Choice, control and the NDIS

Service users' perspectives on having choice and control in the new National Disability Insurance Scheme

Choice, control and the NDIS

Service users' perspectives on having choice and control in the new National Disability Insurance Scheme

A community report prepared by:

Deborah Warr
Sue Olney
Amber Karanikolas
Georgia Katsikis
Dave Peters
Michelle Wilcox
Helen Dickinson
Jen Hargrave
Vasiliky Kasidis
Jasmine Ozge
Jacinta Wheeler

Suggested citation: Warr, D, Dickinson, H, Olney, S, et. al. (2017) *Choice, Control and the NDIS*, Melbourne: University of Melbourne

ISBN 978 0 9942709 5 5

First printed May 2017

An electronic version of this document can be obtained from
www.socialequity.unimelb.edu.au
social-equity@unimelb.edu.au

Table of Contents

Acknowledgements

We thank the research participants who talked with us about their experiences of using services and support under the NDIS and acknowledge their significant contribution to this study. We also thank the individuals and organisations in the research sites who provided advice and in-kind support for this study and circulated our call for expressions of interest in participating in the research to prospective research participants.

We thank Professor Bernadette McSherry, Charlene Hue-Ming Edwards, Kathleen Patterson and Claire Smiddy from the Melbourne Social Equity Institute for their support and assistance throughout the project.

Thank you to Owen Cooper, who joined our team as a community researcher and provided valuable input in training sessions before withdrawing from the project because of ill health. We wish him well.

We also thank the many people we met or corresponded with over the course of this project who expressed interest in this research and in our participatory research approach. They included people with disabilities, carers, disability service providers, advocates, bureaucrats and academics.

We acknowledge the traditional owners of the lands on which this research was conducted and pay our respects to their elders past and present.

This research project was funded by the Melbourne Social Equity Institute at the University of Melbourne.

Executive Summary

The National Disability Insurance Scheme (NDIS) is the most significant reform of disability services in Australia in a generation. It aims to increase both the funding available for disability services, and the control that people living with disabilities have over the design and delivery of their care. The experiences of service users in the trial sites offer helpful insights into how these objectives are being achieved. This report discusses a study that explores these experiences among people living with disabilities, and family members providing care and support to people with disabilities, in the Barwon trial site. The findings of the study are important because people living with disabilities continue to struggle to have their voices heard in national and local debates focusing on the implementation of the NDIS.

We used a participatory approach to conduct the research. The research team included university-based researchers with expertise in social research, policy research and analysis and participatory methodologies, and community-based researchers living with disability who brought a broad range of work and life experience to their research roles. We conducted a total of 42 interviews for the study, with people with disabilities in the NDIS (n=26), and parents or adult children caring for people with disabilities in the NDIS (n=16). Our findings shed light on the progress of the NDIS towards giving people with disabilities *more choice and control* over their care; making the funding and organising of disability services *less complex and more efficient*; and promoting *equity of access* to services and support.

Our findings are discussed in this report, supplemented by a visual summary of the findings created during a forum attended by service users, service providers and carers. Key issues that emerged in the study were:

Choice and control:

- Participants' expectations and experiences of the NDIS appeared to be strongly influenced by their circumstances. Parents of young children tended to have high expectations and be strongly motivated to obtain comprehensive packages of services and support. Parents of adult children were more likely to note little difference in levels of support for their children since transitioning to the NDIS but significant increases in administrative requirements and hurdles. People living with cognitive disabilities tended to report few changes in their everyday situations, while people living with physical disabilities had a range of views, from positive changes

associated with increased independence to deep frustration with ongoing struggles to gain access to crucial resources.

- Services and resources to help people to exercise choice and control over their care were not available across the board. Many participants relied on supportive carers, family and advocates to navigate the system. It is important to acknowledge constraints to people with disabilities exercising choice and to recognise the implications of this in a client-driven system, including how it fits with other values that promote the safety, wellbeing, respect and dignity of people living with disability. There are also implications around the capacity of service providers to be flexible and innovative in meeting the needs of service users.

- In some cases, especially in regional areas or where people had specific needs that could not be met by local service providers, service users had limited choice over what was available for them to purchase with their funding package. A significant portion of their funding was being consumed by services travelling to them, or them travelling to access services. Where their preferred options were unavailable, they risked losing funding altogether because not purchasing services, equipment and support set out in plans was taken by planners as evidence that these supports were unnecessary.

- Our findings also revealed that if a participant's health and wellbeing fluctuates over the life of their plan, as is common among people with both physical and psychosocial disabilities, there was no scope for them to have a 'contingency plan' to purchase services, equipment and support on an ad hoc basis.

Complexity and efficiency:

- Most of the participants accepted that the NDIS is a complex system. Many expressed concerns, however, that the views of people with disabilities, their families and carers were often overlooked in planning processes, that communication processes and messages in the NDIS were inconsistent, and that some people with disabilities were disadvantaged because they could not fully understand the system, its costs and its administrative requirements. Many described challenges accessing and understanding the huge volume of information surrounding the NDIS.

The scheme's funding structure and processes for identifying individuals' needs are complex and, to some extent, an inevitable aspect of pub-

lic accountability. However, there is potential to simplify administrative systems, clarify aims and objectives of the scheme and promote consistency in decision-making when allocating resources. In many cases described in this study, gains under the scheme were undermined, or difficulties compounded, by red tape.

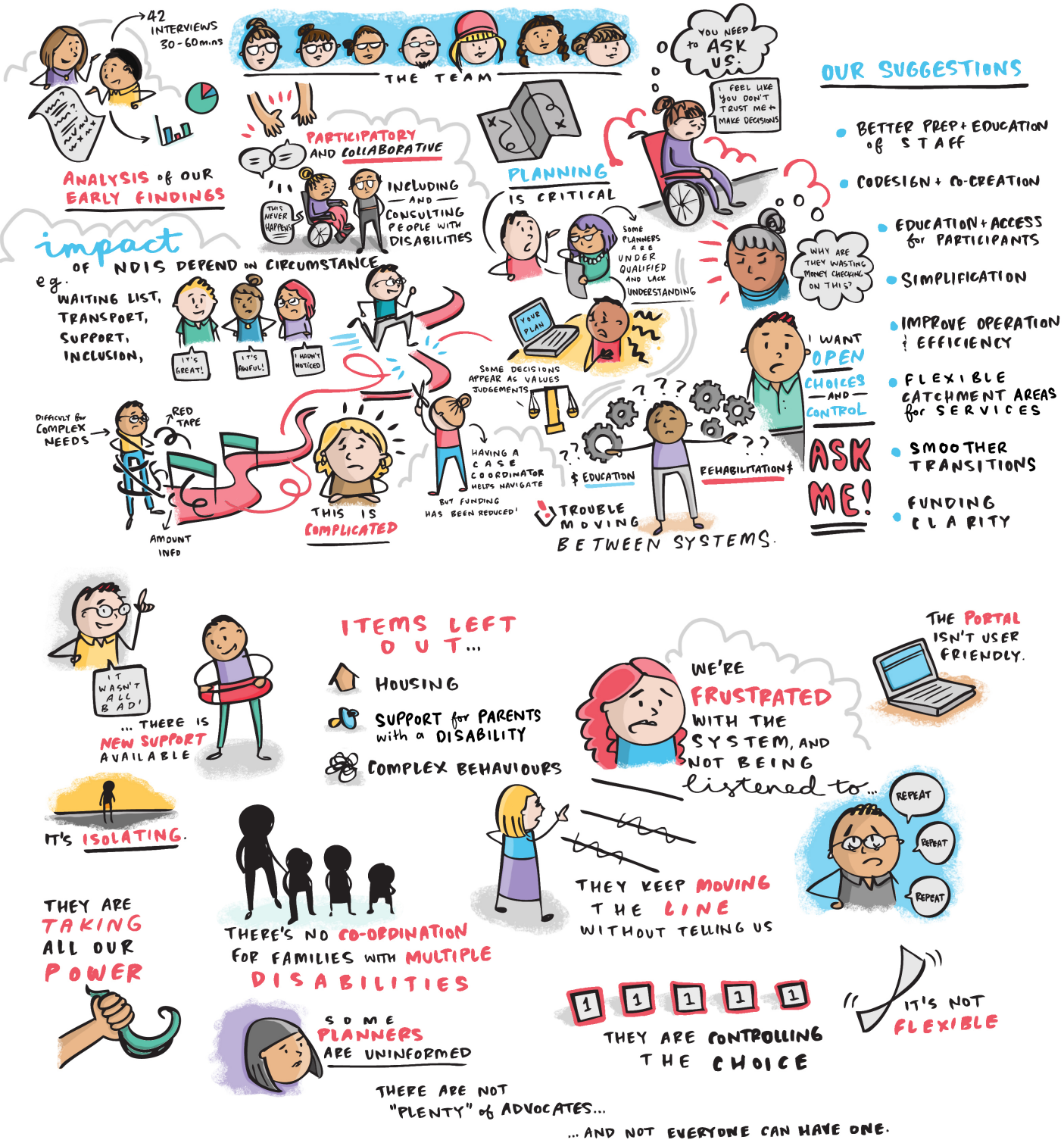
- Administrative issues appeared to be compounded by staffing issues, including staff shortages, high turnover of staff and staff working as planners with limited experience of working in the disability sector.

- There appears to be potential for efficiency gains in approving expenses under a certain amount when service users identify and seek approval for basic services and equipment to meet their needs. Many participants discussed using up funds and substantial amounts of time in gaining approval for inexpensive items and other services that are clearly warranted.

Equity:

- The implications of issues noted above suggest that insufficient attention is being paid to promoting equity of outcomes among service users with diverse needs and circumstances. Factors that are well-recognised in driving inequality – household income, education, residential location and household structure – remain critical in filtering opportunities and capacities for service users and their carers to have choice and control in accessing services and resources under the NDIS.

CHOICE, CONTROL AND THE NDIS



Background and research aims

Introduction

The NDIS is the most significant reform of disability services in Australia in a generation. The scheme aims to increase both the funding available for disability services and the control that people living with disabilities have over the design and delivery of their care. Given the scheme's promise to '*support a better life for hundreds of thousands of Australians with a significant and permanent disability and their families and carers*'[1], it is important to understand the degree to which its objectives and principles are being achieved in practice from the perspectives of service users.

To gain insights into how this ambitious initiative is proceeding, it is important to listen to the views and experiences of people using the NDIS. We therefore conducted conversational interviews in one of the NDIS trial sites with people living with a range of disabilities and/or members of their families, to learn about how they were navigating the NDIS. These conversations offer insights into the changes people are experiencing, and the challenges that they are encountering in exercising choice and control over their care.

1 NDIS 2017a https://www.ndis.gov.au/about-us.html

Explaining the NDIS

The NDIS is based on an actuarial insurance model. Described as 'peace of mind for every Australian - for anyone who has, or might acquire, a disability'[2], it provides no-fault insurance cover for Australians under sixty-five years of age who are born with or acquire a physical, cognitive or psychosocial disability[3]. The insurance approach is a unique dimension to the NDIS[4]. In theory, it means that the Australian Government covers the lifetime costs of disability-related care and support for eligible individuals[5]. Approximately 460,000 individuals are expected to participate in the scheme across Australia by 2019[6]. The NDIS is being implemented by an independent statutory agency called the National Disability Insurance Agency (NDIA).

The case for the development of the NDIS was underpinned by evidence that Australian disability services were underfunded, inflexible, fragmented and built around the needs of the service system, rather than those of individuals[7]. Proponents argued that people with disabilities had *little choice and control* over services they could access, which were largely being determined by professionals, or what was locally available, or what various levels of governments provided. The funding and organising of disability services was *complex and inefficient*, with gaps and overlap in state and territory and federal responsibilities[8]. The complexity of the system was compounded by the existence of insurance-based funding of disability services and disability services funded privately as a result of public liability claims. These issues raised concerns related to *equity of access to services and support that were determined by individual circumstances.*

Significantly, the NDIS is a shift from block-funded disability services to an individualised service model. What this means is it allocates packages of funding to eligible individuals, according by the level of need and self-defined goals, and encourages individuals to use this funding to

2 ibid

3 Collings, S (2016) 'Support planning with people with intellectual disability and complex support needs in the Australian National Disability Insurance Scheme' *Journal of Intellectual and Developmental Disability* 41 (3):272-276.

