concerns were raised about access to funding for accommodation as a result of boundary issues between the NDIA and mainstream services.

#### **9.4 Service Gaps**

- Overall, mainstream organisations felt that the NDIS supported greater access to funded supports and services for people with disability. A particular success, according to health organisations, had been the increase in access to early intervention services, which was facilitated by waiving the assessment requirements for children with developmental delay who were below school age.
- However, a number of service gaps were identified in relation to the living conditions and circumstances for people with disability. Concerns were raised about children with disability being able to remain in foster care beyond the age of eighteen years without their foster parents needing to register as service providers. Similarly, concerns were raised about the lack of funding for accommodation for children living in voluntary out of home care resulting in families having to cover this cost. Mainstream organisations identified service gaps around access to respite, Home and Community Care (HACC) services and equipment, and raised concerns about who would fund home modifications in the future. It was also noted that some providers were now charging for services that were previously free (such as builder who provided quote for home modifications).
- Other service gaps identified by mainstream organisations related to people with specific types of disability and the circumstances of individuals with disability. In particular it was identified that service gaps existed around mental health services, prosthetic services, and rehabilitation for people with brain injury. In addition, service gaps were observed for those not eligible for the NDIS, including refugees and New Zealand citizens residing in Australia, and long service delays were experienced by participants being assessed for eligibility and awaiting plan implementation. Health organisations also observed that due to the increased demand for therapeutic services as a result of the NDIS, clients who were not eligible for the NDIS experienced additional challenges in relation to accessing services.

*If you keep clogging with the kids who could be seeing NDIS you don't see the kids who aren't NDIS and just have a problem with one area of development or whatever. So some of them are getting some service downstairs, but quite often they're getting nothing. And if we assess a kid and say they have autism, OTs downstairs won't see that kid because they're eligible for*

*NDIS occupational therapy. So they'll assess them if we put them in there before their autism assessment, but they won't assess them after it...And they won't provide therapy once the diagnosis of ASD is made, and they're clearly eligible for NDIS. (MS09 SA H)*

- Delays were experienced by participants as a result of the length of time taken to undergo eligibility processes, getting a plan developed, and having their plan implemented. These delays resulted in longer waits for participants to receive necessary services and supports. Delays due to NDIS processes were also creating bottlenecks in mainstream services and contributing to service gaps.

*We've had patients on the ward having submitted their applications and waiting for NDIS to come on board, and then they've sat in a hospital bed for over 12 months. (MS22 ACT H)*

*I've had young children, three or four years old where they've said, 'Twelve months later we still haven't met with a planner.' (MS09 SA H)*

- Duplication of services was identified by mainstream organisations in two areas. First, it was noted that confidentiality processes prohibited mainstream organisations from receiving information about which of their clients were receiving NDIS funding. As a result, issues around the duplication of services for participants were experienced. Second, a higher education organisation identified that NDIS-funded plan management in relation to education goals was duplicating supports provided by their own staff.

*The other thing is just all communication. Like people have a plan, and we don't know what, who their care, they come in to have an appointment with us, or have an admission to us, and unless the patient tells us, and we have absolutely no idea of their plan, who their case coordinator, so we end up duplicating it because we don't know whether they're in NDIS. There's nothing that tells us they're in NDIS. Completely reliant on them or the carers to actually tell us and even when they tell us they might not tell us all of it, and so we have no visibility at that they've been accepted, there's no feedback to us at all, whether they're eligible. (MS 22 ACT H)*

*One of the other issues we've got is that we've got someone there for example who's been there for six months, they go off and they actually have their planning session and there's a plan, but we don't know about that. So the person's in our facility, we're trying to organise discharge into the community but we don't know that they've actually got an existing plan, because we weren't involved in the process. (MS 16 ACT MH)*

- Mainstream organisations identified a number of factors that they felt contributed to these gaps in service provision for people with disability. These factors included boundary issues and conflict between the NDIA and mainstream organisations around their responsibilities, poor communication between the NDIA and mainstream organisations, and also delays in referrals and the ability of NDIS participants to be able to access services as a result of NDIA processes. For example, many respondents made reference to the long delays occurring between the time that participants applied to access the NDIS, to the time that their eligibility was ascertained, and again until planning commenced. These delays were perceived as potentially compromising service provision and health outcomes for individuals living with disability. Delays were also impacting on the ability of NDIS participants to be discharged from mainstream services which was creating a bottleneck effect. This bottleneck was particularly noted as occurring in the health interface.

*We're talking fairly quickly into that and making that phone call to the NDIA and as much as you can getting on to a planner, but there's delays in all of that. As you know, there's delays in getting through to the National Access Team for a start. They say they'll call back, and they*

*don't. We've got a family sitting in hospital waiting for a phone call from somebody and they don't call back so we spend a long time, so we've just recently had a child who waited six weeks just to get the access request form sent to them. So they can't even get past that first step in the process. (MS 08 SA H)*

*Our own allied health is having difficulty keeping kids who are eligible for NDIS but not receiving NDIS, so there's this backlog that kids are being assessed, diagnosed, getting to the NDIS waiting list, and then being left in limbo for a year. And the other impact has been our ability to, what do you do when you're waiting? There seems to be less and less options for families to access affordable therapy services while waiting for their NDIS package. (MS 09 SA H)*

- It was observed that the NDIS had resulted in longer outpatient waiting lists and lengthier hospital stays for clients due to delays in transitioning people into the NDIS and therefore enabling them access to necessary services.

*This has been a huge backwards step really for the way that we have operated for children with disability with complex health needs. In terms of our, from a hospital to disability interface in terms of our ability to move children through the system, that is hugely backward. (MS 06 SA H)*

*...there's increased length of stay. I mean yes it's an impact on us but from my perspective it's the impact on the client which is the hardest. (MS10 SA H)*

*We actually started collecting some stats like waiting list data in outpatients, and we started to collect some information about length of stay in hospital, and we did actually notice a demonstrable increase in length of stay in hospital because it was taking so long to negotiate the system and to transition people out of hospital. Our waiting lists in outpatients also blew out to the point that I was really concerned that we were, the staff in some of our outpatient areas were starting to provide services to people that they would never have usually provided services to, because they were concerned that their delay was going to be impacted, like impounded, I suppose, compounded, because there was such a delay in that access to services through the NDIA, which me, from a purist inter-government relations perspective, went 'Please don't, because what the NDIA is then going to do is point to us and say 'Hang on, you've been providing that service to that person, you should continue from a continuity of care perspective, you should continue to provide that'', and it's like 'But hang on, we're only providing it because you're taking so long to provide your services, we're providing a stop gap'. (MS05 SA H)*

- The potential implications of delays for early intervention services on outcomes for children with disability were also highlighted.

*The timeframes are so exorbitant as well. I mean we've got some children that have been waiting so long that early intervention isn't really [laughs] the right term because they've actually been waiting so long. (MS 13 SA E)*

- In order to overcome some of these service gaps, mainstream organisations acknowledged that they continued their in-kind service arrangements with the NDIA beyond their original agreements. In doing so, they hoped to minimise the impact of these service gaps on their clients.

*And for a while we did the 'We'll advocate within NDIS for you ' and that failed, and so now we've actually put in non-funded services to meet this growing need of people and I think*

*they're the tip of the iceberg, because we don't do it for the adults. We're only doing it for children. (MS22 ACT H)*

*It's actually recognised now that it's not just about who gets access, it's about all the people who don't get access and as part of mainstream we have a responsibility under the bilateral agreement to obviously provide services to those people who don't get access, but also where people don't get access to the full range of services that they might need, that the state also has a role to play in terms of continuity of care. (MS15 SA H)*

## 9.5 Impacts on Referral Pathways

- Referral pathways from mainstream organisations to disability services prior to the NDIS were observed to have been collaborative and to have worked well. While these networks were largely informal and had been developed over long periods of time, they established practices for referral which were clearly defined and efficient.

*I know that there were a lot of good relationships on the ground between clinicians in hospitals and outpatients, and local disability service providers, that were just a series of networks and protocols that they had developed over time and that just worked very well...And what I observed when the NDIS came in is that a brick wall went up in all of those, that all of these networks that people had just had to stop. (MS05 SA H)*

*We did have things like actual protocols which talked to the expectations of Victorian Disability Services system where people were ready for discharge, and what exploration of disability supports we would undertake.... So there were clear authorising documents and clear procedures in which the systems could talk to each other and know how to, expect a response. That of course needs to all be rewritten, and there is absolutely a reluctance from the NDIA to look at protocols to that, or even we don't call them protocols, arrangements, whatever they could be, something which describes how we work together in those typical circumstances. (MS 25 VIC H)*

*They worked very well. They were really smooth. So what we would do is obviously we had two service providers, [NAME OF NGOs]. Or if they were a child with a physical disability we would go to [NAME OF NGO]. If it was early intervention or more of an intellectual disability it would go through [Name of NGO]. We'd ring the service provider, we'd get the forms. We would do the referrals. You know if it was [NAME OF NGO] they'd actually be out here the next day meeting the child, meeting the family, therapy would start, a smooth transition from hospital to home having those service providers in place. (MS 10 SA H)*

- With the advent of the NDIS these referral pathways had been disrupted and many considered that the interface with the disability sector had gone 'backwards'.

*[Prior to the NDIS] we had fairly good systems that were quite responsive. This has been a huge backwards step really for the way that we have operated for children with disability with complex health needs. In terms of our, from a hospital to disability interface in terms of our ability to move children through the system that is hugely backward. (MS 06 SA H)*

- Indeed several respondents reflected that the loss of pre-NDIS referral pathways had disrupted contact between services and clinicians. Indeed the loss of these relationships impeded what mainstream organisations referred to as 'warm referrals' (MS06 SA H) in which clinicians would facilitate the transition from mainstream services to disability services and provide personalised handovers, rather than placing the responsibility for navigating the system on the person with disability and their family.

*It's a fundamental change to the way people access their services. It's not about service providers talking to each other and providing a handover of information, it's about the client seeking services, the client having to go to the NDIA, having to get a plan, having to negotiate a plan and having to then choose the services that they access. It's cut off the ability for service providers to be able to talk to each other to be able to hand over information, and our clinicians found that very frustrating [...] So previously they would have phoned somebody, said 'I've got this person here', and they could have done a direct handover, but they can't do that anymore. (MS 05 SA H).*

*Clinicians had a role in referring to providers. That's been a fundamental shift with the NDIS because it puts the choice and control in the hands of the family, which is good from a philosophical point of view, not necessarily practical [...] at the point of referral the clinician, the clinician would make contact with another clinician. It would be service to service, to say 'Here we've got [name] who's coming to see you. We want to refer him to you. These are his conditions, dah, dah, dah, dah, dah, dah, dah, and particularly note this, this and this' and it's sort of warm referral as opposed to this up to the parent to then go and find someone. (MS 06 SA H)*

- There was, however, some suggestion that 'work arounds' and personalised relationship building with the NDIA at the local level had started to happen.

*I think the people on the ground are starting to develop local relationships and they're starting to develop work arounds to the system, so that they can talk more openly. The people at the start were very purists and saying 'No, we can't do this. No, we can't talk to you. No, we can't do whatever' because they were rolling out a purist model. And I suppose in many ways, shapes and forms that's still there because the NDIA are very clear about what their remit is and what they will and won't do. But what I'm observing is that clinicians on the ground are still developing their relationships, 'Oh no, we shouldn't be giving you this referral form so that you know what's in it but if you could be completing this information and giving it to us well that's going to help the NDIA to be able to make a decision'. So I'm seeing far more work around type situations developing through relationships that are being built now than what was possible in the early days. (MS 05 SA H)*

- Under the NDIS, referral pathways for those who were already receiving services and simply needed to swap their funding provider were reported to have been less problematic than referral pathways for people with disability who had not previously received services. For this latter group, it was observed by health organisations that a number of their clients had needed assistance from frontline staff to navigate NDIS eligibility processes.
- A number of challenges were identified in relation to the effectiveness of the referral process to the NDIS, including difficulties contacting and communicating with NDIA staff, a lack of feedback about eligibility outcomes, delays due to NDIA processes, and the loss of pre-NDIS relationships between mainstream and disability providers.

## **9.6 Individualised Funding**

- Although mainstream organisations supported the philosophy behind the NDIS model of individualised care and welcomed improvements to funding and the individual's choice and control over their services and supports, the fit between their programmatically funded services and the individual funding of the NDIS was not without its difficulties.

- Mainstream organisations observed that the NDIS had created extra work for their administration and frontline staff such as having to learn the new systems associated with the NDIS. For those organisations providing services under the NDIS, gaining access to the portal had also required costly IT changes.
- Mainstream providers reported that they were spending more time engaged in case management activity. They observed staff devoting more of their time to supporting clients to navigate their interactions with service providers and with the NDIA, as well as advocating for clients around their funding needs. In some cases mainstream staff had to upskill their knowledge in relation to working with people with disability in general or with new types of disability, and also around NDIS processes. Conflict between the ethos of the new NDIS system and the values of mainstream staff arose when there were concerns about clients not receiving the services they requires.

*In terms of our clinicians, there's definitely a massively increased workload in terms of advocating for them, trying to educate them, trying to support them through the processes. (MS17 ACT H)*

*That's been a huge shift I think for the staff as well that it will be one of the unintended consequences I would think, where there hasn't been appreciated the impact of staff, and it's not about control I don't believe. I think it's about duty of care. For staff they want to be able to hand over their client to somebody else and know that they're being picked up and cared for. I think it's been hugely challenging for staff to say 'Okay, here you go. Here's, this is what you need to do. Maybe I can help you with this process, because I'm really concerned that you're not going to be able to do it yourself. Let's go through this process. But then basically you're on your own. (MS06 SA H)*

- Mainstream sectors and organisations identified several examples whereby collaboration within service provision had been compromised as a result of the NDIS. It was noted that in the health sector multidisciplinary care teams were no longer able to be supported by available funding. The establishment of a market approach to service delivery was perceived to have introduced a competitive environment that further obstructed collaboration between the sectors.

*We still have a good working relationship with [NAME OF NGO], because we've got a long standing connection with them. But I think it will change over time as they become more like a large private competitive provider. (MS06 SA H)*

*Once the NDIA came on board, [NAME OF NGO] became very aggressive in their marketing and withdrew any services or any involvement or discussion with us, so became a competitor in the market. (MS07 SA H)*

- However, an example of new collaboration was also identified, between educational organisations and the NDIA. An education organisation described their involvement in the School Leaver Employment Supports (SLES) program, in which the school and the NDIA collaborate to provide supports to participants undergoing the post-school transition into employment.

*It's new, and it's actually a bridge. So the Commonwealth have their employment programs but they've introduced SLES as a two year interim period when the child leaves school, although they do the assessment prior to, to actually get supports in place. But it's for the two years after school if they need additional assistance I guess to transition them either to work or transition them onto their traditional employment network programs. (MS13 SA E)*

## 9.7 Equity, Fairness and Navigating the NDIS

- In general, mainstream organisations considered that the impact of the NDIS for people with disability and their families was largely positive. Many representatives from mainstream organisations felt that people with disability had greater access to, and choice and control over, the supports they needed under the NDIS.

*I think it's just opened up opportunities that may not have, or that may have happened, may not have been particularly evident before. (MS38 TAS)*

- A number of mainstream organisations acknowledged that although they had witnessed considerable issues with the NDIS, this was in part because their role placed them in a position to capture instances where the system was not working well and also because participants were still in the more challenging stage of transitioning between systems. Most anticipated that once properly established, the NDIS would greatly benefit people with disability and their families. However there were some design flaws that needed to be addressed before this could fully transpire.

*There's the experience, I think, which has been particularly rocky and the work around troubleshooting plans or the access process whatever, haven't been ideal. But again, they're things which I think will settle in time, and a full Scheme, you won't have the surge of transition, so I guess you could run an operating model more consistently. But this is, I think, we're trying in this conversation to separate transition issues to full Scheme design issues, and I think the design issues are the national consistency is a significant one that won't be resolved if I can't see a design structure yet. (MS25 VIC H)*

*We mostly hear the bad stuff, so, there's been real issues with the agency's communication and planning processes.... you've got to separate the transition issues which the agencies have against the broader impact, and I think also the Scheme has sort of been, it's a disruptive implementation, it's purposely on services and meant that there's been quite a bit of innovation too, and new thinking, and I think that's been really good, too, and people have got some creative results, if they can tell, I don't mean this in a make-it-up way, but they need to tell their story in the right way to the agency, about what they want and their situation, and a lot of them probably need continued support to do that through advocacy and other things, so, I think we spend our days dealing with some of the issues we've got to work through, but overwhelmingly, you've got to say it is all ready and will be a very positive social change. (MS24 VIC DPC)*

- Mainstream organisations were concerned about those participants who were less able to advocate for themselves. The consumer driven model implemented by the NDIS required that the person with disability and their family have a clear understanding of both the NDIS and their own support needs and the ability to articulate those needs to NDIA staff. Moreover participants and their carers needed particular resources including the time, energy and the means (e.g. access to the internet and the ability to afford clinical assessments for providing proof of eligibility) to actively engage with the NDIS. It was identified that the NDIS worked less well for CALD and Aboriginal and Torres Strait Islander participants, those with high support needs or limited capacity, and those who were newly diagnosed or had recently acquired a disability.

*A family cannot be expected to sit down with a planner and talk about their goals and aspirations and dreams for their child, when they've just arrived here. They have no idea what services available, what their child even needs, what they're entitled to. It's just hugely problematic for CALD families. (MS06 SA H)*

*You know it's all well and good the way they've rolled out the Scheme for consumer control, but someone who broke their neck two days ago can't tell you squat about what they need, they just can't. And in fact in a lot of ways it's almost cruel to sit down and ask them that...And that's really the skill of the health service is to support that, you know to support that information sharing and gathering and that sort of thing. So, and like I said this wheel has been invented several times. It's in existence, there's plenty of places to learn from. I'm just, I'm really, really hopeful that that message gets across to the NDIS and they take some learnings from some of that. (MS28 VIC H)*

- People with disability living in regional areas were also identified by mainstream organisations as being a group for whom the NDIS was not working well. This was attributed to the lack of a provider market, and to difficulties with engaging with the NDIA as a result of limited access to the internet.
- Mental health organisation also expressed concern about the ability of the NDIS to be responsive to people with psycho-social disabilities.
- Many respondents were also concerned about recent changes to the way in which initial planning and plan reviews were being undertaken. Undertaking these processes via phone was noted as detrimental particularly for people with mental health disabilities or those from remote areas:

*The expectation that plans happens, either going to happen online or by phone, is certainly not a good way to go for many of our rural and remote clients. (MS 07 SA H)*

*Recently the planner just sort of said, 'Wouldn't it just be easier if we do it over the phone and do a quick review just to get you by and get the child out of hospital and we'll review again in April?' And went you're working with parents with mental health conditions or - you actually cannot do it over the phone. (MS 10 SA H)*

## **9.8 Recommendations for Change**

- Although mainstream organisations were generally satisfied that the NDIS had had a positive impact on participants, they also highlighted a number of areas where the NDIS could be improved.
- The speed of the roll-out and the associated pressure this placed on NDIA staff was identified as having had a negative impact on the implementation of the NDIS. As a result mainstream organisations felt that the quality of services provided by NDIA staff was impeded and that systemic issues identified during the trial phase of the NDIS were not addressed before the roll-out of the full NDIS was initiated.

*The surprising thing is how little continuity, or rather how little things have been learnt in the trial. So there was never an opportunity for the Department to catch breath, or the NDIA more to the point, and say, 'Right, we've ironed out all these problems in the trial. Now the full-scale rollout will be a great deal smoother, won't it?' It has not been like that at all, like starting from scratch again, and the momentum that is building up now is, everybody, what is the word, reeling? (MS25 VIC H)*

- A further concern about the implementation of the NDIS was the complexity of the systems associated with the NDIS and the difficulties that people with disabilities experienced navigating the system as a result. These difficulties were also experienced by mainstream organisations in relation to their own interactions with the NDIA, either as mainstream providers or as NDIS registered disability service providers. A lack of communication and feedback from the NDIA exacerbated these issues.

- Mainstream health and mental health organisations raised a number of concerns about the quality of service provision as a result of the NDIS. The first of these concerns related to the observation that as a result of delays in obtaining NDIS plans, mainstream organisations were filling service gaps and providing services to cohorts of people with disability that they had previously little experience of working with. It was acknowledged that mainstream staff often lacked the disability specific skills required to deliver quality services to these people.

*I mean one example is kids with Down Syndrome, they always went, almost at birth they were transferred. We never actually saw those children. They went immediately to [Disability service provider name]. We never actually saw them. But now we have currently got six infants that we are seeing while they're waiting for planning meetings. Now historically my staff would never have seen them. And do I actually think that's, it's a risk because we really shouldn't, we've historically haven't seen those children. (MS08 SA H)*

- Furthermore, the marketisation of disability service provision had resulted in some providers either not having the appropriate skills to work with, or choosing not to service, more complex clients. It was observed that these more complex clients then inappropriately ended up in mainstream health services.

*We've had evidence of cases where the client becomes too complex in the community and there's a decision made within the organisation that they can no longer provide that support, and they bring them to hospital and that's where they withdraw from care. So then we find ourselves that with people in our acute system that we're not able to discharge because they're complex, and there's really no services that are happy to I guess provide the support for that complexity when they're getting the same rate as providing support for someone that's probably less complex and very easy to work with....the cherry picking isn't it, that kind of 'We'll take the people who are much easier to manage'. (MS29 NSW MH)*

- The second issue raised in relation to service quality was that of quality control and regulation of the market. Mainstream organisations identified the need for accreditation within the disability service sector. However, they cautioned against repeating existing accreditation already being undertaken by organisations which had the potential to create an administration burden to managing multiple accreditation frameworks.

*There's a lack of clarity around how they're going to manage quality going forward at the moment, which we've got on our radar. Because we will really need to take that into consideration as we grow our services under the NDIS...Well we're already subject to a range of different accreditation standards, because of the services that we provide, and the NDIS will be another one. And as I'm sure you're probably aware there tends to be a lot of similarities across those accreditations but not a lot of consistency. So the admin burden is significant. And this will add to that. (MS27 VIC H)*

*That I think is a major issue and we're dealing with sectors in many cases that have never actually had to go through quality assurance themselves. Is there going to be an accreditation framework? How is that going to be managed and undertaken what are in many cases are vastly different types of service, mental health versus chronic care, versus social care? What accreditation framework is going to be used to determine good from bad providers? (MS40 TAS H)*

- Mainstream organisations recommended better collaboration, communication, and information sharing by the NDIA and between sectors. They felt that this would help smooth the transition for clients into the NDIS and later transitions into education, employment and health/mental health services.

*I feel extremely confident that any degree of resource that's available for health services needs to be put into communication pathways. We need people, we need bodies, we need brains who can liaise with health services around these very specific issues and needs and it's, the needs not of the health services but of the participants who are stuck in the health services, and they need to start their day in a hospital and get this information and they need to in the afternoon go to some NDIS office and do the things that they do and process it and then come back the next day and this is what it takes to move these things along. (MS28 VIC H)*

- It was also recommended that measures were taken to improve the accessibility of NDIA staff for people with disability and their families. In particular it was identified that assistance was required around helping people to navigate the NDIS system.
- One suggestion for improving the process of transitioning people into the NDIS was to embed NDIA staff in hospitals and schools to facilitate entry into the NDIS and to expedite more complex cases where needed.

