



THE UNIVERSITY  
of ADELAIDE

# **NDIS Utilisation Project: Understanding Drivers of Plan Utilisation from the point of view of Participants**

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(FES)

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# 1. Executive Summary

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The National Disability Insurance Scheme (NDIS) is a consumer directed model of disability support that provides support to people with disability, their families and carers. It is jointly governed and funded by the Australian, state and territory governments.

A key concept underpinning the NDIS is the ability for people with disability to be able to access the supports budgeted for in their NDIS plans. One indicator of this is the rate of plan utilisation, or the percentage of the budgeted support plan a participant uses over the life course of the NDIS plan. However, the Productivity Commission's 2017 Inquiry raised concerns about low levels of plan utilisation amongst NDIS participants.

Using a qualitative approach, this study aimed to understand the dynamics affecting people's utilisation of their plan funds from the point of view of the participants and to study the potential levers/policy interventions in order to improve plan utilisation. The research targeted five cohorts that have been identified by existing research as being "at-risk" of plan under-utilisation: (1) NDIS participants with psychosocial disability, (2) NDIS participants living in regional and remote areas, (3) Indigenous NDIS participants, (4) NDIS participants from culturally and linguistically diverse backgrounds, and (5) NDIS participants with complex needs.

This consolidated report outlines the findings arising from interviews conducted with 161 NDIS participants and/or their family members or carers in five sites across Australia. These sites were South Western Sydney (NSW), Brisbane (QLD), Townsville (QLD), Eyre Western (SA), and Barkly (NT). The interviews elicited detailed information about NDIS plans, including what elements of plans were used or not used (and why), and the factors that were considered to impact on a person's ability to access the supports budgeted for in their NDIS plan. The main findings of the research are summarised below.

## 1.1 Factors facilitating higher plan utilisation

Five key factors were identified as facilitating the ability of NDIS participants to access the funding and supports provided for in their NDIS plans in the five research sites. These included two factors pertaining to NDIS participants and their family members, one factor relating to NDIS planning, and two factors associated with the disability sector market.

### 1.1.1 Participant factors

In order to effectively implement their NDIS plans, many respondents reported that good understanding of NDIS funding and the types of supports that could be accessed with this funding was required. The possession of knowledge of the disability services that were available within their local area was also considered to be important. This knowledge and understanding came from both formal sources such as support coordinators, service providers, NDIA staff and allied health professionals, and informal sources (e.g. Facebook groups and friends). Some respondents also had personal knowledge of the disability sector through their work experience or previous use of services.

Another factor which was suggested by respondents in all of the five sites as aiding plan implementation related to the effort and perseverance of NDIS participants and family members to ensure that they obtained appropriate funding and disability services. Some respondents described advocating on their own, or on a family member's behalf to ensure that the funding and supports received from the NDIS fully met their needs. This included instances of successfully advocating to the NDIA for increased funding or taking complaints to the Administrative Appeals Tribunal when it was

considered that the initial plan did not adequately meet their support needs. Some respondents had also spent considerable time identifying and arranging appropriate disability services.

### **1.1.2 Plan factors**

Having access to funded support coordination was highlighted by many respondents as a key factor which positively influences successful plan utilisation. Support coordinators were considered to be a vital source of information, with respondents valuing their support coordinator's knowledge of the NDIS and local disability services. Support coordinators were described as recommending appropriate services, connecting NDIS participants with service providers, and helping to arrange funded supports. Once services had been arranged, the support coordinator was able to liaise with the provider organisation to monitor service provision, deal with any issues which arose, and organise the payment of invoices. Support coordinators were also described as playing a key role in interactions with the NDIA. Without this support, some respondents stated that they would not have known how to use their NDIS funding and organise appropriate services for themselves.

### **1.1.3 Market factors**

Support from disability provider organisations and workers was a factor identified by respondents in all five sites as strongly assisting NDIS plan utilisation. Disability providers were seen by respondents as playing an important role in arranging and coordinating appropriate (and at times, flexible and personalised) supports, and - if they could not provide a service themselves - giving recommendations for alternative providers. Individual workers within the disability sector were also identified by respondents as assisting with NDIS plan utilisation and of being important sources of information and support. These workers included disability support workers, medical staff, plan managers, NDIA staff and (of particular note) allied health professionals and disability advocates. Having disability workers who were skilled, experienced, and understood how to meet their specific support needs, also encouraged better utilisation of NDIS funded supports and enhanced NDIS participant's willingness to engage with disability services.

A final factor found to positively impact upon NDIS participants ability to access supports and services provided for within their plans was the availability of disability services within the local area. Having ready access to disability services was strongly felt to increase the uptake of NDIS-funded supports.

### **1.1.4 Which facilitators predominate**

The most common factors reported by respondents in all five sites as aiding plan utilisation were – access to support coordination (plan factor), support from disability provider organisations and workers (market factor), and having knowledge and understanding of NDIS processes and service provision (participant factor). Hence higher plan utilisation was considered to be supported by a combination of participant, market and plan factors.

## **1.2 Barriers to plan utilisation**

Twelve factors that negatively impacted NDIS participants ability to utilise the funding and supports provided for in their NDIS plan were identified in the qualitative interviews across the five research sites. These barriers included five participant, three plan and four market factors.

### **1.2.1 Participant factors**

Respondents nominated five factors pertaining to NDIS participants and their family members which were felt to act as a barrier to plan utilisation. These included (1) knowledge and understanding of

NDIS processes and local service provision, (2) precedence of non-disability needs, (3) managing appointments, (4) reluctance to accept disability services, and (5) the use of technology. Of these barriers, a lack of knowledge and understanding of NDIS processes and local services were most widely seen as impeding plan utilisation.

A very commonly expressed barrier to plan utilisation related to a lack of knowledge and understanding of NDIS processes and how to implement NDIS plans, with many respondents (and especially those in the Barkly region) reporting that they had received insufficient levels of information regarding their plans and local disability services which made it challenging to utilise their NDIS funded supports. The information that had been provided by the NDIA was described as being too complex and not broken down in a sufficiently understandable way. While this barrier has been categorised here as a participant factor, this issue was largely seen by respondents as resulting from NDIS participants not being provided with sufficient and/or accessible information from the NDIA (which could be considered to be a plan factor).

Within the Eyre Western and South Western Sydney regions some respondents reported that at times pressing personal, financial and health issues meant that the arranging and accessing of disability supports was not necessarily a top priority for NDIS participants and their families.

Difficulties experienced with arranging and attending NDIS-funded appointments was considered by some respondents within the Eyre Western and Townsville research sites as hindering their ability to utilise all of their allocated funding.

It was acknowledged by respondents that some NDIS participants were reluctant to accept disability services. This was considered to be due to several reasons including difficulties experienced with provider organisations or workers which led to respondent disengagement, and also personal and cultural preferences.

One further stated participant factor which acted as a barrier to plan utilisation within the Barkly region related to the use of technology. Virtual modes of service provision hampered effective engagement and presented challenges for NDIS participants who did not have access to the internet or the skills necessary to participate in virtual activities.

### **1.2.2 Plan factors**

Three factors relating to NDIS planning and processes were identified in the interviews with NDIS participants and their family members as impeding successful plan utilisation. These were (1) NDIS planning and approval processes, (2) support coordination services, and (3) use of the NDIS portal. The first two of these barriers were especially seen by respondents as hampering successful plan utilisation.

Challenges experienced by respondents with NDIS planning and approval processes represented a key barrier to plan utilisation. Processes were said to be too complex and time consuming, and uncertainty was also expressed regarding the types of supports that the NDIS would fund. A lack of timeliness in the approval and allocation of funding was also reported which had prevented some respondents from obtaining needed supports and services in a timely fashion.

A lack of access to quality support coordination services was a further barrier identified by respondents in all of the research sites with the exception of the Eyre Western region as impeding successful plan utilisation. Some respondents had not been offered the option of support coordination in their planning meeting and several were unaware that funded assistance with plan utilisation was available to NDIS participants. Other respondents considered that the level of funding they had received for support coordination was inadequate and had quickly run out. This had negative implications for the arranging and monitoring of their disability supports. Concerns were also raised

regarding the quality of support coordination services and the time limited nature of it.

A final barrier relating to NDIS planning and processes pertained to the use of the NDIS myplace portal which was described by respondents as being confusing and difficult to use.

### **1.2.3 Market factors**

Respondents identified four factors associated with the disability sector market which were considered to negatively impact upon plan utilisation. These factors were related to the (1) availability of disability supports and services, (2) provider organisations and the disability workforce, (3) cost of disability services, and (4) the interface between the NDIS and mainstream sectors. The first two of these factors were particularly perceived by respondents as being key barriers to plan utilisation within their respective regions.

The availability of disability supports and services was a key barrier identified as impeding plan utilisation. The availability of allied health services (and especially speech therapy, occupational therapy and psychology) was a consistent issue described in all the sites. Problematic access to many other types of disability services was also noted and especially for NDIS participants with a complex disability or for those living in regional and remote areas. As a consequence, lengthy wait times for disability services were frequently reported which made it difficult to obtain certain NDIS-funded services in a timely fashion. It also impacted the ability of NDIS participants to have choice and control over their supports.

A further key barrier to plan utilisation that was reported by respondents in all the five sites related to issues experienced with disability provider organisations and workers. Difficulties with provider organisations centred on four key areas: the quality of service provision, the organising of services, staffing arrangements, and payment issues. Some respondents had also experienced issues with workers who were described as lacking the necessary attitude, experience and skills to provide quality care to people with disability. As a consequence of these issues some respondents reported that they had been forced to halt the receipt of services and change workers or providers.

Concerns were also expressed about the prices charged by disability service providers. In particular the rates for allied health services and group activities were reported by some respondents to be higher for NDIS participants than for non-NDIS clients.

The interface between the NDIS and mainstream sectors (including health, education, housing, youth justice and family services) was identified as a final barrier to plan utilisation by respondents in the Barkly and Townsville regions. Particular issues were noted in the interface between the disability, education and health sectors. The siloing of funds and services within sectors rather than a more holistic approach to the care of people with disability, was perceived by some respondents to be occurring and was affecting their NDIS funding and subsequent plan utilisation.

### **1.2.4 Which barriers predominate**

Of these barriers to plan utilisation, four primary barriers were highlighted by respondents in all of the five research sites. These included two market factors: the availability of disability supports and services, and issues with provider organisations and the disability workforce; one participant factor: knowledge and understanding of NDIS processes and local service provision; and one plan factor: NDIS planning and approval processes. A further plan factor - access to quality support coordination services - was a key barrier identified by respondents in four of the sites as impeding plan utilisation.

## **1.2.5 The temporality of barriers**

It matters a great deal for policy if the barriers NDIS participants identify are experienced for only a short time and are subsequently overcome or whether they occur for longer periods, are harder to overcome and therefore may reflect more systemic problems. We find that for most participant's barriers that are related to NDIS planning and processes are in general only experienced for a relatively short period of time and are overcome with time in the scheme as knowledge and understanding of NDIS processes increases. On the other hand, participant factors and market factors are generally experienced for longer periods by NDIS participants.

## **1.3 Impact of COVID-19 on plan utilisation**

Data collection for this study occurred in midst of the COVID-19 pandemic. While not a primary aim of the study, we were able to explore the impact of COVID-19 on respondents and how they perceived that it affected the way that NDIS plans are developed and implemented. This understanding was important in order to determine whether reported barriers to plan utilisation were solely attributable to the impacts of the COVID-19 restrictions or were ongoing issues faced by NDIS participants and their families.

### **1.3.1 Participant factors**

The demand for social and community based supports had declined as a result of COVID-19. While for most respondents this was a result of the social restrictions that were implemented due to the pandemic, others had opted to reduce or cease their interactions with services. A perceived need for additional mental health supports and assistance for families struggling to balance working and schooling at home was also highlighted.

### **1.3.2 Plan factors**

Respondents noted that changes were made by the NDIA in response to COVID-19 to ensure that the processes around developing and reviewing plans could continue and that funding could be utilised in the most useful manner. The move toward virtual meetings or rolling over existing plans for a further year were identified, as were changes to the rules around purchasing assistive technology. This latter change allowed participants the flexibility to purchase computing equipment using their core funding so that they could engage with their services virtually. However, concerns were raised about difficulties with the provision of information to NDIS participants about these changes. The ability to take advantage of these changes and maximise plan utilisation during the pandemic was seen by respondents as being incumbent upon knowledge and awareness, disadvantaging those who were less engaged and had less effective support networks around them.

### **1.3.3 Market factors**

The availability of supports and services during COVID-19, which directly affected the ability of an NDIS participant to use their funding, was principally determined by how essential a service was deemed and by the ability of the provider organisation to make necessary adaptations to service requirements. Disability service providers implemented a range of adaptations that predominantly acted to optimise the amount of supports that NDIS participants could continue to access despite the various social restrictions implemented throughout the country. These included: adopting virtual and telehealth delivery models; altering the types, timings or locations of services provided; and increasing hygiene protocols to meet new government guidelines. However one adaptation frequently implemented by service providers - the introduction of additional service fees - was considered by respondents as constraining NDIS participants' access to supports and services.

## 1.4 Experience of “at risk” groups

Many of the general factors which facilitate or hinder a person’s ability to access the funds and supports provided for in their NDIS plan were also found to operate for each of the five ‘at risk’ groups. However for some at risk groups, additional factors were identified.

For Indigenous NDIS participants, having access to culturally appropriate supports and Indigenous disability workers (market factor) was valued and felt to enhance plan utilisation. Two additional barriers were also identified for this cohort. A lack of understanding and recognition by the NDIA of the cultural needs of Indigenous people (plan factor) was reported. A lack of cultural appropriate service provision (market factor) was also seen as negatively impacting upon the engagement of Indigenous participants with disability services.

The opportunity to access culturally specific services (market factor) was identified as assisting NDIS participants from CALD backgrounds to utilise their NDIS funding. Three additional barriers to plan utilisations were identified for this group. Language barriers (participant factor) hampered understanding of NDIS processes and plan implementation, as well as communications with the NDIA. Many CALD respondents had small social networks and limited access to informal support (participant factor) which affected their confidence in navigating the NDIS system and implementing their plan. Limited availability of culturally appropriate services (market factor) also impacted upon the ability of CALD participants to utilise all the funds in their NDIS plans.

Three additional factors were identified by respondents as facilitating the plan utilisation of NDIS participants with complex needs. These included having an appropriate allocation of funding in NDIS plans (plan factor). For NDIS participants with complex needs the availability of experienced providers and workers (market factor) enabled them to utilise their plan funds. Flexibility of care provision (market factor) was also felt to contribute to plan utilisation. The availability of appropriate services and staff (market factor) was described as often being challenging for NDIS participants with complex needs and acted as an additional barrier.

For NDIS participants with psychosocial disability, one further market factor - the importance of workers with knowledge and experience of psychosocial disability – was identified as facilitating plan utilisation. Two additional barriers to plan utilisation were highlighted by this cohort. Engagement with services (participant factor) was at times challenging for some NDIS participants with psychosocial disability. Also a lack of supports and services which were appropriate to meet the needs of NDIS participants with a psychosocial disability (market factor) was identified as being a significant barrier to plan utilisation for this cohort.

No additional facilitators or barriers were identified for NDIS participants living in regional and remote areas.

## 1.5 Improving plan utilisation

The interviews explored the perceptions of NDIS participants and their families of potential changes that could be made to improve rates of plan utilisation. Ten factors were identified: (1) enhanced information from the NDIA, (2) improved communication with the NDIA, (3) more appropriate allocation of NDIS funding, (4) greater flexibility of NDIS funding, (5) improved access to disability services, (6) a skilled disability workforce, (7) greater access to support coordination, (8) improved quality of disability services, (9) enhanced collaboration between the NDIS and mainstream sectors, and (10) better recognition and support of the cultural needs of Indigenous participants.

Some of these suggested improvements are difficult to categorise as being solely ‘participant’, ‘plan’

or 'market' factors. For example, in order to support the cultural needs of Indigenous participants, respondents recommended that NDIS funding allocation should better recognise these needs (which is a plan factor) and that the development of culturally-appropriate services also needed to occur (a market factor). Likewise, enhanced information provision by the NDIA (which could be considered a plan factor) was an improvement suggested in order to enhance the knowledge and understanding of NDIS participants (a participant factor).

## **1.6 Limitations, policy relevance and areas for future research**

The findings arising from this research project are not without their limitations. Four main limitations of the research include: (1) the generalisability of qualitative findings; (2) utilisation considered only from the point of time of acquiring a NDIS plan; (3) unobserved longer terms impacts of the NDIS and (4) limited information about the supply side of the NDIS. These limitations should be borne in mind when reading and using the findings to inform future policy interventions.

The research shows that there are numerous areas which could potentially be the focus of future research and policy inventions to improve plan utilisation. The limitations of the research point to some areas for future research but there are others related to (1) participant factors; (2) NDIS/Plan factors; (3) Market factors; (4) Workforce factors and (5) Dependency vs independency.

### **1.6.1 Participant factors**

With the exception of 'knowledge and understanding of NDIS processes and local service provision', which can in part be addressed with consideration by the NDIA as to how information is provided to participants and which are the most appropriate channels of communication, the participant factors that were found to hinder plan utilisation are largely individual, personal factors and depend on an array of socio-demographic characteristics and circumstances. While limited in terms of the focus of policy interventions, these participant factors are useful for understanding how to target policies most effectively.

### **1.6.2 NDIS/plan factors**

The challenges experienced by respondents with NDIS planning and approval processes are amenable to policy intervention. Overcoming these barriers would assist NDIS participant better navigate the complexities of the system. In addition, ensuring the provision and adequate funding of support coordination in NDIS plans, for as long as NDIS participants feel that they need it, is another area that could be the focus of policy attention. However, the problems encountered with the quality of support coordination suggests that further research is warranted.

### **1.6.3 Market factors**

Several market based factors were identified - a lack of disability supports and services; issues with disability provider organisations and workers; high prices charged for disability services; and difficulties in the interface between mainstream and NDIS sectors - which impeded NDIS participant's ability to fully utilise their plans.

These market-based barriers to plan utilisation suggest that systemic problems exist in the supply of disability supports in Australia, particularly the supply of allied health services and in regional and remote areas. They point to questions regarding quality and issues pertaining to the training, skills and competencies of the workforce. They also raise important issues around the regulation of costs and the siloing of services and sectors.

#### **1.6.4 Workforces**

The capacity of disability support providers to widen the scope of, and scale up, their provisions could depend critically on their workforces. The evaluation of the NDIS Trial (2013-2017) identified labour and skills shortages to have impacted the NDIA roll out during its early years, including several professions being in shortage. The question for today would be whether these shortages were resolved through the broader rollout or not, or whether they can be a contributing driver for the observed low levels of plan utilisation.

#### **1.6.5 Dependency vs independency**

An objective of the NDIS is to maximise the independence of its participants and provide choice and control over their supports. Our findings show that the NDIS is perceived as complex and burdensome to navigate, necessitating a reliance on formal support mechanisms such as plan support coordination and plan management in order to utilise NDIS funding. Further research is needed to understand whether this reliance is creating dependencies which may go against the intent of the scheme.

## 2. Introduction

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### 2.1 NDIS plan utilisation

The National Disability Insurance Scheme (NDIS) is a consumer directed model of disability support that provides support to people with disability, their families and carers. It is jointly governed and funded by the Australian, state and territory governments.

The NDIS was launched in 2013 beginning with a trial phase known as the NDIS Launch. The NDIS began to be introduced across Australia from July 2016, with full scheme arrangements coming into place for all jurisdictions except Western Australia by the end of 2020.

The legislative framework for the NDIS is established in the National Disability Insurance Scheme Act (2013).

A key concept underpinning the NDIS is the ability for people with disability funded under the scheme to access the supports budgeted for in their NDIS plans. A key indicator of this ability is the rate of plan utilisation, or the percentage of the budgeted support plan a participant uses over the life course of their NDIS plan.

Low rates of NDIS plan utilisation were noted by the Productivity Commission's recent inquiry as an issue of concern (2017).

The Productivity Commission posited a number of inter-related factors which may contribute to low utilisation rates including:

- Insufficient supply to meet demand which varies geographically, for different support types and disability types;
- Participants' difficulty navigating the complex disability service system, leaving them unable to implement their plans;
- Over-estimation of the support required by participants;
- Lack of a market for support coordination and plan management making it difficult for participants to get the support they need for plan implementation.

Other possibilities include that segmentation of plans means that funds available for some purposes may be fully utilised and possibly insufficient, while funds available for other purposes are not fully used. The latter, however, cannot be utilised to supplement the supports for which funding is fully used. In such instances greater flexibility may enable more of the total funds to be used for supports, albeit in different proportions than were anticipated in the plan.

While research and advocates to date have effectively described the problem, there is a need for more nuanced analyses of the groups and support types that are most affected, the reasons for under-utilisation, and recommendations of how this can be addressed in policy and operational responses.

The key policy focus of this study is to understand the dynamics affecting people's utilisation of their plan funds from the point of view of the participants and to study the potential levers/policy interventions in order to improve plan utilisation.

## 3. Qualitative Methodology

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This study adopted a qualitative approach to investigate patterns of NDIS plan utilisation and to understand why there are such high rates of plan under-utilisation. The methodology adopted in this study had three main stages which are detailed below.

### 3.1 Sample and site selection

The sample selection for this study was designed to fulfil two main objectives, namely, (i) to *obtain a national coverage* and (ii) to *obtain a good evidence-base for “at risk” cohorts of plan under-utilisation*.

To obtain a national coverage, the study took a broad geographical approach and was carried out in six locations across Australia, encompassing urban, rural and remote regions. The specific locations selected for the study were decided in consultation with the Department. These locations were South Western Sydney (NSW), Brisbane (QLD), Townsville (QLD), Eyre Western (SA), Kimberley-Pilbara (WA)<sup>1</sup> and Barkly (NT). Information about the sites that were selected including a brief rationale for their inclusion are provided in Table 3.1 below.

Selected sites varied in terms of their reported plan utilisation rates, allowing the research to compare and contrast the experience of “at risk” groups in high utilisation regions, with those in lower utilisation regions.

The necessary good evidence-base for “at risk” cohorts of plan under-utilisation was achieved through targeted sampling of NDIS participants who have already been identified by existing research as being “at-risk” of plan under-utilisation. This included five key groups of NDIS participants: (1) people with psychosocial disability, (2) those living in regional and remote areas, (3) people from CALD backgrounds, (4) Indigenous people and (5) people with complex needs.

To facilitate this targeted sampling, names and contact details of those NDIS participants and/or of their plan and correspondence nominees who had provided consent to the NDIA to have their details shared with third parties for research purposes were provided to the University of Adelaide research team by the NDIA.

The sampling strategy for the interviews sought to identify and include people with greater or lesser levels of plan utilisation, with a focus on participants with low utilisation. Sampling aimed to achieve sufficient numbers across a range of characteristics – disability types, support types, cultural background (including Indigenous participants), types of plan management, those who are identified as having complex support needs and those who are not – to assist in understanding the relevance of these characteristics to people’s experiences of being able to use their plan funding to obtain the supports they need.

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<sup>1</sup> The research received ethics approval from the University of Adelaide Human Research Ethics Committee and meets the relevant national NHMRC standards. While the research aimed to include the Kimberley region in Western Australia, data collection in that region was subject to additional ethical approvals from The Kimberley Aboriginal Health Planning Forum research subcommittee and The Western Australian Aboriginal Health Ethics Committee (WAAHEC). A number of factors contributed to the approvals not being secured within the project’s timelines. Therefore, with the agreement of the Department of Social Services, the Western Australian research has not been included in the national report.

**Table 3.1 NDIS plan utilisation interviews - site selection rationale**

Site region	Rationale
<b>NSW – South Western Sydney</b>	<ul style="list-style-type: none"> <li>• Metropolitan area to explore utilisation in a well-supplied market</li> <li>• High utilisation - 2<sup>nd</sup> highest region nationally by utilisation out of 79 regions (75% in 2018-19). North Sydney had the highest utilisation nationally but did not have the same diversity of NDIS participants as South Western Sydney</li> </ul>
<b>QLD – Brisbane</b>	<ul style="list-style-type: none"> <li>• Metropolitan area to explore utilisation in a well-supplied market and compare with metro areas in other jurisdictions</li> <li>• Low utilisation - 4<sup>th</sup> lowest region in QLD by utilisation (58% in 2018-19)</li> <li>• Can be compared to QLD - Townsville as another metropolitan region within the same state with higher utilisation</li> </ul>
<b>QLD – Townsville</b>	<ul style="list-style-type: none"> <li>• Metropolitan area to explore utilisation in a well-supplied market and compare with metro areas in other jurisdictions</li> <li>• High utilisation - 2<sup>nd</sup> highest region in QLD by utilisation (69% in 2018-19)</li> <li>• Can be compared to QLD - Brisbane as another metropolitan region within the same state with lower utilisation</li> </ul>
<b>SA – Eyre and Western</b>	<ul style="list-style-type: none"> <li>• Regional area (population 58,700)</li> <li>• Low utilisation - 2<sup>nd</sup> lowest region in SA by utilisation (51% in 2018-19)</li> <li>• Can be compared with metropolitan and remote areas</li> </ul>
<b>WA – Kimberley-Pilbara</b>	<ul style="list-style-type: none"> <li>• Remote area (population 35,000)</li> <li>• Low utilisation - 4<sup>th</sup> lowest region nationally by utilisation (36% in 2018-19)</li> <li>• Region with lowest utilisation rate nationally can be compared with NSW South Western Sydney</li> </ul>
<b>NT – Barkly</b>	<ul style="list-style-type: none"> <li>• Very Remote (population 8,000)</li> <li>• Diversity - High Indigenous population in the NDIS (92%)</li> <li>• Low utilisation - 3<sup>rd</sup> lowest region in NT by utilisation (40% in 2018-19)</li> <li>• Region allows for interaction effects between remoteness and Indigeneity</li> </ul>

Note: Summary utilisation statistics for the 2018-19 support year as at 31 August 2019, provided by Department of Social Services. NT – Barkly diversity provided by Department of Social Services. Population statistics as at August 2019, provided by Department of Social Services.

## 3.2 Stakeholder consultations

The project commenced with the development of a stakeholder engagement strategy (SES). The SES was essential for the adequate and timely collection of data as well as informing the design of the qualitative research.

The SES had two main purposes:

- To elicit the views of relevant stakeholder groups and ensure that those views informed the research process, underpinning the co-design structure of the project.
- To enlist the support of organisations to assist our research by (i) promoting the research and the opportunity to participate to NDIS participants and (ii) providing a location at which we could conduct interviews, underpinning the user-centred nature of the project.

We commenced the project in April 2020 by undertaking informal stakeholder consultations to understand the factors that impact on plan utilisation in each of the six sites.

Extensive work was undertaken to locate key stakeholders (disability support providers, peak bodies and advocacy groups) in each of the six sites. Drawing from the full NDIA register and additional web and telephone searches, a comprehensive database was constructed listing all disability support providers, peak bodies and advocacy groups within each of the six sites. From this list we purposively selected 20 organisations in each site to be contacted for our stakeholder consultations. Representatives from provider and advocacy organisations working with the five groups identified as being particularly at-risk of plan under-utilisation were specifically included to sensitise the research team to key issues these participants might experience.

Stakeholder consultations occurred via telephone throughout April 2020. Subsequent stakeholder engagement occurred at the time of undertaking interviews with NDIS participants. We note, however, that these consultations were never intended to be formally analysed, but were instead planned to identify key issues for investigation in the subsequent NDIS participant interviews. As the consultations were undertaken at the height of the COVID-19 pandemic they also presented an opportunity to explore the impact of COVID-19 and the suitability of the proposed qualitative research methodology. The results of the informal stakeholder consultations undertaken are not formally reported on in this report but a summary of the main themes arising from these consultations are provided in state specific reports which can be accessed from the Department of Social Services upon request.

### **3.3 Collection and analysis of qualitative data (NDIS participants)**

#### **3.3.1 Interviews with NDIS participants**

Across the course of the project, semi-structured interviews were conducted with 161<sup>2</sup> NDIS participants or their families and carers (for participants aged 17 years and under or adult participants whose severity of disability prevented them from being able to take part in the research themselves).

The interviews sought to obtain in-depth information about NDIS plans, including what elements of plans were used (and why), what elements of plans were not used (and why) and factors that were considered to impact on a person's ability to access the supports budgeted for in their NDIS plan.

Broadly speaking the results of the interviews aimed to address initial hypotheses that plan utilisation is a result of:

- Market factors - availability of desired supports; concerns about the quality of available supports; costs of supports; available providers are not culturally aware/appropriate
- Participant factors - inexperience, lack of confidence and/or lack of information about what is available and how to get it; caution/uncertainty - concern about buying supports and later discovering another provider or form of support would have been better, but the funds are already committed/spent; availability of assistance from family/friends or formal support from providers
- Plan factors - mismatch between participant's view of supports required and supports funded in plan (i.e. participant doesn't see allocation or support types as appropriate to their needs); segmentation such that funds available in some segments are exhausted while funds available

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<sup>2</sup> Note this excludes WA site.

in other segments are not fully used but cannot be applied to buy more of the supports for which funds are exhausted; plans include more funding than the person sees the need to expend.

### 3.3.2 Total qualitative sample

In total 161 semi-structured interviews pertaining to 170 NDIS participants<sup>3</sup> were undertaken for this research: 89 of these interviews were face-to-face and 72 were undertaken virtually (by phone or Zoom).

Table 3.2 provides an overview of the basic demographic profile of the NDIS participants included in the qualitative study. It also provides the same demographic profile of the national NDIS participant population. In the text below we outline the demographic characteristics of our research sample, comparing this to the national profile of NDIS participants.

For the qualitative study, 48 participants (28%) were aged 17 years or below. In these instances, the parent or carer of the NDIS participant was interviewed. A further 26 participants (15%) were aged between 18 and 34 years of age. Forty-one participants (24%) were aged between 35 and 49 years and 53 participants (31%) were aged over 50.

Compared to the national NDIS participant population our study had a lower proportion of participants aged 17 years and below (28% compared to 47% nationally), a slightly lower proportion of participants aged between 18 and 34 years (15% compared to 19% nationally) and a higher proportion of participants aged between 35-49 years (24% compared to 14% nationally) and aged over 50 (31% compared to 21% nationally).

The NDIS participants in our sample were fairly equally distributed between the sexes, with 51 percent of participants being female and 49 percent male. Nationally, males make up 62 percent of the NDIS participant population whereas females constitute 37 percent.

Reflecting the aims of the research the qualitative research sample had a much higher proportion of NDIS participants from remote regions (59% compared to 2% nationally), who identified as Aboriginal or Torres Strait Islander (33% compared to 6% nationally) and as being from a culturally and linguistically diverse background (17% compared to 9% nationally) compared to the national NDIS participant population.

Nineteen percent of the NDIS participants in the qualitative study reported that they were classified by the NDIS as having complex needs<sup>4</sup>. This data was not available from the NDIA.

Around 19 percent of the NDIS participants in our sample identified autism as their primary condition. A further 13 percent of participants identified their primary disability as being psychosocial, with a similar proportion (12%) having an intellectual disability. Nine percent of participants reported their primary disability as being physical.

Compared to the national participant population, our study had a lower proportion of participants identifying Autism as their primary disability (19% compared to 31% nationally; maybe reflecting the lower proportion of young people within our sample) and intellectual disability (12% compared to 22% nationally). However our sample contained a higher proportion of NDIS participants reporting

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<sup>3</sup> In the interviews conducted with family members and carers, several respondents were caring for more than one NDIS participant. These interviews therefore explored the experiences of each of these NDIS participants.

<sup>4</sup> NDIS participants with complex needs are individuals living with a disability who have many different challenges impacting on their lives and need a higher level of specialised supports in their plan.

psychosocial disability (13% compared to 10% nationally) largely reflecting the aims of our research and the target cohorts.

**Table 3.2 NDIS participant demographics - qualitative sample and national population**

Attribute type	Qualitative sample <sup>1</sup>		NDIS participants nationally <sup>2</sup>	
	Number of cases = 170	Percentage (%)	Number = 391,999	Percentage (%)
<b>Age</b>				
0-11	32	18.8	130,364	33.3
12-17	16	9.4	51,987	13.3
18-24	10	5.9	39,788	10.2
25-34	16	9.4	35,639	10.0
35-49	41	24.1	53,306	13.6
50+	53	31.2	80,915	20.6
Not stated	2	1.2	-	-
<b>Location</b>				
Eyre Western	35	20.6	1,101	0.3
South Western Sydney	36	21.2	16,701	4.3
Brisbane	33	19.4	13,962	3.6
Townsville	34	34.0	4,992	1.3
Barkly	32	18.8	162	0.04
<b>Regional and remote</b>				
Yes	101	59.4	5,699	1.5
<b>Gender</b>				
Male	84	49.4	242,441	61.9
Female	86	50.6	145,247	37.1
Indeterminate	-	-	4,311	1.1
<b>Identifies as Aboriginal or Torres Strait Islander</b>				
Yes	56	32.9	25,077	6.4
<b>Identifies as Culturally and Linguistically Diverse<sup>3</sup></b>				
Yes	28	16.5	36,066	9.2
<b>Classified by NDIS as having complex needs</b>				
Yes	32	18.8	-	-
<b>Disability type (primary)</b>				
Acquired brain injury	6	3.5	12,832	3.3
Arthritis	2	1.2	-	-
Ataxia	1	0.6	-	-
Autism	32	18.8	122,830	31.3
Cerebral palsy	12	7.1	15,635	4.0
Dementia	1	0.6	-	-
Developmental delay	8	4.7	26,809	6.8
Down syndrome	6	3.5	-	-
Global developmental delay	-	-	7,642	2.0
Hearing impairment	4	2.4	19,208	4.9
Intellectual disability	21	12.4	84,769	21.6
Learning disability	4	2.4	-	-
Multiple sclerosis	6	3.5	7,494	1.9
Neurological	7	4.1	17,387	4.4
Other sensory/speech	1	0.6	3,037	0.8

Spinal cord injury	5	2.9	4,675	1.2
Stroke	8	4.7	5,648	1.4
Physical	16	9.4	17,143	4.4
Psychosocial disability	22	12.9	37,795	9.6
Visual impairment	7	4.1	8,387	2.1
Other	1	0.6	708	0.2

Notes: <sup>1</sup> The disability type for the sample group describes the primary disability type identified either through the DSS data provided or, for those sourced by stakeholders, as designated by the participant. This measure does not take into account multiple disabilities, or any discrepancies between the participant's understanding of their disability and how they are classified by the NDIA. <sup>2</sup> These results are current as at 30 June 2020. Disability type has been assessed by medical professionals relevant to the disability with only the primary disability indicated. Gender, CALD status and Aboriginal and Torres Strait Islander status are all self-reported. National data regarding the proportion of NDIS participants with complex needs was unavailable. <sup>3</sup> CALD figures for the broader NDIS participant population include any NDIS participants where English is not the primary language spoken at home and therefore may also include people from ATSI backgrounds. The qualitative sample has considered the two cohorts as being distinct and the CALD group does not include ATSI. Due to rounding the percentages presented in the table may not add up to exactly 100.

### 3.3.3 Qualitative sample in each site

#### 3.3.3.1 SA – Eyre and Western region

In total 34 interviews were undertaken in relation to 35 cases in the SA Eyre and Western region: 22 of these were face-to-face and 12 were undertaken virtually (by phone or Zoom).

In the Eyre and Western region of South Australia, the plan utilisation rate of NDIS participants in December 2020 was 53 percent. This is much lower than the rate of plan utilisation in South Australia (68%) and nationally (69%). NDIS participants in the Eyre and Western region had the second lowest plan utilisation rate amongst the sites included in this study.

Table 3.3 provides an overview of the basic demographic profile of the NDIS participants included in our sample from this site. It also provides the same demographic profile of the broader NDIS participant population within this region.

Six participants (17%) in the research sample were aged 17 years or below. In these instances, the parent or carer of the NDIS participant was interviewed. A further six participants (17%) were aged between 18 and 34 years of age. Eleven participants (31%) were aged between 35 and 49 years and 12 participants (34%) were aged over 50.

Compared to the broader NDIS participant population within this region, our sample is again comprised of a lower proportion of young NDIS participants, a similar proportion of NDIS participants aged 18-34 years and a higher proportion of NDIS participants aged between 35 and 49 years and over 50.

The NDIS participants in our sample were fairly equally distributed between the sexes, with 51 percent of participants being female and 49 percent male. The broader NDIS participant's population within this region however is not as equally divided between the sexes, with males accounting for 63 percent of all participants and females only 36 percent.

Again, reflecting the aims of the research the qualitative research sample in this site had a much higher proportion of NDIS participants who identified as Aboriginal or Torres Strait Islander (26% compared to 12% regionally) and as being from a culturally and linguistically diverse background (6% compared to 2% regionally) compared to the broader NDIS participant population for this site.

Only one participant was classified by the NDIS as having complex needs.

Eight of the NDIS participants (23%) in our sample identified psychosocial disability as their primary

condition. A further five participants (14%) identified autism as their primary disability, and four participants (11%) identified the primary disability as being either intellectual or neurological disability.

Compared to the broader NDIS participant population within this site, our sample again had a lower proportion of respondents who identified autism (14% compared to 34%) and intellectual disability (11% compared to 23%) as their primary disability. In contrast, the research sample contained a higher proportion of respondents identifying their primary condition as being a neurological (11% compared to 6%) or psychosocial disability (23% compared to 5%).

**Table 3.3 SA Eyre and Western site - NDIS participant demographics: qualitative sample and NDIS population**

Attribute type	Qualitative sample		NDIS participants in this site	
	Number of cases = 35	Percentage (%)	Number = 1,101	Percentage (%)
<b>Age</b>				
0-11	3	8.6	375	34.1
12-17	3	8.6	176	16.0
18-24	3	8.6	97	8.8
25-34	3	8.6	109	9.9
35-49	11	31.4	134	12.2
50+	12	34.3	210	19.1
<b>Regional and remote</b>				
Yes	35	100.0	625	56.8
<b>Gender</b>				
Male	17	48.6	689	62.6
Female	18	51.4	398	36.2
Indeterminate	-	-	14	1.3
<b>Identifies as Aboriginal or Torres Strait Islander</b>				
Yes	9	25.7	134	12.2
<b>Identifies as Culturally and Linguistically Diverse</b>				
Yes	2	5.7	21	1.9
<b>Classified by NDIS as having complex needs</b>				
Yes	1	2.9	-	-
<b>Disability type (primary)</b>				
Acquired brain injury	1	2.9	44	4.0
Autism	5	14.3	372	33.8
Cerebral palsy	1	2.9	35	3.2
Dementia	1	2.9	-	-
Developmental delay	1	2.9	65	5.9
Global developmental delay	-	-	36	3.3
Hearing Impairment	-	-	34	3.1
Intellectual disability	4	11.4	251	22.8
Learning disability	2	5.7	-	-
Multiple sclerosis	2	5.7	23	2.1
Neurological	4	11.4	62	5.6
Other sensory/speech	-	-	13	1.2
Spinal cord injury	2	5.7	11	N/A
Stroke	2	5.7	18	1.6
Physical	1	2.9	62	5.6
Psychosocial disability	8	22.9	59	5.4
Visual impairment	1	2.9	17	1.5
Other	-	-	11	N/A

Notes: Data has been modified in line with the data sharing agreement with the NDIA. Low participant counts have been modified along with any related data to protect the privacy of the participants. The aggregated totals have not been modified. Due to rounding the percentages presented in the table may not add up to exactly 100.