4 Needham, C & Dickinson, H (forthcoming) "Any one of us could be among that number': Comparing the policy narratives for individualized disability funding in Australia and England' *Social Policy & Administration*

5 Walsh, J, & Johnson, S (2013) 'Development and principles of the national disability insurance scheme' *Australian Economic Review* 46 (3):327-337.

6 Productivity Commission (2011) *Disability Care and Support: Productivity Commission Inquiry Report Report* no. 54, Canberra.

7 ibid

8 Purcal, C., Fisher, K.R. & Laragy, C. (2014) 'Analysing choice in Australian Individual funding disability policies' Australian Journal of Public Administration 73 (1):88-102.

purchase services and support that most effectively meet their needs[9]. It also promises greater investment in early intervention, particularly in early childhood[10]. The NDIS began with four trial sites established in 2013[11] and is now being rolled out nationally.

The scheme's funding model spans two levels of government. The Australian Government committed to providing $19.3 billion over seven years from 2012-13 to roll the scheme out across the country. This commitment included redirecting some existing investment in disability services over that period plus a total of $14.3 billion new investment funded in part by an increase in the Medicare levy[12]. At the end of that period, in 2019-20, the total projected running cost of the NDIS is $22.2 billion[13]. The Australian Government has committed to providing funding of $11.7 billion to the scheme in that year - fifty-three per cent of the total cost - with the states and territories providing the remaining funding[14]. However, there are early indications that the scheme's projected costs for 2019-20 may be too low. In January 2017, the Australian Government requested that the Productivity Commission review the NDIS costs, examining such issues as the sustainability of scheme costs; jurisdictional capacity; cost pressures (including wages pressures); changes in the agreed escalation parameters; and the most appropriate levers to manage any potential cost overruns. The review's final report is expected to be delivered to the Australian Government in September 2017[15].

The first objective of the National Disability Insurance Scheme Act 2013 is to "…give effect to Australia's obligations under the Convention on the Rights of Persons with Disabilities done at New York on 13 December 2006 ([2008] ATS 12)"[16]. The Convention on the Rights of Persons with Disabilities (CRPD) applies human rights specifically to the context of people with disabilities and reflects the need for respect for their inherent dignity, individual autonomy (including the freedom to make one's own choices and the independence of the person), the need for them to be able to participate fully and effectively and be included in society, the need for respect for difference and acceptance of people with disabilities as part of human diversity and providing them with opportunities to be actively involved in decision-making processes about policies and

9 KPMG (2014) *Interim report: Review of the optimal approach to transition to the full NDIS* Canberra: KPMG.
10 NDIS 2017b https://www.ndis.gov.au/ecei
11 NDIS 2017c https://www.ndis.gov.au/about-us/our-sites
12 NDIS 2017d https://www.ndis.gov.au/about-us/governance/federal-funding
13 National Commission of Audit (2014) http://www.ncoa.gov.au/report/appendix-vol-1/9-2-national-disability-insurance-scheme.html
14 NDIS 2017d https://www.ndis.gov.au/about-us/governance/federal-funding
15 Productivity Commission (2017) http://www.pc.gov.au/inquiries/current/ndis-costs
16 Australian Government (2013) National Disability Insurance Scheme Act 4

program directly concerning them[17]. The objects and guiding principles of the NDIS recognise the rights of people with disabilities to be provided with reasonable and necessary supports and to have certainty that they will receive the lifelong care and support they need. The role of carers, families and other significant persons is also recognised and respected, with special provision made for the families responsible for the care and education of dependent children.

Having set out the background and principles for the NDIS the next section explains the aims of the study and how it was conducted.

Our research approach and methodology

Aims of this study

The NDIS promises to increase both the funding available for disability services and the control that people living with disabilities have over the design and delivery of their care. This study draws on the experiences of people with disabilities, and in some cases their families, of navigating the NDIS in one of the trial sites. From their perspective, we examine the progress of the NDIS towards addressing the issues identified in disability services before it was introduced: whether it is giving people with disabilities *more choice and control* over their care; whether it is making the funding and organising of disability services *less complex and more efficient*; and whether it is promoting *equity of access* to services and support.

We used a participatory approach to conduct the research. The research team included university-based researchers with expertise in social research, policy research and analysis and participatory methodologies, and community-based researchers living with disability who brought a broad range of work and life experience to their research roles. We explain why this is significant for the research. We then explain the method for collecting and analysing data and note key limitations and strengths of the approach.

17 Australian Government (2016) National Disability Insurance Scheme (Becoming a Participant) Amendment Rules 2016 (No. 2)

Participatory research methods

Our participatory and collaborative method for the research ensured that people with disabilities were involved in designing the study, collecting and analysing the data, and writing up and disseminating the findings. This approach was important in the context of Australia's obligations under the CRPD because people living with disabilities continue to struggle to have their voices heard in national and local debates focusing on the implementation of the NDIS. There appear to have been few efforts to ask people with disabilities, or those caring for people with disabilities, about their experiences of the new scheme and what kinds of changes have they noticed. Our participatory research method brings these perspectives into the research and combines lived experience ('insider') and academic ('outsider') perspectives to enhance the validity and relevance of research findings[18].

The university-based researchers established the project, obtained funding and secured ethical approval to conduct the study (HREC No. 1546001.3). Community researchers were recruited by circulating information about the study on social media, and through services supporting people with disabilities and academic centres involved in disability-related research. The community researcher positions – reserved for people with disabilities with an interest in academic research – attracted strong interest. Nine candidates were subsequently employed by The University of Melbourne as casual academic researchers at the award rate for Research Assistants.

Once recruited, the community researchers participated in customised research training sessions to prepare them for their research roles. This training covered the aims of qualitative research, interviewing techniques, research ethics, data analysis and presenting research findings. Community researchers assisted with promoting the study, drafting interview questions, conducting interviews, analysing interview data and participating in dissemination activities. There were some gaps between our aspirations to fully co-produce the research with community

18 Maclean, S., Warr, D. & Pyett, P. (2008) *Universities Working with and for Communities: Strategies for Collaborative Community Research and Knowledge Exchange*. Melbourne: The McCaughey Centre, The University of Melbourne; Mann, R., & Warr, D. (2009) *Something to Take Notice of: Exploring the Value and Challenges of Peer-interviewing as a Participatory Research Method*. Melbourne: The McCaughey Centre, The University of Melbourne; Minkler, M. & Wallerstein, N. (2003) *Community-Based Participatory Research for Health* San Francisco, CA: Jossey-Bass; Pyett, P. (2002) 'Working Together to Reduce Health Inequalities: Reflections on a collaborative participatory approach to health research' *Australian and New Zealand Journal of Public Health* 26:332-6.

researchers and the limited resources that were available to do this effectively. These limits included the timelines for obtaining funding, seeking ethical approval and consulting with the community researchers on the overall design of the study, and the resources that were available for training and debriefing the community researchers and conducting fieldwork (which required travelling from Melbourne to the NDIS trial site in the Barwon region). The community researchers' experiences and perspectives of these opportunities and limits were explored in a focus group conducted by an independent facilitator towards the end of the study, and will be reported elsewhere.

Conducting the research

We conducted face-to-face semi-structured interviews to gain insights into NDIS service users' perspectives. This approach gave us scope to establish rapport with interviewees and assess the needs of interviewees to participate in the interview, while giving structure to discussions and enough flexibility to interrogate issues that were most relevant to individuals.

We recruited research participants by circulating information about the study in relevant services, newsletters and other available communication channels. Participants were asked to contact the university-based Research Administrator directly if they wished to participate in the study. In some instances, service providers passed on verbal information to potential participants who then decided if they wanted to participate. Most participants were provided with a 'Plain Language Statement' by email in advance of their interviews that provided information about the study. The research team gave a hard copy of the Plain Language Statement to every participant before their interview, explained it to participants prior to commencing the interview and answered any questions participants had about the research. The Plain Language Statement was carefully worded to ensure that participants with varied abilities would be able to understand the aims of the research, how the data would be used and any risks that were presented. Most participants understood that the purpose of the interviews was for research, but it is likely that some did not fully grasp the concept of academic research. In acknowledging this, we were balancing our obligations to ensure informed consent and aims to avoid excluding participants with cognitive disabilities from participating. Participants' consent was verbally recorded.

We conducted a total of 42 interviews for the study, ranging from thirty to sixty minutes' duration, with people with disabilities in the NDIS (n=26), and parents or adult children caring for people with disabilities in the NDIS (n=16). Participants' ages ranged from 20 to 84 years. Some

participants who were parents of NDIS service users discussed the situations of young children and adolescents in their care. Interviews were conducted at a range of sites across the Barwon NDIS trial site.

It is customary to anonymise places where research is conducted to protect the confidentiality of participants, but we decided not to attempt this because we believed such efforts would be ineffective. The study was conducted in a well-publicised NDIS trial site, and the only one in Victoria. In such cases, it can be ethical to name the research sites and use other measures to protect the confidentiality of participants[19]. Therefore, in reporting our findings, we have been careful in selecting quotes to protect participants' confidentiality and removed potentially identifying details. We provide verbatim quotes where possible, but some quotes have been edited mildly to improve clarity while preserving the intended meaning of extended quote. In these cases, we use […] to indicate that a word/s has been inserted or deleted, while (…) indicates that some text has been removed. Interviews are identified using a numerical code.

In interviews, we asked participants about their day-to-day routines; experiences of accessing services; their transitions from other arrangements to the NDIS; and the best and most difficult aspects of the NDIS experience. To conclude, interviewees were asked to imagine what they would say to the Minister responsible for the NDIS as a result of their experience in the scheme. Participants were offered a gift voucher to thank them for making the time to meet and speak with us about their experiences. The interviews were conducted in pairs by university-based and community researchers or two community researchers, with community researchers leading the interviews and university-based researchers taking notes and assisting when required.

All interviews were audio recorded and transcribed verbatim. Transcripts were coded to identify content and themes, and common experiences in participants' accounts. Interviews were also sorted into three subgroups: people living with cognitive disabilities; participants with other disabilities; and participants caring for someone with a disability. This is because the perspectives of participants differed according to their circumstances. Participants living with physical disabilities and some psychosocial conditions (mental health-related disability) tended to provide detailed explanations of their experiences of the NDIS. People living with cognitive disabilities tended to provide more descriptive, and less explanatory, accounts of their experiences. Carers' accounts (which in-

19 Nespor, J. (2000) 'Anonymity and Place in Qualitative Research' *Qualitative Inquiry*, 6(4): 456-569.

cluded mothers and fathers of young children, adolescents and adult children as well as adult children caring for parents) offered insights into their experiences of caring and perceptions of the needs of the people they were caring for.

All the interviews provided detailed and thoughtful insights into people's experiences of navigating the NDIS in its trial phase. Many participants told us that they had been keen to meet and talk with us about their experiences because they were rarely asked about these experiences. Our findings aim to provide constructive insights into service users' experiences of the NDIS that are locally relevant and applicable to other sites. The study's strength lies in capturing the diverse experiences of people living with a range of disabilities and household situations, and in regional and rural settings, under the NDIS. However, we stress that while we interviewed people with a broad range of characteristics and disability for this study, we do not claim that our findings reflect the experience of all people in need of disability services, or of people unable or reluctant to be part of the NDIS. Furthermore, the perspectives gathered in this study are limited to service users; we did not canvass the perspectives of service providers and other stakeholders.

Our study concluded with a community forum in the Barwon region. We invited research participants and local NDIS stakeholders by email and promoted the forum on social media. Approximately forty people attended. We presented the early findings of our research and invited attendees to discuss the emerging themes in small groups facilitated by community researchers. The group discussions and questions at the forum confirmed our early findings and alerted us to some other issues of concern for those who attended, which have been factored into our final findings.

Limitations and strengths of the study

The perspectives gathered in this study are limited to those of service users and there are further limitations within that category. We did not interview service users with hearing impairments, or people from culturally and linguistically diverse communities who do not speak English, or people who are excluded from the NDIS because of their mental illnesses or personality disorders, or anyone not enrolled with the NDIS because they are homeless or are escaping family violence. We also did not interview any Aboriginal and Torres Strait Islander service users. It became apparent as our study progressed that including people with these characteristics and experiences would require some changes to the research

design and additional resources and expertise in the team. It is important that future studies of the NDIS consider the needs of these service users.