*Having somebody come in a couple of times a week who we could ask, families at least, the other day because we've had a couple of inpatient and refugee families where we've been working very closely with them, said 'While you're here, we want you to see this family and can you also bring the forms for this family' and so we've been able to do it as a, because it's worked, and we've pulled it all together. But we could do that more often if they were a presence here. (MS06 SA H)*

*I think they should actually put one of their staff members in the hospital, and I think it would actually almost be a full-time position. Because there's a huge clientele that come from here, and I have proposed the idea to them, and even through the clinical partner model I think that they could have someone on site, but they sort of half warmed to the idea through the clinical partner but we haven't heard anything further. (MS08 SA H)*

- Better education for people with disabilities and their families about NDIS processes was also recommended to help alleviate some of the difficulties created by unrealistic expectations about the planning process and supports which could be funded.

*I think a lot of the issues that the parents may have had have been because they haven't fully understood the process or they've had some misinformation and gone into meetings expecting something and it hasn't happened. (MS23 ACT E)*

- A further suggestion made by mainstream organisations was to increase the involvement of mainstream professionals in the planning process to allow them to advocate and provide expertise. This was thought to be important given the vulnerability of some people with disability who may be unaware of what supports they need.
- For those who already had an NDIS plan, it was proposed that it would be beneficial to increase the use of plan managers to assist people to navigate their services. However in doing so it was cautioned that the use of case management needed to be implemented in an effective and efficient manner to ensure there was no doubling up on assistance already being provided by mainstream services.

*Like an example I've got here is a student who I've dealt with the last year or two and she has now moved on to campus this year, and so she's got an insurance scheme and she's got a case manager. And so they became involved and it just seemed to be duplication, because I was there providing advice and the Uni was there providing advice, and then this person was*

*coming, and she seemed to come to meetings where I didn't think she needed to come to meetings, and I could just see it as a making of money because every time she came, ching, ching. The money adds up. (MS32 TAS E)*

- Recommendations for improvements to the NDIS at the broader systemic level included the need for more assistance for mainstream organisations preparing to register to deliver services through the NDIS and, within the employment sector, the need for more integration between open and supported employment programs.

*They talk about one of the biggest risks to the success of the NDIS being workforce and the availability of services for clients, and that's based on the results of the trial sites. We're desperately trying to become a service. And if that's flagged as one of the risks then I think they should be putting some effort in to making sure that those services that want to come online can come online. (MS27 VIC H)*

*From a big picture policy position, should there be one gateway into employment for people with disabilities, and that's possibly through some sort of common assessments that's done for everyone that there's supported employment, this door, open employment, that door. But it's all done in more consistent and coherent way, because it seems to be at the moment we're going to have, well, at the moment I don't think, we've got two programs in DSS that don't talk very well to each other. (MS30 NSW EM)*

## 10. Older People with Disability

### Summary of findings

This section summarises the qualitative findings relating to the funding and provision of disability supports to older people with disability.

The Older People with Disability study finds that:

- the NDIS has a clear positive impact on older participants;
- both the aged care reforms and the NDIS roll out are pushing in the same direction of person-centred and consumer-directed care, making comparisons unavoidable and offering opportunities for synergies;
- the NDIS funding levels are higher than for the aged care and state disability systems, as is satisfaction with supports quality, and access, giving rise to concerns about overall fairness;
- instances of unmet demand were reported following difficulties with plan implementations, poorer access for specific minorities and the need for additional specific services;
- both disability and aged care support sectors are undergoing intense change and development, with some uncertainty as to how they will co-exist in the future;
- the extent to which the aged care sector has the capacity, skills and funding to care for people with disability is an important question. Training for specific skills to care for people who are both older and with a disability is needed;
- the NDIS is increasing the choice and control of its older participants, but the main evaluation has shown that this impact is (among all participants) at its lowest for age 50+;
- there are broad concerns about supports being reasonable and necessary and the reported need to top up from other sources;
- uncertainty about NDIS eligibility, difficult bureaucracy and navigation through the system, lack of information give rise to feelings of unfairness and lack of equity for older people with disability;
- many aspects of the review process need attention and fixing. Reviews must not only be disability-appropriate, but also age-appropriate;
- broader concern arises among those older people who will not qualify for supports under the revised systems, with much fear about those who may fall between the cracks of the new system;
- the positive role of charitable organisations in looking after vulnerable older Australians with a disability is mentioned frequently, in the context of both the past and future of such provisions;
- the interface between the NDIS and several mainstream sectors that are important for older people is also a source of uncertainty and anxiety about the future; and
- overall, older people with disability are going through a period of change and uncertainty. The NDIS is presenting modest improvements and some optimism, but the big picture remains uncertain and precarious for some of the most vulnerable older Australians.

### *Supply and demand of support services*

- The NDIS was found to have a positive impact on the supports of older people with disability, including a greater focus on person-centred supports and the development of new services. Similarly, the move to greater consumer-directed care within the aged care sector was leading to changes in the types of supports provided to older people with disability. Concerns were raised,

however, about the future provision of services for older people with disability who were outside both the NDIS and the aged care funding streams.

- Higher levels of funding were available to participants in the NDIS compared to the aged care and state disability systems. Under the NDIS, both the level and types of supports available to many older people with disability had increased. In contrast, the aged care system offered home care packages for a prescribed amount which were often considered insufficient to meet the care needs of many older people with disability. Meanwhile, in the state-funded disability systems, access to funding and supports was perceived to be highly variable.
- Most older NDIS participants were satisfied with the quality of their supports. However, some issues had been experienced around accessing services and the skills of disability workers. Older people with disability outside of the NDIS, and particularly those receiving services directly from charitable or healthcare organisations, also expressed satisfaction with the quality of their supports. Within the aged care and state disability systems, however, issues were noted with waiting lists, fees and charges, and the skills of workers.
- Some instances of unmet demand were reported under the NDIS as a consequence of difficulties with the implementation of planned supports. These difficulties centred on delays in service provision, a lack of registered providers or skilled workers, and issues over service agreements.
- Challenges were reported in accessing appropriate services and supports within the aged care and state disability system. Across all the different funding schemes, poorer access to supports was reported for those living in rural and remote areas, Indigenous and CALD people with disability, and for those needing short-term or episodic services.
- Improvements in the provision of supports to older people with disability in rural and remote areas, and those from Indigenous and CALD backgrounds was seen as being required. Issues around access to specific services (such as assistive technology, home modifications, short-term and episodic supports, specialist disability services and carer supports) for older people with disability in general was also found to need addressing.
- Additional funding to address the current and future support needs of older people with disability within the state disability and aged care systems was seen as being necessary. Moreover, assessment processes and the types of supports funded by the aged care system were perceived to require change to allow these to be more appropriate and responsive to the needs of older people with disability.

### *The disability sector and its workforce*

- The NDIS was seen as encouraging new providers to enter the disability sector. However, issues were raised as to the capacity of these organisations to provide quality supports to older people with disability. The aged care reforms were also leading to changes in that sector including organisational closures and mergers and also the entry of some disability providers into that sector. The impact these changes would have on service provision for older people with disability was as yet uncertain.
- The skills and ability of aged care workers to provide quality supports to older people with disability was questioned. Similarly, disability workers faced challenges in meeting the increasing healthcare needs of people with disability as they aged. Therefore, training which provided workers with more specific skills to meet both the disability and age-related needs of older people with disability was recommended.

### *Choice and control*

- We must recall that the main evaluation found that many of the positive outcomes of the NDIS were less prominent among those NDIS participants aged 50 and over. The comparisons in this Chapter are more specific and they concern only older people who are all either approaching the age of 65 or are already older.
- In general, older people with disability participating in the NDIS had greater choice and control over the content and provision of their supports compared to those within other funding streams. However, not all older NDIS participants had experienced increased choice and control; capacity building and assistance with planning processes was therefore recommended. In response to client demand, some provider organisations were offering more flexible and individualised supports to older people with disability.
- A lack of understanding of disability and the use of standardised assessments in the aged care sector was found to be leading to inconsistency of outcomes and the funding of inappropriate supports for older people with disability.
- Most of the older NDIS participants interviewed had not chosen to self-manage their funding and instead preferred to receive assistance with the management of their support arrangements. Those older NDIS participants who were self-managing either all or some of their funding felt that this had led to greater choice and control over the provision of their supports.

### *Reasonable and necessary supports*

- A majority of the older NDIS participants expressed concerns about the level and types of supports which were funded under the NDIS. Particular supports which were considered to lack funding included transportation, therapeutic supports, equipment and home modifications. Likewise, many older non-NDIS participants reported that the funding and supports they received were inadequate to meet their needs. These respondents were either foregoing needed supports, or were obtaining additional supports through charitable organisations or self-funding.

### *Wellbeing, social, educational and economic participation*

- The NDIS was seen to be improving access to supports which assisted the social and community participation of older people with disability. Access to these supports was perceived to be particularly lacking for older people with disability in the aged care sector.

### *Fairness, equity and access*

- Uncertainty around the NDIS eligibility of older people with particular types of disability including stroke, low vision and mental health issues was reported.
- Moreover the NDIS was seen as being bureaucratic and difficult for older people with disability to navigate. The My Aged Care system was likewise perceived to be difficult for older people with disability to understand and there was a lack of accessible information (particularly about disability support needs). In contrast, pathways to access disability supports directly from charitable organisations were perceived to be straightforward.
- While the ability to have regular reviews of planned supports was a positive aspect of the NDIS, issues were raised about review processes and outcomes. Concerns were highlighted that support needs were not reviewed adequately and having review meetings conducted by telephone was considered to be inappropriate for many older people with disability. Formal review processes for older people with disability outside the NDIS were lacking and adversely impacted upon the ability to have services reviewed as support needs changed.
- Greater clarity around eligibility processes along with adequate time, preparation and support with planning and review processes was recommended.
- Considerable variation in the funding and provision of supports to older people with disability was evident across the different funding schemes. Inequity was observed in levels of overall funding, the types of supports funded, expectations of co-payments, and the extent of choice and control. Older people with disability who were part of the aged care system were felt to be considerably disadvantaged compared to their counterparts in the NDIS.
- Additional funding to address the current and future support needs of older people with disability who were ineligible for the NDIS was reported to be needed. This included the continuation of block funding arrangements to charitable organisations providing supports to older people with disability. Ideally, a single funding system which provided funding and supports to all people with disability regardless of their age was recommended in order to address inequities across the different schemes.

### *Mainstream interface*

- The interface between the NDIS and the health sector was perceived to be unclear and adversely impacting upon the supports accessed by older people with disability. For some older NDIS participants, this had led to the refusal of funding for specific supports under the NDIS. Other older people with disability were reported to have been found ineligible to join the NDIS as their needs were considered to be primarily health rather than disability-related.

## 10.1 Introduction

Entry into the NDIS is available to all eligible people with disability aged 65 years and under. Existing NDIS participants who reach the age of 65 years may choose to continue receiving services under the NDIS or transfer into the aged care system. People who acquire a disability after the age of 65 years are ineligible to participate in the NDIS; these individuals will instead receive support from other funding sources such as the aged care system.

In this section we present key findings arising from the Older People Study. This study was an extension of the broader NDIS evaluation and sought to compare the supports and satisfaction of older people with disability who were part of the NDIS with those who were ineligible to join the NDIS. In-depth qualitative interviews were conducted across one wave with older NDIS participants (aged 59 years and above), older people with disability who were not NDIS participants (aged 64 to 75 years), representatives from provider organisations working with older people with disability, and representatives from key disability and aged care agencies.

As a standalone study, the Older People Study covered all relevant questions considered by the broader evaluation. In this chapter we provide a synthesis of the evaluation evidence around seven main themes relating to the supports of older people with disability. These themes include the supply and demand of disability support services; the disability sector and its workforce; choice and control (including self-management); reasonable and necessary supports; wellbeing and social and economic participation; fairness, equity and access; and the interface between the NDIS and other mainstream sectors.

## 10.2 Supply and Demand of Support Services

### 10.2.1 Disability services and supports - NDIS

#### *Supply of disability supports*

- Provider organisations identified a variety of services and supports accessed by older people with disability. These supports included community and social activities, personal care and domestic assistance, support co-ordination, allied health services, advocacy, accommodation services, and aids and equipment.
- The individualised funding arrangements of the NDIS had led some provider organisations to develop new services to better meet the needs and interests of older NDIS participants. These services included individual support, therapeutic services, group programs, community supports and skill development. The NDIS was also seen to be encouraging a move towards greater person-centred supports and the increased accountability of provider organisations to deliver positive outcomes for clients.
- NDIS pricing structures and the ending of block funding arrangements were impacted upon decisions regarding future service provision for older people with disability. Provider organisations were considering ceasing service provision in some areas due to perceptions of inadequate NDIS pricing. Underfunded services included group activities, individual support, volunteer programs and supported employment.

*We have had to think about what services we can offer based on the unit price that the NDIS is paying...We run a volunteering program in trying to do a small, in a small way trying to remediate social isolation that a lot of the population we work with experience. Under the NDIS there's no component or capacity for that volunteering program to continue to run, so*

*at this stage we're looking at essentially folding and hundreds and hundreds of friendships and relationships being left to sort of fizzle out because there's no support. (OPS06P)*

- A small number of providers had not made any changes to their service provision to older people with disability. This was primarily due to the continuation of transitional funding arrangements.
- The longer-term financial sustainability of the NDIS was a strong concern for older NDIS participants. Several respondents connected this sustainability with a perception that processes within the NDIA were overly bureaucratic, and that the NDIS was over-staffed and paying more than market price for assistive technology and home modifications. Some participants and carers therefore feared that the NDIA was either already, or would in the future reduce the level of funding offered to people with disability.

*I have a fear that the government will find it's costing too much and they'll start to cut back, and that'll make it difficult. (OPS16PWD)*

#### *Demand for disability supports*

- The level of funding available for disability supports within the NDIS was reported to be higher than in other funding schemes such as aged care and state disability. Furthermore, NDIS funding was perceived to follow a needs-based model which enabled older people with disability to continue to live in their own homes and pursue economic and social participation goals.

*Obviously it's a game changer the fact that it's a needs based funding model. It's not a, it's not a budget with a ration, you know in effect they haven't had to say well look we need to put that one on hold because we don't have enough resources. If it meets the eligibility criteria then it is actioned. So that's a game changer in disability and obviously across all types of supports ...There's no priority system needed because everything as long as it's eligible is done. So it's simpler from that perspective. (OPS11S)*

- Respondents considered the level and types of supports available to older people with disability under the NDIS had increased and these supports were focused more on individual needs and goals. Many of the older NDIS participants confirmed that they were now able to access more supports than previously.
- These supports most commonly included aids and equipment, household assistance and gardening, social and community participation, therapy services, home modifications, personal care and assistance with transportation costs. In addition, almost all the older NDIS participants reported receiving funded case co-ordination; on the whole, this support was found to be useful in navigating NDIA systems and arranging services.

*I didn't even know the terminology for the different services, you know, as they are outlined on the plan. And again [my case manager] explained that and again you need somebody to help you navigate through all this paperwork. And again I wonder for people who don't have those, you know especially people who don't speak the language well. (OPS07PWD)*

- In particular, the NDIS was reported to have improved access to assistive technology, home modifications, social and community participation, therapeutic and personal support. The ability to access fully funded supports and services (which required no client co-contribution) was seen as a further positive aspect of the NDIS.
- Improved access to supports for older people with disability under the NDIS was reported to be occurring for three reasons. First, the NDIS was seen as possessing a greater understanding of the

specific needs of people with disability compared to the more general aged care sector. Second, the NDIS was considered to have a more holistic framework than previous state-funded disability schemes, including exploring and addressing the goals of participants. Third, a more long-term view to disability support provision was seen to be occurring under the NDIS with, for example, the initial provision of more costly equipment and supports to increase independence and reduce the need for disability services in the future.

*Taking the longer term view that the NDIS does, so that's in relation to investing to offset longer term costs, they will take that position more readily than the states ever would. The NDIS is taking a more holistic view and going okay well look it may be that we provide a more expensive wheelchair with certain features because the business case is that that person then won't need the extent of attendant care hours or something like that and it pays for itself over a five year period. And so I think there's a lot more willingness to do that. (OPS11S)*

- However, not all older people with disability were receiving enhanced supports under the NDIS. Some newly-transitioned NDIS participants were reported to automatically be receiving the same supports as previously. This was in part to allow transitions into the full NDIS to occur in a timely manner. However, some respondents reported that this was allowing the unmet needs of people with disability (which had been unable to be addressed under the financial constraints of the state-funded disability sector) to continue.

## **10.2.2 Disability services and supports - Aged care system**

### *Supply of disability supports*

- Some provider organisations who had traditionally been working in aged care also reported that their supports for older people with disability were changing as a consequence of the aged care reforms and the move to consumer-directed models of care. This included the ceasing of day centre programs, the introduction of home care package provision and greater supports centred on individual needs.
- Provider organisations were also currently undergoing evaluation of the services they offered to older people with disability through aged care funding. These processes included consultations with their service users to ensure that supports were developed to meet client needs and preferences. Consideration was also being given regarding the ability to continue services that had previously been funded by block funding arrangements. Opportunities for mergers and partnerships with other aged care providers were also being considered.

### *Demand for disability supports*

- The level of funding available for supports for people with disability based in the aged care system was seen as being poorer than that available in the NDIS. Additionally, rather than being based on individualised needs, funding for home care packages was limited to set prescribed amounts. The size of these home care packages (even at the top package level, Level 4) were felt by respondents to be insufficient to meet the care needs of many older people with disability.

*Certainly the aged care system is not well set up to meet the needs of older people with disability...The top level funding is only around 40 something thousand dollars a year...Somebody living with relatively complex disability who is over 65 and doesn't want to move into residential aged care will struggle to get all their care needs met on a top level package. (OPS11P)*

- It was identified that some clients who had transferred into the aged care system had received less funding than under their previous state-disability arrangements. This had negatively impacted their access to disability supports. Likewise, several non-NDIS participants expressed a reluctance to join the aged care system fearing that their current funding and supports would be reduced.
- The amount of administration fees taken from aged care packages by provider organisations was a further area of concern as these charges reduced the amount of funding available for supports.

*[My aged care provider] charge you for administration. The package I think is worth \$1,000 a month, [they] take roughly \$500 out even if you do nothing, that's all administration. And if I wanted to change from [that provider] to another company, they charge \$500 to move, which to me is a rip-off. (OPS14C)*

- In addition, unlike in the NDIS, older people with disability within the aged care system were expected to pay co-contributions towards their supports. The capacity of people with disability (and particularly those with a longer-term disability) to afford these co-payments in order to receive supports was a key area of concern.

*People with disability are unlikely to have worked their whole life and have saved for retirement and have a pocket of money when they are entering the aged care system...So they're not in the same position to have any kind of savings to draw on in terms of co-payments and things like this...They're in a disadvantaged position from the get go. (OPS08S)*

- Over a third of the non-NDIS participant sample were currently in receipt of aged care services; of these, two were waiting for a Level four Package and were receiving limited supports in the interim. A further four respondents were in various stages of applying for aged care funding and services. The supports received under My Aged Care were fairly limited in scope and quantity and included cleaning, home maintenance, gardening, shopping, personal care and respite. Typically these respondents were receiving additional disability supports from charitable organisations and healthcare services.
- Older people with disability were reported to face challenges in accessing appropriate services and supports within the aged care sector. Aged care services were seen by respondents as having a focus on gradual decline and frailty, as well as the maintenance of physical function. It was therefore difficult for older people with disability to obtain specialised disability supports including those which focused on developing capacity, reablement and facilitating independent living.
- The availability of assistive technology and home modifications (and particularly more customised equipment and modifications) were seen to be especially problematic due to funding constraints and a lack of understanding of the support people with disability required. As a consequence, some older people with disability were experiencing lengthy delays to access these services. People with degenerative neurological conditions who may need urgent access to supports as their needs changed were felt to be particularly adversely affected by delays in service provision.

*The rapidly progressive nature of the disease [MND] means that any referral into My Aged Care needs to have a fast-track; something needs to be flagged and it needs to have a fast-track to the assessor, and they need always to be considered as needing the highest level of package being offered to them, and there needs to be somewhere along the line some provision for the equipment, the hire cost, high end equipment that people need...At the moment it's not set up to be able to accommodate people with a rapidly progressive disease. (OPS05P)*

- Concerns were also expressed about the ability of the aged care sector to adequately fund the increasing support needs of older people with disability. It was feared that people with more complex support needs would have to prematurely enter residential aged care if greater funding was not available to provide adequate services within their own home.
- The inappropriateness of people with disability being placed in residential aged care facilities was an issue highlighted by many respondents. In particular, these facilities were not felt to adequately meet the support needs of people with intellectual disability, younger onset dementia, visual impairment and those with complex needs. Insufficient aged care funding for equipment and a lack of staff training and skills were seen as contributing to an inability of aged care facilities to fully address the support needs of residents with a disability.

*What I was approved for [under My Aged Care] would be residential care...I don't want to go into a nursing home. I'd be like a lion in a cage. I can still do my cooking, I can still do a lot of things, and I own my own home so I want to live here. And also, it would cost the government a lot more money for me to be in a nursing home than it would be to give me the extra care that I need...But they would not agree to extra care in the house because it would be a double-up, they reckoned with the state government funding. (OPS07C)*

### **10.2.3 Disability services and supports - State disability schemes**

- In general the level of funding and supports available through the state disability sector were perceived by respondents to be less than that available in the NDIS. Funded supports provided were not always sufficient to meet the needs of older people with disability.
- Around a third of non-NDIS participants interviewed were receiving services funded by state disability schemes – primarily supports relating to an Individual Support Package (personal care, cleaning, social activities and supported accommodation) or assistive technology from state equipment services. These supports were being supplemented by services received from charitable organisations or additional services funded by themselves (predominantly equipment, home modifications, domestic assistance and allied health services).
- Access to state funded disability supports was perceived to be highly variable and dependent on which state a person with disability lived. This variation in supports was seen as leading to poorer outcomes for some older people with disability.
- Variability across states was described as to the financial contributions older people with disability had to make towards their supports. For example within SA it was reported that equipment and home modification services were provided free of charge to all people with disability. In other states, in comparison, client co-contribution was expected and was especially challenging for those on low incomes.
- Continuity of support (COS) arrangements were being established to enable people over 65 years with disability in state-funded disability systems who would be ineligible for the NDIS, to continue to receive their existing supports. While uncertainty remained as to the content of these arrangements, respondents were concerned about whether older people with disability would receive adequate services. The ability to obtain additional supports to address increasing disability-related needs within the state-disability system was particularly questioned.

*It's maintaining the State base level of support as opposed to you know I guess looking at what an enhanced plan might be under the NDIS. It's just maintaining perhaps something that is not really appropriate. (OPS08S)*

- There was a common expectation among all respondent groups that older people with disability would be forced to transition into the aged care system in the future if COS funding arrangements proved insufficient to meet support needs. However, a lack of confidence was expressed as to the ability of the aged care sector to provide adequate funding and services.

#### **10.2.4 Disability services and supports - Charitable disability organisations and healthcare services**

- Many of the NDIS and non-NDIS participants were receiving disability supports which were funded outside the auspices of the NDIS, aged care or state disability system. These supports were primarily received from charitable organisations working with people with specific disability types and were funded through block funding from federal or state governments and/or philanthropic donations. The supports were provided free of charge or at a subsidised rate and included equipment, case management, training, interpreting, recreational groups and allied health services.
- Some older people with disability (particularly those with degenerative neurological conditions) were also receiving considerable disability supports from outpatient and community-based health services; these supports included allied health services and equipment. Many respondents also reported receiving subsidised taxi vouchers and mobility allowance to assist with transport costs.
- Concerns were raised about the future ability of charitable organisations to continue to provide supports to older people with disability who were outside the NDIS. Previous block funding arrangements were coming to an end for these organisations and uncertainty persisted about sources of alternative funding to continue current service provision. It was therefore anticipated that either service provision may cease or older people with disability would have to pay (or contribute more) towards these supports in the future.