### 3.3.3.2 NSW – South Western Sydney region

In total 35 interviews (pertaining to the experiences of 36 NDIS participants) were undertaken in the NSW South Western Sydney region, all of which were conducted virtually (by phone or Zoom). Interviews commenced in this site virtually and a fieldwork trip to conduct face-to-face interviews was planned but subsequently cancelled due to continued and increased border restrictions as a result of COVID-19.

The plan utilisation rate of NDIS participants in the South Western Sydney region was 76 percent in the final quarter of 2020. This is slightly higher than the rate of plan utilisation in NSW (73%) and nationally (69%). NDIS participants in South Western Sydney had the highest plan utilisation rate amongst the sites included in this study.

Table 3.4 provides an overview of the basic demographic profile of the NDIS participants included in the study sample from this site. It also provides the same demographic profile of the broader NDIS participant population within this region.

Around a third (31%) of the NDIS participants in the qualitative sample were aged 17 years or below (n=11). In these instances, the parent or carer of the NDIS participant was interviewed. Around 14 percent (n=5) of participants were aged between 18 and 34 years of age. Almost a quarter of participants (22%) were aged between 35 and 49 years (n=8) and around a third (31%) were aged over 50 (n=11). A majority of NDIS participants were female (58% or 21 respondents). Twenty two percent of participants (n=8) identified as Aboriginal or Torres Strait Islander and 36 percent as being from a CALD background (n=13). A quarter (25%) of all respondents (n=9) were classified by the NDIS as having complex needs.

Compared to the NDIS participant population in this region, our sample had a higher proportion of NDIS participants aged 35 years and above (53% compared to 29% regionally), and a much lower proportion of participants aged 34 years and below (44% compared to 71% regionally). Our sample included a higher proportion of women (58% compared to 35% regionally) and lower proportion of men (42% compared to 64% regionally). It also has a higher proportion of NDIS participants who identified as Aboriginal or Torres Strait Islander (22% compared to 4% regionally) and as being from a culturally and linguistically diverse background (36% compared to 23% regionally) compared to the broader NDIS participant population for this site. Again, this reflects the aims of the research and the target cohorts.

Around 17 percent of the NDIS participants in our sample identified autism as their primary condition (n=6). A further 14 percent of participants identified their primary disability as being an intellectual disability (n=5), with a similar proportion (14%) having a physical disability (n=5). For 11 percent of participants, their primary disability was identified as being psychosocial.

Compared to the broader NDIS participant population within this site, our sample again had a lower proportion of respondents who identified autism (17% compared to 34%) and intellectual disability (14% compared to 23%) as their primary disability. A higher proportion of respondents identified having a physical (14% compared to 4%) or psychosocial disability (11% compared to 6%) as their primary condition.

**Table 3.4 NSW South Western Sydney site - NDIS participant demographics: qualitative sample and NDIS population**

Attribute type	Qualitative sample		NDIS participants in this site	
	Number of cases = 36	Percentage (%)	Number = 16,701	Percentage (%)
<b>Age</b>				
0-11	7	19.4	6,288	37.7
12-17	4	11.1	2,202	13.2
18-24	1	2.8	1,994	11.9
25-34	4	11.1	1,424	8.5
35-49	8	22.2	1,977	11.8
50+	11	30.6	2,816	16.9
Not stated	1	2.8	-	-
<b>Gender</b>				
Male	15	41.7	10,697	64.1
Female	21	58.3	5,840	35.0
Indeterminate	-	-	164	1.0
<b>Identifies as Aboriginal or Torres Strait Islander</b>				
Yes	8	22.2	650	3.9
<b>Identifies as Culturally and Linguistically Diverse</b>				
Yes	13	36.1	3,797	22.9
<b>Classified by NDIS as having complex needs</b>				
Yes	9	25.0	-	-
<b>Disability type (primary)</b>				
Acquired brain injury	-	-	432	2.6
Autism	6	16.7	5,720	34.4
Cerebral palsy	2	5.6	728	4.5
Developmental delay	2	5.6	791	4.7
Down syndrome	2	5.6	-	-
Global developmental delay	-	-	496	3.0
Hearing impairment	1	2.8	917	5.5
Intellectual disability	5	13.9	3,856	23.1
Multiple sclerosis	3	8.3	299	1.8
Neurological	3	8.3	657	3.9
Other sensory/speech	-	-	94	0.6
Spinal cord injury	-	-	160	1.0
Stroke	1	2.8	302	1.8
Physical	5	13.9	703	4.2
Psychosocial disability	4	11.1	1,073	6.4
Visual impairment	2	5.6	433	2.6
Other	-	-	40	0.2

Notes: One interview respondent discussed two NDIS participants and the demographic details of both these participants are included in this table. Data has been modified in line with the data sharing agreement with the NDIA. Low participant counts have been modified along with any related data to protect the privacy of the participants. The aggregated totals have not been modified. Due to rounding the percentages presented in the table may not add up to exactly 100.

### 3.3.3.3 Queensland – Brisbane region

In total 30 interviews were undertaken in the Brisbane region. Fifteen of the interviews were conducted face-to-face and a further 15 were undertaken virtually (by phone or Zoom). It should be noted that two of the interview respondents discussed additional NDIS participants, meaning that the experiences of 33 NDIS participants in the Brisbane region were included in the research.

In December 2020 the plan utilisation rate of NDIS participants in the Brisbane region was 70 percent. This is slightly higher than the rate of plan utilisation both in Queensland and nationally (69% respectively). NDIS participants in the Brisbane region had the second highest plan utilisation rate amongst the sites included in this study.

Table 3.5 provides an overview of the basic demographic profile of the NDIS participants included in the study sample from this site. It also provides the same demographic profile of the broader NDIS participant population within this region.

Thirty three percent (n=11) of the NDIS participants in the qualitative sample were aged 17 years or below. In these instances, the parent or carer of the NDIS participant was interviewed. Around 18 percent (n= 6) of participants were aged between 18 and 34 years of age. A further 18 percent of the NDIS participants (n=6) were aged between 35 and 49 years and around 27 percent were aged over 50 (n=9). NDIS participants were fairly equally distributed between the sexes, with 55 percent being male and 46 percent female. Eighteen percent of the NDIS participants (n=6) identified as Aboriginal or Torres Strait Islander and another 18 percent (n=6) identified as being from a CALD background. Only three respondents were classified by the NDIS as having complex needs.

Our sample had a similar age profile to that which is reflected in the broader NDIS participant population in this site. Our sample included a higher proportion of women (46% compared to 39% regionally) and lower proportion of men (55% compared to 61% regionally). The qualitative sample also has a higher proportion of NDIS participants who identified as Aboriginal or Torres Strait Islander (18% compared to 4% regionally) and as being from a culturally and linguistically diverse background (18% compared to 11% regionally) compared to the broader NDIS participant population for this site. Again, this reflects the aims of the research and the target cohorts.

Around 24 percent of participants in our sample identified autism as their primary condition and 15 percent as intellectual disability. A further twelve percent identified their primary disability as being cerebral palsy. A similar proportion of NDIS participants (9%) identified the primary disability as being physical and psychosocial disability.

Compared to the broader NDIS participant population within this site, our sample had a higher proportion of respondents who identified cerebral palsy (12% compared to 5%) and physical disability (9% compared to 5%) as their primary disability. The qualitative sample contained a slightly smaller proportion of NDIS participants with autism (24% compared to 28%) and psychosocial disability (9% compared to 13%) than in the broader population.

**Table 3.5 QLD Brisbane site - NDIS participant demographics: qualitative sample and NDIS population**

Attribute type	Qualitative sample		NDIS participants in this site	
	Number of cases = 33	Percentage (%)	Number = 13,962	Percentage (%)
<b>Age</b>				
0-11	9	27.3	3,932	28.2
12-17	2	6.1	1,507	10.8
18-24	4	12.1	1,322	9.5
25-34	2	6.1	1,391	10.0
35-49	6	18.2	2,367	17.0
50+	9	27.3	3,443	24.7
Not stated	1	3.0	-	-
<b>Gender</b>				
Male	18	54.5	8,457	60.6
Female	15	45.5	5,386	38.6
Indeterminate	-	-	117	0.9
<b>Identifies as Aboriginal or Torres Strait Islander</b>				
Yes	6	18.2	602	4.3
<b>Identifies as Culturally and Linguistically Diverse</b>				
Yes	6	18.2	1,533	11.0
<b>Classified by NDIS as having complex needs</b>				
Yes	3	9.1	-	-
<b>Disability type (primary)</b>				
Acquired brain injury	2	6.1	596	4.3
Arthritis	1	3.0	-	-
Ataxia	1	3.0	-	-
Autism	8	24.2	3,958	28.4
Cerebral palsy	4	12.1	705	5.1
Developmental delay	-	-	458	3.3
Global developmental delay	-	-	229	1.6
Hearing impairment	1	3.0	1,024	7.3
Intellectual disability	5	15.2	2,647	19.0
Learning disability	1	3.0	-	-
Multiple sclerosis	-	-	263	1.9
Neurological	-	-	692	5.0
Other sensory/speech	1	3.0	49	0.4
Spinal cord injury	1	3.0	272	2.0
Stroke	-	-	192	1.4
Physical	3	9.1	665	4.8
Psychosocial disability	3	9.1	1,824	13.1
Visual impairment	1	3.0	365	2.6
Other	-	-	23	0.2
Not stated	1	3.0	-	-

Notes: Two respondents discussed additional NDIS participants and the demographic details of these participants are included in this table. Data has been modified in line with the data sharing agreement with the NDIA. Low participant counts have been modified along with any related data to protect the privacy of the participants. The aggregated totals have not been modified. Due to rounding the percentages presented in the table may not add up to exactly 100.

### 3.3.3.4 Queensland – Townsville region

In total thirty two interviews (pertaining to the experiences of 34 NDIS participants) were undertaken in the Townsville site: 22 of these interviews were face-to-face and 10 were undertaken virtually (by phone or Zoom).

The plan utilisation rate of NDIS participants in the Townsville region was 69 percent in the final quarter of 2020. This was on par with the plan utilisation rate both across Queensland and nationally (69%). NDIS participants in Townsville had the third highest plan utilisation rate amongst the sites included in this study.

Table 3.6 provides an overview of the basic demographic profile of the NDIS participants included in the study sample from this site. It also provides the same demographic profile of the broader NDIS participant population within this region.

Over a third of the NDIS participants (38%) in the qualitative sample were aged 17 years or below (n=13). In these instances, the parent or carer of the NDIS participant was interviewed. Around 15 percent (n=5) of participants were aged between 18 and 34 years of age. Over a quarter of participants (27%) were aged between 35 and 49 years (n=9) and around 21 percent (n=7) were aged over 50. The NDIS participants in our sample were fairly equally distributed between the sexes, with 53 percent (n=18) being male and 47 percent (n=16) female. Eighteen percent (n=6) of the NDIS participants identified as Aboriginal or Torres Strait Islander and another 18 percent (n=6) identified as being from a CALD background. Over a third (35%) of all participants were classified as having complex needs (n=12).

Compared to the broader NDIS participant population within this region, our sample is comprised of a lower proportion of NDIS participants aged 24 years and below (41% compared to 58% regionally), a similar proportion of NDIS participants aged 25-34 years (12% compared to 9% regionally) and a higher proportion of NDIS participants aged 35 years and over (47% compared to 33% regionally). Our sample included a higher proportion of women (47% compared to 37% regionally) and a lower proportion of men (53% compared to 63% regionally). It also has a similar proportion of NDIS participants who identified as Aboriginal or Torres Strait Islander (18% compared to 19% regionally) but a considerably higher proportion of NDIS participants who identify as being from a culturally and linguistically diverse background (18% compared to 3% regionally).

Around 29 percent (n=10) of NDIS participants in our sample identified autism as their primary condition. A further 17 percent (n=6) of respondents identified their primary disability as being psychosocial and 12 percent (n=4) as being a developmental delay. A similar proportion (9% n=3) identified the primary disability as being Down Syndrome and intellectual disability.

Compared to the broader NDIS participant population within this site, our sample had a higher proportion of respondents who identified autism (29% compared to 24%) and psychosocial disability (18% compared to 8%) as their primary disability. In contrast, a lower proportion of NDIS participants in our sample identified intellectual disability (9% compared to 22%) as their primary disability. A similar proportion of NDIS participants identified a developmental delay (12% compared to 13%) as being their main condition.

**Table 3.6 QLD Townsville Site - NDIS participant demographics: qualitative sample and NDIS population**

Attribute type	Qualitative sample		NDIS participants in this site	
	Number of cases = 34	Percentage (%)	Number = 4992	Percentage (%)
<b>Age</b>				
0-11	9	26.5	1,785	35.8
12-17	4	11.8	610	12.2
18-24	1	2.9	476	9.5
25-34	4	11.8	455	9.1
35-49	9	26.5	673	13.5
50+	7	20.6	993	19.9
<b>Regional and remote</b>				
Yes	34	100.0	510	10.2
<b>Gender</b>				
Male	18	52.9	3,143	63.0
Female	16	47.1	1,830	36.7
Indeterminate	-	-	19	0.4
<b>Identifies as Aboriginal or Torres Strait Islander</b>				
Yes	6	17.6	956	19.2
<b>Identifies as Culturally and Linguistically Diverse</b>				
Yes	6	17.6	144	2.9
<b>Classified by NDIS as having complex needs</b>				
Yes	12	35.3	-	-
<b>Disability type (primary)</b>				
Acquired brain injury	-	-	179	3.6
Arthritis	1	2.9	-	-
Autism	10	29.4	1,213	24.3
Cerebral palsy	2	5.9	211	4.2
Developmental delay	4	11.8	670	13.4
Down syndrome	3	8.8	-	-
Global developmental delay			39	0.8
Hearing impairment	1	2.9	313	6.3
Intellectual disability	3	8.8	1,090	21.8
Learning disability	1	2.9	-	-
Multiple sclerosis	-	-	59	1.2
Neurological	-	-	220	4.4
Other sensory/speech	-	-	51	1.0
Spinal cord injury	-	-	86	1.7
Stroke	2	5.9	97	1.9
Physical	-	-	254	5.1
Psychosocial disability	6	17.6	409	8.2
Visual impairment	1	2.9	87	1.7
Other	-	-	14	0.3

Notes: Two respondents discussed additional NDIS participants and the demographic details of these participants are included in this table. Data has been modified in line with the data sharing agreement with the NDIA. Low participant counts have been modified along with any related data to protect the privacy of the participants. The aggregated totals have not been modified. Due to rounding the percentages presented in the table may not add up to exactly 100.

### 3.3.3.5 Northern Territory – Barkly region

In total, thirty interviews (pertaining to 32 NDIS participants) were undertaken in the Barkly region in the Northern Territory. These interviews were all conducted face-to-face.

In December 2020 the plan utilisation rate of NDIS participants in the Barkly region of the Northern Territory was 54 percent. This is lower than the rate of plan utilisation both in the Northern Territory (66%) and nationally (69%). NDIS participants in the Barkly region had the third lowest plan utilisation rate amongst the sites included in this study.

Table 3.7 provides an overview of the basic demographic profile of the NDIS participants included in the study sample from this site. It also provides the same demographic profile of the broader NDIS participant population within this region.

Twenty two percent (N=7) of the NDIS participants in the qualitative sample were aged 17 years or below. In these instances, the parent or carer of the NDIS participant was interviewed. Around 13 percent (N=4) of participants were aged between 18 and 34 years of age. Another twenty two percent (N=7) of participants were aged between 35 and 49 years and around 44 percent (N=14) were aged over 50. The NDIS participants in our sample were equally distributed between the sexes. Eighty four percent (N=27) of the NDIS participants identified as Aboriginal or Torres Strait Islander. Only one participant identified as being from a CALD background. Around twenty two percent (N=7) of all participants were classified as having complex needs.

Compared to the broader NDIS participant population within this region, our sample is comprised of a lower proportion of NDIS participants aged 24 years and below (25% compared to 39% regionally), a similar proportion of NDIS participants aged 25-34 years (9% for both groups) and a higher proportion of NDIS participants aged between 35 years and over (66% compared to 51% regionally). Our sample included a higher proportion of women (50% compared to 40% regionally) and a lower proportion of men (50% compared to 60% regionally). It also has a lower proportion of NDIS participants who identified as Aboriginal or Torres Strait Islander (84% compared to 90% regionally) and a lower proportion of NDIS participants who identify as being from a culturally and linguistically diverse background (3% compared to 57% regionally).

Around twenty two percent (N=7) of NDIS participants from our sample identified a physical disability as their primary condition. A further 13 percent (N=4) of respondents identified their primary disability as being intellectual. A similar proportion (9% or N=3) identified the primary disability as being acquired brain injury, autism, cerebral palsy, and stroke.

Compared to the broader NDIS participant population within this site, our sample had a higher proportion of respondents who identified a physical disability (22% compared to 16%) as their primary disability and a lower proportion identifying intellectual disability (13% compared to 25%) as their primary disability.

**Table 3.7 Barkly Site - NDIS participant demographics: qualitative sample and NDIS population**

Attribute type	Qualitative sample		NDIS participants in this site	
	Number of cases = 32	Percentage (%)	Number = 162	Percentage (%)
<b>Age</b>				
0-11	4	12.5	34	20.9
12-17	3	9.4	11	N/A
18-24	1	3.1	11	N/A
25-34	3	9.4	15	9.3
35-49	7	21.9	32	19.8
50+	14	43.8	51	31.5
<b>Regional and remote</b>				
Yes	32	100.0	162	100.0
<b>Gender</b>				
Male	16	50.0	98	60.0
Female	16	50.0	64	40.0
<b>Identifies as Aboriginal or Torres Strait Islander</b>				
Yes	27	84.4	146	91.1
<b>Identifies as Culturally and Linguistically Diverse</b>				
Yes	1	3.1	92	56.8
<b>Classified by NDIS as having complex needs</b>				
Yes	7	21.9	-	-
<b>Disability type (primary)</b>				
Acquired brain injury	3	9.4	11	N/A
Autism	3	9.4	12	7.4
Cerebral palsy	3	9.4	11	N/A
Developmental delay	1	3.1	11	N/A
Down syndrome	1	3.1	-	-
Global developmental delay	-	-	11	N/A
Hearing impairment	1	3.1	12	7.4
Intellectual disability	4	12.5	40	24.7
Multiple sclerosis	1	3.1	11	N/A
Neurological	-	-	11	N/A
Other sensory/speech	-	-	11	N/A
Spinal cord injury	2	6.3	11	N/A
Stroke	3	9.4	18	11.1
Physical	7	21.9	26	16.1
Psychosocial disability	1	3.1	11	N/A
Visual impairment	2	6.3	11	N/A
Other	-	-	11	N/A

Notes: Two respondents discussed additional NDIS participants and the demographic details of these participants are included in this table. Data has been modified in line with the data sharing agreement with the NDIA. Low participant counts have been modified along with any related data to protect the privacy of the participants. The aggregated totals have not been modified. Due to rounding the percentages presented in the table may not add up to exactly 100.

### 3.3.4 Further detail on qualitative interviews

The qualitative interviews with NDIS participants or their families and carers commenced in May 2020. The implementation of the fieldwork needed to be adapted due to the travel restrictions and social distancing requirements resulting from COVID-19. Fieldwork also needed to accommodate the circumstances of each interviewee and be flexible to needs relating to the participant's disability, and other considerations such as culture, language, family, and remoteness. Interviews were therefore carried out in a flexible manner to enable these circumstances to be taken into account.

To progress the research while strict lockdowns and border restrictions were in place due to COVID-19, interviews were initially undertaken with NDIS participants virtually (by phone or Zoom) but we found that many of the harder to reach groups (ATSI, CALD, people with complex needs and psychosocial disability) were either unwilling or unable to participate via this interview mode.

Given that the subjects of this research are those who have low NDIS plan utilisation rates with a focus on these four key hard-to-reach groups, there was a need to conduct the interviews face-to-face to ensure that these groups were appropriately engaged and represented. We therefore undertook fieldwork trips to the following locations as soon as travel restrictions eased: regional SA (Ceduna and Port Lincoln), Brisbane, Townsville and the Barkly region of the NT. We continued to undertake interviews virtually where this was the preference of the participant.

Recognising that the COVID-19 pandemic is a public health emergency, the following fieldwork practices were devised to ensure the safety of FES staff and research participants:

- Researcher/s take and log their temperature every morning – and should a higher than normal temperature be obtained suspend the research activity
- Maintain a log of all close contacts
- Ensure a supply of PPE – i.e. masks are taken on fieldtrips and confirm with fieldwork participants their preference or not for them to be worn
- Ensure interviews are conducted in locations/rooms that allow for appropriate social distancing where possible
- Maintain appropriate social distancing within interviews
- Before and after each interview ensure all surfaces and shared pens have been wiped down with a disinfectant wipe
- In each interview ensure the provision of hand sanitiser and tissues.

The interview guides were modelled on those developed for our previous evaluations of the NDIS (conducted by members of the research team while employed at the National Institute of Labour Studies, Flinders University) and the University of Melbourne's Victorian Plan Utilisation study so as to allow the possibility of the comparison of data collected. Interview guides also incorporated culturally appropriate and accessible content and protocols developed in conjunction with senior researchers from FES and key stakeholders.

Recruitment was conducted in accordance with ethics approval granted by the University of Adelaide Human Research Ethics Committee. A combination of direct and indirect recruitment of NDIS participants was undertaken. In the first instance NDIS participants and/or their plan and correspondence nominees who had consented to the NDIA to have their details shared with third

parties for research purposes were contacted directly by the University of Adelaide research team. First contact was generally via an introductory email (if an email address was available) containing detailed information about the research. The research team then followed up with a phone call to ascertain their willingness or not to participate. A maximum of three calls were made to attempt to contact eligible NDIS participants. If we were unable to contact them after three attempts, the participant was withdrawn from the sample.

In addition, our stakeholder engagement strategy (see above) sought to identify organisations that provided support to “at risk” cohorts and enlist their assistance to promote the research and the opportunity to participate to their members. This approach was used to ensure we were able to include the experiences of these diverse groups in our research, resulting in a richer and more inclusive project. This strategy also resulted in the organisation providing practical help in the form of a safe and trusted location where interviews could be conducted when undertaking face-to-face interviewing.

The interviews ranged in duration from 14 to 95 minutes. While as discussed above, face-to-face interviews were principally conducted on the premises of key service provider organisations, several informants instead chose for their interview to be conducted in a quiet public space. All interview respondents were offered a \$50 supermarket voucher to compensate them for their time.

With the consent of respondents, interviews were recorded using a digital recorder and transcribed verbatim by a professional transcription service. The transcribed data was entered into NVivo in order to assist with the management and analysis of the data. The analysis of all interview data was conducted according to the Framework approach (Ritchie and Spencer 1994) which is particularly suited to applied social research. Following familiarisation with the data through the reading of the transcripts, a thematic framework was developed and agreed upon by the qualitative research team. This thematic framework was based around the core topics outlined in the interview schedule and also included the main sub-themes which had emerged during the interviews in relation to these topics. The interview transcripts were then coded according to this thematic framework. Key themes were developed and refined throughout the data analysis to enable further emergent categories to be identified.

The following chapters outline the findings arising from the qualitative research conducted with NDIS participants and/or their family members or carers.

### **The use of terminology and quotes**

In our reporting, we do not identify respondents (by their name). Instead, we use the prefix ‘P’ for a NDIS participant interview and the prefix ‘F&C’ for a family member or carer interview. A suffix follows which consists of the number of the interview and the site of the interview (‘BAR’ for the Barkly region, ‘BRI’ for Brisbane, ‘EW’ for the Eyre Western region, ‘SWS’ for South Western Sydney, and ‘TSV’ for Townsville). This way we preserve the anonymity of all respondents, whilst allowing the reader to follow an individual’s views using the category prefix, the number of the interview and the location suffix.

Please note that when describing the views of respondents, terms such as “perceived”, “considered” and “reported” have been used interchangeably. In addition, the terms “most” and “many” have been used when a majority of respondents expressed a viewpoint. Likewise, the term “some” was used when a sizeable minority of respondents shared an opinion. Finally, the terms “a few” and “several” were used interchangeably when only a minority of respondents expressed an opinion.

## 4. Factors Facilitating Higher Plan Utilisation

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Five key factors were identified as facilitating the ability of NDIS participants to access the funding and supports provided for in their NDIS plans in the five research sites. These included two factors pertaining to NDIS participants and their family members: (1) knowledge and understanding of NDIS processes and local service provision, and (2) personal effort and advocacy; one factor relating to NDIS planning: (1) access to funded support coordination services; and two factors associated with the disability sector market: (1) support from disability provider organisations and workers, and (2) access to disability services.

Three of these factors – access to support coordination (plan factor), support from disability provider organisations and workers (market factor), and having knowledge and understanding of NDIS processes and service provision (participant factor) – were most commonly reported by respondents in all five sites as aiding plan utilisation. Hence higher plan utilisation was considered to be supported by a combination of participant, market and plan factors.

### 4.1 Participant factors

Respondents identified two factors relating to NDIS participants and their family members as facilitating greater plan utilisation. These were (1) knowledge and understanding of NDIS processes and local service provision, and (2) personal effort and advocacy.

#### 4.1.1 Knowledge and understanding of NDIS processes and local service provision

A key factor which was considered by respondents in all of the research sites to assist plan utilisation was the possession of knowledge and understanding of NDIS processes, plans and local disability services. In order to effectively implement their NDIS plans, many respondents reported that good understanding of NDIS funding and the types of supports that could be accessed with this funding was required. The possession of knowledge of the disability services that were available within their local area was also considered to be important. Having this knowledge and understanding was perceived to enhance the self-confidence of respondents when liaising directly with the NDIA or disability service providers.

*We have a voice and we can get what we want...We know the system. F&C13BAR*

*[What's] helped me the most?...I guess it's just more understanding [NAME]'s needs, and really understanding what it is that I want to achieve for her, or at least have some understanding of what needs to be done, because I think that helps you clarify what type of goals you need to set for her. I think with this NDIS form, it's really important to understand what the goals are you want to achieve for your child. It seems to be something that they look for and measure against. So, having a clear understanding of where she's at now, what goals do you want to achieve for her, and really clarifying those goals during the review process, I think is really important. F&C27BRI*

For those respondents who were self-managing their own NDIS funding, possessing good knowledge of how to implement supports - including developing service agreements and hiring workers - was also seen as being crucial. Several of these respondents noted that previous skills and knowledge (developed from their work or experience of the disability sector) made the undertaking of these tasks easier.

*The carers come in, I do a time sheet, I've got a payroll program, I'm registered to pay tax and work cover, superannuation, so those who, and long service leave...I could do it through my years of working in that as an office administrator and in the farm and stuff like that so I could understand it. P22EW*

Respondents reported gaining knowledge of the NDIS and plan implementation from various different sources. This included the provision of information and service recommendations from people within the disability sector. Assistance from support coordinators, service providers, disability support workers and allied health professionals was particularly noted.

*What's really helped me to use the funding is information, I guess, facilitating that via my plan coordinator and my plan manager. That's the important keys. Knowing what I can access. It's really hard, you don't know what you don't know until you don't, you need to have someone to tell you. To help you. P28EW*

*The thing that has helped me the most is when I changed to the new service provider and so they've explained a lot of it to me...understanding my plan a lot more too. Just so I can go to and ask questions and get the answers that I need. P22SWS*

Some respondents also acknowledged that they had received information directly from the NDIA (e.g. from planners and LACs) about how to implement their plans. This included the provision of lists of local registered service providers. While some had found this information to be useful, others considered it overwhelming and had instead preferred to seek recommendations about specific services that would be appropriate for them. Several respondents who were self-managing their NDIS funding also reported being provided with information from the NDIA about the processes involved in self-management such as how to use the portal.

*I think that the planners that we have had explained everything well; know how to use to the portal. F&C11EW*

Informal sources of information were also said to be useful in obtaining recommendations of local service providers who could give quality care which met the specific needs of individual NDIS participants. Respondents frequently described helpful information received from family, friends and other carers living locally who had a child with a disability.

*It's word of mouth for me. I speak to a very knowledgeable mother who's very good with her child and she recommends where to get the support workers, she's recommended me all these big social clubs...So if a mum tells me that this group's okay, that group's not okay, try this group, try that group, that's fine by me. I'm happy to do that. F&C28BRI*

*So the first couple of years of [NAME]'s plan was a really huge learning thing...But I was lucky enough that one of the other mums she's actually got two Autistic boys, I asked her what do you think and how do you cope with it, because I knew that she was doing self-managed and she actually ran through it all with me...Even gave me a whole heap of websites where I could get specialised sensory stuff for the kids...she was fantastic. F&C04BAR*

Particularly within the larger population centres of Brisbane, South Western Sydney and Townsville, the use of social media channels were also a commonly reported source of information. Many respondents (and especially the parents interviewed) described being members of Facebook groups which they utilised to gain more understanding of the NDIS and local service provision including recommendations of which service provider to use.

*Social media. Facebook. I pretty much wrote on there what I was looking for. I pretty much*

*wrote what are people using their funds for? What do you have in place, because I'm lost. F&C26BRI*

*With the psychologist I just kind of put on Facebook hey friends, anyone know a good psychologist? Or, like you know I'm like also on like an Autism support website and stuff for my local area so we also put on there like who do you recommend? F&C23SWS*

Some respondents also noted that their own previous work experience – both within and outside of the disability sector, or pre-existing familiarity with disability services enabled them to better understand NDIS processes and to utilise their plans. Other respondents described making a concerted effort through their own research to develop a better understanding of NDIS planning processes, local service provision and how to go about implementing their plan.

*I work in health so I'm familiar with how things work and I've got contacts so I'm not sure how someone who doesn't have those connections would make it work. Yeah because the different layers of bureaucracy, can be a bit of a nightmare. But I'm comfortable with negotiating them, it's what I do for work. P06BAR*

*I learnt all myself just from conversations I had, experiences I had. I, you know, I put my heart and soul into it basically. I read everything that ever came out on the internet. I downloaded price guides. I just kind of lived and breathed it just because, you know, to me knowledge is power so the more that I knew. F&C04TSV*

Not all respondents, however, felt that they had adequate understanding and knowledge of NDIS and plan utilisation processes. These concerns, and the resulting impacts for respondents on their ability to utilise NDIS funding, are discussed below in the section on 'Barriers to plan utilisation'.

#### **4.1.2 Personal effort and advocacy of NDIS participants and their families**

Another key factor which was suggested by respondents in all of the five sites as aiding their ability to access the funding and supports provided for in their NDIS plans related to the effort and perseverance of NDIS participants and family members to ensure that they obtained appropriate funding and disability services.

Some respondents described advocating on their own, or on a family member's behalf to ensure that the funding and supports received from the NDIS fully met their needs. This included instances of successfully advocating to the NDIA for increased funding when it was considered that the initial plan did not adequately meet their support needs. Examples were also provided of respondents taking complaints to the Administrative Appeals Tribunal in order to obtain greater levels of funding.

*I fought all the way to the point where she now has a very good plan. But that has had its toll. And it shouldn't be like that. And the thing is I know that other people are still fighting that. And that they might not have the sort of assistance that I do to keep on going, not taking no for an answer and so they end up missing out on the supports they need, which can have devastating consequences...But amazingly, you know, I kept on fighting and we got there in the end and we managed to turn it all around. F&C09TSV*

*Her plan...did not provide very much in terms of services and...she had significant behavioural support requirements that needed specialist interventions and support...It took the next 12 months...to fight the agency on the grounds that [NAME] needed more funding and that she needed greater amount of services given to her within her plan...Subsequently we went to an*

*AAT, and that took a year to get there. A year out of my life. It was hard. It was the hardest thing I've ever done. F&C01BAR*

Respondents (both NDIS participants and family members) stated spending considerable time identifying and arranging appropriate disability supports. As was described above, some of these respondents conducted their own research around local service provision including actively seeking out recommendations for good providers. Some respondents also reported contacting disability providers directly to arrange their own supports. Once in place, some respondents took active steps to ensure that these services adequately met their support needs: providing directions to staff regarding their care needs and appropriate service provision, making complaints to providers if dissatisfied with services, and changing support providers if issues could not be resolved.

*When he got the NDIS, the money, through, that's when I started seeking, okay well he definitely needs speech. What else do I need? OT. So, I just built up this myself and I just ran around and got appointments. So, we've moved different companies at a time...I've done everything myself. I've had to source out everything myself and I've had to answer a lot of questions and a lot of the questions I didn't even know, and I didn't even know about autism, so I was trying to deal with that side of things as well, and also a lot of emotional, mental things for myself as well. F&C06TSV*

*Luckily, I had some friends who are in the industry, so these are community therapists, so basically just lots of ringing around, talking to them, and just trying to find the right fit for [NAME]. F&C27BRI*

This was particularly the case for respondents who had elected to self-manage their NDIS funding. These individuals considered that self-management allowed them more flexibility and scope to arrange and obtain the specific services that they needed and wanted. For some, this included hiring their own workers in order to have more control over the quality of the supports received. This had involved writing and placing job adverts, undertaking interviews and work trials, and arranging employment contracts.

*I actually advertised for my own carers...So I advertised and I interviewed for carers for myself so that way I could make sure that I would get along with them and that they have qualifications. P21SWS*

*The reality is there aren't the supports in the community to help me...I've trained up my own staff, I've put them through their own PEG training, their own haemophilia training courses, I said I just want the ability to use my own staff because I've gone to the effort of spending the money to have them trained in my kid's needs. F&C04TSV*

Self-management was also noted by some respondents to provide flexibility in enabling them to negotiate the price of services and to allow their NDIS funding to go further.

*So the self-managed for me was more to make sure I can maintain my current supports that were already there that we were paying for and...I think it was just more about the control over where I spent my money. And also I find I pay my physio and she's \$85.00. I pay my OT who's NDIS registered, she charges me \$193.99. So there's a massive price difference. And yet my physio is still prepared to write reports and I just pay her by the hour for writing the report. So I think it can...save money to make that money stretch a bit further. P08TSV*

## 4.2 Plan factors

In the interviews, respondents identified one factor relating to NDIS planning - access to funded support coordination services – as contributing to higher plan utilisation.

### 4.2.1 Access to funded support coordination services

Having access to funded support coordination services was reported by many respondents as being a key factor which enabled them to successfully utilise their NDIS funding. The importance of support coordination in aiding plan utilisation was strongly acknowledged in all five sites. This was even the case within the Barkly region where there was reported to be very limited availability of support coordination services at a local level and NDIS participants primarily had to receive this support from providers working in Alice Springs and Darwin.

Without support coordination, many respondents felt that they would have struggled to use their NDIS funding and arrange their own disability services by themselves. Indeed, some respondents who had not initially received assistance with support coordination, described the challenges they had faced in organising their own NDIS-funded services.

*I said I didn't want to manage it myself because I had no idea what to do, so when they said you don't have to do it by yourself, that you've got a coordinator...I don't have the pressure of worrying about anything. It's all there, done, and I know [NAME]'s getting the help he needs and I've got peace of mind, really. F&C16TSV*

*I think is maybe why some people aren't using their plan as well as they could be is maybe because they don't have a support coordinator because when I didn't have a support coordinator for my first year of the NDIS...only just managed to get the help of one of my support workers. P18TSV*

Support coordination was seen as being particularly necessary for respondents whose disability or work and family commitments prevented them from being able to arrange and manage their own services.

*I've got a support coordinator who helps me...I want to keep having one of those support coordinators because of vision problems I can't go and look up things...Generally she's just really helpful and I know she's there and I relax more. P30SWS*

*I'm just not able to deal with it. When I'm unwell I'm just not able to follow things up, to be proactive about anything. Then I say okay the ball's over to you. I'm relying on you to go and bat for me...Finding good people around me has been the most helpful thing from the get-go with any of this. People who have a better understanding than I do about the system and give you good advice along the way. P06BRI*

Other respondents reported having limited understanding of the NDIS, acknowledging that planning and plan implementation processes were just too complex and overwhelming for them to manage on their own. As a consequence, respondents reported the benefits of having a dedicated worker to provide advice, assist with decision-making, advocate on their behalf, and manage their funding and supports.

*So we're really happy with the supports that he has in place now...I wouldn't know where to start or where to look or who does NDIS. How do you pay it? I wouldn't know where to start with that...I'm so glad that I have [SUPPORT COORDINATOR] or I'd be so lost. F&C26BRI*

*Being new to NDIS, I mean, it's hard to...I can't do this by myself, because I have a problem with choosing and making decisions because I overthink. And so this is really a big help that they assist me. P12EW*

Many respondents who were receiving funded support coordination considered that they were receiving an excellent service and that their support coordinator was very understanding and responsive to their particular situation and needs. Respondents often spoke warmly of the positive relationship that they had developed with their support coordinator and how this assistance had helped them to obtain quality services which met their needs.

*They're great, I've known them now for I don't know how many years now. So yeah, they became like a big family you know, part of my family sort of thing you know...They make sure [NAME]'s getting the best, that she's entitled to what she's getting, and at the moment they're planning on her moving out of where she is and getting maybe a shared home where she's only [with] two people. F&C14TSV*

Having a two-way working relationship with a support coordinator, whereby NDIS participants and (if appropriate) their family members were actively involved in decision-making about disability services and received regular updates, was felt to be important. Respondents also appreciated being able to approach their support coordinator with queries and suggestions.

*I'm not good with paperwork so if I do it, self-manage it, it'd be a lot harder so if someone else takes the load off, I've got someone to talk to, they help me go through things and talk on my behalf...I'm happy because I've got [NAME] that does all the planning around like if I want something extra done she looks at my plan and says yes I've got the money to do it and she does all the leg work to contact all the services that I wanted...And they've kept in touch with my mum so she had an idea of where the money was spent and I was able to put ideas as well what the money be used for. P11BRI*

*I really need the support coordinator to help with all sorts of things. So no matter how much I know now how to use a plan I still, I call her every week. There's always something I need to ask about. I found her, and I rang her in the January of my first plan and said, you know I need some help, I don't understand any of this, can you explain. I've read the information, I understand this is a therapy budget, this is a core budget, what can I do with it? You know what, I need help with this, this and this where does it fit? P08TSV*

Support coordinators were described by respondents as being a vital source of information about the NDIS and local disability services. From the sharing of this knowledge, NDIS participants and their families were able to understand more about NDIS processes and planning, the services and funding they were entitled to, and how to use their plan as flexibly as possible to access local disability services and equipment.

*They will do a lot of paperwork for me. They will implement, they will explain the plan to me. They would say, okay you've got this funding, that funding, and we can do this and this and this. They'll set up appointments with the speech, they'll set up appointments with OT, they will set up appointments with psychologists and whatever are required. They'll do the review every year. They've got the knowledge. They'll go over and beyond in educating you, I guess, in the plan and making you feel comfortable that you're going to get all the right services, and it takes the pressure off you. F&C06TSV*

*So it was halfway through the first plan before I got a decent support coordinator who told me how to use my plan. And by the time it got through nine months through my first plan I hadn't*

*used anything on it. So it very much depends on your support coordinator how much of your plan you're able to use because they're the key to someone telling you how to use your plan. And how to, what you can and can't do on your plan. P01BRI*

Many respondents reported that their support coordinator played an important role in arranging and monitoring their disability services. This was perceived as helping to reduce the burden on NDIS participants and their families. Support co-ordinators were able to provide important information on the options available to people with disability and make recommendations of who the most appropriate provider may be. These workers were also described as connecting NDIS participants with service providers, and helping to arrange funded supports.