Of the participants we did reach, the method of using semi-structured interviews was constrained in gaining full insights into the experiences of participants with limited cognitive abilities. Future studies could explore the value of other methodologies, for example, visual methods to explore people's experiences.

Recruitment was largely opportunistic. Information about the study was widely circulated across the study site, usually with the assistance of organisations providing services to people with disabilities. Clients who elected to participate in the study were self-selected and this may have influenced the findings if they were motivated because they had extreme negative or positive experiences of the NDIS.

These limitations are important to keep in mind when considering the findings, as well as the notable strengths of this modest study. These include data that examines the experiences of people living with a range of disabilities and household situations, and in regional and rural settings. There was agreement among the team that the involvement of community researchers promoted trust and empathy in the research process that was evidenced in participants' engagement in the interview conversations.

The research team in training

The research team presenting early findings to government

Findings

The data we have collected cannot definitively tell us whether the NDIS is improving access to services for people with disabilities and carers. It does, however, provide insights into the perceptions and experiences of a cross-section of people currently navigating the NDIS system. This section of the report is divided into three parts:

- Participants' experiences of choice and control in accessing services and resources
- Participants' views on the operation and efficiency of the NDIS system
- Insights into whether the NDIS system was generating equitable outcomes among participants

What participants said about choice and control

Participants talked about issues of choice and control in different ways. Many focused on whether the NDIS was actually meeting their needs, while others discussed the extent to which they had increased choice and control in the kinds of services and support they could access. Many participants reported positive experiences of the NDIS, including receiving increased funding to access services and resources, reduced waiting

lists for services and potential positive impacts for local economic development:

> I wanted to come and tell you how good it was because I've got no complaints at all. The people are nice, and they're very understanding when I talk to them. (IV27)

> Since I've been with the NDIS we've got a cleaner in the house and we've also got a cook – I [also] do cooking on a Wednesday afternoon. (IV15)

> There used to be a waiting list for years for people trying to get care. So, with the introduction of NDIS, all these people who were waiting for care won. That was good, that was a positive thing. (IV38)

> The good things about the NDIS is people that haven't had support can now get support. Another positive, it's in Geelong – the headquarters – so its jobs for Geelong. (IV37)

The potential to self-manage funds is a key way in which the NDIS can be considered to offer greater opportunities for choice, control and flexibility in accessing services. This means that service-users or their nominees are responsible for requesting and paying invoices for services and support that have been identified and agreed to in annual care plans. Service-users and nominees are also responsible for keeping records of transactions and meeting reporting obligations. Some participants did not have the capacity to manage their own funding, or had elected not to, and had engaged an agency or 'plan manager' to take responsibility for sourcing and coordinating their services and fulfilling the scheme's administrative requirements.

Most participants in our study who had opted to self-manage tended to be parent-carers of young children and many reported valuing increased capacities to choose services and workers. As one parent-carer explained:

> The best part is the amount of funding exceeds what it was before, [and] the fact that I can choose who works with [her son] is gold. There's no question in my mind that the support that he's getting now is infinitely better than what it was before' (IV09).

Some participants felt that while reform was welcome, the NDIS has not gone far enough and their particular needs and preferences had not been considered in redesigning the system:

> There were choices but it seemed to me still within the parameters of the choices that currently existed. It was just a transfer of what currently existed. That' s been a bit of a disappointment for me where I don't think there' s been enough emphasis or effort put in to actually create a new and different way of doing things' (IV33).

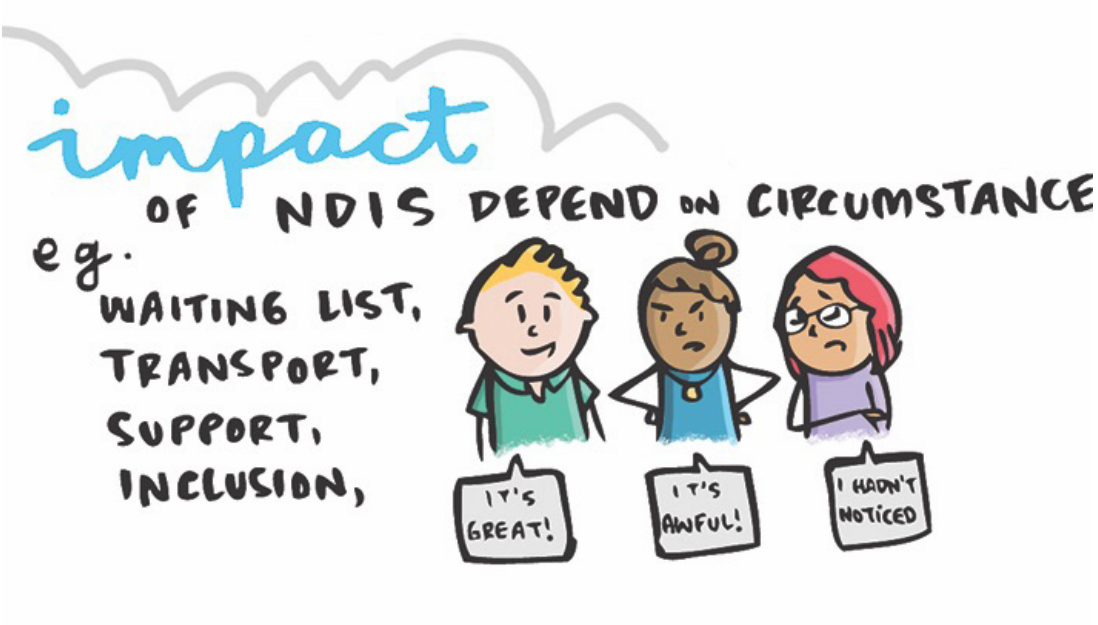
Other participants pointed to gaps between rhetoric about choice and the reality:

> The NDIA talks as though – things I read online - I'm thinking, the NDIA is not like that. They don't give you this $50,000 and say, 'Do what you want.' (IV12).

This participant is referring to the planning and approval processes that participants engage with in order to access funds. Many participants reported a range of difficulties with these processes, including their priorities being dismissed or overlooked. Some participants felt that requests for funding involved identifying personal goals and objectives that were not appropriate given the situations of some service-users.

Many participants commented that they had not noticed any changes in terms of having increased access to, or choice of, services since transitioning into the NDIS:

> It hasn't changed. I've had no change. Everything that we had before the NDIS came in, we've still got. (IV25).



Participants' expectations and experiences of the NDIS appeared to be strongly influenced by their circumstances. Parents of young children tended to have high expectations and be strongly motivated to obtain comprehensive packages of services and support. Because of their children's age, few of these parents had previous experience of accessing disability services prior to the introduction of the NDIS. Parents of adult children tended to note little difference in levels of support for their children since transitioning to the NDIS, but significant increases in administrative requirements and hurdles. People living with cognitive disabilities also tended to report few changes in their everyday situations, while people living with physical disabilities had a range of views, from positive changes associated with increased independence to deep frustration with ongoing struggles to gain access to crucial resources. One young man living with physical disabilities summed it up:

> I'm very happy with the outcomes of what they are happy to do and not do, but just the amount of jumping through hoops you've got to do to get whatever it is that you require. But I don't think that's a thing that's systemic of NDIS. I think it's more systemic of the whole disability sector. (IV04)

From the interview data, it was clear that participants had varying capacities to self-manage their funds, identify and justify the range of support they might need, navigate complex service systems and integrate sources of support. We consider these claims in more detail.

Has the NDIS enabled increased choice and control?

A key criticism of the disability service system before the NDIS was that it did not allow for people with disabilities to exercise choice and control. In this study, some participants described having increased choice in accessing services and how these services were provided. One parent-carer reflected on the positive impacts of the NDIS in enhancing choice and promoting independence for her son:

> Well I guess for me, it meant that I could increase my son's care. I could feel rest assured that I could go off to work and I knew there was someone there with him and I didn't have to worry. It built his independence, definitely built his independence, because just little things like going through a self-serve register, being aware of what's appropriate to say in public and what's not appropriate to say in public, how to catch a bus. Things that we take for granted that we just know with someone with a cognitive disability has to actually physically learn them and they take things literally. Literally. Through that, I've watched him grow. I've really watched him grow as a person

> and his skills and his confidence because he's been able to be more independent. (IV38)

Another parent-carer wanted their son to have more interaction with other men and sought to do this through accessing male service providers:

> I said, 'Right, I'm going to upset the apple cart here. I'm seeing a boy starting to change into a man. He's only around women. We need men. We need to get some men into this, some younger men.' She [case-manager] then gave me a couple of names of different male OTs [occupational therapists]', so we've set that up. [My son] loves it. I've also got a new doctor now for him that's a young male who really put in a lot of effort, which is something you don't see very often. It's bringing him out. (IV08)

A woman living with disability was very positive about the changes she had experienced through the NDIS:

> It's working out really well. See, I used to get mobility allowance through Centrelink, and then they cut that. Once the NDIS came on board, I got a travel allowance for my husband to take me to and from work. That's really worked out really well. They help me out if I've got a problem, they'll work it out. (IV18)

One young woman we spoke with had a mild cognitive disability and was living independently while involved in part-time work and study. She said that:

> It [the NDIS] has been great. It's given me more independence. I can say, 'Look, I can do this myself now. I don't need this support.' It will take me a long process. Like I said it could take you nearly three or four years. It could take longer but it's given me that independence that I can do what I want. (IV26)

Participants' accounts also showed the variety of ways in which funding could be directed to meet people's needs. For instance, in the following quotes, participants show the different ways in which they are using funding to meet practical and social needs:

> Me and my sister have a plan and I've just been trying to get activities organised (…) trips away' (IV15)

> It's helped me branch out into more social things and (…) get out and meeting new people, and also having access to a taxi where I'm not

> able to get transport to and from [places], so I can rely on that to get around (IV16)

Another young man, with significant physical disabilities, was living independently in his own unit and had funding for care providers to visit his home twice daily to assist him in getting up, going to bed, and other needs. He was very positive because he had increased ability to specify how this care was provided to him:

> I feel a bit more like a fully-fledged adult in the sense that I already felt that internally, and I felt that way in other life circumstances, but things like having to go to bed at eight o'clock at night because that was the latest the carers were prepared to come out. Or the latest that the agency was prepared to pay them [for] (…) the fact that I can ring them up a couple of days before and say, 'I'm going to bout until midnight on such-and-such a day' and nine times out of ten that's like, 'No worries, we'll find someone'. So that's fairly new. (IV04)

This was qualified by other ways in which his choices were being curtailed. For instance, he had been obliged to request funding to purchase a new hoist to lift him in and out of bed because the paid carers that come to his home had raised occupational health and safety concerns about using his current hoist with only one worker in attendance. The participant currently used a hoist that supported him to stand to get in and out of bed and he believed this was important in preserving muscle tone and his capacity to bear weight. His concerns that his physical condition would deteriorate using the new hoist were exacerbated by the financial ramifications of changing the hoist. There were long delays in obtaining the new hoist and he was required to pay for two carers to attend his home in the interim, which left him with less funds to pay for higher-cost late night care.