*For my future, I think like [charitable organisation] may not be able to help me anymore, because I'm over 65. The government has said that as of next year the government will no longer provide that block funding...And thinking forward in my future, there's situations that I'm going to be encountering, I'm going to be needing interpreting services, but I'm not going to be able to access them...We've been trying to get some answers with very little response. (OPS16C)*

- In order to ensure that older people with disability could retain rapid access to these services it was recommended that block funding arrangements be continued.

#### **10.2.5 Quality of services and supports**

##### *NDIS*

- NDIS participants were on the whole satisfied with the quality of the disability supports they received. Where issues had arisen with workers being unreliable or poorly skilled, respondents often felt that under the NDIS they had more of a say and could request different staff.
- However, issues were being encountered by older people with disability in the NDIS being unable to fully implement their plans and access services. Delays in the receipt of assistive technology and home modifications were particularly noted.

##### *Non-NDIS funding schemes*

- Older people with disability outside of the NDIS also expressed general satisfaction over the quality of their supports. This was especially the case for those who were receiving their services directly

from charitable organisations and healthcare settings. These particular service providers and workers were perceived to be responsive to client needs and were proactive in providing necessary supports and equipment. This included the ability to receive urgent and appropriate episodic supports when the need arose.

*I think it's built my self-confidence up. I think if I'd been left on my own, as a vision impaired person I might have stayed depressed. Just sitting around looking for things to do. Whereas what the [charitable organisation] has provided has boosted my confidence. I recognise I'm not totally disabled, sitting down doing nothing. That I can do things to help people. Yeah. Built my self-esteem. (OPS20C)*

- Despite these positive elements, non-NDIS participants also relayed difficulties experienced around the receipt of their disability supports. These issues included waiting lists for supports (including assistive technology through state equipment schemes and aged care packages) as well as the fees and charges which were imposed for supports outside of the NDIS. Some non-NDIS participants also reported that the funded supports they were receiving were insufficient to meet their needs. As a consequence of these issues, older people with disability were foregoing necessary supports because they were unable to access or pay for them themselves.
- While many of the non-NDIS participants felt that their disability workers were skilled and provided good quality care, these sentiments were not universally expressed. The quality of care provided by some workers within the aged care and disability fields was perceived to be poor. A lack of true choice and control over their disability supports and workers further impacted upon the ability of non-NDIS participants to receive quality services.

#### **10.2.6 Unmet demand for services and support**

- Unmet demand for services and support was reported for older people living in rural and remote areas of Australia. Specific types of supports (in particular assistive technology, home modifications and carer supports) were also difficult for older people with disability and their family members to access regardless of their location. Challenges were being faced by certain sub-groups of older people with disability in accessing appropriate funding and supports and issues relating to unmet demand for services within each of the funding streams were highlighted.

##### *Geographical location*

- Older people with disability living in more rural and remote areas were felt to be disadvantaged in their access to appropriate supports compared to their metropolitan counterparts. Within these locations, issues relating to limited service provision, the recruitment and retention of disability support workers and transportation to services were reported. Consequently older people with disability outside metropolitan areas were more likely to experience longer waits for services, limited choice of provider organisations and, at times, greater costs to access services.

*The local responses are very much tailored around the services that come into that town or that region, which can be much patchier than if you're living metro areas and so on. So again country people tend to, with disabilities, tend to have a reduced range of services, and if you're a person who develops dementia earlier, you're really buggered...disability don't want to know about you. (OPS19P)*

- The ability of the NDIS to address pre-existing geographical variation in service provision was questioned by some respondents.

*Because there are so many more people going on to the NDIS, and so many more supports being offered, then probably most areas there'll be a 30 per cent to 40 per cent service failure. Which means there will be 30 per cent of people with an NDIS plan in their hand, who won't be able to find a provider to fulfil the needs....And it's not easy to fix in a regional or remote community. It's not easy to find the people to fix it...So look there will be a service failure and again it's a longer term problem. But there's certainly in regional and remote communities it will be a real problem. (OPS15P)*

#### *Access to disability supports*

- Access to assistive technology and home modifications (and in particular customised equipment) was reported by respondents to have historically been problematic for older people with disability. Lack of consistency across state programs, finite resources and long waiting lists in some states were reported. Subsequently, older people with disability (and especially those requiring customised equipment) were experiencing considerable delays in accessing these supports. In some instances where the need was urgent, people with disability reported to be paying fully for their own assistive technology or home modifications.

*For aged people with a disability finding disability supports, particularly equipment and assistive technology, things of that kind, it's a total jungle out there. And there's little consistency across federal programs or across state programs. It's a highly fractured system...They're different according to the condition in every state and the amounts you can get are very different. You know like \$100 for visual impairment say in one state versus \$1,000 in another state. (OPS05S)*

- Given the lack of clarity regarding the future funding of supports for people who were ineligible for the NDIS, uncertainty was expressed about how many older people with disability would access assistive technology and home modifications in the future.

*And then I guess the other really big issue is access to aids and equipment...because in the transfer of roles and responsibilities for the over and under 65's, aids and equipment has been left out, and it's just being left as something that the state and territories are expected to provide to people who aren't eligible for the NDIS. And it's very unclear what that provision will be, and it's been quite patchy for state and territory in any case. And within the aged care system there's not much provision at all for aids and equipment. (OPS03S)*

- Many of the older people with disability interviewed were receiving considerable levels of informal support from family members. While supports for carers of older people with disability were considered to be lacking under all funding schemes, this was particularly the case for the NDIS. This was considered to reflect the NDIS's focus on individual rather than family level supports and a lack of appreciation of the important role played by informal carers in supporting people with disability.

*[With the NDIS] all of those supports for family and carers and so on are pretty much taken away...there's not enough support. If you look at NDIS individualised funding plans, apart from education for carers and families, there's nothing. There's no respite. There's some real key challenges there about supporting carers...they're just not seen as a vital part of this whole process and I think that's a real failing of the NDIS in not recognising the key role that carers have in caring for these people. They fill all the gaps that the NDIS won't be able to fill and I think there needs to be some recognition of what they're doing and how they're going to be supported in that space. (OPS09S)*

- Commonly, the carers supporting older people with disability were themselves aged and dealing with their own health issues; the need for additional carer supports including access to respite was highlighted.

*I did this for three years just about, three years without any respite, none, except what I paid for myself when I had two medical appointments and I had to pay for a nurse to come or a carer to come. And now I get four hours a week, which is fantastic, but I do it seven days a week, 12 hours a day and so four hours isn't much, especially when you've got things that you really have to do yourself, you know...And the other thing that I don't think that's taken into account with this is that I'm nearly 70. I'm 70 this year so who's working like this when they're that age, so I think in some respects it's a big ask, and you do need support. (OPS13C)*

#### *Sub-groups of older people with disability*

- The support needs of older people with disability from Indigenous communities and culturally and linguistically diverse (CALD) backgrounds were not perceived to be adequately addressed under the different funding schemes. Poorer access to disability or aged care services was commonly reported because of accessibility issues due to language barriers, inadequate service provision, and a cultural lack of recognition of disability. The need for disability and aged care workers with appropriate language skills and cultural awareness was highlighted.

*The sub-group of people from non-English speaking background...Traditionally those families tend to keep people at home and not necessarily involve them in the disability system so much so what happens to them when their mother dies or whatever and they haven't even been receiving the services that they might have been entitled to? And if they don't communicate well in English, they're even more at a disadvantage in a service system, whether it is the disability system or the aged care system. (OPS13S)*

- The needs of older people with disability requiring short-term or episodic services rather than ongoing supports were not felt to be currently met well by either the NDIS, aged care or state disability systems. This included people with psychosocial disability needing temporary support to assist recovery and short-term assistance for those with visual impairment to regain independent living skills.
- For people with certain disability types, such as dementia, services previously available to those under sixty-five years from aged care providers were no longer accessible since the introduction of the NDIS.

*There's this clear delineation between aged care and disability of 65 and over and under 65. It's playing havoc for people with, say, dementia. So many services to people with dementia are provided by the aged care system for good or ill, that's where they've been. So people with younger onset dementia are shut out from a number of those if they can't find some way to fund that through the NDIS which we're having huge issues in...So we're seeing some real challenges there about how we provide that support to these people now that a lot of those aged care supports are closed off from them. (OPS09S)*

#### *NDIS*

- Difficulties were described with the implementation of NDIS planned supports. NDIS processes were reported to be leading to longer delays than previously experienced in receiving supports such as basic assistive technology and home modifications. A lack of available registered providers and skilled workers was also impacting on access to supports. Furthermore delays in support

provision were occurring due to some older people with disability being unable to understand and sign service agreements.

*That's what I say to my husband, I say to him, 'I don't think we're any better off!' It's actually more frustrating because now I've got all this money, I can't get all the carers I want, and I'm not being unrealistic with the number of carers we need. I'm not being unrealistic at all, because my husband requires two carers at all times...And I guess my biggest thing is, at the end of the financial year, they're going to say, 'Oh, you haven't used all of the money that we allocated you,' and it's not because I didn't want to use it, it's because I couldn't get the carers and I couldn't get the services I wanted. (OPS19PWD)*

- Certain types of supports were considered to be more difficult to access under the NDIS. Of particular concern was the limited funding for transportation. The effect of this was compounded by participants no longer being eligible for Mobility Allowance payments.
- A majority of the NDIS participants were receiving additional supports which were either provided by other funding schemes (such as charitable organisations or state-funded services) or were self-funded. In particular respondents reported receiving assistive technology and therapeutic supports outside the funding remit of the NDIS.

#### *Aged care system*

- Due to caps on the number of available aged care packages, some older people with disability were experiencing delays in accessing the funding and supports that they needed; lengthy waiting lists for the higher level packages (Level 3 and 4) were especially problematic. Individuals with high support needs or a degenerative disability were reported to be facing particular issues in obtaining sufficient support while waiting for their aged care funding to come through.

*He's got approval for a Level 4 Package, which is a big package.... [ACAS wrote to say] you're on a waiting list. It could be 12 months, it might be three. It depends when the funding comes through....He's getting worse, and I'm going nuts, in tears four times a day...It's the wait period that can be frustrating. And what he's receiving now won't be anywhere near enough as he deteriorates further. (OPS08C)*

#### *State disability schemes*

- Funding constraints within state-funded disability systems meant that some older people with disability were unable to obtain sufficient funding and supports to fully meet their needs. As a consequence, some people with disability were either forced to forego or pay for additional supports.

## Charitable disability organisations and healthcare services

- While many older people with disability who primarily received supports from charitable organisations and healthcare services felt that their support needs were being met, some supports had been difficult to access due to a lack of availability or cost. This included interpreting services, equipment, home modifications, personal care, cleaning and respite. For example, although guide dogs were provided free of charge by several charitable organisations, the costs associated with the upkeep of the dog was seen as being difficult for some older people with disability to manage.

*A participant in the NDIS can claim all the costs associated with the care and upkeep of the dog like food, fees, grooming, but if you're over the age of 65 none of that is available to you....There would be a lot of people that really struggle even if they wanted a guide dog. The costs can be prohibitive and people probably just couldn't afford it, particularly if they're paying rent and things like that. (OPS17C)*

## 10.3 The Disability Sector and its Workforce

### 10.3.1 The disability sector

- The introduction of the NDIS and the aged care reforms had prompted some disability organisations to become registered aged care providers for the first time in order to continue to receive funding and offer supports to their clients with disability aged 65 years and older. This was seen by some respondents as providing positive opportunities for organisational expansion.

*We are a registered aged care provider because we knew that there would be a proportion, albeit small, of the people that we currently support who would be over the age of 65 when the NDIS rolled into their LGA. And we wanted to be in a position where those people if they so choose could continue to receive our services under the continuity of care provisions. We also saw it as strategically a means of diversification of our revenue base with a similar capability applied to a new cohort....We felt that a cross-over between our disability and aged care cohorts would give us both scale and volume. (OPS07P)*

- Other aged care organisations were either exploring processes for becoming an NDIS registered provider or were waiting for the impacts of the NDIS to become more known before deciding whether to move into the disability sector.

*We've had confirmation now that we do have that State HACC money for another 12 months which is great, so that we'll be able to continue the services for people we have now, and some people will be eligible for NDIS and some won't...We're working on how do we then become an NDIS provider so that we can continue to provide for people under 65 and what that looks like, so that's that piece of work that we're doing now. (OPS19P)*

- Provider organisations reported that the level of funding available to them under the NDIS for supports such as in-home services, group support, supported-decision making and services for people with complex disability was less than that received through state-disability funding.
- As a consequence of the new NDIS funding arrangements providers reported that they were evaluating which supports they should provide and the types of client groups they should work with in the future. Financial analysis of the viability of services for older people with disability was therefore occurring and the actual or threatened closure of some programs were noted.

*Services are struggling to make ends meet on the unit rates that the NDIS is paying. For example, if the NDIS is paying \$42 an hour for an hour of direct support and everything has*

*to come out of that \$42 an hour, any management structure, supervision, professional development, coaching, non-contact time, administration staff, everything has to come out of that \$42 an hour including staff member's wage, most places are struggling to make that work...We are considering a number of things and one of them does have to be whether we continue to provide those services or not. (OPS06P)*

- Uncertainty was also expressed about the future provision of services for older people with disability who were not eligible for NDIS funding. If funding issues were not resolved satisfactorily, respondents queried their future ability to be able to provide services to this client group.

*We're trying to get commitments from the state government and the NDIS [about] the money that they currently paid...for that we cover 12,000 clients of which 75 per cent are over the age of 65...We will lose all that funding from the state under the NDIS system as it's been set up, and ...that's only going to provide money for 3,000 people or something. So it's not a big income, if you know what I mean. The biggest problem we've got, of course, is [people with disability] over 65. (OPS06S)*

- Several respondents from charitable organisations reported that they had previously relied on a mix of government funding and public donations to provide services to their members. With the advent of the NDIS, concerns were expressed regarding whether the public would continue to be willing to financially support disability organisations. If not, the reduction in their income could have a detrimental impact on their ability to provide services.
- The NDIS was perceived by some respondents to be opening up the disability support sector and leading to new providers entering the market. Respondents queried, however, the ability of generalist disability and aged care services to provide quality specialist disability supports suitable for the needs of older people with disability.
- The aged care reforms (and in particular the further implementation of consumer directed care) was also felt to be leading to changes within the aged care sector. As a consequence of this and the changes brought about with the NDIS, closures of some providers and mergers of other organisations were anticipated in the future. This could lead to further changes in service provision for older people with disability.

*I think we have to find a way to make it work, to remain active in the market. But it also means that there'll be providers who don't thrive in that space and there will be some consolidation as well. Well we're okay but we're also looking at a merger with [a provider organisation]...They're also a large aged care provider but they're also a hospital provider as well...so it also broadens out the reach to different customer bases. (OPS09S)*

### **10.3.2 The disability workforce**

- For people with disability receiving aged care funding and services, the ability of aged care workers to provide quality supports to these clients was questioned by respondents. Particular concerns related to the knowledge and skillset required when working with people with disability; these skills were felt to be lacking within the aged care sector.
- The need for a work ethos which promoted person-centred care and capacity building when supporting people with disability was also seen as challenging for aged care workers more familiar working with frail older adults.

*Changing the culture of your workforce is quite a big step. Going from doing things for people to this whole new active support and identifying exactly 'What is the priority for this individual*

*and let's forget about the untidy house or whatever else', is quite a big change for aged care workforce. (OPS01S)*

- Workers within the disability sector were also seen as facing skill deficits in meeting the increasing healthcare needs of people with disability as they aged. Therefore the need for training which provided workers with sufficient skills to meet both the disability and age-related needs of older people with disability (regardless of which funding system the individual was situated in) was recommended. This training was also felt to be necessary for frontline staff working for the NDIA and My Aged Care.
- The NDIS model of individualised funding was seen as necessitating workers having broader skillsets (both formal and soft skills) when working with older people with disability. In order to improve service provision, some provider organisations reported that they were looking to recruit workers with particular skills including understanding of mental health issues and fluency in languages other than English.

*There has to be more flexibility within the company, because if they [NDIS participants] don't want personal care on one day, they can cancel it and maybe have shopping. Whereas before, when it was all structured through whatever agency they had, it was set in cement, a little bit of flexibility, but now, you know, there has to be total flexibility because you're meeting the needs of that individual. It's going to take a lot of working around. You need to know your workers and their availability, and you need to have a worker that is multi-skilled as well. (OPS18P)*

- However, the retention of skilled staff within the disability sector was highlighted as a potential area of concern for the future. The anticipated poaching of skilled staff across care sectors (in disability, aged care and health) also had the potential to affect service provision to older people with disability.
- The introduction of an individualised funding model under the NDIS was also reported to be negatively impacting upon the working conditions and shift arrangements of disability support workers. Moreover, some provider organisations were responding to the introduction of the NDIS and the aged care reforms by restructuring their workforces. For example, the streamlining of management structures was occurring and positions were being created to aid the transition of existing clients into the NDIS or My Aged Care and to better engage with potential new clients.

*So what we've developed is service engagement consultants to assist with the transition of clients to become participants. So that's been a bit of providing them with information in their preferred formats about what the NDIS is and what the process is and also sort of make them aware of what that process is and to help them to understand how the NDIA goes about making decisions about what supports and services are reasonable and necessary across the domains. (OPS02P)*

## **10.4 Choice and Control (including self-management)**

### **10.4.1 Development and implementation of support plans**

#### *NDIS*

- Older NDIS participants had very mixed experiences of the NDIS's planning processes. Some (particularly those who had joined the NDIS in the early trial stage) felt that adequate time had been available during planning to fully discuss their goals and support needs. In addition, the

planner was reported to have listened to participant needs and had actively tried to understand how their disability affected their lives.

- Most NDIS participants, however, expressed criticisms of the initial planning of their supports. Many had entered the planning meeting with a lack of understanding about the process ahead or the supports they needed; this was particularly the case for people who had more recently acquired a disability.

*You don't know anything because you have never been in this situation before. How do you know what [my husband] needs after you have a stroke? You've never lived with someone having a stroke. He's never been in that situation before...It was a very basic plan and it wasn't a plan that included much thinking beyond the box. And I had yet to learn that we can use these plans to actually make changes and things within the life. (OPS04PWD)*

- Other participants felt that they had not been encouraged to actively participate in the planning of their supports or that their views had been disregarded. Hence the subsequent NDIS plan was not seen to meet their actual support needs.
- The role of the planner was perceived to have changed over time as the roll-out of the NDIS had progressed. Several respondents described NDIA planners as moving from an advocacy role in which they encouraged participants to consider their life goals to becoming more of a custodian of funds.

*I really would like to see a major overhaul, a major rethink of the role of the planner. I think when they first started out it seemed to me that the planner was very much just somebody who facilitated and advocated for the participant. I think that's moving away from that now and having the planner being a gatekeeper for making sure that the rules of the organisation are followed...[The planner should] be somebody who came out and encouraged people to do things that overcame their disabilities and to facilitate their aspirations. (OPS20PWD)*

- Further difficulties regarding NDIS planning processes were highlighted by respondents from all interview groups. Planners were reported to not fully understand the needs of, and supports required by, people with particular types of disability including degenerative neurological illnesses, psychosocial disability, autism and sensory impairment. This lack of knowledge was felt to be leading to inconsistencies in the types and levels of supports provided to older people with disability through their NDIS plans.

*I just wish NDIS actually had people working in there that had disabilities. Like that they understood the type of disabilities that were there. You know like people that have got hearing problems to deal with people who have got hearing problems. (OPS02PWD)*

- The importance of adequate preparation and time for planning meetings was highlighted by respondents across all groups. The provision of accessible information to enable all participants (including those with visual impairment and communication difficulties) to understand and prepare for their planning meeting was therefore seen as being important.
- The benefits of having an advocate to assist older people with disability during plan development was discussed by many respondents. Provider organisations reported that they were frequently taking on this role and were conducting considerable unfunded work with existing and prospective clients around NDIS planning, reviews and plan implementation. Potential conflicts around provider organisations acting as advocates for older people with disability, however, were also raised.

*With pretty much everyone we've worked out that we probably provide between 15 to 20 hours for each client of preplanning support, and a lot of that's around the fact that the majority of our clients have never used this service sector before, they've never had to use a service sector, they've just been diagnosed with a terminal illness, so they don't really know where to start. (OPS04P)*

- Planning processes were seen by some respondents as becoming less person-centred and more prescriptive as the NDIS roll-out progressed. The use of automated plan development systems were felt to be leading to greater dissatisfaction over funded supports.
- Support to assist older people with disability to be able to implement their NDIS plans successfully was also seen as being vital by respondents. Plan implementation support was felt to be particularly important for older people with intellectual disability, psychosocial disability, dementia and brain injury. In order to fully implement the support plans of these individuals, the provision of NDIA funding for support co-ordination was important.

*[The NDIS] doesn't recognise the difficulties that customers experience in understanding how to go through a review, in understanding how to implement their plan, in, in just understanding what their plan means, what the dollars means, what kind of services they can access. How to manage their funds, all of those things. So I do think that's a gap....I suspect a lot of those customers may never actually find someone to provide that co-ordination and so they never really get their plan implemented properly. (OPS03P)*

#### *Aged care system*

- In comparison to the NDIS, the standardised assessment processes used by My Aged Care to determine funding of supports were seen as having more of a clinical and functional emphasis. Moreover, these assessment tools were targeted towards the concerns and needs of frail older adults and were considered inappropriate for many people with disability.
- Frontline staff within the My Aged Care contact centre and assessment teams were not felt to possess adequate knowledge of disability. Inconsistency in outcomes were reportedly occurring for older people with disability when determining eligibility and funding.
- As a consequence of these issues relating to assessment processes and knowledge of disability, the types of supports which were funded under aged care for some older people with disability were felt to be inappropriate to address their support needs.

*If you [a person with visual impairment] ring up and say, 'I've got trouble with cooking,' their first response will be, 'Would you like to talk to Meals on Wheels?' But we could modify their home, we could also give them some cups and spoons training for recipes and show them safely how to fill a cup of tea, and all those sorts of things, as a rehab independence model rather than a dependence model where you say, 'Okay, well if you can't see any more we'll go and get people to do something, everything for you. You won't have to do another thing yourself.' (OPS06S)*

#### *Charitable disability organisations and health care services*

- Respondents who were receiving funded disability supports from charitable organisations or health care services typically reported that, at least initially, decision-making about the supports they would receive had been largely led by their service provider. However, some non-NDIS participants described becoming more proactive about their supports needs over time. In contrast, respondents with degenerative neurological conditions preferred their service provider to take the

lead and give advice about their likely future support needs and make arrangements for appropriate supports.

*[At the outpatient clinic] they make recommendations about things that you need...They're really good, they know the disease and they know what's going to happen next...So they're always predicting what you'll need and not consulting you about whether you need it or not. You just get. The wheelchair just arrived and by the time the wheelchair arrived we needed it. So those services are just fantastic. (OPS13C)*

#### 10.4.2 Choice and control over supports

##### NDIS

- Older people with disability participating in the NDIS were considered to have more choice and control over their supports compared to their counterparts within the aged care and state-disability sectors.
- NDIS participants and their carers commonly felt that their choice and control increased with time in the NDIS. Many of these respondents considered that they now had a greater say over their disability support providers and workers; this had led in some instances to changes being made as to who delivered their supports. An ability to have flexibility over the timing of services and to make specific requests for workers who met their preferences was also reported.

*The thing I like most about NDIS is that you're in the driver's seat. The disabled person is in the driver's seat. They can hire and fire, they can speak up when they say they're not happy with you, they want to replace you...Too often choices are taken away from the disabled and the mentally ill and someone else says what happens to them and why and when and how and they don't have a voice...And I have a voice, and I'm being listened to and that's the best thing about it. (OPS14PWD)*

- Provider organisations were responding to the emphasis on choice and control under the NDIS by offering more flexible and individualised supports to older people with disability. For some of these organisations, this change in service provision entailed the reconfiguring of staffing roles and working patterns.
- Limitation in choice and control were also acknowledged. Choice and control was not seen as being totally flexible under the NDIS; in particular participants were reported to not have full control over the types of supports included in their plans nor how their funding was spent.