*I just contact her directly and stuff just happens...I think for participants, they need a person that they can talk to. When it's to do with, yeah where we have a need that's not being met...We needed help with such as arranging modifications to the house because it's a rented house so somebody has to negotiate with the landlord. And those things would take too much time for [NAME]. And arranging OTs and physios to come and do all that. Yes so having a coordinator of services for some aspects takes the load off. P06BAR*

*I suppose at the beginning I was doing it myself...It was hard at the beginning because I didn't know what I was doing and I got used to it but then I thought I'll just leave it up to them [support coordinator]...They manage the OTs, the speech just everything. They made appointments for me and I just go...I had a problem getting into the OT and [NAME] has got it like [clicks fingers] that. F&C03EW*

Once services had been arranged, the support coordinator was able to liaise with the provider organisation to monitor service provision, deal with any issues which arose, and organise the payment of invoices. This helped to ensure that quality supports and services were being received by NDIS participants.

*[NAME] is fantastic. I've only been with her for a month and a half but she's gotten things done...I can advocate for myself but I'm also quite shy in following [up with] someone that I don't like them or I don't like what they're doing and things like that. So I can be quite shy in that way and that's when I speak to my support coordinator and she helps me out with that, she will tell them for me. P21SWS*

Support coordinators were also described as playing a key role in interactions with the NDIA. These workers frequently liaised directly with the NDIA on behalf of the NDIS participant to find out information and to discuss plans and reviews. This support was seen as being particularly important if the disability-related needs of NDIS participants changed and plans required revision. Examples were provided of instances where this assistance had led to the subsequent changing of plans and an increase in allocated funding and supports. Related to this, some respondents also discussed the valuable help they had received from their support coordinator to arrange assessments and approvals for the disability services that they needed.

*Having a support coordinator, you know they're already in the system and they know what they are doing, so when I got a support coordinator, all the services were in place...The support coordinator for this review, she organised all the reports...and everything was submitted to NDIS directly...I struggled to put my points with NDIS...This time around, the support coordinator can speak on your behalf. F&C08SWS*

*I use [NAME] now because she contacts NDIS for me. She's an in between person...I got an email only a couple of weeks ago and it was from NDIS saying that they are looking to helping*

*us out with, because of this COVID, technology that might be able to assist us. So I said to her I would really love an iPad...I think she got the okay from NDIS and we can use that for physio aid and for anything else that I need it for...Having [NAME] as well, you just feel so confident. I've got things covered. P01EW*

A final critical role played by support coordinators and plan managers revolved around the monitoring of NDIS plan funds. This assistance helped ensure that all available funds were utilised, spent correctly and, where possible, used flexibly to address pressing support needs.

*At the last minute they said, oh [NAME] still have some funding left, why didn't you use it? Because we didn't know, they never report it to us how much money he has left and all. So now we have [SUPPORT COORDINATOR] who is organising that it's good because he will tell us, you know, now what do you want to do for [NAME]? This is aside for this one, this is for this thing, that this for therapy, blah, blah, blah, blah. So it's very good. F&C20SWS*

*We've got [SUPPORT COORDINATOR] that helps out and he's just lovely...Organising support. Keeping up to date with the budget. Checking how [NAME]'s going. He pops in every now and then to see how [NAME] is...If we've got a problem I can call [SUPPORT COORDINATOR]...He'll liaise with the service providers to go, "Hey listen can [SUPPORT WORKER] come four hours a day instead of three", because [NAME]'s got the funding there for it. [SUPPORT COORDINATOR]'s really, really helpful with things like that, and he's taken the time to meet [NAME] and understand [NAME]. F&C30TSV*

### 4.3 Market factors

Respondents across the five sites described two factors associated with the disability sector market as facilitating successful plan utilisation: (1) support from disability provider organisations and workers and (2) access to disability services.

#### 4.3.1 Support from disability provider organisations and workers

Support from disability provider organisations and workers was a factor identified by respondents in all five sites as strongly assisting NDIS plan utilisation. Disability providers were seen by respondents as playing an important role in arranging appropriate (and at times, flexible and personalised) supports. This included ensuring that there was consistency in the staff providing the supports, and also that workers were suitably skilled and trained. Furthermore, in order to facilitate successful client-worker relationships, some organisations were described as attempting to match the person with disability to workers who met their interests and wishes. The provision of personalised, quality supports increased NDIS participant's engagement with services, thereby increasing their ability to utilise their NDIS plan.

*I'm doing really well. [ORGANISATION] have changed my life...They've been great and they have chosen similar people that I've been with for a while and if one person has a day [off] then the other person steps in. So it's not like, you know, oh God who's today. And I don't like explaining my life every time I meet someone new. P10TSV*

*When I first got the house cleaner in...they're like, "If you don't like them, we can ship them off and do somebody else." So, I've been set up with the right people. It's good...They're very good at matching personalities, I think. P25EW*

Respondents also discussed the usefulness of the information provided to them by their service provider, and the assistance given with obtaining appropriate levels of NDIS funding.

*The thing that has helped me the most is when I changed to the new service provider and so they've explained a lot of it to me...understanding my plan a lot more too. Just so I can go to and ask questions and get the answers that I need. P22SWS*

*I feel like having providers that understand NDIS and have worked with NDIS in the past were good because they knew straight away okay this is what we need to do and they were really the ones that guided me to get quotes and stuff. F&C23SWS*

Ensuring that the supports provided to NDIS participants were of a high quality also assisted in successful outcomes and higher plan utilisation. Likewise the provision of two-way communication channels and the open-door policy of some local providers was seen as contributing to the usage of NDIS funds. In addition, plan utilisation was enhanced by provider organisations dealing effectively with any issues which arose when arranging and delivering supports. As a consequence of this support, respondents frequently expressed the sentiment that they were surrounded by a good support network which enabled them to better meet their needs and goals.

*[ORGANISATION] has been really great...I just go in there and say hi...and all the people would come in and have a cup of tea and coffee and sort of stuff like that so I got to talk to them...Oh they're just great. P31BAR*

*Once we found a good provider they've actually given us what we need for my son to you know, improve on his education. Which the school could not provide. F&C03TSV*

Some service providers were felt to go above and beyond in the care and time they afforded to their clients. Situations were described where providers had responded to crises when assistance was needed urgently or provided supports at a lower cost to ensure that NDIS budgets could stretch further.

*I find anything I just give these guys a ring...I need a bit extra, I can ring them and if they've got someone available I can, they'll pick me up...There's quite a few services around and if you ask them, you know anyone asks them, they go out of their way to help you. Like they'll say oh we can't help you but these guys can. P06EW*

*I think the one thing that helps me is that I'm getting support with all my matters...That's what [ORGANISATION]'s about, they're there to help you out. [ORGANISATION] is an organisation of people with disabilities, so they especially put aside their time to help you out which is why I'm really grateful. P16BRI*

For Indigenous participants in smaller remote communities away from regional hubs, having providers travelling to them and being physically present in the community was a key facilitator of plan utilisation. One family reported that a provider had regularly visited their community to explain their NDIS plan and how to use it, as well as making sure they could access services in their community. These regular visits were important in ensuring participants and their families were confident in their understanding and ability to use their plans, as well as building relationships and a support network around participants in remote communities.

Finally, provider organisations were also seen by some respondents as being a useful source of information on disability services within the local area. This included providing recommendations of alternative providers if they themselves were unable to offer certain types of support. The role that charitable and advocacy organisations played in the provision of advice around NDIS funding and available supports was also noted and appreciated.

*Both [ORGANISATION 1] and [ORGANISATION 2], they shared with us some list of...speech*

*pathologists and occupational therapists in Brisbane. And that really helped to find because quite often they're booked out and it takes time to find a person who has time on your specific date and your specific day...So that was a big help, yeah so we managed to put everything together rather quickly I would say. F&C02BRI*

*It was my advocacy people that I'm dealing with, they knew about him [psychiatrist] and they thought that it would be the best fit for our family and he's friggin awesome. So that's one thing I didn't find and he's a gem mate, a diamond in the rough out here. Yes [ADVOCACY ORGANISATION] been helping me like point me in the right direction to stuff. F&C16SWS*

Individual workers within the disability sector were also identified by respondents as assisting with NDIS plan utilisation. A wide range of workers (disability support workers, case workers/liaison officers, plan managers, medical staff, and of particular note, allied health professionals and advocates) were described as being important sources of information and support.

*[NAME]'s plan manager...she's incredible. I've been lucky to find knowledgeable people who know lots of other people as well. F&C19BRI*

*Going out and getting myself an advocate and getting them to explain it to me more...I was fully informed. Having been fully informed and knowing what I could do with my funding helped. And not just like going on the website and reading about it, it's like actually, 'cause once you meet with someone in person and they explain it and go through it with you, you don't have to go through it again. And you don't have, you actually can ask your questions. You can't ask questions on a piece of paper, you just read what's there. Actually having that person there to go through it with you. F&C31SWS*

Plan utilisation was facilitated by these workers through the provision of relevant information about NDIS processes and plan implementation, as well as supporting communication with the NDIA (including at times attending planning and review meetings). Disability workers were also seen as being instrumental in offering recommendations for appropriate supports and services, and providing assistance in arranging and coordinating services.

*My daughter's OT is fantastic. She's always sending me stuff and, you know, sending me an email about something I can send [NDIS PARTICIPANT] to or I could go to...Our psychologist is trying to get us some names of some good ones [speech therapists]. She said I know a few she said but I want you to get a good one so she's actually sourcing some for us at the moment which is good. F&C26BRI*

More generally, having a good worker who was skilled, knowledgeable and reliable was considered to assist plan utilisation. Respondents reported having good relationships with some of the workers who supported them, describing good rapport and two-way channels of communication. These workers were felt to be experienced and appropriately skilled at working with people with disability. They were also considered to provide a high quality service which met the specific support needs of the NDIS participant. As a consequence, respondents perceived that this encouraged them to utilise their NDIS funded supports and enhanced their willingness to engage with disability services and work towards their goals.

*They've been fantastic. And that's why I'm staying with them, not going through any other services because nearly three years of these guys actually constantly working with my family, everybody's got a really good rapport with each other so why would I change that. F&C04BAR*

*My OT is absolutely amazing...She's just one of the best. She's just brilliant. She works really*

*well with my three children and the speech [therapist], [NAME], is great as well. I'm able to relate to them and they tell me about their progress every session. My kids walk in there and just own the place [laughing]...It's a really beautiful, supportive network...It's like a little family away from our family. It's like a support network that we don't have or never had before, so it's great. F&C01TSV*

Furthermore, some respondents noted the helpfulness of NDIA staff in assisting them with understanding and implementing their plans. In particular, some respondents within the South Western Sydney region stated that their NDIA Local Area Coordinator (LAC) had had a positive impact on plan utilisation. For these respondents, their LAC was described as providing useful information about their NDIS plan, how to use their funds more flexibly, and the services which were available locally within the region.

*If you've got a good LAC they can help you, but I've had funds left over every time... For me, this year personally, I've gone to my LAC, he is awesome as I said before, and was, like, "Can I use it for this?"...Do I know how to spend the funds? Now I do, but I got lucky. Did I really know how to exercise and use my funds flexibly before my LAC this year? No, absolutely not. F&C34SWS*

*At the beginning I had big supports from Local Area Co-ordinators because they give me some relevant information. They played the role of support co-ordinator at the beginning until I started to be familiar with the services...Practically I was a bit dependent on the Local Area Co-ordinator for the short time. P35SWS*

### **4.3.2 Access to disability services**

A final factor found to positively impact upon NDIS participants ability to access supports and services provided for within their plans was the availability of disability services within the local area. Having ready access to disability services was strongly felt to increase the uptake of NDIS-funded supports. For some respondents, the availability and funding of transport or supports to get to appointments, or the ability to obtain services within their own homes when needed was also stated to be important and allowed them to better utilise NDIS funding.

*[ORGANISATION] come to your home as well...Obviously they charge you for it. But I think it was \$25.00, something like that, for them to come to your home but sometimes that is a good thing if you can see them in their home environment...[and] see the dynamic between her and her sister for example or her and her dad, so. So yeah I find that, that would be helpful to have someone come into your house and actually just watch what's going on and her interactions and things like that. F&C35EW*

Within the more remote areas where this research was conducted (the Barkly and Eyre West regions), some respondents noted the availability of specialist fly-in-fly-out disability workers who were able to visit NDIS participants in the area when their assistance was needed.

*[ORGANISATION] has a specialist that does psychiatrist I think or psychologist one of those but she does fly down...we haven't seen her for a little while but she did last year with [NAME]. She came down a few times so that we could see her. F&C34EW*

It should be noted, however, that timely access to disability services was commonly reported to be problematic in all of the research sites. The issues relating to the availability of services and the impacts this has on plan utilisation are discussed below in the 'Barriers to plan utilisation' chapter.

## 5. Barriers to Plan Utilisation

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Twelve factors that negatively impacted NDIS participants ability to utilise the funding and supports provided for in their NDIS plan were identified in the qualitative interviews across the five research sites. These barriers included five participant, three plan and four market factors.

Of these barriers to plan utilisation, four primary barriers were highlighted by respondents in all of the five research sites. These included two market factors: the availability of disability supports and services, and issues with provider organisations and the disability workforce; one participant factor: knowledge and understanding of NDIS processes and local service provision; and one plan factor: NDIS planning and approval processes. A further plan factor - access to quality support coordination services - was a key barrier identified by respondents in four of the sites as impeding plan utilisation.

### 5.1 Participant factors

Respondents nominated five factors pertaining to NDIS participants and their family members which were felt to act as a barrier to plan utilisation. These included (1) knowledge and understanding of NDIS processes and local service provision, (2) precedence of non-disability needs, (3) managing appointments, (4) reluctance to accept disability services, and (5) the use of technology. Of these barriers, a lack of knowledge and understanding of NDIS processes and local services were most widely seen as impeding plan utilisation.

#### 5.1.1 Knowledge and understanding of NDIS processes and local service provision

A very commonly expressed barrier to plan utilisation related to a lack of knowledge and understanding of NDIS processes and how to implement NDIS plans. While this barrier has been categorised here as a participant factor, this issue was largely seen by respondents as resulting from NDIS participants not being provided with sufficient and/or accessible information from the NDIA (which could be considered to be a plan factor).

Respondents (and especially those in the Barkly region) felt that the NDIA had not spent adequate time and effort preparing people with disability and their family members for the coming of the NDIS, and ensuring that people understood the expectations and requirements of the scheme.

*Navigating the scheme back then I remember thinking wow this is a lot, this is like...taking on a small business in your home and making decisions about, to me it felt like we hadn't done enough in the disability sector to prepare people with a disability, so that's adults and also family cohorts to understand what was needed from them and what their expectations could be. F&C03BAR*

Many respondents across all the five sites reported that they had received insufficient levels of information regarding their plans and local disability services which made it challenging to utilise their NDIS funded supports.

*I still don't really understand what the plan normally covers. But I do want to make mention on recording about that aspect of when I rung NDIA and I've said to the girl on the other end of the line, "What is it that NDIS will do for me? Can you actually sort of spell it out?" and she said, "Oh NDIS is just going to make everything nice"...But I need more concrete - that yes you'll get funding for Allied Health services with rehab and for equipment that can make your life*

*better when you're unwell, those kinds of things. P06BRI*

The information that had been provided by the NDIA was described by some as not being presented in an accessible way. The terminology used was said to be too complex and some respondents expressed feelings of being overwhelmed by the level of detail in this information. Respondents also noted that their disability (e.g. visual impairment, intellectual disability, cognitive impairment) made it especially challenging for them to understand and use the information given. Particular challenges were noted for the understanding of people with limited English literacy skills from CALD or Indigenous backgrounds.

*They [NDIA] give us like this really thick of paper with all of the names and everything and we're like woah there's so much. F&C17TSV*

*I didn't understand it. Because I was sick I didn't understand a lot of stuff. Having fits makes you forget things. They'd tell me and they'd give it to me on paper, in paperwork what the plan was for and I'd take it over to my sister and she'd explain everything in just plain old English. Like words I didn't understand in plain old English. So luckily my sister helped me with the lot of it. P06SWS*

Many respondents across all five sites reported that the information they had been provided with by the NDIA was not broken down in a sufficiently understandable way. Complaints were also expressed that there was a lack of opportunity to have the information explained to them face-to-face.

*They approved it from [DATE] I think it was and said you can start looking up services to help you with what you want and I put the vacuuming, mopping and the ironing was the main thing I needed. Then I couldn't look up the services, well-being vision impaired in the first place, but then looking up the records I couldn't find the list of services apparently and the one I did find it was printed so small that it was too hard to read. P23BRI*

As a consequence, some respondents were uncertain about the types of supports that the NDIS were willing to fund and that they themselves may be entitled to. Perceived inconsistencies were also described as to the supports which were funded across the plans of different NDIS participants. Particular confusion centred on access to aids and equipment, exercise physiology and classes, and gym and pool memberships and whether these could be funded via the NDIS.

*So it's never really been explained to me the client, what I'm entitled or any of that or how this money that's been allocated to me can be used. Whatever I want to use it for I get knocked back on. P07BAR*

*I just wish that we could understand what we can do with it. This is our life. What can we do and what can't we do. We can't go to the pub because that's, obviously, that's a big no, but I wish the NDIS had dos and don'ts, where you can say this is what you can do and this is what you can't do...Because at the end of the day, it's our situation, it's our life. P12BRI*

Respondents expressed a lack of clarity regarding their NDIS plan and were unfamiliar with the terminology used within a plan. Particular confusion was expressed around what the different types of funding contained within an NDIS plan meant (e.g. "core funding", "capacity building"), what these funding categories could be used for and how to utilise these funds.

*Then I got the plan. What do you do? I didn't know how to read the plan. I still don't know how to read the plan to navigate what needs to be done, like the support coordination of it all...The wording, the way it's structured, the way it's written in the plan, very, very difficult to understand, very difficult to understand...That's probably why I can understand why people*

*aren't utilising it to the fullest because they don't understand it. You've got your core, you've got your relationships, you've got this, but where do you get the money from to do what you need to do? F&C06TSV*

*I'm not in full understanding what my core budget or this or that is or capacity building. I'm trying. I've asked for documentation. It's never come because I can't print out...However, I feel it's probably a reasonably deliberate thing by government because that money goes back to them...There was a session last year where we were waiting and waiting and waiting and my funding, even though I had a fair amount of money left in the budget, because I wasn't knowing how to utilise it properly. P23EW*

In addition, some respondents were unsure about how to set appropriate goals, the types of disability supports that could best meet their needs, and how to obtain more funding if their support needs changed. Uncertainty was also reported by respondents regarding how to monitor the levels of NDIS funding which remained available to them in their plan.

*I had basically no idea what I was doing. I was just letting them do what they were doing and charging me whatever, so I didn't even know anything about the portal, how to get in there. All I know is that I got sent out an invoice from NDIS, just saying, okay, you'll receive this amount of money for this service, this amount of money for blah blah. Had no understanding, really. P30SWS*

Some respondents reported that they had not seen or read their plan at all and were unaware as to both the overall level of funding and the specific supports they were currently funded for. Particular challenges were noted regarding this within the remote Barkly and Eyre Western regions with one Indigenous respondent in the Barkly describing NDIS plans as being "white fella business" (BARP10) and that they were unaware of the content of their own plan.

*Worker: I don't think, you guys didn't ever read it [NDIS plan], did you? Just handed the sealed envelope over to me.*

*NDIS Participant: I gave it to her. Too much writing. P10BAR*

*I don't even know what's in the plans and I don't even, they say, "You've got plenty of money, plenty of money, plenty of money", but no-one's guiding me on what to do with it...No-one sat me down and said, "Right, you've got this amount of money, you spend there, spend there, spend there", but no-one given any direction...I don't know whether there's a million dollars in there or a dollar-fifty to last another six years. I wouldn't have a clue. P07BRI*

Many respondents stated that they had received insufficient information regarding how to implement their NDIS plan. Confusion was expressed about how to arrange the supports that had been funded for within their plans. Plan implementation was described as being complex and challenging to understand even by some respondents who were familiar with the disability sector (either through previous use of services or their own work). Respondents especially reported a lack of knowledge of local service provision including the specific organisations and workers that could best meet their own particular disability support needs. They were also unsure about how to organise services once a suitable provider had been identified.

*It was just like whoa. What, how do I utilise this? You're just looking at it going okay you've got this much money, what am I allowed to get. So it literally sat there for six months, because I had no idea what I could access...You don't get how from the people that are actually running it. The LACs don't help you...So my son's missing out on those six months and what he could have had, because I had no idea where to use it. How do I use it, where do I use it? Who can*

*we use it for? F&C26BRI*

*We were spoken to about what we could do and then basically let go to go find these people, these services. We had no idea but I've grown up with disability services in my family with my sister. I thought yeah this'll be easy, oh no it was not easy at all. No real guidance I felt...We had to find our own way...We weren't informed on what we could do, like who should we go, is there a list of people in town...They didn't want to give us any details, they wanted us to find it ourselves...I just found it daunting because I didn't know where to go or who was the best person for what he needed. F&C03TSV*

Some respondents felt that the expectations by the NDIA that NDIS participants would be able to arrange their own services was unrealistic especially when many were also dealing with considerable day-to-day impacts of their disability. Many respondents therefore acknowledged that without formal assistance and guidance (e.g. from support coordinators and disability workers), plan utilisation would have been very challenging to undertake personally with their current level of understanding.

*The NDIS have said we've got [amount of money] and all this money to be allocated for all these different supports but what does it actually mean and then who's going to do it, and we don't understand, and how do they get paid...Far too complicated. And trying to deal with things like on top of having a special needs child or being special needs and having challenges anyway...It's all too much for me. F&C30TSV*

Some of the respondents interviewed were self-managing their NDIS funding. A lack of adequate information from the NDIA regarding self-management processes was noted by several of these respondents. This included how to use the portal, develop service agreements, make payments for services, and requirements for record keeping. Other respondents also expressed anxiety about using their NDIS funding in case they were later audited and found to have made errors in their spending.

*I did have some confusion at the beginning because first plan, we had to find a contract, actually an agreement with the provider when NDIA managed. When I first started with self-managed I had to call them because they didn't mention anything about the agreement. I actually had to contact them and ask why don't we have an agreement and they explained to me if I self-manage I just go and pay and then I report back and then make the request. Actually the provider had to explain to it me, like what I can do. After that I had to go to this website. I think it took me like a week or so to figure out how to. F&C22BRI*

Issues with communication with the NDIA were also described by respondents as hampering plan utilisation. Some respondents were dissatisfied that they were unable to contact their local NDIA office directly when seeking information and advice and instead, had to go via the national call centre. Respondents expressed frustration with this as they reported that call centre staff were unfamiliar with their particular case or did not provide consistent answers which led to further uncertainty and confusion.

*There's no point ringing the national call centre because they have no idea what they're doing. I doubt they're even in Australia, useless. They have no idea, they've never once been able to answer a question or help with a situation, they always refer me to someone else so why don't you just give me that someone else's details in the first place. P06BAR*

### **5.1.2 Precedence of non-disability needs**

Within the Eyre Western and South Western Sydney regions some respondents reported that the precedence of other non-disability needs impacted upon their ability to access and utilise supports

funded by the NDIS. At times pressing personal, financial and health issues meant that the arranging and accessing of disability supports was not necessarily a top priority for NDIS participants and their families.

*I struggle with the focus of NDIS being about economic and community participation when I think that's, if I think about Maslow's hierarchy of need, to get to that level you've got to have the core – there's a whole lot underlying – so I think sometimes they've missed the boat on that. Sometimes someone just needs help to get up in the morning and get their breakfast, be safe in their home, be safe in the community, before you can get to economic and community participation. F&C26EW*

In particular, for some of the family members interviewed, work commitments, family responsibilities and financial stress at times challenged their capacity to arrange and utilise services for the NDIS participant they cared for. Several respondents also described experiencing physical and mental health issues, or domestic violence situations which became their priority to address rather than utilising NDIS funding to meet disability-related needs.

*I work fulltime. We've got the kids. Two of my boys have dual diagnoses due to trauma so they don't qualify for NDIS...But I've still got to access for the boys I go to the behaviour support therapist for them trying to reframe their thinking because of the domestic violence trauma. We've got to see an OT to teach them emotional regulation. I've got to take them to the paediatrician. One of them is on medication. Then I've got [NAME] who sees the sexual assault counsellor. She's got the paediatrician, she's got the clinical nurse, she's involved with the weight clinic...I'm forever chasing my tail for one of the kids, I don't know where I'm up to to be honest. F&C11SWS*

### 5.1.3 Managing appointments

Difficulties experienced with managing NDIS-funded appointments was considered by some respondents within the Eyre Western and Townsville research sites as hindering their ability to utilise all of their allocated funding. The organisation and management of NDIS-funded appointments was reported to be challenging for some participants (and especially those with cognitive impairment). If support was not readily available with these tasks, it sometimes led to appointments not being arranged or attended as planned and, hence, NDIS funding not being appropriately utilised.

*Because I'm disabled and I can't remember much with appointments so they give me a day's notice and I can't remember anything after that day's notice. My mind is all over the place at the moment...[NAME] tells me all my appointments and I try to get to them as best I can. P05EW*

The management of appointments was also a particular issue raised by the parents of younger NDIS participants (and especially for families with more than one child with a disability). Juggling multiple appointments was described as being challenging, especially when trying to fit this in with school and work commitments.

*Between my kids on a bad week I have ... appointments to attend a week and often Murphy's Law I'll at least have two that will clash... ..You just need one little thing to throw a spanner in the works and it's like damn it okay back to the drawing board. F&C04TSV*

Also, several respondents within the Townsville region stated that their child's school was unwilling to allow therapy appointments to occur on the premises during the school day. Appointments therefore had to either be arranged outside of usual service provider hours or away from the school

during the day. The latter arrangement was particularly challenging for working parents and also led to young NDIS participants missing greater amounts of class time.

*We were just lucky we found a paediatric physio for [NAME] that had an opening but...to try and take my son to three appointments a week when I'm also trying to maintain my employment and not wear myself so thin...We don't want to take him out of school any more than we have to and as it is he's already missing out a full day Monday every second week to do two therapies. P08TSV*

#### **5.1.4 Reluctance to accept disability services**

It was acknowledged by respondents that some NDIS participants were reluctant to accept disability services. This was considered to be due to several reasons. Firstly, difficulties experienced with provider organisations and disability workers contributed to a lack of willingness to engage and accept the ongoing involvement of disability support services. Secondly, the personal preferences and circumstances of the NDIS participant themselves also contributed at times to a reluctance to utilise the funding in their plan and have supports set in place. For example, as was described above, some respondents were dealing with other pressing family and work commitments which made it difficult to focus on their disability-related needs and utilise their NDIS funding.

Finally, it was noted within the Barkly region that some Indigenous participants were reluctant to accept formal services into their homes, preferring instead to receive informal support from family members. This preference was seen as partly being due to cultural attitudes that care should be provided within the family, but also a result of concerns of potential impacts of engaging with service providers.

*It also comes down to people not wanting people to come into their homes...They might be judged or they might be criticised or the NDIS mob might tell the housing mob or the welfare mob. F&C03BAR*

*I don't want them to come clean up, shame, at my house...I got my niece, she do it. P26BAR*

#### **5.1.5 Use of technology**

One further stated participant factor which acted as a barrier to plan utilisation within the Barkly region related to the use of technology. Due to a lack of available local service provision (resulting either from a lack of supply or inability to access due to wait lists), NDIS participants at times had to rely on the provision of supports by providers based outside the region. This approach frequently necessitated the use of virtual modes such as video conferencing. However, this form of service provision was often seen by respondents to be a poor substitute to in-person support and as hampering effective engagement. It also was identified as presenting challenges for NDIS participants who did not have access to the internet or appropriate devices. Even if they had access to the technology, other respondents acknowledged that they lacked the necessary skills to participate independently in virtual activities.

*Because we're here in Tennant Creek it's just way too hard to try and access all those sort of services so unless you're going to do like I'm doing with either, you know Tele and Zoom and stuff like that with the therapists, it's very, very hard to get services here and access them. F&C04BAR*

## 5.2 Plan factors

Three factors relating to NDIS planning and processes were identified in the interviews with NDIS participants and their family members as impeding successful plan utilisation. These were (1) NDIS planning and approval processes, (2) support coordination services, and (3) use of the NDIS portal. The first two of these barriers were especially seen by respondents as hampering successful plan utilisation.

### 5.2.1 NDIS planning and approval processes

Challenges experienced by respondents with NDIS planning and approval processes represented a key barrier to plan utilisation. Respondents expressed concerns that NDIS processes were too complex, bureaucratic and time-consuming. Even people who were working within the disability sector, had high levels of education and good English literacy acknowledged that they faced challenges in navigating the system. Having support with these processes was seen as being essential by many respondents.

*I think we've probably been a little bit fortunate with the way things have panned out for us, because we've had a lot of resources and help from the hospital and from friends who've been able to steer us in the right direction, but I could probably sympathise with other people or other families who go through this situation who may not have the resources or the people to help. It could be such a bewildering process, and when you're trying to also cope with a loved one who's sick, yeah, it's probably not the most user-friendly process. F&C27BRI*

Particular issues with NDIS planning and approval processes were said to be faced by NDIS participants living in remote areas such as the Barkly region which had a large proportion of Indigenous participants and considerable levels of socio-economic disadvantage.

*We were having a debate on the weekend, a very heated debate over how ridiculous it was and who would have implemented that in the first place because it just doesn't work. Why make so complex as it needs to be especially with this one to one people. It's just dumb, and especially in Tennant Creek, and more so, but across the country it's just a lot harder than it has to be. P14BAR*

Concerns were also expressed about the willingness of the Scheme to fully fund and meet the needs of NDIS participants. Some respondents (and especially those living in the Barkly and Townsville sites) felt that individual support needs were not being considered, and instead funds were allocated based on a person's diagnostic category. Indeed, some of these respondents expressed a view that the NDIA was now trying to cost save during planning and review meetings, rather than fully considering and meeting the needs of each individual NDIS participant. Concerns were also raised by some respondents that staff within the NDIA had insufficient knowledge of disability and, as a result, were unable to understand the funding and services that were needed by NDIS participants to meet their specific support needs. Respondents within the Townsville site reported that this factor was particularly problematic for people with complex support needs as there were said to be insufficient numbers of complex needs planners within the region to work with this cohort.

*They're not individualising the clients and personal needs, they put it in a generic basket, whereas you've got CP, he's got CP, she's got CP. So, you're all the same. F&C13BAR*

*Now that we've become a national framework that there's more and more and more and more red tape and the more red tape you have the less personalised it is. So there are times that*

*we're often sort of stuck between...I found in the beginning with [NAME] they didn't have probably the formulas or the budgets that had shown them roughly what different diagnoses needed in terms of supports and in terms of funding so it was a bit more open. Whereas now there's very much a feeling that diagnoses are only funded X amount. F&C04TSV*

Respondents in the Barkly site also expressed concerns that the NDIA did not sufficiently recognise and meet the broader needs of people with disability living in that region. For example, some NDIS participants were described as living in difficult socio-economic circumstances and required assistance with more basic needs (e.g. access to housing and being able to meet living expenses) before they could focus on addressing their disability-related needs.

*There's old [NAME]...They buy him a shiny new scooter right, but...he can't afford to charge that scooter, because he's got to think about keeping the fridge going and shit...So what's the point. That's like giving a kid a bag full of lollies and saying you can't eat them. They should be assisting him so he can benefit from that brand new shiny scooter...Give him something like a \$5 card so he can go and put it in, charge his scooter up and yeah it will be right for a couple of days...They don't take that kind of stuff into consideration. P07BAR*

Issues had also been experienced with NDIS funding approval processes. Perceptions were reported by respondents of a lack of clarity, consistency and transparency as to how funding decisions were made by the NDIA. Some of these respondents reported that their funding requests to the NDIS had been refused. These included requests across many support types including aids and equipment, home modifications, travel, carer support, advocacy, interpreting services, support coordination, in-home support, community activities and therapy services. At times these refusals had been made despite the provision of clinical assessments and recommendations supporting the funding of specific services.

*The biggest issue we had at that particular point in time is the needs of what the clinicians wanted [NAME] to have and myself versus what the NDIS thought was appropriate and so, that delayed her coming out of hospital...I'm sure that they had constraints. I can understand there's a budgetary issue, everyone got to spend within their means, but at the same time, she's not going to get the care that she needs... So, it's a conflict. They're trying to force you into accepting what they want and from a dollar perspective, yes, they want you to get the best of care, but at a level that they were happy to pay for. F&C10SWS*

*The paediatrician had recommended things to me like martial arts and I would have loved – he said that's such a social awareness and a physical awareness of where your body is. I couldn't find anything that fell under NDIS. I had had quite a few recommendations of what would be really suitable for her and a lot of it didn't fall under NDIS. F&C31BRI*

Consequently, some respondents reported feeling as if they had had to constantly fight the NDIA to get the funding that they (or their family member) fully needed, including submitting applications to the Administrative Appeals Tribunal in an attempt to have initial decisions reversed in their favour.

*He really does need support worker hours. He does need help and assistance with the community – social, knowing fears and boundaries and his anxiety, his depression...It was a request from the psychologist that he does get a support worker. The NDIS failed to read the psychologist's report properly to make that decision when this last plan came out...I've been fighting, four times, the review, because I said I wasn't accepting that plan. Four times I put in a review to have the plan changed to include them and four times it's been knocked back, and it's only because I wrote that letter because it's my mental health that's deteriorating and the Member of Parliament rang as well, and now that they've approved it. F&C06TSV*

A lack of timeliness was reported by some respondents in the approval and allocating of funding by the NDIA. This included approvals for home modifications, equipment, allied health services and personal care supports. Consequently, delays had been experienced in obtaining necessary funding, leading to respondents either having to forgo services or to fund these supports themselves in the interim. These delays were felt to be particularly detrimental for NDIS participants with a progressive type of disability.

*You have to provide them with all the paperwork before they even start to assess it. That process can take quite some time because if you don't put it in the right form then it gets rejected or it waits for someone to get back to them. So, it does take a long time through the NDIA, sometimes you have to jump through a few hurdles. F&C12SWS*

*I had all the supports start, thinking it would be fine. So they've been working for us for about six weeks. And, well, like I said, I still haven't had any money. I've paid the first four weeks of all of that with my savings but, yeah, I've had to call them all now and say, I'm so sorry, they've not paying me and I've paid you out of my money so now I can't do anything. That's been a real barrier...I will be calling the NDIS again...They tell me every time they're escalating it but escalating it hasn't made anything happen. So that's a big barrier, trying to get to the person who can just fix it. F&C19BRI*

Concerns were expressed by respondents regarding the level of reports and clinical information required to evidence NDIS funding requests. Challenges were also noted in obtaining specialist assessments and reports with some respondents highlighting that the limited availability of specialist staff who could prepare required reports was problematic and long waiting times existed to see these practitioners.

*I needed some home mods done back then – well, I'm still waiting on that. NDIS – “that's too dear.” “Get a cheaper one or you pay the difference.” They want individual quotes of everything, or “that's the homeowner's responsibility”...Finding it very hard to get that assistance. Now, it's not like I'm asking, you know, for the world. I just need stuff to help me. And all of this has been in my plan right from the start, especially the home mods, and it's just so difficult, I find...And you think, well, why are they providing you this money if they're not going to help you achieve what you need? That's what I don't understand, you know. P16EW*

*The kitchen at the moment is the one that keeps changing...They keep measuring up, they keep taking photos. The occ therapist keeps saying oh yeah, yeah we'll do this, we'll do this...There's a plan for this and then the plan's rejected. New plan...then it's rejected again...and it gets to the point where I said I really just don't give a s\*\*\* now, don't f\*\*\*\*\* put the, like this is where I start swearing because I think don't worry about the kitchen, I'll live with my old crusty kitchen. P31BAR*

Furthermore, the costs incurred in obtaining necessary evidence (e.g. specialist fees, travel and accommodation) had also been prohibitive for some respondents and they had been unable to afford to have assessments conducted. This issue was seen as being particularly problematic by respondents living in more remote areas such as the Barkly region. Respondents in that area reported having to travel long distances to Alice Springs or Darwin in order to obtain assessments due to a lack of provision within the local area.

*They didn't want to believe [NAME 1] and [NAME 2]'s reports...The NDIS did say it once to me, about getting a psychiatrist to do a diagnosis...I said there is no psychiatrist here in [LOCATION]. We'll have to go to Alice Springs...I said a psychiatrist is going to charge us \$300.00 an hour, they're going to want to see the child for at least two hours, I said I have two*

*children, I said so there's \$600, you know \$1,200...I said we'll have to stay in Alice Springs for a few days I said so there's going to be another \$500-600 in accommodation, I said not including food, fuel and everything else, I said we're already up to \$1,500. Who's going to pay for it? Oh, oh well it should be up to your responsibility...I said because unless you pay for it I'm not going. F&C04BAR*

Respondents also highlighted that the allocation and use of NDIS funding was too prescriptive. In particular a lack of flexibility to utilise funding from other NDIS support categories within their plans was described by some respondents (and especially those in South Western Sydney) as hampering their ability to fully meet their disability support needs. This had led these respondents to run out of funding for certain services and to limit access to these supports.

*At the moment I've got funding that I can't access to put over to my occupational therapy and psychology and I only have \$1,200 left in that. But I need a lot more than that for it, like my psychology I'm seeing that once a week for an hour, now that costs a bit. My funding for her is going to run out real quick but then I need my occupational therapist who's been helping me get back on my feet and helping me with my balance and walking. So what do I get rid of? I need my psychologist otherwise I literally will go into really severe depression to the point of suicide so I don't know. P21SWS*

## 5.2.2 Support coordination services

Access to quality support coordination services was a further barrier identified as impeding plan utilisation by respondents in all of the research sites with the exception of the Eyre Western region. While many of the respondents interviewed had received NDIS funding for support coordination (if this had been wanted), some stated that they had not been offered this option during their planning meeting. Others reported that they were unaware that funded assistance with the coordination of supports was available to NDIS participants.

*In this last plan, they did put an iPad in which we went and got, but they still failed to put through the support coordination, so now I'm fighting for that. F&CP06TSV*

As an alternative to support coordination, some respondents within the Brisbane region described receiving assistance with plan implementation from NDIA Local Area Coordinators (LACs). At times, however, this support was not felt to have been sufficient and was seen to be a poor substitute for support coordination.

*The LAC only told me, gave me the link to the occupational therapist website, instead of not help find a suitable occupational therapist who's into mental health and autism, just "There's a link, I've done my job"...Considering the uselessness of the LAC and being/acting in the support coordination role...support coordination, that would actually be a useful thing. P25BRI*

Several respondents stated that they had needed support coordination to assist plan utilisation but had not initially been offered funding; on appeal to the NDIA this decision had subsequently been reversed and the necessary funding allocated. Other respondents considered that they had received insufficient levels of NDIS funding for support coordination and this had limited the amount of time their support coordinator could assist them with their service arrangements.

*I can't remember the number of coordination support hours that he had but it was token. Then there was a move in town to increase everybody's coordination of support hours and then it got changed, it got dropped but we managed to keep [NAME]'s up...It needed to be lots of hours in his COS bucket for that person to be able to continually to engage with the family.*

## F&C03BAR

Furthermore, the cost of support coordination was perceived by some respondents to be too high and that they had received a poor quality service for the amount of funding budgeted for this support in their NDIS plan.

*After two months it's like sorry all your money's gone, your support coordination's gone. I can't help you anymore. And I'm like huh, excuse me, but you haven't really done anything for me. And then I said I need to see the bill. So they charge \$1.60 for every minute. So if you email them, every time they think about you \$1.60 a minute, and I was not told that... We have no idea what he did in the office time but we sure had to pay for it under the NDIS. P18BRI*

A lack of access to, or inadequate funding for, formal support coordination was considered by some respondents to have led to them encountering difficulties in identifying and arranging their disability services. This had negatively impacted upon their ability to use their NDIS funding in a timely manner.