Many participants reported that, since transitioning to the NDIS, they had not experienced increased opportunities for exercising choice in accessing services:

> It hasn't made a lot of difference to me. I think it's been very good for a lot of people with physical disabilities who were getting no support at all. I think it'll be good for some people in other states who were not getting the same sort of support that people in Victoria were getting. (IV39)

Many people living with a cognitive disability tended to report that their circumstances had not changed and that the transition to the NDIS was largely an administrative matter. This was particularly evident among

people living independently with some support, and among those being cared for at home and in institutions. Interviews with people living with cognitive disabilities suggested that they had not received information about things they could ask for, or that this information had been presented in an accessible format. This limited the significance of the NDIS and the potential for increased choice in accessing services that it offered:

> INTERVIEWER: Can you tell me about the process of registering with the NDIS?
>
> INTERVIEWEE: They just said you have got to go for this meeting. NDIS is running it. You need to sign this otherwise you cannot work here. They never really went into detail why we have to do it.
>
> INTERVIEWER: Was it explained to you why?
>
> INTERVIEWEE: The NDIS started? Not really. They said it's for people who need help with whatever they want. We never got told what it was really for.
>
> INTERVIEWER: Were you asked what you might need?
>
> INTERVIEWEE: No.
>
> INTERVIEWER: Who worked with you, the person doing the plan?
>
> INTERVIEWEE: I'm not sure. It just changed. (IV13)

Some carers made similar observations:

> INTERVIEWER: Has the NDIS made it easier or harder for you to get services and support?
>
> CARER: Nothing has really changed. She lives at the residence and she goes to day programs and really that is basically it. (IV11)

Others were concerned that the NDIS was not offering choice and control in ways they had been anticipating:

> They talk about self-managing and choices and control but there really is not the choice and control. We are getting professionals to

> assess our child and to give a recommendation and they are deciding that they know best. (IV02)

Another parent, with a young child with a congenital condition, was concerned that families were given no sense of what services could be provided. She felt that the principles of choice and control were strongly determined by professional understanding of the needs of her child, and furthermore, that both the opinions of families and professionals were often disregarded without explanation in planning processes:

> I think a similar analogy is Medicare. If you go to Medicare, you don't have someone with no expertise behind the desk saying, 'You can have this', or maybe you can't. It's either PBS-approved or it's not. If your doctor, physio or surgeon recommends that something is necessary, then these things are covered by Medicare. You don't actually have an interface with Medicare, really. Patients don't come to me and ask what they want; my job is to present them with what the options are, give them a recommendation and then go from there. It would be completely unethical of me to not present them with the options. You go to these planning meetings and nothing's presented. It's only what you are prepared to ask for. Even respite isn't presented. (IV09)

While it is important to distinguish between assigning monetary values to medical costs and generating a standardised menu of costed supports and resources to meet the diverse caring, social and other needs of people living with disability, this quote expresses widespread views among participants that there is a lack of clarity in what might be considered reasonable to request or why requests might be turned down. It also illustrates where power is thought to reside within the system. In the example of Medicare, the power is seen to reside with the medical professional who diagnoses the issue and offers a solution in the form of drugs, tests and other procedures, which are then reimbursed by Medicare. In the case of the NDIS, although choice and control is in theory to be in the hands of the disabled individual, in practice, choices about care services have to be approved by a care planner or other professionals.

Another participant noted that these options are limited by a lack of information, or an ability to frame requests in an 'appropriate' way: '*If you did not know the jargon you virtually got zilch' (IV01).* Another reflected:

> Philosophically I still think [offering people choice is] the right approach, but a lot of families of people with disabilities didn't really seem to know actually what they wanted to do because they're not practiced at making choices, or making real choices. They're

> practiced at making choices from what's available, but not necessarily saying I don't like anything that you've got available for me, this is what I want 'cause that's what will make a difference to my quality of life. Again, I think that that's something that over time hopefully will help and people will get better at saying, 'for me this is what's important and that's all I need you to do.' We're not there yet. That's an evolutionary process. (IV33)

Several parent-carers were concerned that although the funding they were allocated might have increased, a greater proportion was being directed to cover administrative and other costs, such as travel time for people providing caring and professional services. The latter quickly added up for people living in regional and rural areas if service providers were not locally based.

> [My daughter] is getting more money but the service really is just about the same so a lot of that money [seems] to me [to be] going on administration and other things. Well, that's where I presume it's going. Everything's costing more than it was before because her program hasn't changed a whole lot. (IV39)

Participants also felt that flow-on effects from the rollout of the NDIS in local service networks was further restricting their choices. For instance, new service providers were moving into delivery of services traditionally provided by local government and promising to deliver at a lower price. Local government was then opting out of delivering these services, sometimes before the new market was ready to cope with demand, reducing choice for service users and in some cases, leaving them without services. Some participants also expressed concerns that new services were employing less qualified and less experienced staff to reduce costs and provide a service that was cost competitive.

> You've got staff with no long term training of any sort. The previous qualification was a DDS01 or Cert Four in Disabilities and now some places are employing people without that qualification. They might have Cert Three but a lot of them haven't got anything and they're calling them Educators and other names. I don't think that's very good at all, because for someone like [name] who's got very rigid routines and autism, I don't think that anybody that's coming in off the streets with no qualifications is going to understand what he needs. I know other families feel like that. (IV25)

These concerns extended to staff in the NDIA. *"A lot of the NIDA staff left and new people came in. We are on our sixth case worker. They just chop and change all the time... our first case worker had never done work with*

disabilities before. Had no knowledge of what could be given, what was required – a person with a disability required. She did not last long." (IV1).

Some participants reflected that an unanticipated effect of services being restructured to offer increased potential for 'choice' was decreased flexibility to meet the needs of some service users:

> I think the staff are getting frustrated because in a way, they are limited. Whereas before they had choice and they could move things around within the organisation to make things work for everybody. (IV01)

Another participant raised concerns that in an individualised system, service providers had increased capacities to exercise choice about which clients they want to attend or to 'cherry pick' clients who are perceived to be more cooperative and compliant.

Because NDIS plans are required to be reviewed annually, many participants could reflect on their experiences over time. Some felt that as the scheme settled in and 'teething problems' were resolved they were gaining improved understanding of processes. There was increased flexibility to respond to emerging contingencies by adjusting funding allocations within their budgets. Many participants, however, expressed frustration at apparently high staff turnover in NDIA offices and having to constantly engage with new planners who had varying levels of familiarity with disability services.

> They (the NDIA) got a lot of staff come in and then some of them said it was just too hard with chopping and changing in the NDIA itself. Even that staff did not really know what was going on. A lot of the NDIA staff left and new people came in. We are on our sixth case worker. They just chop and change all the time. (IV01)

A few participants were growing anxious and distressed by what they perceived as recent efforts to decrease funding allocations. One participant with a degenerative condition and limited mobility described having meal preparation reduced from seven to five days a week. He had also encountered disagreements over whether structural changes to his home were for the purposes of 'rehabilitation' rather than disability support, and therefore not funded by the NDIS. This participant had previously worked as a management professional and was drawing on his experience and skills to contest decisions to reduce his services. However, he believed that his capacity to be assertive, combined with physical aspects of his condition such as involuntary shaking and jerky limb movements, was causing him to be perceived as aggressive and a

potential threat to care staff and he felt he risked missing out on services as a result. He had limited options for accessing alternative services and this was heightening his anxiety and attendant physical and emotional reactions:

> I can advocate for myself but I can't handle the stress. I'd like to, but unfortunately my body reacts to any stressful issues now. (IV35).

Parents and carers of people with cognitive disabilities suggested that the principle of choice and control had limited value for people with cognitive disabilities who were more comfortable with routine and stability. They also suggested that shifting funding from group activity to individualised services could have an adverse impact on those people emotionally, socially and financially. A parent caring for an adult child explained that her daughter:

> 'Will want something but if you give her too many choices she dithers and is just in a muddle and she cannot make a decision' (IV01).

Another parent noted that:

> The NDIS is a bit concerned about organisations with day programs like this. They want everybody out in the community doing their own thing but with people with cognitive disability if they're out in the community and they're not able to do it on their own they need an individual support person which is going to cost 10 times more than somebody who's in a group situation. (IV39)

Participants' accounts raised diverse issues around the value of choice, the ways in which the NDIS can support people to exercise choice, and limits on choice that were being encountered. many participants said they were overwhelmed by the amount of information they had to process and the number of decisions they had to make to develop their plans. Some participants were keen to have increased control in managing funding, particularly spending on specific 'line' items, because they felt that annual planning processes reduced potential to respond to contingencies such as nominated services not being available.

Several participants reported that requests for funding in new plans had been declined because funds previously allocated for similar items hadn't been spent. In most cases where participants were not purchasing all the support in their plans, it was because the market for those supports was not yet developed. Underutilisation of agreed services, equipment and support was particularly evident among participants living in regional areas or those needing highly specialised services and supports - thin

markets of limited appeal to providers of goods and services seeking economies of scale. However, the supply side of the equation is not the only issue. Our research also found that some participants are ill-equipped to push for new services or to utilise different services, either because they could not access information about their entitlements in a form that suits their needs and circumstances or because they were concerned about being labelled 'difficult'. Furthermore, if their health and wellbeing fluctuates over the life of their plan, as is common among people with both physical and psychosocial disabilities, they may only need some services, equipment and support on an ad hoc basis. These situations elicited anxiety as participants grappled with the present and future consequences of not having access to required services, and fears that their needs would be deemed redundant.

Finally, planning and approval processes were guided by considerations of whether requests for funding were 'reasonable and necessary'. This is open to being assessed in different ways and from different perspectives, and participants' views could be in tension with the views of those charged with approving funding requests. Many participants felt that their capacities to exercise 'choice and control' were undermined by assessments that their requests were not reasonable or necessary without clear notions of what this actually meant. Planning and approval processes relied heavily on professional advice provided by physio-, occupational and speech therapists, over the opinions of carers and families, although these professional assessments also appeared to be frequently disregarded in decision-making processes within the NDIA. This may be partly because the NDIA recognised potential for conflicts of interest of professional therapists who were assessing the needs of service users and providing these services. Nonetheless, a reliance on professional opinions, and inconsistent measures of what was 'reasonable and necessary' was fuelling concerns among some participants.

What participants said about the operation and efficiency of the NDIS

A key rationale for establishing the NDIS was to address the complexity of the existing service system. Responsibilities for different parts of the system were shared across state and federal levels of government, giving rise to a lack of consistency across the country. While it is difficult to definitively answer whether the NDIS offers more streamlined processes and increased efficiency in allocating resources, because this would require different kinds of data, we can provide insights into how participants and carers perceived these issues. We consider this question by examining what participants said about the complexity of the system, communication processes, the NDIS portal, and how the NDIS operates

alongside other mainstream services. As this section shows, there is potential for overlap and/or duplication in the new scheme, and many services are working hard to defend their boundaries in the face of its introduction. We also consider participants' perceptions of the efficiency of the NDIS system.

The complexity of the NDIS system

Several participants reported that the NDIS offered a clearer and less complicated pathway for integrating services than they had previously experienced:

> We are on to our second plan now. I have never done one bit of paperwork for NDIS. [A service provider] did my initial contract with NDIS and I went into the office and filled out the rest of the paperwork and then we got the approval letter. Four weeks later we went in and had a planning appointment. It was a pretty smooth process to what I have heard. A lot of people have a few issues. I think we were just lucky that we got in when we got in. (IV05)

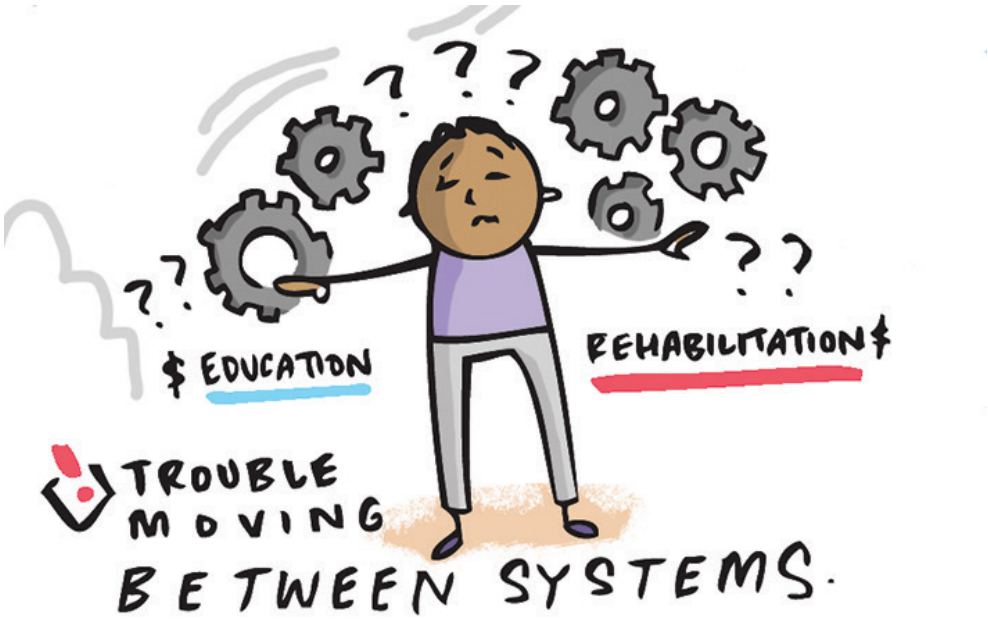
> The best thing with NDIS for me is just the support. If I have a problem, and you need someone to talk to, there is always someone [at a service], if it's not your worker, there's always someone there that will listen. (IV18)

> The difficulty I found was that I didn't really know a lot about the NDIS before we actually went to the meeting. I didn't know what we were entitled to get help with. I didn't know a lot about it so I was a bit confused, but it all just went pretty smooth sailing and we had all the doctors' letters and supports to get on the program and it was pretty much approved pretty well straight away. Well, probably over a few months. There was a little bit of a process but I was quite happy with it actually. (IV 36)

> It's less stress. It's amazing. I've been so stressed for so many years (…) I just want someone to say, 'Do this, do that and do that. All good.' So, the stress factor. That's the absolute best thing for me. It's awesome (…) [different support services] contact each other and I love that, and I encourage that. I say, 'Please, if you need to use the hours I'll sign it.' It is so much less stressful. (IV29)

While these accounts express high levels of satisfaction with the process, some participants had not developed an integrated package of services to meet their individual objectives and needs. Rather, they had opted for a care package which served to reduce the burdens of self-management.