*Not having that choice, you know, that's possibly the biggest thing, being told, 'You have this bucket of fund', but not having a choice as to how to use it. I don't want to be stupid, I don't want to go and buy lollipops with it or a fur coat, but at least we had a choice [before] of being able to say, 'This is what you need at the moment.' (OPS13PWD)*

- Some older NDIS participants (including people with intellectual disability, complex needs or who had been in the disability support system for a long period of time) were reported to find it difficult to exercise effective choice and control over their supports. Moreover, older people with disability were less likely to have family members or carers who could actively assist with decision-making. For these individuals, adequate support to arrange and monitor their disability supports or capacity building to enable them to better express their wishes was recommended.

*We found that for a lot of them just having that independence, that choice and control, is quite challenging in itself because they've been so used to being told what they can have. So it's a real re-education process for a lot of participants. (OPS03P)*

#### *Aged care system*

- A lack of choice and control was perceived to exist within the aged care system by many respondents in the provider and key agency interviews. While the introduction of consumer directed care (CDC) was bringing in elements of choice and control to the sector, this was limited due to a lack of flexibility around the level of funding and types of supports received. In addition, there was a lack of provision within the sector for older people with disability to fully manage their own packages of care.

*Even if you can choose your provider you pretty much have one provider for your whole package. The price is not set so different providers can charge different amounts and there are a lot of hidden costs around case management, administration and exit fees...So in a sense the aged care system favours the market providers more than it favours the consumers. And so choice and control in the aged care space is much harder to actually exercise which is a disadvantage. (OPS11P)*

- The non-NDIS participants receiving supports under the aged care system, expressed mixed views about the level of choice and control they had over their supports. Some respondents felt that they had a say over the supports they needed and the workers who delivered them. Others, however, reported a lack of control over the content of their support package and their care arrangements.

#### *State disability schemes*

- Opinions as to the level of choice and control held over their disability supports were also diverse amongst the non-NDIS participants receiving funding through state disability schemes. As with aged care, some respondents felt that they had considerable control over their support arrangements, particularly over the choice of staff and the tasks undertaken by these workers. However, others reported a lack of choice and that their disability support provider had been automatically allocated to them by the state-funding body.

*If there's a new person going to be coming they send them for a meet and greet beforehand, so you can sit and chat and see how you feel in the company of that person. And then after the first time that they come you're asked to ring in and let them know how things went, if you were happy or if you weren't. So that works out really well as far as I'm concerned. (OPS07C)*

### **10.4.3 Self-management**

- A fifth of the older NDIS participants interviewed had chosen to fully or partly self-manage their own supports. Through self-management, these respondents felt they had more of a say over their workers and supports. While a further three participants wished to self-manage their funding in the future, others preferred to retain assistance with their support arrangements.

*We have ended up self-managing everything because that seems to be working well for us at the moment....I already had found someone to clean my house and we already had someone doing our grass...and I thought, well, if I want to keep using those they said that was okay as long as they had an ABN. But [our case co-ordinator] thought that it was better if we had more flexibility, if we self-managed, so we could make the choices. (OPS09PWD)*

- The option to fully self-manage supports was not available to older people with disability who were receiving funding through the aged care and state-disability systems. Several respondents, however, expressed a preference to be able to have more control over their disability funding including being able to independently employ their own workers.

## 10.5 Reasonable and Necessary Supports

### NDIS

- Around a quarter of the older NDIS participants interviewed were satisfied that the supports funded in their NDIS plans met all their support needs. However, most expressed reservations about the level and type of supports funded by the NDIS. This included insufficient funding for therapeutic supports, home modifications, holidays, aids and equipment, fitness activities and transport.

### Aged care system

- The funding of disability supports within the aged care sector was considered to be poorer than within the NDIS. Indeed the supports received under the aged care system by the non-NDIS participants interviewed were limited both in scope and quantity. Although two of the respondents had been allocated a more comprehensive Level 4 home care package, these were yet to start due to a lack of available packages.
- In order to supplement the services received through aged care funding, most of these respondents were receiving additional disability supports from charitable organisations, healthcare agencies or through self-funding.

### State disability schemes

- A majority of the non-NDIS participants currently under state disability funding arrangements reported that the level of their funding was inadequate to meet their needs, with no ability to obtain more funded supports. As a consequence these respondents were either paying for additional supports out of their own funds or were foregoing needed supports.

*Although I have substantial supports through [state disability], I cough up quite a bit of money to support myself...Paying around about a \$1000 a month. That's for services over and above [state disability] allocation...Some people can say, 'okay, well I won't have any care on weekends.' I can't do that, I'm dependent on care, three times a day. (OPS01C)*

## 10.6 Participation (Social, Economic and Educational), Wellbeing, and Aspirations (Goals)

### NDIS

- The NDIS was considered to be enabling older people with disability to obtain supports which could address their individual needs and goals. This included improved access to supports which assisted social, educational and community participation.

*The NDIS is focused on independent living, community participation and building community participation. It's about your place in the community and being viewed as an active contributor. (OPS08S)*

- Several respondents described being able to pursue more activities outside the home and had enhanced wellbeing and independence as a consequence.

*What I like best about the NDIS? They help provide the things that I need to be an independent adult. And they help, they help provide the things that make me stronger and able to do more. Which is really, really good. (OPS04PWD)*

- The financial situation of some NDIS participants and their families had improved as they no longer had to fund certain supports out of their own pocket.

*Before you used to have to battle to get funding, and now it seems to be given to you. So, it's more readily accessible, and not many questions are asked about, 'Do you really need that service?' The amount of care we needed, the gardening services, the equipment that we asked for, it seemed they readily accepted it. (OPS19PWD)*

#### *Non-NDIS funding schemes*

- In contrast, funding constraints outside of the NDIS (and particularly within aged care) were perceived to prevent older people with disability having adequate access to supports which promoted their economic and community participation. Concerns were also raised that a lack of funding for social activities within the aged care sector was leading to the social isolation of people with disability as they aged.

*Under the NDIS people might be accessing supports to help them engage in employment in the future, under aged care that really isn't part of the deal because you're not expected to have employment prospects in the future...It's much more just helping you to stay at home. (OPS05S)*

- Despite these acknowledged constraints in the levels and types of disability supports funded outside the NDIS, some of the non-NDIS participants reported satisfaction with the supports they received.
- The positive impacts of these supports included being able to live at home, pursue chosen activities and have increased social contact. The ability to access disability supports was also seen as contributing to improved wellbeing (both physically and psychologically).

*My fatigue, as I said to you earlier, is not good. But by having these people come and help me get to and from the shower and things in the morning, it's helped that because I'm not struggling as much therefore my pain level doesn't shoot up high. That is where it's made it a lot easier for me. (OPS07C)*

#### *Transitions*

- Many of the older NDIS participants reported a lack of awareness that at 65 years they could decide whether to continue with the NDIS or move into aged care. Several respondents believed that the aged care system was now part of the NDIS while others had assumed that they would automatically be transferred into the aged care system on reaching 65 years. A lack of available information to aid informed decision-making about this transition was reported.
- Despite this lack of awareness, there was general consensus among participants that they would be better off staying in the NDIS. This was due to perceptions that the aged care sector did not have an adequate understanding of disability, could not provide appropriate supports and had

long waiting lists. Also respondents were reluctant to switch systems and go through eligibility and assessment processes for another funding body.

*I will stay with the NDIS...Up here there's many months' waiting list for an assessment, an ACAT assessment. And then you know, the services are terrible and in fact because the NDIS offers much more of an ethos of having meaning in your life and doing the things you want to do and with the necessary supports to enable you to do that, it's much more individualised...whereas with aged care you're really at the mercy of the organisation. (OPS17PWD)*

## 10.7 Fairness, Equity and Access

### 10.7.1 Eligibility and navigation of funding systems

#### NDIS

- When reflecting upon entry processes for the NDIS, the automatic eligibility of people with certain types or levels of disability was viewed positively by respondents as this negated the need for further assessment.
- However, issues relating to the eligibility requirements of the NDIS were a common concern for respondents. Access to the NDIS for some older people with certain types of disability (e.g. stroke, mental health issues and low vision) was considered to be unclear. Provider organisations reported that some of their clients had been found ineligible to transition into the NDIS and concerns were expressed about the continuation of their services.

*We had a run of people [stroke survivors] contacting us who had basically been told that their disability was not severe or permanent enough for them to receive support.... [Some] people are getting a blanket no on the phone and not a lot of information about where to go from there. So it's hard to know...because there seems to be a bit of smoke and mirrors around really how those eligibility assessments are being made. (OPS12S)*

- Respondents from provider organisations also reported that some of their existing clients were reluctant to transition into the NDIS. This reluctance was attributed to a lack of awareness of the NDIS, issues surrounding individual capacity to negotiate transition, and concerns that current supports would be reduced if transition occurred.

*Some people have been hesitant because as part of the legislation you have a choice to join the NDIS, that's the whole part of choice and control, but some people are concerned when they get this call from this random person [at the NDIA] they think it's some market researcher or telemarketer. Why are you asking for my name, why do I have to consent to the NDIS? Some people are confused so they'll say no I'm actually quite happy with what I've got, no I don't want to switch...They don't realise if you don't say yes you're going to lose your funding anyway. (OPS08P)*

- Experiences of entering the NDIS had been mixed. For some, including those automatically rolled into the NDIS, joining the NDIS had been relatively straight-forward. Difficulties were reported by many others however, including a lack of available information about the NDIS, issues obtaining necessary documentation for access requests, and delays in entry processes. For many of these respondents, considerable support to navigate entry processes had been required from a family carer or provider organisation.

*It's hard work and one wrong step and you won't get it, sort of thing...I had someone help me, I don't think I could have been able to do it on my own. It's a lot of paperwork and stuff. (OPS17PWD)*

- The NDIS was perceived by respondents to be bureaucratic and difficult for older people with disability to navigate. This was noted particularly for individuals who had not previously been part of the formal disability sector but had instead received their supports direct from charitable organisations.

*In the past a person with Motor Neurone Disease would register with us; we would allocate them to one of our staff, if they wanted that...But now they still register with us because we're usually their first point of call after they've been diagnosed...So then they have to register with NDIS, then they have a planner, a LAC or at least one or both. Then the plan has to get implemented so it's back to us...So instead of having us or the staff member here, and then making the appropriate referrals out, now they've got two other layers on top of that with the LAC and the planner before anything's happening. (OPS05P)*

- Experiences of communicating with the NDIA were variable for NDIS participants and provider organisations. Some respondents were satisfied with the contact they had had, while others had experienced issues particularly around contacting the NDIA call centre and timeliness in responses to queries.
- Difficulties with some NDIS operational processes were reported by NDIS participants and providers alike. The portal was seen as being difficult to navigate for older people with disability, while provider organisations described particular issues regarding the payment of client fees.

*Every time you seem to go into the portal though they're always changing the look of it...There's a big percentage in our age group that aren't that coordinated with computers. They can do the basic stuff, but how would they get on and the NDIS, along with everybody else today, just assumes that everybody has a computer and everybody knows what they're doing and they want you all to do internet banking and this and that, and there's still a lot of old people that don't want to do that. (OPS09PWD)*

- Improved accessible information which provided clear messages about eligibility, assessment, funding and the implementation of supports was needed to allow people with disability to make informed decisions about their supports. For some older people with disability, access to an advocate or case manager who could guide them through all processes from initial entry into the NDIS to being able to fully access their supports was important.
- Specific changes were also suggested to improve processes for older people with disability within the NDIS. Greater clarity was needed around eligibility processes, in particular around the interface between the NDIS and the health sector. Adequate preparation and time was required for planning and review meetings and a preference for face-to-face meetings was expressed by respondents. For some older people with disability, additional support or capacity building was required to enable their full participation in planning processes and also with the implementation of their supports.

#### *Aged care system*

- Entry into, and navigation of, the aged care system was seen as being challenging for many older people with disability; this was especially so for those who did not have family members to assist in this process. The My Aged Care system was perceived as being difficult for older people with disability to understand and accessible information both about the NDIS and their disability

support needs were difficult to obtain. Sufficient information regarding co-contributions towards aged care services and processes for approval and assignment of a care package were also seen to being lacking.

*It's very difficult to know what you can access in My Aged Care... [With the NDIS] there's been a wealth of information for that group of people and it's a new Scheme so they've had webinars and seminars and all sorts of information coming out but we get nothing in My Aged Care...Consumers deserve to know what's available but it's very hard to find that out unless you actually access the Scheme or get an interview. (OPS17C)*

- For some of the non-NDIS participants, processes to join the aged care system had progressed smoothly, with the initial referral to My Aged Care followed quickly by a home assessment. However, other respondents had encountered issues in navigating the system, reporting a lack of understanding about My Aged Care processes, difficulties making initial contact and subsequent delays in assessment and service provision.
- A lack of provision for case management within the aged care system meant that provider organisations were frequently assisting older people with disability to understand and navigate My Aged Care. In part this unfunded work was being conducted with an expectation that older people with disability would choose the organisation as their service provider. Direct advocacy with My Aged Care and its assessment teams was also reported by provider organisations.

*There's no-one, there's no case manager that I can go to and get information. Which is probably the most disappointing thing that we've come across. And they all talk about packages, and you qualify for this package, and oh, we'll have to wait for the funding to come through. But they don't actually tell us what the package is, if we can pick and choose out of that package. So they talk about hours, the package is a bucket of money that can be translated to hours of assistance. I don't fully understand it. (OPS08C)*

- Concerns were expressed as to whether people with disability (such as those with visual impairment) would be eligible for aged care funding given the emphasis of the NDIS on ageing and frailty. Respondents also reported that older people with disability may not perceive themselves as fitting within the aged care sector and would therefore be reluctant to apply for funding for supports.

*[There's a] kind of schism between people's internal perception of 'Well I just have a disability but there's nothing else wrong with me' and the need to go into an ageing system to get access to the supports that they need for the disability specific...So there's that concern about whether or not people will be eligible, and even whether they will want to engage with My Aged Care, if their issues are not about frailty. (OPS10S)*

#### *State disability schemes*

- State disability funding schemes were perceived by some respondents as being more fragmented and challenging for older people with disability to navigate than the NDIS system.

*The NDIS is just so much better than the state funded system that people don't have to battle, you don't have to navigate, you don't have to trawl through websites to try and find out what package you can get. There are no waitlists. (OPS08P)*

### *Charitable disability organisations and healthcare services*

- In contrast many non-NDIS participants who were accessing funded disability supports directly from charitable organisations or healthcare services described easy eligibility processes which had quickly led to the receipt of their services.

### **10.7.2 Review and dispute resolution processes**

#### *NDIS*

- The ability to have regular reviews of planned supports was considered to be a positive element of the NDIS. Reviews could potentially enable changing disability support needs to be considered and appropriate supports put in place.
- The interviews with NDIS participants and their carers, however, revealed mixed experiences of NDIA plan review processes. Some reviews had led to increased levels of funding and supports, while other respondents had had their supports reduced (as a consequence of either not needing their current level of care or cuts made to funding for episodic supports). A further group of participants described that the NDIA assumed that previous planned supports would continue and consequently their support needs were not properly reviewed or addressed.
- Some respondents from stakeholder and provider organisations observed that funding in plans was routinely being cut at review, partly due to an underlying assumption that NDIS participants would need less support over time.

*We're also seeing people whose plans are being systematically reduced in dollar value...There's this assumption by the agency that people are developing more independence and that they no longer need as much service or perhaps the agency was too generous originally and they're having to, you know, rebalance that. Whatever the assumptions being made in the agency we're seeing many, many people whose plans are being reduced year by year and people of course are not satisfied with that. (OPS11S)*

- Issues were also raised regarding the format of reviews. Several NDIS participants reported that their review meetings were being conducted by telephone; this was felt to be inappropriate for many older people with disability and their carers. Other respondents described review processes as being stressful and that any proposed changes in supports had to be fully justified to the NDIA. A lack of a consistent planner across initial planning and subsequent reviews was also felt to be detrimental to the ability of the NDIA to understand the support needs of older people with disability.
- Examples were provided of interim reviews which had had to be requested to reconsider NDIS plans not seen as adequately meeting the needs of participants. Some of these plans had subsequently been successfully altered with advocacy from peak body and provider organisations.

*We had a carer come in whose wife had younger onset dementia...his wife's initial plan was \$700. Their second plan was \$600, and when they had a review of the plan with the assistance of a key worker they were able to get nine hours of home care and a week of full respite with 24/7 care. That jumped to \$32,000. I think that is a real great snapshot of the difference of having someone to come in, advocate and really also prepare the person for their meeting. (OPS09S)*

- NDIS review processes were not considered to be rapid or flexible enough to address changing support needs or crisis situations. These issues were of particular relevance for older people with degenerative conditions such as dementia, MND and multiple sclerosis.

*For some people they might have a plan in place now but in six months' time things will have really changed. And it's quite a process to apply for a plan review and you know, have all that done, particularly when the supports are needed kind of quite urgently for a lot of our clients. (OPS04P)*

#### *Aged care system*

- Non-NDIS participants receiving funding through the aged care system did not describe any formal review processes that were open to them following initial decision-making about their supports. However, when their support needs changed, some respondents reported that they had informally contacted My Aged Care to discuss amending their home care package.

#### *State disability schemes*

- A lack of, or at best infrequent, formal review processes within state-disability funding schemes were described by respondents. This was seen to hamper the ability of older people with disability to have the level and type of their services reviewed when support needs changed. Some of the non-NDIS participants, however, reported having an allocated state disability case worker who they could contact if issues arose.

*One of the struggles we've had is that sometimes people were allocated a funding package from the department, the state system when they were in their 30s and despite requests for reviews and things that funding hasn't been reviewed in many, many years even though the person's needs have increased...and that's been an issue because getting that additional support for those people it's been very, very difficult. (OPS06P)*

### **10.7.3 Equity and fairness**

- A lack of equity in the funding and provision of supports to older people with disability across the main funding schemes (NDIS, aged care and state disability) was reported. Those receiving funding from state disability and (in particular) aged care, were felt to be considerably disadvantaged compared to people with disability participating in the NDIS. Indeed many people with disability (who were ineligible to join the NDIS due to age restrictions) expressed a strong desire to participate in the NDIS as they felt that they would be able to access more supports both currently and into the future.

*There will be people who are inside the NDIS then and then people who are outside of it but who are two years different in age but have exactly the same level of disability but who are receiving very different services because of when they acquired the disability or because one of them will have been in the right place at the right time and able to come into the system and the other one isn't. (OPS13S)*

- The schemes providing funding for the supports of older people with disability were perceived to differ across several domains. These included levels of overall funding, the types of supports which were funded, the expected co-contribution of clients, and the ability to have choice and control over supports.
- The underlying philosophies of the NDIS and the aged care sector were seen as being very different by many respondents. The NDIS was perceived to have a greater focus on identifying and meeting

an individual's holistic support needs including enabling greater social and economic participation. In contrast, the funding of disability supports within the aged care sector was not seen as prioritising the promotion of independence nor the pursuit of personal goals and aspirations.

*It's [aged care] a much more restricted and completely different focus and underpinning philosophy than the NDIS because it's not about choice and control and it's not about looking at your life and being able to contribute in community life. (OPS08S)*

- Many of the non-NDIS participants felt that the onus was placed on older people with disability themselves to approach funding schemes outside the NDIS for needed supports. However, service provision and funding within the aged care and broader disability systems were seen as being complicated and fragmented. To compound these issues a lack of information and guidance for older people with disability regarding the different funding schemes was observed. As a consequence many older people with disability who were ineligible for the NDIS were unaware about the funding and types of support available to them.

*Since I lost my sight...there's not one single thing that's happened to me that I haven't organised myself. That's local government, state government, federal government, if I haven't initiated it then it doesn't happen. (OPS24C)*

- In order to remove the perceived inequities in the funded supports of people with disability who were older than 65 years and ineligible to participate in the NDIS, respondents strongly advocated for a single funding system which provided supports to people with disability regardless of their age.

## 10.8 Mainstream Interface

- Issues in the interface between the disability, aged care and health sectors were reported to be negatively impacting upon the availability and provision of supports for older people with disability.
- The current interface between the disability and aged care systems was seen as being unclear; as a consequence it was feared that some older people with disability who were not part of the NDIS were missing out on needed services.

*Prior to the NDIS rolling out if you had younger onset dementia, so under 65 with a dementia diagnosis, it was considered to be an age-related illness so you had to receive your services through the aged care sector....Because not everything has rolled out, we're kind of straddling these two systems. But because My Aged Care are saying we're for people over 65, they're really cracking down on providing any service to anyone under 65 and are really pushing back with our clients and saying no, no, no, we can't service them, they have to get a service through the NDIS. [But if] you're not rolling out with the NDIS until 2019, and you need a service now, where do you get it from? It's a massive issue. We've got a whole bunch of clients sitting there who are not in receipt of services and need it and cannot get it from either system. (OPS04P)*

- A lack of clarity in the interface between the NDIS and the health sector was also perceived to compromise the funding and supports available to older people with disability. Some people were being found to be ineligible to join the NDIS, while others within the NDIS were denied funding for specific supports if their needs were seen as being primarily health rather than disability-related. Particular issues were described for older people experiencing disability due to health conditions, stroke and progressive neurological conditions.

*We see the NDIS turning down things that they say are health conditions and are refusing to provide support. I think the NDIS has a very shallow understanding of what the interface between NDIS and health actually looks like. So for an individual that has a number of different health conditions the health treatment for each of those conditions individually is not going to be necessarily sufficient to minimise the functional impairment that comes from the combination of health conditions. And so they don't have a very nuanced understanding of that and the fact that having multiple health conditions leads to disability which is separate from the health condition itself. (OPS11P)*

## 11. NDIS in the NT (with a focus on the Barkly trial site)

### Integrated findings

This section summarises the qualitative findings relating to the roll-out of the NDIS in the remote Barkly region of the NT.

The NDIS evaluation in the remote Barkly region finds that:

- While awareness of the NDIS improved with time, understanding of the NDIS and its processes remained low;
- levels of unmet demand for supports were high, particularly for allied health services and respite;
- supply of disability services was inadequate prior to the NDIS and did not improve despite the new funding;
- there was limited evidence of new providers entering the region and the market size remained inadequate to support additional service demand;
- shortages in the disability workforce were coupled with the NDIA workforce encountering continual challenges;
- while attempts were made over time to adapt NDIS processes to local need, this was made difficult with the high turnover in the NDIA workforce;
- choice and control remained an almost theoretical concept and the processes were challenged by the virtual absence of a viable market;
- outcomes for NDIS participants were variable and were poorer for those living in remote Aboriginal communities;
- strong advocacy had led to improvements in services and levels of social participation for some participants;
- wellbeing was improved for some families and carers, but the majority of people with disability did not record higher wellbeing; and
- the number of participants in the NDIS did not reflect the high levels of disability within the region. The NDIS trial in the Barkly region was never expected to be an easy task, but at the end of the evaluation period it was still felt that both its approach and implementation were ineffective and that the NDIS had not managed to adapt sufficiently to the specific needs of the region.