*The first one [NDIS plan], it was like self-managing, so before there wasn't any support coordinator... If you are just dealing with the providers yourself, sometimes when you book for whatever, they will do it on their own time, and then when you call them and you can't wait, you have to look for another person here and there, but then, at least with the support coordinator, they understand what they are doing, so they help you to get whatever you needed on time. F&C08SWS*

Perceptions were also expressed (especially within the Townsville site) that the NDIA considered support coordination as being only an interim measure and that NDIS participants should be able to develop the capacity to arrange and monitor their own services. This was felt to be an unrealistic expectation particularly for individuals whose disability or time commitments meant that they were unable to personally manage their supports.

*They've been trying to take support coordination away from us every single year. I was even told that, "Well, after two years of using NDIS, you should be really familiar and trained up on how to do all this." Why would that be true? If somebody else is doing all the support coordination for me, and organising everything for me, exactly how do I learn from that process? And then I was told, "Well, if you wasted your time and didn't bother to learn," I've been wasting my time apparently. Just been wasting my time. And that was in a plan review I was told that. F&C02TSV*

Some respondents reported that funding for support coordination was not being provided on an ongoing basis and several examples were given of this funding being removed at review meetings despite the respondent's perceived ongoing need for this service. Other respondents were concerned as to how they would cope if their support coordination funding were withdrawn in the future as they did not feel that they had sufficient skills or knowledge to arrange and manage their own NDIS services.

*I know in the second plan, I think it was, they took that out, the service coordination. They were no longer providing that service which I think is a big mistake. You've got to remember that full-time carers are under so much pressure anyway and the last thing they want is to have to go and do all this sort of stuff themselves. As far as I can understand, they're saving money, pretty much. It wasn't just me; it was across the board from my understanding that no one after a certain date was eligible for service coordination, which is a mistake because people's needs change, carers go away and businesses close. Even the amount of funding changes. F&C30TSV*

While many respondents who had received funding for support coordination were satisfied with the services received, some had had poor experiences. These respondents reported that their support coordinator was not proactive with providing information and updates or involving them in decision-making. A lack of communication with the NDIS participant was also described as being problematic in some instances.

*[SUPPORT COORDINATOR] got in and she organised kite surfing for him and she did a really good job, he was over the moon...And then that was it, she didn't do anything else. So [NDIS PARTICIPANT] said he could handle it, he would phone her, there was no response, no answer, emails weren't working, phone calls weren't working, nothing was happening...It dragged on and on and on for months. Nothing happened. F&C10BRI*

Examples were provided of instances when supports had not been organised for NDIS participants as agreed or in a timely fashion. This had led to the respondent either having to go without services or do much of the work to arrange their supports themselves.

*She has a reputation of being like the best in Townsville or whatever, but I'm not really that impressed...I end up then just having to chase her to chase them because she doesn't kind of act very quickly... And quite often things I've asked her to follow-up or find out about, yeah, it just takes so long that I can't wait that long or...she kind of half looks into it, or yeah, I just feel like, well, I need a little bit more from you, you know...I'm still left doing the bulk of it. F&C09TSV*

*Between the [support] coordinators, I'm on my second one, looking to my third one because they just can't manage the funds properly, they can't manage what you actually need properly. The lack of communication and even when you do communicate, you get billed out the whazoo for it, like what the hell? This funding is supposed to be helping these kids, it's not helping feathering your nest. And you are acting like you are helping and getting nothing done...You guys got \$2,500 to manage this s\*\*\* and what, you're asking me, I have to chase it up, I have to do your leg work? F&C16SWS*

At times, and most notably within the Barkly region, respondents also reported that their support coordinator was not adequately skilled or experienced and possessed insufficient knowledge of the disability sector to assist them properly. A lack of consistency in the workers providing this service was also noted by some respondents.

*The support coordinators who kept leaving - because I've had eight in two years - they didn't tell me how to use my money...I just have to figure it out for myself and mostly I was teaching them how to use it by ringing up NDIA and asking them what the rules were and how to do things. PO1BRI*

Further issues with the receipt of support coordination services were noted in the Barkly site. Due to a lack of local support coordinators within the region, these services often had to be obtained from outside the Barkly from providers unfamiliar with the local disability services sector. High rates of staff turnover was also noted by some respondents in this region which had led to considerable delays being experienced in obtaining a replacement support coordinator and in arranging services.

*She's not utilising any of her plan...It's about nine months waiting with this new COS woman to make the connection...We were waiting for the COS, waiting for the COS, waiting for the COS...And the COS came last week and openly said I don't know what to do. I'm brand new, I'm learning all of this. Please let me know what I should be doing. P25BAR*

*I've seen a fail of support coordination. I've seen people, so obviously they're paying out a lot*

*of money for support coordination, but yet they're still running around doing stuff and not getting the things that they should. F&C13BAR*

### **5.2.3 Use of NDIS portal**

A final barrier relating to NDIS planning and processes pertained to the use of the NDIS myplace portal. This issue was raised by some NDIS participants or family members who were self-managing their own funding within the Barkly and Brisbane regions. The portal was described by these respondents as being confusing and difficult to use.

*The NDIS is not an easy system. Across the board it is probably the worst coordinated computerised managed system I've ever come across. It takes that long to do anything, to log in and to claim and to get the system, that even NDIS will tell you to, "Oh, just take it out of that funding" when you know you're not allowed to...I'm happy to upload my invoices...The problem is, once you've uploaded you can't see what you've uploaded, you can't get them back...So, if you were to have an audit, you can't say go in and get all your paperwork back and go, "I know it's all in there". F&C13BAR*

*We rang up [NDIA] a few times because we couldn't get into my portal...and I am not very computer wise, but my husband is and one day he was trying to get in for me. I said can you get in there? I said I can't get into this thing. So he tried to get into it and he goes what the hell? So we rang the girl [at the NDIA], I said you talk to her because I don't understand computer stuff. So he's talking to her and he's asking her well where's this, where's that? She goes I don't know and she wasn't very helpful at all. P23BRI*

Issues had been experienced with the system crashing, and with the ability to access NDIS plans and submitted payment requests via the portal. As a consequence of these difficulties, a few respondents reported experiencing delays in arranging services or having to pay for their own supports as they were unable to access their allocated NDIS funding.

*When we got our funding...you're supposed to go into MyGov and enter your access number. And it links your NDIS plan with your MyGov account so I did that for [NAME 1], no worries...Now with [NAME 2], I get his access number, I go to use it, it logs me out, the screen times out, I can't get in and I spent ages trying to figure this out...So [NAME 2]'s plan I think came through in January or February, I still had not been able to log him in with a MyGov account. So that money that I had for him, is sitting there, he's still getting his therapies but I'm still paying for it. F&C32BRI*

## **5.3 Market factors**

Respondents identified four factors associated with the disability sector market which were considered to negatively impact upon plan utilisation. These factors were related to the (1) availability of disability supports and services, (2) provider organisations and the disability workforce, (3) cost of disability services, and (4) the interface between the NDIS and mainstream sectors. The first two of these factors were particularly perceived by respondents as being key barriers to plan utilisation within their respective regions.

### **5.3.1 Availability of disability supports and services**

The availability of disability supports and services was a key barrier identified as impeding plan utilisation in all five research sites. While COVID-19 had led to further challenges in accessing disability

supports, the limited capacity of local disability services was described as being challenging even prior to the pandemic.

This issue was found to be even more problematic within remote areas where the supply of locally provided disability services was said to be extremely limited. Indeed, within the Barkly and Eyre Western regions, a lack of access to disability services was the primary barrier to plan utilisation raised by respondents.

*I can't get much service down here sweetheart so it's not even worth bothering with it. Until I get out of this town and then it will be a different story...Probably about half of my service that I don't actually use because of the town I'm in...There's basically nothing here...Just a small farming town...about two and a half hours from Ceduna. P10EW*

NDIS participants and their family members living in these remote locations contrasted the lack of disability services locally with perceptions of the greater availability of supports in metropolitan areas.

*We have noticed the difference between access to services between Adelaide and here, and that's probably not something that's exclusive to disability services; it's just services in general...We did talk to someone at NDIS...The money value of her plan is quite generous and we would definitely be underspending on her plan, just purely because there isn't the, like, I keep ringing agencies, we would love her to go to [ORGANISATION], have a day option everyday...but there's no capacity; they're full. And they won't even put her name on a waiting list; that's how full they are. F&C26EW*

*Lack of services in [LOCATION]. That's always been the biggest issue. We're remote. If we were living in Darwin it'd be completely different...They've got many different services...But because we're here in [LOCATION] it's just way too hard to try and access all those sort of services. F&C04BAR*

The supply of local disability services in the Barkly region was said by respondents to have been particularly problematic for many years, and was not considered to have improved greatly since the introduction of the NDIS. While some disability services (e.g. allied health provision) in that region were reported to operate on a Fly-In-Fly-Out basis with workers coming to visit Tennant Creek every few months, this frequency of service provision was considered by respondents to be ineffective and not address the needs of NDIS participants who required more regular support and intervention.

*No-one available living in remote and very remote...no therapists...We did think it would improve. All we've seen is more people coming through with money, but not actually the services. F&C13BAR*

*The speech therapist comes once every six weeks or very similar to that and...for me, I think this is too darn useless, if I'm honest...If my daughter is going to have some professional help, we need to have help about two or three hours a day...She needs attention all the time. F&C30BAR*

More generally, the availability of allied health services (and especially speech therapy, occupational therapy and psychology) was a consistent issue described in all the sites. Problematic access to many other types of disability services was also noted and especially for NDIS participants with a complex disability or for those living in regional and remote areas. This included the availability of mental health services (for both children and adults), support coordination, advocacy, equipment services (to both provide and repair equipment), home modifications, community access/day activities, respite services, disability accommodation and skilled support workers. Moreover, challenges were also

reported by respondents in the Eyre Western and Barkly regions in obtaining necessary reports and approvals. In particular, long waiting lists for occupational therapy assessments had resulted in issues accessing equipment and home modifications.

*In country communities it's really hard to find carers, a lot harder than maybe in the city and when you've got hour, hour and a half shifts here and there carers seem to not want to do them...I haven't got as many carers as I have had in the past...and that's one of the reasons I haven't used my physio because I need someone to get me out of the car and get me in the car. P22EW*

*They [advocates] have huge waitlists. And soon after we got in I think they actually had to close even the waitlist because it was so huge. And this impacts other people because there's so much NDIS needing advocacy. F&C09TSV*

Consequently, lengthy wait times for disability services were frequently reported. These waiting times were considered by respondents to have increased with the roll-out of the NDIS in their area and the enhanced demand for disability supports. Some disability service providers were described as being so inundated with service requests that they had been forced to close their client books and were no longer even accepting NDIS participants onto a waiting list.

*There's nothing in Townsville. You've given all this money. Okay, well what do you do with it? I've been on a waitlist for eight months for an OT for my son. I still can't get him to see an OT...He's got funding for OT but I can't utilise it because there's no one out there and there's a waitlist. F&C06TSV*

*He was on the waiting list forever...he's only started the OT and speech since the COVID stuff. Before that, he just did that bit of ABA [Applied Behaviour Analysis] and we had a psychologist, and that was it, he was waiting for the other stuff. The waiting lists are ridiculous. Since NDIS rolled and now everyone can use that money to get the service, the services are booked out completely. F&C07SWS*

Respondents reported that these long wait times made it difficult to obtain certain NDIS-funded services in a timely fashion. Delays in the receipt of services had therefore been experienced by many respondents. As a consequence NDIS funds for some services were being underspent and concerns were raised that this could lead to a reduction in allocated funding upon review. Within the Barkly region, several examples were provided of NDIS plans subsequently being reduced due to an inability to use the funds.

*I need to get him to a psychologist and they're very hard to come by up here. For children anyway...It's been a real struggle for us...We could not get services straight away. We had to wait nearly 4 months before we started OT and even speech because of availability. So we know if we don't use funding it gets reduced the next year, that's my impression, so that's the thing too like if there's no services then we can't use that funding in the time we need to, we get penalised. F&C03TSV*

*So he had about 34,000 in his plan last year, they cut it back down by 10,000. Which came out of mostly therapy and behavioural stuff because I didn't get a chance to actually spend the three grand that was allocated to him for behavioural support purely because I couldn't find a service. F&C04BAR*

Limited provider availability was also said to affect the choice and control that NDIS participants had over their supports, as respondents felt unable to readily switch providers if dissatisfied with the

supports received.

*Once again I feel like we've stalled on the progress. But you can't change because now that everybody's got NDIS money, everyone's got a waitlist. Absolutely everywhere is a waitlist, so if I leave, we literally stop therapy until we have to wait a few months until we can get on another person's books. So once again, trapped...It's a bit scary because what if we end up with no therapist? Then he goes, you know, I don't want him to not be getting the therapies. Surely even bad therapy is better than no therapy? I don't know. F&C02TSV*

Finally, some respondents described challenges in obtaining services which met their specific disability support needs. This included the availability of supports which were suited to an individual's level of disability and also workers being available at a suitable time or location (e.g. within a school environment, in the home or outside regular office hours).

*We're also looking for activities but the problem is the people that go there...My level of disability is much, much lower than theirs and there are brain acquired injuries so it wouldn't be suitable for me...So I'm having a great deal of difficulty with that, both [NAME] and I are having a great deal of difficulty trying to find somewhere that would suit me. P21SWS*

In response to the service capacity issues discussed above, respondents had been forced to forego their funded supports and, for some, this had had an adverse impact on their disability. Others had resorted to paying privately to get the services they needed in a timelier fashion.

*I didn't get any physiotherapy for more than 18 months. Didn't get any help whatsoever...I was screaming for it. In Alice Springs I was getting it every day...and I was actually coming good, my foot was coming good, my arm was coming good...I'm getting through now where my little finger doesn't move with other fingers. My toes, I've broken them all because I can't feel anything. It upsets me that I've lost all of that. But that's the way it is. I live in [LOCATION] and I don't want to go to Adelaide or Alice Springs. I want to stay here. P17BAR*

*The initial thing was that I was told that I could have one [an electric wheelchair] for free...and I waited for about six to eight months...No one ever came and interviewed me about it. I just got worse and worse with walking, and then my legs got worse and the doctor started asking things. Anyway, so I said stuff it, I'll get one myself. So, I bought one myself. P02EW*

Respondents also reported having to rely on disability services based outside their local area which had had consequences on the availability of funds for care worker support or transportation. This was especially challenging for respondents living in the remote Eyre Western and Barkly sites who, in order to access some services, were forced to travel extremely long distances to other towns or cities. Several respondents in these areas also reported having to relocate away from their home towns in the Barkly or Eyre Western region (or were considering making such a move) in order to receive the disability services that they required and had been funded for within their NDIS plans.

*So she is in a full time care facility, up at [LOCATION]... I've not even been up to see her since she's been up there because it's four hours up the road for me...I've put her name down at the three that are nearby. That's my goal, is to get her back down here...I do feel bad for her...Other than this woman that is paid by, through her fund to go and see her every Tuesday afternoon, she has no visitors, she has no phone calls, she has no birthday cards, no Christmas visits, she has nothing. She just is in a place with a bunch of strangers. that's why I'd like her to come back down here and be closer by so that she's got someone that she knows to go and see her on a regular basis and just go and hold her hand or have a cuppa, that would mean the world to her. F&C13EW*

*I knew that things could be implemented in terms of supports for her and I knew the challenges that I faced with that in the Barkly given the fact that there wasn't very many service providers...There was a complete lack of services in terms of Allied Health services in [LOCATION]. If anything, it was intermittent and irregular in its intermittency...Some of the biggest things have been key for us, have been an ability to cut the cord from [LOCATION] and move down to Alice, recognising that she can get physio twice a week here, that she can have access to the full range of medical facilities that she needs. F&C01BAR*

A lack of culturally appropriate disability services was a particular issue raised by respondents within the Barkly region which negatively impacted upon plan utilisation for Indigenous participants. In particular, respondents expressed concerns that disability providers and also the NDIA did not sufficiently understand and account for the cultural needs of Indigenous people with disability. A lack of local Aboriginal staff within the disability sector in that region was also seen as being problematic by several respondents and as affecting the willingness of Indigenous people to engage with services and utilise their NDIS funding.

*I should send [ORGANISATION] a bill for educating [SUPPORT WORKER] because nothing's ever been explained to him. They just sent him out to do all their pick-ups and nothing has ever really been explained to him...They've never really explained to him what kind of culture is here. He's not culturally aware because I don't think they are. They think they're doing good by everyone, but no they're not...A lot of the departments like [ORGANISATION] and that, they need a crash course in what it's all about...I don't think they're really aware of that kind of environment and the social structure of the [local Aboriginal] people. P07BAR*

### **5.3.2 Provider organisations and the disability workforce**

A further key barrier to plan utilisation that was reported by respondents in all the five sites related to issues experienced with disability provider organisations and workers. Difficulties with provider organisations centred on four key areas: the quality of service provision, the organising of services, staffing arrangements, and payment issues. As a consequence of these issues some respondents reported that they had been forced to halt the receipt of services and change providers.

Some respondents were concerned that they were receiving a poor quality service from their disability provider. As a result these respondents stated that their current services were not meeting their needs or enabling them to make sufficient progress towards identified goals. Dissatisfaction was also expressed by some respondents regarding their provider's lack of understanding of disability and poor accountability.

*We were with [ORGANISATION] for a couple of years, you know, really trying and [NAME] just was making no progress. I just figured that that's maybe just [NAME]. But then I spoke to other families, like, no, no, he should be making progress. What are they doing? Oh, why would they do that? And then I realised essentially that [ORGANISATION] was basically hiring the dregs, the therapists that were the dregs, and if I wanted better therapists I'd have to go elsewhere. So we dropped them. We started with a different therapist and we had more than a year's worth of progress in three months. F&C02TSV*

*Because [ORGANISATION 1] charge more per hour, that made [NAME] then second guess using those. So he fell back into the trap of using [ORGANISATION 2] who don't have the experienced staff and he had to handle his staff management himself, but it comes at a cost. You're going to get cheaper rates, but also comes with sometimes cheaper staff unfortunately...and they don't have anybody direct managers or team leaders or even case notes...There's not as much accountability for if he used another mainstream service that is more expensive. P28SWS*

Respondents also reported being dissatisfied with the level of communication that they had with some provider organisations. This included providers not responding to service enquiries or giving agreed progress updates or reports. Furthermore, concerns were expressed about providers not following the NDIS participant's support preferences and goals. It was also noted that some disability organisations were providing a minimal level of service (including inadequate client time) rather than agreed upon supports and activities.

*I don't have confidence in them thinking that one on one means that they've assigned a person's name to the child but not actually following the one on one needs of the child...There's just too many opportunities for her to take off and if they've got one person looking after three children something seriously could go wrong. So that's why I don't use the service. F&C04BAR*

*To be honest, with most providers I feel like they could be doing a lot better...for what they get paid, and that's an all-round thing with everyone...I wish they would actually just do what they're meant to do properly the first time and put a bit of effort in instead of just taking the money and doing the minimum. F&C09TSV*

*[ORGANISATION] they're just like a law unto themselves. They only care about themselves because they'll be audited. They don't care a stuff about me or my goals. P18BRI*

Within the Barkly region, as described above, respondents were also concerned as to a lack of culturally appropriate service provision. Some providers said to be unaware of the cultural needs of local Indigenous participants and unable to offer suitable services to this cohort. In that region also, concerns were expressed regarding the inadequate facilities provided by some disability organisations which impacted upon their quality of care.

*Have you seen the [SERVICE] here? It's absolutely awful. It's old and dinghy, yeah it's terrible. P06BAR*

Some respondents had encountered issues in setting up their NDIS-funded supports by their chosen service provider with unanticipated delays experienced. Also at times, disability provider organisations were reported to have been unable to source workers for preferred days and times. In addition, several respondents described instances where their care had been stopped at very short notice which had negative repercussions for the receipt of NDIS-funded services.

*I guess I'm having support from [ORGANISATION]. I've been waiting for them to assign me a support worker, I've been waiting for so, so, so long...I'm trying to look for another organisation for the support worker. F&C05BRI*

*I had one service that I won't mention who it was, who gave up suddenly. One Friday they were there and the next Friday I had that service and I was told they were finishing up that day and suddenly I had to find a new service. Quite suddenly and that was very hard...No warning whatsoever and I know you're supposed to get at least two weeks' notice or something like that and they did not give two weeks' notice. They didn't even give one day's notice. They just turned up for the service that particular Friday and said well that's it we're not coming anymore. P29SWS*

Issues with staffing arrangements were also noted by many respondents. Respondents stated that it was challenging for provider organisations to recruit and retain skilled workers who were experienced in working with people with disability. High staff turnover was said to be common across all of the five sites (and especially for disability support workers and allied health professionals), leading to inconsistency in the workers allocated to NDIS participants. Remote locations such as the Barkly region

were said to be particularly adversely affected by employee turnover.

*So it's just been a struggle to actually find people that will work with [NAME], like for what he needs...The girl that [NAME] had, she left to go to [LOCATION] and that sort of put him off...Yeah, high staff turnover, there's a lot of social issues here in Townsville, you know. Employment, theft, crime, the works. So people coming and going. F&C03TSV*

*The downside of going straight through an organisation is, you don't get consistency from week to week of who's going to be your support, which doesn't work out. P25BRI*

A lack of continuity of care was perceived as being difficult by some respondents who disliked having to continually start afresh with a new worker who was unaware of their situation and needs. Staff inconsistency and turnover was also felt to hamper the development of rapport and effective engagement as well as the provision of quality care. Furthermore, progress and the achieving of agreed goals was considered to be negatively impacted upon by staff inconsistency.

*You know, you get services and then they leave you and then they replace them with other people and then they leave and it's like I get that that's a normal thing that people come and go but seriously four psychologists in one year? And then having to tell your story all over again...It's not fair. It's not consistent. And they're not taking into the fact that these children, a lot of them can't, dealing with a new person or a new face can be triggering, and changing routine is triggering. F&C31SWS*

*So, services here in town, we live in very remote, speech, a physio, things like that you have to travel 500k's or they come here once every three months or every 12 weeks. There's a huge turnover...Too much transitional people coming through without enough continuity...Very rarely we get the same one and that's the biggest part isn't it?...I mean, we don't even engage some of our therapies because what's the point? You've got to go through how many different ones. F&C13BAR*

Other respondents noted that the workers allocated to provide their NDIS supports were not a good fit and did not meet their specified preferences (e.g. gender and age). This factor, alongside the issues discussed above of high staff turnover and inconsistency, made some respondents reluctant to accept services and utilise their NDIS funding.

*It's actually really difficult and confronting to have another person come into your personal, private space...I have to be really comfortable with the people. And even just coming into my space, I have found it very hard with a few support workers in the past, especially older women, they seem to think that they know how everything should be done best and therefore they know how it should be done for you...I find I have to...screen them...And it's been tricky with some managers at some of the agencies, it's not like they're listening to your wants and needs and who they can get available. P28EW*

*I wasn't happy with [ORGANISATION] because...I said I wanted a lady and they got me a man who they said, oh he's Mr Wonderful, and he didn't speak much English. P27SWS*

Finally, issues were noted by some respondents around the payment of disability services. Examples were given of providers sending payment invoices for NDIS-funded supports which were incorrect or delayed. This included instances where providers had overcharged for the supports received or had requested payment for services which had not been provided at all.

*A person who was working with [ORGANISATION] at the time was allegedly looking after me. He was coming around about every three months...He would come and get me to sign a form,*

*he wouldn't tell me what it was and I used to say, can you explain it because I can't read it? No, no, no, you just sign it, we'll look after you. Then he'd disappear for another three months. So I wasn't getting anything...And went and saw them [NDIA] in February this year again and said, "Nothing changed, I still haven't seen anybody." "Oh no well [ORGANISATION]'s looking after you." I said, "well what are they doing for me?" "Oh no they look after you every day." "No they don't. I see somebody from [ORGANISATION] every three months." P17BAR*

*The first company...I had a gardener overcharge me, and when I spoke to him, he said to me, "Don't worry about it, it's only NDIS money." And I said, "No, that's my money. That's my money that the government has given me. It's not just for you to go and spend"...So, I spoke to the coordinator at that particular service and I got abused like buggary off her...So, I said to my husband, enough is enough. So, I looked at another group. P16EW*

Some respondents held the perception that roting of the NDIS was occurring and that certain provider organisations were in the disability sector to make money rather than provide a quality service to people with disability.

*We've got some people here who really don't want to do the job properly, because all they want is money for themselves and when they finish right, it's finished. It's not an ongoing program. So all this has to stop, because it's no use coming down here and listening to someone and then go back and forget about that poor person who lives in an isolated area and don't get any support. F&C05BAR*

*The other one is a big organisation, so we have a feeling that they're just doing it for the money. There's no heart there. There's no heart involved. It's just for money. F&C17BRI*

Respondents also reported issues that they had experienced with workers within the disability sector including disability support workers, allied health workers and NDIA staff. These issues affected the willingness of some respondents to continue with their NDIS-funded services and at times had led to disengagement. While many disability workers were said to provide good levels of support, others were thought to lack the necessary understanding, experience and skills to provide quality services to people with disability.

*We couldn't find the right speech therapist with the first plan. It was just a mess because the service provider guy, he brought two girls...they're young, they looked like straight out of uni, they looked like my daughter's age. When I met them, I'm like, oh, God, this is not going to work, because they had zero experience with anyone with special needs...They had no idea what do with [NAME]. He run all over them. F&C17BRI*

*Sometimes I feel, for my situation, that the service provider just sends anybody. I had one person who was a carer and no experience in aged care. She came from childcare. I was charged for her being here for two hours at a higher paid service and here I am paying for somebody who can't even do personal care. It's frustrating. P30SWS*

Some workers were also described as not having received sufficient training or information about the specific needs of the person with disability that they were supporting. As a consequence, these workers were considered to have inadequate understanding of the NDIS participant's disability and support needs. A lack of availability of skilled workers had impeded the timely arranging of NDIS-funded services for some respondents. Particular concerns were expressed within the Townsville site of the impact this had for people with complex disability.

*You get different people all the time. I don't like it really, invading your home and your personal*

*privacy but we understand that and we're thankful. But most of them haven't got any form of training...When they've come to me, I've expected that [ORGANISATION] or NDIS or somebody would have actually said to them..."Here is information on each person that you're going to be working with"...but then the people that are actually coming out to support you have no idea. P23EW*

Examples were also provided of workers within the disability sector displaying a poor attitude or being untrustworthy. Other workers were said to be unprofessional, did not listen to or respect client wishes, or exhibited inappropriate behaviour when working with people with disability.

*We started having issues with them not listening to what he was telling them. Like if he's getting cranky you don't stay and put yourself in danger. You get yourself out and they would stay and then wonder why he would attack them...It's just finding people that don't treat [NAME] like an idiot. He may be. He may not know everything, however if you make the assumption they're inadequate I suppose is the word and need, you can make some of them very angry. And that gets him very annoyed. F&C20TSV*

*He [support worker] was drunk. Yeah, was doing the shouting to that. Yeah. I ring the police were there. P15BAR*

Issues had also been experienced with the unreliability of some disability workers. This included workers not turning up for shifts as arranged, being late or cancelling at the last minute. Language barriers were also stated by some respondents to hinder effective communication and service provision, particularly when staff with limited English skills were working with people with complex needs.

*I can have a support worker but I haven't had it at the moment because it's tricky to find. Yeah reliable, honest, truthful, caring, compassionate, everything...The problem is that we can't find the support workers. And I have a very big problem with that. There are issues and I cannot put anybody with [NAME]...All of them are not very reliable. What they say and what they're going to do is completely different...it's just finding the right person with the right set of mind, the right attitude. That's my biggest hurdle in the problem is that it's just, you know, [NAME]'s got the funding, it's wonderful, it's great, but I'm not going to waste it. P32SWS*

*I was finding that they were telling me that they were sick and they were actually having interviews with other people while they telling me they were sick and they were lying to me. And doing things like that and I didn't appreciate that and then they kept making interviews with me and cancelling at the last minute. P01BRI*

Finally at times, the high caseloads of workers were said by respondents to impact upon their ability to undertake agreed work or respond to the requests of NDIS participants. This led to workers having insufficient time to spend with NDIS participants and also contributed to perceptions of not being listened to or receiving quality care.

### **5.3.3 Cost of disability services**

The cost of disability services was identified by some respondents (in all of the research sites with the exception of the Barkly region) as hindering plan utilisation. The cost of these services were considered to be too high and to have increased considerably as a result of the national roll-out of the NDIS.

Concerns were expressed about the prices charged by disability service providers. In particular the rates for allied health services and group activities were reported by some respondents to be higher

for NDIS participants than for non-NDIS clients. Furthermore perceptions were held that some disability providers were only in the sector to make a profit rather than to offer a good quality service to NDIS participants.

*I feel like it's all about money for them...It's all about business. I understand that they've got a business to run, I understand that. It's just that NDIS has set some price guide, it's just a guidance. It doesn't mean that it can charge up to the maximum, but because that's what the NDIS is given, then why not...Some of them are a bit greedy. F&C17TSV*

*She was also doing another group thing which was an after school, like an evening night...a games night and pizza...And interacting with other kids or kids who are also, you know, not necessarily Autistic but all have some sort of disability. And so she would attend those. She really enjoyed them and...we were paying \$75 through the NDIS for that but if I wanted to pay privately myself I'd only pay \$25...It's like why is that so different?...We'll get a lot more out of our budget if we weren't paying those really high prices. F&C35EW*

Some respondents also felt that the administrative costs charged by provider organisations to manage NDIS-funded services were too high. In addition, as described above, several instances of overcharging by providers as well as a lack of transparency around service costs were reported.

*Every hour that I work for [NAME] NDIS provides I think it's something like \$76 and I get less than half of that...That much goes to administration. It's a lot of money...That money could be actually being spent for another carer. P18EW*

*I've noticed with the charges that providers are charging her that things can be very unfair. The support coordinator was charging her for the time she spent to talk to the receptionist. If the receptionist picked up the phone, you can see it on the itemised bill, it's charged per minute...They don't say we're all going to charge you for every time you speak to the receptionist. P18BRI*

As a consequence, some respondents questioned whether their current service provision represented good value for money and expressed concerns that their NDIS funding did not stretch as far as they had hoped. This was perceived to limit their level of access to disability services and did not enable disability support needs to be fully met.

*The quality of service that is being offered by NDIS accredited people such as physios, OTs, the physios have been a bit iffy and the OTs are mediocre...If we could organise these things we would have half the pricing they're charging NDIS. The pricing is unbelievable...The physios charge, I think it's \$186.00 per hour...We've had no trouble spending the allocated money but I personally don't think that we're getting value for money...You feel you're being taken for a ride. F&C30BRI*

Several respondents noted that as a result of NDIS funding models and audit fees, it was unviable for their existing service provider to become a registered NDIS provider. While some of these respondents had had to change providers as a result, others had opted to self-manage their NDIS funding in order to continue accessing their preferred provider.

*I'm on my second psychologist. The other psychologist I had to leave her...because she said she couldn't afford to pay the NDIS audit. P18TSV*

### 5.3.4 Interface between the NDIS and mainstream sectors

The interface between the NDIS and mainstream sectors (including health, education, housing, youth justice and family services) was identified as a final barrier to plan utilisation by respondents in the Barkly and Townsville regions. Particular issues were noted in the interface between the disability, education and health sectors. The siloing of funds and services within sectors rather than a more holistic approach to the care of people with disability, was perceived by some respondents to be occurring and was affecting their NDIS funding and subsequent plan utilisation.

Problems were reported to have occurred when a person's support needs were perceived by the NDIA as being a "medical condition" rather disability-related and therefore the responsibility of the health sector (or vice versa). Also as described above, the ability of respondents to obtain diagnostic assessments from medical practitioners to provide evidence for applications for NDIS eligibility and funding was described as being challenging at times due to the cost of private assessments or lengthy waiting times within the public health system. As a result this had led to delays in the receipt of needed supports.

*So it's financial constraints in his budget for things we put forward...and when we go and see his neurologist and his medical team, they tell us that if it's not medical...and it's up to NDIS but then he goes to NDIS and they'll say no, that's medical that's not his disability. F&C07TSV*

*They [NDIA] were pushing that his was more mental health, that he could go and get therapy through Community Services and he could get support and we know that there aren't any Community Services for things that [NAME] really, really needed...I think the biggest problem there is the people that run it in the end, they don't understand disability or medical conditions or things like that, because their argument was [NAME]'s condition or [NAME]'s disabilities were based on a medical condition and it's not disability. I'm like well most disabilities are based on a medical condition. If you're blind that's a medical condition. If you have cerebral palsy that's a medical condition. Hello. F&C30TSV*

Difficulties had also been experienced by respondents in the Barkly region around the provision of allied health services (such as physiotherapy). Several respondents reported that these services were available in local primary health care and hospital settings (with some previously accessing these supports prior to participating in the NDIS). However, NDIS participants were said to be ineligible for these services and, as a result of the limited availability of allied health services within the disability sector, these respondents stated that they had been forced to go without services.

*Here's a bumble with the NDIS, this is one of my bitches. I used to go to [ORGANISATION]...I'd go to physiotherapy, it was really nice...then suddenly when NDIS had approved you can't go there anymore because you're not covered, we don't, NDIS don't cover this yet...the hospital will have physiotherapy sort of thing. Well I found a physiotherapist, I'm sorry no you're NDIS, no it's public, we don't cover NDIS things here at the hospital. So there you go. So therefore for a while I've not had physiotherapy...It's been probably a couple of years now. Yeah so it's ridiculous the way it goes. P31BAR*

Likewise, difficulties had been encountered by some respondents in the ability of school-aged NDIS participants to fully utilise their NDIS plans and receive appropriate supports. Insufficient interaction between the NDIS and the education sector was reported by these respondents and said to hamper plan implementation. Several respondents within the Townsville region noted that this made it challenging to obtain permissions for therapy services to be conducted within school settings, and to know whether disability support recommendations were being followed and adhered to by schools.

*There's things that the therapists are trying to implement but with them not knowing what actually occurs in the classroom, it's hard to get everybody to work together...And the school is being resistant to have anybody observing what they're doing. So it's really frustrating...He takes his talker box to school...and then the last words were, what he ordered for breakfast with me. So it wasn't used at all during the day...Super frustrating just trying to get people to work together...We've tried to coordinate to get our therapist to be able to have access and all of this, that and the other. And the school just stonewalls you. F&C02TSV*

*I don't think they [his school] actually interact with NDIS. I hope to think they've got supports there for him. They do have a disability officer there that does a plan up for him every year of area needs and that's about it though...Whatever he requires at school I've been buying myself for him, to support him. The school, I don't know what they do. F&C06TSV*

Schools within the Barkly region were described by some respondents as being unable to provide adequate support to children with disability during the school day and concerns were expressed that both the educational and disability support needs of younger NDIS participants were not being met. This was attributed to a lack of sufficient resources within school settings including support staff with disability experience, accessible facilities, and curriculum modifications. Perceptions of a lack of clarity and responsibility for the funding of/provision of supports between the NDIS and the education sector were also expressed. For example, therapy services were said to be available within local schools in the Barkly region but were unable to be accessed by students who were participating in the NDIS. Due to the thin markets within the disability sector in the Barkly as described above, difficulties had been experienced in obtaining these supports elsewhere.

*So the school is now, has [ORGANISATION] going in...So that's one of the things that annoys me is that where NDIS said that we're not supposed to use the services in the school. Because I think it should be able to. If there is no real allied services available in a small town like this they should be allowed to do that...All the other kids can because it's funded, like it's paid for by the government. Whereas because the NDIS is paid for by the government they don't like to cross budgets. Which to me is just stupid. Does it really matter? I mean if they're not using the budget that's been allocated to [NAME 1] and [NAME 2] anyway why can't the budget from NDIS be used? F&C04BAR*

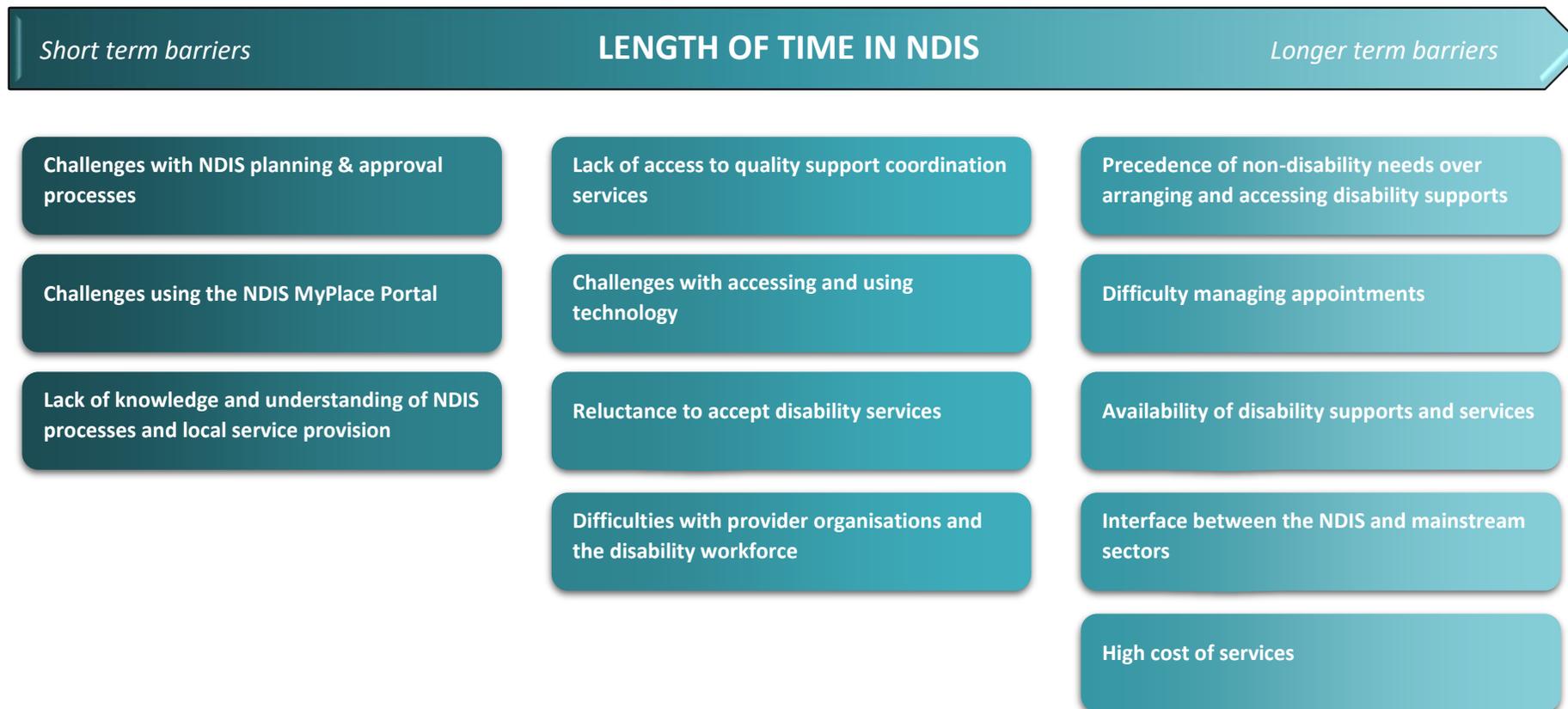
## **5.4 Temporality of barriers to plan utilisation**

It matters a great deal for policy if the barriers NDIS participants identify are experienced for only a short time and are subsequently overcome or whether they occur for longer periods, are harder to overcome and therefore may reflect more systemic problems. Figure 5.1 below provides a visual presentation of the temporality of the barriers outlined in Chapter 5 above experienced by NDIS participants.