Other participants raised a host of concerns about the complexity of NDIS processes, including planning processes, coordinating care packages and using the online 'Myplace' portal (used to view plans, keep track of budgets, request payments and manage services). Many participants claimed that the NDIS has not made things clearer for people with disabilities and had created another complex system with different moving parts and numerous chances for miscommunication and/or breakdown in continuity of care.



Annual planning reviews, which involve forecasting a person's needs over the next 12 months, required considerable preparation, especially for those opting to self-manage their funds. Many participants made negative comments about the planning processes because of the time and effort that was involved. A mother of a four-year-old child with a physical and cognitive disabilities explained the effort they go through in preparing their annual plans:

> When we go into a plan, we do a lot of preparation with our therapists, hours and hours of talking about what do we need for the next 12 months, what are we going to foresee, what shall we ask for in terms of therapy hours and time. They do a lot of research at their end [the therapists], go to a lot of effort (…) my husband and I sit down together and we talk about it as a family (…) we go in and have this meeting with our planner (…) what I find really frustrating is that you sit there and you have a chat (…) [the planner] sits there jotting notes. Then they give you a plan. They email you a plan and that is it (…) I was horrified at some of the goals she came up with (…) I did not feel comfortable with these goals. One of the goals was for [the child] to continue living with his family at home! (…) I was horrified

> that it was even in there as a goal, as if he might be taken away from us. It just did not feel right at all. (IV02)

> Initially, moving from the basic setup they had before the NDIS was quite complicated (…) purely because of the amount of information that was given, it was given in bulk. I mean I understood it but I know there are a lot of people like myself who did not quite understand what the information was for, what to do with it, how to use it to your advantage (…) the Case Manager who put me onto this actually helped me with my housing, with the real estate and with the landlord and all that sort of thing. She recommended that I go onto it and see how it goes and see whether I can get another form of social life, moving on, a little bit of extra help with living on my own and getting around where I'm not able to and stuff like that. (IV16)

Despite careful preparation, some participant-carers felt that their views and experiences were overlooked:

> You feel like you have been talking to a brick wall. (IV03)

Another participant reported that:

> We had a lot in place and then it was slightly changed. They tell you one thing, write down another thing and you get something else. (IV01)

One participant, caring for two children with disabilities, brought two large folders of letters, forms, reports and notes to the interview to show us the enormous amount of paperwork involved in self-managing her children's plans.

Another participant wondered if these situations arose because:

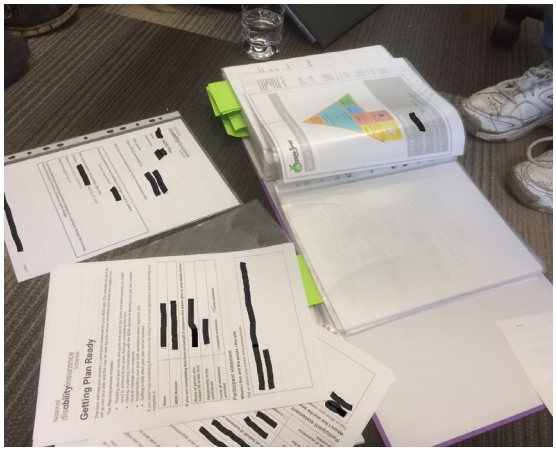
> There's not adequate induction support and supervision training provided to the people who are doing the planning (…) If we can't get the planning right we're not going to get the scheme right. (IV33)

We touch upon other issues related to care planning in discussions below. While it is to be expected that the NDIS is a complex system, participants believed that the views of people with disabilities, their family members and carers were readily overlooked in planning processes, and that some people with disabilities were disadvantaged because they could not fully understand the system. Many participants flagged issues associated with communication processes in the NDIS and we explore these in more detail.

Communications channels in the NDIS

Effective communication strategies are critical for complex systems to operate effectively. Participants raised a range of communication-related issues, including difficulties in obtaining reliable and accurate information from the NDIS, understanding information that has been provided, communicating with the NDIS when queries or issues arose and using the portal system.

Information about the NDIS is available in a range of ways, and there is a strong onus on service users and carers to engage with this information so they can effectively advocate and manage their support needs. The complexity of the system and the need to synthesise complex information about administrative procedures and service providers meant that many participants - particularly if they did not have access to informal sources of support from families and carers - had no capacity to self-manage and needed to engage a disability service to manage funds on their behalf.



Many participants raised concerns that some service users with special communication requirements, as well as families under pressure, struggled to access, process and apply this information. Participants in these situations may have little sense of available options. For example, a participant with a learning disorder reported being satisfied with her current situation but had little sense of how it worked:

> I would say [we get] the support we need. I don't know what I wanted. I didn't know what was there (IV26)

Later in the interview she also noted:

> Half the time it's hard to understand a question because you've got to answer it the way that they want it to be answered. With my read-

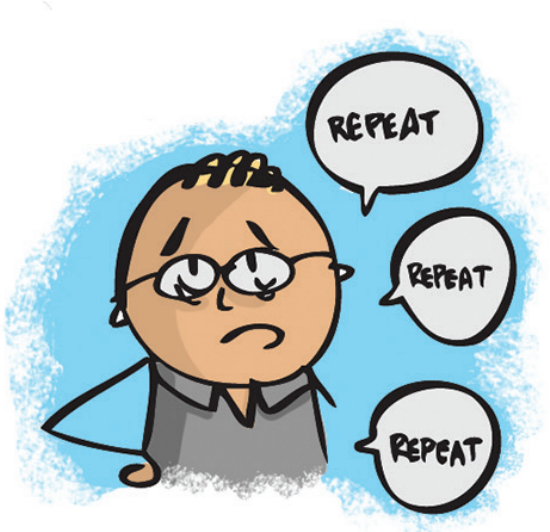
> ing and all that, it's pretty hard. I don't understand a lot of stuff. I'm just thinking, 'Right, that's it, I'm taking that in for you guys [a case manager] to fill in. (IV26)

Even if participants had capacities to engage with and apply information, many complained about poor communication channels, contradictory information coming from the NDIS and feeling that they weren't being listened to:

> [T]here is a huge disconnection, a gaping hole, between what the senior bureaucrats and government think is happening and what's actually happening on the ground. (IV33)

Another participant discussed the frustrations of poor communication processes in complex service systems:

> [Y]ou get sick of rehashing the same thing over and over and over again, your story from naught to whatever, and you forget things and (…) the story gets longer [over time] and you think, 'No.' The first thing I said to the planner the very first time we did it was, 'Right, this starts here. I'm not going back through anything, not rehashing anything.' That was probably not too bad, but the planning's evolved, I suppose they've got better at it (…) We had three or four very good providers, they offered a great selection of programs, so I suppose it's just been streamlined a little bit and more formal and more accountability. There are still problems with the actual planning process. We actually have had the same planner for three plans, which is amazing, because they seem to change quite frequently. At the moment, the supports are there. We can access mainly what we need at the moment. (IV41)



Others reported being involved in one-sided planning processes:

> [I sit there and think], 'Are you listening?' One of the biggest problems I have: 'Are you really listening to me?' There was a meeting with the woman that I had in there and she had this young fellow that was training. When we finished I pulled him aside and I said, 'I can give you one big tip that's going to help you right through this whole training process and working with families. Listen to the carers. If you go off with your own ideas, it is going to fail.' (…) That's probably a struggle most families have. We're just not listened to. We do know our child pretty well. (IV08)

> They put together this recommendation for a package and then our planner just came back with an email and said you have been approved for $19,000. She said, 'I have worked out that includes a period of intensity so you should be able to do that, and I felt that the goals the therapist were working towards overlapped so I felt that you did not need that many hours with your therapist'. Then that was it. Then she moved to another job. So, I could not get any more information. I said I would really like to know how you have worked it out? What is the frequency of therapy? What are the goals you felt overlapped? How am I going to make this budget work? I just need more information. But, there was no information to be given. (IV02)

Using the NDIS online portal

Many participants reported problems in accessing the Myplace portal[20] which they are required to use to manage their packages, and which has had significant teething issues[21]. These issues led to difficulties in accessing care and resources, as well as frustration, stress and an increased administrative burden for service users and carers. One participant offers insights into how some of these challenges unfolded in her situation:

> I am not self-managed but I do get on [the portal] to show my supports left over and who has claimed when. They shut the [portal] down in the middle of June and it is still not back up and running. I cannot see what my son's plan is. He has had two more things approved. Cannot approve it until that MyPlace is up to date. The plan that is on there at the moment is only last year's balance and they have just made up completely different line items. It is just a mess. It is really frustrating. I did not want to self-manage because I thought I

20 *NDIS 2017e https://www.ndis.gov.au/participant-portal-user-guide.html*

21 https://www.dss.gov.au/disability-and-carers/publications-articles/general/ndis-myplace-portal-implementation-review-final-report

would struggle with the paperwork but at the moment I am self-managing because I need to keep a track of what we are missing out on, how we can make it up so that at the end of the plan you have not gone over or have got money left over. No one will return your emails, phone calls. Some people are on hold for four hours on the NDIS. It is a debacle. It is really frustrating. Also, in terms of the therapies provided, we have had two services cancelled so far because of the portal issues. Say for example our psych, who is based in Melbourne. Has not been rolled out there yet. Before they change the portal, could claim, no dramas whatsoever. Works in Geelong with another lady. That lady can claim. She cannot. So, she stopped all services in Geelong. (IV05)

Issues with the portal were particularly prevalent in low-income households and we spoke to many participants, particularly those with cognitive disabilities and older parent-carers, who had limited or no access to mobile phones, other devices or the internet. An elderly parent-carer had recently purchased an iPad (at her own expense) and was overwhelmed with the amount of information she had to process:

> For people self-managing it's an awful lot of work and yet if we just let NDIS manage everything we don't know anything about it. Have you seen their portal system? (…) My IT skills aren't very good but I went to a meeting to try and learn a bit about it and this is what we were given [shows us a lengthy photocopied document] (…) It's 37 pages with a step by step guide so it gives you some sense of

> [interviewer: How complex it is!] I'm not even sure if it's working 100 per cent. There's been a lot of trouble over it. (IV39)

A young woman with a cognitive disability reported:

> We're [with her case worker] working on the new portal thing at the moment. Because none of us have got an idea how to do it (IV26)

Complaints about the portal were largely made by carers who had opted to self-manage because they felt sufficiently motivated and competent to take on the administrative tasks to assemble a suitable portfolio of services for a family member. Other participants had been cautioned against self-management; in some cases, advice against self-management came from service providers, posing a risk of conflict of interest. There were different levels of choice in 'outsourcing' the management of individual packages to an agency or a Plan Manager. For some service users, this model of service delivery simply replicated the previous system but with more administrative costs associated with providing 'individualised' packages rather than standardised packages. Many participants with cognitive disabilities that we spoke with appeared to have packages that involved little change from previous arrangements. This was evident in the accounts of participants who were unable to describe their care plans, or recall discussing these plans with anyone, or whop reported that their situations had not changed in the transition to the NDIS.

Generally, participants described complex service systems, challenges accessing and understanding a volume of information and difficulties navigating administrative requirements. Potential for choice and control in accessing services was closely tied with being able to access and assess varied information and this clearly disadvantaged some participants. The potential for increased choice and control in designing care packages and accessing services was also linked to capacities for self-managing funds. Many participants were unable to this because of the nature of their disability, while others were deterred by the administrative challenges and responsibilities. Most participants who were self-managing their packages were parent-carers of young children. They valued the opportunity to tailor a package of services and support that best meet their needs, although they reported that administrative requirements were onerous and time-consuming.