#### *The evaluation of the NDIS in the Barkly*

- In local Indigenous contexts, disability is an increasingly common phenomenon that communities are still struggling to understand and incorporate into cultural explanations of health and wellbeing.
- Discussions about disability are not straightforward, as Indigenous definitions of health place less emphasis on physical concerns and more on a holistic sense of wellbeing. There is also often a reluctance to discuss disabilities as some Indigenous people may feel or believe that speaking about such issues aloud can aggravate matters for the individuals concerned. These beliefs are more likely among remote populations and less so among town-based populations.
- Considerable prevalence of disability exists within the Barkly region. Furthermore, a high incidence of chronic health conditions which predisposes people to disability, through amputations or other impairments, was evident.

- Family members provide much of the care for people with disability; for Aboriginal people, the responsibility is determined by roles under kinship systems. However, many carers had their own existing or looming health and support needs, adding to the impact of disability on the community.
- The health and support needs of NDIS participants and their carers in the Barkly region were substantial. Mobility, housing, home modifications, and transport supports were the major requirements of many of the people with disability interviewed.
- The evaluation of the NDIS in the Barkly region posed a number of challenges including the high mobility of the local population, isolated travel and associated issues of safety, cultural activity, gate-keeping, vicarious and intergenerational trauma and cross-cultural communication.

#### *Supply and demand of support services*

- Many NDIS participants in the Barkly trial site had minimal understanding of their NDIS support plan and this did not change over time. For those who were aware of their NDIS plan, satisfaction with funded supports was variable. Some participants were now receiving additional supports while others reported gaps in the services funded under the NDIS. The NDIS had had a positive impact on access to equipment and in particular the availability of mobility aids. However, a lack of adequate funding for transport, respite, support coordination and skill development was noted.
- The NDIS had led to little improvement in the supply and quality of disability services within the Barkly trial site. As a consequence the types of disability supports able to be accessed by NDIS participants did not change over time.
- Although peak body and service provider organisations reported that the NDIS had led to increased funding for disability supports, participants were not necessarily receiving more services and high levels of unmet demand due to a lack of service provision were being experienced. Unmet demand was particularly reported for allied health services and respite.

#### *The disability sector and its workforce*

- Limited evidence was observed of new providers entering the disability service market within the Barkly region. Moreover, concerns were expressed that the small number of new providers who had begun to offer services in the area, would choose to withdraw when the NDIS roll-out expanded into the larger population sites of Darwin and Alice Springs.
- A lack of market development was attributed to the small numbers of NDIS participants within the trial site and a lack of provider experience and infrastructure for remote service provision. NDIS pricing structures were also not felt to be adequate because of the higher costs of providing disability supports in remote areas.
- The NDIS had also not had an impact on the size or diversity of the disability workforce in the Barkly region. Worker recruitment and retention continued to be problematic, and a lack of provision within NDIS funding for staff training further stymied workforce development.
- The NDIA workforce within the Barkly trial site had also encountered challenges. At least initially, insufficient numbers of local Aboriginal staff had been employed which impacted upon the capacity of the NDIA to engage with Indigenous people with disability. Although NDIA staff reported good working relationships within their team, difficulties adjusting to working in an isolated area were commonly experienced by staff who were new to the region.

#### *Choice and control*

- NDIS planning processes were considered by participants and carers to be too bureaucratic and difficult to navigate. Plan development was perceived to work better for people with good English literacy and/or computer skills and for those with strong advocates. The quality of the plan was also dependent upon the skills and knowledge of the NDIA planner. Understanding of processes of plan development and implementation was reported to be particularly poor for many Aboriginal participants which adversely impacted upon levels of choice and control.
- Limited evidence of the impact of the NDIS on the choice and control people with disability had over their supports was found at both waves 1 and 2. Non-Indigenous participants and those who were self-managing their NDIS funding were reported to exercise greater levels of choice and control. A lack of local disability service provision was a primary impediment to enhanced choice and control.
- The self-management of NDIS funding was very uncommon amongst participants in the NT trial site. While self-management was seen as providing opportunities for increased choice and control over service providers and budgets, the associated administrative requirements were considered challenging. Concerns were also expressed that self-managed funding could leave some NDIS participants at risk of exploitation.

#### *Reasonable and necessary*

- Understanding amongst NDIS participants and their carers of the concept of 'reasonable and necessary' supports remained low throughout the evaluation. This lack of understanding was exacerbated by variability in the supports included by the NDIA staff in participant plans. Many NDIS participants were also unsure as to the types of supports they could request to have included in their plans.

#### *Participation (social, economic and educational), wellbeing and aspirations (goals)*

- Some improvements in wellbeing and social and economic participation were noted for NDIS participants who were actively involved in support planning or had strong advocates. Access to mobility aids had improved the community participation and autonomy of some NDIS participants. The wellbeing of carers had also been improved through the provision of new equipment to NDIS participants and greater funding of supports was reported to have reduced financial burden.
- Improvements to wellbeing and participation were not being experienced by all NDIS participants in the Barkly trial site. Moreover, progress towards enhanced wellbeing and social and economic participation were constrained by the limited availability of disability services and a lack of employment opportunities within the region.
- Understanding of the use of goals and aspirations to inform support planning was challenging for many NDIS participants in the Barkly region. Inadequate time was considered to have been allocated to discussions around goals and aspirations and the appropriateness of this approach when working with Aboriginal people was questioned.

### *Fairness, equity and access*

- Awareness and understanding of the NDIS and its processes was greater amongst non-Indigenous participants. While awareness of the NDIS grew over time, knowledge of the NDIS remained limited for people with disability living in remote Aboriginal communities. This was in part a consequence of a perceived lack of effective engagement between the NDIA and local communities.
- The number of people with disability participating in the NDIS was felt to underestimate the total prevalence of disability within the Barkly region. Access to the NDIS for people with mental health conditions, the homeless, those in the criminal justice system and people with disability who had not previously accessed services prior to the NDIS was a particular concern.
- The NDIS was viewed as not having been adapted to fit the specific circumstances of the Barkly region. In particular, the NDIS's focus on disability was considered to be too narrow in the context of pressing health and social issues within remote Aboriginal communities. In addition, the individualised approach of the NDIS was considered inappropriate when working with Indigenous people with disability. The adoption of a model which was more culturally sensitive and appropriate to remote needs and service delivery was recommended. Concerns were also expressed that the lessons learned from the Barkly trial site were not being used to inform the roll-out of the NDIS in other remote areas.

### *Mainstream interface*

- Little change occurred over time in the type and frequency of the mainstream and community services being utilised by NDIS participants. A lack of clarity between the disability and health sectors, however, was described regarding respective funding responsibilities and eligibility criteria for entry into the NDIS.

## 11.1 Introduction

As a nationwide scheme, the NDIS covers rural and remote areas, and vast distances. People with disability living in rural and remote areas often face additional challenges that are distinctly different from those faced by people who live in metropolitan areas. It is therefore imperative that the NDIS is responsive to, and appropriate for, people with disability and their families and carers living in rural and remote areas. Furthermore, there are many challenges involved in the delivery of disability services in rural and remote areas including small populations dispersed across vast geographic regions, limited infrastructure, and difficulty in attracting skilled personnel. The NDIS recognises the need to ensure that it supports service delivery in rural and remote areas, particularly those that include a higher proportion of Aboriginal and Torres Strait Islander peoples.

In this section we present key findings arising from the evaluation of the NDIS in the Barkly region of the NT. As an extension of the broader NDIS evaluation, this study sought to explore specific issues regarding the operation of the NDIS in a remote location. In-depth qualitative interviews were conducted across two waves with NDIS participants and their families and carers, non-NDIS participants, disability service sector representatives, and NDIA managers and staff.

The NDIS evaluation in the Barkly region covered many of the key questions considered by the broader evaluation. In this chapter we provide a synthesis of the evaluation evidence around seven main themes relating to the NDIS trial in the remote Barkly region. These themes include the supply and demand of disability support services; the disability sector and its workforce; choice and control (including self-management); reasonable and necessary supports; participation, wellbeing and aspirations; fairness, equity and access; and the interface between the NDIS and mainstream sectors.

We start the chapter by detailing contextual information about disability in Aboriginal and Torres Strait Islander Communities, and more specifically within the Barkly region of Australia. There were many challenges of undertaking the evaluation of the NDIS in the Barkly region of the NT. These are briefly described in Appendix A1.2.

## 11.2 Cultural Context of Disability in Aboriginal and Torres Strait Islander Communities

- In local Indigenous contexts, disability is an increasingly common phenomenon that communities are still struggling to understand and incorporate into cultural explanations of health and wellbeing. Traditionally people would have experienced disability as a result of injury or congenital influences, but increased risk factors today have seen disability impact Indigenous Australians at disproportionate rates to other Australians.
- Discussions about disability are not easy, as Indigenous definitions of health place less emphasis on physical concerns and more on a holistic sense of wellbeing. This tends to mean disabilities can be minimised for individuals who are otherwise well-connected and embedded with family, culture and country. Where these core cultural values are intact, the individual with a disability is well integrated and supported. Unfortunately, where families have been dislocated or impacted by dysfunction, it is much more likely that some people with disabilities can be left vulnerable and unsupported.
- Local Aboriginal people may sometimes use physical or psychological impairments to describe an individual without the sensitivity and stigma experienced in the non-Indigenous population. When referring to a specific individual, people may say things like ‘blind one, crippled one’ or even ‘mad one’ for a range of disabilities. This is not intended to be insensitive (although can be experienced as such), but rather as a feature of a visual and descriptive way of experiencing the world. It is also

usually followed with an expression of empathy and compassion, such as ‘kunye’ meaning ‘poor thing’.

- There is often a reluctance to discuss disabilities as some Indigenous people may feel or believe that speaking about such issues aloud can aggravate matters for individuals. This is more likely among remote populations and less so among town-based populations.

### **11.3 Cultural Context of Disability in the Barkly Region**

- The health and support needs of NDIS participants and their carers in the Barkly region were substantial. Mobility, housing, home modifications, and transport supports were the major requirements of many of the people with disability interviewed. Some participants with a physical disability required support with activities of daily living - feeding, showering, dressing and mobilising. Participants with psychosocial and intellectual disability needed advocacy, social and emotional support. Access to early intervention, including therapy services, specialised equipment and respite support was required by children with disabilities.
- A high prevalence of chronic health conditions which predisposes people to disability, through amputations or other impairments was evident in the Barkly. Family members provide much of the care and for Aboriginal people, the responsibility is determined by roles under kinship systems. However, many carers had their own existing or looming health and support needs, adding to the impact of disability on the community.
- Tennant Creek – the largest town within the Barkly region - has poor access and infrastructure (including pavements and building access, including to basic services such as the post office and some banks) which negatively impacts on the people with disability living in the area. Existing accommodation in Tennant Creek was rarely modified to meet the needs of people with disability. Most respondents other than those in purpose-built housing were struggling with a lack of adequate ramps, rails and bathroom infrastructure. This situation was exacerbated in the remote communities surrounding Tennant Creek.
- A lack of appropriate residential and respite care within the Barkly region meant that sometimes young people were placed in aged care facilities or transferred unnecessarily to hospital settings for respite. Suitable facilities for dealing with people with acquired brain injury or other mental health issues were also lacking, which impacted on individuals, their families and the organisations providing supports to these people. At different times, it was reported that certain individuals who could not be managed locally, were sent to Alice Springs. The NDIS was seen as pivotal in advocating on behalf of people with disability and coordinating better support options.

### **11.4 Supply and Demand of Support Services**

#### **11.4.1 Disability services and supports**

*The perspective of NDIS participants and their family members or carer*

- In wave 1, there was limited awareness of the NDIS among participants in the Barkly trial site, particularly Indigenous respondents, even though they had been identified by NDIA to the evaluation team as having already been accepted into the NDIS. For those who were aware of the NDIS, expectations were mostly positive, although there was confusion about what supports could be funded and a more pervasive confusion about the role of the NDIA overall. People with disability participating in the NDIS mostly hoped for greater access to services, such as after-hours support, respite, and transport.

- In wave 2, expectations and enthusiasm for the NDIS had diminished as expected benefits failed to eventuate for many NDIS participants. Confusion about the NDIS and the role of the NDIA; a lack of resources and infrastructure; and a lack of sufficient disability services and supports all contributed to a sense that the NDIS had not lived up to expectations.
- Many NDIS participants were either unsure if they had a plan or, if aware of the plan, had minimal knowledge of its content or processes relevant to it. There was little evidence of change in the level of awareness relating to NDIS plans over time.
- For those who were aware of having an NDIS plan, levels of satisfaction with their funded supports varied. Some respondents were extremely satisfied that they were now receiving services and support previously unavailable to them, while others were very dissatisfied and considered that the supports they needed were either underfunded, missing from plans or not delivered.
- The most commonly funded supports included in NDIS participants' plans in the NT were equipment and therapy. Other supports included transport, supported accommodation, community participation, respite, personal care and development of daily living skills. There was little evidence of change in the levels or types of supports and services included in NDIS plans over time.
- The most obvious change in disability supports in the region was in relation to equipment provision. In particular, a significant increase in the number of people using mobility aids in the community was noted. Equipment most commonly provided included scooters, gophers and walking frames to assist with mobility, and in several cases hoists and shower chairs to assist families to better provide personal care.

*(In the last 12 months) we did get him a new wheelchair...He got the new chair now. We also have the hoist that we needed. (F16\_C W2)*

- While nearly a third of NDIS participants had been provided with equipment since the introduction of the NDIS in the region, others were still seeking to have equipment included in their plans. There was evidence of a lack of clarity and consistency about what equipment could be funded in NDIS plans, particularly assistive technologies.

*So for example like one of the things we originally were told that they could have a learning iPad, [Name] could apply for a learning iPad, to help with his speech... When the lady first signed us up... she was the very first one who said about the learning iPad....she was great at explaining it but then when I tried to start putting some of that through with (NDIA staffer) last year... everything I suggested I just kept getting knocked back on. Saying no we don't do that, no we don't do that, no we don't do that and then I get told yesterday yes in fact we do do that. (F06\_C W2)*

*So we need a screen reader at (service provider), we need a screen reader here (at home)... You know we need those types of things and we're not, they're not in the plan at the moment so we haven't got them. (F37\_C W2)*

- Respondents identified transport, respite, support coordination and developing skills for daily living as supports that were either not included or not funded sufficiently in NDIS plans.

### *The perspective of people with disability not participating in the NDIS*

- The types of disability supports and services non-NDIS participants in the comparison group were receiving included accommodation, equipment, advocacy, case management, attendance at day programs (including an Australian Disability Enterprise), respite, personal care, therapies and travel and transportation.
- A few respondents stated that they had little or no disability supports in place. For some, the reason why they were not currently receiving disability supports was a result of their own choosing and a capacity to manage with informal support arrangements. For others, the lack of supports were a result of a shortage of service providers, poor knowledge of what services were available, and a sense of personal responsibility by their carers.

*Well, we don't know (about services), but then again, we don't make a lot of noise about it either, we just get on with it... Well, she's my responsibility. And as long as I can look after her, I will. (F11 C W2)*

- Most non-NDIS participants were receiving supports and services from the NT Government (e.g. Department of Health and Office of Disability). However, some were receiving services as part of a compensation payment (e.g., Motor Accident Compensation Scheme, or through victims of crime or workers compensation programs).

### *The perspective of the service provider and peak body organisations*

- In wave 1, respondents from service provider and peak body organisations considered that the NDIS had brought little change to service provision.
- By wave 2, many people with disability participating in the NDIS were reported to be receiving more services than prior to the NDIS, including access to services for people who had previously not received any disability supports.

*I met people that had never had services ever, that have had a disability their entire life. Like a 40-year-old, actually maybe 50, sorry, had never received any type of services because no department or no service had ever picked up on him. So once NDIS arrived and they found him and he got services... it did give a big sense of, 'We've got support.' You know, it's not all up to the family to look after and provide all that support ... so NDIS has been a big help in the community, which was definitely needed. (F18S W2)*

- NDIS participants were felt to be better able to access equipment that suited their needs. The availability of increased supported accommodation services for people with disability in Tennant Creek was positively attributed to the NDIS and meant these participants were '*definitely mixing with people of their own age, which is good*' (F06S W2) rather than being placed in aged care facilities with older people.
- There were reports, however, that the number of hours of support coordination being funded in NDIS plans was inadequate, particularly for Aboriginal clients living in remote communities.
- In wave 1, disability service providers and peak bodies expressed concerns that the NDIS had been rolled out without an adequate understanding of how to engage and deliver services to Aboriginal people with disability, particularly those living in remote communities. A current lack of disability service provision within the Barkly region was perceived to undermine the operationalisation of core NDIS principles such as individualised services and participant choice and control.

- In wave 2, concerns remained about the effective delivery of the NDIS in remote locations. Disability providers and peak bodies viewed the NDIS as being Eastern-centric and the NDIA as being unwilling to adapt the NDIS to the specific circumstances of the Barkly region. The adoption of a model more appropriate to remote service delivery was recommended.

*And it's working successfully in all those big cities no doubt but here it is going to be very tough unless they make some big changes into that or they just make participants sit into one place. (F09S W2)*

- Respondents expressed concerns that lessons from the Barkly trial had seemingly not informed the further roll-out of the NDIS in the NT or other remote locations across Australia.
- The success of the NDIS in the Barkly region was seen to strongly depend on market development and the increased provision of disability services; this would both address current unmet demand for services and provide some choice for service users. The financial viability and sustainability of disability service provision under individualised NDIS funding, however, was identified as a barrier to market development.
- Turnover of NDIA staff in the Tennant Creek office had affected relationships between providers and the NDIA. This had led to earlier connections no longer being relevant and some providers struggling to establish good working relationships with NDIA staff.

#### *The perspective of the NDIA staff*

- NDIA staff reported that the type of disability services available in the region were primarily focused on community access, coordination of services and daily living.
- There was concern from NDIA staff that choice over the type of services able to be accessed by participants had not altered over time and remained constrained even with the introduction of new providers.

### **11.4.2 Quality of services and supports**

#### *The perspective of NDIS participants and their family members or carer*

- While there were accounts of satisfaction with particular providers, complaints about disability service quality predominated.

*Because [name of service provider] are incompetent, they couldn't manage their way out of a paper bag ... I wanted to remove the management of [NAME'S] care plan from their hands because in my opinion they were incompetent to do it. So I certainly wasn't going to give them a heap load more money to keep doing a bad job. I thought I could do it better just to put it bluntly. (F01\_C W1)*

- Most complaints about service quality centred on concerns about the lack of skills, training and experience amongst support staff and high staff turnover. However, many respondents also acknowledged the difficulties of recruiting and retaining a skilled workforce in a remote region.

*The level of staff training and/or experience in working with clients with disability is extremely poor... I think it's the remote experience is that the workforce is always going to be either a transient type population and/or people who are coming with very little skills and experience. And the other aspect is that the attrition is huge. (F37\_C)*

- NDIS participants mentioned staff turnover within disability support agencies as a significant issue. High staff turnover resulted in new staff being unformed of the specific care needs of the person with disability, and restricted progress towards outcomes and the development of effective relationships between staff and clients. High staff turnover also impacted on service quality and continuity.

*The perspective of people with disability not participating in the NDIS*

- Several non-NDIS participants indicated being satisfied with their disability supports and services, but noted this was the result of considerable advocacy on their own part.
- A larger number of respondents expressed dissatisfaction with available supports. Reasons for dissatisfaction were principally related to the quality of disability support workers or programs offered by providers, high staff turnover within agencies, and unreliability of care arrangements.

*Once I get that change, fluctuation of carers, that's when everything just goes back to square one. (F05 C PWD W1)*

- Respondents also reported concerns that some NDIS plans were of poor quality and did not adequately address support needs or fund sufficient hours for support services to be effective. Poor quality plans were attributed to NDIA staff lacking skills and experience and also a lack knowledge about possible and appropriate supports amongst some NDIS participants and families which constrained their ability to speak up about their support needs.

*The perspective of the service provider and peak body organisations*

- Representatives from service provider and peak body organisations reported few instances of improvements in the quality of disability services. One peak body noted, *'I think there have been improvements in the quality of supported accommodation... But again, it's coming at the low base'*. (F02P W2)

### **11.4.3 Unmet demand for services and supports**

*The perspective of NDIS participants and their family members or carer*

- High levels of unmet demand were reported by NDIS participants and their carers in the Barkly region.

*So overall? I think the frustration has been in knowing yes we've been approved funding for services but being remote the service providers... so nearly a whole year and we've spent two per cent [of NDIS funding in plan]....Because we can't access stuff yes. It's all very well to be allowed to buy things but if there's no-one selling you know, you can't buy services that don't exist. Unless we move and then we're outside the NDIS sphere of influence anyway. (F01\_C W1)*

- A third of NDIS participants reported having therapy services included in their NDIS plans, but most were unable to access these supports due to insufficient service provision in the region. There were also some reports of reductions in therapy services occurring, including those delivered in remote Aboriginal communities and some fly-in services no longer travelling to Tennant Creek.

*The package is more than adequate. It's not something I can complain about. Accessing the therapy is the hardest. He's had four appointments this year, and they've all fallen through... he hasn't been able to see a therapist this year at all, (they keep changing the appointments), or they're overbooked. That's been really disappointing... They are good. I can't complain with*

*it, because they are supported. But at the same time, because they are good, they're in demand. (F33\_C W2)*

*Having visited some of the other (remote) communities, they said we used to get physios visiting, we used to get OTs visiting, now the NDIS has been rolled out we're not getting that. (F21\_C W2)*

*He was seeing a really good OT for his first two and a half years, and she worked up a really good rapport. She's both registered with NDIA and with the original grant that he was under. Only the place that she works with, they stopped her travel down here because they were trying to encourage an OT placement here in Tennant Creek. (F33\_C W2)*

- As in wave 1, access to respite care continued to be limited as were education and support services for children with special needs.
- A lack of services, especially allied health services in Tennant Creek, also impacted on obtaining the assessments required to access NDIS supports. Particular concerns were raised about problems with equipment repair and the provision of some assistive technology such as bed lifters which were reliant on an OT assessment before being sourced from interstate.
- The lengthy wait times for disability supports experienced by many participants in other trial sites were seemingly nominal when compared to the wait times to receive a service through NDIS funding in the NT. Many respondents in the NT reported they were still waiting on supports that had been funded in NDIS plans more than 12 months previously.
- Those seeking to access services outside of the region to overcome the problem of insufficient local service provision were sometimes constrained by travel costs, as a funding for travel was not being included in NDIS plans.

*If I took (NDIS participant) to services elsewhere I have to actually pay to get him there myself because ... In this, the last 12 months no they only allowed \$528.00 in that (for travel). (F06\_C W2)*

#### *The perspective of people with disability not participating in the NDIS*

- There was also considerable unmet demand for services for people with disability in the comparison site of Alice Springs, again resulting from a lack of service providers due to the remote location.

*Services could improve... cause there's a lot of people with disabilities in this town, with physical or mental. The services are lacking. (F02 C C W1)*

#### *The perspective of the service provider and peak body organisations*

- In wave 1, peak bodies and disability service providers reported that a lack of expansion in disability support provision since the introduction of the NDIS meant that the availability of these services remained limited for people with disability living in the region. There was a concern that the lack of new providers since the NDIS trial began, alongside a winding back of services by the NT Government, had resulted in less disability services than prior to the NDIS.
- In wave 2, peak bodies and disability service providers reported that despite some increase in service provision, this was still not adequately addressing need in the region. Also, respondents

contended that the number of people with disability living in the Barkly region was considerably higher than the number of NDIS participants identified and with active plans.

*In the Northern Territory, we already had a huge pool of people that need services and a limited number of people that can provide that because of the limitations of our environment, and I don't know that the core numbers or the core needs with the NDIS rolled out is going to be terribly different to what it actually already is now. (F06P W2)*

- It was acknowledged that the Northern Territory Bilateral Agreement (COAG 2014) included a 'provider of last resort' to ensure services continued. However, there was continued confusion about how this would work in practice alongside the NDIS.