In summary we find that for most participants barriers that are related to NDIS planning and processes are in general only experienced for a relatively short period and are overcome with time in the scheme as knowledge and understanding of NDIS processes increases. On the other hand, participant factors and market factors are generally experienced for longer periods of time by NDIS participants.

It is important to note that the diagram is plotting the temporality of barriers in general terms. Some participants may experience some barriers that are plotted towards the shorter term end of the continuum for longer than others. For example, understanding of plans and content of plans, may be overcome quickly by some people once they are in the scheme for a while, but other groups of people (such as those with limited English proficiency etc.) may experience these barriers for longer periods.

Figure 5.1 Barriers to plan utilisation by time



## 5.5 Case study of plan flexibility

To conclude this chapter on barriers to plan utilisation, we present a case study exploring the specific issue of plan flexibility.

Plan flexibility in relation to the segmentation of funding has been an area of interest since the onset of this study. Of particular concern has been whether inflexibility around moving funding from a support category with available funds to bolster supports in an exhausted funding category is a barrier to plan utilisation. This section outlines some key findings from the qualitative data regarding plan flexibility.

### **Ranking plan flexibility in relation to other drivers of utilisation**

Plan flexibility was discussed as a facilitator of plan utilisation by some respondents and a barrier for others. However, as shown in Chapters 4 and 5, plan flexibility is inexorably entwined with other drivers of plan utilisation (e.g. understanding, markets, support provision, poor quality support coordination/plan management etc.). These drivers of plan utilisation have been discussed throughout this report, however key points of intersection with plan (in) flexibility are highlighted below:

- Recognition of plan flexibility as a barrier of plan utilisation is impacted by respondents' understanding of NDIS policies and plans. For instance, some respondents stopped accessing supports when they ran out of funding in a category and did not frame this as a flexibility issue, but rather as a lack of funds. Because NDIS funding was earmarked for particular categories, respondents did not necessarily consider that funding could be structured differently and as a result did not highlight this as a barrier.
- Plan flexibility also intersected with some respondent's anxiety around interacting with the NDIS and/or being fearful of misusing funds and being audited. This particularly applied to respondents who were aware that they could move funding around but were reluctant to do so due to these anxieties. This indicates that making funding more flexible in itself is not enough, communication needs to be clear and effective on what is and is not allowed, with participants supported to legitimately move funding around.
- Participants who were underutilising their plans due a range of barriers (such as thin markets, poor quality support coordination and others detailed throughout this report) were unlikely to have come up against flexibility as a barrier, as lack of funds was not one of the pressing issues they faced.
- Not having particular supports included in a plan was highlighted by many respondents, however this was seen to be a planning issue with focus placed on the need to convince planners/the NDIA that these supports were needed, rather than something that might be solved with a more flexible approach to funding use.
- Those who spoke positively about flexibility indicate that transferable funds are likely to facilitate higher plan utilisation for participants who find themselves in need of this flexibility.

### **Additional considerations: extending understanding of flexibility**

Evidence from the qualitative interviews demonstrates that the question of plan flexibility is a lot broader than simply the segmentation of funds and balancing the use of funding across a range of funding categories:

- Respondents also described inflexibility around NDIS approval of spending on some items, inflexibility in the planning process (having to have a formal review to make a small change to a plan) and what could be termed 'unofficial' flexibility - flexible use of plan funds respondents made for themselves by self-managing or working with a plan manager who perhaps knew how to move funding around to better meet their needs.
- Inflexibility was also reported to be a source of frustration by NDIS participants with a psychosocial disability when (due to the fluctuating nature of their disability) supports were no longer required from one funding category but more supports were needed from another category.

## 6. Impact of COVID-19 on Plan Utilisation

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Since the outbreak of COVID-19 in Australia which first began in January 2020<sup>5</sup>, the virus and the associated transmission prevention measures instigated by both the Federal and State Governments have affected the lives of all Australians. This includes NDIS participants, their families, and carers.

Our data collection for our study on NDIS plan utilisation occurred in midst of the pandemic. Thus, while not a primary aim of this study, we were able to incorporate an account of the impact of COVID-19 on respondents and how they perceived that it affected the way that NDIS plans are developed and implemented. This understanding was also important in order to determine whether reported barriers to plan utilisation were solely attributable to the impacts of the COVID-19 restrictions or were ongoing issues faced by NDIS participants and their families.

Interviews were completed in the different sites throughout the year, therefore the impact of COVID-19 on each site at the time of interviewing varied. However, given the aim to complete interviews face-to-face where possible, most sites were interviewed at times when case numbers were low or non-existent and it was safe for both interviewers and respondents to meet in person. The exception were the interviews conducted in South Western Sydney, which were all conducted virtually after the region was declared a hotspot immediately before a fieldwork trip to undertake interviews was planned. When interpreting the findings outlined in this section it should be noted that the interviews may have elicited different responses from respondents if discussions had occurred at different times, i.e. when COVID-19 was more or less front-of-mind for respondents.

Although not raised by all respondents, the impact of COVID-19 on NDIS participants and on plan utilisation was discussed by over three quarters of our sample. Themes raised in these discussions are described below and have been arranged according to whether they relate to the participant, plan or market factors that influence NDIS plan utilisation.

### 6.1 Participant factors

Three primary themes emerged around the impact of COVID-19 on individuals: knowledge of, and concerns about, COVID-19; the impact of COVID-19 prevention measures on activities outside the home; and the impact of working and schooling from home on NDIS participants and their families. These themes affect plan utilisation by altering the demand for supports and services at the individual level in response to the COVID-19 pandemic. Responses indicated that the demand for social and community based supports had declined at the time of the interviews. A perceived need for additional mental health supports and assistance for families struggling to balance working and schooling at home was also highlighted.

#### 6.1.1 Knowledge of and concerns about COVID-19

The response to COVID-19 amongst respondents was varied, ranging from observations that “*it changed big time*” (P24BAR), to reports that the pandemic had very little personal impact. In general, respondents in the urban research sites of Brisbane and South Western Sydney, where cases of COVID-19 were more prevalent, expressed greater awareness of COVID-19 and increased concern about the risk of infection. Meanwhile, respondents in regional and remote sites (i.e. Eyre Western, Townsville,

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<sup>5</sup> Australian Government Department of Health. (2021, January). *Coronavirus (COVID-19) health alert*. <https://www.health.gov.au/news/health-alerts/novel-coronavirus-2019-ncov-health-alert/coronavirus-covid-19-current-situation-and-case-numbers>.

and the Barkly), where case numbers were very low, expressed less concern about infection and more frustration around prevention control measures such as restricted access to services, both general and disability related. In the Barkly region, and especially among Indigenous participants, awareness of COVID-19 was particularly low.

Some respondents, more predominantly but not exclusively in Brisbane and South Western Sydney, expressed anxiety about contracting and/or transmitting the virus. This was either because they themselves were particularly vulnerable due to pre-existing health issues, or because close friends and family members were susceptible. As a result they, or the NDIS participant that they were representing, opted to reduce or cease their interactions with services.

*See normally I ten pin bowl, but because of the coronavirus I haven't had much of a chance to. We've only just started back, but I said to them I won't be going back until next year. And the only reason is because I have an elderly father who's 92 and if I was to get sick, he'd end up catching it. P09BRI*

*I haven't been using the services because I have a trust issue with the support workers...During this COVID I can't let [NAME] be exposed with different types of support workers...This virus is deadly...she can't afford to get sick. P32SWS*

*I don't think it's worth the risk. Because a normal flu and pneumonia nearly kills her so yeah I don't think anything else is worth the risk. I'd rather it die down a bit first.F&CP29TSV*

Other respondents observed that in order to feel more comfortable accessing their current services, they implemented specific strategies to reduce the risk of COVID-19 transmission. These predominantly involved either increasing the hygiene processes within their household, or limiting their interactions with others.

*So we were trying to do a Zoom session through, it was just insane. So in the end I just said to my physio I'm more than happy, so the arrangement was that she would come, she'd have a quick shower, I'd have, you know detergent and everything in there, I'd have her own towel set up for her so she can have a quick shower, clean herself, dry herself off, put on fresh clothes that stayed here...And then she'd have a shower, change clothes back into what she was wearing when she arrived, and then off she'd go again. F&C04TSV*

*Anyway, I stipulated the two carers that I wanted working with [NAME], that I knew had a bonding with her. I think they had six or seven carers out there, but I said, I just didn't want anybody coming into our house, I just wanted those two that I knew. I know their background, know if they've been socialising with tourists, or people coming from overseas, so I had to stipulate those two carers, which they did for a month. They'd come into our home three days a week. They shared it between those two because the carers are out there, they wanted to spread the work out around, I said, "Nah, I just want those two." F&C27EW*

However, several respondents also reported that they had altered the types, or amounts, of supports that they were receiving, primarily in lieu of their existing services that had ceased due to the COVID restrictions. For example, one respondent had swapped their shopping excursions with a support worker for having the worker deliver their shopping. Another respondent who was self-managing their NDIS funding had reduced their speech therapy hours to allow them to engage with a psychologist to help them to overcome their anxiety induced by COVID-19.

*And I've had to utilise my plan in a bit of a different way and I've been using my plan to be able to get me supplies in and out of my apartment. And that's been allowable, I had to get my*

*support coordinator to tell me how to use my plan that way and that's worked out very well. Using Category 01 to get supplies in and out of my apartment and get the support workers to do unaccompanied shopping for me. P01BRI*

*So I decided to self-manage and...this year I've had to change things because of COVID. So, you know, I've stopped speech therapy because we needed more, more psychology...The flexibility is so much better when you self-manage. F&C29BRI*

Within the Brisbane region, several NDIS participants were reported to have experienced a deterioration in their mental health during the pandemic. One respondent, who had previously experienced trauma associated with a prolonged period of being bedbound due to her disability described how the social restrictions impacted her.

*I was very freaked out so I had a bit of binge eating, you know what I mean, because I knew obviously Dad couldn't come over. I live alone in a very, very small flat. It's social housing. It was very isolating...And this COVID time like it was just so sort of scary and especially, so being in the house too long reminds me of being in the room. It's like a trigger, okay. F&C19BRI*

Another respondent highlighted how anxiety about COVID-19 had affected her teenage daughter, who has an intellectual disability, in particular around her engagement with her support services.

*I've only just got her out of the unit in the last month. She wouldn't go outside because she had asthma and she was afraid she was going to get sick and die. So, her mental health has deteriorated quite a lot, but prior to that she was a very social, outgoing girl...She won't let me engage in a support worker. She won't let me get the OT, who she did have a rapport with, come back in and do some one-on-one work with her. She won't let me engage in anybody, primarily because of the COVID and her anxiety of getting sick. F&C28BRI*

This respondent raised concerns about the lack of mental health supports available for NDIS participants who do not have a mental health diagnosis, particularly during circumstances such as COVID-19. The need for additional psychology supports to address the anxiety created by COVID-19 was corroborated by other respondents.

*I guess, because of the mental health side of things not working out for [NAME], I'm just really centred on that. They just didn't seem to be open about what I can do about that other than telling me to go and pay for. In order for [NAME] to be confident and motivated and willing to do the stuff that we want her to do, part of it in her plan, to leave home, number one...To get outside and become involved in her community, they need to address issues like anxiety mental health. Because she doesn't have something diagnosed, whether that's an issue too. Her only diagnosis is intellectual impairment. She doesn't have an official mental health diagnosis. It certainly impedes her from doing anything. The COVID just made it worse. F&C28BRI*

### **6.1.2 Impact of COVID-19 prevention measures on activities outside the home**

Unsurprisingly, the strongest theme relating to the impact of COVID-19 on individuals that emerged in the interviews was that opportunities for engaging in activities outside the home had been curtailed as a result of the social restrictions that were implemented due to the pandemic.

It was primarily observed that NDIS participants had to “stay home” (P12BAR) and were unable to engage in their usual activities including work, social activities (e.g. going out to a café or pub, participating in sport or theatre groups), and leisure activities (including holidays). Many respondents

highlighted that these social restrictions caused them to be “trapped in the house” (P03EW) and had left them feeling “very isolated and lonely” (P16EW).

This disruption to their usual routines had broader affects for some people with disability, for example impacting their behaviour regulation and general functioning.

*A lot of her activities stopped, her community, social kind of stuff. And for [NAME], being busy and out of the house keeps her very regulated and is what maintains her functioning. F&C09TSV*

The broader family unit was also affected by NDIS participants having to spend more time at home due to the cessation of their regular activities. Respondents reported that some parents were having to provide more informal care and supervision to compensate for reduced service provision outside the home.

*It has really had an impact on my services a lot. Yes, it has really weighed the family down and it has really cost us a lot because you can't do anything and then you have to do more hours and [NAME] can't do a whole lot. F&C08SWS*

### **6.1.3 Impact of working and schooling from home on NDIS participants and their families**

Across all sites, except the Barkly region where home schooling was only briefly implemented in response to COVID-19, home schooling and working from home deeply affected both NDIS participants and their families. Primarily, respondents observed that this change brought negative impacts including an increased the burden on families who were often already quite overwhelmed. One NDIS participant described how the added burden of schooling her children at home, along with managing her own disability needs, had negatively impacted both her physical and mental health.

*I have to say I have never felt so under water. Like I can't, just there's so much pressure. To do everything with less supports than I've got and not be able to send my kids to school. So I, essentially I have extra after school care and vacation care because I have a disability. So instead of 52 hours I get 100 hours. So I would often take advantage of that and come home and have a sleep or I would go to my therapy appointments. So I was juggling therapy appointments with children in the house. I was not getting a rest because I have children in the house. So I think my physical health, it's probably why I've had two colds in the space of three weeks. My physical health has just plummeted. P08TSV*

Other respondents, who were parents of children with disabilities, acknowledged the burden of balancing working and schooling from home, particularly while caring for a child with a disability.

*It is what it is but it certainly has made it very difficult for me trying to work part time, teach the kids and a child with a disability who needs a lot of assistance with nothing from the school. P08TSV*

Meanwhile, successfully implementing virtual learning for child NDIS participants was observed to be reliant on the ability of schools to cater to the learning needs of children with disability. The ability of the child to engage via technology, and for the family to have access to the correct technology was also reported to impact upon the success (or not) of home schooling. In some instances these requirements had not satisfactorily been addressed, and respondents were concerned that their child was not having their educational needs met during the pandemic.

*When the kids were supposedly home schooling and all of that, none of that was occurring. [NAME] was receiving absolutely no schooling. School just did not have a means to be able to support a non-verbal remotely. F&C02TSV*

*COVID-19, well that was just a complete disaster. My son, I couldn't cope at home with him. We couldn't do any underlying learning, so I've had to download a lot of books, do writing skills with him at home every day. I was running out of things to think, but we did a lot of activities, a lot of art and crafts and we did a lot of cooking. He did a lot of maths with cooking, so that's how I sort of kept him interested in things, because I never had a device at home for him or a camera on it to be able to do any online learning. F&C06TSV*

In addition to this, several respondents across various sites observed that the move to home schooling resulted in the need for extra supports while the NDIS participant in their care was not attending school. This had resulted in an increase in the amount of funding that they were using and concerns were expressed about whether their current levels of funding would be sufficient. For example, one respondent from Townsville with two children who were both NDIS participants observed:

*We were flying through the funding and I was getting a bit worried because obviously the kids aren't at school, so I need the support worker, like, we were really ripping into the support funds. F&C02TSV*

Similarly, another respondent, this time from South Western Sydney, who was also a parent of an NDIS participant described the frustration they experienced as a result of the impact of home schooling, and the extra supports this required, on their funding use.

*This whole COVID thing, like [NAME] was off school, I had to work, they didn't class me as an essential worker and the school had told me that he couldn't be at school...I had to have an in-home support worker with [NAME]...So it was really frustrating. And that's like \$6,000 out of the budget that we can no longer get back. F&C31TSV*

However, the move to working and schooling at home was not always perceived as a negative experience for NDIS participants and their families. It also provided some valuable opportunities for families to spend time together. For example, one respondent in the Eyre Western region described the positive impact working from home had on the relationship between her husband and their daughter with autism.

*I mean especially with my husband working from home now he's having a little bit more interaction with her with picking her up from school and so that has been good I think for them whereas before he'd be gone, get home 5:30-6:00 at night and she's just over it, tired by the end of the day and she's got no time for him and is quite rude to him but we find with him working at home now it, yeah the relationship's a lot better than it was that's for sure. F&C35EW*

## 6.2 Plan factors

Respondents identified three key plan factors that had been impacted by COVID-19. These factors were: (1) the impact of COVID-19 on planning and review meetings; (2) the perceived impact of COVID-19 on future funding allocations; and (3) changes to assistive technology purchase requirements.

Discussions with respondents revealed some of the changes made by the NDIA in response to COVID-19 to ensure that the processes around developing and reviewing plans could continue and that funding could be utilised in the most useful manner. The move toward virtual meetings or rolling over

existing plans for a further year were identified, as were changes to the rules around purchasing assistive technology. This latter change allowed participants the flexibility to purchase computing equipment using their core funding so that they could engage with their services virtually. However, concerns were raised about difficulties with the provision of information to NDIS participants about these changes. The ability to take advantage of these changes and maximise plan utilisation during the pandemic was seen by respondents as being incumbent upon knowledge and awareness, disadvantaging those who were less engaged and had less effective support networks around them.

### 6.2.1 Impact of COVID-19 on planning and review meetings

In each of the five sample sites, respondents described the impact that COVID-19 and associated social restrictions had had on the way that their planning and review meetings were implemented. Face-to-face meetings were substituted for virtual meetings conducted via telephone and email correspondence, with meetings delayed if in-person discussions were required. Where possible it was reported that plans were being 'rolled over', i.e. existing plans were extended without any changes. Although overall respondents were resigned to this being an adequate option in light of the social restrictions, some frustration was voiced by respondents who found engaging in interviews virtually "a little bit tricky" (P28BRI). For example, one respondent in the Barkly region reported that undertaking their review by telephone added to their difficulties understanding their plan.

*But because of COVID-19 we're not going down to the NDIS office because you can't do that. We've got to make a phone call one on that so which means that I'm going to listen what you read on the plan so then even though I might have a plan in front of me I still won't understand it so they need to explain things and it changes, things change. P31BAR*

Across all sites, most respondents who identified that they had been offered the option of rolling over their previous plan rather than undertaking a review reported that they had opted to do so, or that it had been done automatically, and they were satisfied with this approach.

*My plan, mine wasn't due until November. But we put in for a new socket for my leg and so of course they sent that through so then I got a phone call from NDIS to say it's been approved...And they just redid my whole plan for 12 months without having to go through the meeting or anything because of the COVID and whatever. P22TSV*

However, some respondents, predominantly those who were not satisfied that their previous plan was meeting their needs, had opted to review their plan rather than roll it over.

*But I know with COVID that you don't have to get a review, you can just say keep it for the 12 months and I said no to that, because I'm like no I need more funds. That's what I did with the first one and that wasn't enough. They reviewed it again...I thought no my son needed way more supports. F&C26BRI*

For a small number of respondents this resulted in delays in scheduling a review meeting, which in turn delayed their receipt of a new plan and their ability to engage the supports and services they needed.

*It's like a two-year plan and it's under par so I was just trying to get a review or something like that and I was trying to get more funding because of the virus and stuff, and everything got put on hold. P24SWS*

It should be noted that respondents in the Barkly region were much less aware of, and engaged with, NDIS planning and review processes in general than were those in other regions. This was particularly

the case for Indigenous respondents. Many only had vague recollections of their previous interactions with their NDIA planner and as such were unaware of how these processes were affected by COVID-19. In addition, the lack of awareness around interactions with NDIA staff may have been exacerbated by the COVID-19 restrictions, given that during the pandemic reviews were conducted by telephone rather than in-person. One disability support provider who was asked by an NDIS participant to assist with their review meeting articulated this:

*She is part of the plan review which went well but because it was COVID and we had to do it over the phone they wouldn't see that association with the purple shirt mob. The local area coordinators don't leave the office...They don't have much of a presence in town. P14BAR*

## 6.2.2 Perceived impact of COVID-19 on future funding allocations

Across all sites, respondents discussed their understanding of how the COVID-19 restrictions would impact their NDIS funding at their next review. In general, respondents observed that prior to COVID-19 funding decisions made during the review process were heavily reliant upon whether they had utilised the funding in their previous plan. One respondent noted "...it's like, Oh, if you didn't use it they're going to take it away..." (P33SWS).<sup>6</sup> Given that COVID-19 severely constrained the ability of NDIS participants to use some types of supports and services, concerns were raised around the impact this would have on future funding decisions by the NDIA. A number of respondents expressed concern that their future funding may be impacted because they had been unable to use the funding in their current plan.

*Well, it is a concern. Just because she hasn't used the money doesn't mean that something might come up and she might need the money, you know. F&C08BRI*

*I hope that NDIS take COVID into consideration, because all the agencies closed down, so there's been whole months where we've not spent money and I hope that's not reflected badly for [NAME] that then you're penalised. F&C26EW*

However, the views of respondents relating to this issue were mixed. Those who were more engaged with the messaging from the NDIA - either because they had been contacted by NDIS staff or their Plan Support Coordinator or because they had the capacity to stay up-to-date with information themselves - demonstrated awareness that the NDIA had guaranteed that unused funding as a result of COVID-19 would not negatively affect future funding decisions.

*When I got my second plan, it was at a time when things started to go downhill with the COVID-19 situation, therefore I was stuck at home, wasn't able to utilise most of my money, therefore, money was still left, unspent money, but I was reassured that I wouldn't lose that...Because the NDIS rang me...Yeah, to say that I wouldn't be losing any unspent money at that time, because of that situation. P24BRI*

*I even remember screen-shooting somewhere a statement that they actually put out to say supports, if you don't use all your supports due to COVID they will not be cut next year. So that will get stuck in their face because I'm very good at advocating. P08TSV*

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<sup>6</sup> There were some exceptions for NDIS participants with degenerative disorders, who respondents observed often had funding allocated for certain supports "in case" they declined to the point where they needed that support prior to their next scheduled review meeting. This funding was not affected if they did not use it.

### 6.2.3 Changes to assistive technology purchase requirements

A small number of respondents observed that they had experienced difficulties around accessing assistive technology with their NDIS funds despite the temporary broadening of the flexible approach to the purchase of assistive technology enacted by the NDIA in response to COVID-19. Some respondents were unaware that they could purchase assistive technology using their plan.

*I never had a device at home for him or a camera on it to be able to do any online learning, and I couldn't access anything because it wasn't in his plan to go buy it. So he missed out on a lot of therapy and we couldn't go in because we couldn't do his therapy sessions online either, but we got that in the last plan which is too late now. Most of it's over. F&C06TSV*

Other respondents encountered difficulties around the messaging that they were provided from the NDIA about the purchasing of assistive technology. For example, one respondent was informed that they could purchase devices to support their child to participate in virtual therapy sessions, but was provided conflicting accounts of how much they were permitted to spend on these items.

*If you're self-managed, they said you can just buy it, purchase from JB Hi-Fi or whatever and just claim it back. There's just so much inconsistency though. With the NDIS initially the boss said, "You can purchase up to \$1,500" and then they retracted it the next day and said, "No it's \$750". "Is it \$750 or \$1,500?" I don't want to get into trouble so I just buy \$750, but then they said you can buy something else, so I got the headset because it's for Zoom and then just a mouse and that's it. When the local area coordinator checked the plan for [NAME] she said, "I'm happy. It's all good. You've done the right thing". F&C17TSV*

Meanwhile another respondent had learned that they were able to purchase equipment to undertake their therapy sessions online but, because they could not obtain advice from their provider or the NDIA about the processes involved in doing so, they had been unable to have those costs reimbursed.

*So actually we had to change the laptop and printer and all kind of things for him. The thing is we couldn't claim any of those expenses because they say on the website that the new policy that you can change those equipment using his funding but then when I contacted the provider they didn't know how to claim, and then I also contact the NDIS through the form but they couldn't help that much I think...We didn't really figure it out. F&C22BRI*

For others, purchasing assistive technology alone was not adequate to enable them to continue engaging with their supports over a virtual format. One respondent who was considering purchasing an iPad to link with his allied health therapists acknowledged that, given his disability needs, he would not be able to use the iPad independently. He therefore needed the assistance of a support worker in addition to the assistive technology in order to access his supports.

*Coordinator of Supports: Obviously there's the possibility of you getting an iPad at the moment in COVID for participants you know, and so that is possibly a way that we could actually link [NDIS Participant] up to Allied Health you know from telehealth you know if I can get him an iPad. And then like when in Darwin, you know if she can't fly down, at least then she can do a session with him, you know, like through somewhere, something like that. And so that's...*

*NDIS Participant: There's a problem there. I can't use an iPad.*

*Coordinator of Supports: [Support Worker] has to do it for you. BARP17*

## 6.3 Market factors

In relation to market factors that affect NDIS plan utilisation, COVID-19 was reported to have two main areas of influence: (1) access to services and supports; and (2) service adaptations implemented by provider organisations.

Discussion in relation to these themes demonstrated that the availability of supports and services during COVID-19 restrictions, which directly affected the ability of an NDIS participant to use their funding, was principally determined by how essential a service was deemed and by the ability of the provider organisation to make necessary adaptations to service requirements. Disability service providers implemented a range of adaptations that predominantly acted to optimise the amount of supports that NDIS participants could continue to access despite the various social restrictions implemented throughout the country. These include: adopting virtual and telehealth delivery models; altering the types, timings or locations of services provided; and increasing hygiene protocols to meet new government guidelines. However one adaptation frequently implemented by service providers - the introduction of additional service fees - was considered by respondents as constraining NDIS participants' access to supports and services.

### 6.3.1 Access to services and supports

One of the primary themes that emerged in respondents accounts of how COVID-19 affected plan utilisation was in relation to access to certain supports and services within the community. Many services, predominantly those providing social and community-based activities and some therapy services (including physiotherapy, occupational and speech therapy and counselling) had closed while social restrictions were in place in each of the research sites. Respondents highlighted how a reduction in the availability of these services had negatively impacted NDIS participants and their ability to utilise the funding in their plans.

*But of course with COVID-19 the world changed in a big way. So suddenly this, for a long time we couldn't do things and [ORGANISATION] it's not open gates people coming in and just have a cup of tea now so it's sad, sad, very sad. P31BAR*

*The Coronavirus happened then everything's just put to a stop. No programs for me to do, no nothing. Like my support worker checks up on me once a week and that's it. Massive impact on the funding, like everything's to a standstill. F&C03SWS*

However, essential services such as in-home support (including personal care and cleaning services), and therapists who could adhere to the social distancing regulations or move their practice to a telehealth format were able to continue despite the social restrictions implemented in each site.

*The carers came in and they were all fine. They were allowed to come into the house and everything's been fine. We've had no issues at all. F&C10SWS*

*I: And then has kind of the recent COVID-19 restrictions had any impact on your supports or...?*

*P: No, because our exercise physiologist is very, very small, there's only two girls there and they do a one-on-one. So you know, if you're there with your support worker and you, and [NAME] so there's only the three of them and [NAME] might have someone out the back room that she's doing a Zoom program with or something like that. P22TSV*

In the Barkly region, access to services and supports was challenging under normal circumstances and was further affected by the border closures implemented by the Northern Territory Government in response to the COVID-19 pandemic. Given the remote location of the Barkly region, NDIS participants in this site at times relied on interstate supports and services. It was noted that some visiting allied health therapists, who would usually fly-in from interstate every 2-3 months to deliver services locally in Tennant Creek, had been prevented from doing so by the border closures. In addition, several respondents identified that the border closures had prevented them from travelling to access services interstate, including therapy sessions and equipment fittings and servicing.

*It used to be once every two to three months. But with the COVID thing the person hasn't actually been here since February. They went back over to New South Wales because they'd finished their stint here in [LOCATION] and then they got told they weren't allowed to come back. Because of the whole COVID. F&C04BAR*

*Well was getting serviced each year in Melbourne because once a year I have a two week rehab stint at the [NAME] Hospital and the chair gets serviced at the same time. But now COVID-wise, so that's not happening this year. P06BAR*

The tyranny of distance experienced by NDIS participants in this region, however, was not always a barrier for respondents in terms of the impact of COVID-19 on disability supports and services. For example, one respondent observed that because they had been accessing their therapy sessions virtually due to the remote location in which they lived, the broader move to greater online support delivery within the disability sector during COVID-19 had no effect on them. Another respondent observed that the greater use of virtual activities due to the pandemic had actually increased the support options available to them. They reported that whereas before they were unable to access acting classes locally to help them achieve their NDIS goals, due to COVID-19 they were now able to access these classes virtually.

*This is where COVID has been to your advantage in a way because the acting people that we're talking to, acting classes have moved online and your plan will pay for those acting classes because it's one of your goals, just like the singing lessons get paid through your plan. P16BAR*

### 6.3.2 Service adaptations

Respondents observed that disability service providers had implemented various adaptations so that the delivery of services and supports could continue in the face of the COVID-19 restrictions. The primary adaptations reported were an increased uptake of telehealth and virtual platforms for service delivery, increased hygiene protocols including greater use of Personal Protective Wear (PPE), alterations to the types of services that organisations provide, and the introduction of additional fees and surcharges.

#### 6.3.2.1 Telehealth and virtual service delivery

The move to telehealth and virtual platforms for service delivery received mixed reviews from interview respondents. Some respondents found telehealth to be successful once they had adjusted to it. In fact, one respondent observed that it was more convenient for them to access their services online because of the distance they previously had to travel to access services.

*[ORGANISATION]'s quite far from us because I live in the suburb and if I go there I have to get two trains and one bus. So now that we're Zooming, wow excellent. F&C20SWS*

However, many respondents found that service delivery via telehealth and other virtual means was less effective. Virtual modes of service delivery were considered to be especially challenging for

children with autism who struggled to engage with their therapist via a screen, and for those therapy types that require more face-to-face contact (such as occupational and speech therapies).

*I mean it did take them a while to even look at the computer screen as well...It's that whole video link thing you know how you see yourself and the other person? ...It was that yeah they wouldn't even look at the screen at all. F&C34EW*

*[NAME] very much lost a lot during the pandemic...absolutely the pandemic had a negative effect especially on [NAME]. Any time you use telehealth, she doesn't engage; she can't do it, so that was very hard. F&C34SWS*

Some respondents were concerned that the move to providing supports online was not always viable, particularly when they did not have the appropriate technology to participate in virtual sessions or were unable to fully engage in therapy appointments virtually. One parent of a child with disability felt that this was simply organisations paying lip service to providing alternative service options rather than a genuine attempt at service provision.

*I felt that a lot of providers were kind of getting away with saying we're offering an alternative and so they'd satisfied they ticked their little box, but it wasn't actually an alternative that was viable for [NAME]. So in my mind, no, you're not actually offering an alternative because she can't actually participate in that. So that was a bit tricky, and I felt that wasn't quite right. I think it should've been a bit more case by case...I think for clients that couldn't participate online, that they should still offer face-to-face and just, hey, give the room a clean, you know, do that sort of thing. F&C09TSV*

Despite these challenges, some respondents acknowledged that, while not optimal, the online format enabled them to maintain the relationship with their therapist and receive ongoing support. For example, one respondent who was the mother of two children with disability described how she was able to liaise with their therapists online to establish a regime of exercises and activities that could be done at home.

*Speech wasn't successful I didn't find as much. [NAME 1] just totally tuned out because she couldn't, she communicates a lot by lip reading and she found it too hard to try and lip read over iPad and then [NAME 2] for example just fell asleep. Because if you're not there to actually like physically touch her and keep her entertained just, a speechie on the other end of the phone trying to get her to make sounds was completely boring and she would fall asleep every session. So I found they were only mostly useful with giving me the strategies and again I'd always have a support worker sitting in with me and then my support worker would go out and then do everything we'd just learnt with me teaching, you know, [NAME 2] or [NAME 1], that was the only way we made it successfully work. F&C04TSV*

### 6.3.2.2 Increased hygiene protocols

In addition to the move towards virtual service delivery, organisations were also reported to have adopted greater hygiene protocols to continue to deliver more essential services using a face-to-face format. Temperature checks were reported to be required of clients by many organisations, as was described by one NDIS participant from the Barkly region:

*P: You have to put the thing on the head. The check.*

*I: So, you get checked every time you go.*

P: Yeah, every morning. P20BAR

Other adaptations implemented by providers to enable people with disability to access their services during the COVID-19 restrictions included the use of additional PPE by staff, i.e. gloves and face masks. Social distancing measures had also been put in place such as constraining the number of different staff that delivered in-person services to minimise the risk of exposure for clients.

*The personal care organisation that I'm with is under COVID guidelines anyway, so, you know, for wearing protective equipment and gloves. P19SWS*

*Because they give you three workers and they juggle the rosters out per fortnight and so when this COVID thing happened, I just got those three workers and that was it. No others. P12TSV*

Respondents also reported that regulations were enforced whereby staff were not permitted to work their shift if they were sick or awaiting COVID-19 test results.

*The carers regularly wash their hands and they don't come near the house if they're feeling a bit ill or anything like that. I've got a couple of carers at the moment that they're just waiting on their test results to come back, because they've been in the vicinity with somebody that had the COVID, not to say that they've actually got it. But those carers aren't working at the moment. They've been put off. They're not seeing any clients at all until such time as their test results come back negative. P22SWS*

### 6.3.2.3 Adapted service delivery models

Organisations were also reported to have adapted their service delivery models to ensure that clients could continue to receive services, albeit perhaps in a different manner, or could receive their current services in a way that maximised the effectiveness of the activity.

Several respondents in the Barkly region described how their local service provider, which usually prepared and served meals to clients on-site in addition to providing opportunities for socialising, altered its service delivery model during a lockdown period in the region. While the organisation closed their doors to clients, a home delivery model for meals was instituted thus ensuring that clients continued to have access to food and that staff could check in on them albeit in a socially distanced manner. Furthermore, a respondent from the Eyre West site described how their provider changed the time of their regularly scheduled shopping trip to ensure that they were able to access the items they needed during a period of panic buying.

Meanwhile, a respondent from Townsville described how they had successfully altered the location of the service they were receiving, transferring it from a group-based setting to in-home so that they could continue with the activity in a safe manner.

*We actually got special permission because [NDIS PARTICIPANT] lives on her own and...I could still take [NAME] into [NDIS PARTICIPANT]'s home. So instead of, because we do cooking together. We actually did cooking at home...And, yeah so we were able to like meet all that. P10TSV*

### 6.3.2.4 COVID fees

A final change which was reported by a number of respondents from a range of sites was an increase in the cost of the disability services that they accessed. It was observed that organisations were charging an additional COVID-19 loading on top of their usual service provision fee.

*Support Worker: Didn't the psychologist, didn't he charge you an extra COVID fee?*

*NDIS Participant: Yes.*

*Support Worker: \$20 extra.*

*NDIS Participant: Yes, yeah.*

*Support Worker: And he didn't even have to come out [laughing]. P18BRI*

Respondents were concerned about the impact these additional costs were having on their ability to access the service hours that their plan was designed to cover. As a result, respondents expressed concerns about their level of services and that their funds may not last until their next review.

*There is a 10% loading for the COVID thing, I'm not sure if that's still current or not but they took extra money for that, and so even though I was given more money I've ended up with less hours. So I don't know. P18TSV*

## 7. Experience of “At Risk” Groups

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We have outlined above the findings arising from the qualitative research conducted with all NDIS participants and/or their family members or carers. These findings include the experience of the five "at risk" cohorts that have been identified by existing research as being "at-risk" of plan under-utilisation and who were the target of our research: (1) Indigenous people, (2) people from CALD backgrounds, (3) those living in regional and remote areas, and (4) people with complex needs, and (5) people with psychosocial disability.

Many of the factors outlined above which facilitate or hinder a person’s ability to access the funds and supports provided for in their NDIS plan were found to operate for each of the five ‘at risk’ groups. We do not describe their operation again. Instead, we highlight in the next sections, which factors predominate for each group and outline any factors that are unique to particular ‘at risk’ cohorts. For each ‘at risk cohort’ we also provide two composite case studies<sup>7</sup> to show variability in ‘typical’ outcomes. The composite case studies illustrate the characteristics of those who typically record ‘high plan utilisation’ and ‘low plan utilisation’.

### 7.1 Indigenous NDIS participants

The qualitative study included 56 NDIS participants who identified as Aboriginal and/or Torres Strait Islander. Of these, nearly half (n=27) lived in the Barkly region, and the remainder resided in the Eyre Western region (n=9), South Western Sydney (n=8), Brisbane (n=6) and Townsville (n=6).

#### 7.1.1 Factors facilitating higher plan utilisation

Six key factors were identified as facilitating the ability of Indigenous NDIS participants to access the funding and supports provided for in their NDIS plans in the five research sites.

Several of these factors have already been discussed in detail above in Chapter 4 and include: (1) knowledge and understanding of NDIS processes and local service provision, (2) the personal effort and advocacy of participants and their families, (3) access to funded support coordination, and (4) support from disability provider organisations and workers.

One additional market factor, the cultural appropriateness of supports, was identified by respondents as facilitating the plan utilisation of Indigenous NDIS participants and is discussed below.

##### 7.1.1.1 Culturally appropriate supports

Indigenous respondents highlighted the importance of having access to culturally appropriate supports. Indigenous participants valued being supported by disability workers who were also from an Indigenous background. This allowed them to feel more comfortable and resulted in better engagement with service providers which facilitated higher plan utilisation. The importance of extended family groups to Indigenous NDIS participants was also recognised and seen as being an important factor to consider when services were being planned and arranged.

*It is important for the Indigenous children or adults you know, because if you’re an Indigenous*

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<sup>7</sup> Composite case studies are developed by amalgamating material from multiple cases to construct a single account that highlights a specific issue (Duffy, 2010). The benefit of this approach is that it allows the author to convey the depth and complexity of information gained by contextualising a case in a manner that is accessible to academic and non-academic audiences alike, while also preserving the anonymity of the source (Willis, 2019).

*worker they can communicate with you more than a non-Indigenous worker...It's good because she feels comfortable and she feels safe. Not safe but more comfortable with them. F&C14TSV*

*No actually it was my advocacy people that I'm dealing with, they knew about him and they thought that it would be the best fit for our family and he's friggin awesome. So that's one thing I didn't find and he's a gem mate, a diamond in the rough out here...Because my daughter is Aboriginal as well so as a cultural thing as well for her. F&C16SWS*

*She comes and sit down and we have a yarn or a chat first. She was saying she wants to get to know me better and she tell me about her family too. Like the other support workers are not like that. They just come in and ask, "What do you want to do today?" and things like that. I find different with other support workers....I like that. P28TSV*

## **7.1.2 Barriers to plan utilisation**

Respondents identified factors which were felt to act as barriers to plan utilisation for Indigenous NDIS participants.

This included several factors which have already been identified and discussed in detail in Chapter 5: (1) knowledge and understanding of NDIS processes and local service provision, (2) reluctance to accept disability services, (3) NDIS planning and approvals processes, (4) support coordination services, (5) provider or staffing issues, (6) cost of services, and (7) the interface between the NDIS and mainstream services.

Two additional barriers to plan utilisation were identified by respondents as negatively impacting Indigenous NDIS participants plan utilisation. These included (1) a lack of understanding of the cultural needs of Indigenous people (a plan factor) and (2) a lack of cultural appropriate service provisions (a market factor). These are outlined below.

### **7.1.2.1 Lack of cultural understanding**

Indigenous respondents perceived that the NDIA did not sufficiently understand and account for the cultural needs of Indigenous people with disability. The lack of cultural understanding impacted on Indigenous participants' utilisation of NDIS funds, as well as their use of supports if inappropriate purchases were made (or supporting infrastructure was not in place). For instance, failure to account for electricity costs in housing which relied on the pre-purchase of power cards saw some Indigenous participants with electric scooters unable to use them as they could not be charged.