Coordinating services and support

Individuals and families do not live their lives in quite the same 'neat' way that government services are organised. There are challenges and issues that cross multiple different administrative boundaries and this is likely to be particularly the case if you live with a complex or chronic disability. What became apparent in our interviews is that there is some debate concerning what services (and therefore responsibility for funding) sits within the NDIS and what should reside with mainstream services (for example health or education). It is important to note here that the NDIS supports citizens who are often excluded from the labour market and suffering from generally poor health, so its users are likely to be concurrently accessing other government-funded services such as housing, employment programs, education or health services.

Several participants discussed the need to navigate the boundaries of various service systems when requests for support and resources were deemed to be for the purposes of rehabilitation, which sits under the responsibility of health services, or education, were not allowed. Participants were also required to demonstrate that support and resources would clearly meet objectives identified in their plan. Older participants were more likely to struggle to justify that needs were not for the purposes of rehabilitation. One participant living with a physical disability explained his struggles to obtain exercise equipment:

> They said to me, 'We're not going to fund that for you because its rehab and we don't fund rehab'. I said, 'That's fine. What you don't understand, my needs are not rehab. I don't expect to get better'. (IV35)

These system boundary issues also arose for parents of young children who were keen to integrate support for their children into mainstream activities to intensify potential benefits, but found it difficult to achieve in practice:

> They have a very strong policy about keeping the NDIS separate to the Department of Education. I am really worried about it. I have heard a lot of things about how therapists cannot go into the classroom and things like that. Really worried about how that is going to impact his learning, basically, and how that is going to work. It has impacted us already. Before he was accepted into kinder, there was no day care centre that basically wanted us. They turned us away. (IV02)

Some participants recognised the importance of framing goals and activities to ensure they would fall under the remit of the NDIS:

> With the second plan (…) I was thinking there's not a lot of fine motor stuff and was wanting to make sure we had OT [occupational therapy] hours allocated for that. I said [to the planner] I thought we needed an extra goal there around fine motor skills (…) to improve [my son's] fine motor skills so he can learn to write. She said she was really sorry but that's an education goal and they don't fund those. I literally sighed at her and said, 'I'd like to work on [my son's] fine motor skills so he can learn to do up his buttons. She said that was great, and an excellent goal. (IV09)

Clearly, not all services users or carers would have the insight or capacity to be able to frame goals and activities using NDIS terminology.

Inefficiencies in the system

Participants also had a range of views on whether the NDIS is working efficiently in terms of delivering value for money without compromising quality of services. One participant living with physical disabilities was one of a few participants who reflected directly on the potential of the market model adopted by the NDIS to better met his needs. He had moved to the trial site to be closer to family, and had previously experienced difficulties (in another state) in procuring adequate standards of care:

> The good thing about the NDIS is they're under an obligation to provide better service provision because there's more to answer to and they want good reviews from their clients. It's like a real business whereas in the past it was like it didn't really matter what we provided because there's no accountability and you can get away with it. Whereas this system actually forces them to want to produce the best that they can, keep their clients happy so their clients, one, will stick with them and, two, keep giving them positive reinforcement. (IV04)

Another parent-carer speculated that established specialist programs were being disbanded because of their cost:

> They have actually got rid of all their early intervention advisors because they said, in a PC way and I've got the letter, but I know the actual truth. They said they weren't worth their money because we have to pay them too much. (IV40)

Participants living with disability expressed similar concerns about services closing because they were no longer competitive (for example those provided through local governments). There were also perceptions that competition, rather than encouraging innovative practice, was driving providers to cut corners or to restrict services to those that are the cheapest and easiest to deliver. Some participants were particularly concerned about the viability of specialist services and units within organisations. One parent-carer said that the imperative for services to be profitable could discourage service providers from trialling new services, because the risks of straying beyond what is known to work, and then failing, would jeopardise the sustainability of organisations. Innovation that could better serve people with disabilities, including promoting economic and social inclusion, required scope for experimentation:

> You have to try stuff and give it a go; be prepared to not make any money out of it, or run at a loss. But to just give it a go and for people to experience it. (IV33)

Other parent-carers were concerned that in 'thin' markets some services simply weren't available:

> For some groups like people with autism there aren't the programs around. They might have the money, the finances, but they don't necessarily have the programs to support them so it's not just all about money. (IV39)

Efforts to ensure accountability in the allocation of funds also appeared to impact on the efficiency of the NDIS scheme. This claim is complex because, on one hand, inefficiencies are being passed on to service users. For example, many participants reported incurring additional costs in accessing services because they were now obliged to cover travelling costs for specialist service providers (which could be considerable for people living in rural areas) and obtaining professional advice to support requests for services and equipment. The Myplace portal was another measure that aimed to improve the efficiency of the NDIS by shifting administration costs to clients.

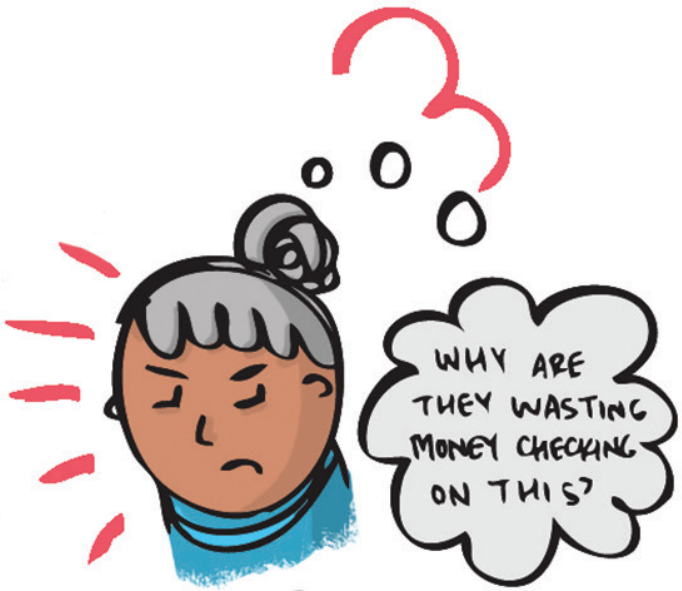
While there was wide acceptance among participants on the need for accountability in distributing public funds, they reported that requirements could be disproportionate and time-consuming. Several participants related examples of requirements of approval processes being both confusing, arduous and inflexible:

> [The planner] told my husband and I to go and look at these things and make a list and say, 'Yes, do you think that they would be suitable

or not'. Then she told me she didn't tell me that, and that I needed an OT [occupational therapist]. Then we got the OT out [and they] wrote the report. Then [the planner] said, 'No, you can't have it because [it's not] to my standard, to what she thought was reasonable for me having these pieces of equipment (…) Aldi had kettle tippers for $29 (…) and [it] ended up costing nearly $100 which to me was ridiculous and unwarranted. (IV11)

The staff at the NDIS were great. It's out of their hands. They have to go to higher management to get everything approved. Everything took so long. We got a new wheelchair. Just getting an OT out to do an assessment or get a quote - and things like hand splints. Dad's hands naturally go like this after a while [demonstrates]. Hand splits kept them out, kept that stretch, kept that blood flow. It took us a good year and a half to get some hand splints. It's more just, 'Yes, okay'. The OTs put an invoice through for hand splints, then the hand splints have to get approved through another person and then another person and the NDIS, and NDIS give the company the okay. There were just so many middle people. Everything takes so long just to get funding. (IV37)

Let's say what I wanted to use the dietician money on physio. If we're staying within the budget, who cares? How much nit-picking are you [NDIS] going to do? How much are they spending at that end to do that nit-picking that could be better spent? That's pretty frustrating. (IV09)



In another interview, the elderly parents of an adult with physical and cognitive disabilities who lived in a supported accommodation setting, related their efforts to procure a footrest for their daughter whose feet clearly didn't touch the floor when sitting down. An occupational therapist was required to assess and approve the purchase and, six months later, they were still waiting for the footrest to arrive. Along with other participants, these parents had since engaged a 'plan management service' to assist them in navigating the NDIS.

The following participant felt that the efforts of clients were undervalued and being taken for granted:

> When we started with the NDIS, they lost all my paperwork twice and I had to fill it in a second time. I had to go to the doctor twice, and it was embarrassing that a government agency lost my paperwork. They were trying to blame me, but I sent it to them in the form that they sent it to me. It got sorted but it took six months. The other thing is I never know how much I've spent because I can't access my portal because I don't have a computer and my mobile phone and home phone are incompatible to it. So, I couldn't tell you if I've spent $2,000 or $3,000. (IV22)

Some participants in their second or third round of planning processes were concerned that previous levels of funding were being cut. One participant explained that this had recently happened despite her efforts to demonstrate their value:

> [E]ven therapists that my kids were already using, under the plan, the therapists have to show that they [are meeting requirements] on the plan (…) provide a report to say what he did about gains and stuff because if you're not meeting the goals in the report they're going to say its insufficient (…) the lady who does the hippotherapy (…) she fulfilled her goals, the speech did her letter, the psychologist did her letter (…) this year [we were told], 'No, you're not going to get it [the planner] dismissed [the hippotherapy] and the after-school program. (IV40)

Despite limited household resources, this parent had obtained some of these reports at the family's own expense to ensure the smooth implementation of her children's plans and she was perplexed and upset about the decision not to fund some requests. These issues were linked to growing concerns expressed by many participants that in recent planning processes, the NDIA was focused on reining in escalating costs:

> I think the initial start, the commencement of NDIA was great, the approach was great with the plan as they were very generous in what they gave me and I know with other clients as well, they're very generous, and I know now they're pulling back on that. Pulling back on that big time, with the money things. I think there's been some clients who have been disadvantaged and I know the NDIA's motto was that a client wouldn't be disadvantaged. I don't believe that's true. I don't believe that's true at all. (IV38)

Other participants were concerned about perceived cost-cutting measures in the scheme. They said these measures were leading to requests for services being rejected despite being approved in previous plans. In the absence of official explanations, seemingly poor communication between the NDIA and service users, and a lack of clarity about why and how decisions are made, were combining to undermine participants' trust and confidence in planning processes.

Several participants also reported that requests for funding in new plans had been declined because funds previously allocated for similar items hadn't been spent. Unspent funds were usually related to difficulties in accessing high-demand services or administrative obstacles , such as plans not being finalised and problems with the portal. These situations elicited much anxiety as participants grappled with the present and future consequences of not having access to required services, and fears that their needs would be deemed redundant.

This section has considered a host of issues associated with coordinating services across system boundaries and inefficiencies in the NDIS processes. Many of the participants' experiences served to highlight systemic issues that could be addressed by consulting with service users to identify ways for streamlining approval processes while sustaining the integrity of the scheme. This includes identifying instances where the demands of accountability are disproportionate to the risks that are presented and may be doing more harm in undermining potential for harmonious and productive relationships between NDIA staff and clients. Participants' insights suggested that it may be more efficient - both for claimants and the NDIS - if requests for funds under a certain amount, or requests for equipment where the need is clearly self-evident such as many of the examples discussed by participants, could be approved without involving intermediary professionals. Increased flexibility in planning processes to enable service users to respond to unanticipated contingencies would also likely enhance efficiency for the NDIS and service users alike.

What participants said about equity and the NDIS

Amidst the general difficulties that many participants were experiencing in navigating the NDIS system, their accounts highlighted the ways in which factors that drive inequalities, such as age, gender, socioeconomic status, residential location, and household structure, can operate as fault lines in the NDIS system by working in different ways to further constrain potential for choice and control. These kinds of issues were rarely directly addressed in participants' accounts, but surfaced in discussions of related issues. For instance, one participant commented that the concept of choice will be more familiar to individuals who have been encouraged to consider their personal preferences and who are presented with options for achieving them:

> A lot of families of people with disabilities didn't really seem to know actually what they want to do because they're not practiced at making choices, or making real choices. They're practiced at making choices from what's available, but not necessarily saying, 'I don't like anything that you've got available for me, this is what I want 'cause that's what will make a difference to my quality of life.' (IV33)

The same participants said that facilitating potential for choice required:

> 'A lot of work around capacity building for families and carers, and for people with disabilities who want to manage things for themselves' (IV33).

Differing emphasis that is placed on the value of choice, and potential to exercise choice, is likely to undermine the potential for equity of outcomes across NDIS. The circumstances for people living with disability, particularly for those also living on low incomes and in rural areas, means that they may not be practiced in contemplating and asserting notions of choice for different reasons, including a lack of fully operational markets leaving some people with few, or no, services to choose from.