## 11.5 The Disability Sector and its Workforce

### 11.5.1 The disability sector

*The perspective of NDIS participants and their family members or carer*

- In wave 1, many NDIS participants were enthusiastic that new disability service providers would enter the region as a result of the roll-out of the NDIS. However, this enthusiasm diminished after little change was evident in available services.
- In wave 2, there continued to be limited evidence of new providers entering the local provider market.
- Respondents believed that the remote location continued to deter new providers. The cost of remote service delivery and a lack of affordable housing to encourage staff to move to the region were viewed as barriers to expansion in the provider market. Some respondents disputed the viability of the NDIS market model in remote locations.

*I can see that in theory it can work well in a capital city. I can't see how in a small town where the services are so minimal and that the quality of staff is so low and there's such a high turnover of staff and this whole thing that it's going to be driven by the market, well there is no market. It's too expensive. (F21\_C W2)*

*The perspective of the service provider and workforce stakeholder organisations*

- In wave 1, peak bodies and disability service providers reported little change to the disability sector in the Barkly region as a result of the NDIS trial. The sector was considered still to be experiencing considerable flux and little market development had taken place. Although several new providers were noted to have registered with the NDIS, they had not yet begun operating within the area. The lack of market development was attributed to the low number of NDIS participants, alongside the need for service providers to have prior experience, cultural competence and infrastructure to deliver services to remote communities. Most providers reported their organisation had undertaken preparatory work or had begun to adapt to the NDIS.
- In wave 2, while peak bodies and disability service providers reported a small number of new providers entering the local provider market and a slight increase in service provision among existing providers, barriers to expansion continued to be reported.
- Financial viability and sustainability of disability service provision under the NDIS individualised funding model was perceived as a key barrier. Concerns included funding not reflecting the true cost of remote service delivery; NDIS pricing not adequately covering management, training and

administrative costs; and particularly for small fly-in-fly-out (FIFO) therapy providers, exposure to financial risk associated with travel costs when delivering services in remote communities. Smaller organisations were again identified as being more vulnerable and unable to absorb these unfunded costs and therefore less able to sustain disability services in the Barkly region under the NDIS.

- Peak bodies and disability service providers also noted that unfunded work such as engagement work to create relationships with potential clients, assistance with planning processes, case management work and extra administrative work was further impacting on their financial viability.
- Low numbers of NDIS participants also affected the financial sustainability of services and programs. Several providers who had entered the trial site reported they were not able to create sustainable services as they were not able to access many NDIS clients (despite being advised by the wave 2 interviews that there were 154 NDIS participants with plans in the Barkly region).

*My difficulty as a service provider with that number is that we have 20....154 might only have equipment needs but where is everybody? We can't find them. We don't know where they are to even try to provide support and from a business perspective try to raise our revenue. That's an absolute flaw in the whole Scheme that we can't find those people and that they can't seem to be finding us. (F13S W2)*

- Respondents reported that the NDIA had failed to adequately consider the appropriateness of an individualised funding model in the NT and the challenges of remote service delivery.

*They should do their homework before they start. They should know that, don't try and roll out a national program in places like the Northern Territory without significant consideration beforehand about what the pitfalls are going to be. Because it's not going to work. (F06P W2)*

*It's really hard to provide services in remote areas. Even if you get more service providers ... the market's only so big, you know? There's only so much work here... You're not going to make a fortune working out there. If you're a private organisation – if you're a for-profit – I think that it's always going to be challenging. (F04P W2)*

- Concerns were raised that when the NDIS is rolled out across the NT, providers who had begun offering services in the Barkly trial site, would withdraw and focus on Darwin and Alice Springs where there are less remote servicing challenges and greater financial service viability.

*I think my sense is that by rolling out, particularly in the Northern Territory, by rolling out the outlying areas, the remote areas first, that they will receive service, and then as Darwin and Katherine and Alice Springs are rolled out that perhaps we will go back to being in the situation that we're in now where services then become centralised again. (F03S W2)*

#### *The perspective of the NDIA staff*

- NDIA staff highlighted that services to people with disability (which were very limited pre-NDIS) were provided locally by mainstream or generalist services, or by specialists from Alice Springs or flown in from further afield. Services were largely blocked funded and disability supports typically constituted only a very small percentage of an organisation's total service delivery.

*If we're talking to the [Name of service provider] for example we are a very small part of their business you know so they might provide in-home care or meals to a lot of people but 95 per cent of those will be through the home and community care, HACC Scheme. A very small percentage of their client base will be through disability programs. (F08N W1)*

- The shift to an individualised funding model, was thought to have led to some providers whose main business focus is not disability to consider withdrawing from the sector.

*Disability is just not their core business. And it might have been tacked on the end and now we've got a totally different financial system, how money's allocated; they're just saying 'Look there's just far too much and it's not a huge part of our budget. We'll just hand it on'. (F06N W1)*

- NDIA staff reported in wave 2, there were 28 disability service providers registered with the NDIS within the Barkly region, of which 24 were actively providing supports. Three large new providers had begun operating out of Tennant Creek and four new supported accommodation homes had been established. Beyond this it was noted that there was further interest from providers currently operating in Alice Springs and Darwin as well as providers from the Aboriginal controlled health sector in moving into the disability provider market in the Barkly region.
- Allied health provision in the region consisted of the use of existing allied health services through the Office of Disability for assessments and initial consultation, and the use of FIFO therapists brought into the region by local Aboriginal Health organisations. However, there continued to be an under-supply of allied health services in the region attributed to the high cost of service provision.
- Whilst services in the region were both government and Aboriginal controlled, the arrival of the NDIS provided scope for the Aboriginal service providers to include non-Indigenous clients. Previously, this was not allowable under funding arrangements.
- Although no service providers had exited the market in the Barkly since the wave 1 interviews, several NDIA staff acknowledged that they knew of a few current providers who were reassessing whether they should continue in the region.
- NDIA staff also voiced concerns about whether the new providers in the Barkly region would remain once the NDIS was rolled out in other regions in the NT. It was believed that once provider resources were constrained by the extra demand in other sites, providers would no longer have the time, nor would they find it cost effective to continue to travel to those more remote areas such as the Barkly.

*If you haven't got the people that want to go to them, well, where are they going to get their money from? So I'm not sure if it works in little places like this. (F15N W2)*

- The financial viability of disability service provision in the region was a major concern given the distance required to travel both to and within the region and the small number of participants requiring services.
- Confusion and lack of understanding of either the purpose of the NDIS or the processes involved in delivering services under the NDIS were viewed as a further challenge.

## 11.5.2 The disability workforce

### *The perspective of the service provider and peak body organisations*

- Peak bodies and disability service providers reported that the NDIS had not enhanced the size or diversity of the disability workforce in the Barkly region and that worker recruitment and retention continued to be difficult. Respondents reported specific challenges in recruiting and retaining Aboriginal workers including problems with police checks and identification documents, alongside a lack of qualifications and literacy or computer skills.
- Disability service providers considered that these workforce challenges predated the NDIS: *'historically it's been difficult, not impossible, but difficult to recruit to these positions in remote areas'* (F06P W2).
- Providers noted the need for experienced allied health staff and those with cultural competency to work in remote locations. Several providers reported that advertised allied health positions were not being filled over some months due to a lack of suitable applicants. Providers seeking to attract allied health staff noted the need for competitive salaries and opportunities for professional development. It was also claimed that these potential employees were often seeking permanent appointments, which were no longer being offered due to uncertainty about future service provision under the NDIS.
- Providers noted the cost of training and developing their own staff was problematic under the NDIS as there was no provision to fund training. The extra costs involved in training staff in remote locations was also highlighted.

*Yet they want your staff to have all this training. So who's going to pay them for all those days off, who's going to pay them to get to there, who's going to pay their accommodation, their travel, their, come on. Yeah. Not good for us. It really isn't. (F17S)*

## 11.5.3 The NDIA workforce

- At the time of the wave 2 interviews there were 10 employees based at the Barkly NDIA site. Of these employees, six identified as Indigenous. A further six employees were based in the NT regional hub that had been established in Darwin. It was anticipated that in the future the number of employees based in the Barkly region would decrease, while the total number of NDIA staff in the NT would increase to approximately 80 employees as the NDIS was rolled out across the territory.

### *The perspective of NDIS participants and their family members or carer*

- In wave 1, a lack of local Aboriginal NDIA staff within the Barkly trail site was noted. It was suggested that the employment of local Aboriginal people would have enhanced the capacity and cultural appropriateness of the NDIA to engage the community from the outset.
- In wave 2, while several respondents welcomed the appointment of more Aboriginal NDIA staff, others believed that the Agency had not fully appreciated the cultural and language skills that were needed to effectively work with local Aboriginal people.

*I think they've... employed two, two of the staff members only this year... Well they both don't speak language... And that's my big concern is they are really missing the point again... They're the mob, all of them Aboriginal but they don't tick box, culture box or language for me. (F03\_PWD W2)*

- As in wave 1, many NDIS participants perceived NDIA staff to lack disability experience, knowledge and training.

*Again the training with the NDIA staff is that, I believe that they have been trained but they're not coming from a position of working with disability for very long, there's still a very many of them are just stepping in out of communities and into the roles or out of Centrelink and into the roles and they don't come with the inherent knowledge around disability that they need to be performing in that role. (F37\_C W2)*

*So the thing is that NDIS in this office in Tennant Creek... none of them have disability certificate, have no aged care or disability experience, looking after or responding to needs of a child, or a person, with a disability so how can they write a care plan and then how can they also look after carers and parents of people with disability? (F35\_C W2)*

#### *The perspective of the NDIA staff*

- NDIA staff recognised that rolling-out the NDIS in the remote and largely Indigenous context of the Barkly region required changes to the ways in which the NDIS had been implemented elsewhere.
- In addition to the remote context, the Barkly region is characterised by a low socio-economic profile reflecting high unemployment, low levels of education, and poor health. NDIA staff recognised the additional challenges this presented to the roll-out of the NDIS in the NT, including the problem of multiple disability and disadvantage.
- In wave 1, NDIA staff indicated that their involvement in the Barkly region trial site primarily came about in response to an Expression of Interest circulated by the NDIA or by being directly approached. Respondents reported that decisions to work in the Barkly trial site focused on the opportunities this provided in terms of living in the NT or pursuing employment opportunities such as working with Indigenous people.
- NDIA staff highlighted the importance of having experienced people from other trial sites on staff in the NT in the early stages of the roll-out, to share their knowledge and skills, and to give context to how things would need to work differently in the NT.
- NDIA staff were optimistic about the hiring of local people within the Barkly region. However, given their current skill level, there was also some concern about the ability of these new staff to undertake their necessary working responsibilities. The more skilled and experienced staff were therefore having to devote time to training new staff, adding to their already high workloads. In addition it was observed that a number of local staff exhibited high levels of absenteeism that negatively affected the rest of the team.
- In wave 2, recruitment placed a stronger emphasis on seeking interest from local people, and *'they are probably the first jobs too within the agency where we actually had specific Indigenous criteria that we ask people to address to in their jobs (F01N W2)'*.
- NDIA staff in the NT trial site enjoyed being in a small team and reported good relationships with colleagues. Several respondents indicated appreciation of the skills and experience of other team members, contributing to feelings of being supported when at work and fostering a learning culture.
- The principal challenge for staff (and especially those who were temporarily placed in the trial site) was associated with the personal impacts of working in an isolated region, away from family and friends. NDIA staff in the Barkly experienced a number of challenges around living and working

within such a small community. In particular, managing relationships could be difficult especially when responsible for determining whether people they know receive funding or services. The level of support provided to NDIS staff new to the region was considered to be insufficient.

- A lack of available disability services due to the remoteness of the region, provided NDIA staff with an additional challenge. The dearth of existing services meant that much more effort needed to be devoted to market development. This was further exacerbated by NDIS pricing for services which was considered insufficient in such a remote area and the logistical difficulties around service provision even in those instances where a provider was available.

*There's also the issue around pricing, so the cost of remote service delivery is very high. And whilst they've got a remote and very remote pricing catalogue it still doesn't cover, for some providers or businesses that are looking at providing services, it's just not viable for them to be providing those services... the sheer cost of delivering services to very remote locations and the staff that you need, and the vehicles, and the time. (F10N W2)*

- NDIA staff reported needing to provide considerable support to providers both to negotiate NDIA processes and also on how to use the provider portal. Educating providers was complicated by frequent staff changes within these organisations so that the NDIA needed to 'start again' whenever someone new came on board. A particular issue in the Barkly trial site was the uncertainty about the ongoing provision of therapy services by the NT government.
- Respondents felt the NDIA should have a stronger focus on staff wellbeing in light of the additional stress factors of working in a remote and challenging location. They also described the need for the NDIA to work towards a greater community engagement and relationship building with mainstream services in the NT, and felt this should ideally happen well ahead of any future roll-out to new geographical areas.

#### *Role specific challenges*

- As already discussed, as part of the rollout of the NDIS in July 2014, the NT trial site started operation staffed with PSCs, rather than planners and LACs as in other trial sites.
- While in other trial sites the role of the PSC encompassed plan development and implementation, in the Barkly trial site, this role also involved locating potential participants and undertaking assessment as part of eligibility and planning. They were also required to undertake tasks associated with provider and stakeholder engagement (along with managers). As one PSC described it 'up there you really just rolled your sleeves up and did a little bit of everything (F02 W1)'.  
*'up there you really just rolled your sleeves up and did a little bit of everything (F02 W1)'*
- Performing the role of PSC in a remote location had different challenges compared to other trial sites. Travelling between the trial site office and Aboriginal communities took considerable organisation and advance planning and coordination. However, working in a small, remote team was also reported to have a number of benefits, including increased flexibility in their role and the ability to try different things rather than adhering to a prescribed process. For some, this was a closer match to their expectations on starting work with the NDIA.

*I think you have to be flexible in a small, remote team. And I think that's probably why staff up here like their role, because they do get that... Just really getting into it and going 'Yes, this is what I signed up for in the first place, this is what I thought I was going to be doing.' (F05N W2)*

- Staff new to the NDIA, however, still had some difficulty adjusting to what they described to be ‘bureaucratic processes’, found NDIA procedures hard to understand, and felt the Agency was ‘top heavy’.
- Other challenges related to the burden of paperwork (in context of inadequate IT systems) and the detrimental impact this had on availability of time to spend with participants and their families (echoing feedback given by NDIA staff in other trial sites).

### *Skills and training*

- In both wave 1 and 2, NDIA staff identified that they had experienced some challenges with training as a result of the remoteness of their location.
- Initial training for staff was reported to be very ‘Barkly site’ specific, involving four wheel drive and first aid training. Cultural awareness training was considered to be inadequate and consisted of: ‘A very unsatisfactory online module which assumed that you had no knowledge at all (F03N W1)’.
- Staff often relied on the experience and knowledge of the fly-in-fly-out staff members to bolster their understanding of disability areas. A decreased use over time of fly-in-fly-out staff in the NT trial site, reduced these opportunities for learning.
- Another training resource that staff used was having colleagues from national office or independent contractors come to the Barkly site to deliver training. However, difficulties were experienced both in getting training providers to come to a remote location as well as staff availability to attend training sessions due to frequently working away in remote communities.

## **11.6 Choice and Control (including self-management)**

### **11.6.1 Development and implementation of NDIS plans**

#### *The perspective of NDIS participants and their family members or carer*

- In wave 1, experiences of the processes of plan development varied across individuals. Plan development worked well for people with good English literacy and/or computer skills and those with strong advocates. However, a number of Aboriginal participants were unaware of the process for developing plans and therefore had limited or no control.

*I think I’m lucky because I know these sort of forms and I’ve been there before, but I think for some other people it’s really hard and it needs to be broken down so that it’s in English that people can understand. (F24\_C W1)*

- Respondents were frustrated that NDIA staff were not more prescriptive about what could be included in plans and thought there should have been greater engagement with local and potential service providers prior to opening the NDIA offices.

*The only thing that was frustrating me was the fact that nobody at the time knew what the hell was going on, like I was ringing them up and saying, ‘What service is being provided?’ and they’re like, ‘Oh, we have to wait to the services to sign up.’ And I said, ‘Well, have you got anything signed up?’ and they weren’t able to tell me. (F06\_C W1)*

- In wave 2, a similar lack of involvement in planning and review processes was frequently reported. This included legal guardians who expected to be included in these processes.

*No, we weren't included...I don't know who attended with her to be quite honest. It sort of seemed to be very much driven by NDIS... I haven't gone back through the files to kind of see how that fell off and how she ended up with this plan without any kind of proper planning. (F21\_C W2)*

- Amongst those who had been involved in the planning development process there were further concerns that NDIA staff were not listening to participants, carers or family and their input was not necessarily reflected in completed plans. Confusion amongst some respondents about whether a planning conversation had taken place, or if a NDIS plan was in existence, continued in wave 2.
- In wave 2, goals and aspirations remained a limited concept amongst participants in the Barkly site, with non-Indigenous carers or guardians more often using this language and citing goals for those they were caring for rather than participants articulating goals for themselves. There were concerns of a lack of time for an adequate discussion of goals and aspirations to occur, and a need for more contact, or a different approach, when working with Aboriginal people was recommended.
- It was also evident that many NDIA participants who were interviewed for the evaluation were unaware of supports and services they could potentially ask to be included in their plans. Such supports included equipment and home modifications. For example, one woman, who cared for a husband with an amputated leg, when asked about what would she like to make things easier, said after considerable thought that she would '*...like a milk crate (F05\_C)*', so her husband could sit down in the shower.
- Across the respondents, a strong theme of self-sufficiency was expressed. People asserted their independence and capacity and their wish to ensure they were not 'a burden' to anyone. For Indigenous participants in particular, but not exclusively, people did not like to see themselves as a person with disability or in need of help from others. This contributed to a lack of engagement with the planning process and plans not meeting needs.
- In both wave 1 and 2, the process of plan implementation was not clear with respondents believing that the responsibility for implementing NDIS plans lay with the NDIA and not individual participants. Some respondents attributed delays or inaction implementing funded supports to a lack of expected follow up or assistance from NDIA staff. In one example, a visually impaired NDIS participant had been funded and delivered a computer with a braille function by the NDIA but had not used the computer as he was '*still waiting for them to come back and set it up for me (F09\_PWD W2)*'. In the absence of knowledge to the contrary this respondent believed that the setting up his computer was an NDIA responsibility.
- Respondents identified NDIA staff turnover and/or lack of availability as contributing to the delays and lack of continuity experienced with planning and implementation.
- In wave 2, several respondents noted that support coordination services were particularly important to plan implementation. However, a lack of support coordination included in NDIS participant plans in the NT was reported.

*The perspective of the service provider and peak body organisations*

- In wave 1, peak bodies and disability service providers had limited experience of NDIS planning processes due to the small number of plans developed at the time.
- In wave 2, there were concerns that the plans being developed may not truly reflect the needs and wants of Aboriginal people with disability. This was seen to be exacerbated by insufficient time available for NDIA staff to undertake the engagement work needed to establish effective relationships and better discern the needs and desires of Aboriginal participants. Many respondents considered the NDIS planning process to be very bureaucratic and difficult to navigate for participants and their families and reported that the online portal was not useful for those without access to technology.
- In wave 2, respondents also identified the importance of involving third parties in developing and reviewing plans to ensure that plans were achievable and met the needs of individual participants.

*The Office of Guardian ... make sure that the plan is achievable and is what's required to continue to support the person that actually has the plan, realistic rather than pie in the sky. (F03P W2)*

- While including more services and supports over time, peak bodies and disability service providers considered NDIS plans to be of poor quality. They were described as 'very poorly written' (F04S W2) and 'completely inadequate' (F13S W2) for clients with complex needs and in some instances were considered to not be tailored to individual needs.

*We have seen some cases where the plan is nothing. It just seems like they have... It's like a tick and a flick... Give everybody the same and ... Pump them out. (F09S W2)*

- Respondents attributed poor quality NDIS plans to a lack of both experience and skills amongst local NDIA staff and poor knowledge about possible appropriate supports for many NDIS participants. The ability of participants and families to articulate their needs effectively also impacted on the quality of the plan.

*None of them have a health background, so they're allocating things in people's plans and funds and services when they have no idea what services someone with a certain disability needs... when I get these plans that just make absolutely no sense for a certain type of disability, and that comes down to the planner has no idea what they're doing. (F18S W2)*

*Our clients here also, some of them don't understand their own disabilities, so they don't know the services that they need, so they aren't able to speak up about what they think that they need as well. (F18S W2)*

- Processes introduced by the NDIA to assist staff in the Barkly site with planning decisions were considered inadequate.

*This morning the planner pulled out a World Health Organisation disability tool and started asking questions of the person and it's just so off the mark... You know in the last 30 days have you been able to walk a kilometre without help? What's a kilometre?... type in these answers to this new system on her computer and it tells us what the plan needs to look like. And that just terrifies me. I asked about the cultural considerations. 'Oh no culture doesn't come into,' she said. (F13S W2)*

- Finally, there was some tension around the idea that goals and aspirations shaped the NDIS plans. Some believed that the concept of goals and aspirations could be problematic for Aboriginal NDIS participants who may be focused on more immediate needs.

*Because if you ask these families what they want, they would say, 'We want some food. We want some help to buy some clothes. We want a swag. We want somewhere to stay tonight... it's been our experience ... that people think very much in the moment – 'What do I need now?' It's very hard for families to think about the future when they're struggling in this moment. (F04P W2)*

- However, while acknowledging this, others considered it to still be important that goals and aspirations were recorded to ensure supports could reflect what Aboriginal participants wanted.

*I think culturally that whole thing about goals and aspirations can be a bit difficult. But essentially that's a document where they get to say what support they want and for what reason... I don't think it's accurately doing that yet but... it's there and at least that we're all orienting around that rather than working on what we think that that person should get or do or whatever. (F04S W2)*

#### *The perspective of the NDIA staff*

- In wave 1, NDIA staff reported that a low number of plans had been completed due to difficulties finding and engaging participants. It was observed that given the context of the Barkly region they needed to work differently to other less remote trial sites. Plan development required longer time and more face-to-face contact to build trust and relationships. Support planning also often took place in different settings (e.g. in the front yard under a tree rather than inside the participant's home) and with more people involved (i.e. extended family and neighbours).
- At the time of wave 2 interviews, NDIA staff again highlighted the need to work differently when developing plans in the region in order to establish trust with the participant. Indeed, trust was thought to be even more important with this group of participants than was goal setting. One-on-one, face-to-face discussions with participants were considered integral to this process of building trust and rapport.

*Ours is more one-on-one too, but the questions, I guess the information that we need to collect has been more personal, so that's been an interesting, that's been definitely a difference in planning. (F12N W)]*

- Flexibility was considered by a number of NDIA staff to be key in successfully conducting plan development, particularly when working in communities. Another successful strategy for plan development was to be able to show participants concrete examples of how supports and services had worked for other people in the community.

*'Look this is what's happened to X, Y, because we sat down and we had a plan, and now that person has a wheelchair' or 'That person can get to school' and it's showing those concrete examples of what we would do. (F09N W2)*

- A lack of available services in the region was a significant challenge to plan implementation for NDIA staff. In particular, concerns were voiced about the lack of allied health services in the region and the dearth of disability services for those living in communities beyond Tennant Creek.

*So you know the plans themselves it looks great on paper, the next step of actually ensuring you know services made it to those communities that was – that was probably the bigger challenge. (F04N W2)*

## 11.6.2 Choice and control over supports

*The perspective of NDIS participants and their family members or carer*

- In wave 1 a number of participants expected improved choice and control over disability supports would occur with the arrival of the NDIS.