Other respondents had previously accessed cultural activities such as camping programs prior to the NDIS, but this funding was said to not be available through the current scheme. For one of these respondents, the lack of cultural activities had deterred him from engaging with his plan manager at all and his allocated NDIS funding had not been used. Another respondent reported being refused access to previously agreed travel supports for cultural reasons:

*The first year we were told that they could pay for flights for cultural reasons for me to go back up to Broome to sit with my grandmother. But then when it came down to it, me wanting to go up there for Aboriginal women's business, they said no. They shut me down completely. So which totally confused me because this lady said yeah we can do that. This lady said no we can't do it. P32EW*

Other Indigenous respondents reported that the individualised approach of the NDIS to funding and services was unsuitable and did not acknowledge the cultural importance of family to Indigenous people. For one respondent, this was a barrier to utilising their plan as they did not want to engage in

any supports they would have to do alone.

*I don't want mentors and that stuff. I rather be with my family. I don't want to go out go karting. I'd rather all of us family get together as one and chuck in go karting money, but I'm not talking about go karting, but rather chucking all the money together and go out ourselves. P07EW*

A further example of this issue was provided by the mother of a teenage NDIS participant who had been relocated to Adelaide due to lack of available mental health services locally and was now an 11 hour bus ride away from his family. However, there was no funding for travel supports included in his plan to enable his mother to visit. This respondent therefore considered that the NDIS did not take family connection seriously, did not give due consideration to her son's need to be with family and that as a result his health and well-being was being jeopardised.

Respondents talked about the need for more culturally appropriate communication and processes with the NDIS to foster deeper (mutual) learning about Indigenous participants' lives and how NDIS funded supports fit in with these existing arrangements.

*The main, biggest problem is that no one from NDIS come and sit down and talk about disability...We need to sit with people who come and interview us, need two months in advance to make their plan, and after that plan, they have to sit down, and we should write what people really want in their community. F&C05BAR*

The bureaucratic processes and complex language encountered in trying to navigate the NDIS also were also considered by respondents to alienate Indigenous participants from their plans, further demonstrating the need for more culturally appropriate communication.

### 7.1.2.2 Culturally appropriate services

Indigenous respondents noted a lack of culturally appropriate support options made them reluctant to engage with some services. One respondent who was seeking an Indigenous support worker to provide personal care highlighted how a lack of Aboriginal carers prevented them from hiring additional support staff.

*If I was going to get a second person in, it would be an Indigenous person from her cultural group because that is what would be appropriate. I wouldn't even let a white person because that's personal... when you're living with disability that's your personal time, your personal care. F&C13BAR*

Participant engagement with services was impacted by how comfortable they felt with the staff providing their supports. Lack of effective rapport and engagement had a negative impact on plan utilisation, with Indigenous respondents reporting that this led them to access these services less often as a result, choosing not to utilise this funding.

*I wasn't comfortable there...I felt they were a bit snooty so didn't want to be there. F&C13TSV*

Other Indigenous participants preferred not to hire services that visited their homes instead preferring to have family assist with personal care, cleaning and other tasks in the home. For example, one Indigenous respondent advised she did not seek formal care support and instead relied on her long term partner for her care needs which she thought may be due to cultural norms.

*No, (just my partner) because then like I don't know if with me or just my cultural, because with Aboriginal women we get shy around other people you know. But yeah he's, I'm pretty*

*comfortable with him. P32EW*

Below we provide two composite case studies to show variability in 'typical' outcomes for different groups of Indigenous NDIS participants. The case studies illustrate the characteristics of those who typically record 'high plan utilisation' and 'low plan utilisation':

### **Composite case study 1 – High plan utilisation for Indigenous NDIS participants**

#### **Participant and family details**

Nathan is an 11 year old Indigenous boy who lives with his mother Kath, 8 year old brother Brenton and 6 year old sister Fiona. Nathan's siblings do not have a disability. Nathan exhibited developmental delays and some challenging behaviours as a pre-schooler and was diagnosed with an intellectual disability and Autism when he was five. Kath moved into a city to maximise support opportunities for Nathan.

Nathan has ongoing developmental delays (including limited speech and feeding issues) and becomes frustrated easily leading to angry outbursts. His behaviour and care needs places a strain on the family. Overall though, he is a loving child and his parents are determined to give him every opportunity in life.

Nathan attends a small mainstream independent school where he has support from an education assistant and also a speech therapist and behavioural therapist who work with him several times a week at school as well as outside of the school environment.

Kath has been working as a disability support worker for a large child focused disability service provider for nearly five years. Kath has a cousin who lives in the same town who provides some support and her mother and sister visit regularly to see Kath and the children and help out.

#### **Participant factors**

Kath has been the driver of supports for Nathan and his NDIS plans. Working in disability services has allowed Kath to develop knowledge of disability services and the NDIS and connections within the disability sector. She drew on her own knowledge and her connections to assist with the NDIS application and continues to draw on support from a range of sources. Her perseverance has led her to find good quality services and she has worked hard to establish strong positive relationships with those providers.

Kath had established Nathan's support needs by drawing on the expertise of allied health workers, disability providers and staff, the family GP and her own knowledge and independent research. She connected with a professional advocacy service when applying to the NDIS a little over two years ago to help her articulate Nathan's care needs to ensure he was funded for all the supports he needed.

#### **Plan factors**

Kath felt well prepared for her first planning meeting and viewed it as a positive experience. She had the reassurance of the advocate's presence and felt listened to and understood by the skilled and experienced planner she met with face-to-face. Subsequently, she has been happy to have the consistency of this same planner at Nathan's reviews. She feels she has built a good relationship with this planner and that this planner knows her family and Nathan well now.

Nathan's plan includes all the supports Kath was seeking and she believes it addresses his support needs. Funded supports include support coordination, therapy (speech therapy, behavioural therapy, and occupational therapy), and support with daily living, some equipment and community participation activities. Kath has also been able to draw on transport funding including assistance to take Nathan on visits to her extended family.

Kath's connections in the disability sector had advised her of the value of good support coordination, particularly given her busy life as a single parent and this had led her to seek and be approved for funding for support coordination in Nathan's plan. Kath was able to find an excellent support coordinator via her sector connections and she has been working with this coordinator since Nathan's first NDIS plan. She is in regular contact with the support coordinator, who is alert to new opportunities that may benefit Nathan.

Kath also decided to use a professional plan manager as she wanted some flexibility in how the funding could be utilised but wanted to avoid spending time on self-managing due to the time pressures in her life.

Nathan's funding did not reduce at his plan review and was increased in his latest plan to allow for the addition of behavioural therapy to work on his challenging behaviours, particularly with him soon to transition into the teenage years. To date, Kath has found the funding adequate and her plan manager has ensured the funding is budgeted to last the whole year with little left over but no short fall.

### **Market factors**

Kath was keen to obtain culturally appropriate supports and services for Nathan and connected with a local Indigenous health service who provided advice and links to disability providers and also community programs and activities for Indigenous children and teenagers with disability.

Nathan has developed strong relationships with various staff who work with him. He has two Indigenous support workers, one male and one female who provide some after school care and take him to activities. His current support workers have been with him for about 18 months and are considered to be like family. He calls his female support worker 'aunty'.

Nathan has worked with his speech and occupational therapist for several years and loves seeing them each week. He has recently started behavioural therapy and is responding well but yet to develop the deep connection he has with the other therapists.

Kath is glad she decided to move to a city to be able to access a wider range and choice of available services and supports for Nathan. While there have been some small wait times for some services, there have been no times when an appropriate service was unavailable.

## **Composite case study 2 – Low plan utilisation for Indigenous NDIS participants**

### **Participant and family details**

Shirley is a 48 year old Indigenous woman who lives in a town in a remote area of Australia. Her main disability is a physical disability due to the amputation of her lower right leg. She has significant health problems relating to diabetes and requires dialyses 3 times a week. She is experiencing major kidney failure and her life expectancy is short. Her need for such frequent dialysis has resulted in her having to relocate off her traditional lands, to a regional hub. Shirley has moved in with her sister's family and her sister provides care for her. She has several cousins and nieces who also provide some informal care support but the rest of her family continue to live a long distance away on their traditional lands. Her family try to visit her as often as they can but she has been unable to return to country for a visit since the move to town.

### **Participant factors**

Shirley was not aware she had joined the NDIS and did not know what supports were included in her plan. She had little understanding of the NDIS and did not understand how the scheme operated. For

example, she spoke of meeting the “disability mob”, but did not understand that this meeting actually was the planning meeting where the support and services she required were discussed.

Shirley also has no knowledge of the supports or services that may assist her or what services are available locally. She does not know who to contact for any help and relies on her sister who also has little knowledge of services or the NDIS.

Although Shirley speaks English, it is not her first or preferred language. She had limited schooling and is not able to read complicated documents. Shirley and her family have experienced racism and discrimination. She has grown up with the trauma experienced by some of her family who were part of the Stolen Generation. As a result, Shirley is fearful and not comfortable dealing with government departments or many mainstream organisations.

Shirley is not confident with technology and while she has a mobile phone, she does not use the email account set up for her or use her phone to access the internet. She has never attempted to access the NDIS website or portal and does not possess the skills to utilise these resources.

The town where Shirley lives has poor street infrastructure and a lack of wheelchair accessible transport which limits her ability to move around the community.

### **Plan factors**

Shirley’s entry to the NDIS several years ago was facilitated by the hospital where she goes for her dialysis treatment. She was not involved in the process other than attending a meeting with “the disability mob” where she struggled to understand what was being discussed and didn’t feel comfortable to ask any questions.

Shirley’s doesn’t remember ever seeing her NDIS plan and no one explained to her what was in it. Her plan did not include any culturally appropriate supports and did not account for her broader family members and the care that they provided informally to her. She had some funding for a support worker and equipment but did not have funding for support coordination or transport included in her plan.

### **Market factors**

The hospital provided a temporary wheelchair to Shirley and then a worker from a local disability provider helped get her a NDIS funded wheelchair after she and her sister went to the NDIA office on the main street.

Shirley’s sister asked for some assistance with home maintenance and home modifications to help Shirley including a ramp into the house, some shower rails, a shower chair and a better bed. Home maintenance was not funded but someone visited about the home modifications. Shirley and her sister thought that the amount of money charged to get these items was very expensive. So far, only the ramp has been delivered. Shirley and her sister haven’t been told if or when the other equipment will be provided.

Shirley has been allocated several hours a week of support worker time but has not continued with the support after not getting along with several non-Indigenous workers who visited. Shirley found these people rude and was not comfortable with them coming into the home. She would have preferred her own family to be paid for the informal care they provide or for Indigenous support workers. However, she was told she would need to use support workers from a disability service provider but no Indigenous workers were available at the time and she has not pursued it since.

Shirley wants to be able to travel to visit her family living on traditional lands but is unable to afford this trip and cannot travel without a carer accompanying her.

## 7.2 Culturally and Linguistically Diverse NDIS participants

The sample included 28 NDIS participants from Culturally and Linguistically Diverse (CALD) backgrounds. These participants were more prevalent in the samples from South Western Sydney (n=13), Brisbane (n=6) and Townsville (n=6), reflecting the higher proportion of NDIS participants from CALD backgrounds in these regions.

### 7.2.1 Factors facilitating higher plan utilisation

Five factors were identified by respondents as aiding the plan utilisation of NDIS participants from CALD backgrounds. These factors included participant, plan and market factors.

Many of these factors have previously been identified and discussed in Chapter 4 and include: (1) knowledge and understanding of NDIS processes and local service provision, and (2) the perseverance of participants and their families, (3) access to support coordination, and (4) support from providers and workers.

A further market factor - access to culturally appropriate supports – was also identified as assisting NDIS participants from CALD backgrounds to utilise their NDIS funded services and is discussed below.

#### 7.2.1.1 Access to culturally appropriate services

The opportunity to utilise culturally specific supports with their NDIS funds was welcomed by many CALD respondents. The ability to access these supports was felt to promote the engagement of this group with disability services and to therefore enhance plan utilisation.

Respondents considered it important that services could address the cultural needs of NDIS participants from CALD backgrounds. This included having workers who could communicate with participants in their first language. These services were also seen as providing this cohort with the opportunity to connect with their cultural heritage.

*[They] are going to a Russian school here so that's a private school that has developmental sessions for their age. And they are in Russian because we're from Russia, we speak Russian at home so that's why, so to support the language and to have some interaction with their Russian speaking peers. So they go there and we used to pay that, well from our own pockets but it seems like that there's no need, also this will get paid from the NDIS as well. F&C02BRI*

### 7.2.2 Barriers to plan utilisation

Respondents identified nine participant, plan and market factors which were considered to act as barriers to plan utilisation for NDIS participants from CALD backgrounds.

This included six factors which were applicable to the general sample and have been presented in Chapter 5. These were: (1) knowledge and understanding of NDIS processes and local service provision, (2) NDIS planning and approvals processes, (3) support coordination services, (4) issues with providers and workers, (5) access to disability services, and (6) the costing of services.

Three additional barriers to plan utilisation – (1) language barriers (participant factor), (2) limited access to informal support (participant factor), and (3) availability of culturally appropriate services (a market factor) – were identified and are outlined below.

### 7.2.2.1 Language barriers

Some of the CALD respondents reported that they had limited written and oral English language skills. This was felt to hamper their understanding of NDIS processes and plan implementation. One participant highlighted how the intersection of cultural diversity and disability impacted on their plan utilisation:

*We come from a multicultural background and we have vision impairment as well, sometimes we don't understand why the funding has been lapsed to that account, for two years. Like they'll tell you this one is going for two years, but then you don't know how (...) why, you know...And suddenly you realise, oh, oh oh, I didn't do my sums properly, I sort of didn't use the funds properly, now I've run out of funds...Because you weren't explained that properly, there's no proper explanation given. P19SWS*

Respondents also described challenges that they had faced in their communication with the NDIA. For instance, while interpreters may be offered or required (by the NDIA) at planning and review meetings, some respondents stressed that this did not necessarily result in better understanding, particularly if the interpreter did not speak the same dialect as the person with disability. Other respondents said that although they spoke English fairly well, the complexity of the language used by the NDIA was a barrier to understanding the content of their plans and how to access services.

*I'm quite okay with reading and so I find all the documents okay to read...I understand the language in general but they obviously some terms that I have to look in their website, know what it means in that particular context. I struggle with reading the plan or how to implement it...so not really about the language but about the network. I can understand but I don't know many people who can provide me with information. That's what I mean. F&C22BRI*

Some CALD respondents described previous experiences of miscommunication with the NDIA, particularly when meetings had been conducted over the phone. In order to address this and promote improved communication, these respondents stressed that information from the NDIA should be provided in a face-to-face format (either in person or via video conferencing) or translated into their own language.

*I won't have, I want face to face, I won't have phone, sorry. Because of miscommunication, misunderstanding. If I have papers I can show it in front of you like this. You know? I don't want because life is stressful as enough as it is on top of [NAME]'s illness, I just can't be beating around the bush. That's it. So I just want a Zoom. P32SWS*

*We couldn't even get a copy of the plan ahead of time to be able to read through it and go, yeah, I like this, or no, I don't like it. They would literally call you, read out a 17-page document and ask you, "Are you happy with that?" And if you're not happy with that, AAT. So you need to tell me right here, right now on the phone, if you're going to accept this plan, and if you're not going to accept it, I can't help you, AAT. F&C02TSV*

### 7.2.2.2 Limited access to informal support

Many respondents from CALD backgrounds described having small social networks within Australia as their extended family members and friends often still lived overseas. This lack of informal support was felt by some of these respondents to negatively affect their confidence in navigating the NDIS system and implementing their plan. NDIS participants or their family members who had limited English language skills in tangent with a small support network were considered to be particularly at risk of lower plan utilisation.

*I think mostly I am new and then, most of the time, I am alone. F&C05BRI*

Consequently, NDIS participants from CALD backgrounds were felt to have a great need for information and support from formal channels (including providers, support coordinators and advocacy organisations).

*I think because we come from overseas as well, and the system is new to us, all the kinds of support. It's new to us as well so probably we don't have the right network of friends, family who have similar experience. I didn't really benefit much from anyone else. I think our situation particularly it would help a lot with the plan, just try find information about that. F&C22BRI*

### 7.2.2.3 Availability of culturally appropriate services

As discussed above, having access to culturally appropriate services was considered by respondents to be a factor which positively influenced plan utilisation for people with disability from CALD backgrounds. However, the availability of these services was described as being fairly limited by many CALD respondents, impacting upon their ability to utilise all the funds allocated within their NDIS plan.

Some of these respondents described the difficulties that they had encountered in identifying and accessing services that specifically supported their cultural background. This included having workers (particularly disability support workers and allied health professionals) who could communicate with them in their first language or services that understood and met their cultural needs. Consequently, these respondents were forced to either forgo funded supports or engage with general disability services where their full support needs were less likely to be met.

*It would be nice to have a Pacific Island disability service that I could engage in and that could really help me with my needs. It would help me to participate and be inclusive in my culture. That would be really lovely, but that's just not available. P36SWS*

Below we provide two composite case studies to show variability in 'typical' outcomes for different groups of CALD NDIS participants:

#### **Composite case study 3 – High plan utilisation for CALD NDIS participants**

##### **Participant and family details**

Rosa is a 6 year old girl whose primary disability is autism. She lives with her mum and dad, Sonia and Bruno who are both from culturally and linguistically diverse backgrounds, as well as her brother and sister. Rosa's parents both work part-time and try to arrange their work days so that someone is available to care for the children and take Rosa to her appointments. Sonia's extended family lives nearby and help out with child care sometimes.

##### **Participant factors**

Rosa's family were well supported when applying to the NDIS and they felt comfortable with the application process and were satisfied with the plan they obtained. Prior to joining the NDIS, Rosa was already attending a school that focussed on children with special needs. The school runs NDIS information sessions to keep parents updated with current information and changes happening with NDIS. Rosa's family also attends a local multicultural centre, which ran information sessions about the NDIS that used diagrams and easy to understand language to explain what to do in their application and what the process would look like. They have an advocate, Sara, who prepared them for what to expect in the planning meeting and attends NDIS meetings with them to make sure they understand what is being discussed and their wants and needs are communicated and taken seriously by the

planner. Rosa's family say that because of this support network they had a good understanding of how the NDIS works and a lot of people they can go to if they have any questions.

### **Plan factors**

Rosa's parents are very happy with her plan and find that it meets her support needs well. Rosa's plan included funding for therapy that could pay for the number of hours recommended in her specialist reports, as well as respite funding, core funding, plan management and support coordination hours. When Rosa needed a little bit more funding for sensory tools her support coordinator, Marie, was able to organise a plan review and have her plan increased so that Rosa could get the items she needed. The support networks that assisted Rosa's family to navigate the planning process have continued to support them in understanding and implementing Rosa's plan. Whenever Sonia and Bruno have questions about what the different categories of funding can be used for, they have knowledgeable people that they can ask. Marie works well with Rosa's plan manager, and Rosa's family feel that everything is running smoothly.

### **Market factors**

Rosa and her family live in an urban location with a lot of services around. Her family heard about a good support coordinator, Marie, from other parents at Rosa's school and were able to hire her without too much of a wait. This has made accessing services much easier for Rosa's family as Marie has a lot of experience and relationships from her long career in the disability sector and has connected Rosa with excellent therapists in their local area.

There was a little bit of a wait time to access therapies like speech therapy and occupational therapy, however this was only a few weeks and Rosa has been attending regularly since. Rosa has disliked therapists in the past and refused to work with them, so Sonia and Bruno know it is important to find workers who 'click' with their daughter. They were relieved to find that Rosa gets along well with her therapists and she sees the same person every time she goes to her appointments so they have built up a good relationship.

Accessing services that support their cultural background is important for Rosa's family, and they were very happy to find that Rosa is also able to have her visits to a local cultural school on the weekends paid for by NDIS, as they offer classes specifically for children with special needs. This supports Rosa's connection with her culture, while also meeting her support needs.

## **Composite case study 4 – Low plan utilisation for CALD NDIS participants**

### **Participant and family details**

Ismail is a thirty year old man who has a physical disability due to loss of limb. He also has a secondary condition that can make it difficult to remember things and makes Ismail feel very tired sometimes. Ismail is from a CALD background and is living in Australia away from his family who all remain overseas. He lives alone, and while he has made some friends in Australia he does not feel that he has a strong support network in place. He talks to his family on the phone often, but wishes they lived nearer so that they could help. Ismail has tried his best to engage with his NDIS plan, but has found it difficult to access the support he needs and a lot of his funds have gone unspent each year.

### **Participant factors**

Ismail wasn't heavily involved in the process of applying to NDIS and feels disconnected from his plan and the NDIS system. He hasn't encountered anything like NDIS prior to living in Australia and finds it difficult to understand what NDIS is or how it can help him. Following his amputation, the hospital Ismail was staying at connected him with an organisation who submitted an NDIS application on his

behalf. Ismail isn't sure of the name of this company and, although he was present at the planning meeting, isn't sure what happened in it or what is in his plan.

Ismail speaks some English, but finds it difficult to follow very complex conversations especially when he is fatigued. An interpreter was provided for Ismail in the planning meeting, however they spoke a very polished version of his language, rather than the regional dialect he was used to. Although he could pick up some of the words, he still wasn't sure what the discussion meant for him. When asked if he understood at the end of the meeting, Ismail said 'yes' and hoped he would work out what his plan meant later but it has been trickier than he thought. Ismail is not able to drive, and although he asked friends for a lift a few times to go to doctor's appointments, he doesn't feel comfortable asking them for assistance regularly. Ismail says that the disability system is very complicated and overwhelming, and he isn't sure where to go for help on how he can utilise his funds more effectively.

### **Plan factors**

Ismail isn't sure what is included in his plan or what it can do for him. Although he has a copy of the plan, he has trouble understanding the language and isn't sure what the support categories mean. He says it would be helpful if there was some sort of orientation for him to learn about the NDIS and what to do with his plan. Ismail's plan includes funding for therapies, transport, support coordination, home modification, a meal delivery service and core supports. He was connected with a support coordinator initially but doesn't hear from them very often and isn't really sure how to organise supports and services other than to wait for the support coordinator to do it. Ismail was really glad to hear that he would have assistance with transport to help him get to his appointments, but he isn't sure how to use this funding and no-one has explained it to him so he has never used it.

Ismail can see there is a lot of money in his plan, but aside from the therapy he accesses he isn't sure what this can be spent on or how to go about it. A lot of the funds, such as funding for home modification, have never been spent even though these supports would be helpful in supporting Ismail to achieve his goals.

### **Market factors**

Ismail lives in an urban location but has struggled to access appropriate services. He was connected with a support coordinator when he first joined NDIS, and they have linked him with some therapy services but he doesn't hear from them very often. Ismail experienced a considerable delay in accessing these services, which he thinks might be partially due to his support coordinator taking a long time to organise supports, as well as the long waiting lists he had to join. He used to call the support coordinator to try to find out what was happening, but after he ran out of support coordination funds partway through his last plan Ismail is too scared to call unless he absolutely has to.

Now that he is able to access his therapies, Ismail likes the physio and occupational therapist he sees, and they are located in a complex just down the road from his house so he can get himself there without needing transport. However, because they are overwhelmed with clients he isn't able to see them as often as his specialist recommends and his therapy funding is underspent as a result. He would like to find another organisation that can provide the frequency of support he needs, but his support coordinator hasn't gotten back to him about arranging this and Ismail is worried there won't be any other options near his house.

Although Ismail has been happy with his therapists, he says it would be nice to be able to work with someone who understands his cultural background. Similarly, while he is grateful for the meal delivery service that brings him food every day, the food is very different to what he would usually choose to eat and he wishes there were more options to suit different cultural cuisines.

Ismail is trying his best to navigate the complex NDIS system, and would like a more responsive support coordinator but isn't sure how to go about finding one and is afraid of what will happen if his current coordinator cuts off his support. Ismail is grateful for the support he receives and hopes that one day he will be able to learn more about what his NDIS funds can be used for so that he can access more services.

## 7.3 NDIS participants in regional and remote areas

The sample included 101 NDIS participants living in regional and remote areas. These participants were located in the Eyre Western (n=35), Barkly (n=32) and Townsville (n=34) sites.

### 7.3.1 Factors facilitating higher plan utilisation

NDIS participants in regional and remote areas highlighted key participant, plan and market factors that facilitated higher plan utilisation. Given the large number of participants from regional and remote areas, all of the factors identified by respondents as aiding plan utilisation have been identified and discussed in Chapter 4. These include (1) knowledge and understanding of NDIS processes and local service provision (2) the personal effort and advocacy of participants and their families, (3) access to support coordination, and (4) support from disability provider organisations and workers.

### 7.3.2 Barriers to plan utilisation

Regional and remote respondents mentioned five participant-level factors impeding NDIS plan utilisation: These included (1) knowledge and understanding of NDIS processes and local service provision, (2) precedence of non-disability needs, (3) managing appointments, (4) reluctance to accept disability services, and (5) the use of technology.

Two plan factors were considered by many respondents to negatively impact on plan utilisation of NDIS participants living in a regional or remote area: (1) NDIS planning and approval processes, and (2) support coordination services.

Respondents in the regional and remote cohort highlighted four market factors negatively impacting on their plan utilisation: (1) availability of disability supports and services, (2) provider organisations and the disability workforce, (3) cost of disability services, and (4) the interface between the NDIS and mainstream sectors.

All of these factors have been identified and discussed in Chapter 5.

Below we provide two composite case studies to show variability in 'typical' outcomes for different groups of NDIS participants living in regional and remote areas. The case studies illustrate the characteristics of those who typically record 'high plan utilisation' and 'low plan utilisation':

#### **Composite case study 5 – High plan utilisation for NDIS participants in regional and remote areas**

##### **Participant and family details**

Ken is a 52 year old male, living in a small town in a remote region of Australia. He is divorced, lives alone in a public housing unit, and has two grown children who do not live locally. Ken is living with Multiple Sclerosis (MS) and as a result experiences muscle weakness that impacts his mobility, as well as mild cognitive impairments, including problems with planning and remembering, and depression.

Ken has accessed various pieces of equipment via his NDIS plan including a walking stick and a specialised chair. He has a cleaner who comes once a week and a support worker visits daily to assist him with food preparation and to accompany him with community-based activities including grocery shopping, attending appointments, and accessing the gym and pool facilities at the local sports centre. Ken also accesses psychotherapy once a month and an occupational therapist, when required.

### **Participant factors**

Even though he is the only person in the local community with his condition, Ken actively participates in an online community of people who are living with MS and tries to stay up-to-date with the latest approaches to new treatments. As a result of this he has a clear sense of what supports he needs and what types of supports others in similar situations are accessing via the NDIS.

Ken has been unable to work in the last few years because of the deterioration of his mobility, but previously he ran his own farm. He feels that the administration skills he acquired in his work mean that, when he is having a “good day” and his ability to think is not compromised, he is generally able to understand his plan and how to implement it. However, he does admit to some confusion around the language used to define the different support budgets in his plan and what supports align with each budget.

Because Ken has difficulties with thinking clearly and with memory, he keeps detailed records of all his interactions with NDIA staff, his support coordinator, and service provider staff in an exercise book that he calls his “NDIS book”.

### **Plan factors**

Ken feels fortunate that he was allocated adequate funding in his NDIS plan to engage properly with a support coordinator. Ken’s support coordinator Amanda has known him for approximately 5 years through various Government and NGO positions she has held in the town pre-dating her involvement with him via the NDIS. As such, she is well acquainted with Ken’s situation and they have an established a good working relationship.

Amanda advocates for Ken both with service providers and with the NDIA. Amanda arranges and tracks the delivery of NDIS-funded equipment, and helps to follow up with the suppliers if there are issues. She also helps Ken to liaise with the organisation that supplies his support workers when he has concerns with particular staff members.

Amanda also assisted Ken with requesting significant changes to his first NDIS plan. Ken felt that this initial plan did not reflect his support needs and was lacking in support around daily tasks, such as food preparation and maintaining his fitness levels. In the lead up to his plan review, Amanda helped Ken to collate the necessary evidence to support his argument that he needed additional supports. As a result, Ken not only was funded for this additional support, but his subsequent plan also contained funding for specific supports that he does not need at present, but may need if his condition deteriorates, e.g. a specialised bed and additional therapies. He acknowledged that unlike others who were concerned about losing any funding that they are unable to use, he had been assured that this “buffer” funding would remain in case it was needed in the future.

Ken is also funded for plan management and this allows him the flexibility to access supports from any provider (which is necessary in a remote area where service providers are limited) while also delegating the financial management of the plan to a professional. This not only alleviates some of the stress for Ken, but is beneficial given that his condition affects his cognitive processes. Additionally, Amanda keeps on top of Ken’s NDIS budget and his spending. She helps him to find ways to access supports and use his funding if his spending is low, and flags when he is using supports too frequently and might need a plan variation to prevent his funding from running out.

**Market factors**

Ken had already been a client of his main service provider, the organisation that provides his support workers, prior to the NDIS. As a result of this, his transition into the NDIS was facilitated through this organisation and from Ken's perspective occurred quite seamlessly.

With the assistance of his support coordinator, Ken has been able to be flexible and work "outside the box" to help him get the supports he needs despite there being limited supports available in town. Ken has been able to access some supports, such as the fitness regime designed to delay the progression of his MS symptoms, through mainstream services in town. Other supports, such as his psychotherapist, Ken accesses remotely via telehealth and did so even prior to COVID-19 and the move toward virtual services. Finally, Amanda has helped to link Ken with support workers and services in other regions so that when Ken visits his adult children and their families, he is still able to access the supports and services that he needs.

**Composite case study 6 – Low plan utilisation for NDIS participants in regional and remote areas****Participant and family details**

Ella is a 14 year old girl who lives with her mother, younger brother and sister on a property approximately 15 kilometres outside of a remote town. The family recently moved to the region and are still establishing themselves within the community. As a young child, Ella was diagnosed with moderate intellectual disability and has difficulties with her speech, learning difficulties and demonstrates challenging behaviours, including becoming aggressive towards her younger siblings.

Ella's mother, Jessica, is a single parent and has a full-time administrative job in town. She acknowledges that she is overwhelmed balancing three kids, a new job, and settling into a new town. Jessica herself struggles with anxiety and depression.

**Participant factors**

Jessica is stressed, time poor, and struggles to find the time to devote to understanding and implementing Ella's NDIS plan. In the past she relied on Ella's service provider as a "one-stop-shop" to access all her supports. In effect, the service provider managed Ella's plan on Jessica's behalf. However, that provider does not service their new town and Jessica needs to source new supports and services for Ella now that they have moved.

Because Jessica and her family have only recently moved to the town, she is not yet familiar with the local service providers and has not established relationships with other parents of children with disability in the area.

Ella finds change quite difficult and the move has been challenging for her. She misses her friends and her old routine. This has escalated her aggressive behaviours and has made life for the rest of the family more difficult. As a result, Jessica is concerned that she has not been able to devote enough energy towards her other children.

Ella is strong-willed and discerning with her carers. She refuses to engage with workers that she does not like and does not cope well with constant staff changes amongst her carers. Instead she prefers to work with a few, select staff members that she trusts.

**Plan factors**

A recent review of Ella's plan, conducted over the phone because the LAC was located outside the region, has negatively impacted Jessica's confidence in the NDIS. She felt frustrated that the LAC was

not able to communicate with Ella herself due to the review being conducted by phone. This review was conducted by yet another new LAC, the third that Jessica has dealt with on Ella's behalf thus far, which meant that she had to retell their story - an exercise that Jessica finds quite traumatic and draining. Furthermore, she felt that the LAC had little experience with disability, and did not fully understand Ella's needs. Instead, she made several insensitive comments about Ella's disability and, based on the new plan that Ella received, Jessica is convinced that the LAC only passed on some of the information Jessica provided to the Planner. Jessica was very anxious because the funding allocated in the plan decreased significantly from previous years and she is not sure that it will cover Ella's support needs for the entire year.

Ella's NDIS plan does not have funding allocated for a support coordinator. Because the family are new to town, they have little awareness of what services are available. The LAC assigned to Ella did provide Jessica with a list of services, but it was a long list, many of the services listed were not local and Jessica felt that it was "a lot to process." In addition to this, the LAC was not located in the region, instead operating out of another regional town 4 hours away, and did not seem to have more familiarity with the services available than did Jessica.

Despite assurances from the LAC during the review meeting that the plan would include respite services, no funding was allocated for this in Ella's plan. Given the escalation of Ella's behaviours since their move and the negative impact this has had on the rest of the family, Jessica feels that she needs to take some time to devote to her younger children but as a single parent has not been able to do this.

Another exclusion from Ella's current plan was funding for transport. Given that the family live outside of town, Jessica is concerned that even if there are activities that Ella can do in town, if she is not available to transport Ella herself then she will not be able to access the services.

### **Market factors**

Ella likes dancing, art and spending time with her friends. Before moving to their current location, the family lived in a major city and Ella enjoyed access to a range of supports including dance and art classes as well as group-based activities targeted at teenagers living with disability. She had a range of young support workers who shared her interests and could take her to her various activities as well as taking her out in the community. Ella also had regular therapy sessions with both a speech therapist and a behaviour therapist. Since moving to town, Jessica has managed to connect with a local disability provider and from this Ella has a support worker to assist her with community participation activities for 6 hours per week. As far as Jessica is aware, this provider is one of only two providers in town - both of whom supply support workers and run day-programs and other group activities.

Being a small, remote community, the availability of support workers is limited. Ella is a teenager however the only staff in the region are older women who do not share her interests. Given that they have yet to be able to access any group activities, these support workers are Ella's main opportunity to engage with other people. Jessica had hoped to be able to access younger support workers so that Ella could spend time engaging with people closer to her own age rather than hanging out with someone who was no different to hanging out with "boring old Mum." There is also a high turnover of staff within the organisation, and the constant changes to her support worker staff upsets Ella and her routine. The other provider in town is fully booked and has a long waiting list. Jessica is therefore reluctant to raise these issues too frequently with the provider she is using because she does not want to get black listed and stranded without any supports for her daughter.

Jessica has attempted to enrol Ella in some of the group activities available in town but they are popular and have long waiting lists so she has not been able to access them yet. The difficulties that Jessica has had in finding supports for Ella has increased her anxiety She is worried that Ella's plan will

be further reduced next year if she is not able to use the funding they have been given and Jessica is starting to lose sleep over this.

Because the community is small, therapists only visit town on a fly-in/fly-out basis for a few days every two or three months. As such there is a huge demand for services when they are in town, creating long waiting lists to access the limited number of appointments. It is rare that the therapists who visit last for more than six months - which is only two or three appointments. This means that there is no continuity in the therapies provided. Because of COVID-19 restrictions, no therapists have been able to visit since Jessica and Ella moved to town so they have not been able to access therapy. Jessica considered the option of going to the city to access her speech and behaviour therapists but Ella's current plan does not cover the travel costs.

## 7.4 NDIS participants with complex needs

The sample included 32 NDIS participants with complex needs. Most of these participants were located in the Townsville site (n=12), followed by South Western Sydney (n=9), Barkly (n=7), Brisbane (n=3) and the Eyre Western region (n=1).

### 7.4.1 Factors facilitating higher plan utilisation

The plan utilisation of NDIS participants with complex needs were reported to be facilitated by seven factors covering participant, plan and market factors.

Several of these factors have already been discussed in detail above in Chapter 4 and include: (1) knowledge and understanding of NDIS processes and disability services, (2) the personal effort and advocacy of participants and their families, (3) access to support coordination, and (4) support from disability provider organisations and workers.

Three additional plan and market factors were identified by respondents as facilitating the plan utilisation of NDIS participants with complex needs and are discussed below. These were: (1) the appropriate allocation of funding (plan factor), (2) availability of experienced providers and workers (market factor), and (3) flexibility of care provision (market factor).

#### 7.4.1.1 Appropriate allocation of funding

For NDIS participants with complex needs, respondents reported that it was vital that the funding allocated in their NDIS plans appropriately met their needs. This was seen as enabling people with complex needs to receive suitable services and utilise the funding in their plans.

Respondents considered that a flexible and supportive planning process was crucial for obtaining plans that would fully address these support needs. For NDIS participants in this cohort, support needs could be extensive and change often. It was also recognised that people with disabilities that were degenerative, rare, or co-occurring in nature provided additional complexity that needed to be accounted for in NDIS plans. Some respondents reported having had excellent experiences during planning and review meetings with planners who had understood the complexity of conditions and the need for plans to change in future. As a consequence these respondents felt that the services subsequently funded within their plans were appropriate and fully met their needs.

*She did her homework obviously before we went there, because it was sitting with the paperwork, and she approved it and it was fantastic. She said, "Let's review his case. We don't have to wait for ...", you know what I mean, "If you really need, if you get stuck, just contact me, then we could review his case." F&C17BRI*

*We just told her what was going to happen, what we've seen with his dad and that sort of stuff so she worked with that, so that was fine. And she's been great and said, you know, we can review this at any point. F&C19BRI*

Formal support (from providers, advocates, support workers and support coordinators) was perceived as being crucial in ensuring that NDIS participants with complex needs received appropriate funding and services. Support had been provided to respondents with the provision of necessary documentation to support funding requests, advice given regarding appropriate services, and assistance given in dealings with the NDIA (including attending planning and review meetings).

*We had the lady who was running the respite place, she came because she was quite knowledgeable. She also has a lot of background with the out-of-home service as well, so she knows that as well. So, that's we're heading anyway when he's old enough. Then we had our support worker, another one, the other one said [Name]'s situation was very complex for him. F&C17BRI*

*When we had the meeting, they could see, because we had so many documents and evidence to show to prove that, all these incidents of paper, like that much, from police, from everything. We had so many, you can't deny it. F&C17BRI*

#### **7.4.1.2 Availability of experienced providers and workers**

For NDIS participants with complex needs, having access to providers and workers who were experienced and skilled in working with this cohort was one of the most highly cited facilitators of plan utilisation. Some respondents stated that they were only using particular funds in their plan because they had found workers who had connected well with them or the person that they cared for and provided a quality service.

*If she wasn't there, [NAME] wouldn't be going there. So, that would be another service we wouldn't be utilising. F&C13BAR*

*And we have said to [NAME] that's the sort of people we need. Someone who doesn't let him get away with it, but can turn him quietly or steer him away and get him to do what's required, what he's being taught, whether it's exercising or doing his speech or doing his calming. They know how to steer him so he is not escalating and if he's escalating that they listen and say okay we'll take you somewhere to talk to someone. Can we get an appointment, can we get you to the doctor if you're not well. Can we do this. What do you want to do today and they listen to what's he's saying. F&C20TSV*

Respondents also stressed the importance of having a network of good providers who worked together, and could provide an effective multidisciplinary team approach for NDIS participants with complex needs.

*We have all of the range of expertise that we need for [NAME]...They then connect with my other staff that I have on the ground here, again, it's around building the relationships with great OTs, a speechie and those types of things that we have been able to. F&C01BAR*

*I am very happy with the young girls, she looks enthusiastic and that does speech therapist and occupational therapists and that's the therapy...they are working together as a team. F&C30BAR*

### 7.4.1.3 Flexibility of care provision

Finally, for NDIS participants with complex needs, having providers who were understanding and flexible in their care delivery was appreciated and felt to contribute to plan utilisation. Respondents indicated that it was highly important for providers to be flexible if participants were having a bad day or were unable to access their services due to their circumstances, without being penalised. This increased the likelihood of supports continuing and encouraged the engagement of people with complex needs. For instance, a parent described the empathetic approach taken by a provider for her son who was living with a degenerative condition which allowed the continuation of his services:

*[NAME] had a little breakdown at the beginning of this week and rang everyone and said, I'm quitting, I'm leaving Brisbane and I don't need anyone's help anymore. And they all called me and went, is everything alright and I'm like, whoa, I don't even know what's happening. And they're like, that's okay, we understand that these things happen, we won't be cutting him off, you just let us know what to do. F&C19BRI*

## 7.4.2 Barriers to plan utilisation

Respondents identified eight factors which were felt to act as barriers to plan utilisation for NDIS participants with complex needs.