In terms of navigating the system, our data suggests that parent-carers of young children were highly motivated to obtain optimal resources and support for them to ensure that they had the same opportunities as other children to live a meaningful and fulfilling life. Participants and parents who could draw on professional experience which gave them an understanding of the logics of meetings, preparing funding requests and liaising with professionals, appeared to be more confident and assertive in their interactions in planning processes, compared to participants who had previously had limited exposure to these kinds of processes. Access to computers, the internet and other material and digital resources enabled some participants to research and identify available opportunities, while others were excluded. These capacities and resources were important if participants wanted to self-manage their care packages. In some interviews, there were suggestions that participants' socioeconomic status played a part in shaping their expectations of the scheme, as well as their relationship with care planners and service providers. For example, people living in communities where poverty is a common experience may compare their situations with those of others around them and express satisfaction if basic needs are being met. This was evident in many interviews where participants expressed gratitude for any help they received under the scheme even when it fell short of what they had hoped, or they were uncertain about what they could ask for.

In one interview, a service user, a young woman in her early twenties and living with a cognitive disability and some mental health issues, outlined a series of disagreements between her father, with whom she lived, and an NDIS planner. The participant's account suggested that the planner may have had concerns about the behaviour of the father, such as feeling unsafe when visiting their home, and that he was accessing his daughter's pension payments. The young woman's account, reflecting the limits of her own experiences due to both her disability and her family's socioeconomic circumstances, suggested the planner had trouble distinguishing risks that required immediate response from the everyday

circumstances of poverty. The young women herself did not appear to be troubled by her home situation that had led to conflict with her planner:

> I get some [pension] and Dad takes the rest, but he must keep some of it because it's a bit hard at home moneywise (…), things are a bit tough. That's one reason why I'm working here [in supported employment program], because working here is helping. (IV21).

Nonetheless, there were hints in this and other accounts that some participants living with disability may be in exploitative, or even abusive, relationships with some carers and that there may be legitimate concerns for their safety and wellbeing. Responding appropriately to these complex situations is even more difficult if NDIS staff have minimal training and preparation for their roles, are overwhelmed by high workloads and lacking previous experience working in the disability sector.

A further concern raised by participants was a heightened sense of vulnerability in receiving individualised care in their homes, especially because of the personal and intimate nature of some care services that were being provided. These concerns were intensified when people with disability were engaging with people outside their familiar support or social networks, or who were unfamiliar with their specific needs. When people receiving care were feeling anxious and stressed, there was increased potential for some behaviours or interactions with workers to be perceived as threatening or disturbing. This was evident in various participants' accounts, including that of a young woman with autism who felt that many NDIA staff had poor understanding of her condition, which she felt contributed to distressing interactions:

> I was actually in tears with tears pouring down my face and I still had the planner firing questions at me. Common sense says you don't do that. (IV12)

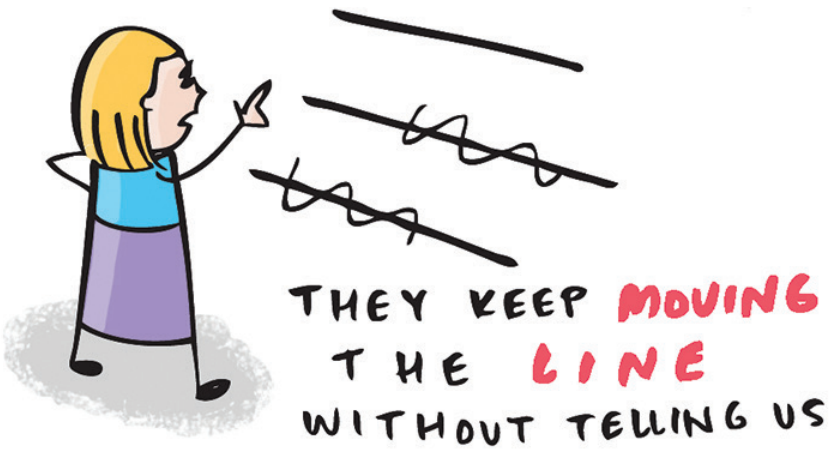
Participants' accounts also suggested that some service providers had similar concerns when entering participants' homes. Staff providing caring services are also likely to be feeling increasingly vulnerable and particularly if they have not received adequate training and are under pressure to provide services in a timely way. Another participant with physical disabilities and who lived alone, had been experiencing friction with some NDIS staff. The physical effects of his emotional disturbance he was experiencing was causing to lose some control over his body this then led to him being labelled as aggressive:

> I got to the point where I said, 'I'm not prepared to talk to you anymore', so I got my MS [multiple sclerosis] nurse to handle all the is-

sues from then on. When they were giving me another planner, I said, 'I want to know whether this planner's had any understanding of MS.' They said I wasn't allowed to ask that question. Because I was trying to solve my problem, they saw me as an aggressive threat (…) That's why I have a real finger to point at the management. Seriously, they've set everyone up to fail. If they're going to go nationwide still with that mandate, you're going to have more nightmares than you can imagine. But the thing is that if it was another person who couldn't communicate like I can, how are they being treated? I was one that could articulate and have a crack at them. What about the others? I've asked around a few carers and a lot of other professionals and said they really treated people with awful delays and stuff like that. The main issue of delivering on time, every time as you promise was never addressed because no one could complain. (IV35)

Some participants feared that this could lead to situations where they (or others) were at risk of being denied services because they were perceived to be too difficult by staff who, in circumstances there is high demand for services but limited supply, could exercise their own choices about who they were prepared to attend:

People talk about us having choice and control but a lot of agencies are finding that they don't even have control. It's the individual workers. They've got individual workers saying, 'No, I don't like that client, that client's got behavioural problems, I'm not working with them'. So they've got individual workers that are now picking and choosing their clients. So you've got clients with the most complex needs, they might get the funding in their packages for them – might being the operative word – but then they can't use the hours because they can't find support workers because support workers, 'No, I don't want them. I can find this person, that person who's nice to be with.' (IV12)



Another participant suggested that questions of what constitutes 'equity' are vaguely conceptualised and appear to be shifting over time and. She reflected on her involvement in the initial campaign inspired by ideals for equity for people with disability, which she felt were being steadily diluted:

> When it first came, I reckon we were at a meeting every fortnight about NDIS and NDIA and what it was going to be (...) with our campaign red t-shirts on, banging things and marching up and down saying, 'This is what we want!' And then it slightly changed from you will get everything and then it was, what is reasonable and appropriate and within reason? All those words suddenly started appearing. (IV01)

Questions of equity and fairness in the NDIS raise many practical issues that also drift into political, ethical and philosophical questions that are largely unaddressed in NDIS documentation. This is leading to uncertain expectations about the aims of the scheme and what it may be able to deliver. If the NDIS aims to improve equity for people with disability, closer attention must be paid to assumptions and practices that are potentially exacerbating inequalities among service users.

Discussion

In summing up findings from this study it is important to keep in mind that the region was a trial site for an ambitious social policy initiative. In a trial, it would be expected that many anticipated and unanticipated issues would arise when working out how the NDIS will operate on the ground, and these issues need to be identified and addressed. The NDIS framework was very broadly conceived and it was acknowledged from the outset that there would be challenges during the implementation process that would need addressing. It is also important to remember that NDIS moved quickly from being a broad set of aims and principles to being implemented in community settings. The history of the NDIS is one where timescales have continually been brought forward and the implementation of the scheme has been described as being 'rushed'[22]. Where other countries have introduced comparable schemes this has typically been over longer timeframes. For example, England created a market for disability services in the late 1980s/early 1990s at a time when local governments divested themselves of disability services. This

22 Morton, R. (2016) 'Rushed NDIS rollout a 'major risk'' *The Australian* 9 November 2016 http://www.theaustralian.com.au/national-affairs/rushed-ndis-rollout-a-major-risk/news-story/b8ab249c69917a01cab1e8a5b6bdb176

was followed by phased introduction of different options for individualising funding for care services, starting with the introduction of direct payments in 1997, before personal budgets were introduced in 2008 with an expectation that these would become standard for all people with disabilities by 2015[23]. It is important to acknowledge that in under five years, Australia is implementing a scheme that England took nearer 25 years to develop and implement.

The NDIS rose from a grassroots movement with high aspirations and expectations that the new scheme would deliver much-needed resources and support to some of Australia's most disadvantaged citizens. But it is called upon to meet the needs of very diverse service users with very diverse needs and circumstances, which entails working around a broad range of disabilities, personal situations, life course contexts, locational contexts and extant service systems. These factors ensure that there will be many challenges in meeting people's expectations and delivering effective and efficient services. It is also important to remember the many challenges that people with disabilities faced in accessing appropriate services prior to the introduction of the NDIS and the poor quality of outcomes many encountered. A study from the OECD found Australians ranked lowest in terms of quality of life for disabled people[24]. Australians with disabilities have low levels of income and labour force participation[25], experience social exclusion[26] and significant levels of violence[27]. Moreover, longitudinal evidence suggests that these trends have worsened over time and inequalities persist[28]. Criticisms or critiques of implementation of the NDIS must be considered within the parameters of the accelerated timescales within which the scheme has

23 Glasby, J. & Littlechild, R. (2016) *Direct Payments and Personal Budgets: Putting Personalisation into Practice* Bristol: Policy Press, 3rd edn

24 OECD (2009) Sickness, disability and work: Keeping on track in the economic downturn. Paris: OECD.

25 Milner, A., LaMontagne, A.D., Aitken, Z., Bentley, R. & Kavanagh. A.M. (2014) 'Employment status and mental health among persons with and without a disability: evidence from an Australian cohort study' *Journal of Epidemiological Community Health* 68 (11):1064-1071.

26 Mithen, J., Aitken, Z., Ziersch, A. & Kavanagh, A.M. (2015) 'Inequalities in social capital and health between people with and without disabilities' *Social Science & Medicine* 126:26-35.

27 Kmjacki, L., Emerson, E., Llewellyn, G. & Kavanagh, A.M. (2016) 'Prevalence and risk of violence against people with and without disabilities: findings from an Australian population-based study.' *Australian and New Zealand Journal of Public Health* 40 (1):16-21.

28 Kavanagh, A.M., Kmjacki, L., Beer, A., LaMontagne, A.D. & Bentley, R. (2013) 'Time trends in socio-economic inequalities for women and men with disabilities in Australia: evidence of persisting inequalities.' *International Journal of Equity in Health* 12:73.

been developed, the huge scale of reform involved and the parlous state of many disability services prior to the introduction of the NDIS.

Within this broad context, we encountered a wide range of views and experiences among those who were involved in the NDIS trial site to inform ongoing implementation of the scheme. Key insights are summarised below.

Is the NDIS meeting service users' needs?

Our findings indicate that the NDIS is meeting service users' needs in some cases and not in others, and to varying degrees depending on individual service users' needs and circumstances. Some participants were relieved to be able to access to essential equipment and have more control over how services were delivered. Others had experienced a few changes; some reported no changes at all. Participants with capacities and confidence to identify and justify their needs in planning processes tended to express satisfaction with the scheme and report positive impacts in their lives.

For most participants, positive gains were undermined, and negligible inconveniences were compounded, by complicated and burdensome administrative processes. The scheme's funding structure and processes for identifying individuals' needs are complex and, to some extent, this is inevitable. However, there is potential to simplify administrative systems, clarify aims and objectives of the scheme to promote consistency in decision-making when allocating resources and increase flexibility in response to the varying capacities and resources available to service users. There was evidence that for some service users, processes and procedures were improving over time and this is encouraging. Other issues suggested changes are needed to better meet the needs of other service users.

Administrative problems appeared to be compounded by staffing issues, including staff shortages, high turnover of staff and staff working as planners with limited experience of working in the disability sector. It is imperative to address the administrative burden for service users. For many participants, administrative burdens outweighed any positive change in their practical situations. Some requirements were inefficient and had adverse effects on participants', families' and carers' emotional (and potentially physical) wellbeing. Further, carers and family members believed that their critical role in ensuring that many service users could

exercise choice by engaging with planning processes, and in providing unpaid care and support, was unrecognised and under-valued.