*Yes it sounded – it was very positive thinking that yes I'd be able to get the higher assistance that I need which is outside of the hours which my current service provider works which is eight until four and so I thought yeah, great to be able to manage that and have the ability to choose the products that I need to use and not just get told this is what's available but have more choice with that. (F01\_PWD & C W1)*

- Few participants though were confident about how to choose service providers, preferring to rely on the NDIA for this. Only a minority of respondents reported that they were well-connected with disability services and felt confident in searching out service options. The new reality that people were no longer constrained by local or even NT based providers with the NDIS was not clearly understood; only the non-Indigenous participants seemed fully aware of this option.
- In wave 2, there was little change evident in how NDIS participants chose their service providers. As in wave 1, those exercising choice were non-Indigenous and self-managing NDIS funds; some had been able to access therapy services outside the region.
- The lack of local disability services was evidenced to be the main impediment to improved choice and control in both waves 1 and 2.

*Before the NDIS I was receiving support with Home and Community Care... I'm still using their services now that I'm in the NDIS because they are the only support people available but I'm fortunate that they are a really good bunch of people as well.... there are no other service providers. (F01\_PWD W1)*

*There is no personal choice because there is nothing to choose from. Those fundamental things are just completely missing. (F21\_C W2)*

- Some respondents attempting to access alternative service providers when implementing their NDIS plans expressed concerns about a lack of organisations willing to provide services outside normal business hours.

*Yeah in theory. In practise they don't provide services after hours or on weekends....That's outside the brief of NDIA. They can't demand what service providers do, it's a business... if it's not in their interest to provide you can't force them to or they'll go broke. Because (name) needs half an hour support on a Saturday night... she needs support to get to bed but if they call someone in they have to pay them three hours overtime which costs them a bomb but we can't reimburse them for three hours overtime, we can only reimburse for the NDIS agreed rate for the amount of time that (name's) had help. Which means they are significantly out of pocket to do anything for (name) out of hours. (F01\_PWD & C W1)*

- However, there was some limited evidence that service providers in NT were slowly adapting to the NDIS and becoming more flexible in their service practices.

*I do feel I have autonomy in we're not just doing what they dictate... my now that we've been doing NDIS for a while, (service provider is) comfortable with knowing that they're personal care assistance with me is not limited to what they were restricted with earlier in the different funding before I went into NDIS... Well there was no disability... So it had to be an aged care package because it was the only thing that even remotely fitted, but it didn't fit very well as you can imagine... And if it wasn't part of the each package then they couldn't do it. Yeah. And quite often we got services because that was what we could provide rather than that was what (was) needed. (F01\_PWD&C W2)*

#### *The perspective of people with disability not participating in the NDIS*

- A limited provision of disability services in the comparison site also restricted options for people with disability not participating in the NDIS to change services.

*Services could improve... cause there's a lot of people with disabilities in this town, with physical or mental. The services are lacking. (F02 C C W1)*

- Even when services were available, some respondents described the problem of having infrequent service provision. This was especially apparent in relation to allied health therapies and led to concern about the detrimental impact for the developmental progress of young children with disabilities.

*You get a speech therapist, she had one last year that came in and did a couple of things on her... But you wouldn't see one for two or three years... And if they do, if something is doing there's only so many lessons that they'll, or appointments you can have... And no-one comes back. You don't hear of them again. (F01 C C1 & C2 W1)*

- One respondent was quite frustrated by perceptions of his disability service providers failing to listen to his needs, thus limiting his options for choice and control.

*I normally get staff telling me what I'm doing at a certain time. Instead of getting asked what I'd like to do, or if I want to be involved. (F05 C PWD W1)*

- Indigenous people with disabilities appeared disproportionately impacted by limited availability of, and options for choosing, their disability support workers. Examples were given of staff providing culturally inappropriate care. This situation was thought to be exacerbated by the perceived lack of safety in Town Camps and constraints this imposed on service provision: 'Most of the current service providers who do personal care and housekeeping and shopping won't go into the camps here' (F05 C C W1).

#### *The perspective of the service provider and peak body organisations*

- In wave 1, among the peak bodies and disability service providers, there was evidence of support for the NDIS principle of choice and control. Some respondents considered that the focus on participant choice made providers more accountable. There was, however, common acknowledgment that choice was, and continued to be, considerably constrained in the Barkly trial site due to a lack of disability services and providers, particularly in remote Aboriginal communities. Scant evidence was therefore provided of increased choice and control for people with disability with the roll-out of the NDIS. Some respondents concluded that the NDIS model which assumed enhanced participant choice would generate increased competition in the disability services market was unsuitable in the Barkly trial site.

- In wave 2, while choice was still ‘very limited’ it was ‘heading in a positive direction’ (F03P W2). Most observations about increased choice concerned NDIS participants having more say in choosing what they wanted, particularly around equipment provision.

*It’s good that the NDIS is actually rolling out across the Territory, gives a different perspective and gives people a bit more of a, what do you call it, and whether it be choice or not we don’t know, but it’s that concept of choice and that ability to say, ‘Well, I can buy whatever I want. If I want to go, I’ve got this, then I can buy, I’ll go down to Adelaide, I can access this,’ and it’s something that’s never been there before, and that’s new. (F07S W2)*

- However, in wave 2 it was again commonly reported that a lack of service providers in the Barkly region restricted choice and the appropriateness of the NDIS model for remote regions continued to be questioned.

#### *The perspective of the NDIA staff*

- In wave 1 NDIA staff were focused on building capacity for participants to be able to exert choice and control over their services. Particular focus was given to Aboriginal participants who had often been afforded little or no say over their services or other aspects of their life in the past.
- NDIA staff in wave 2 provided limited examples of participants exercising increased choice and control. These examples focused on participants requesting particular types of mobility aids and different service providers. Further promotion of the concepts around choice and control had been undertaken with participants and interpreters used to allow participants to speak for themselves and make their own choices.

*No, they’ve made some new changes. There’s some participant made new changes with their plans this year...Yeah, now they’re asking for a lot of different other things now...People are asking to get out, like some people, they want to change their type of mobility they’ve got, you know, the mobilised wheelchairs, they want to get better ones that’s got more stuff on it. And...Yeah, some people ask for different type of service now, they want, change from their other service to another service. (F17N W2)*

- The lack of a provider market within the Barkly region was seen as being a major barrier to effective choice and control. Also given the historic lack of choice around service provision for the Indigenous population in the region, many Aboriginal participants were reported to find this concept difficult to understand and put into practice.

*So it’s a very long journey and I think that’s going to take a lot of years and that’s no different over here as well because people are used to being told what they can have. All of a sudden we’re saying well actually you can choose. (F05N W2)*

*People aren’t used to choice and control, definitely not used to the choice, that’s for sure. (F12N W2)*

### **11.6.3 Self-management**

#### *The perspective of NDIS participants and their family members or carer*

- In wave 1, only two participants were self-managing their NDIS funding; these were non-Indigenous people, with strong English literacy skills and high levels of awareness of the requirements for self-management. One Indigenous participant proficient in English felt she would like to undertake self-management with appropriate training, yet this option had not been put to

her. Another Aboriginal respondent believed that staff had advised that self-management was not an option at this stage.

- In wave 2, self-management remained uncommon amongst respondents, however, four respondents now reported self-managing all or part of their own or their family member's NDIS plan. These respondents had good English literacy skills and self-management was not restricted to non-indigenous participants. Offers to self-manage from the NDIA remained inconsistent; several respondents reported being offered the option while others stated it was not discussed with them during interactions with NDIA staff. There was some evidence that NDIA staff were providing more information and support for self-management than in wave 1.
- Self-managing provided opportunities for increased control over budgets and supports and increased choice of service provider.
- Challenges reported by those undertaking self-management included the administrative requirements. There were also concerns about the need to pay up front for services before being reimbursed by the NDIA and a lack of clarity about legal liability if using unregistered service providers. Concerns were also expressed that self-management could leave some NDIS participants vulnerable to exploitation or 'humberging' by family members and others.

*'No, I'd rather someone manage it, because there's too much... other people that can't be trusted...I would manage it myself, because I'd understand. But what I see in a lot of my people, they still don't understand how to manage money. And then on the other hand they have families that will take, take a lot. I see it all the time. They'll take a lot of money off family members that don't know how to manage their own money. (F01\_PWD & C W1)*

#### *The perspective of the service provider and peak body organisations*

- In both wave 1 and 2, disability service providers and peak bodies offered very few insights into the self-management of NDIS funding in the Barkly trial site. Providers had limited experience of self-managing participants in the trial site.
- Several respondents noted particular barriers to self-management for Aboriginal NDIS participants and families including problems of trust with government programs, financial abuse and a lack of capacity to self-manage due to language barriers.

#### *The perspective of the NDIA staff*

- In both wave 1 and 2 NDIA staff reported that the incidence of self-management in the Barkly region were very low. Those few participants self-managing their plans were observed to be non-Indigenous. Although acknowledging that further work needed to be done around self-management, NDIA staff reported that this was not a current priority within the trial site.
- Challenges to self-managing in the Barkly region centred on concerns about the suitability and capacity of participants to self-manage. This included the lack of access to IT resources and therefore use of the portal, as well as concerns about the risks of exploitation and 'humberging'. In addition, NDIA staff acknowledged a lack of interest in self-managing by participants, who were seen as not being keen to take on the associated responsibilities.

## 11.7 Reasonable and Necessary Supports

### *The perspective of NDIS participants and their family members or carer*

- In wave 1, NDIS participants were unclear about what constituted ‘reasonable and necessary’ supports, particularly in regards to transport. There was considerable evidence about how little people sought for themselves, either through not knowing what would be reasonable to request or through not wishing to prevail on others or be viewed as ‘a burden’ on society.
- In wave 2, respondents remained unclear about what supports were considered reasonable and necessary by the NDIA. For some respondents this confusion was exacerbated by the inconsistency among NDIA staff about what could and couldn’t be included in NDIS plans. Other respondents were unsure about what supports were available or what they could ask to have included in plans.
- Carers’ needs were not prominent in the plans, and funding for this was limited.

*Well I don't think I rate too much of a mention in that area. (F04\_C W2)*

*They were very clear about that; the plan is for (name) they are not in the business of supporting the carers, other people get funded to do that. (F01 PWD & C W2)*

### *The perspective of people with disability not participating in the NDIS*

- Many respondents in the comparison site also indicated a lack of, or limited funding for disability supports and services. This included restricted funding for personal support or respite hours, home modifications and transport.
- Some non-NDIS participants indicated that these gaps in funding led them to have out-of-pocket expenses. The impact of limited funding for transport was particularly problematic, with significant costs involved in travelling long distances to access services, or to enable the person with disability to connect with family and country. Others noted the financial impost of acquiring vehicles suitable for wheelchairs or of disability adapted recreational equipment (both required to facilitate the independence and participation of the person with disability).

### *The perspective of the service provider and peak body organisations*

- Peak bodies and disability service providers considered that NDIA staff in the NT lacked the disability specific skills and experiences required to understand what were reasonable and necessary supports.

*I suppose when the planners sort of are, don't necessarily have the skills to identify, oh okay this is clinically indicated, or this is, yeah this is necessary. (F12S W2)*

- Some respondents claimed that NDIA staff did not utilise reports from allied health professionals when assessing appropriate supports to include in plan. Planners were reported to ‘receive reports but they don’t actually read them’ (F18S W2) and don’t ‘necessarily understand the recommendations’ (F06P W2).

*They always throw the line back at you, ‘Oh, we only fund what’s reasonable and necessary.’ And I just say straight back, ‘Well, the physio has recommended this. This person needs this equipment, so clearly it is reasonable and necessary.’ Yeah, they don’t have that background, like I said before, so that’s where it falls apart I think in that part. (F18S W2)*

### *The perspective of the NDIA staff*

- In wave 1 NDIA staff reported that communicating the concept of ‘reasonable and necessary’ supports was a key component of the planning process. Although staff did not feel that this was understood well by participants,
- Challenges remained around enabling participants to understand that there were supports available to them.

*I think it's more about getting people in the Barkly to understand that they, there are supports there. You don't have to just make do. So I think there's a bit of work there that needs to be done. [NT09N W1]*

- In wave 2, however, NDIA staff were not confident that the concept of reasonable and necessary supports had been successfully communicated to, and understood by, participants.
- Moreover, it was observed that the determination of what can be considered reasonable and necessary supports was now conducted through internal decision making about the funding for supports rather than being shared with participants. There were indications that the new customer relationship management (CRM) system facilitated this decision making for NDIA staff.

*I think we've used 'reasonable' and 'necessary' more so under the decision tree to work out what we think is reasonable and necessary to make a decision on the delegate's behalf, but I don't think most of our participants have exercised that real decision-making or thought on what they think is reasonable and necessary. (F12N W2)*

*Well it's all in the CRM now, like, before we used to have to do a manual decision tree which really made you think about it. So, and you had to, it was quite wordy 'cause you had to but now when you, in the CRM when you get to the end, you submit your plan it's all there. You've still got to put in why it's reasonable and necessary 'cause obviously someone else has to approve it but it's much simplified, so just you slide the button, yes it's approved or yes it's, I mean, you wouldn't put it in there if it wasn't reasonable. (F15N W2)*

## **11.8 Participation (Social, Economic and Educational), Wellbeing, and Aspirations (Goals)**

### **11.8.1 Wellbeing, social, educational and economic participation**

#### *The perspective of NDIS participants and their family members or carer*

##### For NDIS participants

- In wave 1, there were some improvements in wellbeing, quality of life and social participation for those NDIS participants in the Barkly trial site who were involved in the development of their NDIS plans or had strong advocates.

*There wasn't a lot going for him. He would just be either in the wheelchair or on his mattress that he was sleeping with on the floor. So through NDIA coming he's been able to receive funding for a hospital bed that suited to his needs. So it started from having access to the therapies that he needs like the OT coming to assess him, everything that he needs. So he's come from sleeping on a dirty mattress with really not much there to a nice comfortable safe hospital bed and a good wheelchair that's accessible for him but also, like, play mats and*

*things that he doesn't have to be in the wheelchair all the time. ... just looking at him of interacting with the others and he just seems in a better place and just happier.'* (F21\_C W1)

- However, the full extent of possible improvements to wellbeing and quality of life were constrained by limited disability services being available.
- For others who remained unclear or uninformed about the NDIS, the impact on their lives was negligible.
- In wave 2, respondents continued to report some positive impacts of the NDIS for participants. Most commonly cited were benefits from equipment provision; in particular equipment supporting mobility had led to opportunities for greater community access and social participation.

*The impact of my new chair, because, yes, it's been a good impact on my ability to be out and about... it's given me a better frame of mind, more positive attitude... And all the social benefits. Because this chair can lift up to high level sitting, so communicating with people at eye level, but also can stand fully vertical and then talk to people just normal, normal conversation.* (F01\_PWD&C W2)

- Several respondents noted the positive impact of engaging in activities and community access, in some instances supported by disability support workers. However, in most cases, satisfaction about increased social participation were tempered by concerns about a lack of skill development being funded or delivered to these participants which limited their future potential.

*He was a young man, about 27 years old, who'd never ever experienced much outside of Tennant Creek. And so the NDIS has been invaluable... since he's been with the NDIS he's been to football games in Sydney... he's gone (elsewhere) for some Gospel stuff as well... He probably just needs someone to actually look at his life, look at all the options that he has, and direct him to those. Because he is so high functioning. If there was a computer course in Tennant Creek and he could be directed to it and helped... he certainly needs someone to help gather all those threads that were happening for him and like tie it together so that it became something that would enhance his life. And develop his skills.* (F18\_C W2)

- Finally, although evidence of increased economic participation amongst NDIS participants was very limited, several respondents did report NDIS participants entering employment as a result of their involvement in the NDIS.

*She works two hours a week at (local organisation), and then she has four other hours during the week where she goes to the (disability service provider) team, and hopefully this job that's coming up (in another organisation), she'll have work three hours Monday, three hours Friday, and then the other days, Tuesday, Wednesday, and Thursday, she'll have a couple of extra hours at (local organisation during summer)... So there's small things in the pipeline. It's just been a long process.* (F24\_C W2)

#### For carers

- In wave 1, several respondents noted positive outcomes for carers and families as a result of the NDIS. These included reduced concern about who would care for the NDIS participant in the future; and financial relief as a result of NDIS funding items previously being paid for out of household income. The NDIS was also thought to have improved the physical wellbeing of some carers with the provision of new equipment for the NDIS participant. As one mother revealed: *'It's really good, getting more service now... got nothing before...they bought him (a) new hoist, before I use to lift him up with my hands and I hurt my back.'* (F13\_C W1)

- In wave 2, respondents again reported positive outcomes for families and carers as a result of the NDIS. For many there was also a sense of relief that the support needs of the person for which they were caring were no longer solely their responsibility, particularly as they aged.

*I appreciate the whole thing about NDIS coming and working in with giving (NDIS participant) that support at the ground level through (provider organisation). You know now and it's taken a lot of pressure off me as you can imagine. (F03\_C W2)*

*(I'm) more relaxed. You know, because he's doing things for himself... because that's what I want him to do. So he can be independent when I get old or something else happen. (F14\_C W2)*

- Others advised that supports funded for participants within NDIS plans had provided carers with opportunities to contemplate employment or study.

*Right now with the support (NDIS participant is) getting it just frees me up. To do more study. To do travel, to work. So I'm not worrying about him, you know. Sitting at home and doing nothing. (F03\_C W2)*

#### *The perspective of the service provider and peak body organisations*

- In wave 1, while the full impact of the Barkly NDIS trial was yet to be realised, it was anticipated that the NDIS would bring beneficial outcomes for people with disability. The person-centred philosophy of the NDIS was expected to empower people with disability and enable them to have increased control over their supports. It was also anticipated that by being enabled to direct their own goals and supports, the quality of life for NDIS participants would be improved.
- In wave 2, the impact of the NDIS on wellbeing was mixed. Some peak bodies and disability service providers reported that there had been an overall improvement in the wellbeing of participants as a consequence of better access to equipment and assistive technology that suited their needs. Improvements were also noted in the lives of people with disability needing supported accommodation.
- However, some respondents considered that there had been little improvement in the wellbeing of people with disability and their families and carers under the NDIS. This was due to the poor quality of some NDIS plans which failed to adequately address participant needs.
- In particular, there were concerns that the number of people with disability living in the Barkly region was considerably higher than the number of NDIS participants identified and with active plans. There were also concerns about service gaps for people with mental health conditions who were deemed ineligible for the NDIS, people with disability who were homeless and those transitioning out of the justice system.
- In wave 1, disability service providers and peak bodies reported little evidence of increased social participation as a result of the NDIS trial in the Barkly region. However, at the time of these interviews few NDIS plans had been implemented in the trial site.
- By wave 2, evidence of an increase in social participation among NDIS participants in Tennant Creek was emerging. Examples cited included clients attending Men's Shed, more people with disability being visible in the community and an increase in the frequency of community outings for some people living in supported accommodation. However, other respondents did not believe that social participation had improved for NDIS participants, in part due to few options in remote locations.

- In wave 1, disability service providers and peak bodies provided no evidence of increased economic participation amongst NDIS participants in the Barkly trial site, again in the context of few implemented NDIS plans. However, several peak bodies were enthusiastic about the potential of the NDIS to facilitate economic participation in future including in remote aboriginal communities.
- A lack of employment opportunities throughout the Barkly region, including Tennant Creek, was highlighted in the wave 2 interviews as a barrier to increased economic participation for people with disability. Consequently, evidence of increased economic participation as a result of NDIS funded supports was limited to individual examples. These included two NDIS participants who had entered employment, a single parent of a child with disability able to return to work, and the partner of an adult with disability able to increase work hours and travel for work. There was no evidence reported of the NDIS impacting on employment opportunities in remote Aboriginal communities.

#### *The perspective of the NDIA staff*

- Overall, it was believed that the NDIS had a positive impact on the wellbeing of participants. Staff felt that *'the people feel that the trial is theirs (F01N W2)'* and that it had made a difference in people's lives, especially because prior to the NDIS many of the participants had not been receiving any supports.
- Improving the social participation of NDIS participants was a primary focus for NDIA staff in wave 1. In particular, efforts centred on the provision of cultural activities and supports which increased community inclusion.
- In wave 2, NDIA staff reported focusing on providing people with funding for mobility aids and community participation supports. These included the provision of activities such as cultural outings, and taking participants to musical and sporting events.
- One concern for NDIA staff around social participation was the need to go beyond simply delivering supports around attending community events to provide services that built capacity and helped people with disability to interact more fully with their community.
- In wave 1 NDIA staff observed that improving the economic participation of NDIS participants in the Barkly region was problematic due to the lack of employment options in the region. Although a few isolated examples of progress in this area were cited, overall staff felt that they more systematic approaches were needed around economic participation goals.
- At the wave 2 interviews, the economic participation of participants continued to be much less of a focus for NDIA staff than was social participation. NDIA staff were again able to cite a few isolated examples of people with disability or their family and carers making progress towards their employment goals. In particular, it was noted that a number of participants had been employed as staff within the NDIA.

## **11.9 Fairness, Equity and Access**

### **11.9.1 Eligibility and navigating the NDIS system**

#### *The perspective of NDIS participants and their family members or carer*

- In wave 1, non-Indigenous participants were more aware of the NDIS and better informed about the NDIS than Indigenous participants. It was suggested by some respondents that NDIA staff were

not initially well prepared for engaging with the Indigenous populations. Limited knowledge and awareness of the NDIS was particularly evident for those in remote communities.

- All but a few respondents were confused between whether the NDIS was service provider or a funding source.

*One thing I've noticed ...people don't understand that NDIS is a funding scheme, they're not a service provider. So they'll say like you know NDIS should do this or NDIS should do some more home care, it's like well no, they just pay the bills. It's like the insurance company, you wouldn't expect the insurance company to fix your car when you have a crash, you get the crash repairer to do that. And I don't think people are very clear that NDIS is just the insurance funding scheme. All they do is pay bills. (F01\_C W1)*

- In May 2015 the NDIA sponsored a football match in Tennant Creek. From that point, awareness of the NDIS improved as people began to associate the purple branding of the NDIS with the new 'NDIS mob' that had come to town to help with disability issues.

*It was really good when they had that NAIDOC week, NDIS put a thing there at the oval... there's lot of people in wheelchairs end up going... NDIS mob was running that program... next year come again should do another one. (F13\_C W1)*

*He enjoyed the football, NDIS mob they wanted that special football... he went along and he enjoyed that one...Lot of people, we were all wearing purple hats. (F14\_C W1)*

- In wave 2, it was evident that while awareness of the NDIS was more widespread, knowledge about the NDIS remained limited. Many respondents, and particularly Aboriginal respondents, were unsure of what supports could be funded by the NDIS, how to access supports outside the region, and how to implement NDIS plans.
- NDIA staff turnover and a lack of public presence of NDIA staff in the community, hampered ongoing engagement with the NDIS.
- In wave 1, potential participants of the NDIS in the Barkly trial site were mainly identified through the client lists of existing services, particularly health services. Most participants' transition into the NDIS had occurred following NDIA staff making direct approaches to these individuals. However, there was a concern that some people with disability may not have been identified by these processes unless local advocates ensured they came to the attention of the NDIA. This was particularly the case for people living in remote communities.
- In wave 1, a range of concerns regarding eligibility for the NDIS and transitioning into the NDIS were expressed. Many respondents were unclear about how the NDIS defined disability and how eligibility was determined. Some indicated that obtaining assessments to establish eligibility was difficult and time consuming. It was therefore feared that many individuals who would be eligible might be missed because they did not have the resources or opportunity to establish their disability.