This included seven factors which have already been identified and discussed in detail in Chapter 5: (1) knowledge and understanding of NDIS processes and local service provision, (2) reluctance to accept disability services, (3) NDIS planning and approvals processes, (4) support coordination services, (5) provider or staffing issues, (6) costing of services, and (7) the interface between the NDIS and mainstream services.

An additional barrier to plan utilisation which related to the availability of appropriate services and staff for people with complex needs (a market factor) was discussed by respondents and is outlined below.

### 7.4.2.1 Availability of appropriate services and staff

Many respondents indicated that finding staff members who were trained in complex care needs and could provide appropriate support was difficult. As a result some NDIS participants with complex needs struggled to utilise their funding. Identifying providers with the appropriate training and experience to work with people with challenging behaviours (e.g. violent behaviour) was said to be especially difficult. Several examples were given of services not having the capacity to manage this behaviour, subsequently withdrawing service provision and leaving the NDIS participant with no formal supports.

*The provider we had, they stopped, they said they wouldn't work with her anymore because she'd like assaulted one of them and they'd witnessed her being suicidal, witnessed her assaulting me, etc., etc., and they said it was a risk thing, that they couldn't do it and nobody else would take her. So she actually had no support, even on the plan she had. F&C09TSV*

*We started having issues with them not listening to what he was telling them. Like if he's getting cranky you don't stay and put yourself in danger. You get yourself out and they would stay and then wonder why he would attack them. F&C20TSV*

Respondents also stated that it was difficult to find support workers who were skilled in working with people with complex care needs and could provide suitable activities and stimulation. Other respondents had experienced unreliable or inattentive care which resulted in them being left without

support workers, or the NDIS participant being placed at risk through a lack of adequate supervision. These issues resulted in lower plan utilisation as some respondents lessened or ceased services in response to unsatisfactory care and were unable to find suitable alternative supports.

*They're happy just to babysit her in the house. F&C23TSV*

*They're not really putting any effort into finding activities for [NAME] to do when she's there... I mean, I could stick her in front of a TV. F&C09TSV*

Issues with high staff turnover was described by respondents as a related issue that resulted in a lack of available, appropriately trained staff and limited plan utilisation for people with complex support needs. This was particularly the case for NDIS participants with complex needs living in more remote areas.

*Schools are classic. There's no-one there qualified. Do you use your funding to get someone qualified? There's no point 'cause in six months' time they'll probably leave. So, no, we probably don't use as many services as we could, but there's not really a lot for us to utilise. F&C13BAR*

Below we provide two composite case studies to show variability in 'typical' outcomes for different groups of NDIS participants with complex needs. The composite case studies illustrate the characteristics of those who typically record 'high plan utilisation' and 'low plan utilisation':

### **Composite case study 7 – High plan utilisation for NDIS participants with complex needs**

#### **Participant and family details**

Kenny is an 8 year old boy whose primary disability is Cerebral Palsy. As a result of his disability, Kenny has very complex support needs and requires assistance with all his activities of daily living. He and his 3 older siblings live with their parents, Jean and Ted, in a regional area. Two of Kenny's siblings also have NDIS plans, and Ted works from home to try to manage everyone's appointment schedule. Although things are very busy, Kenny's family feel that they are navigating the NDIS system fairly well and utilise most of Kenny's plan.

#### **Participant factors**

Jean and Ted both worked in health related fields prior to their children joining the NDIS, and their pre-existing knowledge and professional networks were very helpful when the time came to organise Kenny's plan. For instance, Jean and Ted had heard through a friend that having a lot of documentation to support their requests in the planning meeting would increase their chances of obtaining an appropriate plan for Kenny. This prior knowledge meant that they were able to gather extensive evidence to support their requests, and were satisfied with the supports they were able to have funded. Both of Kenny's parents have a good knowledge of local disability providers and researched service options these ahead of time. For Kenny, this meant that his plan was implemented right away, and his support coordinator, therapists and support workers were able to be recruited quickly.

#### **Plan factors**

Kenny's plan has a good amount of funding allocated for his therapies, respite, daily living, support coordination and core supports. His parents also enlisted a disability support advocate to attend their planning meeting to make sure they had someone there who could support them, and was able to speak 'NDIS language'. When they received Kenny's plan, Jean and Ted immediately hired a support coordinator, Lucy, who was highly recommended. As they planned out Kenny's supports for the year Jean and Ted realised that Kenny's plan was well crafted to meet Kenny's support needs.

Over time, Jean and Ted have learned a lot about what they can use Kenny's NDIS plan for through conversations with Lucy and his therapists. Sometimes NDIS policies can be a bit confusing, like when Kenny needed to purchase some technology to access his supports on Telehealth during a Covid-19 lockdown and his parents weren't sure whether they were allowed to purchase a tablet without checking with NDIS. But whenever they run into something confusing about Kenny's plan, they email or call Lucy and she responds very quickly. This means that Kenny uses a lot of his NDIS funding because his parents feel supported in making the right decisions, and aren't afraid they will get into trouble for purchasing something that isn't allowed.

### **Market factors**

Kenny's family knew from their conversations with others in the field that finding workers who were qualified to support clients with complex needs would be important to make sure Kenny had the care he needed. It was difficult to tell this from the provider lists online, so Jean and Ted asked their colleagues and posted in a local disability-centred Facebook group for recommendations. Through this, they found a great support coordinator, Lucy, and have assembled a team of therapists that get along well with Kenny and meet his support needs.

Through some trial and error Kenny and his family have worked out what kinds of supports work best for them, which helps them to make appropriate choices. When Kenny's favourite support worker, Meg, moved to another company, his family had initially decided to stay with the organisation as they had built up a good working relationship with them. But when they realised Kenny just wasn't clicking with a new support worker, they decided to move him to the organisation Meg was now working at and Kenny is happier with this arrangement.

The support workers and therapists who work with Kenny are able to recommend activities and new ideas to build his capacity because they have gotten to know him well, and are invested in helping him discover and achieve his goals. They also shape their services around what works for Kenny, and Jean and Ted were happy to find providers who were flexible in their service provision and were willing to change appointment times, use telehealth and/or come to the house to provide support if necessary. This flexibility has been really important for Kenny and his family, especially as his siblings also have appointments they need to attend.

## **Composite case study 8 – Low plan utilisation for NDIS participants with complex needs**

### **Participant and family details**

Ron is a 64 year old man whose primary disability is cognitive impairment associated with dementia. His wife, Lily, manages his NDIS plan. Ron currently lives in an aged care facility which is a fair distance from the family home. Lily does not drive and cannot visit him as often as she would like. Lily and Ron have tried their best to use Ron's NDIS funding, but they have found it difficult to manage and a lot of Ron's plan goes underspent each year.

### **Participant factors**

Ron's diagnosis and subsequent cognitive decline have been quite traumatic for both Ron and Lily, and they find it upsetting to discuss and plan for what the future holds for Ron. Ron's cognitive impairment makes it difficult for him to remember things and understand what is happening with his NDIS plan so Lily does her best to talk to him when he is lucid, however this is becoming less frequent.

Ron's disability affects his behaviour, and sometimes his frustration manifests in violent behaviours. At the moment, he has been unable to attend any of his therapies until his behaviour is under control, which means he is not utilising any of his therapy budget and will likely have to re-join a waiting list

when he is able to attend again. The nursing home has also warned that Ron will need to find somewhere else to live after multiple incidences of violent behaviour towards residents and staff. Lily says that she understands staff can't be put in an unsafe situation but she doesn't know how to help Ron with his behaviour if he isn't able to attend any of his funded supports. In the first few years of his plan Ron didn't engage in violent behaviours but he would refuse to work with therapists he didn't like or participate in activities when he wasn't in the mood. Although Lily and Ron have a support coordinator who has arranged supports for Ron, his unwillingness to engage with them has meant that a lot of Ron's plan goes unused.

### **Plan factors**

Ron's plan has changed quite a lot with each review, which Lily says seems to depend on the planner they see and what they decide to include. This makes it hard to trust the planning process and one year Ron's budget was reduced so significantly that Lily called the NDIS every day before breaking down in her local NDIS office. Seeing how upset she was, the plan was quickly revised to be closer to Ron's previous allocation of funds, but the experience has made Lily very anxious about reviews. Lily says that having a different planner every time they go to an NDIS meeting is really hard, and she often gets upset while having to relay the details of their situation again each year. She wishes she could have the option of seeing the same person each time so that their planner would already understand their circumstances without having to repeat it.

Ron's plan includes funding to pay for his accommodation at the nursing home, access to therapies and core supports. He doesn't have sufficient funding to facilitate a move to another assisted living facility which could meet Ron's needs better, so Lily is trying to have his plan reviewed to allow for this. She is worried about how this review will go after her previous experiences, and isn't sure what she will do if the plan isn't increased before Ron is expelled from his current nursing home.

### **Market factors**

Finding a behaviourist who specialises in complex behaviours has been difficult as there are only a few in the region. The first organisation Lily called were so overcommitted they were no longer taking people for their waiting list. She tried several others and eventually found one that put Ron on their waiting list, but the expected waiting period was at least six months. Although Ron's plan is managed by a plan manager and he has a support coordinator to arrange his supports, Lily says she almost feels like she has a second full time job as she is constantly chasing people up to make sure services are arranged and invoices have been paid. Previously, when Lily wasn't chasing people up as much she found that Ron's funding had been unexpectedly depleted in some areas and unpaid invoices held up equipment purchases, so now she tries to make sure she keeps tabs on what is going on.

Lily isn't entirely satisfied with the quality of supports Ron receives - in particular, she has found that the nursing home often doesn't have activities for Ron to do that are engaging or stimulating. For instance, sometimes she has found that Ron is simply placed in front of a television for several hours which he dislikes. Other services haven't had the required equipment to safely transport Ron from the nursing home to activity centres in the community and have asked Lily to source this equipment herself so that Ron can engage with these services. Lily says she feels like these organisations should already have, or be willing to obtain, necessary equipment if they are going to advertise themselves as capable of meeting complex support needs. Because of the lack of available services which could effectively work with Ron's behavioural issues, Lily doesn't feel like they have choice and control over the supports he accesses.

While Lily is doing her best to utilise Ron's plan and assist him to access the support he needs, she has experienced significant barriers that impact on Ron's utilisation of NDIS funds. Lily is getting tired and isn't sure where to go to get support with the NDIS, and these difficulties are taking a toll on her well-being.

## 7.5 NDIS participants with psychosocial disability

The sample included 26 NDIS participants with psychosocial disability. Most of these participants lived in the Eyre Western (n=8) and Townsville (n=7) sites followed by South Western Sydney (n=6) Brisbane (n=3) and the Barkly region (n=2)<sup>8</sup>.

### 7.5.1 Factors facilitating higher plan utilisation

Respondents in this cohort highlighted five key factors (participant, plan and market) which they considered facilitated plan utilisation.

Four of these factors have previously been identified and discussed in detail in Chapter 4: (1) knowledge and understanding of NDIS processes and local service provision, (2) the personal effort and advocacy of NDIS participants and their families, (3) access to support coordination, and (4) support from disability providers and workers.

One further market factor - access to workers with knowledge and experience of psychosocial disability - was identified by respondents and is discussed below.

#### 7.5.1.1 Access to workers with knowledge and experience of psychosocial disability

For NDIS participants in this group, having a worker (and particularly a support coordinator or support worker) who had good understanding of psychosocial disability was considered important. This allowed respondents access to appropriate supports and to receive quality care.

*Now I found one, [NAME] is fantastic. I've only been with her for a month and a half but she's gotten things done...when I was changing from, see [ORGANISATION 1] don't help people with mental illnesses, they don't understand it, they're only with people with disability. I'm with [ORGANISATION 2] on a program called [PROGRAM NAME] and that supports mental health... I followed [NAME] because she gets things done and in the past I've had many people come on board and things just gone disastrously wrong. So I didn't want to change again so soon so I want to stick with [NAME]...It's only taken four and a half years but I've found someone. P21SWS*

*Yeah they've all been good and they get selected with, if they've dealt with people with... 'cause I also have post-traumatic stress disorder, so they look for workers who have dealt with trauma patients before. P27SWS*

Aligned with this, respondents highlighted the importance of having the “right workers” for people with psychosocial disability. Being allocated a worker who matched the specific preferences and wishes of the NDIS participant was therefore important for this cohort’s satisfaction with the supports provided to them under their NDIS plan. Some respondents described experiencing issues with the workers previously assigned to them by provider organisations, at times contributing to increased psychological distress. As a consequence several of these respondents had hired their own workers to control this process and ensure the correct match and quality.

*I advertised and I interviewed for carers for myself so that way I could make sure that I would get along with them and that they have qualifications. And it worked, I got a few good ones but I also got a few bad ones but everyone does so yeah...I didn't want an agency to send me*

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<sup>8</sup> These numbers included people who identified having psychosocial disability as a secondary condition. The number therefore do not match those presented in chapter 3 which documents primary disability only.

*workers like because I'd been with [ORGANISATION] for so long and I went through so many care workers because we just didn't get along. And they just kept sending the same person, I'm like oh my God, please stop, I was getting stressed. I wasn't looking forward to the day I just didn't like it and I thought I can't do this, I can't have another agency do this to me...and I found that it worked really well for me. P21SWS*

## 7.5.2 Barriers to plan utilisation

Ten participant, plan and market factors were identified by respondents which were considered to act as barriers to plan utilisation for NDIS participants with psychosocial disability.

Many of these factors were also applicable to the broader sample and have been presented in depth in Chapter 5. These were: (1) knowledge and understanding of NDIS processes and local service provision, (2) precedence of non-disability needs, (3) managing appointments, (4) NDIS planning and approval processes, (5) support coordination services, (6) issues with providers and workers, (7) the costing of services, and (8) the interface between the NDIS and mainstream sectors.

Two additional barriers to plan utilisation were identified and are outlined below. These were engagement with services (participant factor) and the availability of appropriate services (market factor).

### 7.5.2.1 Engagement with services

Engagement with services was described as being challenging by some NDIS participants with psychosocial disability. For instance, some participants had to cancel appointments due to 'bad days' and others disengaged from services for long periods of time when their support needs changed and were no longer considered as being met by NDIS supports. In these circumstances, respondents stressed that underutilisation was not a reflection of a lack of support needs, but rather indicated a requirement for increased flexibility of service provision for participants with psychosocial disability. This included providers reducing the amount of notice required to cancel an appointment without being charged or the NDIA taking these circumstances into consideration when making funding decisions in subsequent plans.

*[NAME] was very reluctant to accept people coming to his house because he's just afraid of everything...They'll look at his supports this year and go, "Well [NAME] cancelled ten times. Obviously he doesn't need that much help". Then they'll reduce it. You go "Hang on a minute", they're going to have a bad day...that's something they need to recognise as well. Just because they don't use all the support, it doesn't mean that they don't need it. F&C30TSV*

Not identifying with a psychosocial diagnosis as their primary disability was a further reason respondents gave for not engaging with the supports in their plan. These respondents were not in agreement with the services that had been funded within their NDIS plan and did not perceive these as meeting their true needs. These perceptions then impacted upon their subsequent utilisation of plan funds.

*They brought a person around who said, "Oh, we'll come around and talk with you." And I'm like, "Well, I'm trying to clean the shed up before I have a hernia operation"..."Oh, no, I won't help you with that. I'll come and talk with you, but I won't get my hands dirty doing it." It's like, well, f\*\*\* oath, I don't need you. I'm not going to have you getting money from my thing just because you were here. "Oh, yeah, [NAME] was depressed today," that's his personal opinion. I don't give two s\*\*\* what someone else's opinion is about me. P19EW*

### 7.5.2.2 Availability of appropriate services

A lack of supports and services which were appropriate to meet the needs of NDIS participants with a psychosocial disability was identified as being a significant barrier to plan utilisation for this cohort. This was particularly pronounced in the Eyre Western region where some mental health services were not available locally (such as 24 hour psychiatric care facilities), necessitating lengthy travel and stays away from home in order to access these services. At the time of data collection, NDIS participants with psychosocial disability in some locations within that region were supported by only one provider and due to funding cessation this program was considered likely to end soon leaving them with no suitable local service options.

In other sites, a lack of providers who were qualified to work with clients with psychosocial disability was reported. This had resulted in long waiting times for appropriate services while other services were said to not be offered at all within their region. Within the Townsville region, for example, a lack of child mental health services and adult psychiatric supported accommodation was noted by respondents.

*There's not enough accommodation. There's private organisations but I've been to a lot of them and they are not NDIS ready...I'm still on the waiting list, they've done all these support letters and nothing's getting done. P15TSV*

*There was a massive gap between the age of like 10 and 17. I remember going to there was like an education forum on one of the mental health providers and ...they recognised that there was a big gap in that age bracket for any support for children with mental health problems. F&C30TSV*

Below we provide two composite case studies to show variability in 'typical' outcomes for different groups of NDIS participants with psychosocial disability. The composite case studies illustrate the characteristics of those who typically record 'high plan utilisation' and 'low plan utilisation':

#### **Composite case study 9 – High plan utilisation for NDIS participants with psychosocial disability**

##### **Participant and family details**

Kate is a 46 year old woman who has depression and anxiety. She is single and lives in an inner city apartment with her 19 year old daughter. Although her condition has prevented Kate from working for the past 5 years, she previously worked in an administration role and hopes that she will be able to return to this work in the near future.

She currently accesses a cleaner, support worker and psychologist with the funding in her NDIS plan. Kate's cleaner comes once each week and helps her to stay on top of her household tasks. She also has a support worker who routinely comes twice a week to help Kate with her shopping and to take her on outings such as going to the beach and out to the local café for lunch. Further to this, Kate's support worker is available beyond these regular hours if she needs further assistance with tasks such as attending appointments. Kate also has a psychologist who she sees once a month.

##### **Participant factors**

Kate has a good support network. She has strong relationships with a core group of family and friends. In addition to this, Kate participates in a mental health advocacy group who champion the needs of people with psychosocial disorders within the community. She has a lot of expertise and assistance that she is readily able to draw upon while navigating the NDIS and the supports that she accesses.

This has provided her with knowledge of providers in her local vicinity and who to contact if she needs

questions answered. Her previous work experience also provided Kate with the skills to navigate the NDIS portal and she acknowledges that she is very comfortable looking up her plan and consulting the support budget information when needed.

### **Plan factors**

Prior to applying, Kate was aware that people with psychosocial disorders had more difficulties being accepted into the NDIS. Therefore, when her psychologist recommended that she apply for the Scheme, Kate asked a close friend who works as a disability advocate to help her with the application process and gathering the necessary information. This friend also attended Kate's initial planning meeting with her to provide moral support and help her to advocate for her needs.

Kate receives funding for a support coordinator and was able to find a coordinator who has a history of working with people with psychosocial disorders. The support coordinator, Jill, works closely with Kate to implement her plan. She keeps Kate on track with her supports and services and suggests other supports that Kate might find useful. She reminds Kate of her appointments with any new service providers and also advocates on Kate's behalf during her plan review meetings. Kate finds this invaluable because it is quite overwhelming for her that all of her funding for the upcoming year hinges on a single one-hour conversation with a LAC.

Kate's NDIS funding is plan managed. She is very happy with this arrangement and acknowledges that it is a weight off her chest. She simply forwards any invoices to her plan manager, Paul, and he deals with it. Paul regularly sends her clear accounts of what she has spent and what is left in her budget, and is easily contactable if she needs. Although Kate admits that she does not always read the reports she receives from Paul, when she has needed to check something she has found them useful and because she has them she feels confident she can trust him to take care of her funding.

### **Market factors**

Initially she tried sourcing her support worker through several disability support providers operating in her local area. Kate had a number of difficulties with the workers she was assigned, including one worker who she discovered was stealing from her and several others who were more accustomed to working with the elderly and people with intellectual disability and treated her condescendingly. Eventually Jill, her support coordinator, suggested that Kate try sourcing a support worker herself and so, with the help of both Jill and her daughter, Kate advertised for her own worker. She found a lady who she gets along with, who is available when she needs and has spent many years working with people with anxiety and treats her like a normal person. Kate is extremely happy with how this worked out and very proud of herself for taking a risk and trying something new.

Kate sourced her cleaner through a mainstream cleaning company on the recommendation of a friend. She recalls being happily surprised that, because her funding is plan managed, she could hire any cleaner she liked. Over the years Kate has gradually developed a good relationship with the lady that does her cleaning. This lady has a brother with a mental health condition so she is understanding of Kate's "quirks". Kate feels that having assistance with keeping her house clean and tidy keeps her "on top of things" and that helps her manage her anxiety.

## **Composite case study 10 – Low plan utilisation for NDIS participants with psychosocial disability**

### **Participant and family details**

Jim is a 40 year old male, he is currently homeless and living out of his car. He has a girlfriend but concedes that it is best for their relationship if they do not live together. Although Jim describes his disability either in vague terms or refers to chronic back pain that he experiences, his disability registered with the NDIS is schizophrenia. Jim admits that he often has trouble remembering things

and struggles with interpersonal interactions. He has a history of drug abuse but is adamant that he has been clean for several years.

Jim is not employed at present and financially is reliant upon his Disability Support Pension. The only support that Jim is currently utilising through his NDIS plan is the travel allowance that is directly paid to his account.

Jim's primary concern at present is finding somewhere safe and secure to live. He is not interested in entering a shared accommodation facility as he recognises that he does not get along well with others and therefore has to wait until social housing becomes available. He is working with staff from a local housing organisation to achieve this.

### **Participant factors**

Jim is illiterate and has difficulties with his memory. This impacts his ability to recall details and makes him unreliable with appointments. Being homeless, Jim does not have the facilities to print out appointment letters, he does not own a laptop and he often cannot afford phone credit. As a result Jim often misses meetings with his support coordinator or appointments that have been set up with service providers and he is difficult to contact to remind him about appointments.

Jim also struggles to understand his plan and openly admits that he has no idea what it all means. During his initial meeting he was overwhelmed with information. He cannot read the paperwork that he received and although his girlfriend sometimes reads things for him, she does not understand what the paperwork means either and he does not want to burden her too much with helping him.

Jim is a difficult person to get along with. He often dominates conversations, fixates on unrelated topics and it is hard to keep him on topic. Working with him takes a lot of time and patience, which means that staff often avoid him when he does engage with a service, and he experiences a high turnover of workers.

### **Plan factors**

Although Jim is funded for support coordination, he has not found this particularly useful. He has had 4 or 5 support coordinators since he joined the NDIS two years ago. In his experience, once they have made their initial contact with him he does not hear from them again and it is impossible for him to make contact. He has not had any services arranged for him through most of this time. When the company responsible for support coordination in his region changed last year, Jim discovered that almost all of his funding for plan support coordination had been used despite only having successfully talked with that coordinator once. He was not aware that he was being charged by the minute every time he spoke with the receptionist to try and arrange a meeting with the plan support coordinator. Jim found it very distressing to realise that his funding had been used without his knowledge.

Jim is not happy with the level of funding he is receiving through the NDIS, although this might be because he is not sure what funding he has available and is not currently accessing any services. What he would like is assistance securing housing so that he can move out of his car. Jim would also like to be able to get his sessions with the massage therapist that he uses for his back pain paid for by his NDIS plan. He is frustrated that every time he would like to use his funding he is told that it is not covered by his plan. Jim is also worried because he has heard that if people do not use their funding they lose it. Because of this, he avoids contacting his Local Area Coordinator to discuss his plan and check what types of services and supports he is able to access with his funding.

### **Market factors**

Although Jim is not currently accessing any supports using his NDIS funding, he did initially have a support worker who would spend time with him three mornings each week and a psychologist that

he saw weekly when he first started with the NDIS. This was all arranged for him by his original support coordinator.

However, Jim had difficulties with his support worker. He was not getting along with the man who was assigned to him and, despite requesting a different worker, the service provider continued to send the same person. This caused Jim a lot of stress, especially when the man started acting inappropriately, including offering Jim drugs and bringing his girlfriend along when they went on various outings. In the end, Jim decided that it was not worth the hassle of trying to get a different worker assigned to him and cancelled the service instead. He has not been able to source a new support worker since because he does not know how to do so. This is something that he has been trying to contact his support coordinator about.

Jim has also cancelled the therapy he was receiving through his psychologist because he does not feel that it is something that he needs at this point. However, while he was still seeing the psychologist he felt that it was unfair that he was unable to cancel sessions without incurring a fee. The nature of his condition means that some days he does not feel well enough to attend appointments, especially when his back pain is bad, and this can occur without prior warning. The NDIA requirement of 2-days' notice for cancellation of a service provided a source of frustration for Jim as he commonly either forgot or was not well enough to attend his therapy sessions. This contributed to his decision to stop attending.

## 8. Improving Plan Utilisation

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The interviews explored the perceptions of NDIS participants and their families of potential changes that could be made to improve rates of plan utilisation. Ten factors were identified: (1) enhanced information from the NDIA, (2) improved communication with the NDIA, (3) more appropriate allocation of NDIS funding, (4) greater flexibility of NDIS funding, (5) improved access to disability services, (6) a skilled disability workforce, (7) greater access to support coordination, (8) improved quality of disability services, (9) enhanced collaboration between the NDIS and mainstream sectors, and (10) better recognition and support of the cultural needs of Indigenous participants.

Some of these suggested improvements are difficult to categorise as being solely 'participant', 'plan' or 'market' factors. For example, in order to support the cultural needs of Indigenous participants, respondents recommended that NDIS funding allocation should better recognise these needs (which is a plan factor) and that the development of culturally-appropriate services also needed to occur (a market factor). Likewise, enhanced information provision by the NDIA (which could be considered a plan factor) was an improvement suggested in order to enhance the knowledge and understanding of NDIS participants (a participant factor). As such the improvements to plan utilisation which were raised by respondents are outlined below in order of reported frequency across the five sites but have not been assigned as being 'participant', 'plan' or 'market' factors.

### 8.1 Enhanced information from the NDIA

Many respondents suggested that plan utilisation could be best improved with enhanced information provision from the NDIA. Respondents considered that if they were provided more information, NDIS participants and their families would have greater understanding of both NDIS processes and how to implement their plans.

A need for more information for NDIS participants who were new to the scheme was especially recommended. Greater education was felt to be required around NDIS funding and plans. This included information about the types of supports the NDIS would fund (and not fund), the level of funding an individual may be entitled to and the processes involved in obtaining funding.

*Just if the people's families had more knowledge about what they're entitled to...to help the people. Because I found myself it's a real learning curve and it changes a lot and, and you, and you're not always given that knowledge...It's been a real process to try and work all that out. It wasn't forthcoming from the start and yeah I think if it was forthcoming and people were aware more that would improve the situation. F&C29TSV*

Many respondents expressed uncertainty about the contents of their NDIS plan, especially the meaning of the different funding categories contained within these plans. Clearer explanations of the meaning of these categories and what the funding contained within each category could be used for were therefore requested.

*Why do I have separate buckets? Like why do I have a consumable bucket, why do I have a daily activities bucket, why do I have a social bucket? It would be easy if there was like a brochure like just breaking it down like this funding's used for this particular thing, like you know what I mean? F&C23SWS*

*I would like to know more to be honest. Because she could have money sitting there and it could be, she could be getting things that would improve her quality of life or her, just her daily being...if I was educated a bit more about a better breakdown or if I understood it, if I could*

*get my head around and understand what these little pockets of money are for, if I was more educated about it I think I could be more helpful to [NAME]. F&C13EW*

Respondents also wanted more information to be provided regarding plan implementation, so that they could better understand how to use their plan once NDIS funding had been approved. In order to enhance plan utilisation, respondents desired more comprehensive information about the disability services that were available within the region (including key personnel and contact details) and how to go about accessing and organising funded supports.

*I don't completely understand what's available for me. It would be lovely to be sent a list of things that are available to you and the people with their contact numbers for your area, you know. P15EW*

Other respondents stated that they needed additional assistance when starting to arrange their supports, and the provision of a list of registered disability service providers by the NDIA (which had been the experience of some respondents) was not considered to be sufficient. Instead, these respondents wanted greater direction and specific recommendations as to local service providers who could best meet their individual support needs. This was particularly seen as being important for NDIS participants and their family members who were new to the NDIS and unfamiliar with the local disability services.

*Give me some suggestions, because I don't get out very often, and people giving people suggestions, it's an everyday occurrence...If they give a suggestion, oh, okay, I'd like to try that sort of thing, but they don't. They wait for you and say, "Oh, you're old enough. You're big enough, you can decide your own decisions." How can we if you don't give us any information to feed off? It's like I'm a puppet waiting for my strings to be pulled. P14BRI*

*For a first timer they should have recommended, like instead of us having to go different places...They could in this area recommend you go here or you go over there or you go there and we help you sort it out...Make it easier, you know what I mean. But yeah, they lack that side of things...[It's] jump in the water, bye, see you later....Yeah a bit of help, not to hold my hand but just to guide us. F&C31TSV*

Some respondents also recommended that information be provided about how to check on the levels of funds remaining in a plan. Others suggested a need for regular updates from the NDIA as to the amount of funding that remained in their plan. Respondents felt that this would better enable them to utilise their allocated NDIS funding.

*If I can actually check how much money is left in the funding, it will be easier. Because I may miss something. I'm able to do it but I don't know how to. If I can easily see how much is left in the fund, it will be easier. F&C05BRI*

*You send the parents a monthly statement to tell them where their child's s\*\*\* is up to and you give them at least three to four months' notice that their funds may be running low for their therapies. To maybe adjust some of their therapy times or extend it a little bit so it can last that little bit longer or they might incur some costs, to give them the heads up. F&C16SWS*

In addition, more information and support for NDIS participants and their families who were self-managing their funds was said to be needed, e.g. about using the portal, and setting up service agreements.

*The self-management for [NAME], it's great because I can choose who we want to employ and choose what we want to do...I'm still trying to learn to navigate through doing all that myself*

*too. I guess, something that could have been helpful would be to sit down with someone who would have shown me how to do all that, rather than having to learn it all myself. F&C19BRI*

It was considered vital by respondents, however, that any information provided by the NDIA be presented in a user friendly and accessible format. The provision of clearer information was considered to be necessary in order to avoid confusion and allow accessibility for as many people with disability and their family members as possible.

*I think that some of the language is confusing. You get the plan and it's got, you know core supports and this, that and the other, I just think it's all, it's a little bit, I don't know it could be the language could be dumbed down a bit, you know, it could be actually made to sort of be a little more...Even though I'm actually trained as a social worker I find it a little bit complex to, to decipher the language to actually know what it's supposed to be delivering, you've got all your different buckets. P18EW*

Respondents suggested that information from the NDIA should be provided in a variety of formats in order to better meet the wide range of communication needs of people with disability. The use of simpler language and less jargon, including the provision of Easy Read documents and brochures was recommended. Respondents also recommended the greater use of visual aids (e.g. figures, diagrams and flow charts) and video presentations alongside written text. In order to improve accessibility for those with English as a second language, a need for information to be translated into different languages was highlighted.

*I would go back to the documentation then. A lot of words that don't really clearly convey how the system works. A diagram would be really nice, especially if somebody's brains a bit befuddled. You can actually see that and then you can read through the words and then sort of pull out, understand what's important in that. P06BRI*

*I also would like to see more sort of videos or visuals, visual products like charts or something in different languages...like even the portal should be translatable in different languages. The portal information, the portal summaries. P19SWS*

Many respondents expressed a preference for information from the NDIA to be provided to them face-to-face rather than online or in writing. These respondents felt that the direct provision of information which was tailored to the specific communication needs of the NDIS participant would better aid understanding and thereby support plan utilisation.

*If somebody in the beginning sat down and explained it all to you and thoroughly and said, "okay", it's no good having a 1 hour meeting and trying to, you need to explain [NAME] and her needs and everything in her life to a complete stranger, if you know what you mean? They need somebody involved or understands [NAME] and can suggest things that she could use her NDIS for. F&C32TSV*

It was also acknowledged that for some NDIS participants an in-person format for information provision was required in order for them to fully understand their plan and how to utilise their NDIS funding. This was considered to be especially pertinent for people with certain types of disability (e.g. visual impairment and intellectual disability) or complex support needs. Further groups who were also felt to require face-to-face support to develop their understanding of the NDIS included participants with low literacy skills or English as a second language, as well as those without access, or the necessary skills, to use the internet.

*It is a good system if it's, I think if everyone is informed more and helped more...They really do*

*need more education and be able to explain things easier. Make it easier for people because not everybody is computer wise and some of them don't even have the internet. So it's just so hard. P23BRI*

*When you're talking to our mob, always talk in the standard English and try and break it down to give us better information. P24BAR*

## 8.2 Improved communication with the NDIA

Aligned with a need for enhanced information, respondents also frequently identified that the strengthening of communication channels between the NDIA and NDIS participants could aid plan utilisation. Specific suggestions for the improvement of planning and review meetings were made by respondents. It was felt that the allocation of funding and supports could be improved if the same worker was allocated to an NDIS participant to conduct the initial planning and subsequent review meetings. This would enable better recognition and understanding of the needs of individual NDIS participants and ensure that funds were allocated to meet these needs. As a consequence, respondents suggested that NDIS participants would receive more appropriate levels and types of funding and therefore be more likely to utilise the supports funded within their plans. Further suggested improvements to NDIS planning and the allocation of funding are discussed below in the next section ('More appropriate allocation of NDIS funding').

It was also suggested that more time be allocated to meetings between the NDIA and NDIS participants and their families. This was seen as being especially necessary for people with communication difficulties to allow them adequate opportunity to express their support needs and be provided with information about using their NDIS funds.

*Make it user friendly, so that they can understand the whole process...Sometimes because not all people can understand the process, so to make it more flexible, take time with it, you know, it's not rushed and that. P24BRI*

*Some people who have physical disability also have communication impairments, and sometimes it takes them longer to think about what to say, so when you ask them questions on the spot they may get anxious or get frozen up with their words not coming out at the same time. So the formulation of speech, and the formulation of communication needs to be done in such a way where you're not pressured, where your consent is not taken, and then said, okay, you consenting to this? Yes. The person says yes, you do it automatically thinking the person understood everything. P19SWS*

Respondents further recommended that plan utilisation could be enhanced if there were greater levels of ongoing contact and engagement with the NDIA. It was suggested that NDIS participants should have an allocated worker who kept in regular contact with them in between reviews to monitor if funds were being used and services arranged, or if their support needs changed. Ongoing follow-up was particularly seen as being beneficial when plan funds were not being utilised in order to identify and address the reasons why funding was not being used.

*More communication with us as parents would be really good, just to make sure that we're doing the right thing or we're okay too, you know. F&C03TSV*

*We keep changing workers with them, you know. Every time you go to NDIS they've changed or they've retired or they're gone...I think you should have a worker with you for the two years, or beyond that when you have your next meeting I think because they know all about you. Where when you start again, you've got to go all over it again and all this and that, and I don't*

*think it's fair to us...I don't think there's enough contact. They could ring up once or twice a month or every three months and just say, "Is everything going alright" and things like that; and you don't get that. F&C09SWS*

The need for an allocated worker from the NDIS was especially iterated by respondents living the Eyre Western and Townsville regions, who reported experiencing difficulties contacting the NDIA for information and advice. Rather than having to contact a general helpline and be unsure of who they would be speaking to, these respondents recommended that NDIS participants be given a named contact person who they could approach directly. It was considered that if such consistent contact was maintained, the NDIA would be familiar with their personal circumstances of the NDIS participant and could better assist with queries regarding the development and use of their plans. Several respondents within the Eyre Western site also considered that it would be useful for the NDIA to have a local office where NDIS participants could go directly for assistance.

*I guess it's always going to be an impersonal kind of, what do you call it, bureaucracy, because that's the nature of the beast as a government organisation...It's a bit intimidating, it's a bit daunting, even for someone who talks a lot, to actually [call the] NDIS and say, da-da-da....No, there's no one you can contact. It's very, it's so impersonal that I find that difficult...If we had a local office which I appreciate we don't have the population to justify always, that of course would make things so much easier. At least you could go down there, submit your paperwork or pick up forms. P28EW*

Several respondents within the Townsville site described their current relationship with the NDIA as being "adversarial" in nature. These respondents wished for a more open two-way relationship with the agency with issues dealt with immediately rather than being allowed to escalate.

*They just seem so adversarial, just don't understand what it's like and not willing to understand what it's like...That could all have been avoided when the initial complaint came in, to do a mutual understanding call. It's like, Hi, I've received this complaint. Can I just confirm that the thing that you're complaining about is X, Y, Z? F&C02TSV*

Finally, respondents in the Barkly region highlighted the need for improved on-the-ground communication with NDIS participants and especially people with disability living in remote Aboriginal communities. Enhanced communication was considered to be a way of improving levels of engagement with the NDIA and ensuring that Indigenous participants received appropriate services and utilised their NDIS funding.

*If you go to community those people wouldn't move from their community. You have to send someone who can sit down with you and collect information...They can sit around in a campfire, do cooking, these sort of things where we can talk to the people in our own community and these are the things. It would be better...consult with them personally at their home. F&C05BAR*

*There needs to be a greater amount of emphasis on supporting the Aboriginal families and families in general to understand how the different supports may make a difference in the lives of people living with disability. They need to be able to have the resources available through either advocacy or case management type principles to be able to unpack where the deficits are, where there's an underspend in the person's plan. F&C01BAR*

### **8.3 More appropriate allocation of NDIS funding**

A common area of potential improvement to plan utilisation suggested by respondents related to NDIS

funding. Respondents considered that the allocation of NDIS funding needed to be centred more around the specific needs of each individual participant. When the supports funded in an NDIS participant's plan were felt to reflect their actual support need, respondents felt that higher plan utilisation was more likely to occur.

*I think the NDIS is doing a marvellous job, but there are some things that need to be considered...It needs to be more individualised, [to] people's conditions. It's all very well for them to have certain expectations of basically getting people out into the community, into voluntary work, into working part time and all these type of things. Because the whole purpose of NDIS is to basically to get them off of NDIS as quick as possible and that's the goal. But you see some people's chronic illness is chronic, just as it says and it will never happen...Because sometimes [NAME]'s felt pushed in the sense of a bit anxious about are they expecting this goal or that goal and I'm not meeting those goals. Will the next review...will there be an issue about that. P26TSV*

In order to be provided with appropriate funding and services, respondents suggested that the NDIS be more responsive to individual circumstances, needs and goals. Respondents felt that NDIA staff required more knowledge of disability in order to be better able to understand and identify each participant's specific support needs. These factors were thought to be particularly pertinent when decisions were being made regarding funding for NDIS participants with complex support needs.