Where service users can clearly identify and seek appropriate support to meet their needs, there may be efficiency gains in approving services and equipment under a certain financial value. Many participants discussed using funds and substantial amounts of time in gaining approval for items that are clearly warranted and in some cases, inexpensive. These requirements also put pressure on high-demand and scarce professional services, such as physiotherapists and occupational therapists, in rural and regional locations.

Potential for choice

In theory, choice is facilitated by the availability of a range of services and resources. In practice, services and resources were not evenly available to participants, and the capacity to exercise choice was frequently enabled by supportive carers and advocates. Some parent-carers who met and spoke with us were working in disability services (often because they have developed strong interest in disability issues or moved into paid positions after having voluntary roles) and had good knowledge of service systems and potential resources. However other participants struggled to mobilise capacities for choice and were not aware of their entitlements or what might be available to them. These situations suggest there could be more focus on building capacities for service users and carers to be informed and to exercise choice, in order to reduce risks of the NDIS exacerbating other inequalities, and vice versa.

It is also important to recognise constraints in exercising choice and the implications of this in a contestable, client-driven system. Fostering discussions about the principle and value of choice is important here, including how it fits with other values that promote the safety, wellbeing, respect and dignity of people living with disability, as well as the capacities of organisations to be flexible and innovative in meeting these needs.

Navigating complex service systems

The NDIS has a complex organisational structure and processes, and it interacts and intersects with other service systems, creating complex environments for service users to navigate. Many service users interact with case managers, planners, service providers and business managers in a range of contexts and across organisational tiers and entities. Several participants expressed high levels of dissatisfaction with NDIS planning processes, which they attributed to a range of factors, including lack of experience among planners, high turnover of staff, receiving inconsistent

advice, unwieldy approval processes, difficulties with technology (both with the system's portal and in gaining access to computers), and issues related to individual budgets. Increased investment in training and equipping NDIS staff for their roles may go some way towards addressing the concerns of service users, as well as reducing stress among NDIS employees who are likely to be a target of people's frustration and anger with the system.

Many participants commented on perceived lack of communication within and between tiers of the NDIS and between the NDIS and service providers. These included large organisations providing a suite of disability-related, educational and health services as well as small business providers, health and allied health professionals, such as medical specialists, physiotherapists and speech, occupational and other therapists. Participants also expressed frustration with system boundaries that limited the ways in which support and resources from different service systems could be accessed and integrated to achieve optimal outcomes for people living disabilities.

Promoting efficiency in the system

Participants felt there was significant potential to improve efficiency in the NDIS scheme while enhancing individual capacities for choice and control. This included reduced accountability hurdles for purchasing lower cost items that are self-evidently required because of participants' conditions or circumstances. Participants who were caring for someone with a disability also spoke of wanting increased recognition of their insights into the support needs of service users, which they felt was often dismissed by professionals after brief and decontexualised contact with service users.

Assumptions that markets are the most effective mechanisms for ensuring efficient delivery of social care services remains unproven and debatable. In this trial site, a market model has been imposed on established organisations that have long provided care and support to people living with disabilities. Further, markets are difficult to fully develop in many settings, including where needs are varied and the demand in the population is limited and geographically dispersed. This means that services, and particularly specialist services, are not always available in ways that offer service users potential for choice, or are made more expensive because they must be brought in by service users. There were

concerns that efforts to maximise efficiency in the delivery of services can also limit potential for service innovation.

Systemic issues associated with a shift from block funding to a client-driven model, sudden increased local demand for services and resources, and technical difficulties with the portal, ensured gaps between what was promised and what is being delivered to many of those who are involved in the NDIS trial. Unspent funding allocations also lead to assumptions by planners that services are not required. Together, these issues suggest that some people living with disabilities still struggle to have their needs met, which impacts on their health, wellbeing and quality of life.

Implications for Equity

The implications of issues noted above suggest that there is insufficient attention being paid to promoting equity among service users with diverse needs and circumstances. Factors that are well-recognised as driving inequalities – household income, education, residential location and household structure – remain critical in filtering opportunities and capacities for service users and their families and carers to have choice and control in accessing services and resources. Other factors that appear to be associated with inequities in the NDIS are age, where older participants reported no change in access to services and resources but a significant rise in administrative burdens, and the type of disability that people have. Most participants with intellectual disabilities reported little difference in levels of support since moving onto the NDIS. The devolving of administrative responsibilities onto service users is generally inequitable because it presents an additional burden to people with disabilities who already encounter many barriers in securing social and economic inclusion, and to households that are already stretched for time and money. It also serves to exclude those who do not have capacities to fulfill these responsibilities.

Concluding comments

In her 2016 Sambell Oration for the Brotherhood of St. Laurence[29], Rhonda Galbally AO, a prominent disability activist and member of the NDIS board, reflected thoughtfully on the promise and limitations of one of the biggest social policy initiatives of recent times. She noted that:

> Choice and control is central to the NDIS – it means that, for the first time, people with disabilities can be in the driver's seat of their own lives. But in order for choice and control to become more than a mantra, people need a vision and aspiration for what is possible, and encouragement and support to realise those aspirations.

She went on to point out that the focus of these reforms to date have rested on the demand side of the equation – i.e. affording people with disabilities the opportunity to make decisions over the design and delivery of their care. However, less attention has been paid to the supply side and it has largely been assumed that an effective market will emerge to service these needs [30]. Our data shows that issues of supply – the availability of services – is crucial, but it also suggests how issues of demand are important for achieving the principles and values of the NDIS. Ms. Galbally warns that those who are dependent on these services are vulnerable to having their needs overlooked in the interests of providers. Rather, providers must be responsive to the needs of service users and this requires users to be empowered to recognise their rights to have choice and to be able to exercise choice. If the demand side of a market is not adequately activated, then there is potential that inequities in the system will deepen alongside a massive expansion of services that do not meet the range of needs of people with disabilities and which are not sustainable in the long term. Our findings suggest that challenges in supporting capacities to exercise choice are undermining the demand side of the equation, and are most concerning where individuals need increased support to consider their needs and exercise choice.

One solution to these risks, according to Ms. Galbally, is to reinvigorate the National Disability Strategy that provided the policy framework for the NDIS because its significance has been fading amidst the practical challenges of rolling out the scheme. It is timely to acknowledge her insights as the findings from this study foreshadow many of the concerns

29 Galbally, R. (2016) 'The genesis of the NDIS: bringing competing agendas together' Sambell Oration Brotherhood of St Laurence, Melbourne, 1 December 2016

30 Carey, G., Malbon, E. & Dickinson, H (forthcoming) 'The vexed question of market stewardship in the public sector: examining equity and the social contract through the Australian National Disability Insurance Scheme' *Social Policy and Administration*.

she raises. They should be carefully considered and addressed so that the NDIS achieves its objectives to, in Ms. Galbally's words, 'bridge the gap between a disabled life and an ordinary life'. This shouldn't be too much to hope for.

Finally, in this research project we deliberately adopted a participatory research approach with the aim of providing a voice to people with disabilities and sharpening the findings of our research. We believe that our findings are richer and more nuanced as a result and give a sorely needed voice to people with disabilities. This is one modest project, but we hope will be an encouragement to others.

References

Australian Government (2013) *National Disability Insurance Scheme Act* https://www.legislation.gov.au/Details/C2016C00934

Australian Government (2016) *National Disability Insurance Scheme (Becoming a Participant) Amendment Rules 2016 (No. 2)* https://www.legislation.gov.au/Details/F2016L01122/Explanatory%20Statement/Text

Carey, G., Malbon, E. & Dickinson, H. (forthcoming) 'The vexed question of market stewardship in the public sector: examining equity and the social contract through the Australian National Disability Insurance Scheme' *Social Policy and Administration.*

Collings, S. (2016) 'Support planning with people with intellectual disability and complex support needs in the Australian National Disability Insurance Scheme' *Journal of Intellectual and Developmental Disability* 41 (3):272-276.

Department of Social Services (2016) *NDIS MyPlace Portal Implementation Review - Final Report* https://www.dss.gov.au/disability-and-carers/publications-articles/general/ndis-myplace-portal-implementation-review-final-report

Galbally, R. (2016) 'The genesis of the NDIS: bringing competing agendas together' *Sambell Oration* Brotherhood of St Laurence, Melbourne, 1 December 2016 http://library.bsl.org.au/jspui/bitstream/1/9353/1/Galbally_Genesis_of_NDIS_Sambell_Oration_Dec2016.pdf

Glasby, J. & Littlechild, R. (2016) *Direct Payments and Personal Budgets: Putting Personalisation into Practice* Bristol: Policy Press, 3rd edn

Kavanagh, A.M., Kmjacki, L., Beer, A., LaMontagne, A.D. & Bentley, R. (2013) 'Time trends in socio-economic inequalities for women and men with disabilities in Australia: evidence of persisting inequalities.' *International Journal of Equity in Health* 12:73.

Kmjacki, L., Emerson, E., Llewellyn, G. & Kavanagh, A.M. (2016) 'Prevalence and risk of violence against people with and without disabilities: findings from an Australian population-based study.' *Australian and New Zealand Journal of Public Health* 40 (1):16-21.

KPMG (2014) *Interim report: Review of the optimal approach to transition to the full NDIS*. Canberra: KPMG.

Maclean, S., Warr, D. & Pyett, P. (2008) *Universities Working with and for Communities: Strategies for Collaborative Community Research and Knowledge Exchange*. Melbourne: The McCaughey Centre, The University of Melbourne.

Mann, R., & Warr, D. (2009) *Something to Take Notice of: Exploring the Value and Challenges of Peer-interviewing as a Participatory Research Method*. Melbourne: The McCaughey Centre, The University of Melbourne.

Milner, A., LaMontagne, A.D., Aitken, Z., Bentley, R. & Kavanagh. A.M. (2014) 'Employment status and mental health among persons with and without a disability: evidence from an Australian cohort study.' *Journal of Epidemiological Community Health* 68 (11):1064-1071.

Minkler, M. & Wallerstein, N. (2003) *Community-Based Participatory Research for Health* San Francisco, CA: Jossey-Bass.

Mithen, J., Aitken, Z., Ziersch, A. & Kavanagh, A.M. (2015) 'Inequalities in social capital and health between people with and without disabilities' *Social Science & Medicine* 126:26-35.

Morton, R. (2016) 'Rushed NDIS rollout a 'major risk'' *The Australian* 9 November 2016 http://www.theaustralian.com.au/national-affairs/rushed-ndis-rollout-a-major-risk/news-story/b8ab249c69917a01cab1e8a5b6bdb176

National Commission of Audit (2014) The Report of the National Commission of Audit 2014 Appendix Vol 1 9.2 http://www.ncoa.gov.au/report/appendix-vol-1/9-2-national-disability-insurance-scheme.html

NDIS 2017a About Us https://www.ndis.gov.au/about-us.html

NDIS 2017b Early Childhood Early Intervention https://www.ndis.gov.au/ecei

NDIS 2017c Our Sites https://www.ndis.gov.au/about-us/our-sites

NDIS 2017d Federal Funding https://www.ndis.gov.au/about-us/governance/federal-funding

NDIS 2017e Participant Portal User Guide https://www.ndis.gov.au/participant-portal-user-guide.html

Needham, C & Dickinson, H. (forthcoming) ''Any one of us could be among that number': Comparing the policy narratives for individualized disability funding in Australia and England' *Social Policy & Administration*

Nespor, J. (2000) 'Anonymity and Place in Qualitative Research' *Qualitative Inquiry*, 6(4): 456-569.

OECD (2009) *Sickness, disability and work: Keeping on track in the economic downturn*. Paris: OECD.

Productivity Commission (2011) *Disability Care and Support: Productivity Commission Inquiry Report* Report no. 54, Canberra.

Productivity Commission (2017) *National Disability Insurance Scheme (NDIS) Costs* http://www.pc.gov.au/inquiries/current/ndis-costs

Purcal, C., Fisher, K.R. & Laragy, C. (2014) 'Analysing choice in Australian Individual funding disability policies' *Australian Journal of Public Administration* 73 (1):88-102.

Pyett, P. (2002) 'Working Together to Reduce Health Inequalities: Reflections on a collaborative participatory approach to health research' *Australian and New Zealand Journal of Public Health* 26:332-6.

Walsh, J, & Johnson, S. (2013) 'Development and principles of the national disability insurance scheme' *Australian Economic Review* 46 (3):327-337.

MELBOURNE
SOCIAL EQUITY
INSTITUTE