*Because (NAME) was diagnosed out of Adelaide through a particular organisation down there, ...they wrote a full descriptive report on (Name's) autism. I gave them that when I enrolled him and they used that to determine his eligibility...No problem at all, but it was only because he had that diagnosis first. What I will say is without a diagnosis there is very little you can get in terms of support, and I think that's the hardest thing for a lot of families living here is getting the diagnosis and knowing ...the system and what to do. I pushed, I really*

*pushed for the appointments and the doctors and everything. Without the pushing it can take a long time. (F33\_C W1)*

- Being a remote area, the choice of services to conduct eligibility assessments were limited. One participant had to have eligibility assessed through the Aged Care Assessment Team (ACAT), which was seen as being inappropriate given her young age.
- In wave 2, individual reports concerning eligibility issues were less evident due to respondents having already gone through this process. The NDIS were reported, however, as not currently accepting additional NDIS participants into the NDIS in the Barkly region.

*NDIS are aware that I'm wanting to put him on. He's eligible for it. But their quota is for - their quota is 154 for the region, and that's participants and funding. They're over that now, they're edging closer to 200 at the moment and they can't take any more on. (F33\_C W2)*

- Also in wave 2, general concerns were raised about how people with disability, in particular those with mental health conditions or living in remote Aboriginal communities, were identified and transitioned into the NDIS; some people were feared to be 'falling through the cracks'.

*In the Barkly they withdrew the [NT Government] services, there was nothing to catch them or help them in that process and all these clients have fallen through the cracks... what happens with the mental health clients? And my understanding is that there were a lot of mental health clients who were referred to NDIS, which were rejected. And now in looking at them, it's like well they were rejected because there was insufficient information or evidence. (F21\_C W2)*

*So the agency refused to on the basis of privacy, refused to share information about who they had rejected from the Scheme... so therefore people were receiving letters out at (remote Aboriginal community) with a 28 day you've got to respond rate, response rate, but of course they couldn't speak English or read or write English and so therefore they would not know that they were being rejected by this new thing called the NDIS. (F37\_C W2)*

- In wave 1, respondents offered suggestions for improvement of the NDIS. Recommendations were made regarding the need for flexibility in NDIA processes when approaching diverse populations with disability. This included improving the engagement and understanding of Indigenous participants by developing pictorial planning tools and employing key local liaison people (but understanding some participants may prefer not to use these officers for privacy reasons); allowing local based health professionals to authorise certain support items to overcome difficulties in getting assessments for services and equipment; and the need for accountability and evaluation. Suggestions regarding NDIA staffing included the need for staff training in cultural safety and intercultural communications; up-skilling local staff to be able to manage minor problems on the ground, including education about specific conditions and repair of equipment; and significantly increasing the level of staffing within the Barkly region in recognition of the size and complexity of the region.
- In wave 2, recommendations to the operation of the NDIS in the Barkly region focussed on workforce development strategies and funding for training. Respondents also recommended that the NDIA employ staff with disability knowledge or provide more training to staff in disability as well as administrative procedures.

*Qualified staff for starters. Because a lot of the staff have no idea about disability at all, no idea... I'm not saying they have to go out and get fully qualified and, you know be 100 per*

*cent, you know, have certificates hanging off the wall but at least have some sort of experience. (F06\_C W2)*

- Other suggestions included more funding in NDIS plans for support coordination; a greater focus on quality and safeguards; improvement in communication between health services, disability support providers and participants; improved NDIA cultural responsiveness in communicating with Aboriginal people; and the development of more respite services in the local region.

#### *The perspective of people with disability not participating in the NDIS*

- Even though the NDIS trial and control sites (Barkly and Alice Springs, respectively) are within relative proximity within the NT, participants in the comparison group were largely uninformed about the NDIS.

*Well I was oblivious really, and then I started looking into it. I'm under [funding name] so that won't affect me will it? I don't know. I honestly don't know. (F12 C C W1)*

*Never seen ads or heard about it. (F01 C C1&C2 W1)*

- In wave 2, despite the NDIS roll-out scheduled to commence within the next month in the comparison site, respondents (even those working in the disability sector) continued to report little knowledge of the NDIS and were unaware that an NDIA office had opened in town.

*No one's certain, and then when you try to push to find any more information it's always said, 'Well, we don't know yet. Nobody knows yet.' It's like, 'Well guys, this is coming close.'... We're not prepared... We just really don't know how it's going to work... I don't think they've even got their office set up yet. Five weeks out and I don't think they even actually have an office in town. I'm pretty sure they don't. So it's very unpredictable, very disorganised, but that doesn't surprise me here. (F05 C C W2)*

- Respondents felt there was a need for the NDIS to be more effectively promoted prior to roll-out.

*It would be really good to have a forum... here before it's implemented, with all the allied health people and service providers and all the people that really need to be involved. (F01 C1 & C2 W1)*

*Need to promote it more– training or resources for the employees who are caring...1800 number or something. (F08 CC W) 1*

#### *The perspective of the service provider and peak body organisations*

- In wave 1, peak bodies and disability service providers advised there was a general lack of awareness of the NDIS amongst people with disability in the Barkly region and as a consequence there had been lower than expected demand to join the NDIS.
- In wave 2, respondents reported that while awareness of the NDIS and the NDIA had increased, actual understanding of the NDIS remained poor. Respondents thought that on the whole people were confused about how the NDIS worked, whether they would be eligible, what was offered and whether the services they had received previously would continue. This was reported in both Tennant Creek and in remote Aboriginal communities.

*I think there's still perhaps a little bit of confusion around how it actually works and what they're entitled to perhaps. (F15S W2)*

*I think there's a consensus that most Aboriginal individuals and families, and communities engaged by the NDIS have a pretty poor understanding of the Scheme. (F02P W2)*

- Several respondents considered the building where the NDIS was located in Tennant Creek acted as a barrier to participation in the NDIS and limited the interaction of NDIA staff with Aboriginal people.

*The building that they're in. It used to be the government building. Well, it's still a government building, but the actual building, it took a long time before any Aboriginal people wanted to go into that building. They didn't understand that it had changed to NDIS and that NDIS was, you know, a helpful service. Also because they don't engage with the staff at NDIS up at that office; they don't know them, so they're not going to feel comfortable going there and talking about their health needs, their disabilities. (F18S W2)*

*That's the white fella building. That's where everyone comes for a certain time, says what they've got to say, then disappears. (F03P W2)*

- In wave 1, peak bodies and disability service providers reported a number of challenges regarding processes for determining eligibility under the NDIS. These challenges included the NDIA allowing insufficient time to engage with potential NDIS participants living in remote aboriginal communities, some Aboriginal people not identifying as having a disability or having a formal diagnosis, and uncertainty as to how eligibility determinations were made by the NDIA. Specific issues were raised regarding the eligibility of people with certain types of disability. The poor fit between the NDIS language of permanent disability and the episodic nature of some forms of mental illness for people with psychosocial disability was noted and queries were raised as to whether Foetal Alcohol Spectrum Disorders (FASD) were recognised by the NDIS as a disability.
- By wave 2, the most prevalent concern about eligibility for the NDIS, was the number of potential participants who had not yet been rolled into the NDIS. Respondents had received no information from the NDIA about future estimates or intentions regarding participant numbers in the NT. Concerns were raised that the number of participants would be capped due to bilateral target limits and a lack of acknowledgement of the level of disability in the region.

*So really when you look at the burden of disease in this region compared to others, and you're only given 150 plans and they're already maxed out, when you've got more and more coming back from Alice Springs with disabilities and yet we still have people in the community that do have a disability, however there's nothing that we can do for them in relation to NDIS, it's not acceptable. (F18S W2)*

- There were also fears that specific cohorts, such as those who had not previously accessed disability services prior to the NDIS, people with mental health conditions, the homeless and those in the criminal justice system would be overlooked.

*They're not actually supporting the needs of Indigenous people of this region under mental health... (but when block funding for mental health services ceases) there's going to be a gap, absolute huge gap. (F17S W2)*

*Homelessness is not getting picked up. I would think there's other groups that are at risk, so the people in prisons and institutional settings and on that pathway would be another group that I think would not be on the agenda, not be on the radar. (F07P W2)*

### *The perspective of the NDIA staff*

- In wave 1 NDIA staff were aware that longer time for engaging and building relationships with NDIS participants and service providers was needed in the Barkly region compared to other trial sites. However, facilitating this need was complicated by having temporary staff working in the trial site.
- Other barriers to engagement were related to the lack of knowledge about the NDIS amongst both disability and mainstream service providers. NDIA staff recognised that more could have been done in the early days of implementation to ensure the support of providers in promoting the NDIS to potential participants and the community more broadly.

*In the remote communities... even amongst the services, so whether it's the school, the health clinic, the Barkly Council staff, there's very limited understanding about who we are as a service or an agency... those people aren't as, I suppose, informed and on board as they could be. Because the way I look at it is that they're the people on the ground in the community, they're the people who can reinforce those positive messages about the NDIA and the potential benefits of the Scheme. (F04N W1)*

- It was also acknowledged that disability service providers had a lack of understanding about the processes involved in providing services under the NDIS. A particular challenge for NDIA staff was the high turnover of staff within the sector and the effort required to maintain relationships within this context.
- Another challenge for NDIA staff related to the historical lack of trust towards government organisations among the Indigenous participant cohort, at least in part a consequence of the 'stolen generation'. Other NDIA staff described perceptions that many government initiatives and interventions in Central Australia had failed to deliver, leading to considerable scepticism that the NDIS would be any different.
- Respondents (as in other trial sites) also noted that NDIA processes were difficult for many participants to navigate on their own. This was exacerbated in the Barkly region by low literacy rates in the area and the large number of participants for whom English was not their first language. This problem contributed to the need for NDIA staff to spend more time with participants to assist them with required documentation.
- In wave 2, while NDIA staff perceived awareness had increased, concerns continued about how well the community understood the NDIS.
- A number of cultural considerations were identified by NDIA staff in relation to working in the context of Indigenous communities. While these may provide some valuable learnings for the future operation of the NDIS in remote areas, each Indigenous community is unique and will have its own cultural considerations. Therefore working with Indigenous communities is not a 'one size fits all' (F10N W2) endeavour.
- NDIA staff from the Barkly trial site emphasised the importance of differentiating the NDIS from previous Government initiatives, most importantly from the Northern Territory Emergency Response otherwise known as 'The Intervention'. In doing so, the importance of clearly communicating what the NDIS is about, the role of trusted individuals from the community in spreading this information, and the time that will be needed to establish trust and acceptance in the initiative was highlighted.
- NDIA staff emphasised the importance of working closely with the community when establishing new NDIS sites in remote areas. Having local Aboriginal people working for the NDIA team was a

successful strategy which not only added credibility in terms of their cultural standing, it also had the added benefit of ensuring that the community felt 'open' to go into the NDIA office when needed. Increasing the presence and recognition of the NDIA team within the community also aided engagement.

- In wave 1, NDIA staff identified numerous challenges in establishing the eligibility of potential NDIS participants. Many potential participants did not retain records or evidence of their disability, resulting in NDIA staff being required to collate 'credible' evidence. This process was hampered by the reluctance of other agencies to share and exchange information in the early days of the NDIS. Locating potential participants, especially given the transient nature of much of the population in the region was also a challenge in itself.
- NDIA tools established to assist with making decisions regarding eligibility were considered unsuitable for the Barkly region context due to limited access to IT supports and a lack of information that was translated 'in language'.

### 11.9.2 Review and dispute resolution processes

*The perspective of NDIS participants and their family members or carer*

- Plan reviews were not yet occurring at the time of wave 1 interviews.
- In wave 2, respondents reported that the NDIA did not adequately involve participants and/or carers in the plan review process, provided insufficient information about plan review processes and other possible services and supports, and did not adequately consider changes in participant needs when reviewing plans. Reports were also given of a failure to review NDIS plans in a timely manner.

*She has now had her plan reviewed, even getting the plan reviewed was extremely difficult. We were having problems with getting copies of the plan, we couldn't get copies of it. (F21\_CW2)*

*The current plan (following review), it still doesn't have everything in it probably that (NDIS participant) would like. He wasn't, again, to his knowledge, consulted or sat down in a plan arrangement; he certainly hasn't been to the office in #Tennant Creek and he hasn't had planners come and meet with him. (F36\_CW2)*

- Evidence was provided of funding for therapy services being cut from NDIS plans at the time of review due to funding not being utilised because of a lack of available local services and limited travel funding to access services outside the region.

*Respondent: The kids are being, they're actually getting more visits from specialists provided by the school... they can charge some of it to kids plans, whoever's registered with the NDIS, but a lot of times it's actually done through the Education Department where, so that they can do their own in school evaluations of all their students... (The NDIA) said they took the money back (when the plan was reviewed) because it wasn't getting used.*

*Interviewer: And why wasn't it getting used?*

*Respondent: Because there was no providers. (F06\_CW2)*

- Respondents reported negative experiences with NDIA dispute resolution processes. Some had experienced difficulties in being able to contact the NDIA to lodge complaints due to calls through the national phone line not being answered or transferred to appropriate staff. Respondents also

indicated that the NDIS did not adequately respond or address complaints, or if they did, did not do so in an adequate timeframe.

#### *The perspective of the service provider and peak body organisations*

- In wave 1, respondents were not able to report on NDIS plan review processes as they had not been undertaken in the Barkly trial site.
- At the wave 2 interviews, respondents reported that rectifying problems identified by participants or providers with NDIS plans was difficult. This was due to NDIA staff being seen as lacking disability specific knowledge and skills. NDIA staff high turnover made follow-up challenging.

*The opportunities for providers to remedy what they consider to be defects in the planning are pretty limited and confusing, and certainly impacted by the experience, or lack of experience from the NDIA staff available to consult with them on these things. (F02P W2)*

*(If participants have) got something wrong with their plan, that person no longer works there, no one know what planner has that person's plan. I've actually seen this happen multiple times now. Even when I'm chasing one of my participant's plans, they have no idea which planner has the plan now. (F18S W2)*

#### *The perspective of the NDIA staff*

- In wave 1 NDIA staff reported that plan reviews had not yet been undertaken.
- NDIA staff acknowledged in wave 2 that plan reviews provided them with a means of reversing some of the 'bad decisions' made in the early days of delivering the NDIS in the region.

*I suppose the thing is that after the trial site, we're going to have to make some tough decisions and some providers aren't going to be happy because some of the decisions that were made initially were just made just to get people on the Scheme I think, I'm not really sure, but yeah, some bad decisions that now have to be rectified. (F15N W2)*

- There were concerns expressed, however, about the ability to review all existing plans in an adequate timeframe given the limited numbers of NDIA staff in the Barkly office.

### **11.9.3 Equity and fairness**

#### *The perspective of NDIS participants and their family members or carer*

- In wave 1, the evidence suggested that the NDIS in the Barkly trial site, had worked well for English-speaking and literate non-Indigenous people with disability and their carers. Those participants with strong advocacy from guardianship or individual service providers also reported better outcomes. The NDIS also appeared to work better for people living in, or close to, the major center (Tennant Creek).
- The NDIS worked less well for Aboriginal people living in remote communities and those without English language skills or advocates. For these people a lack of communication and, effective engagement with the NDIA was observed. Even where Indigenous respondents spoke English well and could communicate with NDIA staff, historical perceptions, misunderstandings, past experiences and beliefs may have hindered engagement and comprehension. Considerable confusion about the specific role of the NDIS and NDIA were also reported.

- In wave 2 there was some evidence of change for whom the NDIS worked well and less well. The NDIS continued to work better for those who were English speaking and non-Indigenous. However, whereas participants with advocacy had also previously reported better outcomes, Aboriginal participants with advocates and guardians were not faring well in wave 2, and efforts to review plans or raise complaints with the NDIA were failing to always have an impact.
- There was still evidence of considerable confusion amongst Aboriginal participants in particular about what was included in their NDIS plan, and in some cases, a lack of understanding of what had been discussed with NDIA staff and whether they even had a plan. For some of these respondents, confusion about the role and responsibilities of the NDIA and what was within the scope of the NDIS also remained evident in wave 2.
- The early stages of data collection in wave 1 in the Barkly region raised concerns about equity and fairness. Although the potential of the NDIS to be equitable and fair was acknowledged, there seemed to be inadequate preparation and resourcing of NDIA staff to undertake effective community engagement across the region. Thus some participants and service providers suggested that the number of people on the NDIA lists for enrolment (and particularly Aboriginal people with disability) would be an under-representation because of the difficulties of effectively engaging all sectors of the community.
- In wave 2, equity and fairness remained a concern. As in wave 1, it was suggested that the number of people on the NDIA lists for enrolment were an under-representation of the true number, and that some potentially eligible people had been rejected from the NDIS due to poor communication and engagement by the NDIA; as a result there was the perception that people were ‘falling through the cracks’. It was also noted that non-Indigenous participants were better serviced by the NDIS than their Indigenous counterparts. Concerns were raised about access to services for participants, in particular those living in remote communities.

*The perspective of the service provider and peak body organisations*

- In both wave 1 and 2, peak bodies and disability service providers considered that the model adopted for the Barkly trial site was not appropriate for Aboriginal people with disability. This model was not felt to fully understand or meet the real needs of Aboriginal people with disability. The NDIS’s focus on disability was perceived to be too narrow and inflexible to manage important health and social context issues within remote Aboriginal communities and address the prioritising of needs. Furthermore, the individualised approach of the NDIS was considered to be unrealistic and inappropriate when working with Aboriginal people with disability as it was contrary to the familial and community ethos of remote Aboriginal communities. All of these factors undermined engagement with the NDIS.

*Talking to families about, you know, allied health professionals coming out to work with their child in a months’ time or something is often really irrelevant when someone – when there’s not enough food in the house. I think that the NDIS should also have some capacity or some discretion, to a limited degree, to be able to respond to those sorts of situations, otherwise we’re always going to struggle to engage with remote people. (F04P W2)*

*Overall my view of the trial has been that it was completely unplanned how they would tackle this really new cross-cultural extremely remote, the model, the pricing, nothing was going to, you could foresee that all these things plus all the cultural differences and the extreme disadvantage, meaning that on the hierarchy of needs specialist disability services are relatively, are less important. (F04S W2)*

- Across both waves, respondents reported a number of challenges the NDIS brought for people with psychosocial disability and the provision of mental health services. There were fears that many clients with mental health conditions would be ineligible for the NDIS due to the episodic nature of mental illness and a lack of formal diagnosis especially among Aboriginal people. The permanent disability model of the NDIS was viewed as incompatible with the recovery model used in mental health services. Reports were given that most mental health clients were being ‘*found as ineligible, because it’s not, it can’t be determined that it’s a lifelong... permanent disability*’ (F08S W2).
- Fears were expressed over time that clients not eligible for the NDIS would be left without mental health services when block funding ceased.

*Well I think the tension for us if they’re not eligible for this Scheme, and there’s going to be no generalist community based mental health services, so it means that they fall into a gap, that’s I guess, to me it’s like there’s something missing from the Scheme that it’s not, it can’t pick up those people, particularly in a remote context, where there won’t be a formal diagnosis. (F08S W2)*

#### *The perspective of the NDIA staff*

- By wave 2 NDIA staff felt that overall the NDIS had successfully achieved equity and fairness for those who had entered the NDIS. It was considered that modifications to plans through the review process would further increase equity and fairness.
- Strategies to improve equity and fairness for NDIS participants included changes to the layout of the office to increase accessibility and NDIA staff engaging in storytelling in communities to ensure that information about the NDIS was given in culturally appropriate ways.

*I think the team done a great job with engaging and getting people to access, changing the office around and making it very office, you know people friendly, we yeah absolutely... And engaged communities in storytelling and, you know, displayed it in the office and yeah no they did a really good job. (F05N W2)*

- NDIA staff felt that the NDIS worked best for participants with physical and psychosocial disabilities, and in some cases for Indigenous participants. The provision of early intervention supports was also viewed favorably for children with disability.
- The NDIS was acknowledged to be less effective when there was a communication barrier between staff and participants. Language was a barrier which affected full participation in the NDIS for many participants in the Barkly region. Moreover, cultural sensitivities about what could be discussed and with whom created another barrier for NDIA staff in developing effective plans for Indigenous participants. Beyond these difficulties, challenges in the ability to engage and remain in contact with many NDIS participants in the region provided a further barrier to both NDIA staff and disability service providers in implementing the NDIS.
- Although improved outcomes were occurring, NDIS staff indicated a number of challenges specific to working with people with psychosocial disability in the Barkly region. Finding and engaging with potential participants in this group was more problematic as these individuals were perceived to be more likely to be itinerant and reluctant to receive services. Issues relating to establishing eligibility were also noted and ranged from the difficulty of ‘talking’ to mental health services that had a poor knowledge of the NDIS and the NDIS Act, to dilemmas around determining ‘permanency’ of disability for potential participants.

#### 11.9.4 Unintended changes resulting from the NDIS?

- There were many reports that the number of people with disability living in the region was considerably higher than the number participating in the NDIS. There were also fears that specific cohorts, such as those who had not previously accessed services prior to the NDIS, people with mental health conditions, the homeless and those in the criminal justice system were going to be overlooked. People with mental health conditions were considered particularly at risk as mental health providers reported that most of their clients had been assessed as ineligible for the NDIS and that the continuation of services for these people was uncertain.

#### 11.10 Mainstream Interface

##### *The perspective of NDIS participants and their family members or carer*

- In both waves of data collection, respondents reported little change to the type and frequency of mainstream and community services being utilised by participants since the roll-out of the NDIS.

##### *The perspective of the service provider and peak body organisations*

- In both wave 1 and 2, peak bodies and disability service providers noted the importance of good connections between the NDIS and mainstream and community services.
- Several local providers advised that good links had already existed prior to the NDIS between disability and mainstream providers in the Tennant Creek community and that these had continued with the roll-out of the NDIS.

*I think they all work in partnership with each other out of necessity, as the situation might dictate. Particularly in aged care, I think... there's a good collaboration with aged care and disability support in the Barkly. But other allied health services and broader health services I think the dynamic hasn't changed a whole lot... overall I think there's a general theme of cooperation. (F02P W2)*

- However, in both waves 1 and 2, respondents also noted a number of challenges that hampered connections between the disability sector and mainstream and community services. It was suggested by one peak body organisation that a lack of consultation by the NDIA prior to the Barkly trial had negatively affected working relationships.
- Respondents reported ongoing confusion amongst providers and the NDIA about funding responsibility between the disability and health sectors and a lack of clarity about NDIS eligibility criteria. These concerns included clients being turned back due to NDIA's insistence that they were 'Health's responsibility'. In contrast, a peak body was concerned that some people were accessing NDIS funding for conditions the respondent considered to be health related.

*There will be people we would have expected to be getting services through a palliative care response, or even just your mainstream health service response, it's around, well, how broad is that footprint because it's blurred some of those other mainstream service response lines. (F01P W2)*

##### *The perspective of the NDIA staff*

- In wave 1 relationships between the NDIA and mainstream sectors were believed to be strong. NDIA staff observed, however, that mainstream providers in the Barkly region had less knowledge

of the NDIS than did their counterparts in other sites. As a result NDIA staff had needed to take more of a role in promoting and informing community and mainstream services about the NDIS.

- In wave 2 NDIA staff felt that their relationships with mainstream and community services had further strengthened. This was attributed to a focussed effort on fostering relationships and sharing information with these services. NDIA staff did so by attending forums, engaging in collaboration and establishing advisory groups. They had also collaborated with the education sector to establish a referral process for schools to refer students to the NDIA team.
- The primary challenge for NDIA staff in relation to their interactions with mainstream services continued to be the disentangling of disability from other sectors and establishing the boundaries for responsibilities. It was noted that other services were 'antsy (F05N W1)' about the introduction of the NDIS when it was first rolled out in the region and, although now improved, had initially impeded the interaction with these services. Beyond this it was also observed that the NDIS funding model discourages linkages with mainstream services.

*Look, I think the funding model doesn't encourage the linkages, but I think what we've got to do is develop a bit more of a relationship base around how do you facilitate the coordination of service delivery a bit better. (F11N W2)*

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