*I think it would have to be part of your job description that you actually have some experience in disability...The hospital wouldn't employ Joe Bloggs off the street with no qualifications to...be a nurse in a hospital. So, why would NDIS disability and NDIA hire normal people to look after disability people with disability needs? And that's where I think I would change the whole system, is that every single person that works in the NDIS office, except for administration staff should be 100% have experience and work in and have certificates for, and be qualified for disability. Full on, full start, no questions asked and that's it. That's where I'd change the whole system because then NDIS would, by far, understand the clients' needs and work out and know that every single person is not the same with the same conditions, full stop. F&C13BAR*

*They could have sent me a person who knew what to do. I think maybe they can assess the grade of autism. My boy has level 3, on top of that oral dyspraxia and motor dyspraxia and a global developmental delay, which ages him at one-year old. So, if they get a case like this, maybe they should send me an expert, and then they can have their new people just going to someone who has a lisp or something and needs a bit of speech therapy, or adults who have a long-term disability that just need, they know exactly what they need as the same every year, or something. But in my case, a new case, very extreme issues, and I got a beginner? F&C07SWS*

Aligned with this, respondents proposed that planning and review meetings become more personalised and additional time be allocated for these processes to allow NDIA staff (planners and plan approvers) to fully understand the support needs of an individual.

*I think it should be more, I know it sounds weird because they're supposed to do it but it needs to be individualised...They don't, they're not medical, they don't understand the disability, it's hard because you need someone that understands it. And if you don't understand then how can you fund it? It's just like ticking boxes and then it produces funds...They just need to be more educated and have more training, and be more human. F&C31SWS*

While acknowledging the need for decision-making to take account of individual circumstances, funding decisions were at times said to be inconsistent. Respondents raised perceptions that

sometimes NDIS participants with similar needs received different funding outcomes. Greater consistency was therefore perceived to be required as to the types of supports that were approved in NDIS participant plans.

*[I'd like] more funding...Some support workers say that there's people out there that have so much funding that it's starting to be a joke. So much of it that they don't even use...and I'm like I only get \$25,000 and I can't even go to [ORGANISATION] half the time. P28SWS*

The provision of enhanced levels of funding to NDIS participants was also recommended by some respondents to enable plans to better address the full range of support needs of NDIS participants. This included more funding for advocacy, equipment, transport, respite services, psychosocial disability supports, and services assisting training and employment. Also as will be discussed in more detail below in Section 8.7, respondents also wished for more funding to be allocated to support coordination services.

*But the thing that is missing, but it's not really missing out of the plan because there's no services anyway, is any avenues for respite. Yeah because the plan doesn't include anything for the carer because that's just not, the plan is for [NAME]. P06BAR*

*I think they should improve access to support coordinators...because that's what has helped me and...at least some budget for having extra support workers to help you get into volunteering and work, that might help them more as well. P18TSV*

Describing situations where they felt overwhelmed in supporting their child with a disability as well as maintaining other commitments (e.g. work, family and school), some respondents also highlighted the need for enhanced funding and services for carers under the NDIS.

*I know I'm not going to fix him, but I still need the support and it's so difficult out there. There's nothing, there's no...There's literally zero support for parents with family...So you do struggle alone a lot. F&C06TSV*

Within the Barkly site, some respondents reported that people with disability within the region had broader (non-disability related) needs that would benefit from being better recognised and met. In particular, many NDIS participants were said to be living in challenging socio-economic circumstances and required greater support with basic needs such as housing and finances.

*Nobody really cares about these people and every plan comes from NDIS. The local people don't have their say, because NDIS want to spend the money the way they want. Not according to disability clients to help them out, to listen to their concerns. What they really need. No, they're locked inside the NDIS building...They haven't got any social worker...People who can help people if they have difficulties to find money for emergency relief funds to help people who are disability and it's the same with little children. They need people to help them. F&C05BAR*

## 8.4 Greater flexibility of NDIS funding

Current funding rules and approval processes were considered to be too rigid by some respondents. These respondents therefore recommended that more flexibility be introduced into these processes including the types of supports that the NDIS would fund.

*Number one is if the funding was flexible, more flexible than it is now...They need to be more flexible...Because right now it's very tight. Everything you get done has got to be approved by*

*this and approved by that and if it's not approved it's another thing that's put on the wait list. P31BAR*

An example was provided by a respondent within the Barkly region who wanted to be allowed funding for equipment to maintain his property and enhance his own independence, rather than be funded for someone to come and do the work for him.

*One of them called me up from NDIS to renew my plan...She said well what can we do for you. I said well because the grass around my house was that high and now to me the logical thing is get a whipper snipper and that way I benefit out of it because I can maintain my yard. It gives me therapy and all that physical and mental therapy...But no I can't...I've got to turn around and waste money employing other people to come and do what I can do. That doesn't benefit me...The money is supposed to be for me to help me improve my life. Well to me, yeah as I said hey, that it be taken into serious account when you need something. If I ask for something it's because I need it, not because I just want it...Instead of just lining us all in one basket and dictating to us how we got to run our lives and s\*\*\*. P07BAR*

Respondents also felt that current NDIS funding approval processes were too complex and lengthy. It was therefore suggested that the introduction of more streamlined and faster processes would allow NDIS participants to receive the disability services that they needed in a timelier manner.

*The only thing that I can say is maybe the review process doesn't take so long. As an example, so I took [NAME] in to get her AFOs [splints] assessed. The lady, the therapist there said, "Well, now I've got to send this assessment application to NDIS to get it approved, and it could take up to three, four weeks". So, I guess, is there a streamline approvals process? If the equipment or the kit is already identified and approved in the plan, is there a need to go through another review process, which can take up to a month? I think that's unnecessary. F&C27BRI*

*I lodged lots of complaints to NDIS about how long it was taking and they emailed me back and said that under the legislation there's no timeframe in which they have to carry out the internal reviews. It's like, excuse my language, but what the F. Why not? And if that's still the case, why isn't something being done about that? How can anyone think that's okay that they don't have to have a timeframe? ...If you need something, you need something. You need it now. Not in a year. F&C09TSV*

Some respondents who had had funding requests denied, suggested that the NDIA should provide more comprehensive explanations of the reasons why. It was perceived that this would assist NDIS participants and their families to have better understanding about the types of support which could be funded under the Scheme.

*When I got rejected initially if they give you like a proper response that why it was rejected, you know like the bullet points, like this is the reason you got rejected. So more reasoning is well more appreciated. P15SWS*

The ability for greater flexibility so that funding could be accessed from different plan support categories was also recommended by respondents. It was felt that this would enable NDIS participants to better prioritise the services that they most needed and address changing support needs more easily. Additionally, if an NDIS participant or their plan nominee were unable (or did not feel it was appropriate) to use their funding on allocated services, enhanced flexibility was suggested to allow the funding to be spent on other needed supports and items instead.

*One minute you need something and then a month later you might not need it and...six months*

*into that plan has everything changed and now you've got a different set of circumstances well that can happen and is happening now with us...Can it be made any more flexible than it already is?...People's needs change even in the space of 12 months. Sometimes that can be an awful long time. F&C04SWS*

*I should be able to chop and change where the money goes to. Not dramatically, but like even if I call the NDIA and say look I have run out of money for my psychologist, can I please have some of my core supports transferred over to my psychologist so that I can continue accessing them. If I can do something like that, nice and simply, that would be fantastic, that would be the best thing ever. P21SWS*

The ability to choose from a greater range of providers (including mainstream service providers who were not registered with the NDIS) was also suggested by respondents within the Brisbane site. These respondents felt that this would enhance the choice and control they had over their funded supports and also allow their NDIS funding to stretch further.

*She would love to do more swimming, but it had to come under hydrotherapy. I just feel like the movement of swimming is as good as a physio session for [NAME] because they're getting your arm to move all the way around and all that. So those little things I would love. And you don't want to have to go well I'm going to pay a physio to put her in the water, that becomes very costly. You'd be using a lot of NDIS funds if you did it that way. Whereas if it was just a normal swimming lesson, but it covered it for your child with special needs, that would be great. F&C31BRI*

## **8.5 Improved access to disability services**

Having better access to local disability services was a fifth area of improvement suggested by respondents as having the potential to improve plan utilisation. As described above, the availability of disability services was found to be more limited within regional and remote areas. Therefore, respondents in the Barkly, Eyre Western and Townsville sites were especially vocal about the need to address this issue. An expansion of the supply of local disability services (particularly for those living in very remote areas) was seen by respondents as being necessary if rates of plan utilisation were to be improved.

*Well, being a rural town, I think we need a lot more support and more people to help us people with disabilities who's on NDIS and that needs the help more than anything else. It's the people that struggle more need the help. P10EW*

Within the Barkly region, this expanded supply included more on-the-ground services as well as an enhanced frequency of those services that were provided on a fly-in-fly-out basis.

*More time and more services....[a] speech therapist in here regularly...I would cry of happiness. F&C30BAR*

In order to address current waiting times for services which hampered the receipt of supports, an expansion of the disability sector workforce was seen as being necessary. A pressing need for more allied health professionals, therapy assistants and disability support workers was especially noted.

*Once you've got the money, the lack of services, the lack of variety out there. We need more therapists. We need more speechies, more OTs. The unicorn teeth of therapy assistants [laughing] and are pretty much non-existent. F&C02TSV*

## 8.6 A skilled disability workforce

As described above, in order to address current disability service supply issues, respondents considered it important to increase the size of the disability workforce. However, respondents also recognised that these workers needed to be adequately skilled and experienced. Having access to skilled disability workers who had understanding of disability and experience of providing disability supports was considered by respondents to be an important element of quality service provision. It was also reported that a better skilled workforce would enhance the ability and willingness of NDIS participants to engage with disability services and utilise their NDIS funding.

*Plan Support Coordinator: He had \$8,954 in his plan to address a particular goal – to be involved in activities that increase his mobility including his gross motor skills. We spent none of that because we put an application in to [ORGANISATION] who are an NDIS registered provider to provide physiotherapy, and [NAME] was on the waiting list for over eight months...I'm hoping now that we can actually...find the right people who do the right things. P25EW*

Many respondents also suggested that improvements were needed within the NDIA workforce. In particular, NDIA staff were perceived to need more understanding of disability and the range of funding and supports required by people with disability. This was felt to be necessary in order for the support needs of NDIS participants to be better understood and for the allocation of appropriate levels/types of funding.

*The best people to work at NDIS would be people with children or young adults with special needs because then they'd really sort of understand. I felt like a lot of the time when I was suggesting "Oh could she do this", it was like, "Oh no that's not it, because that's not going to help her" but really it does. The things we were bringing up, wasn't bringing it up for any other reason than to help her. F&C31BRI*

The employment of people with a lived experience of disability (including people with disability themselves) or extensive experience working in the disability sector was recommended by some respondents as a potential way to increase the knowledge base of the NDIA.

*To help me use the funding, it will certainly help to get funding. People who do the assessments or the plans at NDIS need to be qualified, or they need to have some kind of f\*\*\*experience...So I think, yes, NDIS should employ people with disabilities or at least train their planners. P28EW*

*And I truly feel it's a lack of lived experience over there. I've had people doing reviews who are, I'm trying to explain that I need respite and it's been really difficult, and if I could just get a little bit of help around the house and that and the other...When I go to the NDIS office, I never see a disabled person who has an obviously visible disability. Maybe there's somebody there who has a disability, but when you look at the stats for the lack of employment for people with disabilities, golden opportunity, get them into the NDIS, get that lived experience in there...People writing plans need to have lived experience of disability. Then I think we'll start to see a change, and only then. F&C02TSV*

The need for additional training for NDIA staff was also advocated by respondents. As well as assisting better understanding of disability, training was considered to be important in order to address a perceived lack of consistency in the information provided to NDIS participants.

*I think it should be more, I know it sounds weird because they're supposed to do it but it needs to be individualised...They don't, they're not medical, they don't understand the disability, it's*

*hard because you need someone that understands it. And if you don't understand then how can you fund it? It's just like ticking boxes and then it produces funds...They just need to be more educated and have more training, and be more human. F&C31SWS*

Aligned with this, it was also suggested that NDIA staff needed clearer guidelines regarding the types of supports that could be funded. This would ensure greater consistency in both the advice provided about funding to NDIS participants and their families, and decisions that were made about their supports. Some respondents highlighted a particular need for additional training for NDIA call centre staff in order to ensure that the advice provided by these employees was more consistent.

*I think it needs to be a bit more black and white what you can and can't do; there's a lot of grey...You call the call centre and one person will say, yes, sure, you can do that. You literally hang up and dial again, you'll get a different answer; there's no consistency...Probably be the only thing is making it a little bit more black and white with what you can use your money for, having it a bit more streamlined with those questions, and it's got to be consistent. F&C33SWS*

## 8.7 Greater access to support coordination

A further area of improvement raised by respondents (and especially within the Brisbane, Eyre Western and South Western Sydney regions) centred upon better access to funded support coordination services. Many of the respondents interviewed reported that they had benefited greatly from the presence of a support coordinator to assist them in using their allocated NDIS funding and accessing appropriate disability services. It was therefore suggested that the funding of support coordination by the NDIS continue and be more widely offered to the Scheme's participants.

*I think definitely everyone getting a support coordinator. Definitely that one person who you can go to help. Come to my meeting with me. You probably know more. You probably have knowledge than what I have and sit there and break it down. You know lingo, jumbo of NDIS. Break it down for us, you know translate for us. So we know where to go from there. F&C26BRI*

*But I really think that support coordination probably would've helped me a lot because it's a new thing and even if it was just if your appointments to explain the actual content and what the core funding or the core something, what are they?...Yeah so I think that would've been a benefit and I think that would be a benefit to anybody really. At least for their first plan to actually understand it because I had no idea. F&C11SWS*

The need for support coordination to assist with plan utilisation was identified as being particularly important for more vulnerable people with disability who were unable to articulate for themselves, and for NDIS participants with English as a second language.

*I've seen some of my friends have awful things happen in their lives, and just not articulate it well enough in their NDIS meetings, and as a consequence, get plans that don't allow them to go to work, because there's not enough money in that plan for their person with a disability to be cared for if they're out of the home. So it's pretty big impacts on people's lives. So support coordination has to be in every plan; it just should be a foregone conclusion...They need to bridge that gap at the moment, as I said, plans fall off the radar and no one rings you unless you chase it up. F&C26EW*

## 8.8 Improved quality of disability services

The quality of disability service provision was a further area of improvement which was recommended by respondents (and especially those in the Barkly, Brisbane and Townsville regions). As discussed

above, concerns had been raised by respondents that some disability providers were not offering a quality service and were perceived to care more about profits than supporting people with disability. A need for providers to have a good understanding of disability and be experienced at working with people with disability was therefore seen as being necessary. Respondents also felt that providers should be more accountable and prioritise the care that was provided to their clients.

*To be honest, with most providers I feel like they could be doing a lot better...for what they get paid, and that's an all-round thing with everyone...I wish they would actually just do what they're meant to do properly the first time and put a bit of effort in instead of just taking the money and doing the minimum. F&C09TSV*

*I hate to say it but everybody that I'm engaged with if I don't pay attention things drop off. Sometimes that's because of a service not doing what they say they're going to do. There's still not enough accountability. There's a manager in Darwin supporting coordinator of support here and they are both anti me, anti-advocacy. All I'm trying to do is do what they're trying to do, get that person the best life possible, they're not prepared to work, it's become a fight. F&C01BAR*

Greater oversight was felt to be needed by some respondents to ensure that disability organisations were providing quality supports to NDIS participants and their families. In particular, it was suggested that enhanced regulation and monitoring be introduced, as well as more transparency regarding costings and operational activities.

*There needs to be somebody checking up on the companies. All the companies, like [ORGANISATION] is a really good example of service providers not doing their job. Not only not doing their job but abusing their job...They are abusing the clients who have disabilities and the support workers that have disabilities. They are just abusing them and grabbing the money. These companies are set up to grab quick money. Reap in the money. This is the cash cow for them. And that's how they're seeing it and they don't care about the people...There needs to be intervention. Somebody checking on them to make sure they're doing the job. And not just checking on them and taking their word for it, but talking to their clients and seeing how are things going? That's what needs to happen. F&C10BRI*

*You're dealing with very vulnerable people and you're making them learn the lessons of the free market. But it's like incumbent on you to try and navigate this free market. I think there should be a lot more regulation...I think the whole system needs to be overhauled. P18BRI*

## **8.9 Enhanced collaboration between the NDIS and mainstream sectors**

Greater collaboration between the NDIS and mainstream sectors was a further area of improvement which was suggested by respondents (and particularly those living in the Barkly, Brisbane and Townsville regions). This was considered necessary in order for the support needs of people with disability to be more appropriately resourced and met. A need for enhanced cooperation across the disability, health and education sectors was particularly noted by respondents.

*I don't know what's holding the school back from some kind of engagement with the NDIA to say...what can the department of education and the NDIA do together to focus on this school and who knows what could come of that conversation as well but I'm not aware that that has happened and so there's a malaise... So I think that suggests to me that the interfacing agency work that the NDIA bangs on about is, they're thin threads, really thin threads, not good*

*enough. F&C04BAR*

Some respondents were concerned about the siloing of resources within the NDIS and mainstream sectors. In order to address this issue, a more holistic approach to the funding and provision of supports for people with disability (and especially school-aged children) was suggested.

*Education isn't covered under NDIS. And as far as I'm concerned it should all be one because this person's disability doesn't stop when they leave home. The disability is, you know, 24 hours a day seven days a week, it should all be under the one thing...This whole NDIS needs to be the whole system...because somebody would be supported if they were going to work but because it's a child they go to school, oh sorry that's the Education Department's problem or you as a parent's problem. F&C29BRI*

## **8.10 Better recognition and support of the cultural needs of Indigenous participants**

A final area of improvement centred on the need for the NDIA and disability services to better recognise and support the cultural needs of Indigenous participants. This improvement was suggested by respondents in the Barkly region and included the identification and funding of appropriate supports and services for Indigenous people with disability. As such, it was felt that the model used by the NDIA may need to be adapted to better fit the remote Barkly location.

*I think with the remote and very remote communities, they need to take a very bespoke position and work within market teams to be able to address the specific needs of the specific communities...I do think that the agency could reframe culture and how they respond to culture within a person's plan, and therefore they may set the example about what is possible. F&C01BAR*

Respondents within the Barkly site also suggested a pressing need for the development of more culturally responsive services in the region. In order to achieve this goal, the employment of greater numbers of Indigenous workers within the disability sector was also felt to be needed. The hiring of local Indigenous people was perceived by respondents as assisting services to better engage and support NDIS participants from Indigenous backgrounds.

*For me, it's some of the ILC funding could be diverted to creating spaces where Indigenous people could go and have some respite in a beautiful setting doing cultural activities and that be paid for and that would be culturally responsive. It would fill a gap in the market...But they need to start to rethink about how they use current infrastructure or develop new infrastructure to be able to deliver some services to people out there. F&C01BAR*

The provision of more on-the-ground services was also considered important in enabling Aboriginal people with disability to both have their support needs met and to remain living in their own communities.

*We're asking for people who got aged care and disability should be based in their own communities. You bring someone from his homeland where she want to stay with her people, you're bringing her or him to a place where that person won't fit into this environment here. Because they know their environment from where they come from. F&C05BAR*

## 9. Limitations, Policy Relevance and Areas for Future Research

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This research has shown that there are a number of factors facilitating the ability of NDIS participants to access the funding and supports provided for in their NDIS plans.

These include factors pertaining to NDIS participants and their family members:

- Knowledge and understanding of NDIS processes and local service provision, and
- Personal effort and advocacy.

A factor relating to NDIS planning:

- Access to funded support coordination services

Factors associated with the disability sector market:

- Support from disability provider organisations and workers, and
- Access to disability services.

The most common factors reported by respondents in all five sites as aiding plan utilisation were – access to support coordination (plan factor), support from disability provider organisations and workers (market factor), and having knowledge and understanding of NDIS processes and service provision (participant factor). Hence higher plan utilisation was considered to be supported by a combination of participant, market and plan factors.

The research has also uncovered twelve factors that negatively impacted NDIS participant's ability to utilise the funding and supports provided for in their NDIS plan. These barriers included five participant, three plan and four market factors.

Factors pertaining to NDIS participants and their family members which were felt to act as a barrier to plan utilisation included:

- Knowledge and understanding of NDIS processes and local service provision
- Precedence of non-disability needs
- Managing appointments
- Reluctance to accept disability services, and
- The use of technology.

Factors relating to NDIS planning and processes which were identified as impeding successful plan utilisation included:

- NDIS planning and approval processes
- Support coordination services, and

- Use of the NDIS portal.

Factors associated with the disability sector market which were considered to negatively impact upon plan utilisation included:

- Availability of disability supports and services
- Provider organisations and the disability workforce
- Cost of disability services, and
- The interface between the NDIS and mainstream sectors.

The most common factors reported by respondents in all five sites as hindering plan utilisation were the availability of disability supports and services; issues with provider organisations and the disability workforce; knowledge and understanding of NDIS processes and local service provision; and NDIS planning and approval processes. Again we see the barriers to plan utilisation were considered to be influenced by a combination of participant, market and plan factors. In addition to those listed above, further factors which facilitate and hinder plan utilisation for particular cohorts were also uncovered and discussed.

## 9.1 Limitations

The findings arising from this research project are not without their limitations. Below we outline four main limitations of the research. These should be borne in mind when reading and using the findings to inform future policy interventions. These limitation also highlight areas for future research.

### 9.1.1 Generalisability of qualitative findings

Given that these findings arise from in-depth qualitative research, they are subject to limited statistical generalisability to broader population groups or other geographic locations. The strength of the qualitative research methodology is that findings are derived from deep and wide coverage of the views, circumstances, expectations and opinions of NDIS participants and their family members or carers. However, the qualitative findings presented in this report are not intended to be interpreted in the form of statistical statements of how frequently perceptions and issues were raised. Readers should note that, like other findings from in-depth qualitative interviews, the views of respondents that are included in this report are respondents' perceptions. The accuracy of statements made by respondents has not been independently verified because the primary objective of these in-depth interviews was to gain an understanding of respondents' perceptions.

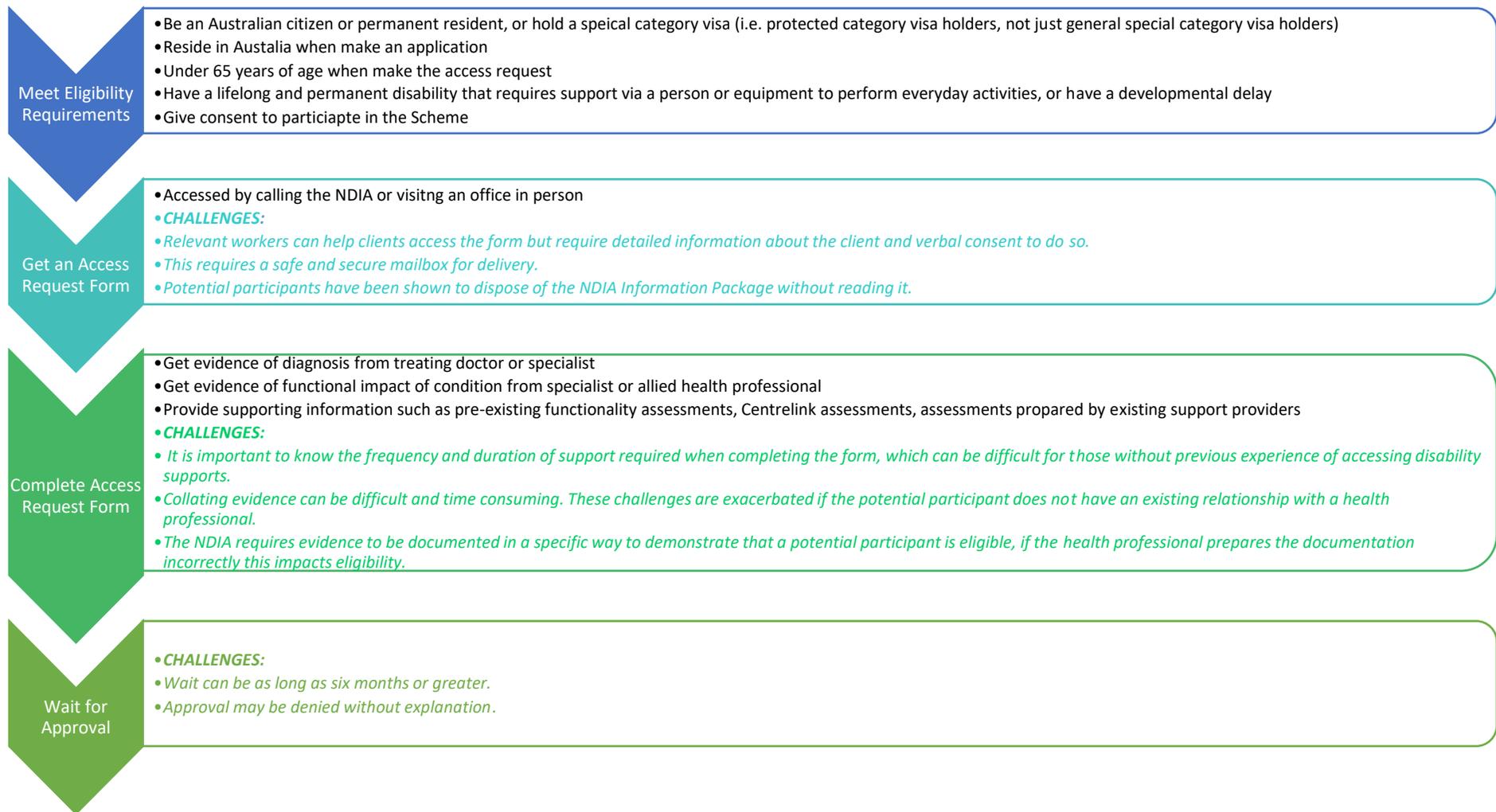
### 9.1.2 Utilisation only from the point of time of acquiring a plan

This research has only considered the factors that facilitate and hinder plan utilisation from the point in time that an NDIS participant is granted a plan. As can be seen from Figure 9.1 there are many steps in the NDIS journey which occur prior to a person with disability obtaining a plan and being allocated its funding<sup>9</sup>. The research suggests that people with disability may experience many challenges and hurdles at any of these stages, which may impact their capacity to obtain a plan and the type of plan they may be able to obtain in order to gain funded access to the services they need.

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<sup>9</sup> See Section 24 of the National Disability Insurance Scheme Act for further detail.

**Figure 9.1 Access to the NDIS**



### **9.1.3 Utilisation also has longer-term impacts that are not considered in this research**

One of the core principles of the NDIS design is the objective to generate longer-term benefits for the lives of people with disabilities. In many instances this objective is as important as it is hard to measure and assess for a scheme that is as young as the NDIS.

This is not a problem particular to the NDIS, as it applies to all major policies that can be reasonably expected to generate longer-term positive impacts. There are many such impacts in the horizon which will need to be put in the list for future research. A good, albeit earlier, number of such potential longer-term impacts were traced by the NDIS Trial evaluation's quantitative panel survey of participants and their families and carers in 2013-2017 where the objective of increased social participation was found to be clearly emerging after a couple of years in the NDIS as a new aspiration and outcome. The slightly more long-term objective of increased educational participation was found to be increased as an aspiration but an increase could not be traced as an outcome. Finally, the clearly longer-term objective of securing future employment was neither traced as an aspiration nor as an outcome. Critically however for the present discussion is that the qualitative impact evaluation research identified the positive role of actual increased social participation in enhancing education participation aspirations and the longer-term relationship of social and education participation with employment aspirations for some respondents.

There are also macro-improvements that can be expected by the implementation of the NDIS in terms of the employment of family members and carers, the improvement of disability specific training and the positive macroeconomic impacts of this new emerging major care sector. The list of such improvements that could be impacted on by improving plan utilisation is long enough to suggest the benefits of further research on the long-term impacts of the drivers of plan utilisation.

The NDIS is still a young scheme that is developing its strengths and its impacts. It must be recognised that it will take a long time for some of its impacts to be traced through formal statistical analyses. Such analyses will be at their most useful if they are anticipated by the early collection of relevant data. The shape of such a data collection ought to be informed by relevant qualitative research today, in order to have the needed data tomorrow. The importance of collecting the opinions of NDIS participants, providers and other stakeholders through qualitative methodologies, is that in-depth qualitative methodologies are the only credible and reliable anticipatory assessment tool of potentially important long-term effects of the scheme. This, of course, applies to plan utilisation with the urgency the views of NDIS participants in this research indicate.

### **9.1.4 Limited information about the supply side of the NDIS**

In order to understand plan utilisation from the point of view of NDIS participants and their families we focussed on how the demand side perceived current demand/supply imbalances. Namely, we obtained views about barriers/facilitators of accessing the supports included in NDIS plans as these were perceived by those demanding the services and noted the imbalances between what participants demanded and what providers supplied. In describing these current imbalances we did dwell directly or indirectly on how providers of these services perceive these reported imbalances. The research presented here is, thus, only part of the broader narrative and considerably more efforts have to be made in the direction of understanding the point of view of providers.

Equally important is the position of the NDIA as the arbiter and supervisor of the NDIS provisions. Understanding the NDIA's role in interpreting the law, setting the rules and implementing them to achieve the best possible outcomes is also critical in the understanding of where and how demand

and supply imbalances may emerge and how and why they may be temporary or long-lasting. In order to develop a complete view of utilisation imbalances, research needs to build a 360 degree picture which is informed by the views of providers, consumers and the NDIA alike.

The research has uncovered many factors which restrict NDIS participant's ability to access funds and supports provided for in their plans. These include 'participant' and 'plan' factors such as having insufficient knowledge and understanding of NDIS planning and plan utilisation; difficulties with NDIS processes and funding approvals which result in funding requests being denied and delays in the approval of funding; and the precedence of other non-disability needs (such as work commitments and family responsibilities) which impact upon the respondent's ability to access and utilise supports funded by the NDIS. But they also include many market factors such as issues with provider organisations and staff (i.e. consistency, reliability and quality service provision); availability of local disability services and supports (and especially allied health services); and the quality of, and access to, support coordination.

Without collecting information and looking at the supply side of the disability services market, the research cannot uncover fully what causes the market imbalances that NDIS participants subsequently report to be reducing their ability to access needed services and supports. For example, our research found that one of the primary factors reducing the ability of NDIS participants to utilise supports provided for in their plan is the limited availability of disability service providers, particularly so in regional and remote areas. However, our research cannot establish what is behind these "thin markets", and the factors that contribute to providers being unable to meet the demand they are presented with by NDIS participants in a timely manner.

We note that what NDIS participants may experience as a factor restricting their ability to access supports included in their plans (say lack of services or long wait lists), may be experienced very differently by providers who are, in all likelihood, striving to provide these supports. For instance, providers may be experiencing problems with the recruitment and retention of staff with suitable skills. They may be experiencing an inability to train. They may also be unaware of funding possibilities that could be included in the plans of NDIS participants, which would help meet otherwise unmet levels of demand. There is a large list of possibilities that could help explain why the scope and the scale of provision may not be responding to unmet demand for services and supports.

Including the particular perspectives of providers and the NDIA into the research frame would enable an understanding of these supply aspects which impact upon a person's ability to access funding in their NDIS plan. This will allow for a more complete understanding of the drivers of plan utilisation.

Any policy recommendations provided to improve plan utilisation for NDIS participants need to account for both the demand and supply side of the market, as there may be issues experienced by providers which if identified and fixed could translate to improved access to services and support by NDIS participants.

## **9.2 Policy relevance and areas for future research**

The research shows that there are numerous areas which could potentially be the focus of future policy inventions to improve plan utilisation.

### **9.2.1 Participant factors**

With the exception of 'knowledge and understanding of NDIS processes and local service provision', which can in part be addressed with consideration by the NDIA as to how information is provided to

participants and which are the most appropriate channels of communication, the participant factors that were found to hinder plan utilisation are largely individual, personal factors and depend on an array of socio-demographic characteristics and circumstances. While limited in terms of the focus of policy interventions, these participant factors are useful for understanding how to target policies most effectively. For instance, the research findings highlight the characteristics of those NDIS participants who are likely to have more difficulties in accessing the services and supports provided for in their NDIS plan. The research therefore provides clues to policy makers as to whom they need to target their policy intervention, and who may need additional support in navigating the complexities of the NDIS system.

### **9.2.2 NDIS/plan factors**

Challenges experienced by respondents with NDIS planning and approval processes, including processes being too complex and time consuming; lack of clarity, consistency and transparency as to how funding decisions are made; and a lack of timeliness around approvals and allocation of funding are barriers to plan utilisation that are amenable to policy intervention. Overcoming these barriers would assist NDIS participants better navigate the complexities of the system.

In addition, ensuring the provision and adequate funding of support coordination in NDIS plans, for as long as NDIS participants feel that they need it, is another area that could be the focus of policy attention. However, the problems encountered with the quality of support coordination suggests that further research is needed.

### **9.2.3 Market factors**

The availability of disability supports and services was a key barrier identified as impeding plan utilisation in all five research sites. In addition, issues experienced with disability provider organisations and workers including the quality of service provision, the organising of services, staffing arrangements, and payment issues resulted in many NDIS participants experiencing problems in accessing services and supports. Concerns about the prices charged for disability services and the interface between mainstream and NDIS sectors were other factors which impeded NDIS participants' ability to fully utilise their plans.

These market based barriers to plan utilisation suggest that systemic problems exist in the supply of disability supports in Australia, particularly the supply of allied health services (e.g. speech therapy, occupational therapy and psychology) and in regional and remote areas. They point to questions regarding quality and issues pertaining to the training, skills and competencies of the workforce. They also raise important issues around the regulation of costs and the siloing of services and sectors.

### **9.2.4 Workforces**

Australian studies suggest that rural and remote provision can present employers with severe skill and labour shortages that can even lead to cessation of commercial activity (Healy et al. 2015). Like with other sectors where the workforce is required to be highly specialised, the capacity of disability supports providers to widen the scope of and scale up their provisions could depend critically on their workforces. Issues of skill shortages and their impact on the disability care sector were explored in previous research which can be a useful reference (Mavromaras et al 2018). Further, the NDIS Trial evaluation (2013-2017) identified labour and skills shortages to have impacted the NDIA roll out during its early years, including several professions being in shortage. The question for today would be whether these shortages were resolved through the broader rollout or not (Mavromaras et al 2018), or whether they can be a contributing driver for the observed low levels of plan utilisation.

### 9.2.5 Dependency vs independency

An objective of the NDIS is to create independence for NDIS participants and to support their social and economic participation. While an assessment of the scheme's intent was not the aim of this research, our findings show that the NDIS is perceived as complex and burdensome to navigate, even for those with the time, knowledge, energy and skills to devote towards doing so. Furthermore, due to the ongoing evolution of the scheme, this complexity is hard to learn to live with and overcome, as processes and rules are continually evolving and changing. This complexity means that many rely on the more formal and standardised support mechanisms such as plan support coordination and plan management to help navigate the scheme. Further research is needed to understand whether the reliance on such formal supports is creating dependencies which may go against the intent of the scheme to provide truly personalised support to people with disability.

# 10. References

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# 11. Interview Topic Guides

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## 1. You, your disability and how it affects your life

*Example questions:*

- 1.1. Can you tell me a about yourself and how you spend your time? (*Probes: age, marital status, children, ATSI/CALD, living arrangements, what do you do in a usual day: education, work and community involvement*)
- 1.2. Could you tell me a little about your disability and how it affects your day-to-day life? (*Probes: type of condition, how condition was acquired etc., carer arrangements*)

## 2. Your NDIS plan and how you feel it addresses your support needs

*Example questions:*

- 2.1. Can you tell me about your NDIS plan? (*Probes: How long have you had a plan? How did you find the process of getting a plan? Have you had any reviews and changes to your plan? Has that been beneficial or detrimental? Did you continue to use your plan while it was being reviewed? Who manages your plan- self or contracted? Have you used more or less of your plan as time has gone on? Why? How?*)
- 2.2. How would you compare your current plan to your previous plan (if you have had one) (*Probes: Has the amount in your plan changed? How much? Have you been given funding for different things in different plans (e.g. therapy, equipment, support to be in the community) Did you try to improve current plan, if so in what ways? Why? What was the role of planners and service providers in improving subsequent plan*)

*In current plan....*

- 2.3. What supports/services are you funded for? (*Probes: what would you like to be able to do with the help of the supports in your plan? What is important to you?*)
- 2.4. How well do you feel that the plan addressed your support needs? (*Probes: Does it reflect your goals and aspirations? Does it reflect your support needs? Do you think anything was missing from your plan?*)
- 2.5. Do you feel that you had enough information and knowledge after your plan was approved to implement it? (*Probes: understanding about 'the next step', information from planner, availability of support to implement plan*)

### 3. How you use your NDIS funding: What supports you are accessing and how well they fit your needs

Example questions:

- 3.1. What supports are you currently receiving through the NDIS? *(Probes: personal care and everyday living, case management, participation in community/social/physical activities, support with transport, therapies and medication, respite, aids and equipment, help at work or with study etc., impact of COVID-19)*
- 3.2. How did you go about implementing your plan and putting these supports in place? *(Probes: identifying potential providers, choosing a support/provider, balancing different supports in a funding category, contacting providers and arranging supports, assistance with this process- either formal or informal)*
- 3.3. Are you using all of the supports that you are funded for in your NDIS plan? If not, why not? Is this due to COVID-19 restrictions? If yes, have you been flexible in using funding from one support category to fund other supports needed?
- 3.4. Are there any supports that you find are easier to access? *(Probes: Is it easier to identify, choose and link in with a certain type of service or service provider? What makes them easier to access? Use of case management services. Are there supports that are easier to access while COVID-19 restrictions are/were in place?)*
- 3.5. Is there anything that has helped you to implement your supports *(Probes: navigating the system- case management services, support coordination funding, informal networks, assistance from friends & family; identifying potential providers; engaging the services of a provider; organising service delivery, e.g. logistics, scheduling; during COVID-19 restrictions)*
- 3.6. How do you feel about the supports you have in place – are they right for you and the people that care for you? Why/why not? *(Probes: type of support and fit with goals & aspirations, fit with provider; has this changed with COVID-19)*
- 3.7. What is the quality of the disability services/supports you receive? *(Probes: have any of your supports and services exceeded your expectations? If so, why? Have you experienced any difficulties with any of the supports you have been receiving? What did you do about it, and were you satisfied with the outcome? Why/why not?; changes during COVID-19 restrictions)*

#### **4. How you use your NDIS funding: What supports you are not accessing and barriers to using the supports/services in your plan**

*Example questions:*

- 4.1. Have you had any difficulties or problems with your plan being put into action? (*Probes: whether resources are sufficient, do you use a case manager/plan manager? Do you have sufficient knowledge/awareness of the system & processes?; impact of COVID-19*) What did you or others do about it, and were you satisfied with the outcome? (*Why/why not?*)
- 4.2. Are there any supports that you are funded for that you have been unable to access? Why? (*Probes: availability of supports, ability to link in with supports, already spent or committed the funding to another service; Has this had any impact on plan review and/or future funding? Is this a concern for participants?; impact of COVID-19 restrictions*)
- 4.3. Are there any supports that you are funded for but have chosen not to access? If so, what supports and why? (*Probes: concerns about the quality of the service/support, concerns about the provider including their cultural appropriateness, service/support does not match funding needs, plan has more funding than what is needed, whether they seek to preserve some funding to use for respite caring purposes or to ensure some reserves for other reasons? Concerns about COVID 19*)
- 4.4. Are you receiving any supports not funded by the NDIS? If yes, what types of supports are these and why are you accessing them this way? (*Probes: number of supports, and frequency of receipt of supports, not enough funds in plan, preference for these supports to be provided informally; difficulties accessing NDIS supports due to COVID-19 restrictions*) How are these supports funded? (*Probes: pay out of own pocket, relying on family and friends or charity*)

#### **5. Summary**

- 5.1. What have you found most helpful in being able to access the supports and services that you are funded for?
- 5.2. What are the biggest barriers for you in accessing the supports and services that you are funded for?
- 5.3. Can you think of anything that could be done to improve how you use the funding in your NDIS plan and your ability to access supports?

**Any other questions? Thank respondent and close**